Helping significant others to cope with cancer related stress: A holistic, Scripture-based, pastoral model

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ABSTRACT

Helping significant others to cope with cancer related stress: A holistic, Scripture-based, pastoral model

With a cancer diagnosis, the patients as well as their family members are challenged to learn about the evolving illness, the treatment thereof, treatment-related side effects, prolonged hospitalisations and the overall uncertainty surrounding the cancer journey.

Because of the shift from hospital-based care to home care, there is an increase in responsibility of IFCs. As a result, IFCs are being asked to shoulder greater caregiving responsibilities for longer periods of time. Studies on family caregiving have shown that the caregiving role can have stressful effects with the potential to bring about psychological, social, economic, emotional, physical, spiritual, as well as personal (identity) risks to IFCs. Therefore, it is important to approach caregiver related stress and support from a multidimensional (holistic) point of view.

Religious involvement among cancer cases has been the focus of considerable research over the past two decades. With growing interest in religious coping of the cancer patient self. There seems to be less research on religious coping of IFCs, even though the level of psychosocial morbidity among IFCs is sometimes comparable to, or even greater than that of the cancer patient.

This study has set itself the task of assessing and evaluating caregiver related stress endured by significant others who take care of a family member with cancer. It further aims to explore relevant Scriptural passages and religious practices to build a healthy God-image and consequently relationship with God believing that inward fellowship with God will give an inward knowledge of the ways of God. It is hypothised that coming to know who God is will help IFCs to deal with difficult questions and cope with cancer related stress.

Key Words

Cancer

Compassion

Hope

Informal family caregiving

Palliative care

OPSOMMING

Hulpverlening aan familielede met die hantering van kankerverwante stres: ‘n Holistiese, Skrif-gebaseerde pastorale model

Met ‘n kankerdiagnose in ‘n familie word beide die pasient en die pasiënt se familie uitgedaag om meer te leer van die ontwikkelende siekte, die behandeling en newe-effekte daarvan, langduringe hospitalisasie en die algehele onsekerheid aangaande die kankerverwante periode.

Daar is ‘n verhoogde verantwoordelikheid op familielede as gevolg van die skuif van hospitaal gebaseerde behandeling na tuis versorging. Die effek van hierdie skuif is dat familieversorgers groter verantwoordelikhede moet skouer vir langer periodes met die potensiaal om sielkundige, emosionele, spirituele, fisiese, sosiale en ekonomiese risiko’s aan te bring. Vir hierdie redes word dit as belangrik geag om versorgingstres te benader vanuit a multidimensionele (holistiese) uitgangspunt.

Die laaste twee dekades het verskeie navorsers geloof die fokuspunt gemaak aangaande kankerdiagnoses en die proses van die siekte. Met ‘n groeiende belangstelling op hoe die pasiënt geloof kan aanwend as ‘n tipe van ‘oorlewingsvaardigheid’ deur hul kankerperiode, is daar ‘n leemte van hoe die versorger geloof kan aanwend deur die versorgingsperiode. Nieteenstaande, die feit dat daar bewys is dat die vlak van psigososiale-morbiditeit tussen pasiënt en versorger op dieselfde vlak is, of selfs dat die familieversorger se morbiditeit dikwels ‘n hoër vlak toon, as die pasient self.

Die studie het ten doel om versorgerverwante stres, as gevolg van ‘n kankerdiagnose te assesseer en te evalueer. Dit het verder ten doel om relevante skrifgedeeltes te analiseer en geloofspraktyke voor te stel met die doel om ‘n gepaste God-beeld by die familieversorger te bou, wat dienoorkomstig sal lei na ‘n intieme verhouding met God. Daar word veronderstel dat innerlike gemeenskap met God sal lei na innerlike kennis van wie God is. Die hipotese van die studie is dat deur te leer wie God is, die familieversorger eerstens versterk sal word om moeilike teologiese vrae aangaande die kankerdiagnose te beantwoord, en tweedens te help om deur die proses te gaan met hoop en betekenis te vind in moeilike tye.

Sleutel woorde

Kanker

Deernis

Hoop

Informele familieversorging

Palliatiewe sorg

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LIST OF ABBREVIATIONS

IFC(s) – Informal family caregiver(s)

PC – PC

IARC - International Agency for Research on Cancer

WHO - World Health Organization

CRHCF - Crossroad Hospice Charitable Foundation

SCCIP - Surviving Cancer Competently Intervention Program

PSST - Poblem-solving skills training

ACT - Acceptance and commitment therapy

CF – Compassion fatigue

CMT - Compassionate Mind Training

MSC - Mindful self-compassion

MBSR - Mindful-based stress reduction

AI - Anterior insula

MCC - Medial cingulate cortex

ACC - Anterior cingulate cortex

DMN - Default mode network

CBT - Cognitive behavioural therapy

DBT - Dialectical behaviour therapy

IBCT - Integrative behavioural couples' therapy

MBCT - Mindfulness-based cognitive therapy

FAP - Functional analytic psychotherapy

RC - Religious coping

PRC - Positive religious coping

RS - Religious struggle

NCCN - National Comprehensive Cancer Network

NCQPC - National Consensus for Quality Palliative Care

NICE - National Institute for Clinical Excellence

FAM - Focused attention meditation

OMN - Open monitoring meditation

LKM - Loving-kindness meditation

PNS - Parasympathetic nervous system

SNS - Sympathetic nervous system

CHAPTER 1: INTRODUCTION, PROBLEM STATEMENT AND AIM OF THE STUDY

1.1 TITLE AND KEY WORDS

1.1.1 Title

Helping significant others to cope with cancer related stress: A holistic, Scripture-based, pastoral model.

1.2.1 Key words

Holistic Scripture based pastoral model, significant others, coping skills, cancer related stress.

1.2 CONCEPT CLARIFICATION / DEFINITION OF TERMS

Family: Katz *et al*. (2018:736-745) define family from a family system perspective “as a system comprised of multiple interrelated parts, including individuals as well as relationships between individuals”. The meaning of family, according to the Cambridge dictionary (2019) is a group of people related to one another such as mother, father and their children**.** Reber and Reber (2001:268) define family as “the fundamental unit of kinship”. In its nuclear form the family unit will consist of two parents and their offspring. In a broader sense the term can signify an extended family, including grandparents, cousins, adopted children, *et cetera*, all operating as a recognised social unit.

Significant other: Includes any person who plays an important and influential part in affecting the social norms, values and personal self-image of another individual’s development. A significant other typically has authority over an individual, providing a point of reflection for the acceptance or rejection of values, norms and behaviours (Reber & Reber, 2001:680). In this study, the significant other refers to a family member that has to take care of another family member who has cancer.

Cope: Wenninger *et al*. (2013:854-861) define coping as a broad concept covering the strategies used by a person to manage stressful life events.

Empathy: Empathy is defined as a manifestation of a persons’ ability to have a viewpoint on someone else’s experiences, sharing these experiences on an affectionate and cognitive level, also appreciating a critical differentiation of the self from the experiencing of others (Stevens *et al.*, 2018:91-120). Empathy involves the ability to understand and to some measure feel the affective states of others, while fully understanding that the feelings are the result of the other person’s circumstances (Singer & Lamm, 2009:81-96). Empathy is to share the feelings of others. Through empathic feelings one can resonate with others’ feelings (both positive and negative). “In empathy one feels with someone, but one does not confuse oneself with the other” (Singer & Klimecki, 2014:875-878).

Compassion: The concept compassion is complex and difficult to define (Berwick, 2013; Van der Cingel, 2009:124-136; Van der Cingel, 2011:672-685; Lown, 2016:332-342). According to Crawford *et al*. (2014:3589-3599), compassion is dependent on an individual's capability to grow a compassionate mentality and orientation, including qualities such as attention, awareness, motivation, wisdom, commitment and courage (cf. Cole-King & Gilbert, 2011:29-37). Stevens *et al*. (2018:91-120) define compassion as recognising someone else's emotional and cognitive discomfort, coupling it with a desire to lighten their suffering. Compassion, for Pires *et al*. (2018) is having deep awareness of the suffering of others that go together with the wish to immediately ease it and offer care as well as understanding without judging or feeling pity. Compassion is an emotional state and its associated behaviours as recognition, understanding, emotional resonance and empathic concern for another's concerns, distress, pain and suffering, coupled with their acknowledgement motivation and relational action to ameliorate these conditions (Lown, 2016:332-342). Self-compassion is directed toward the self in situations of difficulty or suffering (Pires *et al.*, 2018).

Empathy versus compassion: In contrast to empathy (feeling as), compassion (feeling for) is characterised by feelings of warmth, concern, care for someone else, as well as being strongly motivated to improve the other's well-being (Singer & Klimecki, 2014:875-878). Decety and Lamm (2009:199-213) explain the difference between empathy and compassion as follows: "Empathy (feeling as) involves shared feelings; compassion (feeling for) involves a caring concern, but not necessarily shared feelings. Whereas compassion causes prosocial motivation to help others, empathy or standing in another man's shoes can generate a mixture of motivations to help, accompanied by personal distress and avoidance".

Compassion fatigue: Coetzee and Klopper (2010:235-243) define compassion fatigue as a state in which the compassionate energy of the caregiver has been depleted and exceeded restorative abilities. This state comes from witnessing the suffering of others and feelings of hopelessness to do more to help others (Yoder, 2010:191-197). "Compassion fatigue is a secondary traumatic stress disorder that is a reaction to the on-going demands of being compassionate in helping those who are suffering" (Downs, 2013). Jarvis (2019) explains compassion fatigue as physical and mental exhaustion and emotional withdrawal by the caregiver as a result of taking on the emotional burden of others' agony for a prolonged period of time. Compassion fatigue, according to Portnoy (2011:47-50), is a type of burnout, surfacing abruptly and with little warning, normally more pervasive than burnout. Compassion fatigue goes along with feeling a loss of meaning and hope and may have reactions related to post-traumatic stress disorder (PTSD), such as anxiety, irritability, difficulty sleeping and excessive emotional numbness. PTSD is an anxiety disorder emerging from a psychologically distressing or traumatic event such as natural disaster, bad accident, war or rape. It includes experiencing the trauma in dreams, recurrent thoughts and images. These symptoms must be present for a period longer than at least a month to be diagnosed as PTSD (Reber & Reber, 2001:551). According to De Silva *et al*. (2009:52-55), the most commonly accepted definition for burnout comes from Maslach (1981:99-113) who describes it as a multidimensional condition consisting of emotional exhaustion, depersonalisation and reduced personal accomplishment occurring among individuals involved with “people work of some kind”.

Compassion fatigue versus PTSD: The concepts of compassion fatigue, post-traumatic stress disorder (PTSD) and burnout fall under the same disorders. PTSD is a primary stress disorder resulting from the exposure to extreme traumatic events. Whereas compassion fatigue is a secondary stress disorder since the stress happens to someone else. The caregiver (in this study, the ‘significant others’) witnesses the stress and takes it on as their own (Downs, 2013). Compassion fatigue, as referred to in this study, happens when family caregivers start to take the pain and suffering of another family member (cancer patient) they take care of onto themselves. Caregivers going through compassion fatigue struggle with keeping a healthy balance between their concerns for the sick family member and staying objective about their own health. They constantly push themselves harder to the point of complete burnout.

Mindfulness: The term can imply a state of mind that is conscious of the present moment. This kind of mindfulness will have an impact on neurological and cognitive functioning (Bingaman, 2011:477-489; Buttle, 2011:123-134; Garland, 2013:439-448). Symington and Symington (2012:71-77) define mindfulness as the “process of keeping one’s mind in the present moment, while staying non-judgmentally detached from potentially destructive thoughts and feelings”.

1.3 INTRODUCTION

Due to personal experience, the researcher knows that the family or relatives of a cancer patient experience emotional turmoil. Further, working as a director for a foundation in support of children with cancer the researcher realised the desperate need for a deeper insight into the significant others’ caregiving role and related stress associated with the journey with cancer. A cancer diagnosis usually puts the lives of everybody involved on a roller coaster trip and with the intense focus on the person diagnosed, the rest of the family are often overlooked with regards to their own emotional and spiritual struggles in the circumstances. This study aims to explore the impact of cancer related stress on significant others with the goal of helping them to adapt to the circumstances in order to support the patient.

Knowledge about responses in the family regarding a cancer diagnosis and treatment has become a research priority (Moore & Faan, 2004:128-131). Coping with a cancer diagnosis within the family can influence the dynamics of how the family members will be able to adapt to emotional, logistical and interpersonal demands associated with the diagnosis (Long & Marsland, 2011:57-88). According to Cowan *et al*. (1993:3-9), the three elements of responses (emotional, logistical and interpersonal) to altered health circumstances are interdependent with mutual interaction between each other. Lewis (1990:752) states that:

> Families matter. They matter because they provide the context of adjustment in which the person with cancer responds to his or her illness. This context is known to affect self-care behaviours and adjustment. Families also matter because family members, and not just the patient, are directly confronted with the illness' experience.

1.4 PRELIMINARY LITERATURE REVIEW

A thorough analysis of related literature on the theme was done and an extensive electronic search was completed on the following databases at the Ferdinand Postma and Jan Lion-Cachet Library at the North-West University, ATLAS (American Theological Library Association Religious Database), EBSCO HOST (Academic Search Elite Database), Library Catalogue, NEXUS DATABASE SYSTEM (Dissertations and Theses), SCOPUS (Multi – disciplinary Articles Database), ISI (Web of Science) and ISAP (South African Journal Articles).

The following information is relevant to this study.

1.4.1 Psychological elements on the effects of cancer on significant others (RC)

Understanding the factors associated with mental health outcomes in family caregiving is crucial in order to develop a pastoral model that can help the significant others cope with the impact of cancer of a family member. A number of studies associate religious beliefs with mental health and quality of life (Vitorino *et al.,* 2018:1900-1907). It seems that a few studies considered the relationship between religious coping and depressive symptoms in family caregivers of cancer patients (Vitorino *et al.,* 2018:1900-1907). Most studies use the spiritual well-being (SWB) concept, which other authors find problematic (cf. Peres *et al.,* 2018:1842-1855). On the other hand, not including religious struggles at all, this also has the potential of negatively influencing health outcomes of the family caregiver (Vitorino *et al.,* 2018:1904). Vitorino *et al.* (2018:1900-1907) address the role of negative religiousness (feeling anger towards God or punished by God) on worsening caregiver fatigue.

Since family caregivers of cancer patients are exposed to stressful and vulnerable situations, as a result of feeling uncertain and the fear of losing a family member, they stand higher risk to develop psychological problems (Northouse *et al.,* 2012:1227-1234; Gardner *et al.,* 2017:125-132; Adams *et al.,* 2014:1178-1184; Burnette *et al.,* 2017:779-786). Religious struggles in this situation can emerge as a reaction to the situation and furthermore compromise mental health and well-being. These struggles are concerned with conflicts of values, beliefs and essential meaning of life such as anger towards God, a sense of punishment by God or even wondering whether God or the church had abandoned them (Abu-Raiya *et al.,* 2016:1265-1274).

Family caregivers use different coping strategies to deal with the challenges of living with a family member with cancer, making use of help systems such as family, social, spiritual and religious support (Adams *et al.,* 2014:1178-1184; Park *et al.,* 2015:3789-3794). The way in which the family caregiver will interpret a cancer diagnosis, together with his or her role as caregiver can be influenced by factors such as cultural beliefs of illness, health, wellness and death. Spiritual and religious beliefs will influence how the significant other will view the diagnosis and handle the situation accordingly (Levine *et al.,* 2017:1214-1220; Peteet & Balboni, 2013:280-289; Nikfarid *et al.*, 2018:188-198; Masa'Deh *et al.,* 2012:88-95). Studies have shown that lower levels of spiritual well-being relate to poorer mental health (Adams *et al.,* 2014:1178-1184; Kim *et al.,* 2011:762-770) and with lower levels of family support (Adams *et al.,* 2014:1178-1184). It has been shown that religion and faith can serve as an important support source, especially for mothers with children diagnosed with cancer (Levine *et al.,* 2017:1214-1220; Friðriksdóttir *et al.,* 2011:252-258; Nikfarid *et al.*, 2018:188-198).

The adaptive caregivers showed a higher degree of positive religious coping and lower degree of negative religious coping compared to maladaptive counterparts (Levine *et al.,* 2017:1214-1220; Friðriksdóttir *et al.,* 2011:252-258).

More and more health professionals from all areas start to recognise the value of religion as a key component of psychological well-being (Peteet & Balboni, 2013:280-289; Van der Weele *et al.,* 2017:519-520), and a number of studies have noted that religion stand central to many cancer patients and caregivers (Park *et al.*, 2015:3789-3794*;* Peteet & Balboni, 2013:280-289; Balboni *et al.*, 2007:555-560; Phelps *et al.*, 2009:1140-1147; Pargament *et al.*, 2000:519-543; Pargament *et al.,* 2011:51-76*).*

Despite the increasing attention of spiritual and religious beliefs in oncology, most studies in this field have placed more focus on the concept of cancer caregivers' spiritual well-being (SWB) (Van der Weele *et al.,* 2017:519-520; Pargament *et al.*, 2011:51-76), than the disadvantage of religious coping (Vitorino *et al.,* 2018:1901). Religious coping can be defined as the manner in which the individual would cope with stressful situations in their life by means of their spirituality, belief or religious behaviour either positive or negative strategies (Pargament *et al.,* 2011:51-76). Positive strategies will take form in searching for help, spiritual knowledge and a positive attitude towards God. Negative strategies can take form in feeling dissatisfaction towards a religious representative, together with negative revaluation of God or meaning (Pargament *et al.*, 2011:51-76). An increasing number of studies support the association of positive religious coping strategies with improved outcomes in both physical and mental health of people of all ages (Kim *et al.*, 2011:762-770; Koenig, 2012). It is important to recognise both the positive and negative symptoms, because the path of cancer can have a profound effect on religious beliefs placing the person on this path in a personal religious struggle (King *et al.,* 2017:270-277). It has been shown that religious struggles frequently relate to worse mental health outcomes, such as high levels of depression and anxiety (Pearce *et al.,* 2006:743-759; Nikfarid *et al.*, 2018), loneliness, health impairment and a negative effect on the quality of life can also be found (Peteet & Balboni, 2013:280-289; Kim *et al.,* 2011:762-770).

1.4.2 Sociocultural and biological elements on the effect of cancer on significant others

Compassion for family members is unique in nature (Goetz *et al.,* 2010:351-374) because it involves helping and supporting people with whom the caregiver has a close emotional attachment (Curtis, 2014:210-223). Significant others experience a great deal of distress due to the impact of (another's) cancer on every aspect of their lives. It is significant others who provide the context when a family member is diagnosed with cancer, while they themselves are deeply affected by the illness. Lewis (1990:752-759) compares the impact of a cancer diagnosis to the effect of dropping a stone in a pond. In other words, cancer causes a ripple effect resulting in changes to the significant other's identity, roles and daily activities.

Cancer continues to be a life-changing illness, along with a high degree of uncertainty that goes along with equally high caregiving demands. Studies have noted that family caregivers (FCs) are exposed to the weight of both physical and psychological elements during and continuing after the medical care of the diagnosed family member (Northouse *et al.*, 2012:1227-1234; Levine *et al.*, 2017:1214-1220; Gardner *et al.*, 2017:125-132; Rosenburg & Wolfe, 2017:56-67). In effect, the FCs of paediatric cancer patients stand a greater risk of developing different kinds of somatic conditions (Northouse *et al.*, 2012: 1227-1234; Gardner *et al.*, 2017:125-132; Adams *et al.*, 2014:1178-1184) and higher levels of inflammatory markers, such as cortisone and C-reactive protein (Rohleder *et al.*, 2009: 2909-2915). An estimate of 20% to 60% of FCs report significant depressive symptoms (Adams *et al.*, 2014:1178-1184; Friðriksdóttir *et al.*, 2011:252-258) and 20% to 30% of caregivers stand a higher risk for some form of psychiatric illness (Burnette *et al.*, 2017:779-786).

As a result of the impact of cancer on all aspects of the FC's life, most studies document momentous stress among them (Blanchard, 1997:189-194). As a result of the changing demands of the illness, Lewis (1993:127-129) concludes that psychosocial transitions occur in the attempt to cope with the illness. These transitions include new communication patterns within the family, each family member developing new self-concepts, giving up old roles and assuming new roles, management of routines within the family. Studies consistently show a close association between the illness stage and emotional distress, as will be discussed in the following chapters with the fivefold focus on how a cancer diagnosis affects the healthy spouse, parent with a child with cancer, preadolescent/adolescent with a parent with cancer, sibling with a brother or sister with cancer and grandparents with grandchildren with cancer. Children in this study will refer to ages 14 years up to 18 years thus representing preadolescent and adolescent age groups.

1.4.3 Activating the significant other's own caregiving

Caregivers mostly focus on the needs of the patients at the expense of their own well-being. It is vital that the caregiver replenishes his or her own inner needs, which includes daily nurturing activities (Portnoy, 2011:47-50). This study proposes that the significant other's own 'inner caregiver' can be activated and nourished by means of self-compassion and Christian oriented mindfulness, supporting the statement with the neurological benefits of these practices.

An example of an extraordinary caregiver, Mother Teresa, required from her nuns to take a year from their duties every four to five years allowing them time to heal from the effects of caregiving (Downs, 2013). In a situation where a significant other becomes a caregiver of a cancer patient, the caregiver may not be in a position to take an extended break, furthermore, the caregiver often misinterprets his or her need of self-care as being selfish. Several caregivers undergo high levels of stress and compassion fatigue (Figley, 2002a:1433-1441). Compassion fatigue is the natural result of stress stemming from caring for and helping suffering people. It is thus caused by empathy involving a preoccupation with an individual or the trauma of the individual (Portnoy, 2011:47-50). In contrast with this, some research also suggests that long-term caregiving can offer mental and physical health advantages to the caregiver (Brown *et al.,* 2003:320-327; Breines & Chen, 2013:58-64). This implies that giving can grow a positive mood (Dunn *et al.,* 2008:1687-1688), and in turn a positive mood can grow positive self-directed attitudes, for instance self-compassion (Breines & Chen, 2013:58-64).

Confronted with the challenge of balancing the term "we-illness" (Kayser *et al.,* 2007:404-418) from diagnosis till readjustment after cancer, the significant others may find themselves in situations of multidimensional adjustments and sometimes even to a point where their own self is at risk (compassion fatigue). Compassion fatigue holds physical, emotional, social, spiritual and professional implications (Coetzee & Klopper, 2010:235-243; Yoder, 2010:191-197; Jenkins & Warren, 2012:388-395; Aycock & Boyle, 2009:183-191), making the awareness about compassion fatigue a very important first step to manage it. Feedback from healthy significant others can provide an important insight into how caring for the patient influences the caregivers' personal life (Boyle, 2015:48-51). A positive way of optimum self-care is practising self-awareness. A self-care plan must entail all aspects of wellness (physical, emotional, social and religious).

1.4.4 Self compassion

Self-compassion is a central concept by which mindfulness- and acceptance-based interventions influence psychological health (Hölzel *et al.,* 2011:537-559; Baer, 2010:135-153; Keng *et al.,* 2012:270-280; Symington & Symington, 2012:71-77). Self-compassion can be defined as an adaptive form of self-relation containing three primary concepts, namely fostering a mindful awareness of own suffering, being understanding and kind towards the self during difficult times and connecting own stressful experiences to the wider perspective of human experiences (Neff, 2003:223-250). A growing body of literature notes a connotation between self-compassion and positive psychological outcomes, for instance happiness, optimism, contentedness, wisdom, emotional intelligence and adaptive coping (Neff *et al.,* 2007a:908-916; Neff *et al.,* 2005:263-287; Allen & Leary, 2010:107-118; Hollis-Walker & Colosimo, 2011:222-227). Self-compassion consistently associates with lower levels of depression, anxiety and stress (MacBeth & Gumley, 2012:545-352). Of particular relevance to this study are findings that self-compassion appears to lessen specific traumatic stress outcomes. It has been found that self-compassion reduces post-traumatic stress disorder symptoms (Kearney *et al.,* 2013:426-434), assists with coping in the face of challenging experiences (Neff *et al.,* 2005:263-287; Allen & Leary, 2010:107-118; Leary *et al.,* 2007:887-904) and associates with positive emotion regulation, such as emotional clarity and emotional repair (Neff, 2003:223-250).

Neuroscientists have identified that the ability to understand others' emotions, motor and sensory experiences are hardwired in the human brain via neural pathways formed by directly experiencing and / or observing others (Rizzolatti & Craighero, 2004:169-192). The activation of neural networks involved in the understanding and responding to others' experiences is sensitive to various influences. These influences can include attention, valuation of others, the ability to experience and respond to own and others' emotions, contextual issues such as repetitive exposure to suffering and pain, perspective-taking, self-boundaries and the regulation of own emotions (Lown, 2016:332-342). Current research suggests that compassion can be learned through education and training (Singer & Klimecki, 2014:875-878; Lown, 2016:332-342).

The caregiver is often overwhelmed by the pain and suffering of the sick person. In the light of this undeserved suffering, hopelessness and helplessness and spiritual exhaustion set in (Louw, 2015:1-10). Compassion fatigue, according to Louw (2015:5) indicates spiritual stress because the "pain and helplessness of the other infiltrates the caregiver's framework of meaning and conceptualisation of pain and suffering". The reality is that humans are creatures bound to the earth by death. However, sickness and the reality of death yearn for comfort (Pless, 2013:90, 105). The unique feature of caregiving is made up of two basic entities, namely comfort and compassion. Comfort is mainly a spiritual category linked to the theological dimension of the Christian faith: "Comfort and care emerge as a result of the comfort of God" (Louw, 2015:8). Comfort is at heart an exemplification and embodiment of the passion and suffering of Christ. It is therefore the image of the crucified Christ that people should meditate on when spiritual exhaustion sets in, for He is the one to bestow "upon us His righteousness and glory" by virtue of His resurrection (Pless, 2013:101). As a result of the interrelatedness between comfort and compassion, the passion in compassion gives rise to more than feeling, it is an existential category (being-with) within the theological framework of a *theologia crucis* (the cross of Christ as an enfleshment of divine suffering and compassion (Gerhardson, 1981:118). The theological understanding of suffering can help the caregiver to accept his or her limitation of involvement and distinguish between compassion capacity and compassion limitation. The *theopaschitic* notion of a suffering God (Fretheim, 1984:52) in this regard can help to get a clearer perception of the character of God's involvement in suffering (cf. Louw, 2015:1-10).

> In terms of a theological understanding of compassion, compassion refers to God's mercy as expressed in the bowel categories of *ta splanchna*: the divine compassion fatigue of a suffering God. The forsakenness of Christ on the cross (*derelictio*) depicts the helplessness of God. God becomes a Co-Partner in the struggle to cope with the victimisation of human helplessness and vulnerability (Louw, 2015a:9).

Therefore, caregiving is in essence spiritual. It represents "the compassion of God, embodies the presence of God and enfleshes the spiritual realm of hope. Caregivers are beacons of hope within the blurred and dark vistas of life" (Louw, 2015a:10).

1.5 PROBLEM STATEMENT

The entire family system is affected by a cancer diagnosis, the treatment thereof and threat of recurrence where the impact of the illness holds long-term consequences on the inner balance of the family (Lewis, 1990:752-759). According to Hesse (2018), cancer is responsible for more deaths in South Africa than HIV/Aids, tuberculosis and malaria combined. As at the end of 2017, Discovery Health was recognised as South Africa's largest open medical scheme consisting of a membership of 2.7 million people. Their statistics show that during 2017, 7 597 Discovery members were newly diagnosed with cancer equating to an incidence of 277 new cases per 100 000 lives. The incidence went up from 251 in 2011, an increase of 10% (Hesse, 2018). As a result, a substantial number of significant others will therefore have to deal with the challenges of cancer in the family.

This study anticipates that a more holistic perspective would improve knowledge about the reactions of significant others to the experience of cancer in the family. The goal of the study is therefore, to formulate a holistic Scripture based pastoral model in helping significant others to cope with cancer related stress. Caregiving models of multi-disciplinary sciences, such as psychology, sociocultural, biological and neurological studies will be taken into account together with pastoral studies.

1.6 RESEARCH QUESTION AND FURTHER QUESTIONS

1.6.1 Research question

The question to be answered by this research is: What will a holistic Scriptural based pastoral model through which significant others can be helped to cope with cancer related stress, look like?

1.6.2 Further questions that arise from the research question are:

The following subsidiary questions emerge from the main research question:

a. What descriptive empirical insights can be gained from an investigation among multi-disciplinary professionals[1] regarding caregiving related stress noticed while they counsel significant others (family caregivers) of family members diagnosed with cancer?

b. What interpretative insights with regard to caregiver related stress emerge from an investigation within multi-disciplinary sciences?

c. What normative guidelines can be formulated from an inquiry into relevant Scriptural passages regarding caregiving to the sick (cancer patient) and the stress accompanying the caregiving?

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[1] Psychologists, social workers, pastoral caregivers, CHOC/CANSA workers. CANSA (Cancer Association of South Africa) / CHOC (Childhood Cancer Foundation). Refer to 1.9.1 for a thorough explanation of the empirical research.

d. What pragmatic guidelines would a holistic Scriptural based pastoral model entail with regard to a pastoral model of significant others regarding caregiving related stress?

1.7 RESEARCH AIM AND OBECTIVES

1.7.1 Aim

The main aim of this study is to formulate a holistic Scripture based pastoral model in helping significant others to cope with cancer related stress.

1.7.2 Objectives

In order to achieve the main aim of the study, the following objectives are set:

- Assess and evaluate caregiver related stress noticed by professionals while they counselled significant others who take care of a family member with cancer.
- Gain insights with regard to caregiver related stress from an investigation within multi-disciplinary sciences.
- Explore relevant Scriptural passages regarding caregiving to the sick person and the stress accompanying the caregiving.
- Formulate a holistic Scripture based pastoral model with regard to the pastoral guidance of significant others regarding caregiving related stress.

1.8 EPISTEMOLOGY OF THE STUDY

The epistemology of the study is from a pastoral care paradigm, as a subdivision of practical theology. Struggles of life studied in theological and ethical discussions often call for a reassessment of perceptions, as well as the practice of theology (Jaison, 2010). The aim of the study is the formation of a holistic Scripture based pastoral model with regard to the pastoral guidance of significant others regarding caregiving related stress and therefore it is important for the researcher to find a balance between the four basic dimensions of formation. Jaison (2010) describes the four basic dimensions of formation as spiritual, academic, ministerial and personal. These dimensions prove the contextuality of pastoral care. Contextualisation is an attempt to understand the Christian faith in terms of a particular context through the recognition of the present human experience (Bevans, 2016:3).

Contextualisation is also seen in the definition Heitink (1999:6) gives to practical theology, "empirically oriented theological theory of the mediation of the Christian faith in the praxis of modern society". Pattison and Woodward (2000:7) consider practical theology as "a place where religious beliefs and practice meets contemporary experiences, questions and actions and conducts dialogue that is mutually enriching, intellectually critical and practically transforming". Practical theology is thus the *doing* of theology that is firstly informed by peoples' real situations (context), which secondly, allows the pastor by means of a careful hermeneutical process to reflect theologically on the particular situation or problem and thirdly, to revisit the situation for gentle and carefully transformation (Jaison, 2010).

Another definition is: "Practical theology is the application of God's revelation to the individual and the church. It represents the climax and the final point of theological endeavour" (Duce & Strange, 2001:77).

For the practical theologian or pastor, the praxis is meaningful and therefore certain principles or movements are important. Firstly, emphasis is placed on practice in order to highlight the significance of the human context and the realities of lived experience as the field in which pastoral ministry or action takes place. Practice stands for the "embodied expression of particular kinds of knowledge" (Stoddart, 2014:3). While practice can imply something as quite routinised and unreflective, the term praxis suggests something that is more reflexive, value-directed and value-laden. Praxis is the meaning that is brought to practice, together with the meaning-making associated with actions (Graham, 2017:1-9).

Secondly, practical theology (for this thesis: pastoral care) does not only end in practice, it also begins there (Beaudoin, 2016:8-32). According to Grenz (1993:17-18), practical theology "is the intellectual reflection on the faith we share as the believing community within a specific cultural context. But it has as its goal the *application*[2] of our faith commitment to living as the people of God in our world".

Thirdly, practical theology (for this thesis: pastoral care) is lived experiences or faith practices. Practical theology is primarily performative and enacted and secondary written down and systematised (Graham, 2000:104-117). Practical theology is sacramental, incarnational and enacted, stands in relation to God as embodied in faith-filled practices (Graham, 2017:1-9). Bevans (2016:49) sums it up as

> [T]he aim of [practical] theology is not to work out a system that is enduring so much as to meet every day experiences with faith and to express that faith in terms of everyday experience. Theology is an ongoing process. It is the habitus of praying Christians, of reflective ministers, and believing communities.

Contextual practical theology appeals for theological education organisations to acknowledge the inherent holistic challenges of real-life situations when translating the knowledge into practice, by means of critically reflection on theology, culture, sociology, organisation, psychology and any other related disciplines (Jaison, 2010). The tasks of contextual pastoral care that keep the hermeneutical concept at its core should be a problem-based, action-oriented, reflective hermeneutical and critical-correlational approach. Bennett (2013:134) argues that practical theology is not a clear-cut choice between "the text of the Bible and the text of life" and the pastor should therefore, according to Miller-McLemore (2011:17) move beyond the simplistic and static dual of "correlation between the Christian tradition and contemporary experience" to a point of considering how all the inherent values and

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[2] Emphasis by author.

worldviews in a specific situation or context are constructed within an interaction of sources and norms, both religious and secular.

For a holistic approach, pastoral counselling should strive to hold open a certain space between 'secular' counselling and 'Christian' counselling. This space makes a multi-discipline approach possible where different disciplines remain in dialogue and for religion to be seen "as a source of meaning and a resource for living" (Lyall, 2001:15). Cooper-White (2004:131) defines holistic pastoral counselling as follows:

> Pastoral counselling, or psychotherapy, is defined as a distinctive form of counselling in which the full resources, theoretical knowledge, and clinical methods of secular psychology and psychotherapy are brought together with pastoral theological method and practice to provide a holistic approach to psychotherapy that honours and integrates the spiritual dimension of each patient's life and experience.

The practical theologian, Louw (2011a:11), defines a holistic approach in pastoral care as care of souls (*cura vitae*) where a "theology of life and healing of life" form the specific viewpoint. He further concludes: "It is about hope, care and the endeavour to give meaning to life within the reality of suffering, our human vulnerability, and the ever-present predicament of trauma, illness and sickness." In this study, the researcher's point of departure will be the Word of God as the authoritative source for pastoral counselling. The findings of multi-disciplinary sciences such as psychology and sociology on the counselling of significant others will also be taken into account, especially their focus on cognitive behavioural therapy. Two of the earliest forms of cognitive behavioural therapy (CBT) are Rational Emotive Behavioural Therapy (REBT), developed by Ellis (1996), and Cognitive Therapy (CT), developed by Beck (1995). Cognitive therapy focuses on the intellectual abilities of humans, perceiving them as conscious and observing, capable of making meaning of the world, and understanding the self and others. Additional forerunners in this field worth mentioning (but not elaborating on) are Piaget's (1972) stages of cognitive development, Kohlberg's (1969:347-480) six-stage theory of cognitive-developmental morality, and Fowler's (1991) six stage theory of faith development parallels. A third wave of cognitive behavioural therapies differs from the traditional cognitive therapies, by placing greater focus on the process and functioning of thoughts and feelings inside a particular content or setting (Waltz & Hayes, 2010:148-192).

For the PC to promote stress resilience and well-being of significant others in a positive, integrated and sustainable way, this study will include findings of the cognitive acceptance and commitment therapy (ACT), which have proved to decrease stress, as well as the negative effect and anxiety (Stafford-Brown & Pakenham, 2012:592-613; Shapiro *et al.*, 2005:164-176; Shapiro *et al.*, 2007:105-115). ACT places emphases on mindfulness, acceptance, metacognition, emotion, dialectics and the therapeutic relationship (Kahl *et al.*, 2012:522-528). Mindfulness skills learned through ACT can help significant others to remain centred and focused on Christ and biblical values in the midst of their fears and intense emotions (Symington & Symington, 2012:71-77). Sisemore (2015:5-15) and Rosales and Tan

(2016:269-275) also highlight the congruent elements between ACT and a biblical worldview. The basis of ACT is that psychological inflexibility (no union between cognition, emotion and behaviour) causes psychopathology (Harris, 2009:6-19). In contrast, psychological flexibility (Harris, 2009:6-19) is the model of health consisting six core processes that is known as ACT hexaflex (defusing, acceptance, contacting the present moment, self-as-context, values and committed action). ACT thus falls within the boundaries of this study of formulating a holistic Scripture based pastoral model to help the significant others dealing with the trauma of all dimensions of their humanness.

1.9 RESEARCH MODEL AND METHODOLOGY

Although various models were developed in the last century for pursuing research within practical theology, the researcher chose to work according to the model of Osmer. Osmer's (2008) hermeneutical approach has a vast influence on the work of South Africa's contemporary practical theologians (Pieterse, 2017:1-9). The important contribution of this model is the inclusion of an empirical component in the hermeneutical approach (Pieterse, 2017:1-9). Where a reflective practice used to be important, it became particularly so in the face of the challenges of modernity in a post-Christendom, postmodern, globalising world (Osmer, 2011:1-7). "The church needs leaders who can look closely at their own context and ask what is going on, as well as engage the social sciences to understand why certain events and patterns are occurring" (Osmer, 2011:2). Osmer works with four core tasks, namely the descriptive empirical task, the interpretative task, the normative task and the pragmatic task.

The methodology of the study follows a basic type of research, where the research poses intellectually challenging questions to the researcher and includes abstract and specialised concepts. The research will be carried out within a contextual framework (problem-based, action-oriented research through case studies that deal with key terms such as support and empowerment of significant others who take care of a family member with cancer) and builds on preliminary research. The research approach is twofold, namely a literature and qualitative empirical study in the form of semi-structured interviews. The research design is explanatory in nature and aims to improve insight by using a logical process when linking different sets of facts. A thorough description of the methodology is as follows:

1.9.1 The descriptive empirical task

The descriptive empirical task involves gathering information to discern patterns and dynamics in particular episodes, situations or contexts. Osmer (2008:33) grounds this task in a spirituality of presence, which requires attending to what is going on in the lives of individuals, families and community with an attitude of priestly listening. Priestly listening can be informal, semiformal or formal (Osmer, 2008:37).

Practical theology involves the listening to different voices from the text and the context. Empirical research is a form of formal attending (disciplined manner of attending) in a spirituality of presence, making it consistent with priestly listening (Osmer, 2008:39, 58). When doing empirical research, it is necessary to describe the formal aspects of a reliable methodology (Hermans & Schoeman, 2015:45-

63). Fouché and De Vos (2011:89-100) describe the aim of empirical research as one of the following three purposes of research: exploring a topic, describing a situation and events, or explaining the connection between variables and events. The distinction between the three is not absolutely diverse, because in most instances empirical research will consist of all three elements (Hermans & Schoeman, 2015:45-63).

The descriptive empirical task for this research follows an empirical study (chapter 2) and a literature study (chapter 3).

The qualitative empirical study explores current guidelines used by Christian counsellors, social workers, psychologists and CANCA/CHOC workers to gain insight into methods or guidelines that successfully relieve caregiver related stress. Qualitative research supports an inductive style, focusing on individual meaning, as well as the importance of rendering the complexity of a situation (Creswell, 2009:4). Using qualitative data collection methods, the researcher gains a "richness and depth of data", collected from complex and multi-faceted phenomena within a certain social context (Strydom & Bezuidenhout, 2014:173).

The researcher is interested in understanding subjective experiences allowing her to understand things through the eyes of the participants, offering the researcher the chance to understand the what, why and how of the context (Strydom & Bezuidenhout, 2014:173). To understand the activities and practices people engage in and the meaning they attribute to their experiences, the qualitative approach will deal with non-numerical data and a small sample (Osmer, 2008:47-78).

When selecting the data collection method, the qualitative researcher needs to keep in mind that the aim is to explore and understand in order to explain the phenomenon. Further also, remembering that choices made in previous steps of the process will determine what the data collection method should be (Strydom & Bezuidenhout, 2014:174). It is essential that the data collection method will allow the researcher to achieve the desired outcome of the study as anticipated in the research goal and research question. In the same way the choice of data collection method will determine the findings that will be presented (Strydom & Bezuidenhout, 2014:175). Maintaining a coherent research design in any study is essential and also relates to the concept of the golden thread. Aligning the data collection, analysis and interpretation methods to the research goal and question is further important to ensure the validity and trustworthiness of the qualitative study (Strydom & Bezuidenhout, 2014:175).

The qualitative data collection for this study is by using semi-structured interviews within the case study approach. Strydom and Bezuidenhout (2014:178) describe this approach as "a thick and detailed description of a social phenomenon that exists within a real-world context". The researcher will attempt to understand a phenomenon (caregiver related stress) within specific circumstances (families living and taking are of a family member diagnosed with cancer).

The researcher made a pre-selection of 8 individuals in the field of pastoral counselling, social workers, psychologist, CANSA (Cancer Association of South Africa) and CHOC (Childhood Cancer Foundation) working with family members of cancer patients, to interview. These professionals were selected because they represent a variety of multi-discipline counselling methods working with the caregiver and caregiving related stress. This number may increase or decrease where individuals are no longer available at the time of research or where new individuals are identified to add to the number. All information was treated confidentially and therefore the participants as well as their clients' names remained anonymous. In cases where the professionals work for a specific institution the necessary consent was gained from the manager of the institution.

The data collection method was in the form of semi-structured interviews. An interview is a conversation taking place between two individuals in which one of the parties seeks information from the other for a particular purpose (Gillham, 2000:1). Osmer (2008:61) describes a good interviewer as an active listener who attends carefully to both the verbal and nonverbal responses of the interviewee, while guiding the conversation without over controlling it. "Mature interviewers talk less and listen more" (Osmer, 2008:62).

Questionnaires are used to gather the necessary information from the interviewees regarding a specific phenomenon (Maree & Pieterson, 2009:158). The amount of structure and the type of questions are two important decisions to be made prior to the conversation that will shape the interview (Osmer, 2008:62). The researcher used semi-structured interviews with a predetermined set of questions in a specific order, while being flexible and open to deviate from the order if the participant should spontaneously move into an area to be covered at a later point.

The researcher used face-to-face interviews with the selected individuals. The interviews took place in the professionals' own counselling rooms. The interviews were recorded and transcribed with the necessary consent of the participants.

Qualitative content analysis has been defined by Hsieh and Shannon (2005:1277-1288) as "a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns". The researcher identified subjective themes and patterns that emerge from the answers with the goal to provide a detailed description of the social reality (Strydom & Bezuidenhout, 2014:191).

The second part of the descriptive empirical task (chapter 3) is in the form of a literature study to systematically gather information in order to understand different types of caregiver related stress significant others experience while taking care of a relative with cancer. A literature review defined by Hart (1998) is an objective and in-depth summary, as well as critical analysis of relevant research and non-research literature on the studied topic (Cronin *et al*., 2008:38-43).

1.9.2 The interpretative task

The interpretive task finds the reasons for the phenomena observed in the descriptive empirical task by asking the question “why is it going on?” (Osmer, 2008:81). In this task the interpretive guide must identify the issues embedded within the episodes, situations and contexts observed, and draw on theories from the arts and sciences to assist with understanding the issue. Osmer (2008:82) refers to this process as applying sagely wisdom which requires the interplay of three characteristics namely: thoughtfulness, theoretical interpretation and wise judgement (Osmer, 2008:82). Thoughtfulness is the quality to reflect deeply about the question at hand striving to gain insight into the particular circumstances especially when experiences of being brought up short challenge the researcher’s preunderstandings (Osmer, 2008:82-83).

Osmer (2008:83) stresses that all theoretical knowledge is fallible and grounded in a particular perspective and thus is used fully understanding these limitations. Although theories play an important part in understanding and explaining certain features of the situation it never provides a complete picture of the context. For this reason, the researcher must be aware of the difference between theory and reality, acknowledge the complexity and uniqueness of people and events and avoid forcing them to fit the theory, thus calling for wise judgment. Wise judgment relates to Aristotle’s idea of *phronésis* “it involves discerning the right course of action in particular circumstances, through understanding the circumstances rightly, the moral ends of action, and the effective means to achieve these ends” (Osmer, 2008:84).

The interpretative task for this study consists of two chapters in order to find answers to the question “Why is this going on?”

Chapter 4 draws on a literature study from multi-disciplinary sciences discussing the Christian version of ACT, mindfulness, the neurological connection with mindfulness and the role of the PC. ACT assumes that “all human beings are hurting, just some more than others” (Hayes *et al.*, 2012:13). ACT at its core is a behavioural therapy, it is about values-guided action. ACT uses core values to guide, motivate and inspire behavioural change. Furthermore, ACT is about mindful action. Mindful action is a conscious action, with full awareness (being open to current experiences) (Harris, 2009:2). The motivation for mindfulness tools in these practices is to achieve calmness, the ability to observe the self in relation to own thoughts and reactions, as well as adopting a non-judgmental and compassionate attitude towards the self (Trammel, 2017:367-383).

It has been suggested that mindfulness produces vital anatomical and physiological changes in the human brain, similar to those that are introduced during skill acquisition (Munte *et al.*, 2002:473-479). Psychological and neurological studies show how Christian mindfulness and compassion can benefit the caregivers’ well-being. Well-being encompasses the body, mind and soul, in other words it is a matter of the economy, of academic, of intellect, of aesthetics and of spirituality (Ellens, 2011:1-6). Studies of mindfulness confirm the research in neuroplasticity that recognise a range of mechanisms activated during learning, which enables the brain to shape its anatomy and physiology in order to accommodate experiential input (Benfenati, 2007:58-66), and these changes are likely to occur during mindfulness practices (Larrivee & Echarte, 2018:960-978). The main neural features of mindfulness include intentional domains of the brain such as the prefrontal cortex and self-referential regions such as midline, integrative and distributive centres (the anterior cingulate cortex) and emotional centres (the amygdala) (Xue *et al.*, 2011:570-574; Cahn & Polich, 2006:180-211; Vago & Silbersweig, 2012:1-30).

The last section of chapter 4 discusses the pastoral conversation. For Purnell (2003:1) sharing in pastoral conversation is an amazing gift where the PC is invited into the most intimate spaces where people discuss "the very nature of their being human", sharing both joy and pain.

Chapter 5 focuses on the theological implications of coping with illness (sickness and suffering) by mainly focussing on work from Louw (meaning of compassion) and Hudson (intimate relationship with God), as well as practices of spiritual disciplines in the form of centring prayer (contemplative prayer), serenity prayer, *lectio devina* and worship.

According to Louw (2015b:2), there is a quest to find theological clarity on the meaning of compassion in pastoral theology within different contextual discourses. He states:

> In the effort to identify God with human suffering, *theopaschitism* became the theory or doctrine by which theology tries to construe a more passionate approach to our understanding of God's presence within the reality of human suffering (injustice, poverty, stigmatisation, discrimination, stereotyping, illness, violence, the abuse of power, tsunamis or catastrophes) (Louw, 2015b:12).

The *theopaschitic* approach redefines God's Being in terms of suffering. This approach thus connects God with suffering of which the cross completes the connection to reveal God as the "suffering God" (Louw, 2015a:1-15). Feitsma (1956:42) describes this form of *theopaschitism* the ultimate expression in theology of the meaning of God's compassion.

Mindfulness in Christianity can be traced to historical models in the mystical and contemplative traditions who use *apophatic* and *kataphatic* prayers as part of their religious practices (Trammel, 2017:367-383). The practice of mindfulness as an early Christian tradition can include Eastern Orthodox practices, for example the Jesus prayer, Western contemplative practices such as centring prayer and *lectio divina*. Mindfulness is an internal skill of being aware of and examining own thoughts (Lutz *et al.*, 2015:632-658; Smith, 2013:91-102), it is an attachment and unity to God, as well as utilising the skill of listening in order to deepen the relationship with God contained in Christ, the Holy Spirit and God the Father (Keating, 2006:2; Tan, 2011:243-249). Centring prayer is a movement that goes beyond conversation with Christ to communication with Christ (Keating, 2017). "The source of Centring Prayer, as in all methods leading to contemplative prayer, is the indwelling Father, Son and Holy Spirit" (Keating, 2017). Emphasis falls on the deepening of a relationship with the living Christ.

All these elements of mindfulness can be attained by practising deep breathing, guided imagery and sensory identification which are tools rooted in third-wave behavioural practice interventions, such as Dialectical Behavioural Therapy, Acceptance and Commitment Therapy (ACT) and Mindfulness Based Cognitive Therapy (Brown *et al.,* 2011:187-200; Gockel *et al.,* 2013:36-59; Lynch *et al.,* 2006:459-480; Lynn, 2010:289-304; Hayes *et al.,* 2006:1-25; Juarisco *et al.,* 2010:175-190; Ost, 2008:296-321; Twohig *et al.,* 2010:705-716).

1.9.3 The normative task

The normative task "what ought to be going on?" seeks to discern God's will for present realities. This task is referred by Osmer (2008:129) as prophetic discernment. Even though the Old Testament prophets spoke normatively of God, in addition they were also interpreters of past traditions and present revelations. The aim of the term prophetic discernment is to describe "the interplay of divine disclosure and human shaping as prophetic discernment" (Osmer, 2008:33). Prophetic discernment thus entails both divine disclosure and human shaping through God's word (Osmer, 2008:134-135). Three methods are used to discover God's word in prophetic discernment: theological interpretation, ethical reflection and good practice (Osmer, 2008:131-132). As theological interpretation is informed by biblical and systematic theology, it concentrates on interpreting present episodes, situations and contexts with theological concepts (Osmer, 2008:139). Ethical reflection is concerned with ethical principles, rules or guidelines to guide action to moral ends (Osmer, 2008:161). Osmer (2008:153) allocates two roles in good practice. First, the interpretive guide draws on models of good practice (past and or present) with the purpose to improve present actions. Secondly, analysing present examples of good practice "can generate new understandings of God, the Christian life and social values beyond those provided by the received tradition" (Osmer, 2008:153).

The prophetic word arises from "a fellowship with the feelings of God, a sympathy with the divine pathos" (Osmer, 2008:137). Heschel (2001:285) describes it as follows:

> God does not reveal himself in an abstract absoluteness, but in a personal and intimate relation to the world. He does not simply command and expect obedience, He is also moved and affected by what happens in the world and reacts accordingly. Events and human actions arouse in Him joy or sorrow, pleasure or wrath… man's deeds may move Him, affect Him, grieve Him or, on the other hand, gladden and please Him. This notion that God can be intimately affected …basically defines the prophetic consciousness of God.

The normative interpretation is also divided in two chapters.

Chapter 6 gains a deep theological understanding of the significance of God's presence within the context of caregiver related stress by means of firstly, a theological word study on the word "being-with" (Exodus 3:14). This verse finds the priority of compassion specifically the act of "divine presence which is a boundless and unending being-with" (Davies, 2001:20). Followed by, secondly, the suffering God and the theology of the cross as the framework of the *theopaschitic* approach will be discussed; thirdly, the greatest commandment: Matthew 22:36-39 and fourthly, dealing with the power and love of God in the midst of suffering: Romans 8:18-28.

Chapter 7 focuses on the pastoral theology viewpoint by means of "The cycle of Grace" (Hudson & Haas, 2012) and the labyrinth to discover God within. Buechner's (1983) quote fits well with walking the labyrinth: "Listen to your life. Listen to what happens to you because it is through what happens to you that God speaks."

1.9.4 The pragmatic task

The pragmatic task of Osmer's (2008) model will be used to find answers to the question of what kind of leadership model is open to the foundation Jesus laid, "how might we respond?" The study will seek to come up with a fitting response to the situation examined, developing and enacting strategies that will lead to change. Practical theology research offers help by proposing models of practice and rules of arts that disclose how to change things (Osmer, 2008:176). The spirituality of servant leadership is to lead others to deep change "in ways that more fully embody the servanthood of Christ" (Osmer, 2008:192). Christ redefines the nature of power and authority by taking the form of a servant by means of teaching and acting it out (Osmer, 2008:184).

> The Lord is a servant, and the Servant is the Lord. Power and authority redefined. A reversal takes place. Power as domination, or power over, becomes power as mutual care and self-giving. Power as seeking one's own advantage becomes power as seeking the good of others and the common good of the community (Osmer, 2008:191).

This study aims to formulate a holistic Scripture based pastoral model in helping significant others to cope with caregiver related stress. In chapter 8, all the findings of the previous chapters in this study served as building blocks for a holistic Scripture based theological model to assist significant others cope with a cancer diagnosis in the family.

1.10 ETHICAL CONSIDERATIONS / IMPLICTIONS OF THE RESEARCH

The following ethical considerations were taken into account:

1.10.1 Estimated risk level

The estimated risk level is minimal, because the interviews with Christian counsellors, social workers, psychologists and CHOC/CANSA working with families related to cancer do not exceed the stress than they experience daily.

1.10.2 What was expected of participants during interviews?

- Participants were required to adhere to ethical considerations, such as confidentiality.

- Participants were required to answer all questions through an interviewing process that will take no longer than 90 minutes.

1.10.3 Probable experiences of the participants

The selected professionals participating in the interviews answered questions for approximately 90 minutes, which meant that they had to schedule the time in between their counselling hours. If necessary, the researcher would be willing to pay the consultation fee. The interviews were a semi-structured process to allow possible follow-up questions to cover all possible angles of the discussion. The participants shared their counselling techniques because the discussion did not contain personal memories, there was no emotional distress.

1.10.4 Risks and precautions

Possible risks	**Precautions**
Breaking confidentiality	All the participants, as well as their clients' identities will be held as confidential and the final document will not reveal the names of either. Information will be protected under a password protected file on the researcher's computer.
Legal issues due to breach of ethical considerations for instance breach of confidentiality.	Participants will be informed of the ethical considerations and be required to sign an informed consent form before commencing with the interview.

1.10.5 Benefits for participants, society and researchers

The research outcome will benefit Christian counsellors, social workers, psychologists and CANSA/CHOC's existing counselling methods for families coping with a cancer diagnosis within the family. The outcome will furthermore contribute to the existing knowledge in counselling skills concerning caregiver related stress. It will open up opportunities for adjustment for professionals to reflect on and add to their existing counselling methods. Families coping with cancer will holistically benefit greatly from these counselling methods/skills. The study will provide and highlight areas for future research through the needs identified in the study.

1.10.6 Risk/benefit ration analysis

Any risk to the participants is highly unlikely, the benefits of a modified counselling model outweigh any risk or discomfort. As a result, any anticipated risk is almost non-existent with a hundred percent benefit.

1.10.7 Expertise, skills and legal competencies

The research calls for professional communication skills, presentation skills, experience in conducting research and convey knowledge in the counselling domain. The researcher has the necessary skills for conducting the research having directed interviews for an honours degree which was successfully completed by means of qualitative research. The researcher further practises as a counsellor and co-active coach where people skills, confidentiality, empathy and listening skills are key to the counselling process. She is further a director of a foundation bringing relief to paediatric oncology where both patients and families are focussed on.

1.10.8 Facilities

The researcher conducted the interviews at the participant's practices complying as far as possible with their schedules.

1.10.9 Legal authorisation

As the interviews were strictly confidential, the participants did not disclose patients' names, alphabetic letters were ascribed to families (for example, family A, family B). The main purpose of the interview questions was directed towards existing counselling methods that hold positive results; disclosure of patient information was thus not required in the interview. Legal authorisation was requested in cases where the participant is working for an institution before commencing with the interview.

1.10.10 Goodwill permission/consent

Written consent was obtained from the research participants. Some of the participants have already been engaged with and agreed to the interview in principle awaiting the formal written consent documents.

1.10.11 Criteria for participant selection and recruitment

- Inclusion criteria:

The criteria for selected participants are individuals who are counselling individuals dealing with cancer in the family. They must have been practising as counsellors for at least three years. Variation in ages is an important factor in order to gain a broad scope of different counselling methods/styles. Males and females will be included in the study and the geographical area will be limited to the provinces of Gauteng and Free State.

- Justification:

Participants in the counselling industry for at least three years gained adequate experience to contribute to the research project. A range of professions, ages as well as both females and males are selected to get a rich body of knowledge (experiences) of both counselling techniques and different approaching methods. The selected provinces are both in manageable travelling distances for the researcher.

- Exclusion criteria:

Individuals under the age of 18 will not form part of the interviewing process. All participants will be literate in English.

- Justification

The purpose of the interview is gathering existing counselling techniques successfully in use by professionals. With the focus on professional people individuals under 18 does not fall in this category. Interviews will be conducted in English, responding to other languages will be time consuming.

1.10.12 Participant recruitment:

Recruitment of participants started after permission was given by the ethics committee of North-West University and run parallel with the actual research. Participants from different institutions (practices) were selected with the purpose to gain a wide range of counselling styles. The researcher selected one person per category (psychologist, social worker, counsellor and CHOC / CANSA) and asked them to provide one person in their field working with caregiver related stress.

1.10.13 Informed consent (Consent, permission, assent and dissent)

The researcher contacted the participants per email explaining the following:

- The research is of an academic nature;
- The aims and objectives;
- What is required of the participants;
- The benefits of the research
- The expected time for the research;
- The confidentiality level;
- Information about the way the research outcome will be managed;
- That withdrawal is an option and that withdrawal from the study will hold no consequences to the participant.
- Consent form that needs to be signed.

1.10.14 Announcement / Distribution of study results to participants

Participants will be informed via email on when and where the results of the study will be published and how it can be accessed. The results will be shared with the participants within three months of completion and obtaining approval for the study.

1.10.15 Privacy and confidentiality

All the data collected are considered as confidential only to be seen by the researcher. To ensure anonymity, the participants did not disclose their clients' names to the researcher. Alphabetical letters were allocated to clients during the interview and in the process of transcribing the data. Data are locked in a cabinet. Electronic documents and transcripts are secured by a password only known to the researcher.

1.10.16 Monitoring of research

The researcher was responsible for the completion of the research working in compliance with the approved protocols. Ethical considerations were strictly adhered to throughout the process. Progress of study and amendments during study was checked with the research supervisor.

1.10.17 Trustworthiness, validity and reliability

A) Trustworthiness

The study draws on a qualitative study by way of semi-structured questionnaires with selected participants. To gain optimal advantages of the in-depth interviews the researcher considered the following aspects in planning the interviews (Strydom & Bezuidenhout, 2014:189):

- The questions will move from broad to a narrow focus, beginning with broad, general questions regarding the topic. Answers may contain cues indicating that there is more information to be obtained. More focussed follow-up questions will stem from these cues and will be designed to gather as much detail as possible.
- Questions will be semi-structured allowing the interview to progress in a natural and conversational manner.
- To ensure that the participants know what are expected of them the questions will be structured in a clear and simple way that will allow the participants to communicate clear and precise answers.
- Researcher will guard against asking leading questions allowing the participant to express their opinion instead of what they think the researcher wants to hear.
- Questions will address one aspect at a time, thus avoiding double-barrelled questions.

The information given by the participants are based on what they meant, rather than what the researcher feels or thinks they meant. To this end, effective listening was the most important aspect of the interview

- The researcher did not ascribe own meanings and perspectives to the responses of participants.
- The researcher listened for hidden and underlying associations.
- The researcher did not assume that she knows exactly what the participants mean, prompting them to clarify what they meant.

B) Validity and reliability of qualitative studies

The collection method of data was by means of interviews. The processes used in data analysis and interpretation were systematic and thorough with the purpose of allowing a rich and detailed description of meanings in the study's findings Through qualitative analysis and interpretation data were formed into findings (Strydom & Bezuidenhout, 2014:228).

C) Qualitative data analysis

Hermeneutic analysis was used to analyse the collected data through interviews. According to Neuman (2003:76), hermeneutics includes "a detailed reading or examination of text, which could refer to a conversation, written words or pictures", permitting the researcher to consider and describe a holistic picture by looking at the interaction between specific details and broader general context (cf. Strydom & Bezuidenhout, 2014:231).

The data gathered from the interviews were converted or transcribed into written text. When qualitative data are analysed, whether collected through interviews, field notes or observations, it is referred to as analysing text (Strydom & Bezuidenhout, 2014:228). The researcher used the full range of responses, including non-verbal cues displayed by participants during the interview. Transcribing of data helped the researcher to get better equated with the data. The aim of the first round of transcription was to get a general feeling of the gathered information. Revisiting the material created opportunities for reflection. To get a thorough understanding of the material the researcher made notes and wrote down impressions as she worked through the data.

1.10.18 Role of the researcher

- Obtain ethical clearance from the North-West University
- Design participant consent forms
- Explain consent forms to the participants
- Make sure that participants understand and sign the consent forms
- Ensure confidentiality of information
- Keep data secure
- Ensure voluntary participation permitting the participants to withdraw from the research if they choose to

1.11 CHAPTER OUTLINE

Chapter 1: Introduction

The first chapter serves as the blueprint of the subject being studied, the reasons for the study and the process that was followed.

Chapter 2: Empirical study

Qualitative research explored current guidelines used by professionals to gain insight into methods or guidelines that successfully relieve caregiver related stress.

Chapter 3: Literature study on symptoms and effects of caregiving related stress

Literature reviews to systematically gather information in order to understand what caregiver related stress significant others experience while taking care of a relative with cancer.

Chapter 4: Literature study: multi-disciplinary counselling

This chapter draws on a literature study from different arts and sciences discussing the Christian version of ACT, mindfulness, compassion, the neurological connection with mindfulness and the role of the PC.

Chapter 5: Literature study: *Cura Vitae*

This chapter discusses the theological implications of coping with illness (sickness and suffering) by mainly focussing on work from Louw and Hudson, as well as practices of spiritual disciplines in the form of centring prayer (contemplative prayer), serenity prayer, *lectio devina* and worship (music).

Chapter 6: The theological concept of compassion

In this chapter a deep theological understanding of the significance of God's presence within the context of caregiver related stress was gained by means of:

- A theological word study on the word "being-with": Exodus 3:14. This verse finds the priority of compassion specifically the act of "divine presencing which is a boundless and unending being-with" (Davies, 2001:20).
- The compassionate God: Ephesians 2. Discussing the suffering God and the theology of the cross as the framework of the *theopaschitic* approach (passion of Christ).
- Self-compassion through love: Matthew 22:36-39. The greatest commandment.
- A message of hope: Romans 8:18-28. The power and love of God in the midst of suffering.

Chapter 7: Pastoral concept of mindfulness

From a pastoral theological viewpoint this chapter discusses the concept of mindfulness using the Cycle of Grace from Hudson & Haas (2012). The four movements will be practised by walking the labyrinth.

Buechner's (1983) quote fits well with walking the labyrinth, "Listen to your life. Listen to what happens to you because it is through what happens to you that God speaks".

Chapter 8: Model to help significant others with caregiver related stress

In this chapter the research seeks to find a holistic Scripture based pastoral model in helping significant others to cope with caregiver related stress. All the findings of the different points of departure gathered in this study, serves as building blocks for a theological model to assist significant others cope with a cancer diagnosis in the family.

Chapter 9: Summary and conclusions

This chapter presents a summary of the research and findings of all previous chapters. The conclusion provides a counselling model with the aim to assist with caregiver related stress in cases where a family member is diagnosed with cancer.

1.12 VALUE OF STUDY

This study will bring awareness to the significant others of cancer patients and contribute to the body of knowledge regarding caregiver related stress where a member of the family has been diagnosed with cancer. The researcher prays that the model will be used by professionals for example social workers, Christian counsellors, psychologists, CANSA /CHOC to assist with stress related issues as a result of cancer.

CHAPTER 2: EMPIRICAL STUDY

2.1 INTRODUCTION

In this chapter the first part of the descriptive empirical study will be presented by means of a summary of the findings.

With a cancer diagnosis, the patients as well as their family members are challenged to learn about the evolving illness, the treatment thereof, treatment-related side effects, prolonged hospitalisations and the overall uncertainty surrounding the cancer journey (physically, emotionally, spirituality). The unfamiliar nature of the illness can be distressing (Beale *et al.*, 2003:385-397), providing the patient and family with anticipatory guidance, psychosocial support and psychoeducation about what to expect along the illness journey (from diagnosis throughout treatment, after survivorship, and end-of-life) is believed to be an important aspect of care (Ringner *et al.,* 2011:244-251; Vetsch *et al.*, 2015:859-866). Psychoeducation is a concept used in the context of chronic illnesses referring to the process of providing information to patients and IFCs with the purpose of empowering them, assisting them with day-to-day management of the illness and decision-making, relieving uncertainty, and increasing psychosocial adaptation to the illness (Plante *et al*., 2001:435-453).

While many families and cancer patients may cope effectively during the cancer course (Patenaude & Last, 2001:281-283; Patenaude & Kupst, 2005:9-27), it is clear that a significant number of cancer patients and their families will experience substantial levels of psychological distress at the time of diagnosis, during the course of cancer treatment, and after treatment ends (Patenaude & Kupst, 2005:9-27; Kazak *et al.,* 2005:644-655). Studies highlight the importance of providing psychoeducation at the time of diagnosis as the greater part of cancer patients and their families benefit directly from a psychosocial provider (Sahler *et al*., 2005:272; Vannatta *et al*., 2009:319-333; Sahler *et al*., 2013:1329-1335). As such, access to and providing of pastoral caregiving is clearly necessary throughout the cancer experience to the transition to a “new normal”.

Although research and clinicians agree on and emphasise the importance of providing guidance to the cancer patient and their family, and giving them access to psychosocial support and intervention throughout the cancer journey (Steele *et al*., 2015:585-618), IFCs continue to report unmet informational needs along the cancer journey, from the diagnosis (Abum & Gott, 2001:300-305; Zebrack *et al*., 2013:201-214) throughout treatment (Duffey-Lind *et al*., 2006:335-343; Mckenzie & Curle 2012:647-654; Wakefield *et al*., 2012:621-626) into survivorship (McClellan *et al*., 2013:245-262; Vetsch *et al*., 2015:859-866) or end-of-life (Freeman *et al.*, 2004:87-97). For this reason, a study on how to help significant others cope with cancer related stress is worthy.

2.2 THE AIM OF THE EMPIRICAL STUDY

The significant psychosocial impact of a cancer diagnosis on both the patient and family over the course of the treatment and beyond is well established and widely understood (Kazak *et al*., 2015:426-459). Although, there is this recognition about the impact, there is not much written about the support of significant others. Being a significant other herself, the researcher wants to develop a holistic, Scripture-based, pastoral model to help the significant others cope with cancer related stress. This chapter will entail the first part of the descriptive task and will focus on the findings of the qualitative empirical part of the study.

2.3 QUALITATIVE RESEARCH

Qualitative research deals with the fundamental qualities of personal experiences and the meanings associated with occurrences, further assuming that it is difficult to impossible to measure and quantify these occurrences and meanings. For this reason, quantifiable measurements will not be appropriate for researching lived experiences and experiential meanings of individuals (Du Plooy-Cilliers *et al.,* 2014:173). This study is interested in understanding personal experiences which will allow the researcher to see things through the participant's eyes, affording the researcher to understand the "why", "what" and "how" of the cancer journey (Du Plooy-Cilliers *et al.,* 2014:173).

The goal of qualitative research is to get a view or understanding of real-life experiences, because of the interest in the depth of human experiences, including the characteristics of individual encounters and meanings associated with the phenomenon under investigation (Du Plooy-Cilliers *et al.,* 2014:173). Keyton (2011:58) notes that "qualitative research does not convert their observations or participants' observations into numerical form, nor do they separate out or isolate part of the interaction from the whole".

The qualitative empirical study was done using semi-structured interviews with social workers, nurses, hospice representatives and pastors to find out how they perceive and attach meaning to their work associated with families dealing with cancer related stress. The findings of the empirical study will therefore be a thick and detailed description. Qualitative research gives a voice to ordinary people (Gomm *et al.*, 2000:22; Babbie & Mouton, 2002:270), which facilitates the goal to focus on the particular and private experiential realities of the participants. The aim is to represent the study authentically and, in this process, discover symbolic realities that expand and clarify the unique voices of the relevant professionals (Gomm *et al*., 2000:6-7).

2.4 COLLECTION AND ANALYSIS OF DATA

For the collection of data, the researcher made use of snowball sampling where the formation of the sample group for the study starts with only one contact person and was then referred to possible other participants. The referral is recruited into the sample group and he/she also provides a new referral (Strydom & Bezuidenhout, 2014:173). This pattern was continued until the sample group of eight was reached. Having personal experience of the cancer journey, the researcher started with two professionals who assisted her family through their cancer journey.

In total nineteen prospective contact persons in the regions of Bloemfontein (Free State province), Pretoria and Johannesburg (Gauteng province) where invited to take part in the study. From the group of 19 referrals, only eight agreed to face-to-face semi-structured interviews. After the participants showed interest to be part of the study an e-mail was send to them attached with the participant information leaflet and consent form explaining the study and ethical concepts. Once the participants replied to the mail agreeing to participate in the study, the researcher made contact to arrange the interview. To conduct the interviews, the researcher travelled to a predetermined location, date and time most suitable for each participant. All participants are professionals who are currently working with cancer patients and their families. Their occupations ranged among counsellors, hospice representatives, pastors, occupational therapists and nurses.

TABLE 1: Details on representatives approached for interview

Occupation	Contact persons	Geographic setting	Agreed to interviews	Participant
Psychologist	2 2	Johannesburg Bloemfontein	0 0	Not applicable
Pastoral Psychologist	1	Johannesburg	1	G
Counsellor	1 1	Johannesburg Bloemfontein	1 1	H B
Hospice representative	1 1	Pretoria Bloemfontein	0 1	 D
Pastor	1 1	Johannesburg Bloemfontein	0 1	 C
Occupational Therapist	2	Bloemfontein	1	A
Registered Nurse	1 1	Johannesburg Pretoria	1 1	F E
Social worker[3]	1 1 1	Johannesburg Pretoria Bloemfontein	0 0 0	Not applicable
CHOC (Childhood Cancer Foundation South Africa)	1	Pretoria	0	Not applicable

2.5 PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Each participant received a covering letter explaining the relevance, background and aim of the study as well as the ethical process of how each participant’s confidentiality will be respected.

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[3] A telephonic conversation with the social worker in Bloemfontein revealed that the person would not be viable for the study as the social worker mainly focuses on arranging transport for cancer treatments and financial support. The work surrounding the duties of this social worker therefore does not include counselling outside of logistical assistance.

2.6 SEMI-STRUCTURED INTERVIEWS

The researcher gained information from participants by means of interviews consisting of semi-structured questions. The aim of the interviews was to gain insight from the relevant professionals by focussing on the following themes:

- Method of counselling (counselling model)
- Frequency and number of counselling sessions needed
- The differences and uniqueness of the family members (gender, age, support systems, religion as a coping mechanism, homework)

2.7 STUCTURE OF THE QUESTIONNAIRE

Clear questions where formulated in a semi-structured way and the participants were encouraged to add any extra knowledge and information relating to the questions. Questions where organised in three main themes.

<u>Theme 1</u>: The aim in this section was to determine if the participants use a specific model when counselling IFCs, and if so, the reason for using the specific model.

<u>Theme 2</u>: Here the researcher established the reasons for psychosocial care and support from a professional, and how often counselling was recommended and / or needed.

<u>Theme 3</u>: In the last section of the questionnaire the researcher gained information on the uniqueness of IFCs. This segment explored differences in gender and ages, coping mechanisms such as different support systems and religion, as well as possible homework given to IFCs to help them cope with cancer related stress due to the caregiving tasks. Ages fall under two main groups, the adults (parents, spouses, grandparents) and preadolescent/adolescents (ages 14 and up to 18).

The researcher paid close attention to psychosocial risks, for example adjustment problems, family problems (communication), social isolation, as well as resiliencies (coping and well-being).

2.8 FEEDBACK FROM INTERVIEWS

Due to the complexity of a cancer journey the type of support and interventions offered to both, the cancer patient and their family should be provided by an individual with training and expertise in skills for the emotional adjustment to cancer, family systems and or resources the family may need (Steele *et al*., 2015:585-618). To gain rich data, the researcher selected participants with ample experience and insight into the cancer journey. The relevant professional groups identified and interviewed for this study consisted of social workers, counsellors, pastors, hospice representatives and occupational therapists.

The following experts across a range of relevant professional groups from different geographic settings gave consent to take part in the study and thus form the research respondents.

Participant	**Gender**	**Occupation**	**Duration working with IFCs**	**Geographic setting**
A	Female	Occupational therapist	Since August 2019	Bloemfontein
B	Female	Counsellor	10 Years	Bloemfontein
C	Male	Pastor	27 Years	Bloemfontein
D	Female	Hospice representative	5.5 years	Bloemfontein
E	Female	Registered Nurse	16 years	Pretoria
F	Female	Registered Nurse	43 years	Johannesburg
G	Male	Pastoral Psychologist	29 years	Johannesburg
H	Male	Counsellor	30 years	Johannesburg
Follow up interviews: None were required				

The interviews will now be described with emphasis on the identified themes.

2.8.1 PARTICIPANT A

As an occupational therapist in an oncological hospital unit since August 2019, participant A explains that the patients and their family cannot be separated, as the illness influences everyone involved. She explains that the cancer journey cannot be treated in isolation, "patient and family falls under the same umbrella". Although the doctors work physically with the cancer patient, the family is always present and involved in decision-making and in the occupational therapy sessions. For this reason, she spontaneously includes IFCs when it comes to emotional support, answering questions and easing anxiety. Participant A is currently experiencing cancer in her own family, as well. She is married to a pastor and as such she further encounters and assists families in their cancer journey.

Theme 1: Counselling model

As her counselling model, she uses the principles obtained from her master's degree in Mindfulness through the University of Stellenbosch to connect with and counsel both, patient and IFCs. She finds the model most helpful and equally suitable for both, patient and family of all ages and gender. Mindfulness has a very strong interconnecting function with the potential of helping the whole family (individually, as well as connecting as a unit). Her therapy conveys the message, "We are going through this together, and all of us are hurting, feeling unsure and scared".

Theme 2: Counselling sessions

Working in the oncological unit, she attends to new patients, as well as recurring patients and their families. Working in a hospital her treatment programme forms part of routine hospital care for cancer patients. It is thus a situation of reaching out to the patient, instead of families seeking her expertise. The occupational care practice has close relations with all oncological doctors who inform the therapists when cancer patients are admitted.

During the first session, she assesses both physical and emotional needs. On first encounter, most family members and patients do not recognise a need for help, feeling that they are coping well enough with the diagnosis and cancer journey. It is only from the second or third sessions that family members and cancer patients start to admit and / or realise their need for help and accept assistance from the therapists. Once a need has been established, the therapist will determine what the specific need is. She remarks that, "It is important to never assume what the family and patient's needs are".

Daily hospital visitations are scheduled, depending on the patient's personality, need and stage of cancer. Sessions will depend on the duration of stay in the hospital – from a couple of days to weeks or months. The longest period of hospitalisation she worked with up to date was 6 weeks. Because it is in-hospital therapy, the therapy only lasts as long as the patient is in the hospital. Once the patient is discharged, contact with the patient and IFCs is broken and therefore consequently therapy ends. Patients are often re-admitted into the oncological unit. In these cases, the already established relationship with family and therapist will continue.

Participant A places priority on empowering both, the patients and IFCs as far as possible. Therapy is short-term based with the aim to help IFCs cope on their own as far as possible.

Theme 3: Uniqueness of individuals

a) Gender

Participant A recognises gender differences when it comes to handling the cancer journey. Her experience of gender differences is as follows.

Males are generally more hesitant to show their emotions and less comfortable connecting with their emotions. She is of the opinion that males curb their emotions due to the strong western cultural stigma of "boys do not cry". Female patients are also aware of it and admit how difficult their spouse finds it to adjust to the caregiver role in assisting them both emotionally and physically. "Males really struggle to cope with the diagnosis." In cases where a female cancer patient that used to be very active and dynamic in the household, the male spouse will struggle even more to sustain the same standards. "It's almost as if their world collapsed." When offered assistance from professionals (occupational therapist) the male spouse (caregiver) comes across as feeling embarrassed to acknowledge that they are struggling with their emotions.

Females are more willing to admit that they need therapy where males will say that they are coping (this applies to both the patient and IFCs). Females find it easier to accept help or ask for therapeutic assistance.

Participant A suggests the following approaches to accommodate gender differences:

- Make the therapist the same gender (use male therapist for male caregivers)
- Accentuate that the whole family (patient and family) carry the “burden” of the cancer journey. Emotions regarding cancer are evenly endured on a physical, emotional and spiritual level for all genders.
- Break barriers to “normalise” the situation. Let patient and family know it is “normal” to struggle, they should work towards finding new ways of coping with new routines to establish a “new normal”.
- The therapist can only reach out and offer assistance. At the end of the day IFCs must make the decision themselves to accept the offer or reject it. “Free will is key.”

b) Ages

Participant A had no direct contact with preadolescent/adolescents up to date. The oncological unit that she works in is for adults as a result she does not work with preadolescent/adolescents. The only indirect experience with preadolescent/adolescents observed up to date is that the family members tend to hide the diagnosis, stage and prognosis of cancer from their preadolescent/adolescents. They want to protect the preadolescent/adolescents from the cancer journey, sparing them from pain by for instance not even allowing them hospital visitations. Meanwhile, the cancer patient has an intense need to see and have contact with the preadolescent/adolescents. Participant A recommends that the preadolescent/adolescents should be included in the cancer journey, allowed hospital visitations and experience the cancer journey together with the diagnosed person and healthy family members. This is relevant especially in cases of terminal cancer. For the preadolescent/adolescents to gradually see the illness develop, they have the time to come to realise that it is the end for the diagnosed person. Where preadolescent/adolescents are not allowed to experience the steps of cancer, it is more of a shock to lose the member to cancer (only remembering them as healthy). Giving them the opportunity to witness physical deterioration makes it easier for the preadolescent/adolescents to bid their family member farewell and make peace with the imminent loss. In general, parents teach their preadolescent/adolescents that death is something terrible. According to participant A, parents need to teach their preadolescent/adolescents that death is part of life. By allowing them to be part of the cancer journey teaches them how to think about and cope with grief.

c) Support systems

Both, patient and IFCs seek the support of their pastor and key relatives. Participant A finds that people will fall back on familiar (existing) support structures. From her experience, new structures for example church prayer groups and cell groups will be groups or individuals reaching out to support the patient and family, rather than the family or patient seeking additional support.

d) Religion as a coping mechanism

According to participant A, religion can become an obstacle during the cancer journey. She finds it weary to work with people labelling themselves as “good” Christians, because they have a certain set of perceptions of what a “good” Christian should be and how they should handle difficulties in life. They do not allow themselves to feel scared, struggle or doubt, because this will make them “bad” Christians. Holding on to the stigma of “good” Christians becomes a barrier holding them from working through the process as they feel their identities would come into disrepute. Normal emotions of feeling anxious and scared are not allowed because fear is not from God and therefore fear is seen as a sin.

In contrast to perceived ideas of “good” or “bad” Christians, Participant A also notices a deepening of faith in patients and families, a deep appreciation of life and a treasuring of support structures (family, friends, church, wider community) more. This creates a deeper connection with religion, creating a newfound appreciation towards God for giving precious moments in life, because the cancer journey brings a realisation that life is a gift and that there are no guarantees, time is precious.

e) Homework

Mindfulness plays a big part in participant A’s approach to therapy and encounters with the family. Mindfulness based stress reduction (MBSR) makes use of very specific techniques, for example body scan, breathing, mindful walking and mindful eating. Participant A will try different techniques and continue with the technique that the family and patients find most comfortable and suitable to them. She explains her method as, “It is what works for them, instead of prescribing one to them”. Techniques that generally work for most people is the body scan and breathing exercises. Awareness of someone’s body is the first step (to be in the moment). Step two is to move to emotions and thoughts. Applying the body scan technique in the hospital, participant A will encourage both patient and family members to continue the exercise in their own time between sessions. Feedback is an important aspect in participant A’s therapy, apply a technique and then enquire, “How did the technique make you feel physically and emotionally?”, “What did you experience?”, “Did you encounter any emotions?”

A body sensation or “turning towards” technique invites the participant to search his/her own body for pain (physical pain is a sign of some sort of emotional pain). A normal reaction to pain is to get rid of it or block it as soon as possible. The contrary is avoiding and/or pushing pain away, but this will only escalate it. Mindfulness invites the participant to stay in the pain, inviting the person to sense uncomfortable sensations and to stay with it – allowing it to be there – turn towards it, being curious, investigate it (where does it begin and end, give it a structure, colour, intensity). With this the participant will realise that there are more emotions (sensations) than just pain. Realising that pain differs in intensity for example, can shift from an intense pain to a lesser pain. This brings awareness that their pain is not constant, making it easier to acknowledge, accepting and working with it makes it less overwhelming. “Knowing that moments of intense pain will pass, makes it easier to bear with it.”

Body scan feedback is very important in order to pinpoint the emotion and especially the effect thereof. Like pain, people also try to suppress or get rid of uncomfortable emotions as soon as possible. Further thinking that they are not allowed to experience the emotions, doubt, anxiousness and fear. With body scan the therapist invites the participant(s) to stay with the emotion, “Where do you feel it in your body?” Staying with this emotion, people realise that emotions are like a wave where the intensity differs. The actual emotional reaction lasts a minute, the lingering effect is thus not the emotion, but the thoughts connected to the emotion that had already passed. Thoughts and perceptions thus keep the emotion alive and growing.

One application highly recommended by participant A, is sleeping aid (smiling mind). From experience she finds this application to be diverse and equally suitable for all ages. “Smiling mind is a unique web and app-based programme developed by psychologists and educators to help bring balance to people’s lives”.

Participant A is very mindful of the religion of the family and works accordingly. Authors using mindfulness in a Christian context is for example Andrew Murray (2004), Willem Nicol (1989, 1990, 2002, 2008) and Richard Rohr (2014).[4] Another Christian based exercise is using a text in combination with breathing exercises. In essence for participant A, it is not about the religion, it is about accepting the person.

Additional information

Participant A struggles with entering and navigating the “sacred space” of family in the hospital often feeling like the outsider, infringing their space. She asks, “How do I enter the space without taking the sacredness away – without taking away the feeling of intimacy?” She feels that it is not her place to enter this space, especially in cases close to death where family members gather together. She further senses that some families are more closed off from receiving help from “outsiders” (therapists) than others. She encounters both emotional and physical blocks, recalling a time where a family physically blocked a door, not allowing anyone except family to enter their space. “There is an intimacy and as a therapist you do not have the same relationship level with all the family members, to break through this intimacy or sacred space is uncomfortable.”

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[4] In his theology of faith healing and belief the South African writer, teacher and Christian pastor Murray (2004) wrote numerous books on meditation and spirituality. After Murray, another South African author Nicol gives the greatest in-depth attention to Christian meditation within the Reformed Church. His work includes ‘Stem in die stilte’ (1989), ‘Naby Jesus’ (1990), ‘Gebed van die hart’ (2002) and ‘In die Hande van die Pottebakker’ (2008). American author Rohr (2014) is also well known for his spiritual books and referred to as one of the most admired spirituality authors and speakers in the world.

2.8.2 PARTICIPANT B

Participant B, a licensed counsellor, has been working with cancer patients and their families for the past ten years. Apart from her private practice, she also volunteers at hospice. As a pastor’s wife she further assists families in their congregation. On a personal level she lost her son to paediatric cancer. On both, professional and personal levels participant B shows a deep understanding and empathy towards the cancer journey. For these reasons, participant B can be considered as a valid candidate for the study.

Theme 1: Counselling model

Although participant B received training in Roger’s method, she does not follow a specific counselling model. Her approach is from a holistic point of view (advanced care plan), which includes the following four components: physical, emotional, spiritual and social. “You can’t concentrate on one aspect alone; you have to see the individual as a holistic entity.” Apart from seeing the individual holistically, participant B further stresses that patient and family cannot be seen as isolated cases; working with the one automatically includes the other as “they form a unit”. Her entry point (main question) is, “what gives meaning to your life?” – these include their environment (nature), the patient’s family, friends, occupation and their passion(s).

As participant B works in a palliative caring environment and sees her most difficult task as to be with the family, helping them to accept that death is imminent. Her work etiquette is to listen without judgement, with acceptance, reflecting on what she hears, looking at non-verbal language and to enquire about the non-spoken language. Through reflection, participant B reminds the client (family and patient) of how they managed previous difficult situations and using their own words to remind them of their power, abilities and existing support systems. It is important to her that the family realise that they can get through the journey, realising that the necessary power and knowledge are within themselves.

Flexibility is key, because every case and individual is unique, thus she shows a deep respect for everyone’s uniqueness and falls into step with the grieving stage they find themselves in. Participant B is intent not to enter a space with preconceived perceptions or ideas. “Therapy depends on how comfortable and willing the members are to open up.” In those cases, where the family and patient are closed and hesitant, she will provide a space of just being there with them in silence and acceptance (being present).

Theme 2: Counselling sessions

Before each session, participant B does breathing exercises, scans personal emotions, and identifies trigger points and conversations that may have an influence on her emotions.

The main purpose of the counselling sessions is to work through feelings such as emotional turmoil, extreme anger, confusion and blame. Participant B works from a point of mindfulness, bringing the family and patient to the current moment by asking, “what happened today that was beautiful?” or “what can you reflect on that was good in your day?” Small miracles are discovered by sometimes just looking out of the window and noticing the clouds, flowers, sun. Her advice will be not to look too far ahead for too long. This does not mean denial; it is about acknowledging the future, but bringing the patient and family back to the here and now.

A cancer diagnosis is a “sickness” drawing attention to old destructive family patterns. Within this journey lies the potential to change negative patterns to healthier patterns by working through them. This is where the dynamic action lies, where change and growth take place, making sense, working through resentment and changing old destructive family patterns.

In her private practice, people will seek counselling when they struggle with their emotions concerning the cancer diagnosis and journey thereof, as well as grieving. Private sessions will include a maximum of six sessions. The purpose of counselling is to empower the client. Her personal experience is that after six sessions the client tends to lose focus, “it is as if the sessions do not serve a goal anymore”, their thoughts start to wander. Sessions are scheduled once a week for six consecutive weeks. Long-term counselling sessions will be scheduled every second week (for instance grief counselling); again she is flexible and works according to the need of the client.

Theme 3: Uniqueness of individuals

a) Gender

In how gender differs in reacting to a cancer diagnosis, participant B notes that the difference lies more in personality than gender. It is rather a matter of how willing the IFC is to step into the caregiving role. Gender plays a bigger role on the practical side of the caregiving role itself. In this situation there is a noteworthy difference.

Usually with male caregivers an additional caregiver is brought in to do the physical caregiving tasks. Males feel intimidated and / or overwhelmed by the physical caregiving of their spouse. In cases where the diagnosed person is female with young children extra help in terms of professional caregivers, as well as family members will step in to assist with the children and house routines. “For males it is more about coping than caregiving.”

Female caregivers appear to be stronger in the caregiving tasks, more practical, do what needs to be done without showing that they are overwhelmed. Generally, emotions will come later (during remission or after death).

b) Ages

There are noteworthy differences in how the different age groups interpret and react to a cancer diagnosis and the journey thereof.

The main factor for spouses is the life stage they are in. Young families with small children always take it harder than older people. Normal reactions from the spouse will be feelings of being overwhelmed, out of sorts and being in denial. There is a journey of treatment and a journey of acceptance. The journey to acceptance is extremely important. The healthy spouse struggles to accept the coming death of their beloved where the diagnosed spouse is more willing to “let go” and accepting the end of their earthly journey. Patients instinctively know when their time has come although they generally find it difficult to voice this “knowing”. The most difficult thing to acknowledge to one another is, “I am going to lose you.” This requires a certain depth of saying goodbye and this is the part where participant B truly adds value.

There is a significant difference between parting with a spouse compared to parents parting with their child (here she is talking from a personal as well as professional point of view). The counsellor should be mindful of the difference and understand that the situation should be approached differently. Participant B understands and respects the huge responsibility of working with parents going through a paediatric cancer journey. “As counsellor you cannot think or feel that you understand their worry and pain; you are not in a position to coerce them to make sense of the diagnosis and journey thereof, the parents are not in a place to hear that.” Respect is key when working with the parents. A soft and compassionate approach is very important; another important aspect is honesty. “Honesty is worth more than empty promises or trying to make sense.” The younger the patient the more the feeling that it is unfair. Parents will say, “he or she still have so much to do, achieve, experience; life has only begun for him or her”, “how can my brilliant talented child with so much potential go through this?”, “how do I (we) make sense of this?”

In cases where an older person is diagnosed with cancer both the patient and family accept the illness quicker and more easily, coming to a place where they can appreciatively look back onto a rich and full life lived. Appreciating what they had and what they gave, acknowledging a rich live. The shorter the “turn back” period of remembrance the more difficult the journey because you imagined a long road ahead.

Grandparents’ pain is underestimated in the cancer journey. They experience doubly the emotions (both in their grownup son or daughter and their grandchildren). Not only do they have to see their grownup son or daughter go through the pain of dealing with their child being diagnosed with cancer, “carrying” their son or daughter’s worry and pain, while they themselves also feel for the grandchild. There is this strong assumption that the normal way of life is that parents will depart before their son or daughter and grandchildren. More and more modern life shows the contrary to this belief (cancer, car accidents, natural disasters, other illnesses). There is a sense of safety in holding on to the assumption that the old will depart before young because the contrary creates immense anxiety. It is only when being confronted with cancer personally that those involved form a different worldview (children can pass away before their parents and grandparents). This is where the counsellor must help families make sense of a world that is not congruent with existing perceptions. Grandparents do not get the attention that the parents get and are rarely part of crucial conversations and debriefings. They just step up and start helping with everyday chores and caregiving but often without the credit and understanding they need and deserve. Parents are so preoccupied with their own worries and pain that they not always recognise that their parents also need information, reassurance and love. As elderlies, their own physical restrictions cause frustration and feelings of powerlessness in wanting to do more. By being able to help with practical tasks gives a sense of value, empowerment, taking control (on some level) of the situation. Not being able to physically be there creates a sense of hopelessness.

Concerning the healthy siblings, their behaviour styles and relationship with the diagnosed sibling before diagnosis will be an indication of how confident they are in sharing their emotions as well as their behaviour during and after the cancer journey. As a rule, participant B notices that the healthy sibling instinctively knows to step back (asking less attention and time from parents). Often this perception of "lesser than" will come out later in the journey by appearing rebellious and demanding attention. Preadolescents/adolescents struggle to find the vocabulary to accurately express their emotions. General language used to express their emotions will be "I feel good, I feel bad, I feel down". They can't name specific emotions and do not know how to handle these emotions. They look to their parents for a cue as what to do and how to react when they for example feel frustration, anger, sadness, and uncertainty. They mimic their parents' reactions. If parents pretend that all is well the preadolescent/adolescents will follow the same trend. These underlying feelings will come out as anger outbursts, rebellion, low marks at school often without realising what the cause is. Participant B advises parents not to only express their feelings by for example saying, "I feel sad", "today I am feeling despondent" or "I am so frustrated today", but also explaining what they need from the healthy sibling for example "I just need to sit and cry, you do not need to comfort me but it would be nice if we can just sit together or if you make me a cup of tea". Voice the emotion and demonstrate appropriate behaviour to express the emotion. This creates the feeling of togetherness as a family and how to process the journey together. It is also healthy to acknowledge that they as parents do not always know how to handle the situation. Being honest gives the healthy sibling the permission to show their emotions.

Preadolescent/adolescents do not want to feel stigmatised (feeling there is something wrong with them). Participant B will take the cue from the preadolescent/adolescents working with what they volunteer without making the session formal and emotional, as they can easily feel overwhelmed during sessions. Preadolescent/adolescents often do not want to make direct eye contact, and taking them outside and walking the labyrinth help them to feel more relaxed. The success of counselling the healthy sibling (preadolescent or adolescent) is to make the session as informal as possible, making them feel heard but leaving choices up to them. It is about empowerment not prescribing but rather giving options.

c) Support systems

Gender differences noted in support systems for the healthy family members (informal family caregivers) are that males' support systems are much smaller than females. Initially male supporters feel uncomfortable talking about the diagnosis and cancer journey. Female supporters take action, are more comfortable and automatically go over in “what do you need?”, “what can we do for you?” Counselling entails in assisting the flow of friendships during a cancer journey. “How do the diagnosis influence your friendships, what changed, how did it change, what is helping, is there something that you find difficult?” Here practical advice on how to manage friendships works best.

d) Religion as coping mechanism

Participant B uses the acronym, FICA developed by Christina Pulchalski (1998:970-974; 2000:129-137) for spiritual assessment.

Box 1: FICA

Faith	**Importance and Influence**	**Community**	**Application**
“What do you believe in that gives meaning to your life?” Do you consider yourself to be a religious or spiritual person?” This is an important question because the individual may relate to one and take offence at the other. The answer to this question tells the counsellor something about the individual but needs exploration of what the terms mean to them.	“How important is your faith (religion or spirituality) to you?” Hearing that the individual is religious or spiritual tells the counsellor little. The counsellor needs to find out by asking, “How is this important?” There is a big difference between for instance a Catholic who has been to Mass sporadically and one who attends Mass daily.	“Are you a part of a religious of spiritual community?” For those who participate in an organised religion community it often forms a central part of their spiritual and social experience. This community often becomes more important during the cancer journey especially as death approaches.	“How would you like me to address these issues in your health care?” “How might these things apply to your current situation?” “How can I assist you in your spiritual care?” Patients and family often feel better because they have been given the permission to share their beliefs

Source: Hallenbeck, J. (2003).

Although a Christian herself, she has no predetermined opinions. She therefore does not work from any religious stance; she approaches the families with respect and acceptance regardless of their belief system. The reason for this is that she finds that families often go through turmoil and uncertainty regarding God and the cancer journey. Participant B experiences that believers often go through a period of religious struggle (RS). “Here is a loving God and it is His will that my wife, husband, child suffer with cancer and intolerable pain.” It is very important for both patient and family to work through their RS (emotional pain, concerns and anger). Participant B will offer her responses of “How can you experience a loving God differently?”, “How can you make sense out of the diagnosis?” She will always offer the help of a pastor, giving access to a pastor if the family requires one.

Participant B notes that depending on how the patient and family perceive God (for example, strict God or loving God) will determine if a cancer diagnosis brings them closer to God. In her experience it is more about making sense out of what is happening. Some will use their religion to help them make sense, understand and come to acceptance. It is making sense of "how is this fair?", "how could this happen?", "how do I make sense out of this?" These questions are important in the process towards acceptance.

Participant B encounters physical, social and emotional turmoil from the patient and family in different degrees, but one constant factor is a spiritual struggle. During the cancer journey, the patient and family must create new meaning, reconnect with themselves and make sense of all previous perceptions about life regarding religion, sickness, family and self. During the cancer journey, one loses connection with the self. For most families and patients their religion is the aspect pulling them through the journey. More often after a diagnosis, the members will initially draw away from religion (God), trying to make sense of the situation, but as they work through their emotions and preconceived perceptions, they will again turn to God. She finds that some churches do not allow the process of RS. They do not allow a farewell process, feeling of loss and sadness, or working through the daily struggle. There is no space for the family to mourn, while they see their loved one fading. Like Elizabeth Kübler-Ross (2014) says, it is the "little deaths", from the beginning of diagnosis, it is the loss and mourning of physical appearance, physical strength, role played, social interaction, *et cetera*. Death is only the last phase of mourning and even in cases of recovery the family still endures and must work through the "little deaths". Many religious practitioners do not allow or understand the dark and deep sorrow of a cancer journey, because they see it as doubt which is a sin. This is denying the individual's experience and feelings. It is more a realisation process asking how this experience helps you to draw closer to God.

Connection with self – unconditionally accepting the self with dark side, positive side, imperfection, strengths and weaknesses, "this is me; this is who I am". This acceptance flows over to other family members, showing emotions allows other family members to equally show their emotions which brings acceptance of self and others, calmness and peace to the situation. Making mindful connections by relating to God through nature (sun, wind, rain, flowers, and music) draws one outside of the self and one's concerns, sadness, tiredness. Participant B refers to these moments as "holy moments" bringing an awareness that humankind is just a speck of eternity; "more families are going through the same process; we are not alone." In these realisations comfort is found. Seeing mortality in the bigger picture: how many people have died before, how many families before went through the same ordeal. In these realisations, humanity and mortality are understood. This is where big changes begin, and God can be found in this process and realisations.

e) Homework

Homework, suggested by participant B depends on the family and their situation. Most general tasks suggested are, being aware of own needs (both emotional and physical) "What do you need to make the situation easier or better?" and then reflecting on these emotions and actions, "What emotions are coming up each day?" She will further encourage communication between family members (including the patient) for example tell life stories, share memories, share what each member means to you and how the patient will be remembered (legacy). Breathing exercises are another task regularly recommended, combined with prayer and Scripture reading.

Preadolescent/adolescents feel helpless, wanting to do something without knowing what to do. Participant B guides the preadolescent/adolescents by giving them options of what they can do, for example to draw something or make something for the patient. Physical activities empower the preadolescent/adolescents making them feel that they are contributing in some way.

The closer to the end of life the smaller the patient's world becomes – the outside world becomes less and less relevant. Friendships are not that important anymore, only key relatives are relevant, distant family becomes irrelevant. Last to remain in the inner world is close family – at this stage, memories take centre stage in the patient's life and words become less and unnecessary. Participant B will ask the family and patient "what do you see when you close your eyes?" From this comes the most beautiful metaphors, images and memories. This part of the journey, the "sacred space" is what drives participant B to do what she does.

Reflection forms an important part of the sessions, asking "what exercise worked best for you?", how did you perceive it?", "what is different today compared to a week ago?", "what can you do more or what can you do less?"

2.8.3 PARTICIPANT C

Participant C has been a pastor for twenty-seven (27) years at a Dutch Reformed Church. Over this time, he counselled several families and patients through the cancer journey. With this rich number of years, participant C can be considered as a valid candidate for the study.

Theme 1: Counselling model

Participant C does not use any specific counselling model. For him the most important aspect of his counselling is palliative care, getting the family and patient spiritually ready, helping and assisting them to mend their relationship with God.

Theme 2: Counselling sessions

Participant C visits the patient and family at least three times a week. When the patient is terminal, he will visit them every second day. During the active therapy stage, sessions will be scheduled once every two to three weeks.

Participant C cannot make a distinction between patient and family; they form a unit especially during a cancer journey. Visiting the patient at hospital or home family members will always be present, for this reason participant C counsells them together. There comes a point when the family need the counselling more than the patient. The patient comes to a point where he/she knows and accepts the end of the earthly journey. As soon as the patient admits that he or she is ready for the Lord to take them, participant C will turn the focus on the family in assisting them with acceptance and grieving.

Theme 3: Uniqueness of individuals

a) Gender

More than gender differences, Participant C experiences that time plays a big part in how a cancer diagnosis and the journey are perceived. People who had a fulfilled time together accept the diagnosis easier, whereas a young couple who envisioned a long life together, struggles to come to terms with the diagnosis.

With gender differences, participant C recalls two examples. One couple was married less than ten years and the other was married fifteen years. In both cases, the male spouse started separating himself from his dying wife – creating both an emotional and physical distance. Men come to a point where they are ready to part with their ill spouse; they seem to accept the coming loss of their loved one and start to move on. This can be a defence mechanism to protect themselves. This is especially true in cases where the couples have small children. The spouse separates him/herself from the dying spouse in order to place all focus on, and tend to their young children (ages under ten years old). According to him, both the patient and family find the process of accepting death (for the patient) and loss (for the family) easier when they believe in God. Knowing where they are going, is comforting to all parties involved. The patient wants to end their physical pain and equally, the family members want the patient not to suffer any longer. Males keep their emotions more to themselves and they do not cry easily in front of others.

Female caregivers are more emotional and appear to be emotionally stronger than the male caregiver. They do not detach (emotionally and physically) from their ill spouse, taking care of the patient from diagnosis through the treatment to recovery or death.

Diagnosis of cancer comes for some people as a terrible shock with a high degree of denial (it is not that bad, he or she will get better). Others accept the diagnosis quite easily and work with the illness as it proceeds. Acceptance for those in denial takes time. According to participant C, knowledge of the type of diagnosis, getting familiar with the process, and knowing what is to come, make acceptance easier.

b) Ages

Participant C cannot comment on noteworthy differences in how the different age groups interpret and react to a cancer diagnosis and the journey thereof. For him, it is more set perceptions that society holds, that influence the reaction towards cancer. As long as life remains within the “normal” circle of life where children bury their parents, illness and the end of life are accepted with more ease, whereas burying a child is difficult to accept.

Participant C does not work directly with preadolescent/adolescents and can therefore, not comment on how they react to, or handle a cancer diagnosis of a family member. From indirect experience what he noticed over the years, is that preadolescent/adolescents (from ages fourteen and up) become rebellious "why is God taking my mother / father now?" Children want to share important milestones with their parents, such as their matric farewell, graduation, first job, first house, wedding, grandchildren, *et cetera*. Although they experience turmoil, children do come to a point of acceptance and realisation that life and death are part of the broken world we live in. Participant C believes that children accept death easier than adults.

c) Support systems

Adults find their support primarily in their family and friends. Children turn to their friends for support. The parents of the healthy siblings' friends will coach their children on how to treat and help the healthy sibling.

d) Religion as a coping mechanism

People turn to prayer during hard times. Prayer changes as the illness progresses. As soon as patient and family accept the coming death, prayer changes from praying for healing and recovery, to prayer for salvation. Participant C asks the patient if they need prayer for healing or for God to take them and rid them of the pain. He will then pray according to their need and assist the family members with the process. Participant C reminds the family that healing will take place, even when their loved one passes away, he or she will be healed in the afterlife. The family want God to heal their family member for this life; God may want to heal the patient in a different way through his or her death.

The effect of a cancer journey on religion will depend on how strong the patient's and family's faith were before diagnosis. People in a strong relationship with God before diagnosis, handle the cancer journey with more acceptance. Those not so close to God, find acceptance more difficult, finding themselves in a vacuum feeling unprepared, anxious and angry.

In general, people draw closer to God during the cancer journey. Emotions of anger and asking theological questions will pass. Believers always turn back to God after the initial shock; God always brings them through hardship, giving them the peace they need to heal. The relationship with God through the cancer journey has a lot to do with how the family and patient saw God before diagnosis (God the punishing God or a loving God). This perception of God before diagnosis will stay the same and escalate with diagnosis and during the cancer journey.

e) Homework

Participant C does not suggest any tasks for family or patient.

2.8.4 PARTICIPANT D

Participant D has five and a half years' experience, first as clinical head of nursing during the eighties and currently as hospice representative. For these reasons, participant D can be considered as a valid candidate for the study.

Theme 1: Counselling model

Participant D does not use a specific model, because each family is different and each situation within the family circle will be different. Participant D will adjust according to the patient's and family's needs. Hospice has to do with different variable dynamics (physical, emotional, spiritual, financial and family) and for this reason, the hospice representatives work according to the requirements of each case. Participant D is very aware that she is entering the family's private space and families share only what they want to – she will never "force" them to open up. She observes, asks tentative questions and reflects on the family and patient. Participant D does not hesitate to refer them to professional help when necessary. When the case needs more attention than she can give, she will forward the information to a higher level for counselling.

Hospice normally reaches out to the families. In cases where families approach hospice, it is more on a level of physical need; counselling is mostly seen by the family as a secondary need. Participant D finds that in most cases, the family does not even realise that they need counselling and emotional support. They are so consumed with the diagnosis and tasks of caregiving that come with it, that they do not acknowledge or have time for emotional needs. It is more the patient's physical needs and problems that need immediate attention. Although the families do not think or realise that they need counselling, most of them really do need counselling during the caregiving process. The family and patient experience the practical physical caregiving advice that hospice provides as a form of counselling. Physical and emotional care falls under the same umbrella in hospice care. Decreasing acute pressure of physical demands and tasks, knowing that they are not alone in the caregiving process releases enough tension for the IFC to cope well enough. Knowing what to expect and how to react, makes the handling of very difficult situations more bearable; it is important to look ahead, prepare and plan. This practical support flows over into handling difficult situations with more ease. The family knows that hospice is always available to them and that they have professionals on standby to step in at any given moment. This relieves pressure, anxiety and gives peace of mind with immediate calming effect.

Participant D takes on a mediating role in cases where the patient does not have the confidence to share certain aspects of their experience and emotions with their family. They will discuss it with her and in turn, she will initiate the conversation with the family members.

Theme 2: Counselling sessions

Visitation depends on the magnitude of the problem, specific needs and the families' coping mechanism styles. Hospice cannot give psychological or religious advice, it depends on the family and patient to what extent they are willing to share their emotions and accept help from the hospice representative.

There are different phases of the sickness. Some families and patients will go through all the phases; others will get stuck in one phase. Participant D will work according to their pace and space, without forcing them out of a phase or speeding up / slowing down some processes. She will stay with the patient and family in their space with acceptance and respect. “If this is the only way they can cope with it, then let it be.” Participant D knows she enters the private and holy space of patient and family. She is conscious of her place as a guest in the patient and family’s space and homes. The sooner counselling starts after diagnosis, the more time there is to work with the family, helping them with the adjustment of treatment, remission or end of life process – more time to give support, the better the adjustment and acceptance. No two cases will ever be the same, even with same diagnosis and treatment plans the patient and family will react differently. Flexibility is of utmost importance, working from day to day with an open flexible attitude. “Respect individuality.”

Theme 3: Uniqueness of individuals

a) Gender

Participant D does not find a noteworthy difference between genders. It depends more on the total situation, taking all variables into consideration that will determine different reactions. Normally females are much more acceptable to the situation; they are more open, voicing their concerns and needs.

Males want to hide their fear and pain from their wives and families. They come across as less emotional. Males struggle to be the caregiver of their spouse; mostly, they will be very honest about not being able to do the physical caregiving. They come over as isolated which is not the case, it is more a coping mechanism. Here it is important to explain to the patient why the spouse is withdrawing and coming across as cold and isolated.

b) Ages

Age differences detected in how the different age groups interpret and react to a cancer diagnosis and journey thereof are as follow.

The healthy siblings withdraw, go into themselves, and communicate less. Preadolescent/adolescents can only be approached by hospice personnel with the permission of the parents. Parents often do not allow these conversations, trying to “protect” the preadolescent/adolescents from the diagnosis and journey thereof. Parents will thus not allow hospice personnel to comfort the preadolescent/adolescents in the loved one’s terminal illness.

Parenting styles change during the cancer journey. Parents and or grandparents often turn towards a much stricter (authoritarian) role towards the healthy siblings. Reason for this, is the healthy siblings withdraw, they start acting out in ways they did not before diagnosis (for example, slam doors, do not want to eat, school performance drops). Parents often see this as misbehaviour and enforce stricter rules. This is the preadolescent/adolescents’ “cry for help”, they are so entangled in the diagnosis and confused by it, that they do not have the language to voice their emotions and do not know how to react. Their uncertainties and fear then come out as rebellion. Most preadolescent/adolescents mirror their parent’s emotions, behaviour and the ways they handle the cancer journey.

c) Support systems

In the present era, there is immense pressure on people to be successful. As a result of the pursuit to success, family dynamics changed drastically. Where families used to be close-knit families supporting each other, enjoying quality time and open communication structures, the modern day living is more focussed on individuality with less face-to-face communication. These factors bring about that families and patients lean more on institutions like hospice, their church communities, pastors and close friends where they feel safe and supported.

Participant D finds that most families she works with have major family issues even before the cancer diagnosis. Families decades ago, were more “intact” and “healthy” with a stronger foundation of support from the wider family and community. Changed family dynamics of modern times bring complex challenges to the counselling space. It is not the cancer diagnosis that causes conflict in the family, certain dynamics already existed in the family, they either ignored it or just learned to cope with it. The cancer diagnosis simply brings these underlining dynamics to the fore. “There were cracks in the family that existed before cancer; cancer diagnosis just reveals the cracks.”

d) Religion as a coping mechanism

Religious activities most frequently turned to are reading the Bible and asking for their pastor. Turning to religion during the cancer journey will depend on how strong the patient’s and family’s religion ties were before diagnosis; do they see illness as sin and punishment, how strongly do they rely on religion and how often do they go to church.

The first reaction of the family and patient concerning the cancer diagnosis will be doubt, “why is this happening to me?”, “I am doing everything that I am supposed to do”, “why does bad things happen to good people?” Participant D feels that it is quite possible to work through the initial shock and withdrawal from God, once they come to a point where they can start to accept the circumstances. Cases where there is more of a distancing from God are when the patient suffers most; suffering tests one’s faith more.

e) Homework

Exercises that work for most families and patients are focused on easing anxiety. Participant D will ask the family or patient to go to your “happy place” recalling a time of feeling safe, carefree. While recalling the safe space, breathing exercises also relax the body and mind. IFCs especially need care after the death of a family member, debriefing, reflection, “what could we have done more or differently?”, “what do you need now?”

Many times, difficulties from childhood and the past will come up in these situations. Participant D will ask the individual to write down all the good and all the bad memories (write a life story). Once written down, they can see how it balances out. Females are more willing to participate in these kinds of exercises. Males struggle to see the meaning of the exercises – they need more persuasion. To help the males feel more comfortable and/or willing to take part, participant D will start the exercise by doing it with them.

Participant D does not recommend specific reading material. The caregiver does not have time to engage in reading during this time, it is seen as leisure time of which there is none. For caregivers, practical advice is more relevant and accepted. One-on-one conversations are less time consuming and more to the point. Debriefing is more important than reading material. The only material recommended by participant D is ‘Heaven is for Real’ by Todd Burpo.

Additional information

Participant D does not see a role for psychologists during the time of treatment. Initially, with the acceptance of diagnosis they can possibly play a role or in cases where patients fear death, she will call in PCs. The cancer journey is so intertwined (patient and family) that one can never be separated from the other. Hospice representatives enter the world of these families, their private spaces and emotions. These spaces are usually very closed off to the outside world, due to feelings of being overwhelmed. Physically there is no time to “go out” to see a psychologist. Hospice respectfully enters the space (home) of the patient and family. This safe space is a close-knit space and time where the family does not always recognise their need for counselling, due to the new time-consuming physical demands. Seeking a psychologist will ask of the family to go outside of this “cocoon” created, taking time to leave the sick member to spend time by themselves. For these reasons psychologists are perceived as “the outsiders” whereas hospice personnel are accepted almost unconditionally.

2.8.5 PARTICIPANT E

As a registered nurse in a paediatric oncological hospital for the last sixteen years, participant E administers treatment (chemo) and assists families with details on diagnoses, treatment and prognoses being there for families and oncological patients emotionally and professionally. Working in a paediatric unit, participant E cannot make a clear distinction between patient and family as the patients are minors and all communication must go through parents or legal guardians. On a personal level, participant E was diagnosed with cancer as a child. As a survivor of paediatric cancer and experiencing the effects thereof on her parents and sibling, she has great understanding and empathy for both the patient and family. For these reasons participant E can be considered as a valid candidate for the study.

Theme 1: Counselling model

Participant E does not use a specific model. Firstly, for her it is more about reading the situation and working according to that. The second important factor is honesty. Honesty will be maintained in all circumstances. Again each situation will be evaluated and handled accordingly. For instance, where parents are still in shock and vulnerable after the news of a diagnosis, she will give less information whereas in cases where parents are stronger, she will give them all the facts concerning the diagnosis and prognosis. Conversations will be opened with what the parents know and are prepared to hear. Conversations will always be honest, factual, conveyed lovingly and with care. Sometimes all that is needed is a hug and other times facts are more appropriate. Her motto is “fewer words are better”, meaning conversations must be short, factual but understandable and clear. There is a lot of information that needs to be processed, too much information at once can create panic, confusion and leave room for misinterpretations. Sayings such as “the Lord takes His most beautiful flowers” is out of place and not helpful. This empathic-age-and-situation appropriate honesty is extended to the healthy siblings, saying that preadolescent/adolescents are extremely perceptive and must not be underestimated.

Theme 2: Counselling sessions

Because participant E works from her office based in the hospital, she sees the patients and their families daily. According to the stage of cancer and treatment plan some children are in patients while others are day visitors or recurring patients every couple of weeks.

Theme 3: Uniqueness of individuals

a) Gender

There is a difference in how males and females handle the cancer diagnosis and treatment thereof.

Generally, males are less emotional, factually orientated, need immediate answers as well as a long-term plan. They come over as aggressive, irritable and rude but this is just their coping mechanism because it is the only way to give voice to their emotions.

Females are more emotional. They reflect on information and will return in a day or two asking more questions or clearing up uncertainties. They are more focussed on short-term events (what will happen tomorrow and the next day).

Keeping gender differences in mind participant E will give males facts with less emotion. By giving them the facts they need she wins their trust and from there a relationship is built from where there is more space for emotions, “it is breaking though the façade”. It is very important to handle each situation and gender with respect and appropriately expressing that the fathers are the group that generally disrupt the whole ward making patients, family members and staff nervous. For this reason, it is important to keep the males satisfied and calm.

a) Ages

Healthy siblings suffer the most. They experience a double loss due to a paediatric cancer diagnosis as both their parents and sibling will be absent due to treatments and hospitalisation. On top of this household routine is disrupted and sometimes they have to spend time in different houses (grandparents, aunts, uncles) during the time of hospitalisation. They perceive the cancer journey as a loss of attention, love, sibling and parents.

Parents go through all the stages of grief. The grieving process is not just applicable to death. Parents' grieving starts at diagnosis and for the remainder of the process parents will go through the various stages. Parents go through moments of absolute denial, anger, bargaining and depression before they accept the diagnosis. Participant E manages the parents according to their emotions and/or stage of grief. Again, working with emphatic honesty according to the situation is key. Directly after diagnosis emotions are in turmoil, as the treatment progresses the parents and patient fall into a "new normal and new routine", in which they settle down. Towards the end of the treatment emotions are again in turmoil because yet again a "new normal and new routine" must be established.

Source: 5 Stages of grief from Kübler-Ross and Kessler (2014).

Grandparents, according to participant E's experience, is the most emotional group and for this reason she offers extra care, time and attention, "a boost". A possible reason for their escalated emotions can be due to their generational perception of preadolescent/adolescents is not supposed to suffer, be sick and/or ultimately die. Paediatric cancer is foreign to them – "it is a grown-up illness". Another reason is they are not directly involved in discussions between parents and doctors leaving them in the dark about facts and keeping them out of decision-making processes. An example called to mind is a grandmother who cried constantly, spending time with her and talking to her participant E realised that the grandmother assumed that her grandchild will die due to cancer. After explaining the diagnosis, treatment plan and prognosis the grandmother realised that treatment of that specific cancer diagnosis was highly successful and that her grandchild's chances of survival were extremely high.

b) Support systems

Many of the oncological patients are out of town making support systems difficult. In general participant E experienced a lack of support systems regardless of families being close or out of town. “A hospital is a lonely place.”

c) Religion as coping mechanism

Over the years participant E noticed two distinct approaches that Christians take. A group who will candidly read their Bible and pray, leaving the Bible in open sight in the hospital room. The other group will not openly display any form of religious activity. Needing to be there for the patient and their family as a registered nurse participant E must treat all equally showing the same compassionate honesty regardless of their belief system, yet again working according to what she gets from each case. If the family and patient use biblical references she will engage, if not she is not in a professional position to open such a discussion.

d) Homework

No specific homework is recommended by participant E.

Additional information

Participant E mentions the following barriers that hinder centres and/or hospitals from providing comprehensive psychological care such as size and location of paediatric cancer centres and funding. Some of these centres cannot obtain the finances to support a comprehensive multidisciplinary psychosocial team (for example, social workers, psychologists and psychiatrists). Such psychosocial teams fill a very important role and the oncological units feel the void in cases where they are not available putting extra stress on nurses trying to fulfil the role of both nurse and counsellor and/or social worker.

2.8.6 PARTICIPANT F

As a registered nurse for the past 43 years, participant F worked in an oncological ward at the beginning of her career and it was during these early years that she developed a love for working in the palliative caring environment. She also did homecare (nursing) for a year for the institution COSMOS, which is a similar organisation to Hospice, during this time she exclusively worked in the palliative caring environment. Currently she still assists terminal cancer patients and their families both physically (nurse) and emotionally (counselling). With this fruitful number of years participant F can be considered as a valid candidate for the study.

Theme 1: Counselling model

Participant F does not use a specific counselling model. Each case is unique and must be treated as such. With this in mind she builds her work on three basic principles, firstly, total honesty at all times, secondly, availability, there must be a willingness of being there for the patient at any time and on every day. Thirdly, her faith, as a Christian she enters each house with the Holy Spirit residing in her, working with and through her. Her prayer is “God less of me and more of You”.

Theme 2: Counselling sessions

Frequency of sessions depends on each case regarding the stage of cancer, the escalation towards the end, physical and emotional needs. The closer to the end the more frequent the visitations as often as once a day or even multiple times a day. This is where the willingness of being available comes in.

The first session is the most complex session where the difficult questions need to be asked. Although participant F does not see the patients and family as separate entities there are times where the patient and family will be separated such as during the first session. Family will be asked practical but necessary questions for instance funeral arrangements, death certificate, all legal aspects concerning the death. Emotional aspects also come into question enquiring if there is anything that is holding the patient from passing. She will then have a private discussion with the patient asking where the patient is on an emotional level about any unresolved aspects in their life. If any concerns come to light participant F will offer to be a mediator between patient and family. A standing question regardless of family, patient or situation is where both patient and family stand in their faith.

For participant F family and patient will reach out for her assistance more for emotional support than for physical support. There is a lack of knowledge and understanding from IFCs of why and how the body will deteriorate creating anxiety, concern and fear. Here participant F uses her medical knowledge together with empathic honesty to emotionally support, answer and educate. To explain the deterioration and imminent death she uses the metaphor of a tent being dismantled peg by peg using Paul’s explanation in 2 Corinthians 4:16, *Though outwardly we are wasting away, yet inwardly we are being renewed day by day* (NIV) and 2 Corinthians 5:1 *For we know that if the earthly tent we live in is destroyed, we have a building from God, an eternal house in heaven, not built by human hands* (NIV). Bringing emotional, physical and spiritual factors together to help the family understand what is happening in the body, mind and spirit.

Theme 3: Uniqueness of individuals

a) Gender

Although there are gender differences participant F notes that each person is unique over and above gender differences.

Participant F notes that one must be patient with males; it takes time for them to trust and build relationships in order to have open conversations about their emotions. Physical contact is restricted to a handshake. In cases where the male become emotional (crying) participant F will offer a tissue and excuse herself from the room in order to give him a chance to compose himself.

Females are emotionally much more “open” to communicate their feelings early in the professional relationship. Physical contact is more appropriate and welcomed by females. Sometimes that is all they need.

b) Ages

During all her years as registered and homecare nurse participant F has not encountered preadolescent/adolescents or grandparents enough to contribute to the behaviour of healthy siblings and grandparents during the cancer journey.

c) Support systems

Support systems differ from family to family for example families with strong family bonds will seek support from each other. Families with less strong family ties will turn to their friends for support. Then there are the socially isolated families with absolutely no support, in these cases she as nurse will be their sole support structure. She observes that affluent families are more isolated involving both family and friends showing that in modern culture, people are isolated with no firm constructive support systems. Being part of a congregation makes support systems during these times easier. Cell groups, prayer groups and support groups will reach out to the family helping in more than spiritual support by bringing home cooked meals, helping the IFC with caregiving tasks, running errands and helping with house cleaning.

Participant F notes slight differences in how gender differences encounter support systems. For instance, males are often more comfortable in comforting a fellow male, understanding their awkwardness whereas a female will encourage the male to be more open to feel their emotions. Both genders therefore play an important role in support.

d) Religion as coping mechanism

Being part of a congregation, the family and patient will turn towards their home cell group. It is within this safe and trusting space that the family can open and ask the difficult theological question “Why?” and voice their anger with God.

For participant F there is no doubt that a cancer diagnosis brings the family and patient closer to God. God is their anchor, there is nothing else to hold onto or turn towards. On the frequently asked question “Why is God doing this”, participant F will honestly reply “I do not know” she cannot even begin to explain why God has put them on this path, but one thing she can be sure of is that God provides the necessary means to get them through the journey and if this includes suffering then it must be endured as such. Her metaphor here is that babies do not come into life without effort and pain and often in order to die in this world to be reborn into a “new world” also involves suffering.

In general people (both patient and family) do not turn away from God during the cancer journey; they feel anger and ask difficult questions but never (according to her experience) turn away from God.

e) Homework

Participant F gives homework on a more practical level teaching IFCs caregiving techniques for example how to prevent bedsores *et cetera*. It is therapeutic for both patient and IFC. To the IFC it gives a sense of doing something constructive and for the patients it is the reassurance of their loved one's love and commitment. Educating IFCs is a way of empowerment where they feel they are contributing to making their ill family member more comfortable. She will recommend the reading material the patient used to love. She furthermore encourages the family to keep on communicating with the patient up to the very end, including the patient in their daily encounters, what is happening in the news, how their children and grandchildren are. "Do not exclude them from life just because they are terminal and confined to their beds." If she can only give a family one piece of advice it will be to not only keep communication open but to communicate more.

Additional information

In her experience families do not seek psychologists during the caregiving time period. There may be a need for grief counselling after the passing of a family member but generally psychologists do not play an extensive (if any) role in the cancer diagnosis, journey or even grief process. When she notices emotional turmoil she always refers to a pastoral psychologist (see Participant G).

One explanation for the absence of psychologists during this journey can be that patient as well as IFCs is homebound either due to illness or caregiving tasks. The home becomes a sacred place. Not physically being there, knowing the routine and energy, and layout of the house makes it difficult to grasp the situation. For this reason, the psychologist is seen as an "outsider". Another possible reason is time. IFCs cannot see the value in leaving the bedside of their loved one and/or find it practical to interrupt their caregiving responsibilities. Apart from a time issue IFCs often think of taking time for themselves as being selfish.

2.8.7 PARTICIPANT G

Participant G has served as a Pastoral Psychologist from 1988. In the first eighteen years, he filled the role of both pastor and counsellor, the last eleven years he solely serves as pastoral psychologist in his congregation. With this number of full years (twenty-nine) and experience both as pastor and pastoral psychologist participant G can be considered as a valid candidate for the study.

Theme 1: Counselling model

He works from a narrative approach. Another important factor in his practice is immediacy focussing on the here and now "working with what the client puts on the table", the client determines the agenda for the session. Participant G also uses the framework of Kübler-Ross and Kessler's (2014) 5 stages of grief (denial, anger, bargaining, depression and acceptance). Participant G notes that before the first stage, denial, comes the "shocking reality" of the diagnosis.

Theme 2: Counselling sessions

Patients and families seeking participant G's expertise will be from the congregation. The families usually need answers to their theological questions and that is the main reason why they contact him. Sessions are once a week for three consecutive weeks from where they will go to the grief sharing group in the congregation where they will work through their grief in a group. Participant G is not office bound; he visits families and patients at the hospital as well as doing home visits.

Theme 3: Uniqueness of individuals

a) Gender

Participant G notes slight gender differences concerning the way they work through a cancer journey. Females are more emotional, opening up quickly and comfortably in sharing their emotions and asking the difficult theological questions. Males are more reserved keeping their thoughts and emotions largely to themselves, asking more practical (medical) questions.

b) Ages

Participant G has up to date not encountered preadolescent/adolescents concerning cancer trajectories and the counselling thereof. He generally counsells grownups (parents) who will then take the insight from the sessions and share it with the preadolescent/adolescents. A possible reason for not involving them is a time factor. Parents will arrange counselling sessions during the day when the preadolescent/adolescents are at school or busy with school activities.

c) Support systems

Because Participant G serves as pastoral psychologist as the main support system with the families and patients, his encounters will be mostly in church activities in the form of cell groups, prayer groups, groups doing hospital and home visitations and the grief sharing group.

d) Religion as coping mechanism

Prayer and group prayer are the main coping mechanism people will turn to. After Sunday service there are opportunities for people to ask for prayer.

Family and patient ask difficult questions and go through a phase of being fractious, but they always turn back to God. Participant G works through numerous theological questions with the family. The standard question asked is "Why can God cure certain people but not my family member?" He works through these questions theologically also admitting that there are no answers to a lot of these questions, but the Lord will never forsake them (Hebrews 13:5). Using the example of Paul in 2 Corinthians 12:1-10 where he spoke about a thorn in my flesh in verse 7 and in verse 8, I pleaded with the Lord to take it away from me. God answered in verse 9(NIV), *My grace is sufficient for you, for my power is made perfect in weakness*. This thorn in the flesh can be anything but in this situation it is the cancer journey. God can make miracles happen. He can cure but we cannot understand or explain why certain people are cured and others not. What we do know for certain is that God's grace is enough. After death there is God's Kingdom and God will be there throughout the journey.

Participant G encourages the patient and families to learn from their struggle and pain as Rick Warren put is fittingly by saying, "do not waste your pain". He will ask, "How and what can you learn from this journey?", "How can you get deeper personal insight?", "How can you see and understand other people better and / or differently?" For example, going through the cancer journey as IFCs can teach one to be more empathic with other people going through trauma or difficulties.

e) Homework

Participant G uses two main exercises namely the narrative where he will ask the participant to write down their life story and giving appropriate texts with the purpose of not just reading it but to ponder on those texts. Appropriate texts are for example: 2 Corinthians 12:1-10 (as explained in 2.8.7 (e) religion as coping mechanism).

Romans 8 promises that there is so much better to come in verse 18 (NIV), *I consider that our present sufferings are not worth comparing with the glory that will be revealed in us.*

Revelation 21 (NIV): comforting the believer with verse 4, *He will wipe every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away.*

Galatians 6:2 (NIV), *Carry each other's burdens,* teaches the believer to be there for one another to pray together.

Philippians 4:6-7 (NIV), *Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus*. These verses teach the believer that through prayer they open their hearts, voice their pain and fear. By being in God's presence "talking" to him brings peace that exceeds all understanding.

2.8.8 PARTICIPANT H

Participant H, a spiritual and bereavement counsellor has his own practice as well as working with hospice. He has been a spiritual counsellor for twenty years and working with hospice for ten years. With a total of thirty years' experience in the palliative caring environment participant H can be considered as a valid candidate for the study

Theme 1: Counselling model

Participant H does not use a set model in his practice. Family and patients' perceptions, stage in life and beliefs should be respected and caregiving should be according to their circumstances and needs.

For participant H the main aim or question concerning the cancer journey is "How does the IFC benefit from the cancer journey?" He is of the opinion that supporting the IFC would be "buying into the fact" that they have taken a challenge which gives it a negative connotation and does not allow growth. It must be about encouraging IFCs to understand what this whole cancer journey is going to give them. Participant H explains that all these questions are still on superficial level, the core is to what extent the family and patient understand life itself.

Participant H never uses the word cope. “How can I help you cope?” is not how the IFC is going to cope, because for him the word *cope* means there is a resistance to the cancer journey. Instead he will ask two questions, “What new are you going to learn about yourself?” This question is more a question of exploration opening opportunities for growth and thus empowering the family and patient. Cope is hindering growth putting the IFC in survival mode asking them to think about what new and rich can come from this experience is forward moving, learning about life, self and the loved one. Teaching the IFC and patient curiosity to ask questions such as “Why does it?” (Why does this affect me in such a way? Why does it make me feel happy, sad, angry?), and “What does it?” (What does this cancer journey do to me?). Practising curiosity is moving away from the “poor me” perspective. The second question is “how do you see the illness?” This question gives opportunity to look back on one’s life and make changes in in the present. “How did I live my life up to this point and how do I want to continue the remainder of my life?”

Honesty is important, but Participant H explains that honesty comes from the mind; he chooses to use the word compassion, for compassion comes from the heart. In this way, honesty will be compassionately conveyed to the patient and family. “Only tell the patient and family what they can handle.” Honesty can be clinical, but compassion always comes from the heart.

His work is twofold. Firstly, helping the family and patient deal with the illness without becoming fixated by the illness and secondly, working on the sense of failure that they cannot overcome the illness or be a good enough carer. “It is remaining the self and growing to the best version that you can be.”

Theme 2: Counselling sessions

IFCs see caregiving as a task they did not ask for and do not necessary want. An ordeal they must endure because they are the family thus making it their responsibility. Medical doctors and some psychosocial support systems engage with the patient alone leaving the family with basic information not asking them what the journey means to them. IFCs generally ask “what must I do?”, “how do I take care of?”, “how can I be a better caregiver?”, “do I keep my job?”, “how much time do I spent with the diagnosed person?” The answer will be what will you regret the least in the future? “How does spending quality time compare to working or focussing on caregiving qualities?”

Some IFCs take the caregiving role as their task. It is easier to nurse and fight the illness than it is just to be present and love the patient. The reason for this, according to participant H, is as soon as the family perceive that they are going to lose their loved one they start to detach themselves from the person thereby switching to the caregiving role instead of opening their hearts and letting the feelings through while being in the moment with the patient and extended family.

Participant H asks the question, “Should the term isolation be something to introduce to the family?” The first step of mourning and grieving is, “are you prepared to embrace and accept isolation?” People tend to run away from anything to do with loneliness; the thought of being alone brings anxiety in this sense “aloneness becomes the ordeal”. The first step in bereavement is working through being alone “are you prepared to be alone?” People use language such as “sorry for your loss”, “you lost your wife or lost your husband”. For participant H, the latter is negative thinking patterns; loss evokes pain and isolation.

Sessions with family members are scheduled once a week or every fourteen days depending on the emotional need. The problem with Hospice care is that families see it as the final treatment. Contacting hospice will be giving in to the illness, accepting death. This is a misconception. The earlier the family and patient seek professional help the richer the learning process and journey. Those who seek counselling early enough will learn to be curious, discover and utilise the power within them.

Theme 3: Uniqueness of individuals

Working with the families is complicated. Participant H does not see it as individualistically bound at all. The first part of the journey is “are you thinking the cancer journey or feeling it?” If they are thinking the journey because they need answers and solutions and they must make sure they get the caregiving tasks just right, they cannot have a relationship with the journey and grow from it. The first question is always “what new emotions have this process evoked in you?” Here emotions must not be labelled as good or bad, happy or sad. Giving the family a voice (not checking how good caregivers they are) is monitoring “what are you feeling?” and “how does it change your attitude?”

a) Gender

Males are very fixed on solutions, they need a plan in order to fix the problem, they must be strong, they must hold everybody together. For participant H, this behaviour is a coping mechanism keeping them from tapping into their emotions. Getting these men to a place of asking “what is this opening up for me?” and/or “how am I relating to the new emotions I am experiencing?” is difficult. Men generally also do not have the language for their feelings, making it difficult for them to voice their emotions.

Females generally define themselves to a certain role (usually the role of motherhood). Females therefore define the self as mother and not a unique individual of many facets. They are more concerned with the emotional well-being of their preadolescent/adolescents than working through their own emotions.

b) Ages

There is a general belief that life should follow certain patterns, for example the young should bury their elders and not the other way around. When children or young parents die, it does not correspond to this norm. If they believe that young people should not die, the heart is already closed to the journey. The reverse of this attitude is implying that elderly should not mourn if they are diagnosed with a terminal illness, because they had a full and rich life and should feel thankful for that. Participant H challenges this belief system by asking, “who are we to decide a person’s life journey as too short or long enough?”

Preadolescent/adolescents do not have the vocabulary to express their emotions and parents try to protect them from the cancer journey. Parents also do not have the language to explain the cancer journey to them and for this reason, it is easier to keep it from them by not allowing them to see the patient, not having open discussions about the illness and not showing the preadolescent/adolescents their own emotions. Parents are further fearful of their preadolescent/adolescents’ emotions; it is a case of the preadolescent/adolescents’ emotions will be too overwhelming for them, so they refrain from cancer conversations. Preadolescent/adolescents are very blunt and open; they will ask if their loved one is dying. These are hard questions that parents generally do not want to face or answer. “It is protecting the preadolescent/adolescents because parents do not have the skills, they do not know what to do.”

Participant H strongly suggests keeping the preadolescent/adolescents part of the family and cancer journey. For instance, in hospitals he will advise the healthy spouse to bring the preadolescent/adolescents and their favourite toys. They can then play in the room where the diagnosed spouse can hear them play and talk, feel their presence even if they are too weak to talk to them. In homebased care, he will suggest keeping the rhythm at home as normal as possible.

c) Support systems

In hospice general support systems will firstly be family, pastors and friends.

d) Religion as coping mechanism

The biggest question is the patient and families’ belief system. Their belief system will be an indicator of how they understand life. Participant H shows respect and support for individual belief systems.

While the patient is dealing with the physical, the family are dealing with a challenge to their belief system. To this participant H will ask, “What experience do you want to have?” If you want an ordeal caused by negative thinking patterns then the journey will be an ordeal, if you want the journey to be something enriching choosing positive thinking patterns then it will be positive and even beautiful. The cancer journey will be experienced with the attitude the patient and family treat it with.

If the family and patient hold the belief of cancer being cruel and unfair, they will show the same characteristics of anger, resentment and fear. For participant H fear is a lack of believing in something greater than earthly life, “not knowing what will happen after life”. Death should not be seen as a loss.

Question regularly asked is, “Why must my loved one suffer?”

e) Homework

Participant H does not prescribe homework. If they embarked on reading, he will suggest that they keep on reading what they used to read. There are two exercises that would be suggested. Firstly, participant H strongly encourages focusing on breathing. The cancer journey is an anxious time and people stop to breathe, they pant and panting causes more anxiety. "Listen to your breathing, be aware of your breathing." Second suggestion would be to become still, become more aware and live mindfully. Participant H will ask the family and patient how many good things they want to experience during the day and then concentrate on those things (look out of the window and notice the sun, trees, flowers, birds, sky. Hear the sounds of water, birds, life outside of the room, if your spouse looked at you with love in their eyes, if the dog jumped up and gave you love). A good or bad day is a conscious decision to take all the good collectively and concentrate on that. "It is a change of consciousness."

Additional information

Families are generally not consulted because the mindset is that it is the patient's journey and/or illness and is all about the patient's needs (families are excluded).

Some cultures view death as something to fight and resist. Medical professions teach that illness needs to be fought and overcome. Participant H sees illness and death as an opportunity to change. People do not aspire to grow, they aspire to reach material wealth and success in order to be safe and survive. If the survival instinct is very high in the family, they will find it very difficult to accept illness and to grow from illness and death.

Bereavement is much more demanding and complicated than death. Participant H does not advocate dying in a hospital, because it is clinical and far removed from your life. "Home is the happy place with all your life's selected furniture that says who you are. It is a place of family and pets; hearing and sensing sounds and smells familiar and comforting."

2.9 OBSERVATIONS

After reflecting on the findings of the interviews, the researcher made the following observations. To effectively deal with the tremendous stress of a cancer journey, the family members must engage both internal (religion, emotions such as doubts, anger, *et cetera*) and external (counselling, financial planning) practical adjustments to find new routines, such as household chores, taking care of siblings, caregiving, *et cetera*. Most families appear to adjust well and even report emotional and spiritual growth. Potential resiliency factors include strong support systems, hospice aid, good communication with medical team, solving problems purposefully, emotion-focused coping mechanisims, such as breathing and living mindfully. The most important IFC needs were related to patient care and emotional well-being, honest, age and circumstance appropriate information, and the least important was the health of the IFC. Focus is thus entirely on the patient. Prolonged distress shows to have a negative impact on the family's quality of life, mental and physical health factors, family functioning and parenting skills (authoritative style) and spiritual struggle.

Theme 1: Counselling model

All participants incorporate the five stages of grief from Kübler-Ross and Kessler (2014), although it does not count as their counselling model. Common denominators that form the foundation of their counselling style are flexibility, respect and honesty. Out of the eight participants interviewed, only two (A and G) based their counselling on specific models. All the participants emphasised the value and respect of the individuality of each case and each person, working with what they get from the patients and family. Respecting the individual includes being appropriately honest communicating with compassion.

Theme 2: Counselling sessions

There is consensus among all participants that the main aim of the sessions is to empower both patient and IFC. Formal counselling sessions where the family travels to the counsellor, vary between three to a maximum of six sessions (participant B, G) scheduled for once a week. Hospital and house visitations are individually assessed, taking variables into consideration such as physical and emotional needs and the escalation of needs towards the end of life. These visitations vary from daily visits to no less than three times a week.

Theme 3: Uniqueness of individuals

a) Gender

Although most participants recognise differences in gender, assumptions about individuals based on their gender should be avoided. Each individual and each case must be tailored to the need of the family system. Participant D comments that the total situation (different variables) will determine reactions more than gender. For Participant B, F and H these variables include personality; each person is uniquely different over and above gender differences. The main variable for participant C is the amount of time spent with the loved one before diagnosis. Noteworthy gender differences are reported as follows:

Box 2: Gender differences in caregiving

Males: Males *think* the cancer journey.	Females: Females *feel* the cancer journey.
i. Reserved, keep thoughts and emotions to themselves.	i. Emotional beings, comfortable in sharing and showing emotions.
ii. Cultural perception of “boys do not cry”.	ii. Come across as emotionally stronger.
iii. Factual oriented, ask practical questions, need immediate answers and long-term plans, fixed on solutions.	iii. Reflect on medical information received and focus on immediate caregiving requirements.
iv. More about coping than caregiving. Detach emotionally and physically.	iv. Focussed on being the best caregiver. Stay connected emotionally and physically.
v. Take a long time to build trust with counsellor.	v. Establish trust relationship quickly with counsellor.
vi. Use more defence mechanisms such as creating emotional and physical distance, come across as irritable and rude, isolated	vi. Comfortable in voicing, showing and sharing emotions.

and do not have the language to communicate their emotions.	

Source: Author compiled the table.

b) Ages

<u>Healthy siblings</u>: Participants A, C, D, F, G do not directly work with (counsel) preadolescent/adolescents but can report on what they observe from family dynamics. Family members tend to keep preadolescent/adolescents away from the illness. This observation is confirmed by participants B, E, H that directly work with preadolescent/adolescents. Initially in the diagnosis and early treatment phase the healthy siblings will instinctively ask less attention and time. As time passes feelings of "lesser than" will come out as anger outbursts, rebellion and low marks at school. The reason for this behaviour is that the preadolescent/adolescent does not have the vocabulary to communicate these complex emotions, acting out is their way of releasing tension and fear. Parents will see this behaviour styles as rebellion and take on stricter parenting roles which escalate the healthy siblings' emotions of loneliness. Healthy siblings experience doubly the loss of both their diagnosed sibling as well as their parents due to treatment obligations keeping them away from home for extended periods. Parents can help by communicating the illness, showing their own emotions and admitting that they themselves do not know all the answers. Preadolescent/adolescents mimic their parents' reactions and emotions. Communication and open emotions give permission to the preadolescent/adolescents to do the same, creating a feeling of togetherness as a family. Participant B, D, E and H report that the healthy siblings and parents experience increased distress, poorer quality of life and difficulties in psychosocial functioning immediately and during the months after a family cancer diagnosis. The healthy siblings are a psychosocial at-risk group and should be provided with appropriate and supportive care from healthcare professionals. Healthcare professionals together with parents should be advised about ways to anticipate and meet the healthy siblings' needs. This feedback is coherent with strong and consistent research from Grootenhuis and Last (1997:466-484) and Kazak *et al*. (2015:426-459).

<u>Spouses</u>: reactions towards diagnosis depend largely what life stage they are in. Young families find it more difficult where older couples can look back onto a rich life lived together. The shorter "turn back" period of remembrance the more difficult acceptance of illness.

<u>Grandparents</u>: Grandparents' pain is underestimated, not taking into consideration that they experience double the pain. Firstly, it is emotions towards their son or daughter as the parent of the child with paediatric cancer and secondly, it is emotions towards the paediatric patient as their grandchild. Furthermore, they do not get the attention and medical information making them feel like outsiders even though they play a major role in the cancer journey looking after the healthy siblings, taking the ill child to treatments and caregiving tasks while keeping household routines as normal as possible.

c) Support systems

Support systems are crucial to help the IFC feel safe to express their needs. All participants state that social support can help the family to weather periods of stress or change in their lives. It has been noted from the interviews that primary support structures the IFC falls back on are key family members, close friends and their pastor. Groups reaching out to support the family include hospice, prayer groups and cell groups.

d) Religion as coping mechanism

Most general religious activities family members' generally turn to are prayer and reading the Bible. There are no noteworthy differences noted in how gender and age differ in the choice and practice of religious coping mechanisms other than as stated in theme 3 section a.

Just as family members go through stages of grief, they also go through stages of faith. Their relationship with God during the cancer journey depends on how strong their faith was before the diagnosis. On average family members draw closer to God during the cancer journey, some individuals will take longer to work through theologically difficult questions and come to a place of acceptance, but generally the relationship grows stronger with God. A main factor that determines the relationship with God during the cancer journey depends on how the individual sees God for example a strict God that punishes sins or a loving and forgiving God. Participants A, B, D, H find that religion can become an obstacle in working through the necessary emotions of a cancer diagnosis and journey. Believers often do not allow themselves to ask the difficult theological questions, feel scared or anxious as though these emotions are sin and doubting God. Participants unanimously state that a cancer diagnosis of a family member opens questions and doubts towards God.

Box 3: Questions regularly asked. Answers and recommended Bible verses

Regular questions asked are	Replies on these questions	Bible verses recommended
i. Why do my loved one have to suffer? ii. Why is God doing this? iii. Why does God cure some people and not others?	i. To simply and honestly state that one does not have all the answers. ii. How and what can you learn from this journey? iii. How can you get deeper personal insight? iv. How can you experience God differently?	i. To explain deterioration of the body – 2 Corinthians 4:16 ii. "Thorn in my flesh" can be cancer - 2 Corinthians 12:1-10 iii. There is so much better to come – Romans 8:18 iv. Message of comfort – Revelation 21:4 v. Social support systems –Galatians 6:2 vi. Staying in God's presence –Philippians 4:6-7

Source: Author compiled the table.

e) Homework

Examples of homework recommended include:

- Write life stories.
- Give Bible texts and ask the individual to ponder on it.
- Communication is very important, not just to communicate but to communicate more than before the diagnosis. Tell stories, listen to each other’s stories, share memories, what members mean to each other, how will the patient be remembered.
- Mindfulness bases stress reduction (MBSR). The aim of mindfulness is to become aware of physical, emotional and spiritual needs. To become still, be in the moment and create awareness of feelings. MBSR exercises generally preferred by family and patient are body scan and breathing exercises (cf. 2.8.1).
- Reading material: most practitioners recommend reading material the patient and family used to love; they do not introduce new reading material. Because, the caregiving process is a full-time situation, the caregiver may not have time to engage in reading during this time. Reading is further seen as leisure time of which there is sometimes none.

The most efficient exercises agreed on are breathing techniques and mindfulness (becoming aware and interact with emotions).

Gender differences noted with exercises are that males struggle to see the meaning in the exercises, they need more persuasion. Females are more willing to take part in the exercises.

Most practitioners do not incorporate religion in the exercises, as their occupation does not permit them to show preference towards a specific religion. Because religion is not incorporated (except for participant C and G) no clear distinctions could be made between religious and non-religious exercises.

Feedback is an important aspect of the sessions. Each session will start by reflecting on the exercises. Examples of feedback questions include:

Box 4: Feedback questions on homework excersis

Feedback: Reflecting on exercises
“What worked for you?”
“How did you perceive the exercise?”
“How did it make you feel?”
“What emotions came up?”
“What is different today compared to last week?”
“How do you feel hearing your answers?”
“How are your emotions changing (what is new, different)?”

Source: Author compiled the table.

2.10 ADDITIONAL THEMES

In the palliative caring environment, the cancer patient and family members cannot be seen as separate entities. Patient and family will be encountered in hospital, as well as house visitations where conversation topics commonly addressed include diagnosis, cancer treatment, medication, caregiving support, important end of life decisions, emotional well-being and theological questions. This observation is consistent with growing literature on the interconnectedness of cancer patients and their family members' mental health (Beardslee *et al*., 2011:1098-1109; Wickramaratne *et al.*, 2011:593-602; Weissman *et al*., 2014:2811-2824) advocating family centred psychosocial care as an essential part of caring for the cancer family (Kazak *et al*., 2006:343-355; Mullins *et al*., 2015:176-189). Given the role that the IFC is expected to play in the supportive care of the cancer patient, health care providers emphasise that the unit of care includes both the patient and their family members (Pitceathly & Maguire, 2003:1517-1524; Kim & Given, 2008:2556-2568; Stenberg *et al*., 2010:1013-1025).

Collaboration among the different professional disciplines is extremely important in order to help IFCs by incorporating a holistic pastoral model, wherein mutual appreciating, respect for different skills and scope of practice, accountability, appropriate communication around consent and treatment, and shared goals for the family forms the cornerstone. In order to enhance the experience of the family, the PC must work closely with social workers, hospice representatives, nurses, and occupational therapists building strong relations with one another in order to refer the family members, if necessary.

Counselling must deviate from the norm of counselling of a set location (office). Participants A – H travel to the families. Family members do not have the time or energy to seek counselling. Additionally, feelings of guilt will keep them from any activity they perceive as "spending time on themselves". For these reasons, the PC must reach out to the family, meeting them at locations and times most suited to the family.

From the interviews it can further be concluded that psychologists do not play a large part in the cancer journey. Possible reasons given are that IFCs do not see the need for psychological help. They are homebound due to caregiving tasks. They do not have the time to leave the bedside of their diagnosed family member. They feel guilty to spend time on themselves. Psychologists also do not always have insight into the *space* the cancer occupies, such as the layout of the house, the energy in the house, family dynamics, routines of the house, beloved pets and the role they play in the family dynamics. This space as experienced by the participants is "sacred" and "holy". "You have to physically be there, spend time with the family in the space to really grasp the situation." IFCs tend to visit psychologists only after death stepped in.

Most family members do not recognise a need for help, feeling that they are coping well enough. Furthermore, families tend to think that family centred psychosocial care and psychoeducation come into play when their loved one is terminal. The sooner the family accepts the caring environment of counsellors, the more time there is to work through emotions. There is consensus among the participants that they are consulted only at a late stage, wishing they had more time with the family. As mentioned by all the participants it is crucial to realise that the cancer journey starts with diagnosis, through to the transition to survivorship. The end of cancer treatment is thus not the end of emotional stress. IFCs are in and out of the caregiving role throughout the cancer journey with no clear precursors that can help predict the future; when or whether they will be called back into the caregiving role. The fear of recurrence and uncertainty has a long-lasting impact on both patient and family members which goes beyond the survivorship phase or bereavement. From the interviews, it is noted that the caregivers need caring services mostly with initial diagnosis and nearing-end-of-life and after. The active caregiving phase (going through treatment procedures) is likely the time where the family will be preoccupied with the caregiving role needing counselling the least (or so they think). It is crucial to extend the model beyond survivorship or death. It seems these are the times when the model will be of most use and where the family members will be more open to it.

The single-most variable influencing acceptance of the diagnosis and cancer journey is the shorter the "turn back" period of remembrance, the more difficult the cancer journey is, because a long road was still imagined with the diagnosed loved one. The circle of life is a strong cultural assumption that the young will bury their elders. Paediatric cancer diagnosis and young couples need more counselling to help them come to terms with the diagnosis.

All participants state that one must not assume that all people within a particular religion practice the same rituals, have the same beliefs or the same language. The FICA question "What do you believe in that gives meaning to your life?" is a key question. Getting to know where the family stand in their religion, how they experience God (punishing or loving) is important, because this will be how they experience the cancer journey. The practitioner must never assume and always ask open questions with respect. Except for participant C and G, the rest of the participants are professionally not allowed to voice their personal religion. Acceptance of the individual is priority. Working from a neutral stance is important in their way of counselling and for this reason they do not enter the counselling space with predetermined opinions, but will approach the family and patient with respect regardless of their belief system and must always be open and ready to give access to a pastor, if so required.

The cancer journey must be felt compassionately. To help the family feel the experience the FICA questions and 5 stages of grief seem to be valuable to consider for the holistic Scripture based pastoral model. Being mindful of changing emotions (emotions towards the caregiving role, God, religion, diagnosis, patient, key family members, support systems and PC). From the qualitative interviews, the researcher concludes that the cancer journey is a choice of attitude (towards God, cancer journey and caregiving role) and mindful of emotions. The main task to empower the family and help them cope with cancer related stress appears to help them feel, understand and accept their emotions towards all the variables mentioned in the interview questions under uniqueness of individuals.

2.11 CONCLUSION

From the interviews, it can be concluded that a cancer diagnosis in the family is an extreme and consistent stressor for both patient and family members regardless of age, gender, support systems and religion during the cancer journey, as well as after treatment or death. The cancer journey further influences the family structure and the beliefs of the family, as well as the family's ability of coping and functioning, as before the diagnosis. There is consistence that social support systems for family members are critically important of which social isolation can be marked as a risk factor for ongoing and escalating distress. In addition, prior history of family dysfunction and the presence of pre-existing problems can further be associated with less optimal psychosocial outcomes. One of the significant conclusions of the interviews is that patient and family cannot be separated, the one co-exists with the other. Although this study mainly focuses on the family, the Scripture based pastoral model is holistic and will thus be equally beneficial to the patient making the pastoral counselling inclusive of whole-family-whole-person caregiving.

The researcher has noted a need to better understand potential health effects of IFCs. The rest of this study will provide additional literature support for the implementation of a standard of holistic care, Scripture based pastoral model to help significant others cope with cancer related stress. The model will facilitate the early identification of risks and resiliencies for families and the delivery of evidence-based treatments to assist all members of the family across the continuum of cancer treatment and beyond.

CHAPTER 3: SYMPTOMS AND EFFECTS OF CAREGIVER RELATED STRESS

3.1 INTRODUCTION

In this chapter the second part of the descriptive empirical study will be presented by means of a literature review from a multi-disciplinary focus with the purpose of discussing the impact of cancer on the significant others (informal family caregivers IFCs). An IFC is someone who takes care of a loved one, who can no longer manage on his or her own with daily needs such as bathing, dressing, balancing the check book and accompanying the cancer patient to doctor's appointments and treatments. An IFC may be a husband or wife, son or daughter, grandfather or grandmother and need just as much information and support as the diagnosed person. Despite everything, if the IFC sacrifices his or her own health and well-being, he or she will not be able to effectively care for the ill family member.

In order to provide some context for the proposed pastoral model, this chapter will firstly give a perspective of various studies on the impact of cancer on the spouse, preadolescent/adolescents, siblings, parents and grandparents. Preadolescence falls under ages 10 to 13 years old, middle adolescence includes the ages 14 to 17 years and late adolescence 18 to 21 years and beyond (Allen, 2019). For pastoral caregiving purposes this study places focus on children ages 14 and up. The three groups (pre-, middle- and late adolescents) will be referred to as preadolescents/adolescents in this study. As the diagnosed child does not fall under the pastoral spectrum - all ages are included, referred to child or children throughout the study. The chapter will then, define and discuss the concept 'palliative care' as a standard of care for IFCs.

Family and or significant others can be broadly defined as:

> We all come from families. Families are big, small, extended, nuclear, and multigenerational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams (New Mexico's memorial task force on children and families and the coalition for children, 1990).

New global cancer data suggest that the global cancer burden has risen to 18.1 million cases (International Agency for Research on Cancer IARC, 2018). According to The World Health Organization (WHO, 20007), "Cancer is the second leading cause of death globally and is responsible for an estimated 9.6 million deaths in 2018. Globally, about 1 in 6 deaths is due to cancer". The International Agency for Research on Cancer (IARC, 2018) estimates that "one-in-five men and one-in-six women worldwide will develop cancer over the course of their lifetime and that one-in-eight men and one-in-eleven women will die from their illness.”

South African statistics	**Male**	**Female**	**Both sexes**
Population	28 160 815	29 237 609	57 398 424
Number of new cancer cases	47 764	59 703	107 467
Number of cancer deaths	28 138	29 235	57 373

Source: South African summary statistics on cancer related issues for 2018 (IARC, 2018)

> Cancer is a generic term for a large group of illnesses that can affect any part of the body. Other terms used are malignant tumours and neoplasms. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs, the latter process is referred to as metastasizing. Metastases are a major cause of death from cancer (WHO, 2018).

IFCs often come into the caregiving role suddenly, quickly taking up the tasks of caregiving without realising that they have taken up the caregiving mantle. Often the IFC don’t recognise the sacrifices they make, viewing the caregiving tasks as simply being there for their diagnosed loved one (Crossroad Hospice Charitable Foundation CRHCF, 2016). Throughout all oncological settings, IFCs assist cancer patients to cope with their treatment, manage their recovery and assist with practical care tasks (Wakefield *et al*., 2016b:1-9). A cancer diagnosis and accompanying treatment thereof will not only change the behaviour, emotional and physical conditions of the patient, but also of their spouses and entire family system (Kayser *et al.,* 2007:404-418). It is widely accepted that dealing with cancer is a family affair, where not only the diagnosed person but their loved ones have to deal with the consequences of the illness and treatment thereof (Hagedorn *et al.,* 2011:205-211). Due to the new and advanced medical treatment available, 68% of cancer diagnosed adults can expect to still be alive in five years’ time (Jemal *et al.,* 2011:69-90). As a result of the cancer’s five-year survival rate, shorter hospital stays, limited discharge planning, together with the growing home care technology, the burden of caregiving for these patients has been transferred to IFCs. As a result, IFCs are being asked to shoulder greater burdens for longer periods of time (Schulz & Beach, 1999:2215-2219; Chen *et al.,* 2004:469-

475; Zivin & Christakis, 2007:772-779). Although, the IFC leads to large savings to the health care system as they lower the cancer patients' time in hospitals (Girgis *et al*., 2013:197-202), it is not the case for the family. According to CRHCF, 60% of IFCs work either full-time or part-time in addition to their caregiving duties, placing strain on the ability to maintain focus and performance levels at work. In time the elevated levels of stress, due to caregiving tasks take their toll on the professional lives of IFCs, often leading to earlier-than planned retirement in order to be a fulltime caregiver (CRHCF, 2016). Numerous studies on family caregiving costs have shown that the caregiving role can have stressful effects with the potential to bring about psychological, social, economic, emotional, physical, spiritual, as well as personal (identity) risks to IFCs (Given *et al.,* 2001:213-231; Haley, 2003:151-158; Pitceathly & Maguire, 2003:1517-1524; Matthews *et al.,* 2004:625-641; Braun *et al*., 2007:4829-4834; Hagedoorn *et al*., 2008:1-30; Li & Loke, 2013:578-587). Therefore, it is important to approach caregiver related stress and support from a multidimensional point of view.

3.2 EFFECTS OF CAREGIVING RELATED STRESS

Life changes due to a cancer diagnosis and the journey thereof can have long-lasting effects, irrespective of the outcome of the illness. IFCs are more prone to depression, anxiety, marital distress and overall lower quality of health than non-caregivers leading to potential burnout (Blanchard, 1997:189-194; Chen *et al.,* 2004:469-475; Matthews *et al.,* 2004:625-641; Braun *et al.,* 2007:4829-4834; Kim & Carver, 2007:714-723; Hagedoorn *et al*., 2008:1-30; Fitzell & Pakenham, 2010:1171-1178; Perz *et al.,* 2011:610-619; CRHCF, 2016). Additional negative caregiving effects include fatigue, loss of sleep and loss of appetite (Blum & Sherman, 2010: 243-258; Dhruva *et al.,* 2012:70-81). An estimate 20% to 30% of spouses endures psychological impairment and mood disturbances resulting from their partner's cancer (Blanchard, 1997:189-194).

IFCs furthermore sacrifice social connections due to the demands of the caregiving roles. They forgo outings with friends, other family members and co-workers and begin to withdraw from all social connections as they move deeper into the caregiving demands. Social withdrawal can overtime lead to intense loneliness and feelings of isolation (CRHCF, 2016). "Social support is a well-established predictor of health" (Eskander *et al*., 2016:691-699). A lack of social support increases the risk for cardiovascular illness, poor prognosis after myocardial infarction, poorer functional recovery after a stroke and increased mortality in general (Welin *et al*., 2000: 629-639; Tsouna-Hadjis *et al*., 2000:881-887; Kaplan & Kronick, 2006:760-765; Lett *et al*., 2007:418-427; Manzoli *et al*., 2007:77-94; Holt-Lunstad *et al*., 2010:1-20; Barth *et al*., 2010:229-238). Social support may further influence surgical outcomes, for instance patients receiving less support stay longer in hospital for recovery time, have worse postoperative functional recovery and increased surgical mortality (Mitchinson *et al*., 2008:292-300; Idler *et al*., 2012:33-49; Neuman & Werner, 2016:194-196). Over 55% of caregivers describe the demands of caregiving as "overwhelming". Overwhelmed feelings for extended durations can have detrimental effects on physical as well as emotional health, leading to an overall negative outlook on caregiving and life in general. Not all consequences of caregiver related stress are readily recognisable by both caregivers and health professionals until the caregiver falls ill. These reviews accentuate the importance of showing concern and support for the spousal caregiver because their mental and physical status affects their capacity as the caregiver to the diagnosed spouse (Northouse *et al.,* 2001:115-136).

WHO's health model (Larson, 1999:123-136) defines health as "a state of complete physical, mental and social well-being, and not merely the absence of illness or infirmity". Thus, a sub-optimal state of health (hidden morbidity) can exist where health is deficient, but before the development of illness. Although the term 'hidden morbidity' is not usually used in the context of cancer caregiving, Li and Loke (2013:578-587) use it in their study to represent a sub-optimal condition of health focusing on three main dimensions (mental, physical and social) in spousal caregivers. The free online dictionaries (2012) define the term morbidity as "the relative incidence of a particular illness" and "an abnormally gloomy or unhealthy state of mind". Morbidity is further explained as a "departure from a state of physical or psychological well-being, resulting from illness, injury or sickness, especially where the affected individual is aware of his or her condition". Hidden morbidity, in Li and Loke's (2013:578-587) study therefore refers to a disorder unknown to both the health professionals and the person suffering from the sub-optimal condition (Braun *et al*., 2007: 4829-4834).

This chapter will further discuss and explore how a cancer journey affects IFCs, concentrating on the following five groups, namely, the spouse, preadolescent/adolescents, siblings, parents and grandparents of the cancer patient.

3.2.1 Spousal caregiving distress

As a rule, the spouse is usually the primary IFC for the cancer patient (Chen *et al*., 2004: 469-475; Li *et al*., 2013:178-187). Studies done during the 1970s and early 80s show that family members of cancer patients also experience stress, concluding that both spouse and cancer patient are equally distressed, and that the distress experienced by the spouse and patient is connected (Blanchard, 1997:189-194; Skerrett, 1998:281-298; Zunkel, 2002:39-55). More recent studies disclose that the spouse's distress may be as high as, or even higher than the cancer patients' themselves (Northouse *et al.,* 2000:271-284; Hagedoorn *et al.,* 2008:1-30). Northouse and Peters-Golden (1993:74-82) identify three basic areas on spousal caregivers' concerns, namely:

- The main concern is the fear of cancer spreading, the extent of the illness at the time of diagnosis and the ultimate outcome of the illness (Northouse & Peters-Golden, 1993:74-82). According to Toseland *et al*. (1995:517-528), the major caregiver concern is the fear of the spouse dying, even when asymptomatic. Both, patient and significant others experience feelings of helplessness due to lack of control, a sense of unpredictability and a heightened uncertainty of the course of and the practical support accompanying the illness (Maughan *et al.,* 2002:27-34; Thomas *et al.,* 2002: 529-544).

- The second major concern relates to assisting the diagnosed spouse to deal with the emotional difficulties of the illness (Northouse & Peters-Golden, 1993:74-82). According to Zahlis and Shands (1991:75-93) and Toseland *et al.* (1995:517-528), one of the most difficult areas for the spouse is dealing with the emotional needs of the patient, reason being that the spouse simply does not know how to help and feel ill-equipped to meet the demands of the patient. Even if the cancer goes into remission the strain of a possible recurrence remains. In cases of advanced cancer, the spouse must deal with the anticipated loss and along the course of the treatment they must kerb feelings of anger and frustration (Cleora *et al*., 2000:65-80).
- The third identified area of concern relates to balancing between the duties and the caring for the patient, both in and outside of the home (Northouse & Peters-Golden, 1993:74-82). Additional responsibilities taken on by the healthy spouse, and the adjustments faced by the couple, include for example breaking the news to family and friends, re-negotiating occupational roles within the family such as managing child-care schedules (parenting responsibilities), and adjusting future plans. The spousal caregiver must meet the needs of the diagnosed spouse, which include assisting in the side effects of treatments, providing transportation to treatments, monitoring of treatment, and managing treatment-related symptoms (Maughan *et al.,* 2002:27-34; Helseth & Ulfsaet, 2003:355-362; Harden, 2005:85-98; Lopex *et al.*, 2012:402-410; Lewis *et al.,* 2015:12-23). The spousal caregiver as co-parent, may further experience substantial stress, reduced quality of life (Stenberg *et al*., 2010:1013-1025; Götze *et al.,* 2015:787-795), and decline in parenting ability (Moore *et al*., 2015:3551-3557). In addition, to provide emotional care and physical support, the healthy spouse is often required to take on the diagnosed's parenting duties together with their own. The spousal caregiver may further struggle with meeting the competing needs of their children as well as their ill partner (Stafford *et al*., 2017:1-9). Outside of home duties include disruptions in employment and recreational activities (Helseth & Ulfsaet, 2003:355-362; Lewis *et al.,* 2015:12-23). Financial difficulties often follow a cancer diagnosis, which can lower the family's standard of living, depriving them of entertainment which would normally ease frustrations due to stress (Cleora *et al*., 2000:65-80). Family routines and schedules can change as often as the status of the illness changes (Helseth & Ulfsaet, 2003:355-362; Lewis *et al.,* 2015:12-23).

Although it is becoming an accepted fact that life stressors, such as cancer not only affect an individual but a wide network of people around the diagnosed person. Research on couples and families remains almost exclusively focussed on the coping efforts used by individuals (Kayser *et al.,* 2007:404-418). According to Kayser *et al*. (2007:404-418), models of stress and coping should incorporate a relational perspective, "to understand fully the relationship between stress and health or mental health, we need to examine coping as it occurs within the context of significant relationships".

3.2.1.1 *Dyadic coping*

Several theoretical frameworks, empirical research and interventions focusing on how couples cope together with life stress have been developed. Theoretical approaches expanding on the original stress and coping theories of the 1970s and 1980s include, relationship-focused coping (Coyne & Fiske, 1992:129-149), interpersonal regulatory processes (DeLongis & O'Brien, 1990:129-149), coping congruence (Revenson, 1994:122-130; 2003:530-559), communal coping (Lyons *et al*., 1998:579-605) and the systemic-transactional coping (Bodenmann, 1995:34-49; 1997:137-140; 2005:33-50). More recently relationship-focused coping has been applied to the development of psychosocial interventions with couples facing cancer (Scott *et al*., 2004:1122-1135; Kayser, 2005:175-194). Another term for relationship-focused coping is dyadic coping which can be defined as "the interaction between the stress signals of one partner and the coping reactions of the other" (Kayser *et al*., 2007:404-418).

This implies that the manner in which one individual copes with the multiple stressors caused by the illness, the treatment thereof and the meaning attached to the illness will affect the others' coping and psychosocial adjustment. Skerrett (1998:281-298) focuses on factors such as communication, beliefs regarding the illness and health, and problem-solving techniques, thus categorising the couples as either resilient or problematic (the majority were resilient). Resilient couples showed features such as adopting a philosophy of coping of mutuality that serves as a basis for dealing with ongoing demands of the illness. These couples firmly believed that they were "in it together" acting as each other's confidante, advisor and sounding board, openly discussing cancer without allowing the discussion to dominate their daily living. For a small group of couples, cancer became part of every aspect of their interactions with the result of the illness having a devastating impact on their lives. These couples were unable to devise a common coping philosophy concerning the multitude of illness demands. Their communication patterns took one of two patterns: retreating into withdrawal and silence or reactive, anxiety-driven, tell-all communication. This group had a difficult time finding ways to understand and make meaning of the experience (Skerrett, 1998:281-298; Zunkel, 2002:39-55).

According to Kayser *et al*. (2007:404-418), most of the mentioned model's shortcoming is focussing on a single aspect of the coping process, namely, the individual coping strategies used by partners to manage stress. Keyser *et al*. (2007:404-418) define relationship awareness as qualities that involve thinking about the relationship within the context of cancer. "It includes thinking about the impact of the illness on the partner and the relationship and how to sustain one's relationship given the extra demands of the illness." Regarding the impact of cancer on the relationship helps the couple to approach their coping in a communal way, as the "we illness". Expanding on previous models Kayser *et al*. (2007:404-418) present a framework of dyadic coping that views coping as a process involving how couples appraise the illness-related stress, react to each other's responses, use behavioural and cognitive strategies to manage stress and meaning making of the illness.

Other studies focusing on how the coping strategies used by one partner can affect how the other partner will adjust to the stress of the illness are for instance: How a wife's adjustment to cancer has been associated with her husband making use of problem-focused coping (Ptacek *et al*., 1994:47-72) and use of active engagement coping strategies (Kuijer *et al*., 2000:256-275).

The diagnosed wife was more inclined to feel distressed in cases where their husbands used wishful thinking (Ptacek *et al*., 1994:47-72), external control-resignation kind of coping (Hannum *et al*.,1991:1-20) and were overprotective (Kuijer *et al.*, 2000:256-275). Similarly, the diagnosed wives coping mechanisms affected their husbands' adjustment. For example, Hannum *et al.* (1991:1-20) note that a wife was using optimism to cope with her husband's negatively related distress. Ptacek *et al*. (1994:47-72) report higher relationship satisfaction with higher levels of mental health in cases where the wife used problem-focused coping and less avoidance; wishful thinking on the wife's part related to the husband's mental health (Ptacek *et al*., 1994:47-72). These studies illustrate a significant crossover association between coping by one spouse affecting the other spouse's adjustment outcomes.

The Skerrett (1998), Zunkel (2002) and Kayser *et al*. (2007:404-418) studies theorise coping as a dyadic process that specify how both, the patient and partner can or cannot handle the illness together. Zunkel (2007:404-418) distinguishes the relational/dyadic process (2002:39-55) and Kayser *et al.* (2007:404-418) the two dyadic processes.

Zunkel (2002:39-55) identifies four relational or dyadic processes in which each of the partners added to the coping with cancer, namely sharing in the patient's recovery, helping the patient, normalising the household and moderating or minimising the intrusion of the illness. Zunkel (2002:39-55) also notes two distinct types of processes. First, the acknowledging type where this process strives to incorporate cancer into the family system where the couple openly discuss their feelings about the diagnosis, its presence and acknowledge their partners' reactions towards the diagnosis, treatment and recovery. Secondly, the moderating or minimising type and this process limits the impact of cancer on the family. Both these processes applied problem-focuses strategies and emotion-focuses strategies, indicating that both patient and partner are affected by a cancer diagnosis.

Kayser's *et al*. (2007:400-418) dyadic processes and relational characteristics consist of:

A. Mutual responsiveness

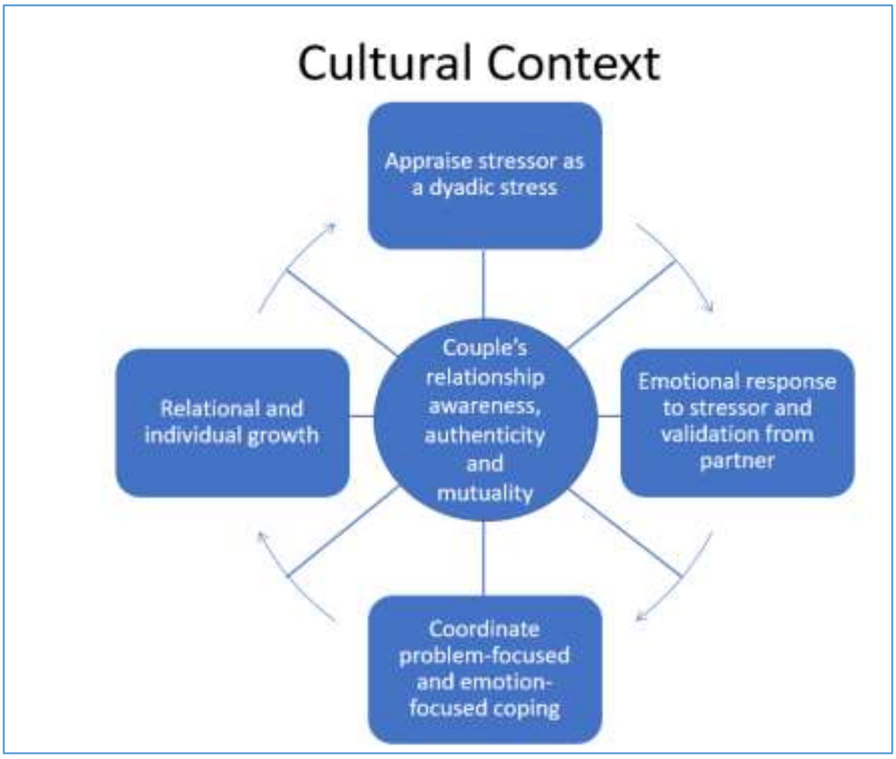
Couples identify the experience of cancer as a dyadic stressor or "we-illness" where the journey with cancer affected both. Partners communicate their reaction to the diagnosis; they listen to and support each other's responses and feelings. Being authentic and open about their stress allows the couple to manage cancer in a coordinated way that involves both emotion-focused and problem-focused coping strategies. Coping in this manner couples report benefits to the cancer experience building strength and resilience individually while exchanging the closeness of the relationship. These findings are consistent with earlier studies by Skerrett (1998:281-298) where couples approached a philosophy of “in it together”. Manne *et al*. (2004:589-599) note that open communication had a positive effect on psychological adjustment for both patient and spouse.

B. Disengaged avoidance

Couples who use a coping style of disengaged avoidance regard cancer as an individual stressor and frequently make “I statements” in response to changes in the relationship since the diagnosis. A possible reason for disengaged avoidance may be due to stressors other than cancer that take priority in the lives of the couple such as, taking care of young children. In this case coping behaviours are directed to problem solving, rather than sharing of emotions where the couple rarely communicate existential issues or the future because their primary focus is on the practical demands of daily living. They avoid talking about the cancer and coping efforts are typically problem-focused coping behaviours that involve dealing with the practical side and/or tasks of cancer instead of their emotional experiences. It is difficult to find any personal or relationship benefits from the cancer experience with couples using the disengaged avoidant coping style (Kayser *et al.*, 2007:404-418). Although the avoidance coping strategies can be an effective way of dealing with the pile-up stresses, previous research found that negative consequences of this type of coping include lower relationship satisfaction and mental health problems (Ptacek *et a*l., 1994:47-72). Avoidant coping can further be associated with unsupportive behaviours (Manne *et al.*, 2005:635-641) and more distress for both spouses (Manne *et al*., 2006:234-247) (cf. 5.3.1.2).

Kayser *et al. (*2007:404-418) draw the process of responding to stress, validation of each other’s responses, the coordination of strategies and finding benefits or growth from the illness in the shape of a wheel. The shape of a wheel is chosen to illustrate the circular nature of the process because coping with cancer may require of the couple to proceed through the cycles numerous times as they initially cope with the stress of the diagnosis then cope with the demands of living with the illness. Additionally, the outcome of the initial coping process is likely to influence later coping processes.

Box 5: Kayser *et al.* (2007:410) circle of the process of responding to stress



Source: Kayser *et al.* (2007:410).

Other than problem-focused and emotion-focused coping identified by previous research, to facilitate couples further Keyser *et al.* (2007:404-418) investigated aspects relating to relationship functioning. Their findings show that these relational characteristics are just as important to the coping process as the strategies partners used. Important characteristics identified are relationship awareness, authenticity and mutuality. The relational qualities facilitate communication between the partners making it easier to discuss the cancer experience and decide on the best options that will suit both partners to manage the emotional and physical demands of cancer. This quality is especially important for those couples who have not experienced major stressors together (Keyser *et al.*, 2007:404-418).

Kayser *et al.* (2007) identify three relational characteristics, namely:

a. Relationship awareness: Sensitivity of stress as "our stress"
   Regarding the relationship in the context of the illness; thinking about the impact of cancer on both partners and their relationship and how to sustain the relationship through the journey.

b. Authenticity: Honest self-disclosure of feelings
   Spencer (2005:287-315) defines authenticity as the disclosing of true feelings to each other and not hiding them. In the context of cancer Keyser *et al.* (2007:404-418) note that it facilitated the relational coping by allowing each individual to be aware of the others' feelings and needs in relation to cancer, ultimately helping the couple to effectively respond to each other's needs.

c. Mutuality: Ability to have empathy towards each other

To participate as fully as possible in a shared experience, “we illness”. Mutuality promotes effective coping by means of emotional support needed to deal with anxiety, sadness, fears and other emotions related to cancer (Kayser *et al.*, 2007:404-418).
Experiencing cancer as a “we-illness” does not necessarily mean that the partners identify the same aspects or changes as being the most stressful. In fact, Kayser *et a*l. (2007:404-418) conclude that in most cases patient and partner identified different changes. They (2007:404-418) noted that the ability to accept different perspectives are important characteristics in partners**.**

In summary, it is widely documented that cancer and the treatment thereof affect both patient and IFCs, from there the term “we-illness” (Kayser *et al.*, 2007:404-418). This is demonstrated in the high rates of psychological distress, firstly, as expressed by IFCs (Janda *et al.*, 2007:617-623) and secondly, because IFCs and the cancer patient’s psychological well-being is closely related (Hodges *et al.,* 2005:1-12). Not only do they have to cope with the consequences of the cancer, but they must also deal with each other’s emotions and coping responses (Hagedoorn *et al.,* 2011:205-211). It can thus be concluded that cancer affects couples to varying degrees as a unit, rather than as isolated individuals (Hagedoorn *et al.,* 2008:1-30). The “we-illness” journey starts with a cancer diagnosis where both, spouse and patient, must learn to cope together through the treatment, as well as readjustment to life after cancer.

3.2.1.2 Adult gender differences in caregiving

The IFC is complex with dynamic relationships, evolving and changing in predictable, as well as unintended ways (Blum & Sherman, 2010:243-258). Several factors play a role in the caregiving experience of which the most meaningful is reported to be gender due to a close link between gendered constructions and expectations of being male or female (Hagedoorn *et al.*, 2008:1-30; Ussher & Sandoval, 2008:945-963). According to Hagedoorn *et al*. (2008:1-30), gender and role are intertwined, particularly among spousal caregivers. It is suggested that gender may be a more noteworthy determinant of distress than role (patient versus caregiver) (Hagedoorn *et al.,* 2008:1-30). Li *et al.* (2013:178-187) and Li and Loke (2013:578-587) also notice gender differences in the experience of spousal caregiving, explaining that gender differences in role commitment can possibly clarify the differences between male and female caregivers.

Box 6: Gender differences in adult caregiving

Female cancer caregivers	**Male cancer caregivers**
Role commitment Emotional attentiveness and coping styles may explain the gender differences in role commitment (Rose-Rego *et al.*, 1998:224-230).	

<table>
<tr><td>Female caregivers regard themselves as expert carers. This concept of the self tends to lead to taking on too many responsibilities and self-sacrifice resulting in distress (Kim <i>et al.</i>, 2007: 294-304; Ussher & Sandoval, 2008: 945-963).
Female caregivers are traditionally prone to perform more care tasks such as personal care and household chores throughout the process of caregiving. This tendency is more time-consuming, demanding and ongoing (Rose-Rego <i>et al.</i>, 1998:224-230; Kim <i>et al.</i>, 2007:294-304).</td><td>Male caregivers who regard caring as a task of competency, rather than as a traditional role, experience feelings of self-mastery or satisfaction (Kim <i>et al.</i>, 2007: 294-304; Ussher & Sandoval, 2008: 945-963).</td></tr>
<tr><td colspan="2">Different coping styles
Differences in emotional attentiveness and coping styles can be explained by general differences observed between genders (Rose-Rego <i>et al.</i>, 1998:224-230)</td></tr>
<tr><td>Coping styles of female caregivers are more emotion focused coping strategies, which are associated with higher levels of negative health outcomes (Miller & Cafasso, 1992:498-507).</td><td>The most difficult aspect of caregiving for male spousal caregivers is expressing themselves (Lopez <i>et al.</i>, 2012:402-410).
Male caregivers showing emotion may be regarded as shameful or as a sign of being “crazy”, which will lead to avoidance as a way of coping strategy. As a result, male caregivers use avoidance as a coping strategy (Ussher & Sandoval, 2008:945-963).</td></tr>
<tr><td colspan="2">Gender differences in social networks
Social norms together with the perception of the quality of the relationship may regulate who offers care to the diagnosed spouse or how the caregiving experience is perceived by each spouse (Yarry <i>et al.</i>, 2007: 24-30).</td></tr>
<tr><td>Female identities tend to be more strongly tied to social networks (Pinquart & Sorensen, 2001:195-213).
Female spousal caregivers receive less social support, provide more emotional support and experience more disruption in their daily schedules (Li <i>et a</i>l., 2013:178-187).</td><td>Male identities may be preoccupied with their partners and their work (Pinquart & Sorensen, 2001:195-213). Consequently, the connection between the perceived support and relationship satisfaction may not be as strong for males as for females (Yarry <i>et al.</i>, 2007: 24-30).
Male spousal caregivers are more affected by their lack of preparedness for the caregiving role as a result reporting a loss of sleep and difficulties in expressing their emotions (Li <i>et al.</i>, 2013:178-187).</td></tr>
</table>

Gender differences in cognitive-behavioural responses	
Female caregivers display to be more capable of planning ahead, keeping busy by helping and undertaking more tangible and emotional caregiving (Li *et al*., 2013:178-187).	Male caregivers practise avoidance and find it difficult to express their emotional reactions to the caregiving process, providing less tangible and emotional support (Li *et al*., 2013:178-187).

Source: Author compiled the table.

In general, female caregivers perceive the caregiving process more negatively in different dimensions. They report higher rates of depression, anxiety, unmet needs and the burden of care (Ussher & Sandoval, 2008:945-963), lower mental and physical health, health related quality of life, life satisfaction and marital adjustment. Although not consistent, greater caregiver distress is associated with younger females, being a spouse, and employed (Pitcearthly & Maguire, 2003:1517-1524; Kim & Given, 2008:2556-2568). Nevertheless, female spousal caregivers are also more likely to experience more personal growth than male spousal caregivers (Li *et al*., 2013:178-187). `

Regardless of gender, factors such as the stage of cancer, physical health and care demands of the cancer patient are associated with the caregivers' physical and mental health. Both, male and female caregivers suffer from spill over effects as a result of secondary stressors for example, role problems, lack of social and emotional support, disrupted schedules, loss of sleep and fatigue. No gender differences were reported in terms of caregivers' spirituality and optimism (Li *et al.*, 2013:178-187).

3.2.2 Preadolescent/adolescent distress due to parental cancer

Preadolescents/adolescents who have a parent diagnosed with cancer experience many changes, threats and challenges that lead to many different thoughts, feelings and responses. It has been found that events such as serious accidents, sexual assault and life-threatening illnesses relate to stress response symptoms in preadolescents/adolescents (Huizinga *et al*., 2010:1421-1428). Having a parent with cancer may be such an event for not only the preadolescents/adolescents (Romer *et al.,* 2002:17-38; Huizinga *et al*., 2010:1421-1428), but the entire family faces disruption and distress (Pitceathly & Maguire, 2003:1517-1524). Parental cancer is a negative life event in a preadolescent/adolescent's life and assumed to have a negative impact on the preadolescent/adolescent's quality of life (Helseth & Ulfsaet, 2003:355-362). Gaining insight in the occurrence of SRS in preadolescent/adolescents with parents diagnosed with cancer is important in order to offer support to the co-parent caregiver.

Preadolescents/adolescents living with parental cancer have to witness their parents suffer from cancer, the treatment thereof with the accompanying side effects and the ultimate fear of losing a parent (Huizinga *et al*., 2010:1421-1428), which negatively affect their behavioural, emotional, physical functioning and school performance (Visser *et al*., 2004:683-694; Barkmann *et al*., 2007:476-481;

Ramchandani & Psychogiou, 2009:646-653; Sieh *et al*., 2010:384-397). The emotional strain of a cancer diagnosis, uncertainty concerning the cancer journey, medical treatments and hospitalisation can lead to alterations in parental availability, communication with preadolescent/adolescents, cause distress, disruptions to the household, family routines and impact family life (Visser *et al*., 2004:683-694; Turner *et al.*, 2007:135-145; Semple & Cance, 2010:110-118; Moore *et al.*, 2015:3551-3557). Family risk factors for preadolescent/adolescents' mental health problems include family dysfunction, poor family communication, low levels of family cohesion and low affective responsiveness, general dysfunction of family relationships, changed roles and constant family disharmony (Visser *et al*., 2004:683-694; Huizinga *et al*., 2005b:1956-1961; Watson *et al*., 2006:43-50). Preadolescents/adolescents are especially vulnerable, because they are dependent on their parents' care and support, and as a result they have limited capacity to cope with such a life altering situation (Faulkner & Davey, 2002:63-72; Visser *et al*., 2005:746-758; Osborn, 2007:101-126) and are at a higher risk of developing problematic psychosocial outcomes (Visser *et al*., 2004:683-694; Visser *et al.*, 2005:746-758; Barkmann *et al*., 2007:476-481; Thastum *et al*., 2009:4030-4039).

Parental cancer affects preadolescent/adolescents in two different ways. Firstly, their concern for the sick parent can have a direct effect on the preadolescent/adolescent's well-being and secondly, the lack of parental support can affect their coping abilities (Moss *et al*., 1996:511-525). How the preadolescent/adolescent copes with these stressful situations will have an impact on both their current, as well as future psychopathology and well-being (Compas *et al*., 2001:87-127; Compas *et al*., 2017:939-991). The most widely acknowledged definition of the resilience to cope, comes from Lazarus and Folkman (1984:141) defining coping as "constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person". Helseth and Ulfsaet (2003:355-362) explain that coping is something preadolescents /adolescents do consciously and unconsciously in order to manage the challenges of living with cancer in the family. Parental cancer appears to put preadolescent/adolescents' lives out of balance (Helseth & Ulfsaet, 2003:355-362) and indicate that they constantly struggle to maintain a balance. The most common strategy used by them to manage the emotional and practical consequences of parental cancer is "going in and out" of the situation both, emotionally and literally. Two purposes are served with this strategy, namely getting away from the illness and secondly, having a good time. The way the preadolescents/adolescents go in and out of the situation helps them with maintaining a balance in life (Helseth & Ulfsaet, 2003:355-362).

Costas-Muñiz (2012:413-417), Krattenmacher *et al*. (2013:252-259), and Küçükoĝlu and Çelebioĝlu (2013:75-80) investigated the use of coping strategies as a buffer for the development of psychological symptoms. According to Costas-Muñiz (2012:413-417), these preadolescents/adolescents usually use adaptive coping strategies such as acceptance, seeking emotional support, and religious comfort which can prevent the development of severe psychological problems. Lindqvist *et al*. (2007:345-351), Krattenmacher *et al*. (2013:252-259) and Küçükoĝlu and Çelebioĝlu (2013:75-80) characterise problem-focused coping methods and emotion-focused coping methods as follows:

- Problem-focused coping methods (techniques used to find solutions to a stressful situation) relate to better adjustment to cancer management.
- Emotion-focused coping methods (strategies aimed at reducing negative emotions) can increase anxiety levels in cases where emotions are suppressed or have been misinterpreted.

Krattenmacher *et al*. (2013:252-259) verify that the protective nature of problem-focused coping strategies is acceptance, cognitive restructuring, and seeking social support, together with emotion-focused coping strategies such as interpretation of intense emotional states are linked with better functioning.

The researcher identified the following variables as the most important factors that play a significant role in helping the preadolescent/adolescent adjust and / or cope with parental cancer:

a) The age of the preadolescent/adolescents (Visser *et al.*, 2004:683-694; Su & Ryan-Wenger, 2007:362-382; Osborn, 2007:101-126; Sieh *et al.*, 2010:384-397)
b) The gender of the preadolescent/adolescents (Visser *et al.*, 2004:683-694; Su & Ryan-Wenger, 2007:362-382; Osborn, 2007:101-126; Grabiak *et al*., 2007:127-137). The gender of the diagnosed parent (Visser *et al*., 2004:683-694; Su & Ryan-Wenger, 2007:362-382; Grabiak *et al*., 2007:127-137)
c) Psychological functioning of the preadolescent/adolescents, especially depressive asymptoms of the diagnosed parent (Visser *et al.*, 2004:683-694; Sieh *et al.*, 2010:384-397)
d) Family functioning (Visser *et al.*, 2004:683-694; Watson *et al*., 2006:43-50; Gazendam-Donofrio *et al*., 2007:1951-1956; Schmitt *et al*., 2008:5877-5883)
e) The duration of the illness (Sieh *et al.*, 2010:384-397)

These factors are identified to play a significant role in helping the preadolescent/adolescent adjust and/or cope with parental cancer and will now be discussed in more detail.

a. The age of the preadolescents/adolescents.

Houtzager *et al*. (2004b:591-605) conducted a study to see how the healthy sibling can be recognised in terms of their individual characteristics such as age, gender, illness specificity and coping strategies, as well as systemic characteristics such as family cohesion, adaptability and parent mental health. Finding differences in psychosocial adjustment to the illness according to the siblings' age and gender (Houtzager *et al.*, 2004b:591-605).

Consequences of parental cancer on the preadolescent/adolescents' functioning can depend on their developmental stages (Faccio *et al.,* 2018:1-11). Studies have shown that emotional and/or behavioural struggles expand in most preadolescents/adolescents during the illness of their parents (Küçükoĝlu & Çelebioĝlu, 2003:75-80; Visser *et a*l., 2005:746-758; Watson *et al.,* 2006:43-50; Thastum *et al.,* 2009:4030-4039; Costas-Muñiz, 2012:413-417; Krattenmacher *et al.,* 2013:252-259).

In preadolescents/adolescents, the occurrence of symptoms ranged from 23% (Visser *et al.,* 2005:746-758) to 30% (Edwards *et al.,* 2008b:1039-1047). These findings fluctuate according to the preadolescent/adolescents' developmental phase and to the perspective of evaluation for example preadolescent/adolescents' or parents' perspective (Jantzer *et al.,* 2013:2611-2616).

Studies show that age is particularly significant regarding the healthy preadolescent/adolescents' adaptation to experiencing a sibling with cancer. Cordaro *et al*. (2012:42-50) confirm that parents perceive their healthy adolescent siblings to have more observable distress than younger siblings. It is further likely that the more mature siblings (pre-adolescent and adolescents) deliberately chose to show as little as possible of their emotions, to avoid adding to their parents' worries (Corado *et al*., 2012:42-50). This explains why parents when questioned about changes in their healthy siblings' behaviour typically respond with: "It is as if he/she has grown up, became more responsible, protective, sensible, organised, independent, particularly well behaved, more conscientious and involved in family life".

In regards to the psychological functioning, the percentages of noteworthy clinically emotional and behavioural symptoms varied from 7% (Möller *et al.,* 2014:2361-2370) to 20% (Visser *et al.,* 2005:746-758) in preadolescents under the age of 11. Possible risky behaviours in adolescents ranged from 3% to 23% (Jantzer *et al.,* 2013:2611-2616).

Family functioning can be defined as "the processes engaged in by families in their day-to-day lives to achieve goals, address challenges, and support and enhance individual members' health and development" (Williamson *et al*., 2011:398). Poor family cohesiveness related to increased stress responses in especially adolescents, due to the sensitive developmental phase (Edwards *et al*., 2008b:1039-1047).

Studies further show that 5-10% of preadolescents recorded anxiety during the period awaiting diagnosis (Welch *et al.,* 1996:1409-1418; Lindqvist, 2007:345-351; Hauken *et al.,* 2017:19-27); while up to 44% of adolescents recorded anxiety during the period awaiting diagnosis (Costas-Muñiz, 2012:413-417; Edwards *et al.,* 2008b:1039-1047), and 29% adolescents expressed clinically relevant stress response signs at time of diagnosis which reduced to 14% one year after the diagnosis (Huizinga *et al.,* 2010:1421:1428). Among 13% to 64% of adolescents showed clinical scores in depression measures during the cancer journey (Costas-Muñiz, 2012:413-417; Krattenmacher *et al.,* 2013:252-259).

b. The gender of adolescents

Numerous studies have reported the effect of age and gender, although the results differ from scholar to scholar. Several studies reported that females struggle more than males (Nelson & While, 2002:15-36; Edwards *et al*., 2008b:1039-1047), while others disagree with this distinction (Visser *et al*., 2006:1178-1187; Huizinga *et al*., 2010:1421-1428).

Box 7: Gender differences in preadolescents and adolescents coping with a cancer diagnosis

Females	**Males**
• Effect of parental cancer treatment	
According to Visser *et al*. (2005:746-758), female preadolescent/adolescents were more affected by the intensity of the parents' cancer treatment.	Male preadolescent/adolescents were more affected by the relapse of the parents' cancer (Nelson & While, 2002:15-36; Edwards *et al*., 2008b:1039-1047).
• Psychosocial functioning Compas *et al*. (1994:507-515) note that the preadolescent/adolescents of cancer patients are more likely to suffer from negative psychosocial outcomes;	
Preadolescent/adolescent females of cancer parents are markedly at risk (Thastum *et al*., 2009:4030-4039).	Males aged four to ten of cancer parents are markedly at risk (Thastum *et al*., 2009:4030-4039).
• Sibling distress due to a brother or sister with cancer	
Females and older siblings appeared to stand a higher risk for adjustment problems. The older siblings reported higher levels of anxiety, feeling more insecure and lonelier, but also showed more emotional involvement with the illness (Pollet & Nettle, 2009:1029-1046). Compared to brothers, the sisters of the diagnosed child they reported higher levels of anxiety, insecurity and loneliness. Females and the older siblings may suffer more from restrictions in their daily lives and overall development because they have more responsibilities and are more involved in the illness. Results from Houtzager *et al*. (2004b:591-605) confirm that the older siblings were more involved in the illness process which related to lower optimism, more reliance on information and the	Gerhardt *et al*. (2012:209-219) report that bereaved male siblings were considered more sensitive, isolated and victimised compared to female siblings.

doctor's capabilities with higher levels of family adaptation and cohesion relating to more unfavourable adjustment.	

Source: Author compiled the table.

Watson *et al*. (2006:43-50) argue that evidence on gender differences remains insubstantial due to the low number of studies that include boys (Grabiak *et al*., 2007:127-137; Krattenmacher *et al*., 2012:344-356).

c. Psychological functioning of the preadolescent/adolescent

A review by Lewis (2004:288-292) notes that most families do not know, understand, interact with or support preadolescent/adolescents who cope with parental cancer. If they are faced with parental cancer in addition to their normal development phases such as building relationships with the opposite sex, assuming responsibility or detaching themselves from their family, a number of coping mechanisms are required, such as searching for information about cancer, spending more time with family or needing distractions to maintain some sense of normality (Grabiak *et al*., 2007:127-137). The stress from both, the diagnosed parent and the preadolescent/adolescent often affects one another, aggravating the risk for the preadolescent/adolescents to develop psychological difficulties (Götze *et al.,* 2015:787-795). Psychological difficulties can be divided into two categories, namely:

- Internalising problems include anxiety, fear, sadness, depression and a sense of feeling guilty. These symptoms often manifest externally in the form of withdrawal from their social environment and poor school performance (Achenbach, 1991).
- Externalising problems is when the preadolescent/adolescents' distress is openly expressed by means of aggressiveness, impulsive behaviour, attention deficits and delinquent behaviours (Achenbach, 1991).

Thastum *et al*. (2009:4030-4039) note that the best predictor of problem internalisation in preadolescents and adolescents was parental depression, whereas the best predictor of problem externalisation was family dysfunction.

Studies emphasise the inconsistency between the parent-reported and preadolescent's and adolescent's self-reported mental health outcomes, with preadolescents and adolescents reporting higher levels of distress, proposing that parents tend to underestimate the preadolescent/adolescents' responses (Visser *et al.,* 2005:746-758; Watson *et al.*, 2006:43-50; Krattenmacher *et al.*, 2013:252-259).

d. Family functioning

Some studies show that preadolescent/adolescents' coping with parental cancer struggle more with emotional and stress-related symptoms than their peers who don't have a parent diagnosed with cancer (Visser *et al*., 2007:67-76; Edwards *et al*., 2008b:1039-1047).

Several studies found a link between parental depression and preadolescent/adolescents' behaviour (Hoke, 2001:361-369; Lewis & Darby, 2004:83-106; Watson *et al.*, 2006:43-50; Edwards *et al*., 2008b:1039-1047; Thastum *et al*., 2009:4030-4039). 45% Female adolescents and 33% male adolescents suffer from anxiety due to maternal depression and poorly defined family roles (Watson *et al*., 2006:43-50; Edwards *et al.,* 2008b:1039-1047), and female adolescents manifested more aggressive behaviour than boys (Visser *et al.*, 2005:746-758; Krattenmacher *et al.,* 2013:252:259). These findings are in line with earlier data linking depression from the mother's side to emotional problems, especially in female adolescents (Lewis & Darby, 2004:83-106). Watson *et al*. (2006:43-50) and Osborn (2007:101-126) observe that maternal depression and poor family functioning are important in order to understand cases where preadolescent/adolescents have emotional and behavioural problems. According to Watson *et al*. (2006:43-50), predictors for preadolescent/adolescents' externalising behavioural problems, for both the mother and preadolescent/adolescent, were poor behaviour control, poor family affective involvement and poor general family functioning (Watson *et al*., 2006:43-50). Thastum *et al*. (2009:4030-4039) conclude that parental depression seems to be a predictor of internalising, externalising and total problems of preadolescent/adolescents. According to Edwards *et al*. (2008b:1039-1047) family functioning has a strong mediating role in the relationship between the parent's psychological condition and the preadolescent/adolescent's levels of distress. Thastum *et al*. (2009:4030-4039) confirm that family dysfunction (little communication, low levels of affect and disrupted intra-familial relationships) is the most important predictor of preadolescents' and adolescents' emotional and behavioural problems. A poor family environment specifically those including depression, anxiety or stress (Watson *et al*., 2006:43-50; Edwards *et al*., 2008b:1039-1047) is related to higher rates of emotional and behavioural problems in preadolescents and adolescents (Möller *et al*., 2014:2361-2370), which negatively influence their quality of life (Vannatta *et al*., 2010:9-16; Götze *et al*., 2015:787-795). According to Möller *et al*. (2014:2361-2370) the level of family functioning, in view of a life-threatening illness in a parent, is the main predictor of the preadolescent's and adolescent's behavioural and emotional symptoms. Family functioning is thus the strongest predictor of preadolescents' and adolescents' symptom status from both parental and the preadolescent/adolescent's perspectives (Möller *et al*., 2014:2361-2370). This verifies findings from studies showing that open communication, affective involvement between family members, flexible problem solving and generally positive family functioning result in less psychological distress in preadolescents and adolescents (Watson *et al*., 2006:43-50; Thastum *et al*., 2009:4030-4039).

It is important to note that a number of preadolescents and adolescents living with parental cancer show a certain level of resilience and report that they are functioning well (Visser *et al*., 2005:746-758; Capelli *et al*., 2005:481-491; Visser *et al*., 2007:67-76; Jantzer *et al*., 2013:2611:2616). Lindqvist *et al*. (2007:345-351) assume that since their parents are seriously ill, the preadolescents and adolescents possibly experience a sense of gratitude towards life and feel less inclined to be concerned about things that normally worry other preadolescents and adolescents. According to Gazendam-Donofrio *et al*. (2007:1951-1956), families with parental cancer function better than the norm where patients, spouse and preadolescents/adolescents describe the family environment as less controlling, and better organised with lower levels of conflict between members. Wong *et al*. (2009:53-63) also report about positive psychological change that can happen during the trauma and report post-traumatic growth experiences such as improved character, increased appreciation for life and strengthened personal relationships. Kennedy and Lloyd-Williams (2009:94-113) also report positive aspects, such as learning to value family members and the important things in life, despite the stress of cancer.

However, although these studies suggest that not all preadolescents and adolescents living with parental cancer require some form of intervention, there is more clinical evidence that some of them become highly distressed or develop psychosocial problems (Grabiak *et al.*, 2007:127-137; Osborn, 2007:101-126). Watson *et al*. (2006:43-50) stress the importance of family focused and preadolescents' and adolescents' focused psychological services within cancer centres, adding that further studies can help to target clinical services and support caregivers by identifying which factors in families, result in preadolescents/adolescents' disturbances, simultaneously also improving the quality of life for the patients. It is therefore important to identify the preadolescents/adolescents who struggle with adjustment, and who develop emotional and behavioural problems, especially those that are exposed to high-risk family functioning or poor communication (Huizinga *et al*., 2011: 239-246). Thastum *et al*. (2009:4030-4039) suggest that, interventions need to focus on family functioning such as problem solving, communication, roles, affective responsiveness, affective involvement and behavioural control. Ernst *et al*. (2012:432-446) propose that in order to identify families in need of support, there must be programmes in place where families can be screened in oncological treatment units to identify family dysfunctions and preadolescent/adolescents' mental health problems, together with parental depression. Higher risk status families should be referred to mental health specialists for example family therapist, preadolescent/adolescent psychotherapist, or PCs. To reduce psychological distress for the whole family, support for both, parents and preadolescents and adolescents must be recognised as an important element of care (Möller *et al*., 2014:2361-2370). The professional (family therapist, preadolescent/adolescent's psychotherapist, or PCs) must look beyond the diagnosed parent to include the wider context and the needs of the entire family in order to protect the development of the patient's preadolescents and adolescents and help the parent caregiver to understand what their preadolescent/adolescents are going through.

e. Duration of illness

Emotional and behavioural problems such as anxiety, depression, somatic complaints, aggressive or delinquent behaviour and cognitive problems (Visser *et al*., 2004:683-694; Saigh *et al*., 2002:462-470; Yule, 2001b:23-28) can delay normal development (Davis & Siegel, 2000:135-154). Studies from Huizinga *et al*. (2010:1421-1428) note that the preadolescent's and adolescent's emotional- and behavioural functioning appear to be more critical in the short-term (up to one year from diagnosis). In term of acceptance and illness, Küçükoĝlu and Çelebioĝlu (2013:75-80) confirm that the period awaiting diagnosis, was a trying time for communication both for the diagnosed parent and preadolescent/adolescent.

Huizinga *et al.* (2010:1421-1428) acknowledge that preadolescents and adolescents with SRS experience both, emotional and behavioural problems during the first year after diagnosis and continue to have long-term emotional problems. Possible reasons for the continued stress after the parent had completed treatment may be that as life returns to a new normal, preadolescents and adolescents have time to process the cancer journey and re-experience cancer-related events. Studies demonstrate that preadolescents/adolescents experiencing parental cancer may have a long-standing post-traumatic stress disorder (PTSD) or traumatic stress responses, including intrusive thoughts and avoidant behaviour (Yule, 2001a:194-200; Huizinga *et al*., 2005a:288-295). Cancer differs from other PTSD stressors given that it is both, a discrete past event, as well as a process with a future life-threatening component (Edward *et al*., 2008:1039-1047). Preadolescents and adolescents with parents diagnosed with cancer can thus experience a series of stress periods, starting from the initial diagnosis, throughout medical treatment, to recovery (Huizinga *et al*., 2011:239-246).

3.2.3 Sibling distress due to a brother or sister with cancer

This study finds it of meaning to address the emotional distress and adaptation that the healthy siblings face when their brother or sister is undergoing cancer treatment. By understanding the siblings' responses and trajectory of family conflict, PCs can identify which family subsystem is at risk and build interventions to target at risk relationships and strengthen families as they face the cancer journey (Katz *et al.*, 2018:736-745). With a thorough understanding the PC can provide more effective family-centred, multidimensional methods to help the family caregivers, be it the parents, grandparents or other siblings. Paediatric cancer affects the significant others, because of its particularly disruptive nature on the daily lives and emotional well-being of the family members. For this reason, Houtzager *et al*. (2004b:591-605) accentuate the importance of a family-system approach where the impact of cancer on the healthy siblings can be incorporated and investigated. From a family system perspective. Family is considered as a system consisting of multiple interrelated parts including both the individuals and the relationships between individuals (Katz *et al.*, 2018:736-745). Although it is widely recognised that a paediatric cancer diagnosis has a severe impact on both, the parents and the diagnosed sibling, less is known on how the healthy siblings are affected (Weiner & Woodley, 2018:109-119) with no evidence-based standards for the psychosocial care of the healthy siblings (Gerhardt *et al.*, 2015:750-804). Healthy siblings thus may have unmet needs and limited psychological support (Ballard, 2004:394-401; Patterson *et al.*, 2011:16-26).

Siblings influence one another in many ways throughout their lifespan. Sibling relationships can influence all aspects of life and have been accepted as one of the longest lasting relationships in an individual's lifetime (Fortuna *et al*., 2011:1366-1373; Mikkelson *et al*., 2011:220-236; Trent & Spitze, 2011:1178-1204; Portner & Riggs, 2016:1755-1764). Studying sibling relationships is further important because the relationship has significant effects on mental (Milevsky, 2005:743-755) and physical health (Senguttuvan *et al.*, 2014:384-396).

Among personal relationships, the relationships between siblings are distinct (Pike & Oliver, 2017:250-255). Firstly, these relationships are emotionally uninhibited with the potential to increase siblings' influence on one another (Dunn, 2002:223-237) and secondly, the amount of time siblings spend together. Research shows that by middle childhood, the time siblings spend together surpasses the time they spent with their parents (McHale *et al*., 2007:227-235). Associations between sibling relationships link with pro-social behaviour (Pike *et al*., 2005:523-532) and social competences have been reported (Buist & Vermande, 2014:529-537). Goetting (1986:703-714), who focuses on pro-social aspects of sibling relationships, identifies three main contributors of sibling relationships during development:

- Direct service:

Refers to several social functions that siblings provide within the family context and beyond. Siblings may for example translate the meaning of each other's actions to the parents. They may also warn each other of the mood of the parent and upcoming punishment.

- Companionship and emotional support:

Siblings may form alliances with each other, as mostly seen in difficult family environments (abusive and or explosive parent(s)). Goetting (1986:703-714) adds that sibling companionship is crucial for both the healthy and the diagnosed sibling. Milevsky (2005:743-755) says that sibling support has the power to compensate for a lack of parental support. Similarly, Senguttuvan *et al*. (2014:384-396) state that the negative effects associated with lack of parental support were lessened by a positive sibling relationship.

- Caretaking:

Goetting (1986:703-714) states that siblings may unite with the purpose to provide a safe and understanding environment for one another and further tend to show high loyalty towards one another, particularly in cases where a parent is absent due to taking care of the sibling diagnosed with cancer.

A paediatric cancer diagnosis is a major life-changing event for not only the diagnosed child but their siblings as well. Adaptation is a broad concept entailing both, emotional and behavioural aspects and strongly links to a preadolescent's and adolescent's quality of life (Cordaro *et a*l., 2012:42-50). The following changes will be discussed.

3.2.3.1 *Emotional changes*

Siblings are exposed to significant stress when a brother or sister is diagnosed with cancer. D'Urso *et al*. (2017:301-317) note a variety of difficult emotions that the healthy siblings experience. Those include shock, fear and uncertainty, especially at the time of diagnosis. Tafoya and Hamilton (2012:49-74) examined the variables verbal aggression and comforting in sibling relationships finding that biological siblings showed closer relationships than half-siblings, further showing that parent-preadolescent/adolescent closeness improved sibling empathy related to diminished verbal aggression between siblings. This finding demonstrates that sibling relationships can be better understood in the context of wider family dynamics (Tafoya & Hamilton, 2012:49-74).

The healthy siblings are referred to as "the invisible children". Self-evidently the diagnosed child becomes the focus of the parents' attention. Healthy siblings often express strong negative feelings, such as anger, jealousy and anxiety (Hagedoorn *et al.,* 2011:205-211). Kolak and Volling (2011:213-226) studied the effects of jealousy between the siblings and define sibling relationships as mutually intrapsychic, as well as interpersonal, where each component influences the other. Further stating that jealously is the result from one sibling perceiving triangulation between a parent and preadolescent/adolescent, in other words the preadolescent/adolescent assumes that the parent and other sibling(s) are excluding him or her from their discussions. Kolak & Volling (2011:213-226) propose that present sibling jealousy could be allied with negative effects in future sibling relationships, as the healthy siblings sometimes express anger and jealousy as the treatment continues, due to the amount of attention directed towards the diagnosed sibling. According to O'Shea *et al*. (2012:221-231), healthy siblings often report that jealousy toward the diagnosed sibling because more parental attention is directed towards the diagnosed sibling, accompanied by more toys, food, gifts and television time.

In addition, feelings of uncertainty and anxiety were also frequent, especially while awaiting accurate diagnosis (Jenholt Nolbris *et al*., 2014:1-7; Long *et al*., 2015:21-31; Rosenberg *et al*., 2015:55-65; Salavati *et al*., 2016:362-372; D'Urso *et al*., 2017:301-317). Having questions left unanswered regarding the illness, but at the same time understanding something is wrong, is extremely difficult for the healthy siblings (Long *et al*., 2015:21-31). This results in feelings of being left out from their own family, as well as the cancer treatment itself (Neville *et al*., 2016:188-194). Some healthy siblings became increasingly withdrawn during the cancer journey (Foster *et al*., 2012:347-354). Other emotions observed include depression, fear, anger, isolation and feeling lonely (Alderfer *et al*., 2010:789-805; Rosenburg *et al*., 2015:55-65; Yang *et al*., 2016:12-21). The healthy siblings expressed that they felt insecure about themselves and suffer the loss of their sense of self-identity due to the cancer experience (Long *et al*., 2015:21-31).

Directly related to the cancer experience, siblings also endure stress which significantly adds to the stressors already present in these preadolescent/adolescent's daily lives (Neville *et al.*, 2016:188-194). In some cases, siblings are asked to be a donor for stem cell transplant, which can cause other ethical and psychosocial concerns (Packman *et al*., 2010:1134-1146). These unique challenges can leave the healthy sibling at risk of intense and long-term psychosocial complications (Gerhardt *et al*., 2015:750-804). A number of the healthy siblings not only admit to their grief, but also feelings of guilt as they took into account that their brother or sister might die (Jenholt Nolbris *et al*., 2014:1-7). Siblings felt most guilty as the sick sibling lost the ability to take part in normal childhood actions, while the healthy sibling was in a position to continue with the activities they enjoyed (Jenholt Nolbris *et al*., 2014:1-7). Feelings of guilt and grief escalate as the healthy siblings watch the diagnosed sibling undergo physical changes (hair loss, weight loss) as the treatment progresses (Prchal & Landolt, 2012:133-140).

Healthy siblings can demonstrate resilient outcomes, such as post-traumatic growth (Alderfer *et al*., 2010:789-805; Duran, 2013:179-197). Studies also reveal optimistic attitudes from the healthy siblings throughout the cancer journey. D'Urso *et al*. (2017:301-317) for instance report that according to some healthy siblings, the illness impacting their family life increases their sense of maturity, empathy and self-confidence. According to Yang *et al*. (2016:12-21), siblings feel optimistic about the future despite their difficult emotions and learn to empathise with their diagnosed sibling. Nelville *et al*. (2016:188-194) agree with the above, reporting that the personal growth led many healthy siblings to show resiliency. Studies examining sibling responses after death found similar response patterns. Focusing on both the bereaved siblings, as well as siblings whose brother or sister was living with cancer Jenholt Nolbris *et al*. (2014:1-7) conclude that all siblings go through feelings of guilt and grief. Both Foster *et al*. (2012:347-354) and Rosenberg *et al*. (2015:55-65), discovered similar patterns of resiliency in bereaved siblings, reporting raised levels of maturity, compassion for others, becoming more appreciative of life, personal growth, confidence and better communication skills.

From literature it is evident that some healthy siblings experience changed emotions over time as the diagnosed sibling moves through the cancer treatment, turning negative feelings into more positive ones by using coping strategies to process thoughts and emotions (Long *et al*., 2015:21-31). Even though the coping strategies stand unique to each preadolescent/adolescent, the siblings go through a process where their coping strategies improved over time with the support of family and friends (Long *et al*., 2015:21-31; Neville *et al*., 2016:188-194).

3.2.3.2 Relationship changes

The disruption of routines in the family, as well as changing dynamics of family relationships can have a negative effect on the well-being of the healthy siblings (Williams *et al.*, 2009:94-113). Foster *et al.* (2012:347-354), Prchal and Landolt (2012:133-140) and Long *et al.* (2015:21-31) find that the healthy siblings were expected to continue with their normal daily lives. Many of the siblings found this very difficult because everything around them was changing. The impact of the diagnosis changed the sibling's relationships with peers. While some friendships changed causing the siblings to lose some of their friends, some new friendships were also established (Foster *et al*., 2012:347-354; D'Urso *et al*., 2017:301-317). Researchers have been testing hypotheses about the effects of peer interaction, for at least the last seven decades (Rubin *et al*., 2015:175-222). Evidence from studies shows that experiences with peers represent an important socialisation field for adolescents (Bukowski *et al.*, 2014:228-250). In particular, it is known that experiences with peers have an effect on how adolescents think about themselves, how they feel, and how they behave (Christiansen *et al*., 2015:674-677). Prchal and Landolt (2012:133-140) and Yang *et al.* (2016:12-21) find that some siblings value their relationships with peers more, because these friendships serve as a distraction from thinking about their sick sibling. These friendships are further an escape from the stressors of the family's experience with cancer. On the other hand, D'Urso *et al*. (2017:301-317) report that several siblings choose to draw closer to the diagnosed sibling by spending more time with him or her. Prchal and Landolt (2012:133-140) conclude that these experiences were not necessarily universal, stating that some siblings became bothered when their peers would ask questions about the diagnosed sibling. According to Samson *et al*. (2016:362-372), many preadolescents/adolescents report some sort of change in friendships, some voicing less amount of time available to spend with friends due to family responsibilities. Others had more time to spend with friends, because the diagnosed sibling was cared for by another.

Concerning parental relationships, D'Urso *et al*. (2017:301-317) state that several siblings became closer to their fathers for emotional support and normalcy, because the mother frequently had to be at the hospital with the sick sibling. During the time after death, the bereaved siblings' responses were shaped by the mothers' state. Older siblings felt responsible for cheering the mother up when they were sad and grieving. An inability to accomplish this put strain on the relationship, despite understanding the mother's sadness. The younger siblings were less able to empathise with their mothers, which led to confusion and fear in some (Kamibeppu *et al*., 2015:165-177).

3.2.3.3 Family and home life changes

Due to advances in the field of oncological therapies and higher survival rate of paediatric cancer, the physical and psychosocial effects of cancer treatment have become increasingly relevant in health care (Houtzager *et al*., 2004b:591-605). For this reason, controlling cancer is no longer the singular objective (Cordaro *et al*., 2012:42-50). Internalisation of problems appears to be the most prominent psychological effect of chronic or life-threatening illness on siblings (Sharpe & Rossiter, 2002:699-710).

With a paediatric cancer diagnosis, family life is turned upside down (Foster *et al*., 2012:347-354). Concern about the ill sibling, disruptions in family roles and routines, taking on additional responsibilities and roles within the family, decreased contact with family members, and additional demands for caregiving are common stressors (Wilkins & Woodgate, 2005:305-319). Because of the increased responsibilities in the house, the healthy siblings felt pressured to grow up fast such as added chores to lessen family stress (Long *et al*., 2015:21-31; D'Urso *et al*., 2017:301-317). For some it led to a greater sense of family unity (Long *et al*., 2015:21-31), but for others it led to strained relationships with the diagnosed sibling (Neville *et al*., 2016:188-194). In an attempt to maintain family normalcy some siblings make an effort to create new roles within the family, for example being more present with the diagnosed sibling and going along to doctors' appointments (Yang *et al*., 2016:12-21). A study conducted by Hamama *et al*. (2008:121-132), examined the relationship between role overload and stress in the healthy siblings and found that siblings with higher role overload showed higher levels of anxiety and higher numbers of psychosomatic symptoms. Siblings with lower levels of role overload however, showed higher levels of self-control skills and higher levels of illness-related self-efficacy. Role overload is when the significant others are unable to fill their specified roles or filling too many roles (Hamama *et al*., 2008:121-132).

During the cancer treatment the healthy siblings observe their diagnosed sibling's physical and psychological distress as well as their parents' anguish. The healthy siblings may further have to cope with unforeseen and lengthy separations from both the diagnosed sibling and their parents, together with changes in their roles (Sharpe & Rossiter, 2002:699-710; Houtzager *et al.*, 2004b:591-605), as well as with disruptions of daily routines, for example, staying with relatives while parents are in hospital with the diagnosed sibling (Hamama *et al.*, 2000:63-83; Murray, 2001:90-104). Times when parents were at home, siblings noticed exhaustion and stress in them that impacted family events such as holidays and vacations (Prchal & Landolt, 2012:133-140). Healthy siblings losing a brother or sister to cancer suffer additional loss as they also lose their parents for some time during the grieving process. As mentioned, healthy siblings are referred to as the invisible children, which become even truer following bereavement.

The amount of distress experienced by the parents may determine the amount of time and energy they have left for their healthy children (Houtzager *et al*., 2004b:591-605). According to Tsimicalis *et al*. (2018:118-131) the lack of quality time with the healthy siblings can lead to the healthy siblings' feeling they have no one to rely on during a time of crisis, thus, left to deal with their concerns on their own. Parents usually give the diagnosed sibling more attention, leaving the healthy siblings feeling neglected or invisible; several healthy siblings furthermore felt like a burden to the family withholding to share problems experienced in their personal lives (Neville *et al*., 2016:188-194; Yang *et al*., 2016:12-21). Jenholt Nolbris *et al*. (2014:1-7) stress the grief that healthy siblings experience, because they feel unimportant and forgotten in their family. Although they fully understand the rationale behind the shift in attention, they still deeply felt a sense of loss (Jenholt Nolbris *et al*., 2014:1-7).

Some parents may further think it best not to talk about the diagnosis with the healthy siblings aiming to protect them from negative psychological effects. The risk of such beliefs is that the healthy siblings could form distorted ideas of the situation (classically far worse than it is) (Cordaro *et al*., 2012:42-50). The healthy siblings are typically concerned about the implications of the illness, the prognosis, what happens to them when the sibling is in hospital, as well as the impact of cancer on their family life as they know it (Cordaro *et al*., 2012:42-50). Even so, parents show concern about the well-being of their healthy children wanting to formalise bereavement support (D'Agostino *et al*., 2008:33-41; deCinque *et al*., 2006:65-83; Welch *et al.,* 2012:335-346; Goldstein & Rimer, 2013:198-202; Flahault *et al*., 2015:665-671).

According to Houtzager *et al.* (2004b:591-605), family adaptability proves to be the most prominent family-system variable to affect the siblings' adjustment. Olsen *et al.* (1979:3-28) define family adaptability as the family system's tendency to change the power structure, role relations and relationship rules in reaction to distress. Defining family cohesion as the degree of closeness and mutual involvement that the family system experiences (Olson *et al*., 1979:3-28). A balanced family structure that includes both stability and change would thus be most functional. Houtzager *et al.* (2004b:591-605) find that healthy siblings with adjustment problems came from families with high levels of adaptability or "chaotic" systems classic of families that struggle to competently deal with stress. Should this adaptability become long-term (remain in constant state of fluctuating rules and roles) it can become harmful to the family members. For the healthy siblings such a family structure requires long-term flexibility, does not offer the needed security, and lacks stability and support which may result in emotional distress. The study shows that even though family adaptability can be effective when transitory, such a process can be harmful when it becomes structural (Houtzager *et al*., 2004b:591-605).

3.2.3.4 Psychosocial and physiological impact

Corado *et al*. (2012:42-50) note that parents tend to underestimate the emotional and behavioural difficulties their healthy children endure that go along with a cancer diagnosis of a sibling. Concluding that the parents may use denial as a defence mechanism, "denial could have induced the parents not to underestimate but rather not to see any" behavioural and or emotional difficulties, believing that the healthy children adapted perfectly to such a stressful situation (Corado *et al*., 2012:42-50). Parents may unknowingly raise their threshold to recognise warning signs in their healthy children, because they regard their healthy children's behaviour in light of the diagnosed child's situation. "This could mean that the healthy children's functioning was assessed not in absolute terms, but by comparison with the children with cancer and consequently seemed much more adaptive than was really the case" (Corado *et al*., 2012:42-50).

Interest also expand to the occurrence of psychological trauma which can be seen in studies of symptoms of post-traumatic stress disorder and post-traumatic growth in long-term cancer survivors (preadolescents and adolescents) as well as their parents and siblings (Kazak *et al.,* 1996:365-380; Alderfer *et al.,* 2003:281-286; Kazak *et al.,* 2004:211-219; Barakat *et al.,* 2006:413-419). Alderfer *et al.* (2003:281-286) witnessed posttraumatic stress reactions in nearly 30% of siblings of paediatric cancer survivors. The number of preadolescents and adolescents considered at risk in these studies proves that despite overall resilience, a reasonably large subgroup of sibling's experience long-term adjustment problems, and they can be distressed for long after the diagnosis of cancer (Houtzager *et al*., 2004b:591-605). According to Houtzager *et al*. (2001:315-324), the distress experienced by the healthy siblings can continue long after the diagnosis of cancer. Houtzager *et al*. (2004a:499-511) note that emotional and social problems can continue up to two years after the diagnosed sibling completed cancer treatment. According to Cordaro *et al*. (2012:42-50), the internal and external factors (post-traumatic stress disorder or post-traumatic growth) have not been studied completely with the healthy siblings receiving the least attention.

Having a sibling diagnosed with cancer and undergoing treatment can be a highly stressful situation for the siblings of the cancer patient. The healthy siblings are vulnerable to a multitude of emotional struggles, as they are forced into a situation where they are confronted with the possibility of their sibling dying. Although severe psychopathology is rare, several studies note that some siblings display symptoms of depression, sadness, fear, anxiety and feeling jealous of the amount of attention received by the diagnosed sibling, lower quality of life and healthcare utilisation, and disruption to academic and social functioning, feeling a loss of their family's way of life and a loss of their sense of self (Alderfer *et al*., 2003:281-286; *Taieb et a*l., 2003:255-264; Wilkins & Woodgate, 2005:305-319; Alderfer *et al*., 2010:789-805). These stressful experiences, thoughts and emotions associated with having a sibling diagnosed with cancer can have long-term negative effects on the healthy preadolescent(s) and adolescent(s) with chances of developing PTSD (Alderfer *et al*., 2003:281-286; Taieb *et a*l., 2003:255-264; Alderfer *et al*., 2010:789-805). Further they observe that the risk of developing PTSD does not necessarily end with remission in cancer, finding that the healthy siblings show a higher risk of developing post-traumatic stress symptoms after the cancer had been treated and cured (Alderfer *et al*., 2003:281-286; Taieb *et al*., 2003:255-264). Kaplan *et al*. (2013:205-217) measured symptoms of PTSD in the healthy siblings and their findings show that one-fifth of siblings met the full criteria for PTSD, while an additional one-third showed some of the symptoms associated with the diagnosis of PTSD. The siblings who met moderate to severe criteria for PTSD had higher self-reported anxiety and depression levels (Kaplan *et al*., 2013:205-217). With similar findings, Long *et al*. (2013a:199-208) conclude that the healthy siblings are further at risk for depression, bipolar disorder and eating disorders. Most struggles improve over the first year after the cancer diagnosis, but can resurface or even worsen with declines in the diagnosed siblings' health or death (Rosenberg *et al.*, 2015:55-65).

Additionally, results suggest that the siblings are not only affected by the death of a sibling, but also by unfavourable prognosis (Houtzager *et al*., 2004b:591-605). Therefore, adjustment problems manifest at an early stage of the illness and need to be recognised as emotional reactions to the uncertainty of cancer and the course thereof. Hospitalisation of the sick sibling appears to diminish the healthy siblings' anxiety levels. Possible reason may be that the healthy siblings feel comforted by the fact that the diagnosed sibling is actively getting treatment, therefore relieving feelings of despair or hopelessness (Houtzager *et al*., 2004b:591-605).

Unhealthy transitions further lead to risky behaviours in some healthy siblings. Rosenberg *et al*. (2015:55-65) report that during the first year after the death of a sibling the bereaved siblings showed increased drug and alcohol use, anxiety and depression. Risky behaviours and psychological distress decreased over time with some siblings testifying to personal growth as a result (Rosenberg *et al.*, 2015:55-65). Interventions aimed at healthy transitions showed positive psychosocial responses, for instance when prepared for the death of their sibling the grieving sibling experienced lower levels of distress (Rosenberg *et al*., 2015:55-65). Being in a position to say goodbye and work through their grief were highlighted as critical to psychological health (Rosenberg *et al*., 2015:55-65). It was further found that family problem-solving, communication, responsiveness and involvement with the bereaved siblings were associated with a decrease in sibling maladaptive behaviours. This suggests that positive family environments and support systems can increase resiliency in the healthy siblings (Humphrey *et al.*, 2015:981-984).

3.2.3.5 Need for information

Another influencing variable is the degree of the sibling's awareness of and involvement in what is happening with their sick sibling (Spinetta *et al*., 1999:395-398; Lobato & Kao, 2002:711-716). When significant others are confronted with paediatric cancer there is little they can do to change the diagnosis or exert direct control (Houtzager *et al.*, 2004b:951-605), making it very challenging for the healthy siblings to helplessly watch as the diagnosed sibling suffers from cancer and the treatment thereof (Jenholt Nolbris *et al*., 2014:1-7). In these situations, the siblings are powerless because they are not seen as directly or actively involved in the process. With little to no control the siblings may have to primarily rely on cognitive or emotion-focused coping strategies. They can choose to rely on the competence of medical specialists and stay positive in the treatment process, or remain hopefully wishing for better times, or in order to gain a sense of control they may choose to better understand the situation (Houtzager *et al.*, 2004b:951-605). Based on the two-process model of perceived control, Rothbaum *et al*. (1982:5-37), Grootenhuis *et al*. (1996:91-102) and Grootenhuis and Last (2001:305-314) developed questionnaires to assess the cognitive coping strategies in paediatric cancer patients and their parents. "Cognitive coping strategies revert to secondary control strategies or attempt to bring oneself in line with the situational demands" (Houtzager *et al*., 2004b:591-605). A relationship between cognitive coping strategies and the patients' emotional well-being were found by Grootenhuis and Last (2001:305-314). Houtzager *et al.* (2003:123-133) establish that these strategies were also relevant for the siblings of the cancer patients and that cognitive coping strategies anticipated the adjustment of siblings of paediatric cancer patients one month after diagnosis. Houtzager *et al*. (2004b:591-605) focus on to what extent are coping strategies and family cohesion and adaptation related to the psychological well-being of healthy siblings during the first two years following a cancer diagnosis, stating that it is still of great importance to know whether and what coping strategies are relevant during the course of the treatment.

Communication with the healthy siblings is important not only during the cancer journey but also beyond. These siblings need information on the illness, treatment thereof as well as opportunities to talk about the impact cancer has on their lives and the adjustment to a "new normal" (Patterson *et al.*, 2011:16-26). A number of siblings have a need to be included in the care of the sick sibling, they want more information about the cancer diagnosis and treatment plan thereof (Weiner & Woodley, 2018:109-119). Siblings should thus be regularly updated and provided with information about the stage of illness and treatment thereof (Gerhardt *et al.,* 2015:750-804). Long *et al*. (2015:21-31) remark that siblings found it helpful to be taught basic health information and be kept up to date throughout the cancer journey. According to O'Shea *et al*. (2012:221-231), the healthy siblings showed interest to understand what was wrong with their diagnosed sibling, including the types of treatment that would be involved. Providing information about the cancer diagnosis and expected journey thereof eases healthy siblings' fears, as well as correcting any misconceptions about the diagnosis and process (O'Shea *et al*., 2110:221-231). Prchal and Landolt (2012:133-140) find that siblings liked being included by the healthcare team showing a desire to become familiar with the hospital environment. Other siblings needed more resources within the hospital setting itself (D'Urso *et al.,* 2017:301-317). Lövgren *et al*. (2016:297-305) questioned bereaved siblings on what they wanted healthcare providers to know about paediatric cancer from their perspective. These preadolescent/adolescents reported a need to be paid attention to; they further wanted information regarding their sick sibling's cancer, treatment and prognosis (Lövgren *et al*., 2016:297-305). In addition, the healthy siblings wanted healthcare providers to advise their parents on how to support them during the cancer journey, and to teach parents how they can involve them in the diagnosed sibling's care. Similar to these studies O'Shea *et al.* (2012:221-231) convey that the healthy siblings did not want to be left out, and preadolescent/adolescent siblings often wanted to be part of taking care of their diagnosed sibling. Yang *et al.* (2016:12-21) establish that siblings allowed to be part of the process became more confident. Jenholt Nolbris *et al*. (2014:1-7) note that healthy siblings needed to talk to someone about the cancer diagnosis, treatment and possible death. Ultimately, the healthy siblings thought it was important for them to take time for themselves by spending time with their friends, listening to music, participating in sport and studies (Jenholt Nolbris *et al*., 2014:1-7).

Siblings serving as donors for stem cell transplants are special circumstances in which communication, informed consent and potential for distress should be evaluated and addressed (MacLeod *et al*., 2003:223-231; Packman *et al*., 2004:233-248; Wiener *et al*., 2008:394-307; Packman *et al*., 2010:1134-1146). Attention to ethical matters and distress associated with preadolescents and adolescents who serve as donors (Committee on Bioethics, 2010:392-404) must be closely monitored by the psychosocial providers during transplant planning, the procedure itself and thereafter (Gerhardt *et al.,* 2015:750-804). Although the healthy siblings are at risk for emotional and behavioural problems, few studies could be found on how the healthy sibling adapts to their altered situation due to a cancer diagnosis of a brother or sister (Cordaro *et al*., 2012:42-50). While findings are mixed, factors such as age, gender (particularly females), premorbid distress, lower social support, and family conflict are linked to worse sibling outcomes (Barrera *et al*., 2004b:103-111; Houtzager *et al*., 2004b:591-605; Long *et al*., 2013b:2503-2510).

3.2.3.6 School life changes

Even though parents do all they can to equally fulfil the needs of all their children, the potentially life-threatening circumstances associated with cancer treatments may involuntarily result in neglecting some of the healthy siblings' needs (Kaffenberger, 2006:223-230; McLoone *et al*., 2013:484-492). As a result, the healthy siblings stand at risk to show a decline in academic success, disrupted social peer relations and other school-related outcomes (Hill & Taylor, 2004:161-164; Wilkins & Woodgate, 2005:305-319; Alderfer *et al*., 2010:789-805). The healthy siblings may not reach their full social, academic and vocational potential due to a sibling diagnosed with cancer (Labay & Walco, 2004:309-314; French *et al*., 2013:160-165; Tsimicalis *et al*., 2018:118-131).

School plays an important role in a preadolescent/adolescent's identity due to the amount of time and effort preadolescent/adolescents devote to this setting (Weiner & Woodley, 2018:109-119). Weiner and Woodley (2018:109-119) reveal that siblings experience significant behavioural and social changes at school. Exploring the impact on school attendance, performance, play, friendships and socialisation in the period after diagnosis will help give a sense of the extent cancer disrupts the life of the patient, as well as their siblings. Just as reintegrating back into school life after an illness plays an important role in facilitating the preadolescent/adolescent's learning and attainment of academic skills, self-esteem, social relations and a feeling of "normalcy" (Eiser & Vance, 2002:317-319), it is crucial to explore the short-term impact of cancer (cf. Tsimicalis *et al*., 2018:118-131).

Studies done on the healthy siblings indicate that they often experience tension, anxiety and disruptions in their lives, serious enough for parents to seek psychological support for them. The distress symptoms can be in the form of problems at school developing after the cancer diagnosis of a sibling; somatic complaints; depressive manners; withdrawal; difficulty in communicating; and inhibition (Cordaro *et al*., 2012:42-50). Tsimicalis *et al.* (2018:118-131) note that after only several days of absence from school, returning to school created excitement, offering a sense of normalcy and opportunity to reconnect with friends.

Findings from a study done by Alderfer *et al*. (2010:789-805) show that a paediatric cancer diagnosis negatively affects the healthy siblings' school attendance, performance and activities due to the fact that parents had to prioritise between the diagnosed sibling's cancer care and/or to tend to the healthy siblings' schooling. Findings from Alderfers' *et al*. (2010:789-805) study reveal how these problems start from the onset of diagnosis while other researchers found the struggle of balancing all the children's needs and priorities will arise over time (McLoone *et al*., 2013:484-492). Prchal and Landolt (2012:133-140) inform that most healthy siblings experience academic difficulties immediately after diagnosis, most likely because of distraction and worry. Several healthy siblings wanted to miss school in order to visit their diagnosed sibling in hospital or help with responsibilities at home (Weiner & Woodley, 2018:109-119). Siblings had less time available for schoolwork due to the hospitalisation of a diagnosed sibling and increased attention received at school led to a lack of concentration and decreased motivation for many (Samson *et al*., 2016:362-372). Bereaved siblings voiced changes in their school attitudes, interests and learning, some could perform better in school because they no longer had to worry about their diagnosed sibling while others experienced concentration difficulties (Foster *et al*., 2012:347-354).

Another way in which the healthy siblings react to the impact of cancer is seen in extracurricular activities (Weiner & Woodley, 2018:109-119). The majority of siblings, in Weiner and Woodley's (2018:109-119) data report a decrease in social and extracurricular involvement after diagnosis due to less time to devote to these activities, experiencing decreased performance levels and lack of interest. Logistic challenges included getting to the activity and lacking parental involvement (Foster *et al*., 2012:347-354; Prchal & Landolt, 2012:133-140; Samson *et al*., 2016:362-372; Neville *et al*., 2016:188-194). In some cases, the healthy siblings grieved the loss of extracurricular activities for their diagnosed sibling (Jenholt Nolbris *et al*., 2014:1-7).

3.2.3.7 Implications for counselling practice

Support from professionals has shown to be important for the well-being of the healthy siblings (Prchal & Landolt, 2009:1241-1251). Barriers providing psychosocial support to the healthy sibling include, limitations in availability of trained psychosocial staff (PCs, social workers) and community resources, a lack of knowledge of issues faced by siblings, assessment of sibling distress and needs, healthcare providers' access to and communication with siblings, and intervention research to inform evidence-based care (Gerhardt *et al*., 2015:750-804).

Houtager *et al*. (2004:591-605) emphasise that when a sibling is diagnosed with cancer the healthy siblings are at risk and therefore in need of professional help. Negative adjustment suggests that the healthy siblings may lack positive distractions. These siblings must be supported and enabled to participate in leisure activities (without feeling guilty). Caregivers must also be informed on how to communicate coping strategies to their healthy siblings. Extra support is needed where the diagnosed sibling receives an unfavourable prognosis. Together with their parents, they should be closely monitored and guided until well after the death of the sibling. The PC should be sensitive to the family context and developmental level of the sibling. Interventions must focus on the family as a whole, because adjustment problems of the healthy siblings are embedded in family dynamics. Partnering with parents, extended family members and other professionals (for example teachers) in order to anticipate and address siblings' psychosocial needs will be optimal. A certain level of balance and stability are of utmost importance to the well-being and adaptability of the healthy siblings. If adaptability becomes structural, the PC must help the family through this phase or attempt to establish a more balanced family climate where all the members can feel safe and secure, and needs of everyone can be sufficiently met.

The healthy siblings also need opportunities to remain optimistic about the cancer diagnosis and treatment. “Parents as well as general practitioners, paediatricians, nurses and other professionals should be adequately informed about this need” (Houtzager *et al*., 2004b:591-605). They further need to be taught how to provide the healthy siblings with realistic information regarding the illness. Parents may find it difficult to give their children information about the illness because it stands in contrast to their natural need to protect them. However, results show that healthy siblings feeling insecure tend to long for more information about cancer and may want to be involved in the treatment process. If parents keep information from their preadolescent/adolescents , they can come to the conclusion that the illness is too threatening to talk about (Houtzager *et al*., 2004b:591-605) causing unrealistic fears and enhancing feelings of isolation, guilt and resentment (Spinetta *et al*., 1999:395-398). For this reason, it is important that the PC guides the parents in how and what to tell the siblings about cancer (the diagnosis and treatment) involving them in discussions about it. Houtzager *et al*. (2004b:591-605) recommend support groups where the healthy siblings can learn cognitive and other coping skills directed at maintaining a positive outlook. In spite of the realistic fears and feelings of insecurity regarding a cancer diagnosis within the family, healthy siblings can become familiar with the different aspects of cancer in a secure setting, express their feelings and experience the support from other siblings of the same age in similar circumstances (Houtzager *et al*., 2004b:591-605; Jantzer *et al.*, 2013:2611-2616). Several studies demonstrate the positive results of such support groups for healthy siblings such as described by Carpenter *et al*. (1990:21-26), Heiney *et al*. (1990:95-100), Dolgin *et al.*, 1997:3-18), Houtzager *et al*. (2001:315-324), Lobato and Kao (2002:711-716), and Prchal and Landolt (2009:1241-1251). The PC must recognise that the healthy siblings form an essential part of the cancer journey and must be included in the care of their diagnosed sibling, which will in turn strengthen the whole family. To provide multidimensional support the PC must further offer parents information on possible ways the healthy siblings may respond, informing parents about the healthy siblings’ need to be involved with the diagnosed sibling’s appointments and visiting them more often in the hospital (Neville *et al.*, 2016:188-194). It is extremely important that information provided to the siblings be age appropriate (Jenholt Nolbris *et al*., 2014:1-7; Lövgren *et al*., 2016:297-305).

It is important for the PC to convey to parents how important it is to monitor their bereaved siblings in cases of death (Foster *et al*., 2012:347-354), assessing their social functioning is important in order to ensure adequate support to these siblings not to undergo any additional social stressors (Gerhardt *et al*., 2012: 209-219). The families must be educated on PTSD in sibling care (Kaplan *et al*., 2013:205-217). Because more stress has been observed during the first few months after diagnosis, it is important for psychological interventions to be implemented early (Prchal & Landolt, 2012:133-140). Structured support groups can give siblings the space to express their thoughts and emotions (Jenholt Nolbris *et* *al*., 2014:1-7). Screening the heathy siblings for psychological difficulties before joining them in interventional support structures is key because these interventions must be tailored to the sibling's specific needs (O'Shea *et al*., 2012:221-231; Salavati *et al*., 2016:362-372).

Support programmes to help the parents to become more aware of their healthy children, could be of value to families experiencing paediatric cancer. Corado *et al*. (2012:42-50) suggest discussion groups for the healthy siblings to facilitate sibling adaptation. These services provide a space for the healthy siblings to express themselves and share their anxiety while the programme grows their understanding of the illness (Murray, 2001:90-104; Sidhu *et al*., 2005:276-287; Corado *et al*., 2012:42-50).

3.2.4 Parental distress due to child with cancer

The parents as caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimise parent and family well-being (Kearney *et al.,* 2015:632-683).

Parents' ability to adapt to their child's cancer diagnosis and its challenges influences their diagnosed child's quality of life (Nikseresht *et al*., 2016:330-337; Pierce *et al*., 2016:1555-1561). Likewise, how parents choose to adjust to the cancer diagnosis will have an influence on the diagnosed child's coping mechanisms (Compas *et al*., 2014:853-861; cf. 3.2.1.1). The trauma of having a child diagnosed with cancer affects the whole family unit with a great impact on the relationships within the family system (Long & Marsland, 2011:57-88). Paediatric cancer is also a highly stressful event with serious social and emotional impacts on the child with cancer, as well as their significant others (parents, grandparents and healthy siblings; Vrijmoet-Wiersma *et al*., 2008:694-706; Ward *et al.,* 2014:83-103; Lau *et al.,* 2014:2277-2284).

From both interviews (cf. chapter 2) and research done by Gage (2013:405-418), it has been noted that IFCs (especially parents of paediatric cancer patients) find it uncomfortable to admit that they need relief from the caregiving role and day-to-day tasks. Asking for support will require that IFCs share personal information about their own struggles with coping with the diagnosis and treatment. Building a good relationship with healthcare providers and close family members reduces the interpersonal burden in making such authentic requests for support due to the trust in the relationship. This will protect the family from the negative consequences associated with the cancer journey (Rini *et al*., 2008:593-603). Parents with social support find better relief through the cancer trajectory with improved psychosocial outcomes (Manne, 2000:372-384; Rini *et al.,* 2008:593-603; Fletcher, 2011:40-55), making support from relatives and friends of utmost importance for the family to avoid depression (Hagedoorn *et al.,* 2011:205-211). Social support has been defined as "a social fund from which the people may draw when handling stressors" (Thoits, 1995:64). Support from healthcare professionals during the illness and death facilitates the family's grief process; more so than healthcare professionals support from family and friends soften the grieving process for many years after the loss (Kreicbergs *et al.*, 2007:3307-3312).

Studies suggest that parents with dependent face a double burden, struggling to balance own medical needs with the care and well-being of their children (Elmberger *et al.*, 2000:485-499; Helseth & Ulfsaer, 2005:38-46; Elmberger *et al.,* 2008:58-66). Concerns related to premature mortality and the impact thereof on their children are concerns among parents in advanced stages of cancer (Elmberger *et al.,* 2005:253-262; Bell & Ristovski-Slijepcevic, 2011:629-649; Park *et al.,* 2017:231-238). The concerns of the diagnosed child are well founded because a cancer diagnosis in the family indeed causes major disruptions (Helseth & Ulfsaet, 2003:355-362; Lewis *et al.,* 2015:12-23).

A paediatric cancer diagnosis affects the diagnosed child and those family members who typically provide the extensive care needed (Waldman & Wolfe, 2013:100-107). Research shows that the psychosocial impact of a paediatric cancer diagnosis may vary although most paediatric survivors and their significant others appear to adjust over time (Schepers, 2018:4143-4149). While meta-analytic and systematic findings show that most paediatric cancer families are resilient in the long-term (Van Schoors *et al.,* 2015:856-868; Price *et al.,* 2016:86-97), 6-15% of paediatric cancer survivors (Zeltzer *et al.,* 2009:2396-2404) and 20-22% of parents go through some form of psychological distress (Price *et al.,* 2016:86-97). Several potential factors have emerged as indicators of risk for parental maladjustment due to paediatric cancer. Around 40% of IFCs of paediatric cancer patients meet criteria of acute distress disorder and PTSD within the first two weeks after diagnosis, through the course of the cancer journey (Pai *et al.,* 2007:407-415; Patiño-Fernandez *et al.,* 2008:289-292). Potential risk factors include for example lower household income due to unemployment as a result of extra caregiver duties (Dunn *et al.,* 2012:176-185), treatment severity and/or risk (DuHamel *et al.,* 2004:92-103; Barrera *et al.*, 2012:855-859). Prior traumatic life events and prior parent psychiatric treatment are also associated with the burden of parental caregiving, distress and poorer adjustment (Boman *et al.,* 2013:57556). Research further indicates that parents of paediatric cancer patients can experience moderate to severe post-traumatic stress at the time of diagnosis, compared to IFCs of long-term survivors of cancer (Phipps *et al*., 2005:952-959). Even the more resilient and well-functioning parents find paediatric cancer an extreme stressor causing transient, marked distress, slowly returning to a “new normal” that will include the reality of the cancer journey. Even more so for those parents that already struggle to cope with pre-existing mental health problems. Such emotional issues can disrupt the paediatric cancer patient, as well as their siblings threatening the family functioning and stability over time (Barrera *et al*., 2004a:630-641; Pai *et al*., 2007:407-415; Kazak *et al.,* 2007:1099-1110). Thus, parents of paediatric cancer patients seem to be at risk for experiencing distress during the early diagnosis phase, as well as after their child’s cancer treatment. Although most data on parental adjustment are based on the mothers, both fathers and mothers have been shown to exhibit significant distress (Bonner *et al.,* 2007:851-856; Poder *et al*., 2008:430-437; Jones *et al.,* 2010:458-493; Cernvall *et al.*, 2012:448-457; Jones, 2012:213-220). Research further suggests that the gender of the parent influences the experience of stress following the child's diagnosis and the parents' coping responses (Hill *et al.,* 2009:1268-1280; Enskar *et al.,* 2011:51-66; Palmer *et al.*, 2011:253-259; Rodriquez *et al*., 2012:185-197). Mothers experience more stressors and distress associated with the child's cancer diagnosis than fathers (Pai *et al*., 2007:407-415; Rodriquez *et al.,* 2012:185-197).

Studies have found that preadolescent/adolescents' long-term adjustment and achievement depend on the parent-child relationship (Orbuch *et al.,* 2005:171-183; Kamphaus & Reynolds, 2006:270). Data also indicate that preadolescent/adolescents' functioning is closely linked and often dependent on parent and family functioning (Hamner *et al.,* 2015:1232-1236). Coming from a history of paediatric cancer can make the family more inclined to engage in overprotective parenting styles, because they perceive the diagnosed child as vulnerable (Hullmann *et al.,* 2010:1373-1380). The protective styles useful during treatment may not be of benefit once the child returns to a normal life entering long-term survivorship. Factors that strengthen the perception of child vulnerability and parental overprotection are due to experiencing the illness as life-threatening, environmental stress, family stress, lack of social support, low socioeconomic status and parental health problems (Pearson & Boyce, 2004:345-349).

Phillips (2014:1323-1339) examined the effect of specific illness phases and specific developmental stages of children. Findings show that advanced stages of cancer, particularly incurable illness and death, bring about emotional challenges while adolescence was identified as the most vulnerable developmental stage characterised by dynamic and essential changes driven by the need of autonomy. The impact of parental distress is therefore of importance not only for the parent self, but their preadolescents/adolescents as well (Park *et al*., 2018).

Due to challenges associated with a paediatric cancer diagnosis and the subsequent treatment thereof, the development and implementation of effective palliative care is of the utmost importance. Such palliative care can be tailored to the paediatric cancer patient, as well as their families (parents, siblings, grandparents) as they face the challenges of the cancer journey.

Intense and continued grief reactions are common with parents losing a child and may become debilitating for some bereaved parents (Arnold *et al.,* 2005:245-255; Kreicbergs *et al*., 2007:3307-3312). Grief reactions, such as prolonged grief disorder, are linked with poor psychological and physical outcomes, including mortality (Li *et al*., 2003:363-367; Lichtenthal *et al*., 2004:637-662; Li *et al*., 2005:1190-1196; Prigerson *et al*., 2009:1000121). Grief reactions may be aggravated because of secondary losses such as, loss of support from the medical team whom the parents have come to trust and rely on for comfort and information during their child's cancer journey (Back *et al*., 2009:474-479). Some parents can experience such a sudden end of contact soon after a child's death as abandonment (Contro *et al.,* 2004:1248-1252; Darbyshire *et al.,* 2013:540-549). The sense of loss, after the death of a child, may be lessened by providing continued care through the bereavement stages to the families

(D'Agostino *et al.*, 2008:33-41). Unfortunately, psychosocial teams (counsellors, social workers) and time are often limited, leaving the families to return to their lives without a sustained connection to any form of psychosocial support (Lichtenthal *et al*., 2015a:834-869). Parents report that a reason, from their side, for breaking contact with healthcare teams, is due to emotional difficulty to return to the place of treatment (Macdonalds *et al.*, 2005:884-890; Darbyshire *et al*., 2013:540-549), suggesting that home visits from psychosocial teams may be more desirable (Welch *et al*., 2012:335-346). The need to provide bereavement care has been increasingly recognised (Hudson *et al.,* 2012:696-702; Hudson *et al.,* 2018:375-387) with data suggesting that healthcare providers have a lasting impact on families when supporting them around the time of a child's death (Brosig *et al.,* 2007. 510-516; Meert *et al.,* 2007:50-55) and can be important to process their grief (Clerici *et al.,* 2006:306-310; Meert *et al.,* 2011:64-68; Throne & Jones, 2012:213-220; Meert *et al.,* 2014:148-157). Medicine AAoHaP, Care CtAP, Association HaPN, Partnership LA, and Organization NHaPC (2004:611-627) consider good bereavement care follow-ups to be, telephone calls, emails, mailed cards or letters, attending funerals, connecting families with other bereaved families, acknowledging birthdays, holidays, anniversaries, visiting the family and holding family meetings (Copnell, 2005:349-360; Macdonald *et al.,* 2005:884-890; Throne & Jones, 2012:213-220; Nikkola *et al.*, 2013:1151-1162; Granek *et al.*, 2015:1626-1631). One of the most constant findings in literature is that generally all parents want, and appreciate, continued connection with the psychosocial and medical teams that treated their child (Fujii *et al*., 2003:54-59; Clerici *et al*., 2006: 306-310; D'Agostino *et al*., 2008:33-41; Darbyshire *et al*., 2013:540-549; Steele *et al*., 2013:253-259). Parents find value in ongoing contact with a provider who knew their child, appreciating providers' connecting them with other bereaved parents (Macdonald *et al.,* 2005:884-890; deCinque *et al.,* 2006:65-83; Aho *et al.,* 2011:408-419). Studies find that practices such as phone calls and family meetings, after the death of a child is beneficial, helping the members feel like the person lost is remembered, facilitating meaning-making, responding to unanswered questions about the care of the child, reassuring them that they did everything they could, and providing a sense of closure (Clerici *et al.*, 2006:306-310; Stein *et al.*, 2006:3705-3707; Meert *et al.,* 2007:50-55; Darbyshire *et al.,* 2013:540-549; Eggly *et al.*, 2013:69-75; Eggly *et al.,* 2015:181-199). No negative effects on follow-up have been reported, with most families expressing their appreciation (Brooten *et al.*, 2013:40-49). In addition, some parents requested bereavement mental health support, in addition to the follow-ups (Barrera *et al.,* 2009:497-520; Welch *et al.*, 2012:335-346; Baker *et al.,* 2013:581-586), sometimes well beyond the first year of bereavement (Lannen *et al*., 2008:5870-5876; Lichtenthal *et al.,* 2015c:2246-2253). Studies note that there are advantages to bereavement interventions focusing on the entire family (Kissane *et al.,* 2006:1208-1218; Aho *et al.,* 2011:408-419). It has been suggested that palliative care physicians have an ethical duty of non-abandonment to care for families of children with life-threatening conditions (from diagnosis through bereavement; Jones *et al*., 2014:8-15). Studies on hospital-based bereavement programmes show that such gestures and or programmes help families feel cared for, reduce the sense of isolation, and improve coping (Donovan *et al*., 2015:193-210).

Additionally, staff engaging in bereavement follow-up report that they too experience benefits as a result of reaching out to the families (Clerici *et al*., 2006:306-310; Meert *et al.,* 2011:64-68; Thrane & Jones, 2012:213-220; Meert *et al.*, 2014:148-157). Lacking a standard practice of care however, follow-up efforts by given medical teams are inconsistent (Hechler *et al*., 2008:166-174; Darbyshire *et al*., 2013:540-549).

Psychological challenges that most of the bereaved parents endure include, increased rates of depression and anxiety (Kreicbergs *et al*., 2004:1431-1441), grief (Lannen *et al.,* 2008:5870-5876), existential distress, challenges to sense of identity and meaning-making (Wu *et al*., 2008:419-433; O'Connor & Barrero, 2014:404-411; Lichtenthal & Breitbart, 2015b:46-51), guilt (Surkan *et al.,* 2006:317-331) and PTSD (Ljungman *et al*., 2015: 1792-1798.). These symptoms have shown to persist over time (Lannen *et al.,* 2008:5870-5876) of which an estimate of 10-25% of bereaved parents experience debilitating levels of grief (Barrera *et al.,* 2007:145-167; Lannen *et al*., 2008:5870-5876; McDarthy *et al*., 2010:1321-1326; Lichtenthal *et al*., 2015c:2246-2253). Studies further show that bereaved parents' grief typically continues or even intensifies after the first year of their child's death (Lichtenthal *et al.,* 2015c:2246-2253), of which poorer outcomes have been reported among mothers (Alam *et al.,* 2012:1-22). Mothers are more likely to report long-term depression, and lower psychological well-being compared to fathers (Kreicbergs *et al.,* 2004:1431-1441).

3.2.4 Grandparent distress due to grandchild with cancer

Literature regarding grandparents' experiences of grandchildren with cancer and stressors accompanying the cancer diagnosis of a grandchild is sparse (Mitchell *et al.,* 2006:805-816; Hagedoorn *et al.,* 2011:205-211; Kelada *et al*., 2018). The impact of distress levels on grandparents' relationships with one another is an additional understudied topic (Moules *et al*., 2012b:133-140). Research regarding paediatric cancer and family functioning characteristically places focus on the perceptions from parents and survivors of nuclear families (Kelada *et al*., 2018). Grandparents consist of a large group, as every diagnosed grandchild can have more than the normal two sets of grandparents (stepfamilies). Despite the important part grandparents play in the lives of these families, very little is known about how these factors relate to multigenerational family functioning, particularly from the grandparents' perspectives (Patterson *et al*., 2004:390-407; Kelada *et al*., 2018).

Grandparents can be an irreplaceable source of informal support to the family managing paediatric cancer (Björk *et al.*, 2005:265-275; Alderfer *et al.,* 2010:789-805; Ångström-Brännström & Norberg, 2014:135-146). The involved grandparents can be highly valued and improve family closeness (McCubbin *et al*., 2002:103-111; Björk *et al*., 2005:265-275; Parry & Chesler, 2005:1055-1073; Nehari *et al*., 2007:66-78; Moules *et al*., 2012b:133-140), providing emotional comfort, practical support such as accompanying the diagnosed child to hospital appointments (Charlebois & Bouchard, 2007:26-30; Moules *et al.*, 2012a:119-132; Williams *et al.,* 2014:39-60; Ångström-Brännström & Norberg, 2014: 135-146). During these difficult times the grandparents' support and comfort can be highly valued by children with cancer (Ångström-Brännström & Norberg, 2014:135-146). One study even reports that parents consider their parents as a key source of help after a cancer diagnosis, especially in taking care of the healthy siblings (McCubbin *et al*., 2002:103-111; Moules *et al*., 2012b:133-140).

Yet, older IFCs face their own challenges as they have to balance own needs with the needs of their family (Moules *et al*., 2012a:119-132). Grandparents may experience shock equal to the "universe shaking" when a grandchild is diagnosed with cancer (McCubbin *et al.,* 2002:103-111) in that instant changing their customary role or family functioning (Moules *et al.,* 2012a:119-132). Grandparents' experience "double trauma", not only worrying about the diagnosed grandchild, but they also suffer with their son or daughter (Hagedoorn *et al.,* 2011:205-211). Grandparents can be deeply involved during the cancer treatment providing both, intangible and tangible support (McCubbin *et al*., 2002:103-111; Björk *et al.,* 2005:265-275; Moules *et al*., 2012b:133-140). This may be because they see it as their duty to support their son or daughter and grandchildren after a cancer diagnosis (Charlebois & Bouchard, 2007:26-30), putting their own lives on hold in order to become more involved in the affected family (Moules *et al.,* 2012a:119-132).

Grandparental involvement can be full of twists and turns regarding their relationships with their sons or daughters, as well as their own undisclosed distress (McCubbin *et al*., 2002:103-111; Nehari *et al*., 2007:66-78; Charlebois & Bouchard, 2007:26-30). They may withhold their own emotions, believing that their distress is uncalled for in the context of their son or daughter's and grandchildren's distress (Janicki *et al.,* 2000:35-56; Nehari *et al.*, 2007:66-78; Charlebois & Bouchard, 2007: 26-30; Moules *et al*., 2012b:133-140). They may also have a history of losing someone due to cancer, connecting that experience with their grandchild's illness (Nehari *et al.*, 2007:66-78). They may further be cancer survivors themselves, which will increase their concerns about possible heredity (James *et al*., 2006: 234-242).

Even though grandparents become immersed in the family after a grandchild's cancer diagnosis, some grandparents feel like bystanders to the family, especially during medical discussions and when medical and/or caregiving decisions need to be made (Moules *et al.,* 2012b:133-140). Possible reasons for these perceptions may be a reluctance to ask for more detail on the diagnosis and communication from their son or daughter. Research found that, according to grandparents, parents of the diagnosed child can become sensitive to perceived criticism and may vent their anger, fear and frustration towards their own parents (Moules *et al*., 2012b:133-140). This may contribute to possible reasons why grandparents may feel they cannot openly communicate their feelings and censor themselves around their son or daughter in an attempt to avoid conflict (Björk, 2005:265-275; Moules *et al.,* 2012a:119-132). Grandparents tend to neglect their own emotional needs by purposefully avoiding sharing their distress and hiding the toll that the grandchild's diagnosis has on their own well-being (Charlebois & Bouchard, 2007:26-30; Moules *et al*., 2012a:119-132). These findings suggest that the family dynamics in the area of especially communication and conflict resolution between grandparents and family may change with a paediatric cancer diagnosis (Kelada *et al*., 2018). Grandparents who feel uncertain about their role in the family, report worse family functioning, compared to grandparents with healthy grandchildren (Charlebois & Bouchard, 2007:26-30).

Studies show that grandparents' experiences of a grandchild diagnosed with cancer may be broad. They describe feelings of helplessness, guilt and isolation during the treatment (Moules *et al*., 2012a:119-132; Moules *et al*., 2012b:133-140; Ångström-Brännström & Norberg, 2014:135-146). Grandparents feel removed from the direct care and treatment decisions concerning their grandchild's cancer despite the vital role they play in supporting the child with cancer, his or her parents, the healthy siblings as well as the extended family through the cancer diagnosis. As a result, they often get less psychosocial support and receive "second-hand" information (Moules *et al*., 2012b:133-140; Wakefield *et al*., 2014a:351-355). The lack of support and information can escalate their concerns regarding their grandchild's health and further increase their feelings of isolation (Moules *et al*., 2012a:119-132; Moules *et al*., 2012b:133-140; Ångström-Brännström & Norberg, 2014:135-146).

Physical symptoms reported by grandparents include a decline in health, eating poorly, less exercising, less sleep and experiencing more "aches and pains" (Moules *et al.*, 2012b:133-140; Wakefield *et al*., 2014b:855-861). It has been noted that grandparents are reluctant to report their physical symptoms to physicians, assuming that symptoms are part of their aging process (Krishnakumar, 2004:19). It is important to note that physical and emotional well-being may be co-dependant in elderly people (Phillips & Murrell, 1994:270), self-reported health is associated with mortality and morbidity (Mavaddat *et al*., 2014:1-13; Brown *et al.*, 2015:21-30). This indicates that the elderly with poorer physical health stand higher risk of distress (Phillips & Murrell, 1994:270) "and that having a grandchild with cancer impacts life beyond emotional well-being" (Wakefield *et al.*, 2016b:1-9). Tending to the needs of grandparents of grandchildren diagnosed with cancer is imperative (Wakefield *et al.*, 2014b:855-861), because an elderly person that recovers from stressful incidents often suffer poorer emotional and physical well-being (Phillips & Murrell, 1994:270). These reports emphasise the need to further investigate the impact of paediatric cancer on the grandparents (Moules *et al*., 2012a:119-132; Moules *et al.*, 2012b:133-140).

In cases where grandparents do seek relief, their preferred coping mechanism will be to turn to non-professionals, such as close friends and family members (Woodward *et al*., 2010:124). Wakefield *et al*. (2014b: 855-861) note that it is a concern that the primary source of support for grandparents appears to be other family members. Since distress of other family members is likely correlated, grandparents are seeking support from equally or even more distressed sources (McCubbin *et al*., 2002:103-111); friends may also be ill-equipped to provide the necessary care (Moules *et al*., 2012a:119-132). It has been reported that almost half of grandparents of children diagnosed with cancer suffered depression, more than double that of the matched control groups. Despite these statistics fewer than 5% of grandparents seek psychosocial support. The capacity to support their sons or daughters and diagnosed grandchild can be limited by untreated stress (Wakefield *et al.*, 2014b:855-861). A possible way to alleviate grandparents' tension and feelings of isolation is by additional psychosocial intervention and information specifically adapted to satisfy the grandparents' concerns (Wakefield *et al.*, 2014a:351-355; Wakefield *et al*., 2016a:361-369). Supportive care interventions with caregivers of cancer patients report improvements in the quality of life (Northouse *et al*., 2010:317-339; Waldron *et al*., 2013:1200-1207). Well supported IFCs have a positive effect on the well-being of the cancer patient (Stenberg *et al*., 2014:531-555), stressing the importance of broadening supportive care interventions beyond the parents (Wakefield *et al*., 2016b:1-9). Referring the clinically distressed family members to professional support is crucial, due to strong evidence of the value of professional support among the elderly (Hendirks *et al*., 2008:403-411).

Examining cancer groups, Kelada *et al*. (2018) found grandparents with recently diagnosed grandchildren reported poorer general family functioning, problem-solving and communication skills. Kelada *et al*. (2018) record that these reports are expected due to higher stress of learning about the diagnosis. According to Wakefield *et al*. (2014b:855-861), grandparents of children diagnosed with cancer showed more feelings of distress, anxiety, depression and anger than grandparents of healthy children. Nearly half of the grandparents with children diagnosed with cancer, had anxiety levels high enough to be considered clinically relevant, with almost one quarter indicating high levels of depressed feelings. Reduced functioning is prevalent across a number of domains such as the psychological, physical and environmental (Wakefield *et al*., 2016b:1-9). Emotional difficulties can be linked to difficulty in falling asleep and using more medications to alleviate stress and anxiety. Sleep disturbances are commonly associated with anxiety. Many caregivers of cancer patients report ongoing sleep disturbances and anxiety after the completion of cancer treatments (Northouse *et al*., 2012:1227-1234). Studies done by Wakefield *et al*. (2016b:1-9) indicate that after grandparents had been removed from caregiving duties, they still experienced ongoing reduced psychological well-being. A possible reason is the "double worry" that grandparents experience, worrying about the well-being of both their grandchildren and their own son or daughter (Moules *et al*., 2012a:119-132). This "double worry" may be a cause of the grandparents' sleep disturbances causing them to turn to pharmaceutical treatment for anxiety and stress (Wakefield *et al*., 2016b:1-9). Research with significant others found that the biggest impact on familial relations usually occurs within the first six to twelve months after diagnosis (Committee on Hospital Care, 2012:394-404). In their review of paediatric cancer and family relationships the Committee of Hospital Care (2012:394-404) note that the family tend to achieve a new sense of normalcy around one year after diagnosis. Families recount that while they may never be as before the diagnosis the family members adapted to new ways of relating and communicating with one another (McCubbin *et al*., 2002:103-111; Mitchell, 2007:94-101; Committee on Hospital Care, 2012:394-404). More research is needed to further explore if, over time, grandparents will also be able to develop a new sense of family normalcy. Further research is also needed to verify if and to what extend family disruption occurs when grandparents take on caregiver roles after their grandchild is diagnosed with cancer (Kelada *et al*., 2018).

Psychosocial interventions for significant others dealing with cancer in the family have been developed, for example the Surviving Cancer Competently Intervention Program (SCCIP), a short family-based, evidence-based intervention developed by Kazak *et al*. (1998:59-66) that showed success in parents and siblings. This intervention involves both cognitive-behavioural and family therapy approaches which relate to family functioning improvements (Phillips & Murrell, 1994:270). The intervention problem-solving skills training (PSST) showed to be enough to improve problem-solving skills among parents of children with cancer (Mancillas, 2006:268-275; Hendriks *et al*., 2008:403-411; Wakefield *et al*., 2012:621-626). Kelada *et al*. (2018) suggest that it may be of value to include grandparents in these interventions to increase unity in families after a cancer diagnosis, which has been supported in the past by experts in the field (Cuipers *et al*., 2009:66-82). These psychosocial interventions appear to be most needed during the early stages post-diagnosis, supporting Wiener *et al's*. (2015:419-424) case that multidisciplinary healthcare teams (for example medical doctors, social workers, occupational therapists, counsellors) should assist significant others living with a cancer diagnosis in the family.

Grandparents can be incorporated into the intervention programmes in cases where they assist with taking care of the diagnosed child and or the healthy siblings. According to Wakefield *et al*. (2014b:855-861), cancer centres could improve on educating grandparents on available services. Even though support groups for grandparents may seem an obvious solution, face-to-face groups are not preferred and therefore not well attended (Moules *et al*., 2012b:133-140; Wakefield *et al*., 2012: 621-626).

From the discussion on grandparent distress due to grandchildren with cancer it can be concluded that grandparents neglect their own health while taking care of and supporting the circumstances around a cancer diagnosis of a grandchild, the healthy siblings and the wider family. This is a noteworthy finding given the importance of factors such as, elderly proactive self-care to prevent premature mortality, developing serious health conditions during old age and at societal level to relieve healthcare costs (Bodenheimer *et al*., 2002:2469-2475).

3.3 PALLIATIVE CARE

Families bereaved by cancer often struggle with feelings of isolation due to fear of burdening their support systems with their ongoing pain (Barrera *et al.,* 2009:497-520) and experience a decrease of support over time (O'Connor & Barrero, 2014:404-411; Lichenthal *et al*., 2015:834-869). Siblings also struggle after the loss of a sibling (Basrrera *et a*l., 2010:22-23; Foster *et al*., 2012:347-354; Gerhardt *et al.,* 2012:209-219; Eilertsen *et al*., 2013:301-310) as well as grandparents (Gilrane-McGarry & O'Grady, 2011:170-176). Being reminded to speak about, and feeling connected to the deceased family member are often described as helpful (Woodgate, 2006:75-82; Foster *et al.,* 2011:420-440; Thompson *et al.,* 2011:153-172; Toller, 2011:17-34) and linked with more positive outcomes (Gerrish *et al.,* 2014:151-173). Therefore, the cancer patient, as well as their family members should be introduced to palliative care concepts early after the cancer diagnosis. Palliative care concepts will have lasting effects throughout the cancer journey and help them in finding a “new normal” after treatment or death (Weaver *et al*., 2015:829-833). The World Health Organization (2007) defines palliative care as an all-embracing care approach which,

> improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and their problems, psychosocial and spiritual.

The early integration of palliative care by the PC will provide meaningful opportunities to attend to the full impact of the illness on IFCs’ psychological, developmental and spiritual wellness (Weaver *et al.*, 2015:829-833). The American Academy of Paediatrics (2000:351-357) encourages an integrated, interdisciplinary approach to competent and compassionate care “in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death” (Mack & Wolfe, 2006:10-14).

According to Guyatt *et al*. (2008:924-926) and Weaver *et al*. (2016:212-223), target areas in which comprehensive care could be improved through palliative care are for instance, communication between the medical teams (social workers, PCs, clinicians), the patient and their family, as well as the ongoing assessment of the needs of the family and tangible support (for instance home visitations) during times of inpatient and home care transition. To effectively form a patient- and family-centred care programme four important elements that need to exist include willingness to collaborate among providers, patient and family. Secondly, good communication. Thirdly, mutual trust, and lastly respect (Gibson, 2009, 327-329; Howell *et al*., 2011). For effective interdisciplinary care the psychosocial providers have mutual value, respect for different skills and scope of practice, accountability and shared goals (Martín-Rodríguez *et al*., 2005:132-147; Yeager, 2005:143-148; Eilertsen *et al*., 2009:355-368; American Psychological Association, 2007:993-1004; Gibson, 2009:327-329; American Psychological Association, 2013,1-6). Team conferences, facilitating patient-family dialogue and patient care, as well as caregiver burnout are all effective communication strategies, together with sharing (with consent from patient and family) stresses, vulnerabilities, and strengths of the family (Kleiber *et al*., 2006:492-496; Knoderer, 2009:1576-1581; Bhansali *et al.*, 2013:31-38). This collaborative approach to care is called the collaborative person-centred practice which is “the continuous interaction of two or more professionals or disciplines, organised into a common effort, to solve or explore common issues with the best possible participation” of the cancer patient and their families (Herbert, 2005:1-4).

It has been found that the quality of life for both patient and their family members can be improved through the prevention and alleviation of family suffering by means of compassionate and honest communication and the psychosocial attentiveness incorporated by quality palliative care services (Jones, 2006:774-788; Wolfe *et al.*, 2008:1717-1723). IFCs needs in relation to patient comfort and care, information, support and communication are all important aspects (Kristjanson & White, 2002:745-762; Fridriksdottir *et al.*, 2006:425-432; Janda *et al.*, 2008:251-258). However, some studies suggest that many needs are not sufficiently met by health professionals (Hwang *et al.*, 2003:319-329; Fridriksdottir *et al.*, 2006:425-432; Janda *et al.*, 2008:251-258; Kim & Kashy, 2010:573-582; Molassiotis *et al*., 2011:88-97). Needs being unmet are associated with impaired work performance (Park *et al.*, 2010:699-706), anxiety (Molassiotis *et al.*, 2011:88-97), greater caregiver burden (Sharpe *et al*., 2005:102-114), with less caregiver satisfaction (Hwang *et al.*, 2003:319-329). Unmet caregiver needs are also connected to the patient's own unmet needs and emotional functioning (Molassiotis *et al*., 2011:88-97) and with reduced quality of patient care by the IFC (Park *et al*., 2010:699-706).

Grieving parental anxiety and quality of life scales have correlated with the levels of the child's anxiety and pain at end of life (Dussel *et al.*, 2010:231-237; Mc Carthy *et al.*, 2010:1321-1326; Rosenberg *et al.*, 2012:503-512; Van der Geest, 2014:1043-1053) suggesting that the early integration of palliative care (as a standard of care) has the potential to improve long-term family wellness outcomes. Research on the grieving parents confirms that parent perceptions of clear and compassionate communication are associated with excellent care and improved psychosocial outcomes (Contro *et al.*, 2002:14-19; Mack *et al*., 2005:9155-9161; Edwards *et al.*, 2008a:1310-1315; Heath *et al*., 2009:656-659). These findings highlight the importance of ongoing supportive communication especially as the illness progresses (Weaver *et al.*, 2015:829-833). Family-centred advance care planning also increases the patients' wishes for families to make appropriate decisions (as needed), improving the patients' understanding about end of life options and increases the family's ability to honour the patients' wishes (Lyon *et al*., 2013:460-467). Effective communication between all parties from the patient and family members to the comprehensive care team (social workers, PC and clinicians) is vital in order to successfully capture the patients' end of life preferences (including the practicalities of location at death; Weaver *et al.*, 2015:829-833). It has been shown that the opportunity to plan the location of death is associated with high quality palliative care suggesting that the communication regarding the planning itself rather than the actual location thereof may be a more relevant outcome (Dussel *et al*., 2009:33-43; Dussel *et al*., 2010:231-237).

3.4 CONCLUSION

With the growing home care technology, the burden of caregiving has been transferred to the informal family caregivers and as a result, IFCs now shoulder greater burdens for longer periods of time. This chapter places focus on how a cancer diagnosis and accompanying treatment thereof change the behaviour, emotional and physical conditions of the entire family system (spouse, preadolescent/adolescents, parents and grandparents), showing that a caregiving role can have stressful effects with the potential to bring about psychological, social, economic and other health risks.

The chapter shows that both spouse and patient are equally distressed, and that their distress is connected, terming it the “we-illness”. The healthy spouse experiences high levels of stress, potential burnout, depressive symptoms, marital distress, poor health and unmet needs. These reviews accentuate the importance of showing concern and support for the spousal caregiver, because their mental and physical status affects their capacity as the caregiver to the diagnosed spouse.

The most important factor to play a role in the caregiving experience is gender with a close link between gendered constructions and expectations of being women or men. Because gender has considerable implications for psychological well-being and coping, this study will regard gender as an important factor concerning the pastoral model for caregivers’ support. The coping styles of female caregivers are more emotion focused coping strategies, which are associated with higher levels of negative health outcomes, whereas the most difficult aspect of caregiving for male spousal caregivers is to express themselves.

With parental cancer showing to have negative effects on the preadolescent/adolescents’ behavioural, emotional, physical functioning and school performance the study finds it of importance to gain insight into the occurrence of SRS in preadolescent/adolescents with parents diagnosed with cancer in order to offer support to the co-parent caregiver. Preadolescent/adolescents are especially vulnerable, because they are dependent on their parents’ care and support, and as a result they have limited capacity to cope with such a life-altering situation. Age and gender were highlighted as the most important factors to play a significant role in helping the preadolescent/adolescent adjust and/or cope with parental cancer.

The disruption of routines in the family, as well as changing dynamics of family relationships can have a negative effect on the well-being of the healthy siblings. For this reason the study also places focus on the emotional distress and adaptation of the healthy siblings. By understanding the siblings’ responses and reasons of family conflict the PC can identify which family subsystem are at risk and build interventions to target at risk relationships and strengthen families by providing effective family-centred, multidimensional methods. A number of siblings voiced a need to be included in the care of the sick sibling, needing more information about the cancer diagnosis, treatment plan, and basic health information and generally be kept up to date throughout the cancer journey. Providing information about the cancer diagnosis and expected journey thereof eases healthy sibling’s fears, as well as correcting any misconceptions about the diagnosis and process, suggesting that positive family environments and support systems can increase resiliency in the healthy siblings.

The study demonstrates that families losing a child to cancer stand at risk for poor bereavement outcomes and need continued connection with the healthcare teams. Feelings of abandonment are felt when contact is lacking which creates secondary loss in addition to the excruciating loss of a child. Contact with the medical teams is commonly wanted and proves to be helpful to families as they transition into a “new normal”, wherein support frequently lessens over time. It has been shown that there is not only a need for bereavement mental health services, but that these services are also beneficial, especially for those family members with prolonged grief. The PC is in a position to link the families with bereavement services and should provide referrals when making contact with the family. Staying in contact with the family on their cancer journey and beyond can prevent or reduce debilitating prolonged grief symptoms. Standard care during the cancer journey and beyond is a priority and should be part of comprehensive emotional and spiritual care for the families.

Literature regarding grandparents' experiences of grandchildren with cancer and stressors accompanying the cancer diagnosis of a grandchild is sparse, despite the important part grandparents play in the lives of these families particularly from the grandparents' perspectives. The involved grandparents can be an irreplaceable source of informal support to the family and improve family closeness by providing emotional comfort, practical support such as accompanying the diagnosed child to hospital appointments. These grandparents tend to withhold their own emotions believing that their distress is uncalled for in the context of their own son's or daughter's and grandchildren's' distress. Withholding their emotions can lead to feelings of helplessness, guilt and isolation during the treatment; furthermore, feeling removed from the direct care and treatment decisions concerning their grandchild's cancer despite the vital role they play in supporting the family through the cancer diagnosis. It can thus be concluded that grandparents neglect their own health while taking care of and supporting the circumstances around a cancer diagnosis of a grandchild, the healthy siblings and the wider family. This is a noteworthy finding given the importance of factors such as, elderly proactive self-care to prevent premature mortality, developing serious health conditions during old age and at societal level to relieve healthcare costs.

Palliative care is the support of the whole-person-whole-family regardless of the anticipated cancer outcome. Effective communication between all parties involves the cancer patient, family members of the cancer patient, PC, social workers, clinicians and shared decision making in palliative care as a standard of care in the cancer journey has the potential to foster improved quality across the cancer trajectory for the cancer patients as well as their family members.

CHAPTER 4: LITERATURE STUDY: AUXILIARY

4.1 INTRODUCTION

This chapter is a study of literature from different arts and sciences in working towards a holistic model to help significant others cope with cancer related stress. Holistic care respects human dignity (Davis-Floyd, 2001:5-23), increases self-awareness (Fahy *et al*., 2010:146-152) and improves harmony between mind, body, emotions and spirit in the ever-changing environment of cancer (McEvoy & Duffy, 2008:412-419). For Hugen *et al*. (2006:409-426) caregiving includes actions that support the physical, material, emotional and social well-being of people. For this reason, the importance of the early integration of pastoral caregiving support to IFCs is emphasised. Pastoral caregiving will help the IFCs cope with the full impact of the cancer journey delivering lasting psychological, developmental and spiritual wellness (Weaver *et al*., 215:829-833).

Because of the shift from hospital-based care to home care, there is an increase of responsibility and burden on IFCs. IFCs form part of an important team consisting of family, friends, volunteers and health care professionals who support the diagnosed person. There is no strict prescribed way to be an IFC, because not only is each situation different, but as the illness and treatment changes, so does the IFC's role. The chapter will be set out in the following order of discussions.

First, the focus will fall on the activation of the inner caregiver by means of self-compassion. With careful planning, sufficient self-care and self-compassion, the IFC's role can be less stressful. This chapter provides a compelling argument for the use of self-compassion as important means to help IFCs to develop emotional resilience and well-being in the face of cancer. This will be done by presenting a conceptual account of self-compassion and a review of research on the benefits thereof. Self-compassion has gained popularity over the past decade and is still growing at an exponential rate as a related and complementary concept to mindfulness (Sirois *et al*., 2015:334-347). In order to treat the self with compassion, one must be able to turn toward, acknowledge and accept personal suffering, meaning that mindfulness is a core element of self-compassion (Neff & Dahm, 2013). It appears as if self-compassion may be cultivated through either a compassionate therapeutic relationship or teaching clients to practise self-compassionate exercises (Germer, 2012:93-110; Germer & Neff, 2013:856-867). Important to note for the purpose of this study is that self-compassion further holds a promise as an inner resource that relieves caregiver fatigue (Finlay-Jones *et al*., 2015:1-19). Self-compassion can be both, a challenge and opportunity for IFCs during a cancer journey. "Self-compassion is a double-edged sword, it cuts through the pain of the present as it opens the pain of the past" (Germer & Neff, 2015:43-58).

Secondly, the focus will shift to the connection between neuroscience and selfcompassion or to live mindfully.

Thirdly, a summary of acceptance and commitment therapy (ACT; Hayes *et al*., 1999) will be given. ACT, as a behavioural oriented psychotherapy addresses one's relationship with cognitions, emotions, sensations and memories in order to help vitality and meaningful participation in life through creating psychological flexibility (Nieuwsma *et al*., 2016:61). Psychological and spiritual flexibility will encourage IFCs to change their relationships, emotions and cognitions through cultivating mindfulness (a present moment, non-judgmental form of awareness). A Christian-accommodative translation of ACT will be offered to demonstrate how the PC can comfortably use this kind of therapy. A Christian psychological approach in assessing a secular therapy is sometimes referred to as a *translation* (Sisemore, 2014:5-16). A significant development that has grown exponentially is the use of ACT in religious contexts to bridge psychological and spiritual care (Nieuwsma *et a*l., 2016: XI).

Fourthly, the focus will be on the passionate PC and guidelines will be given on how to assist IFCs in an ACT way to be open, aware, active and value driven in an environment of acceptance and compassion. The passionate PC will be able to work with IFCs, assisting them in accepting internal experiences such as thoughts, emotions, sensations, images and memories, while at the same time giving support in making and keeping commitments.

Lastly, the chapter focuses on compassion fatigue occurring in both, IFCs and the PC. A lack of self-compassion and mindfulness is a barrier that may prevent IFCs from successfully addressing their concerns. Major life stressors, such as cancer not only affect the cancer patient but also the lives of their spouses, preadolescent/adolescents, parents, friends and others in their social networks (Kayser *et al*., 2007:404-418; cf. chapter 3).

4.2 ACTIVIATING THE INNER CAREGIVER

Compassion is an essential part for the healing process of the cancer patient, their IFCs, as well as a foundation of ethical practice across the health care professions (Riddick, 2003:6-10; South African Nursing Counsel, 2013; National Association of Social Workers, 2019).

4.2.1 Self-Compassion

> It's not just what you face in life that matters, it's how you treat yourself when life gets tough that seems to determine our ability to get through (Neff & Germer, 2017).

Self-compassion fosters greater emotional balance through a mind-set of safety and interconnectedness and reduces feelings of threat and isolation (Gilbert & Irons, 2005:263-325). Goetz *et al.* (2010:351-374) defining self-compassion as the awareness and sensitivity to the experience of suffering joined with the desire to lessen suffering. Since humans cannot be perfect, avoid mistakes, reach all set goals or avoid hardship in life, self-compassion forms an invaluable tool to relate to suffering with a sense of kind and connected presence (Neff & Knox, 2017). The self-compassionate individual takes the viewpoint of a compassionate *other* towards the self, by actively encouraging the expression of warmth, concern and care toward the self (Neff, 2003b:85-101). With such a perspective, one's outlook becomes broader and more inclusive, accepting that life’s challenges and personal failures are simply part of being human (Neff & Germer, 2017). Self-compassion can help the IFC to feel more connected and less isolated in their fear, confusion and pain during the cancer journey. It appears that by treating the self in the same manner one treats loved ones, one become more connected to them and not less. Those who award the self with care and support, appear to have more emotional resources available to give to their ill family member (Neff & Germer, 2017). Compassion is being sensitive to the experience of suffering, together with a deep desire to alleviate the suffering (Goetz *et al*., 2010:351-374). For this reason, in order to experience compassion, the presence of pain must first be accepted. Compassion consists of pausing, stepping out of one’s usual frame of reference to view the world from the vantage point of another.

Self-compassion seems to be an important instrument of action in various forms of therapy (Germer & Neff, 2013:856-867) and acceptance and commitment therapy (ACT) practitioners have been investigating the role of self-compassion in psychotherapy on a continuous basis (Tirch, 2010:113-123; Luoma *et al.*, 2012:43-53). Efforts to better self-compassion in counselling are clearly warranted, considering the consistent evidence that a lack of self-compassion is associated with psychopathology, especially anxiety and depression (MacBeth & Gumley, 2012:545-552).

4.2.1.1. *The three components of self-compassion*

Self-compassion, as conceptualised by Neff (2003b:85-101), involves three key components that may explain why self-compassionate people can successfully cope with stressful life circumstances, such as having a family member diagnosed with cancer. The three components are self-kindness versus self-judgment, common humanity versus isolation, and mindfulness versus over-identification. Self-compassion as an adaptive form of self-relation thus involves cultivating mindful awareness of one’s own suffering, treating the self with understanding and kindness during difficult times and relating to personal stressful experiences to the wider perspective of human experiences.

A. Self-kindness

Firstly, self-kindness is the capacity to act toward the self with kindness and compassion, rather than criticism or harsh self-judgments during challenging times. Western culture teaches that self-compassion is weak and passive or that it will undermine motivation (Gilbert *et al.*, 2011:239-255) and that humans should rather focus on being kind to others (Neff & Dahm, 2013). This stands in agreement with Neff’s (2003a:223-250) review, that most people reported to show more kindness to others, than towards themself. Even when problems stem from forces beyond one’s control, such as becoming an IFC to a family member with cancer, people do not give themselves the sympathy they would extend to a friend in similar circumstances. Being kind towards the self, the person’s inner dialogue will be gentle and encouraging toward the self. In the same way, when external life circumstances are challenging and become difficult to tolerate, the individual will soothe and nurture the self (Neff & Dahm, 2013).

B. Common humanity

Secondly, common humanity involves accepting that painful and difficult experiences form part of the universal human condition, rather than feelings of isolation within own suffering. Often the significant others will feel isolated and cut off from others when taking into account one's struggles and failures, illogically having feelings 'that it is only me who is going through hard times'. Neff (2011:1-12) refers to this as "tunnel vision", making one feel alone and isolated, making suffering even worse. Self-compassion means one takes the stance of a *compassionate other* toward the self, allowing the individual to take a broader perspective on his or her life, remembering shared human experiences and feeling less isolated when enduring difficult circumstances (Neff & Dahm, 2013). Leary *et al*. (2007:887-904) examined how self-compassionate people deal with negative life events or self-relevant thoughts, concluding that those with higher levels of self-compassion had more perspective on their problems and were less prone to feel isolated by them. These individuals tend to not perceive their struggles any worse than what lots of people go through (Neff & Dahm, 2013). Self-compassion thus lessens the effect of negative life events on emotional functioning in general. In this way, self-compassion promotes a balanced perspective of one's negative emotions, allowing the IFC to confront his or her difficult feelings and thoughts, instead of avoiding them or becoming entrenched in them (Neff, 2003b:85-101), recognising that all suffer, fostering a connected mind-set inclusive of others. In Christ one can perceive God's compassion with human difficulties. Particularly true in light of the fact that Christians continually were, are and will feel helpless as they face hostile powers and things that are harmful to human existence. Suffering is an unavoidable part of the daily life of everybody, including Christians (Kolb, 2012:99-123).

C. Mindfulness

Mindfulness as the last key feature involves taking a well-adjusted perspective of one's emotions, particularly negative emotional states instead of becoming over-identified and entangled within a negative state of sadness, guilt or anger (Bishop *et al*., 2004:230-241). Mindfulness is to be aware of the present moment in a clear and balanced manner (Brown & Ryan, 2003:822-848). Mindfulness acceptance or being in a mindful state, is to be 'experientially open' to the reality of the present moment, allowing thoughts, emotions and sensations to enter one's awareness without judgment, avoidance or repression (Bishop *et al*., 2004:230-241). Bishop *et al*. (2009:230-241) propose a two-component model of mindfulness.

- The first component involves the self-regulation of attention so that it is maintained on immediate experience, thereby allowing for increased recognition of mental events in the present moment.
- The second component involves adopting a particular orientation that is characterised by curiosity, openness and acceptance.

Self-compassion involves being mindfully aware of one’s negative thoughts and emotions in order to approach it in a balanced and calm way. When confronted with life challenges, such as dealing with cancer in the family, the IFC can easily get lost in a problem-solving mode, that they do not pause to consider how hard it is in the present moment. There must be a willingness to mindfully turn towards and experience painful thoughts and emotions, so as to embrace the self with compassion (Bishop *et al*., 2004:230-241). Mindfulness is an essential component of self-compassion, because it is important to recognise one’s own suffering in order to be compassionate toward the self. It would seem best to learn mindfulness before self-compassion, since mindfulness is needed for compassion.

Sisemore (2014:5-16) is of the opinion that mindfulness, as used in ACT is compatible with Christian thinking. Symington and Symington (2012:72) indicate that, “Christians need to evaluate the adopted principles and practices of mindfulness from a Christian perspective rather than being distracted by its historical roots”. Mindfulness has some spiritual roots in Zen Buddhism, but can include spiritual traditions such as Roman Catholic and Eastern Orthodox. Concepts from Zen Buddhism are problematic from a Christian (biblical) perspective. Christian meditation places focus on content (contemplating God and his works) as in Psalm 77:12 or the teachings of the faith as in Joshua 1:8 or being present with God. The focus is on a self-engagement with God, instead of aspiring to the Buddhist state of “no self”. Buddhist mindfulness and Christian meditation is in other words not to be confused and made out to be equivalent (Sisemore, 2014:5-16). One moves toward the no-self (Buddhist) and Christian meditation moves to becoming fully self *Coram Deo* (Sisemore, 2014:5-16). However, Buddhist’s emphasis on a gentle, kind and compassionate approach to life and relationships, stands consistend to a Biblical emphasis on the primacy of *agape* (Christ-like love) in life and relationships (1 Corinthians 13). Such love is the fruit of the Holy Spirit and His empowering work in one’s life (Galatians 5:22-23) and not as a result of self-effort (Tan, 2011:243-249).

According to Neff (2003b:85-101), the three components are conceptually distinct, overlap and tend to stimulate each other to create a self-compassionate frame of mind. For instance, the accepting attitude of mindfulness (the present moment dealing with caregiving tasks) assists with lessening self-judgment (not good enough caregiver, parent, son or daughter, sibling, grandparent) and provides necessary insight to recognise common humanity. In the same way, self-kindness reduces the impact of negative emotional experiences, making it simpler to be mindful of them. Realising that suffering is shared with others, eases the degree of self-blame simultaneously helping to control the process of over identification. Self-compassion can thus be best understood as a single experience comprised of interacting parts (Neff & Dahm, 2013). Together they reduce stress by helping individuals self-regulate the negative emotions that result from unexpected and/or uncontrollable events (Neff *et al*., 2007b:139-154). Self-compassion can firstly, decrease stresslevels by reducing coping that cultivates negative emotional responses to stressors and secondly, by fostering coping via adaptive behavioural or appraisal-based responses to stressors (Neff & Dahm, 2013).

4.2.2.2 What does self-compassion do?

It is important to remember that although self-compassion helps lessen the hold of negativity, it does not illuminate negative emotions, it is a balance of the right amount of distance from one's emotions (so that they can be fully experienced), while being mindfully objective (Neff, 2003b:85-101). The self-compassionate individuals are less inclined to supress their unwanted emotions and thoughts than those lacking self-compassion (Neff, 2003a:223-250), and more inclined to acknowledge their emotions as valid and important (Neff *et al*., 2005:263-287; Leary *et al*., 2007:887-904, Neff *et al.*, 2007b:139-154). Therefore, instead of replacing negative feelings with positive ones, self-compassion generates positive emotions by embracing the negative ones. For this reason, self-compassion can be associated with positive psychological strengths (Neff & Dahm, 2013; Neff & Knox, 2017). Research has shown that attempts to suppress unwanted thoughts, will cause them to emerge more strongly and frequently into conscious awareness than if they were given attention in the first place (Wenzlaff & Wegner, 2000:59-91).

Studies done by Leary *et al*. (2007:887-904) indicate that self-compassionate individuals showed fewer extreme reactions, less negative emotions, more accepting thoughts and greater tendency to put problems into perspective, while simultaneously acknowledging their own responsibility. Self-compassion has been found to positively predict coping in the face of difficult emotional experiences (Neff *et al*., 2005:263-287; Leary *et al*., 2007:887-904; Allen & Leary, 2010:107-118) and is connected to aspects of positive emotion regulation, for instance emotional clarity and emotional repair (Neff, 2003a:223-250). People with greater self-compassion therefore, are less likely to supress unwanted thoughts and emotions (Neff, 2003a:223-250). In the same way, compassionate individuals are more willing to experience difficult feelings and recognise their emotions as valid and important (Neff *et al*., 2007b:139-154) allowing the pain to just be there, no more, no less, in order to minimise unhelpful add-on suffering. Part of what contributes to this emotional resilience is the practice of self-compassion and remembering moments of being loved and loving. These routines activate the release of the 'calm and connected' hormone oxytocin, which down-regulates stress levels and brings about calmness (Graham, 2013). Research has noted that self-compassion is linked to well-being. According to Gilbert (2005:9-74), self-compassion improves well-being because it helps the individual to feel cared for, connected and emotionally calm. For instance, it is connected to lower levels of perceived stress (Neely *et al*., 2009:88-97; Sirois, 2014:128-145), increased resilience in the face of stressful situations (Neff *et al*., 2007b:139-154) and chronic illness (Brion *et al*., 2014:218-229). Self-compassion is linked to emotional intelligence, wisdom, life satisfaction and feelings of social connectedness which are all important elements for a meaningful life (Neff, 2003a:223-250; Neff *et al*., 2008:267-285; Neff & Vonk, 2009:23-50). Greater emotional intelligence suggests that self-compassion signifies a more perceptive way to handle difficult feelings (Neff & Know, 2017). The self- compassionate frame of mind further tends to experience more happiness, optimism, curiosity, creativity and positive emotions such as gratitude, enthusiasm, inspiration, and excitement (Neff *et al*., 2007b:139-154; Breen *et al*., 2010:932-937; Hollis-Walker & Colosimo, 2011:222-227). It is an important source of *eudaimonic* happiness, which consists of finding purpose and meaning in life instead of pursuing pleasure and avoiding pain (Neff & Know, 2017).

In addition to the intrapersonal benefits, self-compassion also improves interpersonal functioning. Neff and Beretvas (2012:78-98) note that self-compassionate individuals were portrayed by their partners as more emotionally connected, accepting, autonomy-supporting while being less detached and controlling compared to those lacking self-compassion. Concerning whether self-compassionate people are also more compassionate towards others, Longe *et al.* (2009:1894-1856) find that coaching people to be self-compassionate associated with neuronal activity similar to which occurs when feelings of empathy for others are brought to mind. These findings suggest that the inclination to respond to suffering with caring concern is a broad process useful to both self and others (Neff & Dahm, 2013). Neff and Pommier also (2012:160-176) studied the link between self-compassion and compassion for others concluding that self-compassionate people were less likely to experience personal distress. This suggests that they are more capable to confront suffering of others (cancer) without feeling overwhelmed (with the caregiving task).

“One of the most consistent findings in the research literature is that greater self-compassion is linked to less anxiety and depression” (Barnard & Curry, 2011:289-303; Neff & Dahm, 2013). Gilbert and Irons (2005:263-325) propose that self-compassion turns the threat system off that is associated with feelings of insecure attachment and defensiveness while activating self-soothing systems associated with feelings of secure attachment and safety. In favour of this proposition, Rockliff *et al. (*2008:132-139) note that a brief self-compassion exercise that involves generating a visual image of an ideal compassionate figure sending unconditional love and acceptance to the participant lowered their levels of the stress hormone cortisol and further increasing heart-rate variability which is associated with greater self-soothe ability when stressed (Porges, 2007:116-143).

4.2.2.3 Teaching self-compassion

The ability to be self-reassuring and self-compassionate is sometimes negatively linked to psychopathology (Gilbert *et al*., 2004:31-50). To be self-reassuring when experiencing setbacks is believed to have its origins primarily in temperament and early childhood experiences, which result in resilience (Masten, 2001:227-238). Developments in psychotherapy are starting to focus on the possibility of training people in self-reassurance and self-compassion (Gilbert & Irons, 2005:263-325; Gilbert & Procter, 2006:353-379; Leary *et al*., 2007:887-904; Germer & Neff, 2013:856-867; Neff & Dahn, 2013; Germer & Neff, 2015:43-58; Neff & Knox, 2017). The research thus suggests that compassion can be adapted through education and training and is further associated with positive emotions, a sense of affiliation, reward and prosocial behaviour (Lown, 2016:332-342). The core of developing self-compassion is by regulating and identifying one’s own needs and limits (MacBeth & Gumley, 2012:545-552). Behavioural self-care comes in a variety of ways such as drinking a cup of tea, taking a hot bath, talking with friends, exercising (Germer & Neff, 2015:43-58), listening to gospel music, reading the Bible and praying (to be discussed in chapter five). Practising self-care exercises between therapy sessions provides inner strength between counselling sessions to help the significant others continue to feel the same qualities of kindness, connection and comfort that they felt during therapy (Germer & Neff, 2013:856-867).

Several studies indicate that relatively brief self-compassion training sessions can be highly beneficial. For instance, Gilbert (2009) developed a group-based therapy intervention called Compassionate Mind Training (CMT) to help people develop self-compassionate skills. Gilbert and Proctor (2006:353-379) suggest that self-compassion provides emotional resilience, since it turns off the threat system that is associated with feelings of insecure attachment, defensiveness and autonomic arousal, and activates the caregiving system associated with feelings of secure attachment, safety and an oxytocin-opiate system. Participating in the CMT programme, participants showed a significant decrease in depression, self-attacking, shame and feelings of inferiority (Gilbert & Procter, 2006:353-379).

Shapira and Mongrain (2010:377-389) studied the impact of a self-compassionate letter writing practice for seven days, which involved writing a paragraph about a recent challenge in a kind and understanding way, as a good friend would do. They found that the letter writing practice decreased depression levels for three months, as well as increased happiness levels for six months, thus increasing emotional well-being (Seligman *et al*., 2005:410-421; Sheldon & Lyubomirsky, 2006:73-82; Leary *et al*., 2007:887-904).

Neff and Germer (2012:28-44) developed a programme to teach self-compassion skills called mindful self-compassion (MSC). Participants meet for two and a half hours once a week over the course of eight weeks, including a half-day mini retreat where a variation of practices is taught that focuses on generating self-compassion, for instance calling to mind an emotionally difficult situation in one's life and repeating phrases such as, "May I feel safe, may I feel peaceful, may I be kind to myself, may I accept myself as I am". Informal practices include placing one's hands on one's heart during stressful times or repeating a set of memorised Biblical verses to use in daily life. Accompanying home practices, include writing a compassionate letter to the self. Results indicate that the more MSC participants practised formal meditation, the more they increased their self-compassion levels. Participants practising informal self-compassion techniques in daily life also experienced gains in self-compassion, implying that self-compassion is a teachable skill that is "dose dependent" (the more one practises it the more one learns it; Neff & Dahm, 2013). The self-compassionate break practice is as follows: taking a deep breath and slowly say, "This is a moment of suffering" followed by "suffering is a part of life". The individual will be invited to reflect on the fact that globally many people stand in similar caregiving roles. The next three steps to follow are, putting both hands over the heart, feeling the warmth of his or her hands. Secondly, to notice the touch of the hands over the heart and thirdly, feeling the rhythmic rise and fall of the breath. After a minute the individual repeats two phrases (or similar ones that might fit the individual better) “may I be kind to myself” and “may I live with ease” (Neff & Germer, 2013:28-44). These three components of the self-compassionate break resemble the three elements of self-compassion: mindfulness (“this is a moment of suffering”), common humanity (“suffering is a part of life”) and self-kindness (“may I be kind to myself”). Each of these elements will help the IFC to let go of anxiety and fear, while softening into his or her distress, gradually desensitising it (Neff & Germer, 2013:28-44).

Smeets’ *et al.* (2014:794-807) three-week self-compassion programme involves a combination of discussion, self-compassion practices (putting hand over heart when distressed) and focusing to recognise the inner critic and finding compassionate ways to motivate the self. At the end of the programme the participants showed increased self-compassion, mindfulness, optimism and self-efficacy.

These results show that even brief self-compassion practices can be effective in teaching self-compassion skills and enhance well-being for the IFC. Long-term practices can also improve self-compassion. For example, improved self-compassion seems to be an important outcome of mindfulness-based interventions, such as mindful-based stress reduction (MBSR) and acceptance and commitment therapy (ACT; Yadavaia *et al*., 2014:248-257). The Christian version of ACT will be used for this model and further discussed in section 4.5.

A prayer that incorporates all three elements of self-compassion (mindfulness, common humanity and self-kindness; Graham, 2013) is for instance:

This is a moment of suffering.
Suffering is part of life.
May I be kind to myself in this moment.
May I give myself the compassion I need.

The mindful and compassionate individual knows that pain is true, simultaneously care and concern is also true. When self-compassion skilfully embraces the negative, at the same time it opens the individual to positive possibilities. Self-compassion exercises thus attempt to stimulate hope by teaching the IFC to think more positively about their current situation as well as their future (Shapira & Mongrain, 2010:377-389).

4.2.2.4 How self-compassion relates to mindfulness

Mindfulness involves being aware of the present moment in a clear and balanced way (Brown & Ryan, 2003:822-848). This metacognitive skill that involves self-regulation of attention cultivates a quality of relating to one’s experience with a curious and accepting attitude (Neff & Dahm, 2013). Mindfulness is a core component of self-compassion, both involve turning toward painful experiences with acceptance, so that destructive processes of reactivity are lessened, as shown by a large body of research that links mindfulness and self-compassion to well-being (Keng *et al*., 2011:1041-1056; MacBeth & Gumley, 2012:545-552).

The type of mindfulness that forms part of self-compassion is narrower in scope, than mindfulness more generally. The mindfulness component refers to balanced awareness of negative thoughts and feelings. Mindfulness therefore is the ability to be calmly aware of any experience, may it be positive, negative or neutral (Neff & Dahm, 2013).

Self-compassion is a total construct, broader in scope than mindfulness, because it incorporates the elements of self-kindness and common humanity, soothing and comforting the self during painful experiences keeping in mind that these experiences are part of being human. These are not qualities inherently part of mindfulness (Bishop *et al*., 2004:230-241). Feelings of self-kindness and common humanity may accompany mindfulness of painful experiences so that self-compassion may automatically co-arise with mindfulness. However, mindfulness and self-compassion do not always co-arise. A person can be mindfully aware of painful thoughts and feelings without soothing and comforting the self or keeping in mind that these feelings are part of the shared human experience. In these cases, it will take extra and intentional efforts to be self-compassionate towards own suffering, in particular when painful thoughts and emotions involve self-judgments and feelings of inadequacy during the caregiving process.

Another difference can be found in their targets. While mindfulness relates to internal experiences, self-compassion relates to the experiencer who is suffering. Non-judgmental mindfulness accepts thoughts, emotions and sensations resulting from present moment awareness. Compassion is the desire to be happy and free from suffering. Therefore, self-compassion is a bit of a paradox, while one’s present moment’s experience is mindfully accepted without resistance, one simultaneously hopes to be free from future suffering (Neff & Dahm, 2013).

Research findings suggest that self-compassion may be a stronger predictor of depression, happiness, life satisfaction and psychological well-being than mindfulness on its own because these types of well-being outcomes are more impacted by the calming qualities of self-kindness and emotional safety generated by feelings of common humanity (Pauley & McPherson, 2010:129-143).

4.2.2.5 Is self-compassion Biblical?

Compassion is an instinct found in every person, given by God (Cornelius, 2013:1-7). Self-compassion is about depending on God irrespective of the current situation (journey with cancer). A big help and stronghold in taking care of self and others, is knowing that God knows everything about each person and that He is there to help in all circumstances (Arackal, 2016). Helping people in need facilitates strong faith that is brought about by a growing recognition of their dependence on God and a growing awareness of God’s powerful presence (Hugen *et al*., 2006:409-426). By taking on an IFC role, one participates in God’s redemptive activities (Hugen *et al*., 2006:409-426). According to Jeavons

(1994:50), serving others generates opportunities for living out one's faith, and serving others therefore results in spiritual growth (Cornelius, 2013:1-7). Although humans are created with the ability to care for others, it is God's love within everyone that spontaneously moves one to act on behalf of the person in need. The believer (IFC) becomes God's arms and legs for those in need (diagnosed family member), because he or she knows and loves God and because His love resides within the believer reaching out to others. In this sense *agape* is the essence of care (Nistelrooy, 2014:519-528).

Self-compassion is a balance of truth (I am not a perfect caregiver) with grace (I have worth and value and give myself permission to take care of myself). Together, truth and grace are acknowledging negative experience without minimising it or making it more, while at the same time directing compassion toward the self. Self-compassion helps to handle one's humanness and the current situation with empathy, concern, understanding and kindness. It is a gentle way to relate to the self in both good times and times of hardship (Fredrickson, 2015).

An inspiring passage to treat the self in a biblically sound way, can be found in Mark 12:28-31(NIV).

> One of the teachers of the law came and heard them debating. Noticing that Jesus had given them a good answer, he asked him, "Of all the commandments, which is the most important?"
>
> "The most important one," answered Jesus, "is this: 'Hear, O Israel: The Lord our God, the Lord is one.
>
> Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength.'
>
> The second is this: 'Love your neighbour as yourself.' There is no commandment greater than these."

Ephesians 4:29-32 (NIV) teaches the believer how to love their neighbour, especially the last verse, *be kind and compassionate to one another.* In Galatians 5:22-23 the Apostle Paul teaches the reader how to treat others. But before he does, he reminds the reader of God's one command, *For the entire law is fulfilled in keeping this one command: Love your neighbour as yourself* (Galations 5:14). Then Paul continues his teaching in Galatians 5:22-23 (NIV), *But the fruit of the Spirit is love, joy, peace, forbearance, kindness, goodness, faithfulness, gentleness and self-control. Against such things there is no law*. The Apostle Paul teaches the reader that the way to freedom for self and others is to live by God's Spirit who dwells within the believer. It is through the power of the Spirit, that one is able to treat the self and others with kindness, patience, goodness, faithfulness and gentleness (compassion). This wisdom thus, concerns both interactions with others and self. These verses portray characteristics of a person who is yielded to the Holy Spirit. Being in pace with Him and connected to Him. These features will be naturally experienced and expressed toward others and self (Fredrickson, 2015; Craig, 2017).

Research proposes that compassion can be improved by strengthening the neural networks that facilitate its expression by means of teaching, learning, and reinforcement through modelling and social support (Lown, 2016:332-342).

4.3 NEUROSCIENCE AND SELF-COMPASSION

It is important to know what the brain is doing, because familiarity with the orchestration of internal states as well as reactions to the external is to be mindful of the essentiality of nourishing of the brain (Wolkin, 2016). "The brain is the grand conductor of the symphony of ourselves" (Wolkin, 2016). The brain plays a role in all thoughts, feelings and body sensations including every dream, passion, fear, joy and deepest desire (Wolkin, 2016). The brain and the spinal cord make up the nervous system which consists of billions of nerve cells (neurons) that speak to and through the brain and body.

The nervous system is bilingual speaking both, electrically and chemically. When neurons are stimulated an electrical impulse called an action potential is created leading to the transmission of chemical substances namely neurotransmitters such as norepinephrine, dopamine and serotonin which plays an enormous role in mood functioning (Wolkin, 2016).

Research shows that neuroplasticity makes it possible for lifestyle to play a huge role in maintaining and improving brain function. Neuroplasticity refers to the ability of the brain to adapt and change. Research notes that the brain continues to adapt throughout life in either negative or positive directions in response to both intrinsic and extrinsic influences (Shaffer, 2012:1110-1115). Positive neuroplasticity is the "physiological ability of the brain to form and strengthen dendritic connections, produce beneficial morphological changes, and increase cognitive reserve" (Vance *et al*., 2010:23-30). Negative neuroplasticity is the "ability of the brain to atrophy and weaken dendritic connections, produce detrimental morphological changes, and decrease cognitive reserve" (Vance *et al.*, 2010:23-30). Factors associated with negative neuroplasticity are among others depression and anxiety.

Some evidence suggest that self-compassion stimulates parts of the brain that is associated with other-focused compassion (Longe *et al*., 2009:1849-1856; Neff & Germer, 2017), suggesting that caring for self and others may be neurologically linked (Breines & Chen, 2013:58-64). Similarly, Longe *et al*. (2010:1849-1856) note that helping individuals to be self-compassionate, stimulates neuronal activity similar to that aroused in empathy for others. From a neurological perspective, compassion is generated and regulated by the anterior cingulate (Morrison *et al*., 2004:270-278; Lawrence *et al*., 2006:1173-1184; Shafritz *et al*., 2006:468-475; Morrison & Downing, 2007:642-651; Lamm *et al*., 2007a:42-58). This unique part of the brain enhances social awareness, recognises the emotional states of others and lessens the tendency to express anger and react with fear (Newberg & Waldman, 2009:215). It allows the individual to feel emotionally connected and attached, if it functions poorly, the individual's ability to understand someone else's feelings will be impaired (Berthoz *et al*., 2002:961-967; Moriguchi *et al*., 2007:2223-2234).

Research shows that experiencing or observing someone else’s pain, triggers a core neural network that is involved in affective and motivational processing (Lown, 2016:332-342). This pain-empathy network that involves the anterior insula (AI) and medial and anterior cingulate cortex (MCC, ACC) can be recruited by either the involuntary or voluntary system (Lamm *et al.*, 2011:2492-2502). This involuntary process that is involved in pain-empathy “experience sharing” or “affective empathy”. The voluntary process is referred to as “mentalising” or “cognitive empathy” (Zaki & Ochsner, 2012b:675-680). AI and ACC activation has further been confirmed when witnessing others’ fear, happiness and anxiety (Wicker *et al.*, 2003:655-664; Zaki & Ochsner, 2012a:207-226).

Neuroimaging studies show that compassionate action is linked with activation of areas in the brain connected with reward (Decety *et al*., 2012:38-48). For instance, dopamine-related reward processing areas in the ventral striatum were considerably activated in the individuals who believed they were relieving someone else’s pain (Jensen *et al.*, 2013:392-398). The endogenous reward area was also included when the individuals were asked to imagine relieving others’ suffering (Decety & Porges, 2011:2994-3001). Neuroimaging studies further implicated regions of the default mode network (DMN) in the processing of social emotions (Immordino-Yand *et al.*, 2009:8021-8926). DMN is active when the brain is in a wakeful rest state and the individual is not focused on the outside world or engaged in any kind of task. The DMN regions are activated in tasks requiring interaction with others, perceiving and interpreting their emotions, empathising, understanding and judging the intentions of others (Schilbach *et al*., 2008:457-467).

It is important that the IFC’s counselling assistance must start from diagnosis, through to recovery by assessing family functioning and unmet needs of significant others (Kelada, 2018). This study stresses that treatment cannot stop after recovery (or death), but that support after treatment (or death) is an especially vulnerable time for the family to adjust into a new normal. A self-care plan must embrace all aspects of well-being, stamina, resilience including nutrition, exercise, stress reduction and time for social activities, hobbies and spiritual health (Boyle, 2015:49-51), in other words holistic care. Self-care is not just about making healthy lifestyle choices, it is also about being present with own feelings, sensations and intuitive guidance in order to detect what is best at any given moment (Portnoy, 2011:47-50).

4.4 ACCEPTANCE AND COMMITMENT THERAPY (ACT)

Behavioural therapy can be historically viewed as consisting of three major waves (generations; Hayes *et al.*, 2006:1-25). The first wave is the traditional behavioural therapy, and the second wave is the cognitive behavioural therapy (CBT). The third wave of behaviour therapy emerged from both cognitive and behavioural traditions, including dialectical behaviour therapy (DBT; Linehan, 1993), acceptance and commitment therapy (ACT; Hayes *et al*., 1999), integrative behavioural couples’ therapy (IBCT) (Christensen *et al*., 1995:31-64; Jacobson *et al*., 2000:351-355), mindfulness-based cognitive therapy (MBCT; Segal *et al*., 2002), functional analytic psychotherapy (FAP; Kohlenberg & Tsai, 1991) and several others (Marlatt, 2002:44-49; Roemer & Orsillo, 2002:54-68; Hayes *et al.*, 2006:1-25; Harris, 2009:39).

These therapies have come to occupy a major place in the field of counselling and psychotherapy (Tan, 2011:101-111). It is not easy to characterise the factors that unite these methods, but as a cluster they have embarked into areas traditionally reserved for the less empirical wings of clinical work, putting emphasis on acceptance, mindfulness, cognitive defusion, dialectics, values, religion and relationships. Philosophically they appear more contextual than mechanistic, both first order and second order change methods are highlighted with approaches often more experiential than didactic. One of the primary examples of this third wave is ACT (Hayes *et al*., 2003:69-96). ACT differs from the traditional cognitive therapies by focusing on the process and function of one's thoughts and feelings, instead of their content (Hayes & Lillis, 2012:22). In addition, it also covers elements that go well together with a Biblical worldview (Sisemore, 2014:5-16). Sisemore (2014:5-16) offers a convincing translation of ACT into a Christian framework.

ACT as developed by Hayes and colleagues (Hayes *et al*, 1999) is based on a relational frame theory with six core processes that form the ACT *hexaflex*. These processes help clients to accept painful experiences, instead of fighting to change, control or avoid unpleasant feelings. It further encourages clients to clarify their deepest values and to live by these values, also called committed action (Tan, 2011:243-249). The goal of ACT is to increase psychological flexibility, making ACT a mindfulness, acceptance and values-based psychotherapy grounded in the behavioural and cognitive behavioural traditions (Hayes *et al.,* 2006:1-25; Hayes *et al*., 2003:69-96). Developed to address verbal barriers in order to pursue meaningful life directions, thus focussing on psychological distress related to experiential avoidance and fusion (Waltz & Hayes, 2010:148-192). ACT for these reasons places focus on, not only acceptance and mindfulness with cognitive defusion and psychological flexibility, but further also taking one's values or defining valued directions together with committed action in following values and directions (Nieuwsma *et al.*, 2016: XII).

ACT offers life changing answers to questions such as "Why is it so hard to be happy?" "Why is life so difficult?" "Why do humans suffer so much?" and "What can people realistically do about it?" (Harris, 2009:1). Apart from anxiety disorders, chronic pain, depression, habitual disorders, psychotic symptoms and substance use (Waltz & Hayes, 2010:148-192), evidence for the effectiveness of ACT is growing in several other behavioural health areas such as anorexia (Heffner *et al.,* 2002:232-236), adjustment to cancer (Branstetter *et al*., 2004), epilepsy (Lundgren *et al*., 2008:2173-2179) and type 2 diabetes management (Gregg *et al.,* 2007:336-343).

> The ultimate goal of ACT is to bring verbal cognitive processes under better contextual control and to have the client spend more time in contact with the positive consequences of his or her actions immediately in the present as part of a valued life path (Hayes *et al*., 2012:65).

At its core ACT is therefore "about taking action" (Harris, 2009:2). Firstly, it is about values-guided action, which is the existential component asking, "What do you want to stand for in life?" "What really matters, deep in your heart?" These core values are then used to guide, motivate and inspire behavioural changes (Hayes *et al*., 2006:1-25). "A value is a direction that can be instantiated in behaviour but not possessed like an object" (Hayes *et al.*, 2003:69-96). Here the client is asked to list values in different life domains for example family, intimate relationships, health, self-compassion, acceptance, spirituality, *et cetera* (Hayes *et al.*, 2003:69-96). Clarified values identify achievable goals embodying these values, concrete actions to bring about these goals and specific barriers to accomplish these actions are identified. "In essence it is values that dignify the need for exposure to painful thoughts and feelings" (Hayes *et al*., 2003:69-96). Valued spiritual goals include walking with Christ, being like Christ and fulfilling specific callings in life (Sisemore, 2014:5-16). Secondly, ACT is about mindful action. This is conscious action, being fully aware, open to life's experiences while being fully engaged in whatever the individual is doing.

The aim of ACT is to help the IFC create a rich, full and meaningful life, while accepting the pain that it inevitably brings (Hayes *et al*., 2006:1-25; Harris, 2009:2). ACT does this by teaching the IFC psychological skills to effectively handle painful thoughts and feelings in such a way that these thoughts and feelings will have less impact and influence, known as mindfulness skills. ACT further will help the IFC clarify what is truly important and meaningful to them (clarifying values) and use that knowledge to guide, inspire and motivate the IFC to set goals and take action that will enrich their lives (Harris, 2009:2). ACT makes use of many exercises and techniques to help the client experience the six core processes of therapy. Examples include (Tan, 2011:243-249):

- The PC asks the IFC to "imagine their thoughts written on leaves falling down onto a moving stream, and then floating by, letting their thoughts simply come and go".
- The PC helps the IFC to "engage in cognitive defusion so they realise they are not their thoughts *per se* is for them to say 'I'm having a thought that I'm useless' whenever they think to themselves "I'm useless"

Most therapy models focus mainly on symptom reduction assuming that clients need to reduce their symptoms in order to lead a better life (Hayes *et al*., 2006:1-25). ACT takes a radically different stance, where mindful, values-congruent living is the desired outcome (Waltz & Hayes, 2010:148-192). In other words, ACT aims not to reduce the clients' symptoms, but to fundamentally change their relationships with their symptoms so that the symptoms can no longer hold them back from valued living. Reduction of symptoms is thus a "bonus" rather than the main point of therapy (Harris, 2009:4). ACT assumes that the normal psychological processes of a normal human mind readily become destructive and sooner or later create psychological suffering. ACT speculates that the root of this suffering is the human language itself (Waltz & Hayes, 2010:148-192). "Human language is a highly complex system of symbols that includes words, images, sounds, facial expressions and physical gestures" (Harris, 2009:6).

Individuals use language in two domains, public and private.

> Public use of language includes speaking, talking, miming, gesturing, writing, painting, sculpting, singing, dancing, *et cetera*.
>
> Private use of language includes thinking, imagining, daydreaming, planning, visualising, analysing, worrying, fantasising, *et cetera*.

Private language is also commonly referred to as cognition. ACT uses the word, mind, to explain the incredibly complex set of interactive cognitive processes such as analysing, comparing, evaluating, planning, remembering, visualising and so on. These complex processes depend on a sophisticated system of symbols referred to as human language. Therefore, in ACT the word *mind* is a metaphor for human language (Harris, 2009:6-7).

- What is mind?

The mind is regarded as a double-edged sword in ACT, useful for different purposes but if not taught how to handle it effectively, it can hurt the individual.

The positive of mind (language):

Helps the individual to make maps and models of the world. Predict and plan for the future. Share knowledge. Learn from the past. Imagine things that never existed and go on to create it. Develop rules to guide behaviour effectively. Help people to thrive as a community. Communicate with people far away and learn from people no longer alive (Harris, 2009:7).

The negative of mind (language):

People use it to lie, manipulate and deceive. Spreading libel, slander and ignorance. Incite hatred, prejudice and violence. Make weapons of mass destruction and industries of mass pollution. Dwell on and relive painful events from the past. Scare the self by imagining unpleasant futures. Compare, judge, criticise and condemn both self and others. Create rules for the self with the potential to be life constricting or destructive (Harris, 2009:7).

- What is the aim of ACT?

The aim is to help individuals engage in value-congruent behaviour and continue with this action even when unfavourable private events make the journey difficult (Waltz & Hayes, 2010:148-192), rather than fusion or avoidance in order to "create a rich, full and meaningful life while accepting the pain that inevitably goes with it" (Harris, 2009:7,29; Waltz & Hayes, 2010:148-192). The primary aim therefore is to increase psychological flexibility (Hayes *et al*., 2006:1-25; Waltz & Hayes, 2010:148-192), engaging in positive behaviours rather than attempting to escape difficult experiences and emotions (Harris, 2009:29). Psychological flexibility is getting perspective to see that God's plan unfolds moment-to-moment as illustrated in the life of Joseph in Genesis (Sisemore, 2014:5-16). Psychological flexibility according to Sisemore (2014:5-16) appears to be a valid objective for Christians (keeping in mind that it includes both psychological flexibility and spirituality), translating it into "psychospiritual flexibility" in order to stress one's spiritual understanding is involved and that the individual sees the Holy Spirit as active in the process of nurturing the moment-to-moment faith that is involved in following Christ (Sisemore, 2014:5-16). Psychological inflexibility will keep the individual from positive awareness in the present moment that moves one along life's journey in a valued direction (Sisemore, 2014:5-16). Psychological flexibility is the ability to stay in the present moment being fully aware and open to one's experience and to take action guided by one's values (Harris, 2009:12). Studies show that ACT impacts psychological flexibility and creates positive outcomes when psychological flexibility increases (Hayes *et al*., 2006:1-25).

Everyone experiences frustration, disappointment, rejection, loss and failure, illness, injury and aging. Everyone faces their own death and the death of loved ones. On top of that normal feelings that everyone will repeatedly experience throughout life are inherently painful, to mention a few: fear, sadness, guilt, anger, shock and disgust. Adding to this each individual has a mind that can call up pain at any given moment. As a result of human language, the individual can at any moment relive a painful memory or get lost in fearful future predictions (Harris, 2009:7). As a result of human language one can even experience pain on the best days. For example, completing a cancer treatment which is a reason for relief and thankfulness the IFC can recall the caregiving process and the accompanying emotions fearing a setback or returning of cancer. No matter how good the quality of life or how privileged the situation, all a person needs to do is remember a time when something bad happened, or imagine a future where something bad can happen, judge the self harshly or compare one's life to someone else's that seems better, and right away the individual will feel pain.

Cognition refers to the mental processes involved in the processing of information, concept formation, comprehension and decision-making. These mental processes of cognition are at work in the pursuit of coming to know. "Cognition is embodied in conversation, and conversation emerges from cognition" (Johnson-Miller, 2013:378-391). Conversation is continuous and an active stimulus for ongoing cognition whether it is tacit or explicit, internal or external, conscious or unconscious (Johnson-Miller, 2013:378-391).

Typically, human beings normally handle pain ineffectively. Commonly when an individual experiences painful thoughts, feelings and sensations they respond in self-defeating or self-destructive ways. Because of this, a key element taught by ACT is how to handle pain more effectively through the use of mindfulness skills (Harris, 2009:8).

- What is mindfulness?

"Mindfulness means paying attention with flexibility, openness and curiosity" (Harris, 2009:8). From this definition the following can be deduced.

a) Mindfulness is an awareness process, not a thinking process. It involves paying attention or bringing awareness to a current experience as opposed to being caught up in one's thoughts (Harris, 2009:8).

b) Mindfulness includes an attitude of openness and curiosity even though the experience in the moment is difficult, painful or unpleasant. The individual can be open to it and curious about it rather than running from it (Harris, 2009:8).

c) Mindfulness involves flexibility and attention. The ability to consciously direct, broaden the focus of one's attention on different aspects of an experience (Harris, 2009:8).

Mindfulness can be used to connect with the self, appreciate the fullness of each moment, improve self-knowledge, and connect deeply with loved ones (including the self). "It is the art of living consciously – a profound way to enhance psychological resilience and increase life satisfaction" (Harris, 2009:8).

- Beyond acceptance: God's Grace

Elwell (1997) defines grace as "the unmerited favour of God toward man". Adams and Riggs (2008) define grace as follows,

> In the New Testament grace means God's love in action towards men who merited the opposite of love. Grace means God moving heaven and earth to save sinners who could not lift a finger to save themselves. Grace means God sending His only Son to descend into hell on the cross so that we guilty ones might be reconciled to God and received into heaven. *God made him who had no sin to be sin for us, so that in him we might become the righteousness of God* (2 Corinthians 5:21 NIV).

God's love for people is unconditional even though all are equally undeserving (Garzon, 2014:1-64). Grace is inseparable from a human being's justification (Romans 3:23-24; Ephesians 2:8-9) providing empowerment for the sanctification process (Romans 5:2; 5:21; 6:14; Titus 2:11-14) (Garzon, 2014:1-64).

Where ACT puts emphasis on creative hopelessness in trying to fix the self (Hayes *et al.,* 2012:189), grace invites people to acknowledge that they are powerless in the endeavour as well. Helping the IFC understand God's love and acceptance found in grace during the sanctification process will help the IFC become more accepting of their journey with cancer and the thoughts and feelings that come along with it. Grace dissolves self-judgment (not good enough caregiver) into gratefulness, for God's unconditional love as experienced in meditations, understood in Scripture and expressed through Christ. Self-acceptance therefore results as a by-product of an increased understanding and experience of grace (Romans 6:1-2). Self-acceptance thus becomes a sub goal in a Christian translation of ACT tied to experiencing God's acceptance found through grace (Garzon, 2014:1-64).

4.4.1 ACT consists of six core processes.

According to Hayes (2008), roots of self-compassion and compassion develop from the six ACT core processes, also known as *hexaflex* processes (Hayes *et al.*, 2006:1-25; Rosales, 2016:269-275). These six processes are both overlapping and interrelated where each supports the other and all focus on psychological flexibility (Hayes *et al.*, 2006:1-25). Psychological flexibility can be defined as "the ability to contact the present moment more fully as a conscious human being, and based on what the situation affords, to change or persist in behaviour in order to serve valued ends" (Luoma *et al.*, 2007:17). Dahl *et al.* (2009) outline how these *hexaflex* processes have a direct impact on compassion both for self and others. According to their model, self-compassion involves the ability willingly go through difficult emotions, to mindfully observe self-evaluative, distressing and shaming thoughts without allowing it to dominate one's behaviour or state of mind (fusion) in order to engage more fully in life's pursuits with an attitude of self-kindness and self-validation and to flexibly shift one's perspective towards a broader and transcendent sense of self (Hayes, 2008). The *hexaflex* processes are fundamental elements of the ACT model of psychological well-being also known as psychological flexibility (Hayes *et al.*, 2006:1-25). Just as self-compassion, psychological flexibility is strongly negatively correlated with depression, anxiety and psychopathology and highly positively correlated with quality of life (Kashdan & Rottenberg, 2010:865-878). Psychological flexibility is formed through the following six core ACT processes.

Box 8: Six core ACT processes

Target problem: Area of rigidity/inflexibility	**ACT intervention:** Process to increase flexibility
Experiential avoidance; unnecessarily running away or escaping from emotions and thoughts, even when that creates behavioural harm	Acceptance
Fusion with the mind; arguing with the mind; believing the mind	Defusion
Living in the past or worrying about the future; lack of self-knowledge	Flexible contact with the present moment
Attachment to the conceptualised self	Self-as-context: perspective taking; conscious awareness *per se*; experiencer versus the experienced
A life disconnected from chosen meaning and purpose	Values: chosen qualities of being and doing
Inaction and or avoidance persistence	Committed action: making and keeping behavioural commitments that exemplify chosen values
⇩	⇩
Psychological inflexibility	Psychological flexibility

Source: Six flexibility processes and their inflexibility counterparts (Nieuwsma *et al.*, 2016:50)

- Acceptance (open up)

The first psychological skill is developing willingness or acceptance which means opening up and making space for painful feelings, sensations, urges and emotions; stop struggling with it, give it some breathing space and allow it to be as they are (Batten, 2011:18). Accepting one's situation and thoughts are also called behavioural willingness and psychological acceptance (Sisemore, 2012:12). This process is called defusion which is to recognise one's thoughts in real time (Sisemore, 2014:5-16). The opposite of acceptance is experiential avoidance which is an unwillingness to remain in contact with one's private experiences (Hayes *et al.,* 2012:3). Values are the motivators for accepting the current situation and staying in contact with it, even if it is uncomfortable (Sisemore, 2014:5-16).

It is not about liking or wanting the emotions, it simply means making room for them (Harris, 2009:8). For example, the IFC suffering from anxiety, concern, fear, *et cetera* is taught to experience it as a feeling, fully and without defence (Hayes *et al.,* 2006:1-25). Willingness is the deliberate disengagement from the struggle to control private events (thoughts, images, memories) highlighting that acceptance involves an active process with a purpose. Whilst the effort to control private events narrows the individual's range to only focus on the struggle, willingness extends the range of response alternatives so that additional outcomes can be followed (this happens through repeatedly choosing to disengage with the struggle to control; Waltz & Hayes, 2010:148-192).

Christian translation of acceptance

> Being human brings both joy and sorrow. Life is filled with amazement, growth, love and kindness; yet is also contains pain, sadness, fear, and its own measure of suffering. Among these varied and meaningful experiences, spiritual and religious journeys unfold. Faith is tested, convictions challenged, prayer questioned, and purpose explored, indeed, these very efforts may be part of the suffering itself (Nieuwsma *et al.*, 2016:61).

The IFC for example will accept the cancer journey with more ease by accepting the current situation, ideally seeing it as within God's plan for the moment instead of resisting it and getting caught up in thoughts and overwhelming feelings that is not "God's best" (Sisemore, 2014:5-16). The IFC chooses to become willing to accept the moment (journey with cancer) despite the discomfort surrounding the whole situation. For Christians, this is not complying to life as it is, but yielding to the work of God in using the present moment in his plan to work all things together for the good (Romans 8:28; Sisemore, 2014:5-16).

Seeing thoughts merely as thoughts can be a form of bringing them "captive" (2 Corinthians 10:5) in the sense that they are no longer in control of the individual. This is where ACT introduces mindfulness skills and exercises, not to free the self from the self, but to be free to experience thoughts and the environment as they are (Sisemore, 2014:5-16). A well-known phrase here is "you don't have to believe everything you think". Within the cancer journey IFCs can misperceive what God is doing in their lives. The IFC needs the flexibility to allow the thought that God is in control instead of clinging to emotions of fear, anxiety, worry and anger (unfounded interpretations). For instance, Job explored the difficult question of God's relationship with human suffering, missing what God was doing in his situation, but learning to trust God's wisdom and character (Sisemore, 2014:5-16).

4.4.2 Cognitive fusion (watch your thinking)

The second psychological skill describes how ACT differs from traditional cognitive behavioural therapy (CBT) proposing that when in contact with the present moment, individuals will have the chance to occupy themselves in productive interactions with the environment. Cognitive fusion means entanglement with verbal or cognitive processes to the point of dominating one's awareness and greatly influencing behaviour (Harris, 2006:26). Thus a "tight bonding with one's thoughts" in such a way that it takes control over other potentially more suitable sources of behavioural regulation (Luoma *et al*., 2007:159; Nieuwsma *et al*., 2016:26). "Defusion involves a change in the normal use of language and cognitions such that the ongoing process of thinking is more evident and the normal functions of the products of thinking are broadened" (Luoma & Hayes, 2003:71-78). This is learning to step back and separate or detach from thoughts, images and memories. Instead of getting caught up in thoughts or being pushed around by them, the individual allows them to come and go stepping back and watching the thinking process instead of getting entangled. Cognition is not inherent, rather it is contextually learned. As the individual becomes more verbal his or her cognition becomes their reality for example, thoughts determine who the individual is "you are not a good enough caregiver". In other words, the individual (IFC) becomes trapped because he or she fuses with the content of their cognition (Hayes *et al*., 2003:69-96).

Defusion is to see thoughts for what they are, "nothing more or less than words or pictures", holding it lightly instead of clutching it tightly (Harris, 2009:8). One of the core goals of ACT is to deactivate the power of language when it blocks functional flexibility (Waltz & Hayes, 2010:148-192). "Placing too much emphasis on language to understand intrapsychic states can leave individuals stuck, especially given that the mind is not always accurate in its assessment of both the inner and outer world" (Nieuwsma *et al*., 2016:26). Defusion exercises aim to increase the context of language by providing opportunities to interact with language in different nonliteral ways (Watz & Hayes, 2010:148-192); exercises or worksheets addressing fusion, avoidance and unworkable action including the bull's eye, dissecting the problem, the life compass, the problems and values worksheet, vitality versus suffering diary (Harris, 2009:75-80). Mindful exercises are the positive alternative to cognitive defusion, by contacting events in the here and now (without buying into evaluative and judgmental language) more flexible forms of responding are supported (Hayes *et al.*, 2003:69-96).

A growing body of literature indicates that attempts to supress unwanted private experiences can be harmful. For instance, it has been found that emotion focused and avoidant strategies negatively predict outcomes in several clinical domains such as depression (DeGenova *et al*, 1994:655-663). The literature on thought suppression gives insight into some of the processes underlying the destructive effects of avoidance. Research found that efforts to deliberately attempt to supress target thoughts are likely to lead to amplification (Clark *et al.,* 1991:253-257; Hayes *et al.,* 2003:69-96). These findings show how rules regarding avoidance or suppression of experiential stimuli can become counterproductive.

- Christian translation of cognitive fusion

Christian tradition provides similar mediation traditions when drawing from the early desert Christians and monastics (Stratton, 2015:100-118). A variety of mindfulness exercises will be discussed in chapter 5.

Reducing cognitive fusion with Christian clients is consistent with emphasis on grace instead of legalism (identity tied to thoughts, behaviour and emotion; McMinn *et al*., 2016:203-218). Instead of a legalistic faith similar to psychological inflexibility, defusion enables a healthy dependence on living in God's grace.

In a faith context it is important to understand the central concept of experiential avoidance (EA). In so doing Knabb (2016:49) asks, "what if life is about following Christ, in the midst of pain, rather than waiting for the symptoms to go away?" In other words, Christians may possibly be able to follow Jesus more fully if they can endure their pain rather than avoid painful experiences or even God himself; for example Adam and Eve hiding from God in Genesis 3 (Rosales, 2016:269-275).

Creative hopelessness is an ACT intervention which lessens the emotional control agenda by highlighting the ineffectiveness of EA (Harris, 2009:81) which is particularly good in encouraging surrender to God's gracious care (Knabb, 2016:49). Christians can draw from scriptural examples instead of focussing on deliverance like Paul when he writes how his "thorn in the flesh" brings him to depend on God's grace and to ultimately be content with pain "for the sake of Christ" (2 Corinthians 12:7-10 NIV).

4.4.3 Being present (be here now)

The third psychological skill places emphasis on present moment awareness which is the ongoing, non-judgmental contact with environmental events that appear within and outside of the self. One of the favourable roles of language is that it facilitates one's ability to describe and evaluate the past and plan for the future. With this comes the obligation that current behaviour may be overly influenced by past- and future oriented rules, and less swayed by the present context (Waltz & Hayes, 2010:148-192). Being present is to be psychologically present, consciously connecting with and engaging in whatever is happening at the moment. Individuals find it hard to stay present because they are absorbed in thoughts about past or future, the majority of time operating on automatic pilot (going through the motions). Contacting the present moment is to bring awareness to either the physical world or the psychological world within, or to both at the same time. It further means consciously paying attention to the here-and-now experience rather than wandering off into own thoughts or functioning on autopilot (Harris, 2009:9). The goal of being present is to have the individual experience of the world more directly so that behaviour become more flexible and in so doing their actions become more consistent with their values (Hayes *et al*., 2006:1-25).

- Christian translation of being present

From a Christian perspective, contemplative spirituality has for centuries placed emphasis on the sacrament of the present moment or self-abandonment to divine wisdom in every moment and all areas of life (Blanton, 2008:73-84; Sisemore, 2014:5-16). Often expressed in the spiritual task and process of "letting go and letting God" take control of not only the present or the now, but also on the future with hope (Tan, 2011:243-249). Jesus himself encouraged humans not to be anxious about tomorrow (Matthews 6:34). In the sense of being aware of moment-to-moment happenings, Jesus was aware of his moment-to-moment actions and able to attend to children or the sick even as he went about in his teaching ministry (Sisemore, 2014:5-16). Tan (2011:243-249) warns that Christians must not be passive in regard to their thoughts, but to bring their thoughts to Jesus so that each thought can be brought captive under His control (2 Corinthians 10:5). The IFC thus learns to "watch and pray" (Matthews 26:41). This further implies that the content of thoughts is important because the biblical truth is crucial in right thinking that affects feelings and actions (Romans 12:2; Philippians 4:8). Sisemore (2014:5-16) responds to this by noting that monitoring thoughts instead of clinging to them is a way of bringing one's thoughts under control, as done in ACT. These truths include having hope for the future because of eternal life in Christ and Heaven to come (Romans 8:18; 2 Corinthians 4:17-18). Being mindful of the moment means that the individual is not committed to fusion of thoughts or spending days plotting ways to avoid discomfort (Sisemore, 2014:5-16). The Christian tradition of contemplative, meditative or centring prayer includes aspects of mindfulness and acceptance (Pennington, 1982, 1999; Merton, 1996; Finley, 2004; Keating, 2006; Ford, 2008; Benner, 2011; Foster, 2011). Christian practices of mindfulness will be discussed in detail in chapter 5.

4.4.4 Self-as-Context (pure awareness)

This psychological skill proposes that the individual should be understood as a context of experiencing life instead of as a source of experiences such as thoughts, emotions and memories (Luoma *et al.*, 2007; Sisemore, 2014:5-16).

There are two distinct elements of the mind namely the thinking self and the observing self (Luoma *et al.*, 2007; Sisemore, 2014:5-16).

- The familiar 'thinking self' generates thoughts, beliefs, memories, judgments, fantasies, plans and so on.
- The less familiar 'observing self' consists of the aspect of the individual that is aware of whatever he or she is thinking, feeling, sensing or doing at any given moment. Also referred to as pure awareness.

The technical ACT term is self-as-context (Harris, 2009:11). Self-as-context is important because it makes one aware of own flow of experiences without attaching to them, thus fostering defusion and acceptance. Fusion (the dominance of verbal control to regulate behaviour) with conceptualisations of the self can get in the way of functional flexibility (Sisemore, 2014:5-16). For example, "I am a caregiver" can narrow the range of possible actions one can take. Therefore, the IFC cannot also be a good parent or spouse, or the trauma survivor of the cancer journey. The statement "I cannot handle another setback" requires engagement in experiential avoidance. There is a fundamental danger in the inflexibility that goes with the conceptualisation of the self as being anchored in the content of such descriptions (Waltz & Hayes, 2010:148-192). The IFC might have the thought of "I am not a good enough caregiver" and hold on to this thought as objective truth instead of simply as a thought that most IFC's occasionally have (Sisemore, 2014:5-16). Given that people easily fuse with a conceptualised self, ACT offers the construct of self-as-context as a way of defusion for this and other problematic relational frames. ACT uses less confrontational manners and less directive forms of verbal interaction, by means of looking from the self, instead of at the self (Sisemore, 2014:5-16). Self-as-context in ACT is nurtured by a number of defusion and mindfulness exercises such as metaphors, paradoxes and experiential processes to loosen the entanglement of thoughts and the self (Hayes *et al.*, 2003:69-96; Hayes *et al.,* 2006:1-25; Sisemore, 2014:5-16).

- Christian translation of self-as-context

Self-as-context is a way of learning to attend to where one is at any given moment without evaluating a conceptualised self. For example, Romans 7 where Paul reflects on the conflict between his desires and his actual behaviour, he is free to see the conflict between his goals and actual behaviour. This is important for effective counselling as the individual discovers how to observe the war within instead of getting caught up in fighting it. By focussing on the self-as-context (I am here and now instead of there and then), can loosen the individual from psych spiritual rigidity, making it a place of perspective, "the positioning of the self in a place that transcends the moment-to-moment content of subjective experience" (Sisemore, 2012:100).

Sisemore (2014:5-16) states that the Bible supports the notion behind it by confirming the value of observing and relishing the present moment. Jesus' solution for anxiety (Matthew 6) is not getting fused with anxious thoughts for the next day but staying present in the current day. In the same passage the seeking first the kingdom of God might take this to the next step by using self-as-context as a perspective to move toward the valued end of pursuing God's kingdom. Seeking His word first beyond being fused with internal battles in one's mind attempting in vain to escape difficulties in life (Sisemore, 2014:5-16). The Judeo-Christian tradition embraces "the idea that human suffering is very much the normal state of affairs in life" (Hayes *et al.*, 2012:14). Christians regard suffering as having redemptive value. The purpose of Jesus' passion on the cross was to secure people for himself through atonement for sin and the Bible is clear in calling Christians to share in the suffering of Christ (Philippians 3:10; 2 Timothy 2:3; 4:5; Sisemore, 2014:5-16). Suffering can have a purpose when encountered for the right reasons, such as in pursuit of following Christ which stands in agreement with the idea of pursuing valued goals in ACT. ACT's view of suffering can thus be translated into a Christian model as both systems of thought agree that some pain is unavoidable and some pain is preventable (unnecessary; Sisemore, 2014:5-16).

Theologically suffering follows from the story of the Fall of humankind in Genesis 3 where both creation and human beings are cursed. The pain of the Fall originates from “living in a world tainted by illness, scarcity and natural tragedy, but also from the inhumanity of humans to one another through sinful acts” (Sisemore, 2014:5-16). In addition, the fallen human nature contains minds tainted by sin and consequently irrationality, conflicting motives and wrong appraisals form part of the mind (Sisemore, 2014:5-16).

There appear to be false messages in most therapeutic efforts that “normal” is a total lack of suffering, making suffering a pathology indicating a need for help. In contrast ACT acknowledges that “all human beings are hurting – just some more than others (Hayes *et al.*, 2012:13).

4.4.5 Defining valued directions (know what matters)

One of the primary reasons that avoidance, escape and fusion cause problems is that it is a distraction from constructive direction in life. ACT is one of the few theories to place focus on meaningful pursuit of one’s goals (Sisemore, 2014:5-16). In this theory goals can include a variety of things that are freely chosen, verbally constructed, ongoing patterns of activity that are intrinsically reinforcing (Hayes *et al.*, 2012:14). ACT defines values as “verbally constructed, global, desired and chosen life directions” (Luoma *et al.*, 2007:131). Clarifying values as defined by the client is an essential psychological skill in creating a meaningful life. ACT refers to these values as “chosen life directions”. Values are commonly compared to a compass because they give direction and guide the ongoing journey (Harris, 2009:11).

- Christian translation of defining values

Although values do not need to be religious, for Christians they often are. It is the things that give meaning to life and losing one’s values will affect the individual greatly. Tension may arise when a Christian client has values that stand inconsistent with biblical values to which the client ideally should be directed (Symington & Symington, 2012:71-77). For Christians “to do what matters” (engage in committed action; Harris, 2009:13) implies following Jesus as disciples becoming transformed into the image of Christ (Knabb, 2016:49). Committed action is a “step-by-step process of acting to create a whole life, a life of integrity, true to deepest wishes and longings” (Luoma *et al.*, 2007:158). Values should be linked to ongoing daily life with all its ups and downs, like Jesus enduring the cross for the joy set before Him (Hebrews 12:2). “In short, values must be turned into action” (Sisemore, 2014:5-16). Focusing on values assist in being willing to endure hardships in order to reach the joys beyond it (Sisemore, 2014:5-16).

Rosales (2016:269-275) suggests replacing the word values with the term virtues which acknowledges the shared values of Christian faith. McMinn *et al.* (2016:203-218) note that by focusing on the importance of values in ACT allows rich opportunities for meaningful faith-based motivation and work with Christian clients. The emphasis on values in ACT and committed action in accordance with one's values is affirmed in Scripture in terms of obedience and true faith that lead to deeds and action (James 1:22; 2:15) through the power of the Holy Spirit (Zechariah 4:6; Ephesians 5:18; Acts 1:8). From a biblical perspective values should be based on Scripture as God's inspired Word and eternal truth (2 Timothy 3:16) instead of on relativistic, humanistic values (Tan, 2007:101-111).

4.4.6 Building patterns of committed action (do what it takes)

The last psychological skill is taking effective action, guided by one's values. It is good to know one's values, but it is only via an ongoing values-congruent action that life becomes rich, full and meaningful. Values-guided action opens up a wide range of thoughts and feelings (both pleasant and unpleasant, pleasurable and painful). Committed action therefore means doing what it takes to live by one's values even if that brings pain and discomfort (Harris, 2009:11).

- Christian translation of building patterns of committed action

Like ACT, Christian perspective does not separate values from action (Pieris, 2010: 38-51). This part of ACT may be the most compatible for Christian clients because of the many imperatives in Scripture to act out of faith and in love, for example James 2:14. These core processes help to facilitate making actual movements of tangible actions based on values so that it reveals wholeness and integrity (Luoma *et al*., 2007:17). For Christians this means the ability to live their faith more fully by taking virtue-based action even during trails and hardship (Rosales, 2016:269-275).

The acronym for ACT that sums up the entire model is (Harris, 2009:12):

A = Accept your thoughts and feelings, and be present

C = Choose a valued direction

T = Take action

ACT is consistent with Neff's conceptualisation of self-compassion where each approach to understanding psychological resilience has something to offer the other. The concrete actions and specific psychological barriers identified in the six processes become the final focus of ACT. At heart, the final stage of ACT is "simply learning a generalised strategy of behaviourally moving toward valued ends, dissolving barriers through defusion and acceptance" (Hayes *et al*., 2003:69-96).

4.5 THE COMPASSIONATE PC

The word compassion originates from two Latin roots, *com* meaning "together with" and *patior*, "to suffer" (Godlaski, 2015:942-947). Godlaski (2015:942-947) describes compassion not as a character trait but as a virtue, as such it has an intellectual (cognitive) as well as an emotional (affective) component. Compassion as a virtue is the constant choice of a mean that exists between two extremes. In the case of compassion, it is the habit of one's mind that urges one toward understanding suffering and the habit of will that urges one to do what can be done to lessen that suffering. The extremes would be an uncaring indifference to suffering and on the other hand sympathetic over identification with suffering (Godlaski, 2015:942-947). Compassion in pastoral caregiving is about showing *ta splanchna* where the PC is moved by suffering of others within a spiritual awareness of God's *ta splanchna* (the theological motive in compassion). In this case compassion becomes the PCs' responsibility and duty; it forms part of the spiritual *habitus*, attitude and aptitude. Thus, compassion centres around a Christian calling (professional vocation) instead of an occupation (professional job; Louw, 2015:1-10).

Characteristics of the compassionate PC include the ability to focus his or her attention with the intention to recognise, elicit and the accurate reading of expressions and emotions. Together with the ability to listen, visualise others' perspectives, empathic concern, non-judgemental positive assessment of own and IFCs' emotions. This includes the ability to be aware of any personal subconscious biases and triggers, self-other boundary awareness and the ability to regulate own emotions. The PC must further have knowledge and effective communication skills to draw out and understand the IFC's situation, experiences, hopes, values and preferences. Must collaborate with the IFC, patient and other health professionals in order to act with informed compassion (Berkhof *et al.*, 2011:152-162; Laidlaw & Hart, 2011:6-8; Dwamena *et al.*, 2012:3267; Hoppe *et al.*, 2013:1670-1675; Henry *et al.*, 2013:395-403). Personal qualities that the work further requires include compassion, self-awareness, commitment to teamwork with other psychosocial providers, personal growth, and a belief in the potential for resistance (Kennedy *et al.*, 2015:689-694; cf. 3.3).

Jones (2006:774-788) and Wolfe *et al.* (2008:1717-1723) note that both the cancer patient's and IFC's quality of life can be improved by preventing and alleviating family suffering through compassionate and honest communication and psychosocial attentiveness incorporated by quality palliative care services.

In many ways compassion is more like friendship than anything else. In psychotherapy and counselling this can be a strange and even dangerous concept because it can be misunderstood as a dual relationship. This friendship occurs on a professional rather than personal level where the PC is like a professional friend helping the IFC to live through and talk through their experiences of illness, suffering, loss and grief, while making his or her compassion clear. The PC as professional friend has something other friends lack namely, a source of knowledge and experience that is of direct use to the IFC's dealing with the journey of cancer (Godlaski, 2015:942-947). The PC will offer divine consolation in that God promises in Christ to be with human beings, at their side and on their side, especially during difficult times (Kolb, 2010:13-34).

Compassion further stands central to the ethical practice of the healing professions; in this regard it is not simply the ability to understand suffering of others but to furthermore have an intelligent understanding of the suffering linking it to knowledge of the causes and possible remedies thereof. It is understanding with a scientific component placing the IFC's story within a paradigmatic context of others in the same situation. By understanding the IFCs as unique individuals in unique situations to each case the PC can provide more effective holistic care (Weiner & Woodley, 2018:109-119). In the healing professions, compassion always relates to competence without denying the uniqueness of the IFC's suffering. As such, counselling is always centred on the one who is suffering without aloofness or negation in any form (Pellegrino & Thomasma, 1993:83). Wong (2011:69-81) suggests that the counselling process should strive to help individuals achieve optimal levels of functioning despite difficult life circumstances by growing through negative experiences into sources of strength and well-being. Mindfulness asks the question "What are you experiencing?" and self-compassion asks, "What do you need?" For PTSD clients it is often difficult to know what they need or to show kindness towards the self, so the PC can keep these questions in mind until the IFC can ask them for him or herself (Germer & Neff, 2015:43-58).

The PC as professional friend will help the IFC with compassion through conversation. This form of conversation is not just any kind of talk, but a type of conversation that will awaken the IFC to the depths of God's love and God's truth by entering into a relationship with God through Christ (cf. 5.5). It is a privilege to be invited into conversations with the IFC at times of both, anguished pain and carefree celebrations. These conversations reflect God's presence. "Engaging in deep conversation that meets the heart of the other is the core of ministry" (Purnell, 2003: xi). This transformational teaching goes beyond surface interaction to help the IFC "enter the deep places where God breaks into their lives" (Purnell, 2003: viii). Something as natural, ordinary and enjoyable as friendship and conversation could be a key force for spiritual life and transformation. Through conversation the PC provides the theoretical framework as well as practical methodological dynamics for the IFC's personal and social awakening, knowing, learning and personal growth (Johnson-Miller, 2013:378-391). Conversational learning is a process where the participants make meaning and transform experiences into knowledge through conversations (Baker *et al*., 2002:51). Conversation between PC and IFC provides the space for turning experience of the cancer journey into meaning within this experiential learning process. IFCs will "move through the cycle of experiencing, reflecting, abstracting and acting as they construct meaning from their experiences in conversations" (Baker *et al*., 2002:51). In order to participate in this conversation is to open the self up to think, feel and act differently, inviting a movement towards insight and depth of understanding changing the participants (both PC and IFC) from the inside out. Transformation to a self-compassionate caregiver and conversation thus go together making self-awareness, meaning, self-opening and altered perspectives possible (Johnson-Miller, 2013: 378-391). Purnell (2003:11) explains what makes conversation pastoral.

> Pastoral conversation is grounded in the worshipping life of the Christian community, involves a deep knowledge for and love of the Christian tradition, is shaped by participation in the practice of Christian faith, calls for a reflective awareness of self, demands a disciplined attending to the other, meets people in the circumstances and experience of their living, requires an active and formed imagination, is open to hearing the voice of God in fresh ways, bravely addresses God with life's hard questions, is open to conversion, and

> offers the possibility of love, mercy, peace, justice, healing, reconciliation, new birth, wholeness, nurture and sustenance.

Through conversation the IFCs may become consciously aware of the dynamics of their journey with cancer, the many factors thereof that shape the way they understand and live out their faith as well as current realities of their Christian experiences by means of giving opportunities to meaningful reflection between past, present and future in the counselling space (Johnson-Miller, 2013:378-391). Within this environment of professional friendly conversation both the IFC and PC can give birth to awareness, insight, fresh understanding and vision of the cancer journey. It can be concluded that conversation is essential for IFCs' development and growth on a cognitive, mental, emotional, interpersonal and spiritual dimension (Johnson-Miller, 2013:378-391; cf. 5.7). Conversational epistemology includes God and Scripture, recognising the social nature of the Trinity and that God stands at the centre of knowing via the ever-present illuminating work of the Holy Spirit (Johnson-Miller, 2013:378-391).

According to Newberg and Waldman (2009:214-215), compassionate communication can be used to establish intimacy with others. Intimacy in this sense refers to those qualities associated with friendship, trust and compassion which foster acceptance and greater degrees of intimacy that in turn draw parallel to greater personal health (Sheffield *et al*., 1995:947-956). Newberg and Waldman (2009:214-215) explain that compassionate communication "helps individuals to express vulnerable thoughts while maintaining mutual sensitivity and respect for each other", that is both PC and IFC. Newberg and Waldman (2009:215) define compassionate communication as "the neurological ability to resonate to the emotional feelings of others, to share their suffering and their joy". Even though compassion is part of humans' biological makeup, every human brain has a different degree of emotional sensitivity regarding the reading of others' feelings (Lamm *et al*., 2007b:1292; Saarela *et al*., 2007:230-237). Newberg and Waldman (2009:214-215) note that any person can strengthen his or her neurological capacity to feel greater compassion for others. Compassion is the neurological ability to show kindness, empathy and forgiveness (Farrow *et al*., 2001:2433-2438; Völlm *et al*., 2006:90-98; Güroglu *et al*., 2008:903-910). Like intimacy, compassion is related to better emotional and psychological health (Steffen & Masters, 2005:217-224).

The IFC will seek counselling to be free of suffering, yet the healing process proceeds by moving together into difficult thoughts, feelings and sensations in a supportive, responsive, compassionate and transformative relationship (Germer & Neff, 2015:43-58). In time compassion is likely to transfer to the client in the form of a new relationship to the cancer journey as well as to the self. An explanation of how this happens is that the IFC brings his or her emotional suffering and sense of brokenness to the counselling space where the PC receives it with "open eyes (mindful awareness) and open hearts (compassion)" where the PC then "holds" the client with his or her struggles in compassionate awareness throughout the journey and gradually "lends" back a more compassionate attitude to be carried over into their daily lives (Germer & Neff, 2015:43-58).

The Gospel narratives reveal several characteristics that are involved in transformational conversation. In each of these cases Jesus participated in everyday realities, engaged curiosity, challenged limitations, listened with depth and empathy, encouraged people to think for themselves, and waited for participants to hear in new ways (Johnson-Miller, 2013: 378-391). When reaching out for emotional support the PC must be sensitive towards IFCs' perspectives and emotions. Although there is no "one-size-fits-all" formula in counselling there are some vital components and a variety of methods, approaches and strategies that can be built into a transformational learning experience. Reflecting on the Gospel places attention on at least three major transformational components:

a. The presence of Christ

Incorporating Christ's presence into the counselling space is very important (Purnell, 2003:11). It is not enough to assume that Christ's presence is at work during counselling. The woman in the midst of the crowd who felt God's healing virtue purposely pursued the transforming power of Christ's presence, making her present to the presence of Christ (Mark 5:29-31). Just as a meaningful conversation includes being present to the presence of another, conversational teaching gives the opportunity to be present to the presence of Christ in one another. For the PC to be present in the counselling setting requires intentionality and attentiveness (Johnson-Miller, 2013:378-391).

b. Engaging the deepest dimensions

Conversations in the counselling setting make space for IFCs to identify and explore the state of their soul and their journey with cancer, personal beliefs, perspectives, attitudes, relationships, situations, circumstances, ideals and emotions around the situation. Jesus engaged with the current issues and circumstances of people, responding to their thirst for spiritual life by interacting with questions and listening without providing easy answers and quick fixes. Jesus did not tell people what to think, He allowed the people to wrestle with the complexity of their lives. *Paideia* is the concept for deep learning by ancient Greek philosophers that involves more than transmission of knowledge from teacher to student. It rather challenges the student to recognise the need to examine the depths of their soul and wrestle with the realities of life and faith. *Padeia* takes the conflicts, contradictions, possibilities, paradoxes, pain and potential of the here and now seriously (Johnson-Miller, 2013: 378-391). For the PC to engage with the informal caregiver will require practices such as being fully present, remembering, reflection, contemplation, compassion, deep listening and empathy. "Teaching that transforms incorporates, explores and speaks to the realities of life" (Johnson-Miller, 2013:378-391).

c. Inviting discovery of the sacred mystery

Conversational transformation involves deep internalised engagement with truth, reality and possibility. After listening to the disciples sharing their concerns over the happenings in Jerusalem, Jesus invited them to discover the sacred mystery of his life by explaining the Scriptures and breaking the bread (Luke 24:13-35). Jesus shared God's story and vision with the disciples. God's story consists of all aspect of God's truth revealed in Scripture, church tradition and creation. Interpreting Scripture with integrity means building a bridge between the ancient text of the past and present Christian living. Thus, understanding the Word of God entails much more than merely reproducing or memorising words written in the past (Groome, 1991). Gadamer (1986:354) refers to this bridge-building process as a "fusion of horizons" where bringing the meaning of Scripture into the present requires interpretation and the process of interpretation in itself is a form of conversation. It is this interpretative conversation between past and present that allows the meaning of what was said in the past to be experienced anew in the present (Gadamer, 1986:354-355; cf. 5.7).

Engaging in conversation intentionally and pastorally while being attentive and compassionate the PC must pay attention for possible emotions in the IFC. Herbst (2019:1-17) explains the emotions of IFCs as follows.

Box 9: Possible emotions in the IFC

Anger	They may for instance be angry with themselves, family members or sometimes even with the diagnosed person. Anger can be associated with fear, panic, worry, resentment and other emotions. If anger is detected the PC can use the emotion to help motivate the individual into self-exploration, action and constructive life changes.
Forgiveness	Another important construct to work on as an important act of self-love and support to others. The significant other can be encouraged to release thoughts about past or future by grounding the self in the present moment opening up to new possibilities (mindfulness).
Grief	In cases where the spouse has been diagnosed with cancer it is natural for the healthy spouse to mourn the loss of that loved one's health and life they had together before the diagnosis. Give space and permission to grieve the losses.
Guilt	This may include feelings that the significant other is not helping enough. Help the significant other identify and evaluate guilt and other associated emotions, in order to take control of it before they take control over the life of the significant other.
Anxiety and depression	Significant others may feel anxious and depressed about how they are coping. These feelings can be worsened by the impact of the illness on the cancer patient, the family and finances. Give space and show unconditional acceptance to the significant other to acknowledge these feelings and encourage them to continue with their counselling session.
Hope and hopelessness	These two emotions may be felt to different degrees. Whereas hope is having a vision toward what may change in time such as cure, comfort, peace, acceptance and even joy. Hopelessness relates to anxiety, depression and feeling out of control.
Loneliness	Significant others often feel alone in their caregiving role. Feelings of isolation are the perception that others cannot understand what the IFC is going through. It may further be related to less time to socialise and follow previous routines. To lessen this feeling the PC can encourage the significant other to consciously make contact with others (Herbst, 2019:1-17) and remind them that others are in the same position (common humanity) (Neff & Dahm, 2013).
Stress	All the above emotions experienced by the significant others can become overwhelming making the IFC feel a loss of control. Stress is a response to any kind of demand for change and how the individual will respond to life. Teach the IFC about

	consequences and coping strategies, taking control and conquer stress and in the end negative influence.

Source: Author compiled the table.

In the proposed model, ACT will be used as therapy method. ACT recommends that the PC personally practises it, in order to enrich and enhance his or her own life and to resolve own painful issues.

4.5.1 ACT and pastoral caregiving

The role of the PC in committed action is very important. “Committed action involves an active willingness to experience undesirable private events” (Waltz & Hayes, 2010:148-192). ACT recognises that the PC has his or her own measure of suffering, it is then with this “unique approach and comradery that lives can be lifted and engaged in their spiritual and values-based fullness” (Nieuwsma *et al*., 2016:61).

> Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves receive from God (Corinthians 1:3-4 NIV).

In this way pastoral care is led by “wounded healers” (Rolf, 2003:168-171), who personally also qualify for counselling by being in contact with their own experiences of misery, doubt, suffering and helplessness (Klän, 2018:1-10). The best way to learn and become familiar with ACT is to personally practise it. The PC must take time to identify what he or she fuses with, what he or she avoids, what values he or she loses touch with and what ineffective actions are taken. The more this model is applied to the self and own issues and observing how it works in personal life, the more experience can be drawn into the therapy setting (Harris, 2009:31).

ACT makes use of many techniques, metaphors, worksheets, strategies and other interventions but none of these will be effective if the PC does not have a good trusting relationship with the client. In ACT the aim is to be fully present with the client with an attitude of being authentic, mindful, compassionate, respectful and in touch with own core values (Waltz & Hayes, 2010:148-192; Harris, 2009:41; Hayes *et al*., 2003:69-96). In other words, the PC must aim to live and breathe ACT and to present it with heart and soul instead of cold and mechanically (Harris, 2009:41).

The PC is an important audience that holds the client accountable for value-congruent patterns of action (Waltz & Hayes, 2010:148-192). In the therapeutic process the PC does not do interventions to the client, the PC does interventions with the client. Because ACT allocates much time in helping the client getting to know his or her deepest longings, desires and wishes which come from the heart (Nieuwsma *et al*., 2016:27). It is important for the PC to uphold a compassionate yet challenging approach to create a context for difficult emotional work on the part of the client without being judgmental or evaluative (Hayes *et al*., 2003:69-96). It is about opening a space for the client to voice their despair, fear, grief and anger, and beyond also gratitude and joy (Rolf, 2003:167). Being respectful to the client the PC must repeatedly ask the clients' permission to begin and/or to go on with the exercises. Similarly, amid an exercise where the client is in touch with strong emotions the PC can ask, "I'm just checking is it okay if we keep going with this? I don't want you to feel in any way coerced. We can stop at any point" (Harris, 2009:41). In the first session the PC can say something like:

> One of the things that makes ACT different from many other therapies is that during our sessions, we spend a lot of time practising skills such as learning new ways to handle difficult thoughts and feelings more effectively. You can't learn these skills simply by talking about them – you have to actually practise them. So quite often, if it's okay with you, I'll be asking you during the session to do some simple exercises. Would you be okay with that? (Harris, 2009:42).

The PC must be flexible when leading these exercises, making it longer or shorter as required, changing words to suit own style and adapt them for the IFC. In addition, the PC must be creative incorporating thoughts, feelings, comments or metaphors that the IFC has made in the current or previous sessions. Metaphors and exercises must be directly relevant to the issue being dealt with in the session (Harris, 2009:43).

ACT adopts several verbal conventions with the purpose of increasing the psychological distance between the client and the client's private events. An example of a language convention includes the words 'but' and 'and'. Everything following 'but' contradicts what went before the word, "but that means that there are two things that are inconsistent, that are literally at war with each other" (Hayes *et al.,* 2003:69-96). The PC will replace the word with 'and' whenever possible. This reduces the psychological sense that something is wrong and needs changing whenever literally contradicting reactions are noticed.

- Why should the PC consider ACT?

Sisemore (2014:5-16) explains the answer in terms of the means and ends (valued goals) of processes of which ACT fits both. According to Sisemore (2014:5-16), no secular rooted model of therapy offers a better "fit" for Christians than ACT, both in terms of its ends and its means offering a view of life that is about pursuing valued ends that include more than merely getting over unpleasant life events (emotions). Therefore, for Christians, counselling is directed towards freedom to pursue valued goals (or ends) of the Christian life. ACT acknowledges inevitable suffering in life and argues that suffering is not to put the individual off from reaching his or her goals (Öst, 2008:296-321). The means of psychotherapy are distinctive techniques and several of the techniques of numerous therapies can be used independent of the overall models without running contrary to the Christian belief and practices. For instance, the model considers accurate listening skills of humanistic psychology to be adequate for change because the power lies within each person to make changes once he or she experiences such acceptance. These skills can be helpful to the PC without assuming that they are sufficient for change aside from the power of the Holy Spirit (Sisemore, 2014:5-16).

Health professionals often witness others' emotional distress; regularly relating to suffering in an empathic manner can lead to increased negative effects. Working with caregivers can stir up feelings of hopelessness, inadequacy, self-doubt, grief and fear among health professionals causing them to question their own professional competence (Colli *et al.*, 2014:102-108; Veilleux, 2011:222-228). Considering these findings, the researcher believes that together with personally practising ACT and self-compassion may be an important resource that can help the PC respond to the challenges of therapeutic working in an emotionally balanced way. The more these methods are practised the more effective the PC will be in applying those to his or her clients (Harris, 2009:5).

4.6 COMPASSION FATIGUE (CF)

The well-being of the IFC and PC is crucial to experience and compassion. Burnout and mental or behavioural health issues, inadequate self-care and social support will make well-being difficult as will be discussed in the following sections.

4.6.1 The cost of caregiving

Compassion is regarded as being reliant on a person's capacity to develop a compassionate mentality and orientation (Crawford *et al*., 2014:3589-3599) involving qualities such as attention, awareness, motivation, wisdom, commitment and courage (Cole-King & Gilbert, 2011:29-37). Compassion toward family members is distinct in nature (Goetz *et al*., 2010:351-374) because it has to do with helping and supporting people with whom the caregiver has close emotional attachments (Curtis, 2014:210-223). Compassion fatigue has multifaceted (holistic) effects including physical, emotional, social, spiritual and intellectual effects (Upton, 2018:1-27). Stepping into a caregiver role, a shift in roles and emotions is almost certain to make feelings such as anger, frustration, exhaustion, feeling alone and sad natural. Too much stress, especially over a long period, can harm a person's health.

Early stages caregiver fatigue symptoms include, frequent colds, reduced sense of accomplishment, headaches, fatigue, lowered resiliency, moodiness and increased interpersonal conflicts (Portnoy, 2011:47-50). Caregiver fatigue symptoms further include boredom, cynicism, anxiety, discouragement, intrusive thoughts, irritability, avoidance, numbness, persistent arousal, sleep disturbances, depression, intolerance, detachment, apathy and a loss of compassion (Dominiquez-Gomez & Rutledge, 2009:199-204; Quinal *et al*., 2009:1-7; Hooper *et al*., 2010:420-427; Boyle, 2011; Herbst, 2019:1-17). Isolating oneself from others and not enjoying activities that used to bring joy is another indicator of caregiver fatigue (Boyle, 2015:49-51). Physical symptoms can include increased blood pressure, weight gain, fatigue, stiff neck, immune dysfunction, increase in gastrointestinal problems, cardiovascular illness and diabetes (Aycock & Boyle, 2009:183-191; Herbst, 2019:1-17). If not treated caregiver fatigue can gradually move into an advanced stage showing symptoms of somatic complaints, social withdrawal, depersonalisation, cynicism, exhaustion, irritability, low energy, feeling underappreciated and overworked. In time the caregiver becomes numb, disillusioned, hardened and overwhelmed (Portnoy, 2011:47-50). IFCs taking on caregiver roles thus stand a greater chance to experience symptoms of depression and anxiety. With the main focus on the ill family member the IFC often does not realise that their own health and well-being are at stake with an unawareness of the severity of the negative effects until a health crisis or other significant trauma manifests itself (Portnoy, 2011:47-50). IFCs may furthermore adopt ineffective coping strategies in order to self-manage these emotional and physical symptoms such as avoidance, withdrawal and emotional numbing which in turn can have a negative effect on the quality of care the diagnosed person receives (Dominiquez-Gomez & Rutledge, 2009:199-204).

Although compassion appears to be intrinsic and becomes a personal character trait and in so doing becomes part of the self, the IFC needs to limit the roles taken on. In other words, the caregiving role must not become the caregiver's identity and sacrifice his or her well-being in the process (Cornelius, 2013:1-7). God who created man with the gift of compassion expects the believer to show compassion to those in need, but He does not expect the IFC to over-identify with the caregiving role which will lead to burnout. (Cornelius, 2013:1-7).

- The positive aspects of caregiving for cancer patients

It has been argued that taking the benefits of caregiving into consideration will offer a more holistic view of caregiving needs (Hudson *et al*., 2005:329-341; Semiatin & O'Connor, 2012:683-688). The positive aspects of caregiving can be defined as "the extent to which the caregiving role is appraised to enhance an individual's life space and to be enriching" (Kramer, 1997:218-232). This definition refers to the benefits that are experienced as a direct result of becoming a caregiver for a cancer patient, including post-traumatic growth, benefit finding, optimism, positive effects, hope, and finding meaning in life (Coyne & Tennen, 2010:16-26; Schmidt *et al*., 2011:607-620). Although these benefits were initially used in studies on cancer patients (Coyne & Tennen, 2010:16-26; Schmidt *et al*., 2011:607-620), they have also been broadly adopted in studies on IFCs (Weiss, 2004:260-268; Clayton *et al.*, 2005:1965-1975; Kim *et al*., 2007:283-291; Holtslander & Duggleby, 2009:388-400).

Granting that a cancer diagnosis and treatment thereof can be devastating for the family especially the IFC, caregiving can add meaning to the caregivers' life, enabling them to learn new skills, and strengthen the relationship with the diagnosed persons and other family members (Schulz & Sherwood, 2008:23-27). It has been reported that the 5-year mortality rate of the caregiver who provided emotional support to their cancer patients is lower than among those who did not (Brown *et al.*, 2003:320-327). A study exploring the caregiver benefits identified benefits such as acceptance, empathy, appreciation, family closeness, a positive self-view, and a reprioritisation of values (Kim *et al*., 2007:283-291). Coming to accept the cancer diagnosis of a family member and re-establishing relationships with others are related to greater life satisfaction. Becoming more emphatic and reprioritising values is further related to a lessening of the symptoms of depression (Kim *et al.*, 2007:283-291).

A better understanding of both the cost and benefits of caregiving can help the PC to improve the adaptation and well-being of IFCs, and to develop interventions to support the positive aspects and improve the quality of caregiving

4.6.2 The cost of caring in pastoral ministry

Effective stress management has been identified as an ethical requirement amongst health professionals. As many as 40% – 73% counsellors report levels of distress (Hannigan *et al*., 2004:235-245; Stafford-Brown & Pakenham, 2012:592-613). Stress among health professionals have been associated with different negative consequences such as difficulties with self-esteem (Butler, 2005:55-62), depression and anxiety (Radeke & Mahoney, 2000:82-84; Gilroy *et al.*, 2002:402-407) secondary trauma stress (O'Halloran & O'Halloran, 2001:92-97) and vicarious traumatisation (O'Halloran & O'Halloran, 2001:92-97; Sabin-Farrell & Turpin, 2003:449-480; Sprang *et al*., 2007:259-280; Bride *et al*., 2007:155-163; Craig & Sprang, 2010:319-339). Stress has furthermore been found to undermine attention (Skosnik *et al*., 2000:59-68) and decision making skills (Starcke & Brand, 2012:1228-1248) and may also have a negative impact on the counsellors' ability to empathise and support the client (Lambert & Barley, 2001:357-361; Enochs & Etzbach, 2004:396-400).

Considering these findings, it is essential to develop programmes that will promote stress resilience and well-being in a positive, integrated and sustainable way (Irving *et al*., 2009:61-66; Wise *et al*., 2012:487-494). Both mindfulness-based stress reduction (MBSR) and ACT have been found to decrease stress, negative affect, self-doubt and anxiety among health professionals (Shapiro *et al.*, 2005:164-176; Shapiro *et al*., 2007:105-115; Stafford-Brown & Pakenham, 2012:592-613). Some researchers suggest that self-compassion is a central mechanism by which mindfulness- and acceptance-based interventions influence psychological health (Baer, 2010:135-153; Hölzel *et al*., 2011:537-559; Keng, 2012:270-280). Thus, research and evidence suggest that relating to the self with compassion is a promising method to promote self-care, professional well-being and resilience to stress among health professionals (Barnett *et al.*, 2007:603-612; Patsiopoulos & Buchanan, 2011:301-307; Wise *et al*., 2012:487-494).

Besides the emotional and physical factor of exhaustion, caregiver fatigue in pastoral caregiving mainly describes the "barrier of spiritual exhaustion and its connection to depleted hope and an inappropriate theological framework of reference" (Louw, 2015:1-10). It is concerned with acknowledging personal limitations, helplessness and hopelessness within the domain of commitment, motivation and meaning giving. The quality of the PC's belief system, vocation, professional conviction and appropriate theological theory, normative framework, attitude and philosophy of life is of importance. It is more a qualitative and hermeneutical issue – level of meaning and interpretation, "what is at stake here?" instead of quantitative issue, level of input "how many?" (Louw, 2015:1-10).

Being continually exposed to suffering of others will affect the pastoral caregivers' whole being, particularly attitude (*habitus*), internal make-up and cognitive framework. Internal confusion and over identification can lead to a kind of obsession to help and replace others' suffering. Vicarious suffering then points to internal doubt (spiritual strike) and an increased awareness of a concern for loss as a result of the unavoidable fact of tragedy in life. The PC should focus his or her healing process on reframing their paradigmatic framework, patterns of thinking, commitments, convictions and belief systems (Louw, 2015:1-10).

According to Louw (2015:1-10), pastoral caregiving fatigue should be understood in connection with efficiency in caregiving. Acting according to the expectation of one's caregiving profession as well as the character of one's pastoral identity together with a clear theoretical framework will lead to experiences of satisfaction. Consistency between theory and praxis thus improves compassion satisfaction. This sense of satisfaction in pastoral ministry should be measured in close connection to one's sense of vocation and calling. The question then becomes "To what extend is the caregiver motivated by a personal calling of God to a ministry of compassion?", "Is this passion based on emotions or directed by a clear image of God and the interplay between divine presence and a theology of compassion?"

To prevent pastoral caregiving fatigue, Louw (2015:1-10) suggests finding a quiet place for reflection and debriefing where both the outer space of a retreat and the inner space of internal reflection on the meaning of compassion are needed. In order to heal the PC from caregiving fatigue two levels of compassion should be kept in mind:

- Compassion as an affective category. A feeling of deep sympathy and sorrow towards those suffering accompanied by a strong desire to alleviate the pain (Figley, 2002b:2; Stamm, 2002:107-119).
- Compassion as a spiritual category coupled with a God image. In *theopaschitic* theology God can play a distinct role in the treatment of spiritual exhaustion. During the reframing process attention should be paid to the role of divine compassion in caring (*ta splanchna, oiktirmos*; Louw, 2011a:73).

Another method to invest in a process of continuous healing is the ability to find positive aspects within a traumatic situation which relates to a sense of humour. Moran (2002:139-153) refers to humour as a coping strategy within an emergency situation. Because humour involves incongruity and can be understood in many ways, it can be utilised to shift perspectives regarding stressful situations and as a way to gain a sense of mastery (Rnic *et al*., 2016:348-362). Humour is in this sense more than laughter; it is the ability to see situations from a different perspective understanding the relativity of life events (Moran, 2002:139-153). Research has indicated that some humour styles ease stress in a beneficial way (affiliative and self-enhancing humour), while other styles are maladaptive (aggressive and self-defeating humour; Martin *et al*., 2003:48-75; Kuiper *et al*., 2004:135-168). Affiliative humour facilitates relationships, amuses others and minimises social tension by using spontaneous jokes and funny anecdotes. Self-enhancing involves a cheerful outlook in life with a tendency to be amused by inconsistencies that facilitate emotion regulation and coping with stress and misfortune. This type of humour includes a style of thinking and can therefore be conceptualised as a cognitive construct and therefore related to cognitive reframing (Rnic *et al*., 2016:348-362). Capps (1990:10) defines reframing as the ability to change the frame in which one perceives events with the purpose to change the meaning thereof. When the meaning changes one's responses and behaviour change accordingly. To change meaning suggests changing the emotional setting of a viewpoint in relation to which the situation is experienced and placing it in a different frame which fits the facts of the same situation just as well or even better and in so doing changes the entire meaning of the situation (Capps, 1990:10).

4.7 CONCLUSION

In this chapter the overview of research on self-compassion has shown it to be strongly associated with emotional well-being, motivation, health behaviours, coping and better interpersonal relationships. This suggests that compassion is associated with positive emotions, sense of affiliation, reward and prosocial compassionate behaviour. Research furthermore indicates that compassion can be modulated through education and training through relatively short-term counselling interventions.

Taking care of a relative diagnosed with cancer can take a physical and emotional toll on the IFC. At the same time, it can also be a meaningful and satisfying experience. By taking care of the self the IFC can make sure he or she is able to fill this role for as long as needed. It has been shown that treating the self with care and compassion can be a powerful way to improve intrapersonal as well as interpersonal well-being for significant others and the patient diagnosed with cancer. Self-compassion simply is compassion directed inwards, thus generating kindness toward the self as imperfect humans and discovering how to be present within struggles of life with greater ease. Just as a person can feel compassion for others' suffering, they can extend compassion towards the self during difficult times regardless whether the suffering resulted from external or own circumstances. Self-compassion therefore involves being touched by own suffering, not avoiding disconnecting from the experience but generating the will to lessen own suffering with self-kindness. It involves offering non-judgmental understanding to own pain and failures seeing these experiences as part of the larger human experience. To understand why self-compassion creates a positive mind-set while simultaneously improving negative mind-states it is useful to think of the three key features of self-compassion in terms of loving kindness, connectedness through common humanity and being present through mindfulness. As the IFC holds his or her pain in loving connected presence they concurrently generate positive emotions while lessening negative emotions through self-soothing.

Self-compassion is associated with ACT constructs such as acceptance, perspective taking and psychological flexibility. ACT uses four mindfulness-based processes (accepting emotions, defusion from thoughts, observing inner states from a safe distance and passing values and committed action) together with two values-based processes (values and committed action). Merging acceptance and behavioural action helps the IFC move forward guided by their deeply meaningful values despite temporary verbal content and unpleasant emotions that have the potential of sending them in a contradictory life direction of fear. Taken as a unit the *hexaflex* assists in nurturing psychological flexibility, which involves openness, centredness and a deeper engagement with life. ACT leans into suffering instead of promoting avoidance. Happiness is thus not a goal of ACT but replaced with acceptance. ACT further promotes awareness of values and living in ways that demonstrate commitment to those values. ACT allows the IFC the space and time to step into the present moment, encountering the self in a mindful, compassionate and accepting way. This moment of radical acceptance and love is perhaps the greatest common ground between self-compassion and ACT. The emphasis on values and committed action further resonates well with many religious traditions. In the spirit of providing compassionate, effective, caregiver-centred care to family members diagnosed with cancer this study proposes that the PC integrates ACT and religion.

People are created by God with a gift to care for others, to have empathy for the pain, sorrows, losses and needs of others. Believers act out of their love for God in order to be like God and to obey Him to help those in need. Pastoral conversation is an extraordinary gift where the PC is invited into the IFC's most intimate space where they discuss the very nature of their being human, sharing their joy and pain. In this space the IFC reaches hard-to-find words of genuine faith. If the PC is alert to it, he or she will be blessed with life-shaping wisdom.

Being able to cope with the stresses of being in a caregiver role is part of the art of caregiving. To remain healthy so that the IFC can continue with his or her caregiver role, he or she must be able to recognise own limitations and learn to care for the self as well as the diagnosed family member. Regulation of emotions, self-compassion, self-care, reflection and other resilience-promoting attributes and skills were shown as important factors for well-being. Caregiving fatigue occurs when the IFC takes on the pain and suffering of the diagnosed family member. When in caregiving fatigue the IFC will have a difficult time to maintain a healthy balance between being concerned for the family member and staying objective. By continually pushing themselves harder the IFC will eventually end up in complete burnout. In this chapter coping was categorised into two types: self-compassion and mindfulness to resolve the stressful role of caregiving. Helping others involves some emotional dangers like burnout or being overwhelmed (for both the IFC and PC). For this reason, boundaries or limits have to be set in place in order to avoid these problems.

CHAPTER 5: *CURA VITAE*

5.1 INTRODUCTION

As discussed in the previous chapters, the impact of cancer not only affects the diagnosed person but equally affects their families. IFCs are remarkable individuals who sacrifice a great deal of their personal and professional lives. Careers, relationships, finances and even spiritual needs are often unattended and unfulfilled in the interest of making sure that the needs of the diagnosed loved one are met. Giving constant attention to another's needs (over time) can become a core part of the IFC's identity (CRHCF, 2016).

In the second half of the interpretive task, chapter five discusses the potentially powerful role that religion can have on the IFC's quality of life. Religious involvement among cancer cases has been the focus of considerable research over the past two decades. With growing interest on religious coping of the cancer patient self, less research could be found on religious coping of IFCs (Thombre *et al*., 2010:173-188), even though the level of psychosocial morbidity among IFCs is sometimes comparable to, or even greater than that of the cancer patient (Vickery *et al*., 2003:289-296). Religious involvement is an important resource for many families, making it important to understand how IFCs can draw on their faith to help manage the caregiving demands (Thombre *et al*., 2010:173-188).

Religion as a practice of coping represents a crucial resource for this study. This chapter discusses the link between religion and psychosocial adaption, the theological implications of coping with cancer and the practices of religious disciplines, in order to provide pastoral caregiving to IFCs. The aim is that the guidelines from this chapter can assist with reducing uncertainty and decrease associated stress, establishing trust with the PC and enhancing adjustments to finding a "new normal" across the trajectory of the cancer journey and beyond. The importance of a multidimensional (holistic) caregiving model has been stressed with psychosocial, physical, psychological and spiritual components. Assessment of the psychosocial needs of IFCs is the first step to be taken in order to determine subsequent steps for treatments addressing the psychosocial needs throughout the treatment trajectory and beyond. Literature dating back to the 1970s provides support for the importance of recognising psychosocial concerns during, as well as after cancer treatment (Kazak *et al*., 2015:426-459).

The aim is to educate the PC to help understand what IFCs go through and with this knowledge help IFCs navigate a world turned upside down, searching for meaning and purpose. Beliefs are the blueprint of who an individual is, making habitual thought patterns a powerful construct. The energy behind beliefs drives decisions, attitudes, feelings, coping patterns, life choices and more. For this reason, evaluation of personal belief systems can help IFCs to better understand themselves, how they relate to other people, the cancer diagnosis and journey thereof and life in general (Herbst, 2019). An important belief system frequently relied on during stressful times and uncertainty, including that of caregiving, is religion (McCrae, 1984:919-928; Mickley *et al*., 1998:1-17; Tix & Frazier, 1998:411-422). It has been shown that both patient and IFCs rely on their religion to help them cope with serious physical illnesses (Murray *et al*., 2004:39-45; Kim *et al*., 2007:1367-1374). Reviews have further highlighted the relevance of religion specifically to cancer (Nairn & Merluzzi, 2003:428-441; Stefanek *et al*., 2005:450-463; Thune-Boyle *et al*., 2006:151-164; Yoshimoto *et al*., 2006:481-488).

Multiple professional organisations are officially recognising the importance of religious assessment and the role thereof in delivering quality care, for instance the National Comprehensive Cancer Network (NCCN; 2003:344-374). The clinical practice guidelines of the National Consensus for Quality Palliative Care (NCQPC, 2018) recognise religious aspects of care as one out of eight primary aspects of optimal palliative care. According to Moreira-Almeida *et al*. (2014:176-182), the American College of Physicians, American Medical Association, World Psychiatric Association and American Psychological Association recognise and acknowledge that religious care is an important component of health care and that the health care industry should integrate religious aspects into their clinical practices. Cancer care providers are also acknowledging the role of religion in the care of their patients (Ramondetta *et al*., 2013:2991-2998). Recognition of the importance of religion within the cancer journey is reflected in the inclusion of spiritual care in national, as well as international palliative care guidelines (WHO, 2004; Clinical Practice Guidelines for Quality Palliative Care, 2009).

The outline of the chapter will be as follows. Firstly, the focus will be on bereavement and support, and a refined understanding of the grief response will be discussed as an essential component of palliative care service delivery. Helping IFCs to cope with cancer related stress thus starts with the cancer diagnosis extending through treatment, remission, death and bereavement.

Secondly, the focus is on three coping methods to manage stressful life events, namely theory of cognitive appraisal from Lazarus and Folkman (1984), avoidant coping and religious coping (RC) which is divided into positive religious coping (PRC) and religious struggle (RS). In his theory of religious coping, Pargament (1997; 2001) observes that research tends to overlook possible negative forms of religion (Abu-Raiya *et al.*, 2010:389-411; Exline *et al.*, 2014:208-222). For this reason, Von Gunten (2018) describes religion as a double edge in nature; it can be either a source of problems or a source of solutions. Adding that although there appears to be a relationship between religion and health outcomes, the relationship is a complex mix of different aspects of religion and physical, mental and social health outcomes.

The third and fourth sections will focus on the teachings of two South African authors. Firstly, Louw's concepts of God-images and how cancer can be used as an opportunity to grow closer to God will be discussed. *Theodicy* within the Christian tradition is the endeavour to mend the perception of God's goodness with human suffering and to explain His love and grace in the light of hardship. Louw (2011b:15) proposes that *cura vitae* is a method to explore pastoral caregiving in a way that involves human suffering, enabling both IFCs and patient to live with hope and human dignity. Secondly, Hudson's concept on how to build a positive God-image (a compassionate and nurturing God) by growing a friendship with God, with the purpose to reach a deeper meaning of life and the purpose thereof amidst hardship.

The fifth section focuses on practices of religious disciplines. One of the key attributes of resilient individuals is to draw upon religious beliefs and practices. This section offers practical guidelines on how to nurture a friendship with God into a deeper life of meaning and purpose amidst hardship by means of religious practices, such as Serenity Prayer, Centring Prayer, *Lectio Divina* and worship.

The last section, the combination of pastoral care and life coaching will be introduced as a method that the PC can utilise to assist IFCs on both a past directed (counselling) level, as well as future directed level (life coaching).

5.2 BEREAVEMENT SUPPORT

A focal measure of quality palliative care must be the well-being of IFCs in the years after their caregiving role (Hudson, 2013:581-582). The result of the death of a loved one is often an extremely difficult time where IFCs can suddenly feel lost and alone because so much of their sense of self came from being a caregiver (CRHCF, 2016).

Research shows that preparing IFCs for the role of supporting a loved one with advanced illness, holds valuable psychological and social benefits such as decreasing the inclination for bereavement distress (Hudson *et al*., 2015:19-24). This preparation can include components such as the role of being a caregiver, how to support a person with advanced illness, self-care, support systems and preparing for approaching death and bereavement (Hudson *et al*., 2018:375-387). Several publications acknowledge the importance of bereavement support (NICE, 2004; WHO, 2004; NCQPC, 2018; De Lima *et al*., 2012:118-122).

The public health model of bereavement support categorises bereaved in three risk groups namely high, moderate and low (Aoun *et al*., 2015:1-14). For some individuals the symptoms of stress following the death of a loved one are more intense and persistent (Latham & Prigerson, 2004:350-362), also known as complicated grief (Shear *et al*., 2011:103-117) and prolonged grief disorder (Boelen & Prigerson, 2007:444-452). Prolonged grief has been associated with health problems such as insomnia, substance absuse, depression, depressed immune function, hypertension, cardiac problems, cancer, suicide, work and social impairment that can last for as long as four to nine years after the death (Neimeyer & Burke, 2012:205-224). The experience of caregiving can be positive or negative, due to IFCs being prone to physical and psychological morbidity, financial disadvantage and social isolation (Hudson *et al*., 2011:522-534). A study done by Hudson *et al*. (2013:581-582), shows that almost half of IFCs met the criteria for psychological distress. CHCF (2016) reports that IFCs generally fluctuate between emotions of guilt, depression, confusion about life's purpose and loneliness. Relief is often felt after the loved one's death, because constant and demanding care is not required anymore, their loved one is at rest and free from pain. However, this feeling of relief is short lived and quick to turn into feelings of guilt, because of feeling relieved. IFCs also often feel that they could have done more towards the end of their loved one's earthly journey. With time, the caregiver's task can take or consume the caregiver's whole identity. No longer under the pressure and demands of caregiving, IFCs are left without a sense of purpose and usefulness. As the caregiving role places more and more demands on IFCs consuming their time and emotions, it leads to less frequent outings and loss of social connections. With the loved one's death, intense feelings of loneliness can start to manifest as the last remaining social connection in the IFC's life is gone.

Neimeyer and Burke (2012:205-224) identify the key risk factors in a summary of the clinical literature on pre-loss risk factors for the development of prolonged grief.

Box 10: Key risk factors for complicated grief

Key risk factors for complicated grief
• Background factors
Close bond with the dying relative, especially loss of spouse or child. Female gender, especially mothers. Minority ethnic status. Insecure attachment style. High pre-loss marital dependence. Religious (and spiritual) beliefs and practices. (Religious/spiritual belief can result in lower levels of grief, and for others stronger faith can lead to more severe experiences of grief).
• Treatment-related factors
Aggressive medical intervention such as intensive care, ventilation, resuscitation. Uncertainty regarding treatment. Family conflict regarding treatment. Economic hardship due to treatment. Caregiving burden.
• Death-related factors
Bereavement overload (multiple losses in short period). Low acceptance of impending death. Violent death. Finding or viewing the loved one's body after a violent death.

Hospital death rather than home death.

Dissatisfaction with death notification.

Source: Neimeyer and Burke (2012:205-224).

Bereaved individuals experience grief in the context of their whole being (physical, emotional, cognitive, behavioural and spiritual). Evidence suggests that intervention is both indicated and effective when grief is complicated and prolonged (Currier *et al.*, 2008:648-661).

It has been noted that although bereavement support is an acknowledged integral element in palliative care, it is still not sufficiently resourced, researched and systematically used (Hudson, 2013:581-582; Lynes *et al*., 2014:150-153; Guldin *et al*., 2015:185-189; Stroebe & Boerner, 2015:574-576; Waller *et al*., 2015:132-148). With ample evidence and research showing the importance of bereavement care, there still appears to be a lack of contemporary practice standards stipulating what resources palliative care services should allocate, when they should allocate them, how and by whom, with insufficient evidence-based bereavement guidance (Demmer, 2003:327-341; Mather *et al*., 2008:228-230), insufficient budget directed toward bereavement services (Breen & O'Connor, 2007:199-218) and a lack of guidance on bereavement support and a reliance on intuition over evidence when reacting to bereavement care needs (Guldin *et al*., 2015:185-189). In fact, nearly a fifth of palliative care services do not provide bereavement support (Guldin *et al*., 2015:185-189), on the contrary health and counselling services often do not formally acknowledge IFCs as "clients", placing primary focus on the diagnosed person (Hudson *et al*., 2018:375-387). For this reason, Neimeyer (2014: 125-130) refers to bereavement support as "the forgotten child". Given this background the development of a holistic, Scripture-based, pastoral model to help significant others cope with cancer related stress can benefit the families of cancer patients greatly starting from diagnosis following treatment, after treatment adjustments, death and bereavement.

A concept that the PC should take note of is resilience. A concept analysis of resilience identifies three requirements for resilience to happen: (a) a situation of significant adversity, (b) the presence of a number of resources that can support them to face the hardship and assistance with adaptation and (c) the avoidance of a negative outcome or a positive adjustment to a new situation (Windle, 2011:152-169). Resilience is an ordinary term used in various disciplines. However, the definition of resilience shows inconsistencies. The Dictionary of Medical Terms (Mikel & Charles, 2000:486) defines resilience as the "ability to endure stress (physical or mental) and return to normal even in situations that appear overwhelming". Merriam-Webster Dictionary (2002) gives the following definition "an ability to recover from or adjust easily to change or misfortune". Another dictionary, Mosby's Dictionary (2008:1606) defines resilience as "the ability of a body to return to its original form after being stretched or compressed".

Resilience has been described in the cancer continuum as a baseline feature, an outcome and a means that can promote positive growth (Molina *et al*., 2014:93-101). Despite disparities in defining resilience, a common theme that emerges is that resilience is the ability to recover (return to a balanced emotional state) from harsh changes or hardships (Luo *et al*., 2020). Resilience is described by Masten (2001:227-238) as "ordinary magic" in a way to emphasise that it is inherent and difficult to measure or quantify. Experiencing resilience will differ across an individual's lifespan and the presence of a stressful event, such as a cancer journey can modify the person's resilience ability (Windle, 2011:152-169). Resilience includes both, the result of an individual's personal attributes, as well as the impact by community and cultural factors (Hudson *et al.*, 2018:375-387). Several studies have proved that resilience in cancer cases is higher than in the general population (Straus *et al.*, 2007:511-518; Min *et al*., 2013:2469-2476; Rosenburg *et al*., 2014:185-193).

Box 11: Key attributes of resilient individuals

Key attributes of resilient individuals
Drawing on past experiences of loss survival.
Connecting with family and community for care.
Drawing on religious beliefs and practices.
Identifying internal and external strengths and resources.
Recreating a world of meaning and personal identity following a loss.
Drawing on the experience and support of fellow bereaved individuals.
Obtaining and accepting more practical support.
Holding onto a belief in a just world and acceptance of death.
Gaining comfort by talking and thinking about the deceased.

Source: Boerner & Mancini (2013:55-67).

Bereavement support standards recommended as a minimum level of bereavement support to be provided to IFCs by the PC are outlined in the following box.

Box 12: Principles of bereavement support by Hall *et al.* (2012)

Principles of bereavement support

Bereavement support is delivered:

- In a targeted manner with those who would benefit the most from specialist interventions as identified through structured screening and assessments.
- Focussing on identifying the bereaved person's own resources and capacity that will improve their resilience.
- Spanning over a period from predeath to several months' post-death and beyond as required.
- Focussing not only on the primary caregiver but extending to all significant others (where sources allow).
- In a manner that will support the PC (palliative care staff) through processes such as death reviews, professional development and professional supervision.

Source: Hall *et al.* (2012)

Rebuilding a life after caregiving is crucial, after investing so much time and attention into the caregiving role, but turning focus on the self in an effort to deal with the grief and personal loss generally results in the perception of being secluded from society, normal life and even, feelings of selfishness. Here, the PC can help IFCs to allow themselves to take time to refocus, taking the love and attention they gave to their loved one and pouring it into the self (emotional, social, physical and spiritual levels). CHCF (2016) notes that "coping with grief and beginning to find emotional and spiritual healing is no small effort." Offering the following guidelines as useful methods that can be employed to aid IFCs to heal during the time of rediscovering and coping with the death of a loved one.

<u>Box 13</u>: Methods to rebuild life after caregiving (CHCF, 2016)

COPING WITH GRIEF AND REBUILDING EMOTIONALLY AFTER CAREGIVING

- Use rituals as a tool to help cope with grief: Rituals can be any 'simple' act that brings the family member to a place of calm and remembrance of their loved one's memories. "If it brings you to a place of peace, embrace it and come back to it as often as you need to throughout your bereavement and journey of rediscovery of yourself" (CHCF, 2016).

- Allow all feelings: Grief is a unique journey for every person bringing with it a great range of emotions (some may be unexpected or confusing). Regardless of the type or intensity of the emotion, allow it to be felt. Being honest with self and emotions is crucial during the time of healing and recovery. "Grief does not follow a uniform path" (CHCF, 2016).

- Take time-outs from sadness: Franks (2016) states "as with physical exercise, constant grief exertion can be depleting." The joys of time outs, that take the mind away from grief (if only for a short time) must be pursued and embraced. These time outs can be going fishing, seeing a movie with family or friends, going for a walk, *et cetera*. "Grief takes a lot out of us" (CHCF, 2016).

- Seek professional help from a PC: The path toward healing and embracing a new normal is unique to each individual and can be an arduous journey. Seeking the help of a PC can be a valuable aid to the significant others' grief recovery. The expert insight and coping techniques offered by a PC can serve as a wealth of knowledge and understanding of what IFCs need during this time. "Grief recovery is never a display of weakness – you do not have to face this time of grief and mourning alone" (CHCF, 2016).

REBUILDING SOCIALLY AFTER CAREGIVING ENDS

Developing positive, meaningful relationships with others is very healing during grief recovery and self-discovery – particularly with others who also went through a cancer journey. The following guidelines are suggested to foster social connections.

- Begin reaching out to others: Re-establishing social connections does not have to happen all at once. Take small steps by for instance a phone call to a family member, coffee with friends, after-church brunch. All these small steps lay the foundation for reconnection with those who are important.

- Re-establish connections with church or community programmes: Due to the demands of caregiving activities requiring attendance away from the caregiving place (home) are eventually abandoned. Small interactions with others in the community (church) and just getting out of the house for a little while is the start for re-establishing positive social connections. "Now that the caregiving chapter in your life has passed, begin gradually involving yourself with the groups and missions you were once involved in" (CHCF, 2016).

- Lean on a support network of family, friends, or other former caregivers: Sharing the caregiver journey with people who truly care for one's well-being is very important during the bereavement process. Family members are the most important source to lean on even though they may not be able to directly relate to the emotions their support and presence is a step towards the healing process.

REINVIGORATING THE PHYSICAL SELF AFTER CAREGIVING

Physical care is a very important component not to be overlooked assisting in the rediscovering of one's identity "after setting aside the mantle of caregiving".

- Daily exercise: Physical activity is a proven factor in relieving stress, boosting positive emotions and improving an overall life outlook.
- Adequate rest: Achieving truly restful sleep while in the caregiver role is never much of a reality while the brain is occupied with the next day's events, worrying if one had done enough, general ever-present stress of caregiving makes restorative sleep near impossible. "Your body, mind and soul need rest to recover from the work of grief and rediscovering who you are beyond the role of caregiver" (CHCF, 2016).
- Practise daily meditation: "Meditation is the practice of bringing your mind to a state of calm, relieving you of the incessant activity of thoughts, fears, and stress" (CHCF, 2016).

Source: CHCF (2016).

5.3 COPING METHODS TO MANAGE STRESSFUL LIFE EVENTS

Studying religion from a coping perspective can shed light on how IFCs use their religion in specific life situations and contexts, such as a cancer journey. Pargament (1997:32, 90) defines religion as "a process, a search for significance in ways related to the sacred" and defines coping as "a search for significance in times of stress". According to Canda and Furman (2010:59), religion refers to "an institutionalised (i.e. systematic) pattern of values, beliefs, symbols, behaviours and experiences that are oriented toward spiritual concerns, shared by a community, and transmitted over time in traditions". Broadly defined, coping is the cognitive and behavioural efforts individuals use to ease distress, discomfort and suffering during stressful life events (Patterson *et al.*, 2004:390-407). Religious coping methods as explained by Pargament and Raiya (2007:742-766) are the methods of understanding and dealing with negative life events related to the sacred.

Both, patient and IFCs reach a point of utter loneliness during the cancer journey. This is the point where the true quest for meaning and God starts, questioning whether cancer is a fate to be endured alone or if this path of suffering (physically, emotionally, spiritually) also runs through God's heart. To this effect Louw (2011a:225) observes that giving meaning to suffering is complex and "not arrived at as a matter of course". Linking meaning to the goal of human existence and the movement thereof, which implies that "God himself cannot be the meaning of life. God is more than the sum of meaning" (Louw, 2011a:225). Instead, meaning should be the discovering of the suffering God who can convey meaning to one's life. Thus, making meaning a theological problem and connecting meaning to the *pathos* of God are revealed in Christ's cross (Louw, 2011a:225). The quest for meaning, according to Frankl (1975:172) is not about what meaning life has for the individual, but the meaning one gives to life.

During the cancer journey, the patient and IFCs can harden themselves, becoming embittered or simply submit to a destiny of hardship. In an embittered frame of mind, life becomes meaningless with perceptions such as no life expectations, pessimism and despair which darken their outlook on existence.

The researcher identified four coping methods, namely:

a. Problem-focused coping (e.g. active coping)

Individuals attempt to constructively change or eliminate the source of stress (Block, 2001:2898-2905; Neipp *et al*., 2016:525-535).

b. Emotion-focused coping (e.g. use of social support)

Individuals attempt to work through emotional distress with the intention of minimising the impact of the stressor and maintain emotional stability (Block, 2001:2898-2905).

c. Avoidant coping (e.g. denial)

This coping style does not address the cause or the effects of the stress. It often represents a psychological defence against difficult realities such as a cancer diagnosis (Block, 2001:2898-2905). Louw (2014:1-10) refers to denial as "playing of games" where the individual pretends not to feel sorrow, withdrawing from the challenge of suffering, seeming to accept the journey but in fact losing all hope and joy in life[5].

d. Religion as a coping mechanism

Religious coping is not simply a defence mechanism, it is actively and dynamically involved in each stage of the coping process to help IFCs find, maintain and transform significance and meaning (Pargament *et al*., 2011:51-76). After a cancer diagnosis many individuals report that religion is important to the adjustment of the diagnosis (Asgeirsdottir *et al*., 2013:1445-1451; Khanjari *et al*., 2014:15-25; Nikseresht *et al*., 2016:330-337; Pirbodoghi *et al*., 2016:41-50; Borjalilu *et al*., 2016:545-552). Up to 84% of advanced cancer cases report they are relying on religion as a coping mechanism (Vallurupalli *et al*., 2012:81-87).

Within coping and caring literature, it has been noted that religion and the specific coping methods thereof can be relevant and adaptive for dealing with the stressors of the caregiving role, particularly at

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[5] Among cancer cases, problem- and emotion- focused coping have been positively associated with improved psychological adjustment, mental health and quality of life. Avoidant coping on the other hand has been negatively associated with these outcomes (Lutgendorf *et al*., 2000:1402-1411; Lutgendorf *et al*., 2002:131-140; Stanton *et al*., 2002:93-102; Hack& Degner, 2004:235-247; Kershaw *et al*., 2004:139-155). While problem focused coping and emotion-focused coping are positive ways of managing stressful life events, avoidant coping is the result of not managing stressful life events. Using religion as a coping mechanic can have two effects, PRC or RS depending on what the individual's God-image was before the crisis (cancer diagnosis).

the end of life (Pearce *et al*., 2006:743-759). Firstly, religion provides a set of beliefs that helps IFCs to find meaning and purpose in negative events, as well as providing hope, order and coherence that help with the process of acceptance and adjustment (McIntosh *et al*., 1993:812-821). IFCs secondly, report high levels of religious involvement, regular use and helpfulness from religious coping strategies (Hinton, 1999:19-35). Thirdly, research shows beneficial relationships between religion and well-being among IFCs (Miltiades & Pruchno, 2002:82-91). Religion can be a major coping resource for individuals facing serious illnesses (True *et al*., 2005:174-179; Sulmasy, 2006:1385-1392; Balboni *et al.*, 2007:555-560).

Pargament and Raiya (2007:742-766) assign five functions to religious coping namely, to discover meaning, to acquire control, to gain comfort by virtue of closeness to God, to achieve closeness with others, and life transformation. They (2007:742-766) further categorise the methods of religious coping in three ways namely, benevolent religious appraisal, punishing God reappraisal, and demonic reappraisal.

Many of their empirical studies (Pargament 2001; Pargament & Raiya, 2007:742-766; Pargament *et al*., 2011:51-76) focussed on the identification of the category of religious coping methods used by IFCs. They found that where IFCs' religious coping method was negative (punishing God reappraisal and demonic reappraisal), IFCs experience religious struggles (RS) and are more likely to develop depression or anxiety and their overall well-being was not good. Particularly of importance to this study is the positive category of religious coping methods (benevolent religious appraisal).

Religious coping (RC) is one component of religion that has been studied in cancer patients (Thune-Boyle *et al*., 2006:151-164; Lavery & O'Hea, 2010:55-65) and refers to how IFCs make use of religious beliefs in order to understand and adapt to stress. Individuals using religion as a coping mechanism during illness, generally rely on positive religious coping (PRC), characterised by constructive reliance on faith to promote healthy adaptation (Pargament *et al*., 2000:519-543; Balboni *et al*., 2007:555-560). Studies show that RC offers the cancer family a sense of meaning, comfort, control and personal growth (Pargament *et al.*, 2000:519-543).

- RC is defined as the manner in which individuals cope with trauma, adversities, or stressful events by finding comfort in their religious practices (Xu, 2016:1394-1410).
- RC is also defined as a set of strategies that comprises valuing a secure relationship with a benevolent God, a belief that there is meaning in life and seeking support from congregation members (Pargament *et al*., 1998:710-724).

Although, RC includes a sense of love and compassion (Paragment *et al*., 2011), it is a multimodal (behavioural, emotional, cognitive), dynamic (constantly changing based on circumstances and context), *but* often an unclear process that can lead to positive (PRC) or negative (RS) outcomes on mental health (Abu-Raiya *et al.*, 2016:1265-1274).

Studies that attempt to evaluate *if* and *how* preadolescents/adolescents use religious coping strategies in dealing with different stressors, include for instance the study of Pinnow (2001:2497) on parental death, the study of Pendleton *et al*. (2002:1-11) on cystic fibrosis, the study of Frazier (2004:19-30) on sexual assault, the study of Molock *et al.* (2006:366-389) on suicide, the study of Benore *et al*. (2008:267-290) on serious illness, and the study of Carleton *et al*. (2008:113-121) on depression. Wills *et al*. (2003:24-31) note that when preadolescents/adolescents turn to religion when faced with negative life events, it will buffer them from the impact of certain life stressors, such as substance use. Wills' *et al*. (2003:24-31) findings stand in line with several adult studies, showing that RC either positively correlates with indicators of adjustment (positive effects and life satisfaction), or negatively correlates with indicators of psychological distress (negative effect and clinical symptomatology). The conclusion can therefore be made that RC on various negative life events, are equally beneficial to both preadolescents/ adolescents and adults.

Depending on its use and interpretation, RC could have two outcomes (Peres & Lucchetti, 2010:331-338). Generally, religion is applied in a positive manner (PRC) as a great source of coping; but in contrast, RS has been associated with negative outcomes, such as mortality and worse mental health.

5.3.1 Positive religious coping (PRC)

Evidence on the positive effects of religiousness in health shows consistent personal growth (Lucchetti & Luchetti, 2014:199-215), via an improved sense of meaning or connection to God (Thombre *et al*., 2010:173-188). A body of research has established noteworthy links between religiousness and better physical health, improved sense of general well-being, survival, quality of health and better general functioning (Ano & Vasconcelles, 2005:461-480; Harris *et al*., 2008:17-29; Paragment *et al.*, 2013:1-19; Gall & Guirguis-Younger, 2013:459-475; Moreira-Almeido *et al*., 2014:176-182; Abu-Raiya & Pargament, 2015:24-33). Noteworthy associations have been made between PRC and decreased levels of depression (Bjorck & Thurman 2007:159-167), increased mental health status (Pargament 2004a:713-730; Pargament 2004b:1201-1207) and positive stress related growth (Park & Fenster, 2004:195-215).

According to Koenig (2012), religion can be a resource for coping with stress that may increase the frequency of positive emotions. Religion as a resource provides strongly held beliefs, giving meaning during difficult life circumstances, while it further provides a sense of purpose, altered priorities, closer relationships and a deeper appreciation for life (Calhoun & Tedeschi, 2006:3-23; Thombre & Rodgers, 2009:251-272), and brings about better coping with stress, giving social support, encouraging human virtues, increasing positive emotions such as meaning and peace (Koenig, 2012). These outcomes are referred to as post-traumatic growth by health psychologists (Thornton & Perez, 2006:285-296; Bishop *et al*., 2007:1402-1411) and perspective transformation by health scholars (Mohammed & Thombre, 2005:347-360; Thombre & Rogers, 2009:251-272).

Studies exploring the role of meaning and peace in mental and physical health (Jafari *et al.*, 2014; Whitford & Olver, 2012:602-610) show that peace and meaning highly correlate with quality of life. According to Steger and Frazier (2005:574-582),

> Meaning should be an important element of religion because religions almost universally address issues regarding what in life is important, what people's purposes for living are, and what the nature of the human experience is.

The relationship between religion and meaning has already been shown from several studies (Steger *et al*., 2006:80-93; Canada *et al*., 2015:79-86). According to Whitford and Olver (2012:602-610) "peace could be understood as reconciliation with one's circumstances, a kind of acceptance, but not fatalism".

5.3.2 Religious struggle (RS)

RC has also shown a negative relationship with mental health in the cancer journey. Major life stressors, such as cancer not only affect the cancer patient, but also the lives of their spouses, preadolescents/adolescents, parents, friends and others in their social networks (Kayser *et al*., 2007:404-418; Faccio *et al*., 2018:1-6) which can profoundly target the family and patients' belief system leading to religious struggle (King *et al*., 2015:270-277). For these reasons (among others), RS has begun to receive significant attention in the literature (Exline *et al*., 2016:501-508).

RS is defined as a set of strategies or God-images that regards God as a punishing God, accompanied with feelings of abandonment by God, insecure relationship with God, pessimistic worldview and doubt in one's religious beliefs (Pargament *et al*., 2004a:713-730; Pargament *et al*., 2011:51-76). RS is defined as strain and conflict regarding sacred matters concerning the supernatural, with other individuals, and within the self. Exline (2013:459-475) and Pargament *et al*. (2005:245-268) cover three types of RS:

- Supernatural struggles that involve tension or conflict with supernatural agents, for instance God or Satan.
- Interpersonal struggles that involve strain with other individuals or institutions concerning religious issues.
- Intrapersonal struggles that involve conflict with the self, regarding sacred concerns expressed by means of religious questions and doubts, moral concerns and perceived lack of the ultimate meaning in life (Pargament *et al*., 2005:245-268; Exline, 2013:459-475).

Drawing on a variety of empirical studies, Pargament (1997) notes that major life stressors affect individuals spiritually, psychologically, socially and physically. Studies consider these struggles as general, normal and standard (Johnson & Hayes, 2003:409-419; Fitchett *et al*., 2004:179-196; McConnell *et al*., 2006:1469-1484; Exline *et al*., 2011:129-148; Morgan *et al*., 2014:937-945; Abu-Raiya *et al*., 2015a:631-648). Findings from Pearce *et al*. (2006:743-759) show consistent associations between RS and poor coping outcomes.

IFCs' feeling that God abandoned them, questioning God's power, or perceiving the situation as punishment from God are more likely to report poorer life quality, more burden and less caregiving satisfaction (Pearce *et al*., 2006:743-759). Because RS includes strain and conflict regarding core value systems, beliefs and practice, they hold important implications for health and well-being. Although endorsed at far lower rates than PRC, studies link RS to a selection of indicators for psychological distress, for instance depression, lower levels of life satisfaction and quality of life (Hebert *et al*., 2009:537-545), as well as physical distress (McConnell *et al*., 2006:1469-1484; Park *et al*., 2009a:41-58; Rosmarin *et al*., 2013:182-187; Harris *et al*., 2014:223-229).

The general pattern of findings show that RS is negatively associated with happiness and positively tied to depressive symptoms (Ellison & Lee, 2010:501-517; Exline *et al*., 2014:208-222; Harris *et al*., 2014:223-229; Abu-Raiya *et al*., 2015a:631-648; Abu-Raiya *et al*., 2015b:61-79; Stauner *et al*., 2015). RS is difficult and painful which can pose as a significant risk for poorer health and well-being (Ano & Vasconcelles, 2005:461-480; Exline, 2013:459-475; Exline & Rose, 2013:380-398). RS has been associated with poorer psychological adjustment and various types of psychopathology such as anxiety, depression, obsessive compulsive disorder (Ano & Vasconcelles, 2005:461-481; Conners, 2006: 89-108; McConnell *et al*., 2006:1469-1484; Park *et al*., 2009a:41-58; Harris *et al*., 2014:223-229) and suicidal tendencies (Rosmarin *et al*., 2013:182-187).

RS generally arises when individuals are confronted with stressful life events, such as a cancer diagnosis and death. The illness and death of a loved one are primary stressors, triggering a religious secondary stressor on happiness and depressive symptoms. Being in a position of confronting both, primary and secondary stressors is overwhelming and compromises the resources IFCs might typically rely on. Under such circumstances, IFCs must search outside themselves for sustenance. One place IFCs might look for support is from God, relying on a sense of religious hope to carry them through the cancer journey (Abu-Raiya *et al*., 2016:1265-1274).

The PC can also remind the family that although negative religious coping strategies predict both, short- and long- term negative outcomes, it can also be a path of healing for some. Many religious figures have endured hardships only to report gratefulness at the end of their difficult journey. Potential benefits can be hidden in struggles only to be realised over time (Pearce *et al*., 2006:743-759). Thombre *et al (*2010:173-188) state that even though RS may be related to diminished personal growth, it may also ultimately lead to enhanced personal growth. A crisis of faith may over the long-term serve as a powerful motivation to finding a deeper sense of meaning or valued commitments.

In a nutshell, PRC for example reinterpreting the stressor as meaningful, considering God as a partner, seeking and appreciating God's love and care, conveys a secure relationship with a transcendent force, a sense of connectedness with others, and a compassionate worldview (Pargament *et al*., 2011:51-76).

PRC thus tends to be valuable for individuals under stress (IFCs during their caregiving process). By contrast, RS for example reinterprets the stressor (cancer journey) as a punishment given by God, passively depending on God to lessen the stressor (cancer) and attempting to cope on one's own not relying on God's aid mirror "underlying spiritual tensions and struggles within oneself, with others, and with the divine" (Pargament *et al.*, 2011:51). RS is therefore, more likely to have adverse effects on IFCs. Looking at how RC can intervene between stressors and outcomes, it has been shown that RC performs as a moderating function in that as stress levels rise, RC progressively protects the believer from the damage of stress; at the same time RC acts as a preventing function, reason being it is a reliable predictor of positive outcomes, regardless the intensity of the stressor (Xu, 2016:1394-1410).

Believers often report the benefits of PRC (Ano & Vasconcelles, 2005: 461-480). RS is generally a maladaptive way of drawing upon faith to cope, for instance believing illness is divine punishment (Pargament *et al*., 2004a:713-730; Ano & Vasconcelles, 2005: 461-480). Both, positive and negative religious coping mechanisms consider God to be in control of one's fate, but holding different views on God's will, for example PRC "God has called upon me", as to RS "God has forsaken me" (Phelps *et al*., 2009:1140-1147). According to Nikfarid *et al*. (2018:188-198), the nature of one's religion, how Scripture, guidance and teachings are perceived and practised, will be the determining factors of how the believer will see and approach God, especially during hardships. In other words, the manner how IFCs and patient will approach cancer, depends on their framework of meaning, perception of life and how they understand God (their God-image). The work of Louw will explain this concept in broader detail.

5.4 THEODICY AND GOD-IMAGES ACCORDING TO LOUW

5.4.1 God-images in crisis behaviour

Everyone must adapt to their circumstances (the cancer diagnosis and caregiving part) in their own unique way and according to their personality and life outlook (Moules *et al.*, 2004:99-107; Louw, 2011a:9). Louw (2012:158) notes that a crisis can affect the spiritual realm, invading spirituality caused by the interconnectedness between self-understanding and different God-images. "Different God-images are often a reflection and representation of an understanding of the most burning question in suffering; Why, God?" According to Louw (2012:158) the question "Why, God?" is closely connected to one's cognitive patterns of thought. Referring to Augustine's confessions, Niño (2008:88-102) suggests that facing uncertainties in a complex world and the mystery of God one must understand that the goal of questioning is not to find answers, but to "ask, seek and knock". In the same way, Bondi (1997:99-101) notes that people should not expect that a friendship with God entails getting what one wants when praying for something, because "terrible things happen and are happening at this moment which we simply can't understand". What is known is that God desires friendship with human beings and created humans for this end. *Theodicy* within the Christian tradition is the endeavour to mend the perception of God’s goodness with human suffering and to explain His love and grace in the light of evil.

- If one’s theory is an explanatory model of cause and effect, the outcome will be putting a question mark behind God’s nature. In this case, God is presented as the *cause* behind unsolved problems and unanswered questions about suffering (Louw, 2012:158).
- If God’s omnipotence is understood in terms of a cruel manifestation of power and force, God will be regarded as the *oppressor* in suffering (Louw, 2012:158).
- When power is perceived from the outlook of woundedness and vulnerability (1 Corinthians 2:22-25), as God identifying with human suffering through Christ, a new perspective transpires. God in this case is not regarded as the instigator, but the “Covenantal partner in life” and soulmate in suffering (care, compassion, consolation; Louw, 2012:158).

As a result, IFCs’ God-images will play a role in the way IFCs will perceive suffering (the cancer journey). Van der Ven (1990) and Louw (2012) give an indication of the variety of ways in which IFCs’ relationship with God could be interpreted by describing different God-images in crisis behaviour.

Box 14: God-images by Van der Ven (1990) and Louw (2012)

Theological symbols which play a role in the concept of suffering by Van der Ven (1990:209-210)

- **Apathy:** Suffering does not really affect God; it leaves Him cold.
- **Retribution:** Suffering is a way of God’s punishment.
- **Providence and dispensation:** Suffering is God’s will and there is a purpose and plan with it.
- **Purification:** God uses suffering as a means of purification and education in one’s faith.
- **Compassion:** The suffering God has compassion with the sufferer.
- **Substitution:** In the light of God’s grace, He strengthens people to exchange places with others and help others with sacrificial service, as Christ suffered for humans.
- **Mystical unification:** Through suffering the suffering comes in direct contact with God; humanity suffers in unity with God.

Four possible God-images by Louw (2012:159)

- **God as Lord:** Represented as a king who is in control of life, whose wisdom is a guideline. “Through faith one can rely on the faithfulness of God despite the prevailing crisis.”
- **God as soulmate, partner for life**: Represented as the one identifying with human suffering of which the cross is the representation of God’s woundedness and vulnerability. “God does not always provide a solution to a crisis, but indeed offers salvation (grace) despite our human predicament.”
- **God as parent**: Represented as a caring parent showing compassion and nurturing one in suffering. Within this relationship one is open to His embracement.
- **God as judge:** Represented as a God of justice, judging injustice and evil, dealing with guilt in a fair and just way. In this regard reprimands become a means to a constructive end for example converting people to and instructing them in a new life mode to a lifestyle imitating justice and reconciliation

The theological centre of these symbols and groups is primarily determined by two concepts namely, God's faithfulness and his suffering. The PC must make sure to communicate these two faith perspectives to IFCs (Louw, 2011a:229-230)
• IFCs can rely on God because He is faithful. • In Christ IFCs must realise that God is part of their suffering and suffers "sym-pathetically" with them.

Source: Author compiled the table.

5.4.2 Illness as an opportunity to grow and the role of the PC

"Suffering becomes a theological problem when the connection between God and suffering becomes so problematic that one's understanding of God is inappropriate" (Louw, 2011a:224). With suffering to this extent one's God-image becomes so harmful that it can affect the process of healing, in this regard Louw (2011a:224) refers to suffering as the "spiritual trauma of pain".

While suffering does not come from God, Menzies (2004:141-149) also admits that suffering must, at times, be accepted. Louw (2011a:9) relates coping with illness with art. Illness becomes an art, when individuals succeed if the crisis becomes an opportunity to grow in life, skills and faith (Louw, 2011a:9). Practising the art of coping with illness involves:

- Putting meaning into suffering
- Trusting while everything seems futile
- Living in the face of death

The PC must sustain both the patient and IFCs, assisting and preparing them for the general problems of the illness such as inability to cope with the illness, fear of suffering (witnessing suffering) and anxieties about death (Louw, 2011a:9-11). The PC must also be sensitive and responsive to warning signs of RS in IFCs. Once RS is detected, intervention can be instigated by the PC which is instrumental in preventing the stress to escalate beyond the point of control and infringing on IFCs' meaning making of life (Xu, 2016:1394-1410). Pastoral caregiving is thus a special preparatory and preventative task. Helping the patient and IFCs on "how to be sick" even before the sickness comes about, and "how to die" even before death. In order to achieve this goal, the PC must focus on the creative powers in life and faith, and not on pathology. It is a process of empowerment where the PC must motivate IFCs and patient to rely on their own resources (Louw, 2011a:9-11). The strengths perspective places a high premium on IFCs' inner and environmental resources instead of problems and deficits (Saleebey, 1996, 1997, 2002). According to this, perspective humans have strengths, capabilities and resources; each environment has several resources that can be utilised (cf. Chapter 2).

The PC must be committed to help IFCs "discover and live out the truths of their own lives as they perceive and experience these truths" (Pargement, 2007:19). Louw (2011a:11) provides questions for the PC, keeping in mind that answers are searched for within each individual's unique frame of reference, and knowing that illness and caregiving are a unique challenge to each individual sufferer (Moules *et al*., 2004:99-107).

Box 15: Examples of questions to be used by the PC

Is it possible to live meaningfully and with hope, despite suffering, sickness and death?

Can hardship be experienced as a challenge and task to be wrestled with and worked through?

What is meant by acceptance of illness?

Is it possible that hardship in illness can create a passion for life and sense of victory?

Source: Louw (2011a:11)

Theological questions that arise are, "What is the nature of the link between God and illness?" (Louw, 2011a:11). In the quest for God's presence amid suffering the question, "Why this illness?" becomes critical. Identifying God with suffering is mysterious. God does not give a logical explanation for the origin of suffering (Louw, 1979:172-183). In truth, logical answers do not provide comfort, it only settles the sufferers' doubts temporarily. God does not provide answers to the logical "why" questions, instead in the midst of hardship He proposes the "therefore" (the illogical reason of the cross; Louw, 2011a:225). In other words, Louw (2011a:11) suggests changing the logical "Why?" into the "therefore" by asking "To what purpose?" God does not provide solutions, He provides salvation. In a sense, God was present in the suffering of Christ and His death on the cross. With this explanation the PC can tell IFCs, "God is present in your suffering" (Louw, 2011a:225).

Cura vitae is to find meaning in illness and being determined during hardship. *Cura vitae* is summarised as (Louw, 2011a:11):

> A theology of life and the healing of life from the viewpoint of Christian spirituality. It is about how new life in the risen Christ and the indwelling presence of the Spirit can contribute to the empowerment of human beings. It is about hope, care and the endeavour to give meaning to life within the reality of suffering, our human vulnerability, and the ever-present predicament of trauma, illness and sickness. *Cura vitae* is a theological attempt to create a paradigm shift in caregiving from a predominant focus on our knowing and doing functions to our being functions.

From a Christian spiritual perspective, "to be" is a growth process of anticipation and transformation from performance ethics and unconditional love. From cause and effect to the networking of pastoral hermeneutics, for instance linking fundamental existential issues such as anxiety, guilt, despair, helplessness and anger to fitting God-images and the quest for meaning. Essentially dealing with questions about attitude (ensoulment) and the quest for meaning in suffering. "Do you have grief? Or do you live your grief?" becomes the essential question to work with. To merely have grief has the potential of bringing the individual to the brink of destruction. "To live grief can become an act of human dignity" (Louw, 2011a:12).

5.5 THEODICY ACCORDING TO HUDSON

For Hudson (2015:109) the hardest question is, “Why did God allow this to happen?” When terrible things happen, this is the question that generally follows. While circumstances (illness, loss of job, car accident, natural disaster, death) may differ, the common denominator linking life altering news or painful losses is the experience of overwhelming and unjust suffering. The quest for the PC is how to reconcile these devastating events with a God who passionately longs to be friends with IFCs and patient and what good is a friendship with God when God allows cancer. Hudson (2015:110) explains that it is not helpful to answer the question why a loving God, who desires everyone into existence for the sake of friendship, allows suffering? There is no easy answer to this question, if there exists one at all. The PC cannot give satisfactory answers as to why bad things can happen by an all-loving, all-powerful God. Instead Hudson (2015:110) suggests when overwhelmed by human suffering and tragedy, the hard questions must be approached through the eyes of Jesus.

The bottom line of Christian faith is to know who God really is, one must look at Jesus because through Jesus God’s heart, character and will are revealed (Hudson, 2015:116; Pârvan & Cormack, 2017:1-25). To answer how God feels about human suffering, the PC can use the following profound examples.

Firstly, is to look at how Jesus responded to suffering (Weinandy, 2000:35-41; Pembroke, 2006:27-40; Carson, 2010:323-337; Geen, 2010:127-142; Hudson, 2015:116; Pârvan & Cormack, 2017:1-25). Jesus never said, “This is what God wants for your life” or “It is God’s will, accept it”. God shares suffering intimately, entering human grief and weeps with man. This can be seen in the pericope (John 11:1-35) where Jesus was so deeply moved by the death of Lazarus that he wept (John 1:35). This narrative of a weeping Jesus takes one into the suffering heart of God. Jesus was not weeping because of Lazarus’ death, but because of witnessing the pain of Mary and all the others around her. He did not condemn them; he did not tell them to cheer up or that everything was going to be all right. Instead Jesus entered their grief, shared their pain with them and wept with them. It is important to grasp that the God who wants to be friends with human beings, the God whom one meets in Jesus, does not cause suffering to teach lessons because of disobedience. Phrases in moments of suffering and tragedy such as, “God did this to me, I must find the reason”, “God always takes the best” or “It is God’s will” is therefore unjust and must be refrained from. Tragedy forms part of the broken nature of this world. “God is not the author of sin or evil or suffering” (Hudson, 2015:111).

The second example is that of the cross which not only reveals God’s willingness to identify with humanity, but expresses the Trinity’s suffering with and for creation “for the Father and Spirit are themselves only because of their relationship to one another in and through the Son, as He is Himself only in and through the Spirit and the Father” (Geen, 2010:127-142). Through the suffering of Jesus’ death, God will ultimately bring about redemption. For this reason, Moltmann (1993:152) refers to Golgotha as the “theology of hope”.

What then can the PC do during IFCs' moments of anguish and pain? Xu (2016:1394-1410) suggests lessening IFCs' sense of confusion and to improve their sense of hopefulness. The PC can increase IFCs' awareness of how RS may induce trouble and tribulation but also bring about surprising positive outcomes. For Pargament *et al*. (2011:51-76) from a long-term-perspective RS it is likely to relate with growth and well-being. Hudson (2015:116) proposes that those in pain should not cover up their real feelings, not feel guilty about negative feelings toward God but to weep, grieve, "even rage against God". However, all these emotions are worked through with hope because of the knowledge that God weeps with the suffering, shares their grief and understands the rage. More than this is to remember that the God who came to earth in Jesus is the same God who raised His Son from the grave. "Through the crucified and risen Messiah, God whispers to us in our suffering" (Hudson, 2015:117). Hudson's explanation of how to answer the question "Why did God allow this to happen?" may not entirely answer the difficult questions, it cannot take away IFCs' pain, lessen their sorrow, relieve their grief or totally quieten the dark voice tempting them to think that they are alone in their despair. However, the knowledge that God desires friendship and God suffers with humanity can give IFCs the strength to turn away from the dark voice tempting one to doubt. "You know you're finding God when you believe that God is good no matter what happens" (Crabb, 1993:102). Maintaining a friendship with God, having faith in His goodness in times of hardship is not easy. Although circumstances may bring the sufferer to cry out in fear and despair like Job, the relationship remains with "Christ as saviour, God as father, and the Holy Spirit as indwelling comforter and guide" (Crabb, 1993:105). Even more important, IFCs must further say, "I am still looking for Him". Just as Paul longed to enter a deeper relationship with Christ as he knew that he had not yet accumulated all there was to learn about Him (Philippians 3:12-14). The search to a deeper friendship with God will lead IFCs through struggles, setbacks and confusion (Crabb, 1993:105). This will give them the courage to approach the cancer journey as an opportunity to continue to trust that God can transform suffering into an "instrument of value" (Menzies,2004:141-149) and nourish them through the journey (Alexander, 2009:107).

> With God's help, we can look at our suffering through the eyes of Jesus. When we do this, we find ourselves able to say, 'Divine Friend, help me to trust You. I will refuse to believe anything bad about You. Rather, I will trust You weep with us. Indeed, I will trust that You will make all things new (Hudson, 2015:117).

Louw (2012) teaches that the image of God is very important in how IFCs will perceive, react to and act upon hardships in life (the cancer journey) suggesting turning the question "Why?" into "To what purpose?" Hudson suggests rather than asking "Why God?" IFCs must rather get to know God, build a friendship with God through Christ by asking, "Who is God?" For a Godly perception IFCs must enter into a relationship with God and they must know God and His attributes (as seen in the table below).

Box 16: God's attributes by Knabb and Federick (2017)

God's attributes

The Bible reveals that God is:
• Infinitely knowledgeable and wise (all knowing and omniscient): *Great is our Lord and mighty in power; his understanding has no limit.* Psalm 147:5(NIV). • Infinitely loving and good (omnibenevolence as Jesus stated in Mark 10:18 (NIV)): *No one is good--except God alone.* • Active, present and sovereign (omnipresence and omnipotence): *I know that the LORD is great, that our Lord is greater than all gods. The LORD does whatever pleases him, in the heavens and on the earth, in the seas and all their depths. He makes clouds rise from the ends of the earth; he sends lightning with the rain and brings out the wind from his storehouses*. Psalm 135:5-7(NIV).

Source: Knabb & Federick (2017:3)

Psalm 139:1-18 especially captures God's attributes where this powerful passage from David reveals that God truly knows IFCs (given He is all-knowing). What is more, He is everywhere, active and present in IFCs' day-to-day functioning. For this reason, God is always moving within IFCs' inner as well as outer world, even during those times when they feel alone, anxious and uncertain about the future and what lies ahead with the illness. God cares and has their best interest at heart – despite the storms in life. "In fact, because God is all-knowing, all-loving, and all-powerful, He is an especially important ally in your struggles with uncertainty, doubt, worry, and anxiety" (Knabb & Fererick, 2017:3).

For the PC to help IFCs cope with cancer related stress, come to fitting God-images and the quest for meaning and putting meaning into suffering, this study started with acceptance and commitment therapy (c.f. 4.4). ACT offers life-changing answers to difficult questions; it is about acting in a mindful way in order to help IFCs create a rich full and meaningful life, while accepting the pain that it inevitably brings. This study further suggests that the PC working with IFCs can apply ACT by using pastoral life coaching principles within the frame of *cura vitae* to uphold a compassionate yet challenging approach to create a context for difficult emotional work. The next section will discuss how pastoral life coaching can assist IFCs to restructure their lives according to a new and stronger relationship with God through Christ.

5.6 PRACTICES OF RELIGIOUS DISCIPLINES

Religion is defined by Abu-Raiya *et al*. (2016:1265-1274) as "a system of beliefs, practices, values and relationships that help orient and guide an individual through life". "At its most basic level religion is a means of seeking comfort or intimacy with the Divine" (Grossoehme *et al.*, 2011:424). Though significant others and patients can be shaken by life events such as a cancer diagnosis and journey thereof, religious practices can provide the family and patient with a set of potential resources that can be accessed to help deal with the trauma. In the context of the cancer journey, religious beliefs, behaviours and experiences can be important resources and valuable when dealing with the physical, mental and social challenges of the journey.

In a study 88% of cancer cases reported religion to be important to the adjustment of cancer (Ballboni *et al*., 2007:555-560). Oh and Shin (2014:471-483) and Goncalves *et al*. (2015:2937-2949) find that religious interventions were associated with better mental health outcomes by means of the following mechanisms: changing thoughts, promoting greater acceptance of illness and social support, deeper understanding of existence and encouraging belief and faith. Daily religious practices have been associated with better self-assurance and less fear of cancer recurrence (Park *et al*., 2009b:582-591; Park *et al*., 2013:1630-1638). Higher levels of religious beliefs have further been associated with better perceived social support (Howsepian & Merluzzi, 2009:1069-1079; Grossoehme *et al*., 2011:423-432). Religious beliefs also offer a context to integrate difficult life experiences in ways that can help promote better well-being and quality of life (Sherman *et al*., 2009:118-128). Religion can be a source of strength and clarity. When faced with tragedy that cannot be explained, families often seek spiritual support to find meaning in their changed lives (Mc Cubbin *et al*., 2002:103-111; Moules *et al*., 2004:99-107; Björk *et al*., 2005:265-275; Parry & Chesler, 2005:1055-1073; Grossoehme *et al*., 2011:423-432). Studies show that parents of children diagnosed with cancer turn to religious coping methods to ease anxiety and comfort themselves and others within the same situation (Hexem *et al*., 2011:39-44). Older individuals often report greater religious beliefs, including a greater belief in God's existence (Stark, 2008). Women are more likely than men to be religious, engage more frequently in private prayer, and report more spiritual experiences (Maselko & Kubzansky, 2006:2848-2860). These differences are increasingly being verified among cancer cases (Lipscomb & Donaldson, 2003:699-712; Clancy, 2006:589-592; Butt & Reeve, 2012; Snyder *et al.,* 2012:1305-1314).

Religion is multidimensional consisting of several dimensions which include affective dimensions (religious struggle, guilt, spiritual well-being, existential well-being); cognitive dimensions (meaning, cognitive orientation toward spirituality, paranormal beliefs) and behavioural dimensions (religious practices, organisational religiousness, religious involvement; MacDonald, 2000:153-197; Stewart & Koeske, 2006:181-196; Johnson *et al*., 2008:745:767). In this study the focus will fall on the behavioural dimensions of religion, although a short description of the affective and cognitive dimensions will be given.

A) Affective dimensions of religion

This dimension refers to aspects having to do with subjective emotional experiences such as sense of transcendence (cf.7.3), meaning, purpose or connecting to a source larger than the self (Mascaro *et al*., 2004:845-860) where people can find comfort and peace within their religious beliefs (Peterman *et al*., 2002:49-58). People can also struggle with or feel anger towards God (Wood *et al*., 2010:148-167; Exline *et al*., 2011:129-148), experience spiritual distress and feel disconnected from God or their religious community (Exline *et al*., 1999:365-379; Pargament *et al*., 2000:519-543; Pargament *et al*., 2001:1881-1885; Fitchett *et al.*, 2004:179-196).

B) Cognitive dimensions of religion

This dimension typically focuses on the concept of religious beliefs which are often grounded in doctrinal foundations or a particular faith tradition. With beliefs several aspects must be kept in mind including the strength of the belief and how literally or nonliterally the beliefs are held. Beliefs less bound to a particular doctrine involve illness perceptions, believing that God is in control of health, determining health outcomes (Franklin *et al*., 2008:323-335) and believing in miracles (Mansfield *et al*., 2002:399-409). This dimension also includes religious doubts (Salsman *et al.*, 2015:3754-3759).

C) Behavioural dimensions of religion

This dimension refers to practices or behaviour. The well-known book of Richard Forster, *Celebration of Discipline (1998)* is an example of the various behavioural dimensions found in religion. These practices often form part of one’s daily routines, such as public activities (service attendance) and private activities (prayer, meditation). Sometimes these behaviours serve the purpose of managing stress, illness demands, and life events specifically related to cancer with the purpose of reducing negative outcomes such as depression, anxiety, worry, poor quality of life, and disrupted relations with family and friends. Other examples of religious behaviour include coping by seeking a closer connection with God, pursuing religious problem-solving strategies, or believing that God will resolve the stressor (Pargament *et al*., 2011:51-76).

High rates of daily prayer, meditation and religious study highlight the importance of religion in coping with cancer (Pargament *et al*., 2000:519-543; Balboni *et al*., 2007:555-560). Studies on prayer note that prayer brings about positive effects, personal integration and well-balanced self-expression, also countering depressive feelings and eases stress (Spilka, 2005:365-377). In the context of stress and suffering, religion communicates a continuing achievement of meaning, formation and connectedness that encourages flourishing (Lee, 2018:114). Practices that proved to bring a sense of calm and comfort include prayer, personal and group worshipping, and spending time in church (Schneider & Mannell, 2006:3-24) of which prayer is the most general religious practice among individuals facing illness (Balboni *et al*., 2007:555-560; Alcorn *et al*., 2010:581-588) and a means regularly used by individuals to help them endure and find meaning within the context of the illness (Alcorn *et al*., 2010:581-588). For Christ prayer was an instrument of healing power (Mark 9:29). Around 66% of cancer patients report using prayer to help them cope with the illness (Ross *et al*., 2008:931-938).

Coping styles for comfort or intimacy with God include searching for comfort or reassurance through God’s care, taking part in religious activities to shift one’s focus away from a stressor and searching for spiritual cleansing through actions (Grossoehme *et al*., 2011:423-432). In how to grow in a new and strong friendship with God, Hudson (2015:77-78) suggests three gospel addresses. Firstly, and the most basic but also continuous and everlasting activity is learning how to pray. Together with the second activity to be on a mission of getting to know Jesus through the gospels. The third activity is to regularly share in the worship life of a community that celebrates communion. It is the adventure of finding soul-friends to join one on one’s life journey and the brave and compassionate undertaking to open one’s life and heart to fellow sufferers.

To deepen a relationship with Christ the following practices will be discussed. Starting with a unique way of reading Scripture (*Lectio Devina*), followed by Keating’s (2007) method of centring prayer and Hudson’s (2012) Serenity Prayer and lastly the effects of gospel music.

5.6.1 *Lectio Divina*

Divine reading in Latin, *Lectio Divina,* is an ancient spiritual practice, placing focus on developing a heightened awareness and self-reflection by meditative reading of biblical texts (Trammel, 2015:165-177). It is the skill of listening to God’s word as if in conversation with Christ where He suggests the topics to be discussed. This daily encounter with Christ and reflecting on texts lead beyond mere acquaintanceship to a space of trust, love and friendship. Gregory the Great refers to it as “resting in God” (Keating, 2017). *Lectio divina* consists of four phases (Howard, 2012:56-77):

- *Oratio*: calling on the Divine
- *Lectio*: reading a text
- *Meditatio*: contemplate on the text
- *Contemplatio*: practise listening, becoming one with the text

Keating (2008:47) explains that the purpose of divine reading is to “interiorise the truths of faith so that we can understand them at the level of the heart, as well as the level of the mind”.

According to Dalal (2009:22), “contemplation cannot be separated from listening to the texts”. In this practice, the reader must firstly make a conscious effort to engage with the sentences through listening or contemplation, and secondly allow the texts “to do their work”. On the practice of *Lectio Divina,* Smith (2009:108) explains that the exercise requires a specific way of reading the Bible “that involves listening with the heart”. Instead of studying Scripture with the intention of understanding the meaning of the text, *Lectio divina* studies the reader. Reading selected texts pausing at specific places while concentrating on selected words. *Lectio,* involves only a few verses that are read repeatedly, slowly and contemplatively while reflecting on each word and phrase which allows the reader to become still and aware of God’s presence opening to the possibility of God speaking to the reader through the text. During this time the reader is mindful of the impact that the words have on his or her heart. In other words, the reader is “praying the Scriptures” (Smith, 2009:108).

Box 17: Nine steps of *Lectio Divina* by Smith (2009:109)

Nine steps of *Lectio Divina*

PHASE 1: *Oratio* - calling on the Divine
Step 1: Select a passage from the Bible.
Step 2: Take a few minutes to relax while breathing deeply.

PHASE 2: *Lectio* - reading a text
Step 3: First reading.

- Read the selected passage slowly, pausing between phrases.
- Be silent for a few minutes.

Step 4: Second reading.

- Read the selected passage again slowly using longer pauses between phrases.
- Be mindful of any of the words or phrases that stand out.
- Make mental notes of those words or phrases.
- Write the selected words or phrases down.

Step 5: Third reading.

- Have a second look at the word or phrase up to the part that stood out.
- Stop there and repeat those words or phrase a few times.

PHASE 3: *Meditatio* - contemplate on the text

Step 6: Pondering.

- Reflect on the chosen words or phrase.
- Repeat the words or phrases a few times to allow it to interact with thoughts and memories or any other Bible passages that come to mind.
- Let it touch the heart, desires as well as fears.
- Begin to wonder, “What might God want to say to me specifically?”

PHASE 4: IV *Contemplatio* - practise listening, becoming one with the text

Step 7: Prayer.

- Turn above question into a prayer asking God: “What is the word you have for me in this passage, God?” / “Is there anything you want to say to me today?”
- Listen and write anything that God might be answering down.

Step 8: Rest: (the step from doing to being).

- Be still and silent for a moment.
- Take God’s presence in.

Step 9: Response.

- Ask self and God, “What am I being called to do as a result of the word I have been given?”

Source: Smith (2009:109).

Lectio Divina as one of the most traditional ways of nurturing a friendship with Christ also forms the root of Centring prayer.

5.6.2 Centring prayer

The theological basis of Centring Prayer is Jesus’ intimate experience of God as *Abba* (Mark 14:36), his teaching of the prayer in secret (Matthew 6:6), and the final discourse of the Gospel of John, describing the divine indwelling (John 17:21–23: Ferguson *et al.,* 2010:309).

Centring prayer is one of the practices well described by Keating (1999:31, 32), which aims to bring unity with God in order to improve the ability to be silent, hear God and be filled with the Spirit. Keating (1997) teaches that people form a false sense of self throughout their lifespan. Beginning during the first year of life the child starts to develop a sense of self-dependend on the need for three ingredients:

a. Safety: comfort, security, connection.

b. Self-worth: positive attention, striving to be affirmed and valued.

c. A sense of control and power.

When these three needs during early years are not met by the child's primary caregivers, the child as adult can constantly search for someone to offer them safety; they crave positive attention, strive to be affirmed, valued and struggle to see that they were created in God's image with infinite worth (Matthew 3:17). Furthermore, they try to maintain at least some control over their personal world which can manifest to domination or avoidance. In cases where IFCs struggle with these childhood deprivations, a cancer journey and caregiving tasks can leave IFCs especially depleted and more inclined to take on an identity as caregiver. These three ingredients can further get in the way of a relationship with God. "Based on the notion that the God of the Bible is all-knowing, all-loving and all-powerful, unilaterally pursuing safety, self-value, and control can lead to disappointment, resentment and regret" (Knabb & Frederick, 2017:72-73). Centring prayer can assist in helping IFCs to relinquish their grip on these three components of the false self, allowing them to surrender to God's active, loving presence. Knabb and Frederick (2017:73) believe that by "letting go and trusting in God's wisdom", people are preparing themselves to find their true identity in God.

The contemplative form of prayer, known as centring prayer which is built around a relationship with God is a responsive model of surrendering to God's loving presence and healing action within (Ferguson *et al.,* 2010:306, 310). It is a method to divert attention from the ordinary flow of thoughts, in order to awaken faith. Thoughts in the context of centring prayer is any perception to arise in the consciousness, whether a body sensation, feeling, emotion, image, memory, plan, concept, reflection, psychological breakthrough or spiritual experience (Keating, 2006:122). Contemplative prayer goes beyond thoughts, words and emotions. It also opens the mind and heart (the whole being of a person) to God. "We open our awareness to God whom we know by faith is within us, closer than breathing, closer than thinking, closer than choosing – closer than consciousness itself" (Keating, 2007). Centring prayer can therefore be summarised as a process of inner purification leading to divine union. During prayer one consents to God's presence and action within while at other times attention moves outward in order to recognise God's presence (Keating, 2006:122).

The battle during early stages of contemplative prayer is within one's thoughts. For this reason, it is important to find quiet times of the day away from distractions and foreseeable interruptions. Although one wants to be quiet, wandering thoughts form part of nature, it will happen. Accept this fact and know the thoughts will come. When distracted with a thought or feeling, one must simply acknowledge the experience and gently return focus back to the sacred word. The sacred word stands for the symbol of one's intention to surrender one's will to God (Ferguson *et al.*, 2010:311). The word must be one to two syllable(s) long, meaningful and sacred such as "Jesus", "Peace" or "Yes". The solution is not a blank mind or using the sacred word as a mantra to achieve an enlightened state. Gently returning to the sacred word is to reaffirm the choice to converse with God and to be united with Him. This does not demand effort but surrender. In other words, returning to the sacred word must be done without exasperation or desperation. The sacred word represents the willingness to focus on God, letting go of one's own efforts to understand Him through cognition and affect only (Keating, 2006:120-122; Knabb & Frederick, 2017:4). The aim is to learn in time to rest in God's presence, finding comfort during this time with Him and letting go of the tendency to chase or push distressing thoughts, feelings and sensations away (Knabb & Frederick, 2017:4) especially the uncertainty, doubt, worry and anxiety IFCs may experience during a cancer journey. Adapting to a new routine after a cancer diagnosis, IFCs can have a difficult time to break away from the caregiving tasks and extra daily chores to spend time with God in solitude and silence.

From the perspective of Knabb and Frederick (2017:75), "centering prayer is important for both psychological and spiritual development because it involves stillness and silence". Practising the prayer (pausing for a moment) IFCs may come to find peace within the silence, which can grow into a deeper relationship with God and lessen anxiety. Knabb and Frederick (2017:75-76) believe that centring prayer is all about finding rest, slowing down to rest in the arms of Jesus as one gently returns to the sacred prayer word.

The source of centring prayer is the indwelling Trinity: Father, Son and Holy Spirit making the focus of centring prayer the deepening of a relationship with Christ (Keating, 2007). The prayer is about opening to God, surrendering and declaring "Here I am, fill me". Knabb and Frederick (2017:4) believe that centring prayer can help a person (IFC) relate differently to distressing inner experiences (anxiety, fear, anger, questions) by learning to sit at the feet of Jesus (Luke 10:38-42). Christian contemplatives enquire, "Are you your thoughts and feelings?" proposing that people are not, rather recommending a shift from "God, I am anxious" to "I have a feeling that I am anxious, and, in my anxiousness, I worship God" (Laird, 2006:77). In essence, it is about trusting in God's providence (His active loving presence) in the world. Matthew 6:25-34 teaches the believer that God cares for them, actively intervening in their lives with infinite knowledge and wisdom, love and goodness, presence and power (Knabb & Frederick, 21017:18). Laird (2006:3,8) describes the prayer as "the practice of silence", "the silence of surrender", and "interior stillness", observing that the prayer is about the "surrendering of deeply embedded resistances that allows the sacred within gradually to reveal itself as a simple, fundamental act”. For Muto (2013:84) contemplation is all about recommitting to Christ in body, mind (thoughts) and spirit. Conley (2014:24) defines contemplation as “simply to be alone with the Spirit”. Acceptance according to Heuertz (2017:183) is one of the gifts living a life of contemplation. The practice of letting go teaches one to accept all that is good within together with the wisdom of working though hardships. Muto (2013) and Heuertz (2017) agree that contemplation is a lifetime of surrendering of those desires that stand between people and full surrender to God. Contemplating on God’s word, practising to surrendering to God and being still in his presence will allow time and space for the Holy Spirit to change thoughts to the truth of Scripture.

Box 18: Guidelines for Centring Prayer

The method of Centring Prayer

*Be still and know that I am God (*Psalm 46:10)

Four guidelines

I. Sacred word	II. Surrender	III. Focus	IV. Remain in silence
Choose a sacred word as the symbol of the intention to surrender to God’s presence and work within.	Sit comfortably; close the eyes; settle briefly and silently introduce the sacred word as the symbol of surrendering to God’s presence and action within.	When one becomes aware of thoughts, gently return to the sacred word.	Remain in silence at the end of the prayer with closed eyes for a couple of minutes

Explanation of the four guidelines

I. Sacred word

- Using a sacred word shows the aim of being in God’s presence and surrendering to divine action.
- Choose the sacred word during a brief prayer asking the Holy Spirit for inspiration. Examples of sacred words include: Lord, Jesus, Abba, Father, Love, Peace.
- Do not change the sacred word once it has been chosen.

II. Surrender

- Sitting comfortably enough to avoid feeling uncomfortable during the time of prayer, but not so comfortable to encourage sleep.
- The back must be straight regardless the sitting position.
- In case of falling asleep, continue the prayer for a few minutes when awake (if time permits).
- Close the eyes and let go of activity around and within.
- Gently introduce the sacred word inwardly.

III. Focus

- Thoughts are a normal part of Centring prayer and they include all perceptions for instance sense perceptions, feelings, images, memories, reflections and commentaries.

- During Centring prayer, the only activity initiated is “returning ever-so-gently to the sacred word”.
- While praying, the sacred word can become vague or even disappear.

IV. Remain in silence

- At the end of the prayer time an additional 2 to 3 minutes must be allowed in order for the psyche to readjust to the external senses and enable the person to bring the atmosphere of silence into their daily life.

(Keating, 2007).

Practical points of Centring prayer

- The minimum time for the prayer is 20 minutes.
- Two periods each day are recommended, one first thing in the morning, and the other during afternoon or early evening.
- The end of the prayer time can be indicated by a timer (avoid audible tick sounds or a loud sound when it goes off).

(Keating, 2007).

Centring prayer can help accomplish two imporant tasks

In an effort to relate differently to worry and anxiety centring prayer can:

Firstly: Assist in letting go of own efforts to get certainty which can escalate worry and anxiety.
Secondly: Assist in finding rest, learning to trust in God, acknowledging and surrendering to God’s active presence.

In summary, centring prayer can help with the improvement of both psychological and spiritual functioning as one gains greater awareness of God’s active, loving presence from moment to moment. Consistent with Jesus’ teachings on worry in Matthew 6:25-34, IFCs will turn their focus on God in the present moment, who will sustain them and carry them along their paths of life.

(Knabb & Frederick, 2017:4),18.

Centring prayer is NOT	**Centring prayer IS**
During the prayer avoid analysing the experience, harbour expectations or aim at specific goals such as: • Making the mind blank. • Achieving a spiritual experience. • Having no thoughts. • Feeling peaceful or consoled. <u>It is not a:</u> • technique. • form of self-hypnosis. • para-psychological phenomenon. • discursive meditation or affective prayer. • relaxation exercise. • charismatic gift.	• About trusting in God’s active, loving presence, beyond words. • Surrendering to God, letting go of own efforts. • A symbol of willingness to consent to God in the present moment, focusing exclusively on Him in the here and now. Staying rooted in the present moment. • Developing the ability to spend time with God in solitude, without using words, thoughts, images and emotions to guide the relationship with Him. • Finding rest in God, despite an uncertain future. • Reaching out to God in love instead of knowledge. • Letting go of own attempts to dictate God’s pace and timing, own efforts to reach God instead trusting God’s mercy and grace. (Knabb & Frederick, 2017:71).

The effectiveness of the prayer does not depend on how distinctly the sacred word is said or how often repeated, but rather on the gentleness with which it is introduced in the beginning and the promptness with which one returns to it when mentally or emotionally engaging with thoughts. (Keating, 2006:120;122; 2007).	• A relationship with God and a discipline to foster that relationship. • An exercise of faith, hope and love. • Orientating the self to God's language which is silence. • A method of directing one's attention "from the particular to the general, from the concrete to the formless". (Keating, 2006:120-122).

Source: Author compiled table from relevant literature

5.6.3 Serenity Prayer

God grant me the serenity to accept the things I cannot change;
courage to change the things I can;
and wisdom to know the difference.
Living one day at a time;
enjoying one moment at a time;
accepting hardships as the pathway to peace;
taking, as He did, this sinful world as it is, not as I would have it;
trusting that He will make all things right if I surrender to His Will;
that I may be reasonably happy in this life and supremely happy with Him forever in the next.
Amen.

Niebuhr (1980), the author of *The Serenity Prayer* used various versions of the prayer in sermons as early as 1934. The prayer rapidly spread through church groups during the 1930s and 1940s and was adopted and popularised by Alcoholics Anonymous (Shapiro, 2014; Siegfried, 2014; Crosswalk.com, 2017). Siegfried (2014) describes the words of the prayer as uncomplicated but meaningful and regularly cite the prayer for herself, her co-workers and her patients.

As Hudson (cf. 5.5) explains, humanity is called to friendship with God. This request for friendship can be found in various books of the Bible, such as in 2 Chronicles 20:7 and Isaiah 41:8. In James 2:23, Abraham is referred to as "the friend of God" (NLT), while Exodus 33:11 calls Moses "God's friend" (NLT). In the New Testament, this friendship with the spiritual elite spread to ordinary people which can be seen in John 15:15, where Jesus informs His disciples that they will no longer be called His servants, but His friends (Bondi, 1997:99-101). The factor that makes humanity human, according to Uwineza (2018:75-89) is that people are able to enter into a relationship with God "it is the realisation that only God and nothing else can be our fulfilment, and that nothing about who we are is outside our relationship with God" (Uwineza, 2018:79). Using the Serenity Prayer this divine companionship can reach moments of deep communication, knowing that God who delights in the company of humans, acts wisely and carefully in order to create the largest good possible in all circumstances (Romans 8).

According to Sistler & Washington (2008:49-62), this friendship with God can greatly benefit IFCs who often focus more on the needs of the diagnosed person, than their own. Going on to explain that the Serenity Prayer can assist IFCs to manage their caregiving role more effectively by recognising what can change (their reaction to stressful situations during the cancer journey), cannot change (cancer diagnosis and the progression of the illness), how to deal with the cancer journey and their emotions, as well as where they stand in their religion and build a relationship with God. In other words, although IFCs may not be able to control the diagnosis and progression of the illness (primary control), they can control their cognitions and emotions (secondary control; Sistler & Washington, 2008:49-62). The Serenity Prayer can also be beneficial to the PC, where especially the third section "and the wisdom to know the difference" can prevent burnout (Yanagisawa, 2015).

The PC can assist IFCs by teaching them the value of the Serenity Prayer by using Hudson's (2012) guidelines and how to apply three truths from the Bible compiled and edited by Crosswalk.com (2017):

Box 19: The Serenity Prayer explained by Hudson (2012)

1. God, grant me the serenity

The word serenity goes far beyond being happy or having peace of mind or knowing inner contentment or not experiencing conflict. It is a peace that only God can give, a spiritual peace that lasts and cannot be taken away through hardship, providing an inner assurance that ultimately all will be well. Therefore, "God's peace is a peace that goes beyond all human understanding, it cannot be grasped by the intellect alone but must be experienced in our hearts" (Hudson, 2012:26). In order to receive the gift of peace from God IFCs must enter into a trusting relationship with God, only then will the gift of peace be planted within like a seed by praying the Serenity Prayer. According to Uwineza, (2018:76), "human beings have an orientation towards God, the Absolute, the Ultimate, and this is what offers them the possibility of hearing and participating in God's revelation". This does not mean that IFCs will instantly be filled with a deep and inner peace. Practising the Serenity Prayer will require IFCs to face their journey with cancer (sources of un-peace), changing their thinking processes and lives while working for peace in the practical realities of their daily lives living with cancer.

The depth of this peace can is seen in John 14:27(NIV) in Jesus' words to His followers just before He was put to death.

Peace I leave with you; my peace I give you. I do not give to you as the world gives. Do not let your hearts be troubled and do not be afraid.

2. To accept the things, I cannot change

A cancer diagnosis is an example of a situation that cannot be changed leaving the diagnosed person and significant others powerless over it. The first request of the Serenity Prayer is acceptance, a kind of acceptance that seldom comes easily. For this kind of acceptance, IFCs will need all the grace, help and power that God can give. During the cancer journey the Serenity Prayer can "become a close friend". Praying it during times of fear, anger, regret and loss is not denying one's emotions or pretending to be calm. Emotions need to be acknowledged and felt; losses need to be mourned. "Befriending" these emotions can lead IFCs on a healing path towards a deeper peace.

(Hudson, 2012:29-35).

3. Courage to change the things I can

Inner change can only happen once IFCs face what need to be changed. Examples of what can possibly rob IFCs of their serenity during the cancer journey is the desire to always be in control, to be a perfect caregiver. Wanting everything to be perfect and planned out is not realistic while trying to find a “new normal” and living with the unpredicted ableness of the illness and effects of the treatment. Until IFCs can overcome the deep-seated tendencies to deny their shortcomings (being in control, being perfect, not asking for help, not accepting their emotions) they will not be able to experience inner change. The journey to self-honesty entails a few steps that IFCs can embark on:

- Being quiet on a regular basis, asking God to search their hearts.
- Reflecting on instant reactions towards self and others (especially those actions that can be harmful).
- Searching for what aspects of self and others are criticised.
- Asking loved ones and friends how they changed during the cancer journey.

This inner change can only happen through the work of the Holy Spirit. Ridding the self of possible defects requires special effort from IFCs without doing God’s job for Him. IFCs must acknowledge what aspects of the self require change and express to God the desire to change. Only God can be IFCs’ “heart transformer”. (Husdon, 2012:37-43).

4. Wisdom to know the difference

Especially during hardships finding the best way forward is not easy. During these times one needs wisdom, which is exactly what the Serenity Prayer invites one to pray for. The wisdom needed during a cancer journey goes deeper than knowledge. Cambridge dictionary (2020) defines knowledge as “understanding of or information about a subject that you get by experience or study”. Wisdom is defined as “the ability to use your knowledge and experience to make good decisions and judgments”.

Becoming wiser entails, a three-step process of discernment:

1. Ask God:

Wisdom is a gift from God, something one needs to pray for. James 1:5 (NIV) *If any of you lacks wisdom, you should ask God, who gives generously to all without finding fault, and it will be given to you*. This guidance in question usually comes gradually, “God gives us just enough light to keep us walking” (Hudson, 2012:49).

2. Listen to thoughts and feelings:

Consciously pay attention to what goes on in one’s life, mind and heart. Write it down and reflect on it. God’s voice usually comes through by inner promptings, so unless one listens carefully to what happens within the whispering of the Spirit can be lost to inner noise. Repeat the prayer and continually remind the self that, “God is totally good, totally loving, and totally competent” (Hudson, 2012:50).

3. Decide:

Imagine seeing the self-making one possible decision.

- Envision the self-continuing to live in the current situation without changing anything. Hold this image for a few moments and let it fade. As it fades become aware of emotions.
- Next, imagine pursuing a different way by trying to change the situation in some way. Imagine the self-trying utmost best to make some sort of difference. Hold the picture before letting it fade and again monitor the response. Is it feelings of peace, anxiousness or uneasiness?

A deeper peace will rest on the decision that God wants one to make coming through as a “quiet steady peace of serenity” no excitement or thrills.

4. Living one day at a time

The nightly review is a habit that can help IFCs live one day at a time.

Step 1: Make time to be quiet for a few moments.
Take a few deep breaths to settle down.
Invite God to be with you and to shed light on the past day.

Step 2: Ask God to recall one moment of the day for which you can be most grateful, the moment that gave the most of life or when you received or gave the most love.
If one moment of the day can be recaptured, which one would it be?
Relive this moment.
Breathe in the gratitude you felt and thank God for it.

Step 3: Ask God to recall the least grateful moment, the most draining moment or moment that one received or gave the least love.
Reflect on what was said and done that made the moment so hard.

Acknowledge your emotions about the experience.
Refrain from judging the self.
Share these emotions with God and let God’s love fill you again.

Consistently practising the night review can help IFCs embark more creatively on their caregiving tasks and the cancer journey helping them to live one day at a time. Although the Serenity Prayer teaches one to live just for today it does not suggest that IFCs stop setting goals or that they must quit planning for the future. It simply expresses the desire to focus on the present day allowing one to absorb most of one’s energy, effort and interest. When IFCs start to live in the present moment they will be able to build better foundations for the future, as well as knowing that the past has been lived well.

(Hudson, 2012:55-61).

5. Enjoying one moment at a time

Asking God to help one to live one moment at a time is an invitation to savour the present moment, immersing the self in it and living it to the fullest. It is a reminder that living with a sense of immediacy, there are gifts to be discovered, and one of these gifts is God’s peace. “Enjoyment of the present moment and the genuinely peaceful heart go together.”

The importance of the here and now:

1. It is all that one has. The past can be remembered and future imagined, but one cannot live in either. It is within the present moment that life connects with life making the present moment precious. For IFCs to be preoccupied with the “what ifs” of the past and dwelling on the future they disconnect themselves from the present moment where their loved one is still with them, missing opportunities to build memories and treasure moments.
2. The here and now is the place where God meets His people. “We encounter God in the present, or we don’t encounter God at all”. The gift of peace is received only in the immediacy of the present moment, whatever that moment may be like (glad or sad, high or low, difficult or easy). One can only be in God’s presence in the here and now.

God wants to bestow His gift of peace on His people, but to receive it one must slow down, live gratefully and accept that there is only one life to live. The Bible encourages its readers to see their physical lives as *a mist that appears for a little while and then vanishes* (James 4:14 NIV.)

(Hudson, 2012:63-70).

6. Accepting hardships as the pathway to peace

Life can be hard, a place where no one can escape pain, grief or loneliness. Sooner or later troubles come to all in the shape of external difficulties (cancer journey) as well as internal difficulties (depression, anxiety, fear, anger). There is one of two choices to be made. On the one hand avoidance and on the other hand acceptance (Serenity Prayer).

The encouraging news is that God is deeply present in all the facets of life, especially during hardship. The Bible teaches that there is *one God and Father of all, who is over all and through all and in all* (Ephesians 4:6 NIV). There is no fear, loss, grief, loneliness, despair or suffering that God does not intimately share in. God is continually present and reaching out in whatever circumstances one may be going through at this moment. Knowing that God is with them (even when their worlds are falling apart) IFCs can find the strength to face the pain of the situation with hope and courage.

The Serenity Prayer encourages people not to run away from hardship because it is in this space that the suffering God draws close to the person. In trying to escape hardship one can easily miss the gifts God so generously wants to bestow upon people such as peace, serenity and growth.

IFCs must learn to be gentle with themselves asking God for the strength to take constructive and creative action in those moments when they are tempted to give up. These acts can be ordinary and small such as walking around the block, having a cup of tea in a quiet place of the garden or phoning a good friend (passive diversions like reading or watching television is not enough to rouse from the darkness).

(Hudson, 2012:71-78).

7. Taking as He did, the sinful world as it is, not as I would have it

This part of the prayer begins by acknowledging the reality of a sinful world. It also proposes that one should adopt an attitude toward it (as God relates to the world). When faced with evil and hardship one can learn to reflect God’s attitude. God accepts human beings unconditionally, discerns between the sinner and the sin,

and desires that as much goodness as possible be infused into human life. As one follows God's attitude and example one takes the world as it is and not as one would want it to be.
(Hudson, 2012:79-87).

8. Trusting that He will make all things right

Even through hardship like a cancer journey, IFCs can become whole and fruitful again with the help of God. *And we know that in all things God works for the good of those who love him, who have been called according to his purpose* (Romans 8:28).
God wants to take everything that has happened and use it for good, even the painful times like a cancer diagnosis and the journey thereof. Every detail given to God can be reworked into something beautiful. The Serenity Prayer challenges IFCs to take this promise seriously, asking them to live each day to the fullest trusting that God will make everything all right. This is not easy though, there are strong forces in an around one's life that work against having a genuine, confident trust in God. In the end IFCs must realise that authentic faith comes as a gift from God. With this they must place themselves on the path of trust. This can be accomplished with three steps:

1. Learn who God really is (God image):

To commit to God whole-heatedly IFCs must first truly believe that God is good and trustworthy. Pârvan and McCormack (2017:1-25) describe the nature of God "as a particular kind of love". *God is love* stands on its own in 1 John 4:16 (NIV) as a description of God's nature (an identity statement). Paul teaches in Philippians 2:7 that this kind of love is a self-giving and self-emptying love (Pârvan & McCormack, 2017:1-25).

2. Spend time with other believers:

By connecting with other trustees (family members, friends, cell groups, prayer groups, and church communities) IFCs will discover that trust produces trust. At times where the flame of faith starts to flicker and sometimes even go out IFCs must spend time with others who have also walked through dark valleys and kept their trust in God.

3. Act:

Have daily conversations with God about concerning issues that cause anxiety. Experiencing God's help in these situations deepens one's trust in God.
Regularly meditate on some of the ideas Jesus teaches about God. For example, dwell on the fact that God loves humans unconditionally, centring prayer. Over time (weeks, even months) this truth will sink deep into one's heart to become a real part of one's life.
(Hudson, 2012:89-96).

9. If I surrender to His will

To receive God's gift of peace IFCs must find and do God's will. Everyone has been created with certain gifts (one's uniqueness) placed within by God the Creator. Finding and doing God's will consist of two elements:
1. God's will for humankind is to live a full, loving and as honest as possible life. This involves using and developing one's gifts, giving love priority and walking in the light. The Bible teaches that God is both love and light (1 John 1:5).
2. Personal calling is a lifetime adventure because it changes with the different seasons of one's life. Finding God's will assumes a living relationship with God. Finding God's will not only nourish the individual but also enriches the lives of people around one (a season of IFCs life for example is being a caregiver for a loved one during a cancer journey).
Walking closely with God through the cancer journey, living in the present and finding one's unique gifts will not only nourish IFCs during their caregiving duties but also the diagnosed loved one and rest of family.
(Hudson, 2012:97-106).

10. That I may be reasonably happy in this life

The line about being reasonably happy follows - trusting that He will make all things right if I surrender to His will. This sequence suggests that the more one trusts that God can bring good from hardship and the more one surrenders the self to God's purpose, the happier one will be.
According to Hudson (2012:107), one of the most important questions one can ask is "How happy am I?" and to others "How happy are you?" The pursuit of happiness is universal, through the ages is has been maintained that God created humans to be happy. Happiness in this regard refers to a "deep sense of inner well-being and contentment, the experience of being fully alive to ourselves, to others, and to God" (Hudson, 2012:107).

Fretheim, (2012:5-38) also addresses happiness, stating that happiness is a gift from God to human beings. The most evident example is humans as created in God's image. "Because God's life is characterised by happiness, those made in God's image are also so gifted", for this reason it is God's will for humans to be happy (Ecclesiastes 5:18-20). According to Peterson (2017:71-74), "our very existence, begins and ends with joy. And between the beginning and the conclusion there is joy". Jesus said it in John 15:11 and Paul wrote to the Philippians (1:25) about what he called *joy in the faith* (NIV). The book of Ecclesiastes teaches about joy as God's creation and gift. For Peterson (2017:71-74) "the foundational human appetite is for God".

According to Hudson (2012:109), one of the biggest mistakes people make in their search for happiness is always the insistence on being happy at all costs and all the time. Once people realise that it is unrealistic to be happy all the time it encourages them to pray for reasonable happiness in this life. There is a time and place for happiness and sorrow, for laughter and joy, but also for tears and sadness. God's work turning hardship into something good can take away sorrows, cares and broken-heartedness, so that happiness can include healing (Fretheim, 2012:5-38). Fretheim, (2012:5-38) further notes that it is not helpful to speak of total or perfect happiness. Although humans are gifted with happiness it can never be fulfilled or totalised in this lifetime.

Happiness just like serenity originates within the self. Although external factors do influence people for better or worse, it is temporary. To find enduring happiness one must take a deep look at what happens on the inside. During a cancer journey IFCs often feel ambushed by feelings and emotions that threaten to destroy their happiness. For reasonable happiness in this life, they will have to deal with these emotions as creatively and responsibly as possible. Instead of feeling overwhelmed with emotions or avoiding them IFCs need to identify and name them. Then they need to share these emotions with God and ask God to teach them how to live best with it.

True happiness is another gift from God "a freely given by-product of a particular way of life that comes to us when we stop seeking it".

(Hudson, 2012:107-114).

11. And supremely happy with Him forever

Ideas about death and what comes after death are critical. These perceptions have an effect on one's life in this world. The Serenity Prayer offers three important thoughts about what life in heaven will be like:

1. In heaven a depth of happiness will be experienced beyond all comprehension, enjoying supreme happiness, hearing Jesus's words *Come and share your master's happiness* (Matthew 25:21 NIV).
2. In heaven one will be with God, there will be no isolation.
3. In heaven one will become an unceasing spiritual being.

(Hudson, 2012:115-121).

Source: Author compiled table from Hudson (2012)

Box 20: Applying three truths from the Bible compiled and edited by Crosswalk.com (2017)

Three biblical truths that can be applied to the short version of the Serenity Prayer	
"God grant me the serenity to accept the things I cannot change."	When life feels out of control due to a cancer diagnosis of a loved one, it is easy for IFCs to take charge and control the situation. The other extreme is to avoid the situation and choose not to be part of the cancer journey (cf. 5.3). Peace and serenity will continue to move further from IFCs life if choosing these negative methods to manage the stress of a cancer journey. Accepting, submitting and committing to God's plan (cf. 5.2.1.3) for one's life journey is the only way to find peace during hardships. Although God's plan is not always clear IFCs can let go of trying to be in control and letting God work through them. God promises a supernatural peace when worries and concerns are brought to Him in prayer. • Phillippians 4:7(NIV) *And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus.* • Psalm 46:10(NIV)

	Be still and know that I am God.
“the courage to change the things I can,”	Once IFCs have accepted Jesus Christ as their saviour, they receive the power of the Holy Spirit. Through the Holy Spirit IFCs will receive the courage to follow and act upon God’s plan for the situation. Instead of fearfully ignoring hard decisions or running from difficult situations IFCs can call upon God’s power. • Deuteronomy 31:6 (NIV) *Be strong and courageous. Do not be afraid or terrified because of them, for the LORD your God goes with you; he will never leave you nor forsake you.* • 2 Timothy 1:7 (NIV) *For the Spirit God gave us does not make us timid, but gives us power, love and self-discipline.* • Proverbs 3:5-6 (NIV) *Trust in the LORD with all your heart and lean not on your own understanding; in all your ways submit to him, and he will make your paths straight.*
“**and, the wisdom to know the difference”.**	Wisdom is a gift from God to those who ask for it. More wisdom is sustained each day with the wiser decision-making process as IFCs spend time with God by reading the Bible, praying and worship. God gives answers through the Bible or prayers, when to accept circumstances and when to be courageous to change it. • James 1:5 (NIV) *If any of you lacks wisdom, you should ask God, who gives generously to all without finding fault, and it will be given to you.* • 2 Timothy 3:15-17 (NIV) *and how from infancy you have known the Holy Scriptures, which are able to make you wise for salvation through faith in Christ Jesus. All Scripture is God-breathed and is useful for teaching, rebuking, correcting and training in righteousness, so that the servant of God may be thoroughly equipped for every good work.*

Source: Crosswalk.com (2017)

The following section will focus on the power of music as a gift from God and the possible benefits that music can have on IFCs to help them cope with cancer related stress.

5.6.4 Worship

> Music, it will be claimed, intones the meaning of being human. In the Christian tradition, music is central to liturgy and worship. From its roots in the New Testament, through its approval or prohibition by the Church Fathers, to the Puritan purges, the Classical liturgical commissions, and the revivalist celebrations, sacred music continues to be a means of negotiating the relationship between human selves and the sacred (England, 2017:18-40).

The combinations of music individuals are exposed to are endless depending on family background, culture, religion, personal preferences, different seasons of one’s life, *et cetera*. Because of this, the music individuals enjoy, either by listening to or actively playing, differs greatly. Despite these differences music provides and provokes a response, which is universal, ingrained into mankind’s evolutionary development with the ability to cause noteworthy changes in emotions (Trimble & Hesdorffer, 2017:28-31). Ruff (2007:4) starts his book on sacred music claiming that music is powerful. According to Foley (1984:2), “from time immemorial, the belief has persisted that music contains power to alter the moods and actions of gods and people.” Linman (2010:66) quotes the ancient saying by Augustine “the one who sings, prays twice”, saying that music deepens prayer as the “embodied qualities of music-making carry the Word into ourselves and employ multiple dimensions of our physicality and experience”. Music played a central role in Martin Luthers’ life. Luther (1965:321-324) regards music as a gift from God that makes known God’s word, going on to say that once people realise what God has done for them in Christ, they “must gladly and willingly sing” (Luther & Hazlitt, 1965:129-333), famously and often stating that music is next to theology (Derken, 2019:49-55). Luther writes to composer Sudwig Senfl saying “except for theology there is no art that could be put on the same level with music, since except for theology, (music) alone produces what otherwise only theology can do, namely, a calm and joyful disposition” (Quoted in Leaver, 2006:125). God’s gift of language together with song was given so that people “should praise God by proclaiming (God’s word) through music” (Luther, 1965:321-324).

Music served different functions in the Old Testament, for example the ancient prophet delivered his oracle with the help of music. 2 Kings 3:15 says that God’s hand came upon Elisha while there was music and he prophesised. From 1 Samuel 16:14-23 and 18:10 the Israelites credited music as powerful. Music can also have a calming and relaxing effect as seen in I Samuel 16, where David is described as an accomplished harp player, who, when he played, “refreshed” the king with his wonderful music. Some songs known from the Old Testament includes those of Moses (Exodus 15:1-19 and Deuteronomy 32:1-42), Hanna’s prayer (1 Samuel 2:1-10), Habakkuk’s prayer (Habakkuk 3), Isaiah’s prayer (Isaiah 26:9-20), Jonah’s prayer (Jonah 2:3-10) and the songs of the three young men in Daniel 3:26-83. From above examples, it is clear that religious music did not only belong to the temple, it existed for all occasions, such as personal prayers, love songs, funeral songs, war songs, working songs, drinking songs, songs to praise God, songs during sacrifices and specific festivals. Music and song formed part of formal, as well as informal religious activities of everyday life. Thus, covering every sphere of life, serving as the voice of all people (Viljoen, 2001:423-442).

With regards to the impact of music on the brain, neuroscience teaches that music is a therapy method and a means of accessing that stimulate specific cerebral circuits which are viewed as a way to stimulate the brain (Trimble & Hesdorffer, 2017:28-31). Findings suggest that music therapy is accepted by individuals with depression and linked with improvements in mood disorders (Maratos *et al*., 2008:1-19).

Being an IFC herself, the researcher compiled a song list that helped her through the cancer journey of a loved one. As stated, the choice of music is individualistic. IFCs must be encouraged to find and listen to gospel music that will touch their hearts. This list serves as suggestions of songs that may help encourage IFCs to find some peace during their cancer journey and caregiving season. Artists of these songs wrote the lyrics from their personal hardships, for example the well known hymn by Spafford (1876), “It is well with my soul”. MercyMe (2018) wrote the song “Even if”, due to living with a child diagnosed with a chronic illness. Daigle (2016) shares her story on pain, loss and grief in "The cries from my heart". Hanna (2018) struggled with anxiety and depression, writing her songs from her pain, struggles and growth.

Box 21: Suggested playlist for IFCs

Song	**Album**	**Artist**
All that I'm after	Faultlines.	Kalley
Blessings	Laura story blessings	Laura Story
Even if	Lifer	MercyMe
Even now	Speed of light	Philippa Hanna
Faultlines II	Faultlines	Kalley
Guardian God	Faultlines	Kalley
It is well	Speed of light	Philippa Hanna
Let you lead	Speed of light	Philippa Hanna
Rescue	Look up child	Lauren Daigle
Run to you	Speed of light	Philippa Hanna
Sanctuary	Faultlines	Kalley
The Hero	Come back fighting	Philippa Hanna
Trust in you	How can it be	Lauren Daigle
Vow	Faultlines	Kalley
You say	Look up child	Lauren Daigle

In summary, practices of religious disciplines manage stress, illness demands, and life events specifically related to cancer with the aim of lessening negative outcomes such as depression, anxiety, worry, poor quality of life, disrupted relations with family and friends. Religious practices also include coping by means of seeking a closer relationship with God. Studies on daily prayer, meditation and worship note the positive effects it brings. For example, *Lectio Divina* focuses on refining awareness and self-reflection by meditative reading of biblical texts. Centring prayer brings unison with God in order to improve the ability to be silent, hear God and be filled with the Spirit. Music described as a gift from God has the power to bring a calm and joyful nature to the worshipper and for this reason IFCs should praise God by making God's word known through music.

5.7 PASTORAL LIFE COACHING

The customary understanding of pastoral caregiving is that it is a process focussing on assisting a person dealing with and healing from the consequences brought about by past events. Life coaching aims to guide the individual through a process that will empower them to set clear and specific future goals (Viljoen & Lotter, 2018:1-10). The 21st century's approach to well-being calls attention to a more holistic approach considering not only past experiences, but also the future (Viljoen & Lotter, 2018:1-

10). From the need for a more holistic approach, the question arises if and how life coaching principles can be used within the context of pastoral caregiving. A thorough account of life coaching is beyond the scope of this study, therefore, the exploration will proceed no further than explaining how life coaching principles and concepts can be combined with pastoral counselling, making it possible for the PC to holistically assist IFCs through the cancer journey.

Important to note that coaching and counselling cannot be combined in one session. After a first evaluation, the PC makes an informed decision of which method to start with. The IFC must be notified of which method (counselling or coaching) will be used with each appointment (Pratt, 2017).

Self-compassion (cf. 4.2.1) refers to taking good care of the self both, short-term as well as long-term. In the short-term, the PC wants to build the client's ability to tolerate and transform difficult experiences. In the long-term the PC wants to encourage safe exposure and non-avoidance of these experiences (Germer & Neff, 2015:43-58). Lester (1995:77) establishes that hope is linked to three dimensions of time-consciousness namely past, present and future. Crites (1986:152-173) notes that 'recollecting' the past is the basis to self-identity, while 'projecting' into the future is important for self-transcendence. Recollecting and projecting (especially projecting positive future stories) are key to manifest hope. One cause of hopelessness is the refusal to claim either the past, future or both dimensions of one's life story. Crites (1986:152-173) explains that to be happy and hopeful, in other words to have deep joy and well-being, one must have "psychic strength" which,

> Includes both a strong sense of self-identity, rooted in the past, and an equally strong power of self-transcendence, directed toward the future. This strength must be concentrated in the present, which is the point of tension between self-identity and self-transcendence.

A reason one may fail to claim the future is having a perception of a future that is filled with negativity, for instance carrying emotions such as uncertainty, fear and anxiety because of an unclear future due to a cancer diagnosis and / or feeling concerned with taking on the role of IFC or ultimately coping with the death of a loved one.

5.7.1 Pastoral theology

Thurneysen (1962:205) and Tidball (1997:233) are of the opinion that the Bible is the basis for understanding pastoral theology. According to Lyall (2001:26), "pastoral care is care for the soul of man". For that reason, when examining the theological basis of pastoral caregiving using life coaching principles, one must start with Scripture (Viljoen & Lotter, 2018:2). From Gerkin's (1991:12) explanation, it can be understood that a reformed understanding of *sola scriptura* views the Bible as the basis of a pastoral theological context, but even more important is the hermeneutical focus. For a hermeneutical focus of pastoral caregiving four pastoral theological guidelines guide the way forward.

5.7.1.1 *The care of the human soul (Cura Animarum)*

Here the theological focus is on healing and change. Scholars such as Benner (1998), Clinton and Ohlschlager (2000), Collins (2001), Crabb (2001) and Louw (2011a; 2011) recognise and incorporate pastoral caregiving into the larger ministry of soul care, spiritual formation and discipleship in the church. Soul care covers the scope of helping approaches, such as pastoral caregiving, pastoral counselling and pastoral therapy, each with its unique levels of training and expertise. Despite the different counselling styles, the core of Christian counselling is the commitment to honour Christ and help IFCs find peace, direction and stability as ultimately found in Christ (Clinton & Ohlschlager, 2000:14). Louw (2011a:75-77) also views caring of the soul as an important aspect in pastoral caregiving because of the focus on Christ's resurrection. *Cura animarum* becomes an important aspect in the life coaching discussion because of the focus on IFCs' God-image. Furthermore, IFCs' life expectations can be changed by giving them hope and new direction. Christians believe that through Christ's death and resurrection, He gave humans life in all its fullness. This fullness of life for Louw (2008:426-445) and Hudson (2015) must be seen in the context of the right relationship with God. Life coaching can contribute to this relationship by assisting IFCs to restructure their lives according to a new relationship with God through Christ. This new relationship is made possible through salvation on the cross and Christ's resurrection refers to a coaching process which includes establishment, maintenance, transformation and transfiguration of life and hope (Louw, 2008:426-445). Lastly, life coaching is about new (soulful) attitudes where IFCs' life approach will be influenced by their relationship with God for both in this life and the afterlife (eschatology). In the life coaching context *Cura animarum* incorporates healing, growing and flourishing (Viljoen & Lotter, 2018:2).

5.7.1.2 *New focus on Christology and eschatology*

Christology is the starting point for new possibilities in life, whereas eschatology focuses on hope within God's Kingdom (Viljoen & Lotter, 2018:2). Including eschatology in pastoral caregiving will promote a future of hope for this life. The crucial fact of hope is that it goes above and beyond history (Purves, 2004:128). The task of theology is to instil a vivid hope that promotes meaning and significance in life. To achieve this, Louw (2011a:16) proposes a theology of affirmation within the theological parameters of an eschatological life approach of a quest for meaning. Eschatology is then linked to ontology. The implication of a theology of affirmation in pastoral caregiving is that in addition to a narrative approach to pastoral caregiving, pastoral care must return to ontology and the meaning and significance of 'being' functions. Practical theology is in essence theology reflecting on and dealing with "the praxis of God as related to the praxis of faith within a vivid social, cultural and contextual encounter between God and human beings" (Louw, 2011a:17). Practical theology falls in the realm of praxis, because it refers to the intention, motivation and significance of actions where language, communication, action, hope, creative imagination and the visual dimension of life plays a role. Applying life coaching skills in pastoral caregiving, can inspire IFCs to act and plan goals for a new life according to their status as a child of God (Romans 8:14-17), forming a Christ like identity (Louw, 2012:70).

5.7.1.3 *Christian spirituality*

Christian spirituality is being able to experience the presence and movement of the Spirit in the here and now (DeJongh van Arkel, 2000:142-165). Christian spirituality within pastoral caregiving is primarily the work of the Holy Spirit. The primary aim of ACT is both psychological flexibility and spirituality "psychospiritual flexibility" stressing that IFCs see the Holy Spirit as active in the process of nurturing the moment-to-moment faith that is involved in following Christ (cf. Chapter 4) (Sisemore, 2014:5-16). The Holy Spirit will guide IFCs in heart and mind by means of motivation and teaching (Viljoen & Lotter, 2018:3) as well as placing emphasis on grace, forgiveness, reconciliation, resurrection and hope supported by fellowship, service and sacrament (Louw, 2011b:6). This spirituality in the pastoral caregiving process must be about life determined by norms and values (Louw, 2015b:68) which stand in line with the core of ACT where mindful, values-congruent living is the desired outcome (Waltz & Hayes, 2010:148-192; cf. 4.4), as well as fulfilment and hope (Herold, 2008:183-200).

5.7.1.4 *Human flourishing*

Human flourishing relates to an understanding of eschatology that holds implications for the present life and a holistic Christian spirituality that focuses on well-being and human flourishing (McClure, 2008:189-210). Within pastoral caregiving, human flourishing can be linked to the biblical concept of abundance as found in John 10:10. It is through Christ's death and resurrection that humans receive life in its fullness (Lincoln, 2011:61-80).

5.7.2 Life coaching

Gallwey (1974) laid the foundation for life coaching, writing a series of books in which he began a new methodology for coaching and the development of personal and professional excellence that he refers to as "the inner game". With his first work based on sports, he later applied coaching to the fields of business, health and education. The notion that the 'inner game' of an individual's attitude and psychology greatly influences the 'outer game' of personal performance is an approach based on positive thinking with an application for life coaching (Viljoen & Lotter, 2018:1-10). Using Gallwey's (1974) inner game metaphor in the book Coaching for Performance, Whitmore (2013) developed the GROW model for coaching which became a standard publication in the business coaching environment (Viljoen & Lotter, 2018:1-10). The GROW model is applied to enhance people's purpose and personal performance. It is about developing skills by means of effective questions and active listening skills within a context of awareness and responsibility.

Box 22: GROW model and SMART model

Whitmore's model **GROW**	**Doran's model** **SMART**
• G oals Goals can be short, medium or long-term. Goals is a twofold process: -goals for each session -goals for the whole coaching process	Goal setting is done with the SMART model by Doran (1981:35-36) which brings focus and measurement to goal setting. • S pecific • M easurable

- Reality Refers to how IFCs feel about the reality of the current situation and future predictions. The purpose of this point is to clarify goals because it can focus on sources of motivation and dissatisfaction. - Opportunity Alternative options that IFCs can choose when planning goals. The aim is to create possible alternative actions and evaluate them instead of finding immediate solutions. - Way forward Refers to the way forward allowing IFCs to identify and agree on specific actions and plans to reach set goals. This final stage involves the headway from discussing options to decision and specific actions.	- Agreed - Realistic - Time-framed

Source: Author compiled table

Life coaching is defined by McDermott and Jago (2006:8), as both conversational and focused discipline, supporting the individual to learn how to lead and manage the self more effectively in relation to life issues, their resources, context and potential. Collins (2001:58) explains that the essence of life coaching consists of three parts, firstly understanding where the individual is at present, secondly focusing on what the individual wants in the future and thirdly finding the means to get there.

5.7.3 Pastoral life coaching

The PC can enhance the counselling process by incorporating the life coaching processes (GROW and SMART) into the ACT model, thus ensuring that the PC (who is not always a trained life coach as well) can still add value to the counselling process by placing focus on the past (healing) and the future (growth). It is the PC's task to help IFCs understand how their God-image (perceptions and concepts of God) plays an immense role in the way they interpret suffering (and the cancer journey). This does not imply that there is a correct or incorrect concept of God. The task of the PC is to determine whether IFCs' God-image plays a constructive role with a positive influence on IFCs origin of faith and emotions or whether their God-image is disruptive and destabilising. The questions to be asked by the PC are, "How does the IFCs concept of God function?" and "What effect does it have on faith behaviour?" (Louw, 2011a:228).

In addition, it is further important to consider which pastoral theological concepts are central for spiritual growth. The developments in pastoral theology over the past twenty years place emphasis on a new spirituality in Christology, focussing on soteriology and eschatology (Viljoen & Lotter, 2018:1-10). Describing specific traits in this Christian spirituality, Louw (2011b:6) explains that

> Within Christian spirituality, one can identify the theological categories of grace (unconditional love); forgiveness and reconciliation; resurrection hope; the support system of *koinonia* (fellowship) and *diakonia* (service) and the sacraments as indication of God's faithfulness and fulfilled promises emanating into a life of joy and gratitude.

Pastoral care deals with a very unique human dimension that is called 'soul' from a theological and anthropological point of view. "One can even say that the 'what' in pastoral care is the human soul." (Louw, 2008:78) For this reason, the ailment or illness of the patient is not addressed, or the psyche of IFCs, but the whole of the person as an 'ensouled body' and an 'embodied soul' (Louw, 2008:78). Through time the notion of shepherding has become a classic representation of pastoral care (*cura animarum* related to the notion of salvation). As Hiltner (1958:55) discusses this idea in his theological theory on pastoral caregiving, he argues that all the PC's actions should be understood from the shepherding perspective (*solicitous care*). The fact that pastoral care implies more than empathy, is what sets pastoral caregiving apart from all other disciplines. It exemplifies the identification of the suffering Christ with our human predicament (Osmer, 2008:191). The PC does not wait for IFCs and patient to make an appointment, instead "the shepherd seeks out the sheep to care for them" (Louw, 2008:75). Pastoral care thus meets people where they are (at home where caregiving takes place or at hospital where the patient is admitted) and not primarily the counselling room. Pastoral care is about 'being with', meeting people in their 'being functioning' with deep concern and sincere empathy (Louw, 2008:75).

5.8 CONCLUSION

Caregiving is an all-consuming role, demanding a great deal of life changes so that IFCs can meet the required needs of their loved one diagnosed with cancer. Such a long-term dedication to a singular focus (caregiving) leads to diminishing of the life before caregiving, taking over the identity as sole caregiver. After recovery or death beginning to work towards healing and realising that caregiving is not the core of IFCs' identity, it is the beginning of a renewed purpose. The caregiver may struggle to understand why cancer entered their lives. A cancer diagnosis of a family member may move the significant others to look afresh at their own lives. They may find themselves reflecting more on religion, the purpose of life and what they value most.

This chapter demonstrates that individuals going through the cancer journey generally rely on religion to cope with the illness. The goal of the PC is to empower the family giving them meaning and peace, helping cope with the cancer journey and promoting well-being and quality of life by means of among others the discussed practices (prayer, *lectio devina* and worship).

These findings hold important implications for a better understanding of how PRC as well as RS relates to psychosocial, physical, psychological, and spiritual components. The findings highlight the importance of acknowledging both the positive and negative outcomes of RC.

The practice of prayer will allow IFCs to deeply experience God’s active presence within their innermost being. The result of the Centring Prayer and Serenity Prayer is the increased ability to surrender all efforts to control the cancer journey, with the diagnosed loved one and/or family members and rely on God’s grace and goodness. The types of religious disciplines discussed in this chapter will allow IFCs to become aware of God’s working both internally and externally assisting IFCs respond differently to their anxiety and worry and as a result experience freedom from the need to obtain certainty in their attempts and to deeply trust in God’s goodness.

CHAPTER 6: THE THEOLOGICAL CONCEPT OF COMPASSION

6.1 INTRODUCTION

The normative task “what ought to be going on?” seeks to discern God’s will for present realities. This task is referred to as prophetic discernment (Osmer, 2008:129). Even though the Old Testament prophets spoke normatively of God, in addition they were also interpreters of past traditions and present revelations. The aim of the term prophetic discernment is to describe “the interplay of divine disclosure and human shaping as prophetic discernment” (Osmer, 2008:33). Prophetic discernment thus entails both divine disclosure and human shaping through God’s word (Osmer, 2008:134-135). The normative interpretation is divided into two chapters (6 and 7).

This chapter will gain a deep theological understanding of the significance of God’s presence within the context of caregiver related stress by means of firstly, a theological word study on the word “being-with” (Exodus 3:14). This verse voices the priority of compassion, specifically the act of “divine presence which is a boundless and unending being-with” (Davies, 2001:20). Secondly, a discussion of the compassionate God (Ephesians 2), with reference to the suffering God and the theology of the cross as the framework of the *theopaschitic* approach (passion of Christ). Thirdly, a discussion of self-compassion through love (Matthew 22:36-39) as part of the greatest commandment. Lastly, the focus is on a message of hope (Romans 8:18-28), by means of the power and love of God in the midst of suffering.

6.2 OVERWHELMING EMOTIONS AND FAITH

It is normal for IFCs to feel overwhelmed, which includes emotions such as a sense of anxiety or not coping due to prolonged levels of high stress, which can eventually lead to physical and emotional burnout (cf. 4.6). Scripture contains many stories of how hope carried individuals through their hardships, however, there are also times when hope fades, wavers or seems to disappear (cf. 5.3). Neraas (2009), author of the book “Apprenticed to hope” was diagnosed with chronic fatigue, fibromyalgia and immune dysfunction syndrome. Neraas (2009: ix) describes the difficulty of maintaining hope through the daily struggle of chronic illness.

> Illness grabbed me by the neck, thrust me into the fire, and swung me around with dizzying force, year after year, dissolving old assumptions, rupturing old identities, exposing easy answers, and complicating my relationship with hope.

Feeling overwhelmed is not a sign of failure, not being good enough or even a lack of faith during times of religious struggles. It is a normal human response to a drastic changing environment, due to chronic illness and/or hardships.

a) David

God is also not less pleased with IFCs when they feel overwhelmed as seen for example where David frequently brings his overwhelmed feelings to God. The five books of the Psalms cover timeless themes, which explain why it is as relevant today as when the songs were written. Although the book of Psalms contains some of the most beautiful poetry ever written, many find that it describes hardships so well that it makes excellent prayers (Zavada, 2020). The second book of Psalms (Psalms 42-72) describes deterioration and rescue by God. This part of the Psalms are recordings of times of great uncertainty, where ancient worshippers felt as if *horror has overwhelmed* (Psalm 55:5NIV) them and how hardships caused their hearts to grow faint (Psalm 61:2 NIV; Zavada, 2020). David's prayer in Psalm 143 (fifth book of the Psalms) is a poignant picture of an overwhelmed soul feeling isolated which makes it difficult to feel connected to others, God and self. IFCs can relate to these emotions as the cancer journey makes them aware of their own inabilities and shortcomings mostly because they struggle to get control over their own emotions (inner world) and environment (outer world). The overwhelmed soul is overcome with feelings of helplessness and uncertainty causing an urgency to be freed from hardship. From these feelings of hopelessness David passionately requests three things from God. Firstly, it is to love him. For his soul to heal, David needs to hear that he is loved. Secondly, for God to lead him. David not only asks for a way to get out of his darkness and for instructions on how he furthermore asks the Great Shepherd to personally lead him to still waters. Thirdly, in addition to God's love and presence, David asks God to revive his soul. Like God did to Adam, He must also breathe life into David or else he will perish inside out (Anon, 2019). IFCs can relate to the plea to be loved, led and revived by God, in other words to have a personal relationship with God during the cancer journey. What can be learned from King David's Psalm 143 about dealing with feeling overwhelmed is that IFCs can freely confess their need for and to God, reminding themselves of Gods faithfulness throughout history. The burdened IFCs can ask God to remind them of His compassion and love, to lead them in His light and breathe life into their souls, giving them hope.

b) Paul

Certain themes are repeated over and over in the letters of Paul and it becomes clear that these themes (faith, hope and love) lie at the heart of Paul's concerns. Faith, for Paul has to do with God's trustworthiness (Rich, 2016). Looking back to the salvation history of His people and the covenants God has made with them, as he recalls the foundational experiences by which God has shown absolute trustworthiness of the divine commitment to God's people. These covenants were established with individuals and groups, often during challenging times of crises. The covenant with Noah after the flood, the covenant with Abraham and the covenant with Moses at Sinai are examples that Paul recalls when he speaks about faith as a relationship of trust between God and His people. Paul trusts that God has offered a new and trustworthy covenant by presenting a new relationship through Jesus Christ to all of mankind. To come into a covenant relationship with Christ starts with receiving the announcement of the good news about Him summed up in one brief phrase "Jesus is Lord". This is good news for two reasons. Firstly, it means that Christ is Lord of all and secondly, it means that through a trusting relationship with Christ, one can become an inheritor of all that God has to offer which include love, forgiveness, community and hope of life after death (Rich, 2016).

Due to the connection between comfort and compassion, the passion in compassion brings about more than feelings, it is an existential category (being-with) within the theological framework of a *theologia crucis* (the cross of Christ as an enfleshment of divine suffering and compassion; Gerhardson, 1981:118). Caregiving is spiritually representing the compassion of God, embodying the presence of God and enfleshing the spiritual realm of hope. Eib (2006), an author and cancer survivor writes "even though cancer is an unwelcome intruder in any family, like any trial that comes our way" there is potential within these circumstances to bring the cancer patient and their families closer to Jesus and help them to grow spiritually.

6.3 BEING-WITH (EXODUS 3:14)

God reveals His name to Moses with the words "*I AM*" and "*to you*". With these words God says that He is with His people, bestowing grace and having mercy on them throughout time. Being-with is thus the divine presence making it a boundless and unending being-with – past, present and future.

"I AM" אֶֽהְיֶ֑ה *('eh·yeh)*	"*to you*" אֲלֵיכֶֽם׃ (*'ă·lê·ḵem*)
Strong's Hebrew: 1961 to be, become, come to pass, exist, come into being, to exist, be in existence, to abide, remain, continue (with word of place or time) to accompany, be with.	Strong's Hebrew: 413 to, toward, unto (of motion), in among, toward (of direction, not necessarily physical motion), by, in within.

Source: Strong's Lexicon (2020c)

There are three noteworthy events in Exodus 3, namely (a) the appearance of the divinity, (b) the call and commissioning of Moses and (c) the revelation of God's name. The emphasis is on the deity, *Ehyeh asher ehyeh*, what God sees, says and will do. God said to Moses, "*I AM WHO I AM*." This is what you are to say to the Israelites: "*I AM has sent me to you*" (Exodus 3:14 NIV).

The Septuagint (Pietersma & Wright, 2007) translates *ehyeh asher ehyeh* of Exodus 3:14a into Greek as *ego eimi ho on*, which translates into English as "*I am the one who is*", and it translates the absolute *ehyeh* of 3:14b as "*ho on*", "*the one who is*" (Brenton, 1851).

Examples where God's words "*I am with you*" carried individuals in their desperate times of need are to the stuttering Moses (Exodus 3:12), the hesitant Joshua (Joshua 1:9; 3:7), to the fainthearted Gideon

(Judges 6:12,16) and the youthful Jeremiah (Jeremiah 1:6-8). The three Evangelists, Matthew (14:27), Mark (6:45-56) and John (6:20) tell the story of Jesus walking on the water, stating that Jesus' minimal response when approaching the terror stricken disciples on the boat, when they saw Him approaching was "*I am, do not be afraid*" (Matthew 14:27; Mark 6:50; John 6:20). The main purpose of these words was to identify Himself as their trusted friend and in that way ease their fears (Youngblood, 1972:144-152).

In ancient times there was an intricate relation between a person's name and the surrounding narrative, where the name reflected the person's character, personality and history (Youngblood, 1972:144-152). "Names beget narrative and narrative begets names" (Kermode, 1979:91). What was true of human names in ancient Palestine was also true of divine names (Youngblood, 1972:144-152). God's mysterious answer to Moses' question about His name (*Ehyeh asher ehyeh)* translates to "*I am who I am*" (Exodus 3:14; Sonnet, 2010:331-351). That "*I am*" is a valid divine name and well known from Moses's call in Exodus 3 (Youngblood, 1972:144-152). The Exodus 3 revelation of God's name oriented towards the past, as well as the future; from the Old Testament "*I am*" (Yahweh) to the New Testament "*I am*" (Jesus Christ). The words express completeness, and therefore an unchanging and eternal Being. The name God gives Moses to use, are both new and old. Old in its connection with previous revelations and new in its full interpretation, and in its bearing upon the covenant of which Moses was the mediator (Barnes, 2020). Poole (2020) states that the Hebrew tense includes all times, past, present and future in order to indicate that all times are equal to God and all are present to him "*before Abraham was born, I am*" (John 8:58NIV). "*See A thousand years in your sight are like a day that has just gone by, or like a watch in the night*" (Psalm 90:4NIV). "*But do not forget this one thing, dear friends: With the Lord a day is like a thousand years, and a thousand years are like a day*" (2 Peter 3:8). Therefore, with God all times are called by one name which includes "has been", "is" and "will be". In this regard, *Ehyeh asher ehyeh* suggests necessary existence as well as perpetual providence. With His Name God says, "I am with human beings, bestowing grace and having mercy on those on whom I will have mercy" (Gottlieb, 2011:267).

The turning point in the oppression history of Israel written in Exodus 1 and 2 arises when "*God heard their groaning and he remembered his covenant with Abraham, with Isaac and with Jacob*" (Exodus 2:24 NIV). Similarly, in the self-identification episode of the burning bush (Exodus 3:1-5) God refers to an event of the past "*I am the God of your father, the God of Abraham, the God of Isaac and the God of Jacob*" (Exodus 3:6 NIV). This self-presentation together with God's promise to free the enslaved people incites Moses to enquire after God's name and God answers Moses with the words "*I AM WHO I AM. This is what you are to say to the Israelites: 'I AM has sent me to you*" (Exodus 3:14 NIV). Since the name elaborates on a previous "*I will be with you*" (Exodus 3:12) in a context of promised aid and freedom (Exodus 3:7-10) the announcement is to be taken as a promise, indicating God's compassion in interventions to come. It is God's way to open an unpredictable future, yet guaranteed divine assistance. In affirming His consistency throughout time, God makes a promise that He will "act favourably in the future for the sake of His people, as He habitually did in the past for the sake of the patriarchs" (Sonnet, 2010:331-351). The Cambridge Bible commentary (2020) explains that God will continuously be with His people to strengthen them and help them as their deliverer.

Woods (2014:501-503) comments that Moses was honoured to know God by His name and to be called into a deeper relationship with Him. Moses received God's mission to bring His message of hope to the suffering people of Israel. This mission is confirmed by God revealing His name; offering to deepen the bond; to offer a personal relationship and support to Moses with the powerful statement "*I AM*" has spoken (Woods, 2014:501-503). Woods (2014:501-503) states that "*I AM*" carries the same meaning in this generation as in Moses' generation. The promise that God only seeks good for His people, seeking to help His people to live for more than this fragile earthly life, but for the life of the world to come. When the believer steps out onto the Holy Ground, when the believer meets God who seeks a deep, personal, loving relationship with them, they can truly know (with the benefit of hindsight) that others before them have walked the same path and those to come will follow on the same path, "God is with us; I AM is as unchangeable today as all those generations ago". "*This is my name forever; the name you shall call me from generation to generation*" (Exodus 3:15b NIV).

Youngblood (1972:144-152) explains that the writer of the Exodus 3 passage linked the Hebrew divine name "*Ehyeh*" meaning "*I AM*" to the divine name "*Yahweh*" stating in Exodus 3:15 (NIV) that *"God also said to Moses, 'Say to the Israelites, 'The LORD, the God of your fathers the God of Abraham, the God of Isaac and the God of Jacob has sent me to you.' "This is my name forever; the name you shall call me from generation to generation"*. In this verse the divine name "*I AM*" and the divine name "*LORD*" are connected "*I am has sent me to you*" (Exodus 3:14 NIV), "*The LORD ... has sent me to you*" (Exodus 3:15 NIV). Youngblood (1972:144-152) remarks that even though the word "*Yahweh*" is usually translated "LORD" in the English version, the initial root of the word seems to have a close relationship to the divine name "*I AM*". The Lord repeatedly says, "I will be (*ehyeh)* with" or "I will be (*ehyeh*) the father of" Isaac and Jacob, Moses and Joshua, David and Solomon (Genesis 26:3; 31:3; Exodus 3:12; Deuteronomy 31:23; Joshua 1:5; 3:7; 2Samuel 7:9,14; 1Chronicles 17:8,13; 28:6). The Lord also continually says "*I will be (ehyeh) the God of*", Judah, "*I will be (ehyeh) as the dew to*" Israel, "*I will be (ehyeh) the glory with*" Jerusalem (Jeremiah 11:4; 24:7; 30:22; 31:1; 32:38; Ezekiel 11:20; 14:11; 34:24; 36:28; 37:23; Hosea 14:6; Zechariah 2:9; 8:8). Although these statements are not clear references to the divine name such statements, "*I AM*" at the very least suggest the significance of that name. "*I AM*" when used by God is not simply an announcement of existence, "*I AM*" when used by God is a confirmation of a relationship and it is also what makes the *Ehyeh*, the "*I AM*" of Exodus 3:14 such a hopeful revelation of God's nature by indicating the renewal of the fellowship between God and His people.

Plastaras (1966:98) understands the "*I am who I am*" of Exodus 3:14 to mean, "I will be present (in a dynamic, active sense) wherever, whenever, and to whomever I will be present". When God says, "*I* *am who I am*” He does not merely indicate His existence but His gracious presence (Youngblood, 1972:144-152). Ancient Jewish commentaries on Exodus 3:14 explain the divine “*I AM*” in a way that emphasises God’s eternity. This is done by a triple formula, “I am who I have been, who I now am, and who I will be in the future”. Also, in a double formula, “I am who I was and will be”. The Jewish double formula has its parallel in Revelation 11:17; 16:5 where God is defined as “*the one who is and who was*”. The Book of Revelations with the triple formula, although officially parallel to the triple formula of Jewish tradition, re-establishes to the divine name its active strength in describing God as “*who was, and is, and is to come”* (Revelations 4:8; 1:4,8 NIV). Theologian of hope, Metz (1968:134) stresses God’s inevitable future involvement with the words “I will be who I will be” (Youngblood, 1972:144-152).

On the verse in Exodus 3:12 (NIV) “*And God said, ‘I will be with you’”* Calvin finds it remarkable that God is there for His people to overcome all their fears and to take away every doubt. It does not matter who Moses is or what strengths he has; God is his leader. In these words, the believers are taught that God “is never regarded by us with due honour, unless when, content with His assistance alone, we seek for no ground of confidence apart from Him” and even when overwhelmed with one’s own weaknesses, it must be kept in mind that God is there with and for His people (Bringham 1852). Therefore, when IFCs experience hardships they must “magnify the power of God” knowing that God is with them deeply rooted in their hearts. In Exodus 3:14 (NIV) the verb in Hebrew is in the future tense “*I will be that I will be*” also holds the same power in the present, except that it defines the unending duration of time. God claims eternity to Him alone so that He may be honoured according to His majesty; this assures Moses of God’s omnipotence. God teaches Moses that He alone is worthy of the most holy name and that Moses must not doubt of overcoming all things under God’s guidance (Bringham, 1852).

The concept “*I am who I am*” is one of the most insightful statements concerning God’s being and essence. The Hebrew translation indicates an important promise and expression of God’s faithfulness. Furthermore, it can be understood that God is a unique kind of deity and that God will always be with His people wherever they are (Louw, 2015a:1-15). Exodus 3:14 can for this reason be viewed as the base of a spirituality of hope and a theological understanding of the spirit of compassion as started by the compassionate being of God with the suffering of His people which will be discussed in the following section.

6.4 THE COMPASSIONATE GOD (EPHESIANS 2)

The word compassion is an answer to the questions “How might one speak of God during suffering and what kind of God fashions and participates in pain, suffering and death?” Ephesians 2 defines God as the vulnerable God, the kenotic Creator, compassionate God (*theopaschitic* theology) and the Triune God.

“*He had compassion*” ἐσπλαγχνίσθη (*esplanchnisthē*)
Strong's Greek 4697: To feel compassion, have pity on, be moved.

Source: Strong’s Lexicon (2020a)

An example in the Bible where the compassion of Jesus is referred to, is in Matthew 14:14 (NIV) where Jesus was moved with compassion “*When Jesus landed and saw a large crowd, he had compassion on them and healed their sick*”. In the case of Mark 6:34 (NIV), it is not the sickness of people that moved Jesus, but their ignorance and the lack of someone to guide and teach them in God’s knowledge. “*When Jesus landed and saw a large crowd, he had compassion on them, because they were like sheep without a shepherd. So he began teaching them many things*”. In another case, Jesus shows compassion for the people around him. In Matthew 25:32 (NIV) Jesus called his disciples to him and said, "*I have compassion for these people; they have already been with me three days and have nothing to eat. I do not want to send them away hungry, or they may collapse on the way*." In each of these examples Jesus is moved with compassion where there is a need for healing, for teaching and for nourishment (Pollock, 2017). The compassionate Christ will be discussed in more detail from the Pauline letter of Ephesians 2.

In the first ten verses of Ephesians 2, Paul presents the believers’ past, present and future. In verses 1 to 3 what man was, verses 4 to 6 and 8 to 9 what man is and verses 7 and 10 what man will be. Within this framework the apostle offers six aspects of salvation, namely it is from sin (v.1-3), by love (v.4), into life (v.5), with a purpose (v.6-7), through faith (v.8-9) and unto good works (v.10). Cayce (2002) comments that the main problem of mankind is that they do not have a relationship with God because they are alienated from God by sin. It has nothing to do with the way people live, it has to do with the fact that they are dead even while physically alive. In other words, humans are “spiritually dead while being physically alive”. By being dead to God, mankind is equally dead to spiritual life, truth, righteousness, inner peace and happiness. Jesus Christ took the punishment of death on His body on the cross and paid mankind’s bill in full for all who turn from sin and accept Christ as their Saviour. Romans 8:2 (NIV) “*because through Christ Jesus the law of the Spirit who gives life has set you free from the law of sin and death*”. In Ephesians 2:3 Paul’s primary purpose is not to show how unsaved people are living, but to remind the people how they formerly walked and formerly lived. The two words “*but God*” in Ephesians 2:4 express where the initiative was in offering the power of salvation. God’s desire is to be re-joined with His creation which He made in His image and for His glory. “Salvation for God’s glory is by the motivation and power of God’s great love” (Cayce, 2002). A God that is fundamentally kind, merciful and loving and in this love, He reaches out to condemned human beings offering them salvation and all the eternal blessings it brings. God's mercy and love offers a way for people to participate in the righteousness of His crucifixion. Not only did He love enough to forgive, but also love enough to die for the ones who had offended Him. "*Greater love has no one than this: to lay down one's life for one's friends*" (John 15:13 NIV). Salvation gives spiritual life (Ephesians 2:5). In the place of sin, Christ clothed mankind in His righteousness washed in His blood therefore saved in Christ not because it is deserved but because of God's love (Cayce, 2002).

Henry's (Bible Study Tools, 2020b) commentaries on Ephesians 2 explain that the apostle Paul uses Ephesians 2 to emphasise divine grace in the calling and salvation of sinners by Jesus Christ. Paul highlights how peace is made for and between Jews and Gentiles by Christ the peacemaker and the privileges and blessings to be enjoyed by both because of it. Bringing people together to each other and to God is brought about by the blood of Christ (Ephesians 2:13). There is no more distance and alienation as before, but all belong to the same city and family that are built on the same foundation united together in the same corner stone namely Jesus Christ (Bible Study Tools, 2020b).

For Guzik (2018a), in Ephesians 2 Paul connects the ideas of Christ's great love and His sacrificial death. Paul places emphasis on the work of Jesus on the cross by repeating the idea several times "*made near by the blood", "having abolished in His flesh the enmity", "in one body through the cross*" (Ephesians 2:14-16). The unity did not happen by chance; it was the hard-fought accomplishment of Jesus. Many people think that the story of the crucified Christ is all about a bloody Christ, but the point of Christ crucified is about love – sacrificial, giving and saving love. "What Jesus did on the cross, suffering as a guilty sinner in the place of guilty sinners, brings us near to God" (Guzik, 2018a).

Regarding God as a suffering God, Peacocke (1993) speaks of a Vulnerable God; Polkinghorne (2001:94) of a Kenotic God; Louw (2015a:1-15) of a compassionate God (*theopaschitic* theology) and Schaad (2017:91-107) speaks of a Truine God.

a) The vulnerable God

Peacocke (1993:126) proposes that God must not only be considered in terms of Divine Being (who God is in Godself) but also in terms of Divine Becoming (how God acts in the world). Divine self-limitation is the reason why Christians describe God as love (1 John 4:8). "God was revealed as self-offering love in the self-limitation which was His incarnation in Jesus Christ and in the self-offering of Jesus' human life for men" (Peacocke, 1971:137). For this reason, pain, suffering and death that affect humanity must also be regarded as affecting God (Peacocke, 2001:86-87). According to Peacocke (2001:38), there is a creative self-emptying and self-offering (a kenosis) of God, a sharing in the suffering of His people. This sharing in the suffering is for Peacocke (2001:42) a display of the suffering love primarily in and through Jesus Christs' life, suffering, death and resurrection. Those who believe in Christ as the word-made-flesh, the self-expression of God in human form, find in Him the vulnerable God, self-emptying and self-giving suffering love. Peacocke (1993:300) stresses that the suffering of Christ is not the only display of divine love. The Christ event shows that God not only experiences suffering and death on the cross, but importantly overcomes suffering and death through the resurrection. While God does not prevent pain, suffering and death throughout the life journey, He also does not intend that pain, suffering and death endure or triumph. Suffering and death thus are not final but lead to new life within the embrace of God's love.

b) The Kenotic Creator

Polkinghorne (2001:104) remarks that in Christianity kenosis is translated as "self-emptying" and is mainly associated with the incarnation where Christ emptied (*ekenosen*) Himself by taking the form of a slave, being born in human likeness (Philippians 2:7). In this act of divine self-limitation God's character is manifested in the simplest and most comprehensible way for humanity. "The invisible God took our flesh and became a visible actor on the stage of creation" (Polkinghorne, 2001:94-95,104). According to Polkinghorne (2001:94-95, 104), such divine self-limitation does not make God powerless or prevents God's creative interaction with the world. Instead, it emphasies the freedom of natural processes and therefore rouses the difficult question of the relationship between divine love and divine power regarding suffering. For Polkinghorne (2005:79), the fundamental Christian insight about God's relation to suffering and evil is that God is not a spectator, but a fellow sufferer, who has Himself absorbed the full force of evil. In the lonely figure hanging in the darkness and dereliction of Calvary, the Christian believes that he sees God opening his arms to embrace the bitterness of the strange world he has made. The God revealed in the vulnerability of the incarnation and in the vulnerability of creation is one. He is the crucified God, whose paradoxical power is perfected in weakness, whose self-chosen symbol is the King reigning from the gallows.

c) Compassionate God (*theopaschitic* theology)

The theological discussion of suffering moves in the direction of God's passion and compassion. In theological language, compassion is linked to the ethos of self-sacrifice and finding that in Christ God has already preceded humans (Louw, 2015a:1-15). Davies (2001:21) states that in compassionate thinking the core of compassion is from the principle of self-denying or kenotic love. He goes on to say that compassion functions on the basis of self-emptying for someone else's sake consisting of a rational component built on altruistic ethics (cognitive component of compassion), an emotional component built on an emphatic approach (affective component of compassion), a volitional component built on purposefully opening up for the other (conative component of compassion) and the spiritual component built on encountering Christs' kenotic love – the compassion of God (theological component of compassion). "Aligned with the creational approach is the emphasis on incarnational theology with the emphasis on the presence of God" (Louw, 2011a:430). The essence of incarnational thinking is the theology of the cross (*theologia crucis*) and the effort to prove God's passion. According to Louw (2011a:230), God not only brings about reconciliation on the cross, but 2 Corinthians 5:21(NIV) says, "*God made him who had no sin to be sin for us*" which implies that God shares in the pain of humans to become their "co-sufferer" (Louw, 2011a:430). For Hall (1993:146-148) God is a "revealing Presence, a Companion – your God" to them becomes "God-with-us" (Louw, 2011a:430). Therefore "in Christ, God becomes and is the cancer patient … and the terminal patient" (Louw, 2011a:230). The meaning of the concept "the suffering God" is that God personally identifies with human suffering. God turns suffering around to become an element for the growth of faith and hope (Louw, 2011a:229). "God's compassion: God is a Saviour / Redeemer who suffers vicariously with us; God is a friend and partner for life to support, sustain and assist the sufferer" (Louw, 2011a:230).

d) Triune God

Like Peacocke (1993), Schaab's (2017:91-107) analysis of God and suffering is fixed in God's intimate and enduring relationship with the world He created and His relationships are regarded as wholly Trinitarian. As the creator of heaven and earth (all things visible and invisible) the First person of the Trinity has a transcendent relationship with humanity (creation). As the one who became flesh in Christ, the Second Person of the Trinity has an incarnate relationship with humanity (creation). The Third Person of the Trinity the giver of life who satiates and fills the world and is all embracing has an immanent relationship with humanity (creation). God creating and nurturing the world within the divine being (transcendently, incarnately and immanently) is considered by Schaab (2017:91-107) as experiencing suffering within Godself instead of outside Godself. For this reason, divine suffering is not passive, but active with creative purpose "for suffering is widely recognised as having creative power when imbued with love (Peacocke, 2001:88). God's intimate engagement, investment and involvement in hardships during the life journey have the potential to offer insight and hope (Romans 8:22-25; Schaab, 2017:91-107).

6.5 SELF-COMPASSION THROUGH LOVE (MATTHEW 22:36-39)

Self-compassion through love is directed toward the believer especially during hardships, making it an important factor for the well-being on physical, emotional and spiritual levels. Love for God, the neighbour and self-love are addressed in Matthew 22:36-39.

"*Love*" Ἀγαπήσεις (*Agapēseis*)
Strong's Greek 25: To love, wish well to, take pleasure in, long for; denotes the love of reason, esteem. Perhaps from agan; to love.

Source: Strong's Lexicon (2020d)

Matthew 22 is an extension of Christs' discussions in the temple, two or three days before He was crucified. Concerning the great commandment of the law (vv.34-40) in the Gospel of Matthew the evangelist accentuates that Jesus' Great Commandment contains two requirements of equal importance. Jesus' expression of the double commandment to love God and one's neighbour is rendered as the response to a hostile question, posed by the Pharisees in order to test Jesus (vv.34-35). With the answer all the law is fulfilled in one word namely love.

> Love is the leading affection, which gives law, and gives ground to the rest; and therefore that, as the main fort, is to be first secured and garrisoned for God. Man is a creature cut out for love; therefore, is the law written in the heart that it is a law of love. Love is the rest and satisfaction of the soul; if we walk in this good old way, we shall find rest (Henry, 2020c).

Poole (2020b) comments that the whole Bible is the believers' rule. Where Moses summed up all the rules in ten commands, Christ brings the ten to two in Matthew 22, love to God and love to the neighbour therefore love is the fulfilling of the law. The law supposes that one should love the self or otherwise one will not be able to love the neighbour. Hagner (1995:648) states that these two commands are so important that Jesus concluded that on these two commands hang "*All the Law and the Prophets*" (Matthew 22:40NIV). This means that the commandments of the law and the teaching of the prophets cannot be fulfilled separate from the twofold love commandment which can be seen in Matthew 7:12 (NIV) "*… for this sums up the Law and the Prophets*" and Romans 13:10 (NIV) "*…love is the fulfilment of the law*". The love commandments thus belong together, enfolding the vertical relationship with God and the horizontal relationship with others and self. "The first entails the second; the second presupposes and depends on the first" (Hagner, 1995:648).

Bengel (2020) notes that those who love God will love themselves without being selfish.

> God loves me as He does thee; and thee as He does me: therefore, I ought to love thee, my neighbour, as myself; and thou me as thyself: for our love to each other ought to correspond to God's love towards us both.

Whedon's (2020) commentary on "*as thyself*" – so that we may love the self, explains that the Scriptures teach self-denial, but it does not teach self-annihilation. It forbids selfishness, but does not forbid self-love. For Schaff (2020) one ought to love one's neighbour not as one loves the self but as one ought to love the self; not to the same degree, but after the same manner, which is freely and readily, sincerely and unfeignedly, tenderly and compassionately, constantly and perseveringly.

Henry (2020c) comments that God's love is the first and greatest commandment and the summary of all the commands of the first table. God being good infinitely, originally and eternally must be loved first and nothing loved beside Him. Love is the first thing that God demands from His people and for this reason the first thing that believers should devote to Him as their Creator, Owner and Ruler, is to love with one's whole heart, soul and mind. To love one's neighbour is the second great commandment (v.39). It is implied that the believer must love the self, not self-love that is corrupted and rooted in sin, but a self-love which is natural and the rule of the greatest duty which must be preserved and sanctified.

This kind of self-love is to have due regard for the dignity of one's own nature and a due concern for the welfare of one's soul and body.

6.6 HOPE (ROMANS 8:18-28)

Hope relates to 'what is'. It does not cause the believer to deny reality. In fact, hope provides the courage to face hardships during the life journey. Hope does not avoid the pain felt during hard times nor is it naïve about suffering (Lester, 1995:85). The key event in the Christian story which speaks to the believer during suffering is the crucifixion where God embraces suffering as a reality of human existence. By the cross the believer is reminded that nothing "*neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord*" (Romans 8:39 NIV). Through the resurrection the believers finds hope and comfort for their souls. In Cristian theology hope has been defined in many ways such as a passion, desire, expectation, reliance, virtue and a form of praxis. Each of these definitions portrays elements of the phenomenon of hope that lies at the heart of Christian life (Sain, 2015:197-215).

"*Hope*" ἐλπίδι (*elpidi*)
Strong's Greek 1680: Hope, expectation, trust, confidence. From a primary elpo; expectation or confidence.

Source: Strong's Lexicon (2020b)

Paul starts Romans 8 by celebrating those who believe in Christ and walk under the influence of the Spirit and God sending His son into the world to redeem mankind from sin. Moving to the miserable state of the carnally minded and how Christ lives and works in and through the believers, their blessedness on earth and their happiness after the earthly journey explaining that suffering is the common lot for all of mankind and from which Gentiles and Jews have the hope of being delivered. Paul highlights the importance of hope in Romans 8:24-25 and the Spirit mediating for Christs' followers with the message of hope that all things work together for good to them who love God and live according to His gracious purpose, bringing mankind to eternal glory (Romans 8:29-30). The great blessedness, confidence and security of all believers who, while they hold onto faith and good conscience, have the promise that nothing can separate them from the love of God (Romans 8:31-39; Clarke, 2020).

> Hope is a state of being which corresponds with the quality of our life and the character of ultimate goals. Hope reflects our basic attitudes, disposition and philosophy of life (Louw, 2011a:238).

Louw (2011a:237-239) explains that hope has to do with the psychological event of anticipation and moving forward versus regression. It touches one's awareness of the future. Past and present therefore cannot be separated from the future. The ties between the future and the present are patience, perseverance and endurance. "A mature hope is therefore characterised by an ability to wait", making it a way of living (Louw, 2011a:238). Thus, as one learns to live, one learns to hope and to prepare to die. Christian hope is the resurrection power of Christ making it an intrinsically resurrection hope "because of the resurrection dimension, immortality and the new life in Christ are inseparable" (Louw, 2011a:238). The believers' understanding of hope is part of their being in Christ. In this way hope is a state of being qualified by the cross and the resurrection of Christ. A vital part of Christian hope is the tension between the not yet and the already "*For in this hope we were saved. But hope that is seen is no hope at all. Who hopes for what they already have? But if we hope for what we do not yet have, we wait for it patiently*" (Romans 8:24-25NIV).

Uwineza (2018:75-89) states that the death of Christ and His resurrection ground human hope. "Hope is trust in the promise of God as our absolute future". It is an act of surrendering the self to that which lies beyond; furthermore, it is an acknowledgement of human limitations. Hope empowers the believer "to have trust enough to undertake anew an exodus out of the present into the future" (Rahner, 1991:34). Hope incites the believer to commit the self in both thought and deed to the incomprehensible mystery of God (Rahner, 1991:33). Hope is a theological virtue established on the premise that one's daily commitments and decisions are of vital importance. This requires surrendering the self to God and being aware that despair comes partly because of the refusal to abandon the self to the unpredictable and the uncontrollable. By contrast the person with hope can contribute to the transformation of this world, to plan for the future (however provisional) knowing that this planning is vital for one's well-being knowing that one's ultimate consummation is God (Uwineza, 2018:75-89).

Dunn (1988:464) explains that for Paul history in total reduces to the destinies of Adam and Christ. To exclusively be a member of Adam is to stay short of the excellence of God's purpose for mankind on the way to death. Christ alone has accomplished that divine purpose. Only He has inherited God's glory. Therefore, only those in Christ will share in that inheritance – but only if they have shared in His suffering to death. The full meaning of "*having the spirit of Christ*" (Romans 8:9) means that it is not merely receiving the Spirit, nor merely a sustained quality of conduct and lifestyle (v.14), but an entire life in the course of which the death of Christ achieves full expression (Dunn, 1988:464).

Guzik (2018b) goes on to state that Paul did not have an ignorant or blind approach to the suffering of human existence as he himself experienced tremendous suffering. "*I have worked much harder, been in prison more frequently, been flogged more severely, and been exposed to death again and again*" (2 Corinthians 11:23 NIV). Despite his own suffering he still believes that the future glory far overshadowed the present suffering. "*And we know that in all things God works for the good of those who love him*" (Romans 8:28 NIV). God's sovereignty and capability to manage all aspects of the believers' lives are demonstrated in the fact that all things work together for the good to those who love God; though suffering is a fact that must be faced during the life journey. "*I consider that our present sufferings are not worth comparing with the glory that will be revealed in us"* (Romans 8:18NIV). God can make suffering work together for the good of both man and God (Guzik, 2018b). "The sufferings are small and short and concern the body only; but the glory is rich and great, and concerns the soul, and is eternal" (Henry, 2020a).

According to Rich (2016), for the Apostle Paul hope has to do with God's ultimate triumph over all that are opposed to Him and His ways. Amid the things that God will defeat in the last days are included sin and all forms of brokenness and separation, illness and death itself. The destruction of sin and death and the victory of God's goodness in giving life to those who have put their faith in Christ are the final things for which the believer is to hope. To be able to hope in these things promised makes it possible for believers to endure whatever is broken by sin and death (Rich, 2016).

Also known as the theologian of hope, Moltmann (1965:1) states that Scripture fundamentally has the character of promise and is therefore eschatological in nature. The Bible offers historical recollections under the umbrella of eschatological hope. The life, work, death and resurrection of Christ fall in the categories of expectation appropriate to the God of promise. "Christianity is eschatology, is hope, forward looking and forward moving and therefore also revolutionizing the present… Eschatology is the passionate suffering and passionate longing kindled by the Messiah" (Moltmann, 1965:2). For Moltmann (1965:2) God is not "intra-worldly" or "extra-worldly" but the God of hope (Romans 15:13). As made known in Exodus and in Israelite prophecy, the God who encounters the person in His promises for the future and whom a person cannot 'have', but can only wait in active hope. Christian eschatology therefore speaks of Christ and His future recognising the reality of the raising of Christ and declares the future of the risen Lord. All bases of Christ say who He was but furthermore also state as to whom He will be and what is to be expected from Him. "*He is our hope*" (Colossians 1:27 NIV) announces Christ's future in the world in terms of promise, pointing the believer towards the hope of the future. In this promise the hidden future already declares itself and applies its influence on the present through the hope it rouses (Moltmann, 1965:3).

> Christian hope is resurrection hope, and it proves its truth in the contradiction of the future prospects thereby offered and guaranteed for righteousness as opposed to sin, life as opposed to death, glory as opposed to suffering, peace as opposed to dissension (Moltmann, 1965:4).

Yet this hope does not suppress or avoid the unpleasant realities of life. Death is real, death and suffering remains, even for the believer, there are no ready-made answers. Faith does not overstep hardships into a heavenly utopia and does not wish itself into a different reality. It is by following the Christ who was raised from suffering, from a God-forsaken death and from the grave that the believer gets a viewpoint that there is nothing more that can oppress the believer, “a view of the realm of freedom and of joy” (Moltmann, 1965:5).

> Faith binds man to Christ. Hope is therefore the inseparable companion of faith… Hope is nothing else than the expectation of those things which faith has believed to have been truly promised by God. This faith believes God to be true, hope awaits the time when this truth shall be manifested; faith believes that He is our Father, hope anticipates that He will ever show Himself to be a Father towards us; faith believes that eternal life has been given to us, hope anticipates that it will sometime be revealed; faith is the foundation on which hope rests, hope nourishes and sustains faith (Moltmann, 1956:5-6).

Therefore, faith has the priority, but hope is the primacy. Without faith (knowledge of Christ) hope turns into a utopia, but without hope, faith falls into pieces becoming fainthearted and finally a dead faith. “It is through faith that man finds the path of true life, but it is only hope that keeps him on that path” (Moltmann, 1965:6).

6.7 CONCLUSION

The loving, self-emptying God only seeks good for His people, wanting His people to live for more than this fragile earthly life. The vulnerable God, Kenotic creator, compassionate God, God the Triune seeks a deep, personal, loving relationship with mankind.

In Exodus 3:14 God reveals His name to Moses with the words “*I AM*” and “*to you*”. This revelation of His identity is a promise that God will be with His people, that He seeks a deep, personal and loving relationship with His people, bestowing grace and having mercy on them throughout time. God, being with His people is a divine presence making it boundless and unending throughout time. Being in a relationship with God IFCs can thus truly know that others before them have walked the same path and those to come will follow on the same path. God, “*I AM*”, is as unchangeable today as all those generations ago. To be able to hope in this promise can make it easier for IFCs to endure the cancer journey. IFCs get hope by knowing that *“I AM”, “to you*” will be with them yesterday, today and tomorrow. They can reflect on God’s faithfulness and His forever-enduring love.

In Ephesians 2 The Apostle Paul connects Christ’s great love and His sacrificial death, teaching the people about God’s desire to be re-joined with mankind made in His image and for His glory. God is defined as self-offering love in the self-limitation which was His incarnation in Jesus Christ and in the self-offering of Jesus’ human life for condemned mankind. That is why pain, suffering and death of humanity are also regarded as influencing God. This self-emptying and self-offering (a kenosis) of God, a sharing in the suffering of His people demonstrate the suffering love primarily in and through Jesus Christs’ life, suffering, death and resurrection. God essentially kind, merciful and loving reaches out in love to humans who are condemned offering them salvation and all the eternal blessings that come with it.

Concerning the great commandment of the law in the Gospel of Matthew 22:36-39, the evangelist highlights that Christ's Great Commandment contains two requirements both equally important. This double commandment is to love God and one's neighbour. Christ brings the Ten Commandments to love to God and love to neighbour. All the law is thus fulfilled in one word namely love. This law assumes that IFCs should love themselves (be self-compassionate) or otherwise they will not be able to love others. The love commandments cannot be separated; they belong together, embracing the vertical relationship with God and the horizontal relationship with others and self. It is revealed that those who love God will love themselves without being selfish. The Bible forbids selfishness, but does not forbid self-love. "*As thyself*" therefore means that IFCs may (must) love the self. In fact, IFCs must not love others the same way they love themselves but as they ought to love themselves, not to the same degree, but after the same manner, which is freely and readily, sincerely and unfeignedly, tenderly and compassionately, constantly and perseveringly.

Romans 8:18-23 teaches about hope. God became mankind's "co-sufferer" through His incarnation in Jesus Christ and in the self-offering of Jesus' human life. The Christ event shows that God not only experiences suffering and death on the cross, but importantly overcomes suffering and death through the resurrection. The destruction of sin and death and the victory of God's goodness in giving life to those who have put their faith in Christ are the things that the believer must put their hope on.

A cancer journey brings painful losses or "little deaths" throughout the journey, for example the loss of familiar routines, the loss of health and sometimes the loss of life itself. For healing, IFCs must mourn all the "little deaths" throughout the journey. This process of grieving will allow their hearts to acknowledge the pain and trauma finding hope in the fact that God is love, He is compassionate and with His people through all the seasons of their earthly journey and beyond. God being-there, being-with and being-for His people.

CHAPTER7: PASTORAL CONCEPT OF MINDFULNESS

7.1 INTRODUCTION

The preceding chapters showed the importance of taking a more holistic perspective in order to accompany IFCs to a position of emotional and spiritual well-being, helping them cope with cancer related stress. This suggests that the IFC must be approached as a unique whole-person (physical, emotional and spiritual) within a unique situation starting the therapeutic process from diagnosis to remission, or death and bereavement. Clinton and Ohlschlager (2000:21) state that people “experience suffering in their entire being, affecting and damaging body, soul and spirit. Suffering is pervasive.”

For the PC to promote IFCs’ stress resilience and wellbeing in a positive, integrated and sustainable way, this chapter will include findings of the relevance of mindfulness for both IFCs, as well as the PC. It will be demonstrated that the underlying principles of mindfulness are compatible with Christianity, as well as a method to enhance the Christian spiritual journey and increase value-based behaviour. Where most therapy models mainly focus on symptom reduction, assuming that clients need to reduce their symptoms in order to lead a better life (Hayes *et al*., 2006:1-25), ACT promotes a mindful, value-congruent living as the desired outcome (Waltz & Hayes, 2010:148-192; cf. 4.4). ACT works towards a fundamental change within IFCs’ way of dealing with their symptoms (such as stress) so that the symptoms can no longer hold them back from valued living (purpose and meaning). Mindfulness skills, through ACT can help IFCs to remain centred and focused on Christ and Biblical values amid the cancer journey (Symington & Symington, 2012:71-77).

The outline of this chapter will be as follows. The concept of mindfulness will be discussed within the framework of Christianity, followed by the four movements of the Cycle of Grace by Hudson and Haas (2012). Thereafter, a discussion of the positive effect of mindful labyrinth walking follows. The chapter concludes with thoughts about the mindful compassionate PC. Lakes’ (Peters, 1989:132) teachings on the PC stand central in how the PC needs to enter the caregiving space and relationship with IFCs. The PC is not only a listener, observer and trusted “partner”, but the PC must comprise vital aspects such as compassion, non-judgment and acceptances. Thus, the PC must have a willingness to walk the confusing and painful road of the cancer journey together with IFCs in the present moment, without avoiding pain from the diagnosis to the end (remission or death and bereavement) in the belief that “when God and cancer meet, God always is more powerful. Whether He takes the cancer out of the person or them out of the cancer, he gives every believer the victory” (Eib, 2006).

7.2 MEANING IN SUFFERING

Throughout history, human beings seek to discover the causes of suffering and ways to alleviate it, bringing every individual sometime during their lives to the questions “Why am I not feeling better?” and “What can I do about it?” Human beings will be exposed to pain during their lifetime which is associated with sickness, old age and ultimately death; it is inevitable. Clinton and Ohlschlager

(2000:20) state that human suffering is universal from which there is no escape. There is also the emotional pain and struggles when confronted with hardships such as a loved one being diagnosed with cancer. The concept of mindfulness used in this study is for IFCs to no longer ask, “Why?” and “For what reason / purpose?” but to find meaningful acceptance of suffering. From God’s mercy and faithfulness, these questions will be replaced with “To what purpose?” The *where to* question does not imply that IFCs will receive answers and reasons. It means that IFCs discover God’s faithfulness within their pain and confusion. IFCs will then understand the will of God (love and mercy; Louw, 2011a:226). Louw (2011a:226) proposes that “suffering as such is not so much God’s will, but that which could happen to a person during affliction”. The core of the question of meaning is not what happens to IFCs but what can happen in and through them. God is thus interested in IFCs’ reaction to and spiritual growth through the cancer journey. To merely give in and say, “God sends this illness” and accept it as such is an explanation too easy. The challenge and opportunity of the cancer journey lie in the question, “to what purpose does God use cancer in the life of IFCs and their family?” “The crux of the meaning of illness is not the reality of illness, but the responsibility towards illness in obedience to God’s promises” (Louw, 2011a:226). The PC must lead IFCs to discover the challenge and opportunities connected to the cancer journey. “The opportunity presented by illness is a responsibility before God, a chance to serve fellow human beings and to bear witness to the loving care of God” (Louw, 2011a:226).

7.3 THE CONCEPT OF MINDFULNESS

To find a healthy way of living with pain and hardships, Siegel *et al.* (2008:1-28) propose the practice of mindfulness. They explain that “mindfulness is a deceptively simple way of relating to all experiences that can reduce suffering and set the stage for positive personal transformation”. Rather than trying to escape the pain accompanied with hardships, mindfulness practices will help IFCs to increase their capacity to bear it. By exploring and accepting unpleasant experiences the capacity to bear them increases. IFCs will also discover that painful sensations are different from the suffering that accompanies them realising that suffering arises when they react to their pain with resistance, protest or avoidance instead of moment-to-moment acceptance (Siegel *et al.*, 2008:1-28). The purpose of mindfulness is to empty the mind of personal narratives in order to listen to God and sense His presence enabling IFCs to hear God more clearly. In the discipline of mindfulness, it is not so much acting as IFCs opening themselves to be acted upon. Mindfulness is an invitation to “the Holy Spirit to come and work within [IFCs] – teaching, cleansing, comforting, rebuking” (Foster, 1983). Mindfulness is a core spiritual and psychological process with the ability to alter how one responds to unavoidable difficulties in life to everyday existential challenges to severe hardships. Mindfulness is part of what makes people human, it is the capacity of being fully conscious and aware (Tan, 2011:243-249). “Most people find that the moments they value the most are those in which they are fully present, noticing what is happening in the here and now” (Siegel *et al.*, 2008:1-28). Unfortunately, because people are mostly absorbed in daily tasks and personal narratives, they are generally only mindful of the present moment for brief periods of time, thus most of the time on ‘autopilot’ or being mindless. Examples of mindlessness in the case of IFCs, can be rushing through caregiving tasks missing out on special moments with their loved ones, or in failing to notice their own subtle feelings of physical tension or discomfort, and finding themselves preoccupied with the future (outcome of cancer) or past (cancer free days). IFCs must recognise the sacredness of the present moment with their loved one and surrender thoughts and feelings of anxiousness to God (Tan, 2011:243-249). Even in IFCs pressured and distracting daily lives it is possible to experience mindful moments; each mindful moment then becomes a mindful lifestyle. They can momentarily disengage from their caregiving duties by taking a long, conscious breath. After gathering their attention, they can ask themselves “What am I feeling right now?”, “What am I doing right now?”, “What is most compelling to my awareness right now?” (Germer, 2004).

The National Institute of Health (NIH), formally accepts meditation (mindfulness) as a therapeutic practice that may be associated with conventional medicine (Josephine & Briggs, 2016), keeping in mind that it must be practised daily and constantly to fulfil its role as complementary and preventive medicine (Cardoso *et al*., 2004:58-60). The Brazilian Ministry of Health has included meditation (mindfulness) in its National Policy, which encourages health centres and public hospitals to offer meditation as a therapeutic alternative. The actions of these governments are a sign of recognition and accepting meditation (mindfulness) not only for mental and spiritual well-being, but also for physical well-being (Lizier *et al*., 2018:1-11). With the correct technique of mindfulness, IFCs can reach a state of physical relaxation and respiratory balance in a natural and spontaneous way. The capacity for continous and sustained moment-to-moment awareness (especially amid emotional turmoil caused by a cancer journey) is an extraordinary skill. Fortunately, it is a skill that can be learned. According to Shapiro *et al*. (2006:373-386), there are three critical components of mindfulness which are, attention, intention and attitude. Intentionally paying attention with a non-judgmental attitude leads to noteworthy changes in perspectives, also called decentring (Fresco *et al*., 2007:234-246).

For Bishop *et al*. (2004:230–241), mindfulness consists of two elements, namely, paying attention to the present moment to experience it as it happens, and relating to the experience with a curious, open and accepting attitude. According to Birnie *et al.* (2010), mindfulness is focussing on internal experiences such as emotions, sensory awareness of the body, sound, sight, smell, taste and awareness of passing thoughts and emotions, instead of the self as the experiencer. Symington and Symington (2012:71-77) define mindfulness as “the process of keeping one’s mind in the present moment, while staying non-judgmentally detached from potentially destructive thoughts and feelings”.

Christian meditation (cf. 5.6) can be considered as the foundation of a Christian framework for mindfulness (Tan, 2003; Hathaway & Tan, 2009:158-171) where the believer shifts consciousness from the outer world to the inner world. Mindful practices rooted in Christian religion include awareness, which is the internal ability of observing one’s own thoughts (Lutz *et al*., 2015:632-658; Smith, 2013:

91-102). In the process, the believer learns to regulate his or her emotions through deep breathing and stillness which can lead to unity with God and it applies listening skills to deepen one's relationship with self and God (Keating, 1999; Tan, 2011:243-249). From a Christian perspective mindful breathing is used to reflect on God, finding His loving presence and intention (Symington & Symington, 2012:71-77). IFCs can reflect on their inner thoughts allowing the content of their thoughts to lead them to biblical truths, as well as qualities of compassion and loving-kindness (Tan, 2011:243-249). These skills (awareness, regulating emotions and listening skills) can be achieved by being still in a quiet space and practising for example serenity prayer, centring prayer (cf. 5.6) and deep breathing which are rooted in the behavioural practice interventions of ACT (cf. 4.4). Practising mindfulness-based stress reduction (MBSR) reports a significant increase in both spirituality and emotional mindfulness (Carmody *et al*., 2008:393-403).

Spirituality relates to a personal experience of transcendence, or in other words a personal experience of wholeness (Peterman *et al*., 2002:49-58). Studies show a strong connection between spirituality and self-transcendence, such as being concerned for others, as well as integrating past and future in order to enhance the present (Wasner *et al*., 2005:99-104). Spirituality in this study is defined as a sense of connectedness with God, other people and the self. Spirituality refers to a sense of connectedness to something greater than the self (God) by participating in religious practices, such as scripture reading (cf. 5.6.1), prayer (cf. 4.4.3, 5.6.2, 5.6.3), worship (cf. 5.6.4), mindfulness and finding meaning and purpose through such practices (Kim *et al*., 2012:974-983). Because the IFC is regarded as a whole-person, self-transcendence in this study refers to the development of, or growth in the self in multiple ways, such as intrapersonal (inner potential experiences), interpersonally (connecting with others in IFCs environment), temporally (enhance the present) and transpersonal (through religious practices), forgiveness and a relationship with God (Kim *et al*., 2012:974-983; Reed, 2014:109-139). Besides influencing self-transcendental behaviours and emotions, religious teachings further promote transcendental ways of thinking about the self (understanding one's identity in God) in relation to broader questions and beliefs about for instance, one's existence (meaning and purpose). It is also called self-transcendent cognition. One viewpoint of self-transcendent cognition regards the self as "embedded in something greater than the self" (Benson *et al*., 2003:205-213). In this case, Christians often speak of a oneness among individuals, God and Christ (Galatians 3:28; Lin *et al*., 2020).

Studies have examined the positive intrapersonal benefits of religious self-transcendence particularly focussing on positive effect and well-being that is also the aim for IFCs in this study. Self-transcendence emotions such as gratitude, awe and elevation, defined by Haidt and Morris (2009:7687-7688) as positive emotions resulting from others' praiseworthy actions are believed to characterise religious experiences (Emmons, 2005:731-745). Joining evidence points to strong associations between self-transcendent emotions and religious beliefs. For example, gratitude (McCullough *et al*., 2002:12-127), awe (Van Cappellen & Saroglou, 2012:223-236) and love (Kim-Prieto & Diener, 2009:447-460) have been positively linked to religiousness, suggesting that believers experience such emotions to a greater extent than those less religious (Tong, 2017:70-81). Studies have also proved that religious practices improve the experience of self-transcendent emotions (Lambert *et al*., 2009:139-149; Kashdan & Nezlek, 2012:1523-1535).

Accordingly, mindfulness is not merely a practice to foster self-awareness or improve emotional regulation, but also a practice bringing the believer to deeper biblical truths, such as meaning and purpose of life (Louth, 2012:137-146). For the believer, purpose, meaning and hope can be found within a relationship with God (Keating, 1999; Hathaway & Tan, 2009:158-171). Thus, a relationship with God and the ability to understand God are both on an experiential and cognitive level. Scripture teaches the believer that God is always with them (cf. 6.2). God is a compassionate God (cf. 6.3) who teaches love (cf. 6.4) and gives hope (cf. 6.4). By reading the Bible (cognitive) the believer learns how to live a life committed to God by living the cycle of grace making it an experience or way of living on intellectual, emotional and spiritual levels thus a whole-person experience. “Cultivating mindfulness is, and has always been, a deeply personal journey of discovery” (Siegel *et al*., 2008:2).

It is important to be mindfully aware of hardships in a grounded way in order to extend compassion towards the self (cf. 4.2.1) without over identifying with the situation (cancer journey and caregiving tasks). Mindfulness is the first step, which is turning with loving awareness toward difficult experiences (thoughts, emotions and sensations). Self-compassion comes next, which is bringing loving awareness to the self. Together these two attributes comprise a state of warm, connected, presence during the difficult moments in life. According to Neff (2003a:89), mindfulness is necessary to allow enough mental distance from personal hardship so that room can be made for feelings of self-kindness and common humanity. Mindfulness heightens self-kindness (Neff, 2003a:89) through its non-judgmental and detached stance that in turn lessens self-criticism and increases self-understanding (Jopling, 2000:71), which can help IFCs to take care of themselves and notice early signs of caregiving fatigue. Mindfulness further counters feelings of isolation and separateness by reminding IFCs that suffering and hardships are universal. This realisation can help IFCs put their personal experiences, together with the cancer journey, into perspective by creating a feeling of connectedness with other IFCs, as they support each other (Neff, 2003a:89; 2004:29). In managing mindfulness, the IFC can extend self-kindness and recognise the cancer journey as part of the larger human experience (Neff, 2004:29). In short, mindfulness is a skill which helps IFCs to find meaning and purpose not only in life, but also in pain, grief and sorrow as they learn to operate at a deeper level of intensity (Clinton & Ohlschlager, 2000:21). Thus, allowing IFCs to be less reactive to what is happening in the moment and connecting to all experiences (positive, negative and neutral) in such a way that overall suffering is reduced and a sense of well-being is increased, together with acceptance and calmness (Birnie *et al.,* 2010).

7.3.1 Neuroscience and mindfulness

Studies indicate that mindfulness has the potential to physically change the brain and body, supporting the improvement of several physical and psychological conditions (Lizier *et al*., 2018:1-11).

Neuroscientist Lazarus (2005:1893-1897) did extensive research on mindfulness meditation. The first study by Lazarus *et al*. (2005:1893-1897) reviewed long-term meditators with seven to nine years of meditation experience versus a control group. The results of this study prove that individuals with a strong meditation background had increased grey matter in various areas of their brains compared to the control group, including the auditory and sensory cortex, as well as the insula and sensory regions. These results were to be expected as the goal of mindfulness meditation is to slow the individual down, with the purpose of becoming more aware of the present moment, which includes physical sensations such as breathing and external sounds. Research also found more grey matter in another region of the brain linked to decision-making and working memory of the frontal cortex. To make sure that these findings were not because the long-term mindful meditators had more grey matter to begin with, a second study was conducted by Hölzel *et al*. (2011:36-43), this time using participants with no mindfulness meditation experience. In order to find noteworthy positive results, it was proposed that the inexperienced participants practised mindfulness meditation 40 minutes each day during an eight-week programme. The inexperienced participants reported an average of 27 minutes each day and still produced positive changes (Hölzel *et al.*, 2011:36-43). Other studies confirm that significant positive changes can be seen in just 15 to 20 minutes of mindfulness practices, such as breathing exercises and body scanning (Hoge *et al*., 2013:786-792). In the eight-week mindfulness programme, research found that the inexperienced participants' brains changed for the better (similar to those found in study one with the long-term mindful meditators), showing thickening in several regions, including the left hippocampus (learning, memory and emotional regulation), the parts involved in empathy and ability to take multiple perspectives, as well as the part of the brainstem called the pons where regulatory neurotransmitters are generated. After the eight-week programme the brains of the inexperienced participants saw shrinkage of the amygdala, which is associated with fear, anxiety and aggression (Roemer *et al*., 2008:1083-1089; Hofmann *et al*., 2010:169-183). The effectiveness of mindfulness-based interventions in the treatment of other clinical disorders includes (among others) depression (Teasdale *et al*., 2000:515-623; Hofmann *et al*., 2010:169-183) and chronic pain (Grossman *et al*., 2007:226-233). Mindfulness is also used to treat life transitions and relational difficulties (Symington & Symington, 2012:71-77), which are major factors when dealing with a cancer journey. From these studies it can thus be concluded that mindfulness meditation is equally beneficial for both experienced as well as inexperienced mindful meditators. A study done on regular mindfulness practitioners showed that mindfulness training improves brain efficiency for attention and impulse control compared to non-meditators, suggesting that mindfulness training may improve brain efficiency (Kozasa *et al*., 2012:745-749). While mindfulness meditation has been proved to reduce stress and to induce a relaxing state of mind it also has noteworthy effects on how people perceive and process the world around them and then change the way they regulate attention and emotion (Lippelt *et al*., 2014:1-5). According to Lutz *et al*. (2008:163-169), the kind of effect meditation has on an individual will differ according to the kind of meditation practised. Currently the most researched types of mindfulness meditation include focused attention meditation (FAM), open monitoring meditation (OMM) and loving-kindness meditation (LKM; Lippelt *et al*., 2014:1-5) – each of these types of meditation will have different neural and behavioural effects.

In other words, the mind can be transformed through mindfulness practices and thereby change the brain and the periphery in ways that can be beneficial for mental health, physical health and general well-being (Davidson, 2016). FAM is usually the starting point for beginners where the individual is required to focus his or her attention on a chosen object such as breathing. Once the individual is familiar with the FAM technique and can easily sustain their attentional focus on their breathing for a considerable period of time, they progress to OMM. With OMM, the focus of mindfulness meditation becomes the monitoring of awareness itself. Here the aim is to remain in the monitoring state, remaining focussed to any experience that might come up, without selecting, judging or focusing on any particular object. OMM will start with FAM and gradually reduce the focus on breathing to monitoring awareness. LKM incorporates elements of both FAM and OMM, where the individual focuses on developing love and compassion, first for themselves and gradually extend this love to others. Any negative associations that may arise must be replaced with positive ones such as empathic concern (Lutz *et al*., 2008:163-169; Vago & Silbersweig, 2012:296).

One of the most popular mindfulness practices is mindful breathing, where the individual solely attends to his or her breath. Slow breathing helps instigate less reactive emotion and helps the calming and focusing of intellectual processes. The science of breathing stands on quite ancient foundations. Centuries of wisdom advise people to pay closer attention to their breathing (the most basic of things done each day), and still the importance of breathing is easily ignored, maybe because it is such a basic act.

7.3.2 Neuroscience and breathing

Mindfulness meditation shows positive influences on physical healthy, such as improved immune functioning (Davidson *et al*., 2003:564-570; Carlson *et al*., 2007:1038-1049) and reduced blood pressure and cortisol levels (Carlson *et al*., 2007:1038-1049). It has also been proved to produce positive effects on the physical well-being of healthy individuals (Carmody & Bear, 2008:23-33; Chiesa & Serretti, 2009:593-600) and to improve cognitive functioning (Jha *et al*., 2007:109-119; Ortner *et al*., 2007:27-283; Pagnoni & Cekic, 2007:1623-1627; Slagter *et al*., 2007:138). Brown *et al.* (2007:211-237) define several beneficial effects of mindfulness meditation such as insight, exposure, nonattachment, enhanced mind-body functioning and integrated functioning. From the evidence of above research, this study strongly suggests that IFCs start with mindfulness meditation as soon as possible (before exhaustion, anxiety, fear sets in) in order to remain as calm and healthy as possible during the cancer journey.

A) Controlling one's breathing calms the brain

Therapeutic techniques have been using conscious controlled and awareness breathing for centuries to promote mental calming and clinically used to suppress excessive arousal such as panic attacks, with little understanding of the mechanisms underlying the benefit thereof. Science only recently started to uncover how it works, for instance a study done by Yackle *et al*. (2017:1411-1415) found that the neural circuit in the brainstem plays a key role in the breathing-brain control connection. This circuit forms part of what is called the brain's "breathing pacemaker" because of its ability to adjust by altering one's rhythm of breathing which in turn then influences emotional states (slow and controlled breathing decreases activity in the circuit, whereas fast and erratic breathing increases activity). It has been concluded that simple and controlled breathing exercises, such as the 4-7-8 method may work to regulate the circuit (Yackle *et al*., 2017:1411-1415). Breathing exercises activate the body's parasympathetic nervous system (PNS), which raises feelings of calm and lessens feelings of fear that originate in the sympathetic nervous system (SNS). When presented with an alarming stressor, the body prepares to defend itself by naturally defaulting to the SNS (also known as the fight or flight response) which increases for example one's blood pressure and thereby the risk of certain health conditions, for example heart disease and anxiety. When the alarming stressor was actually a false alarm or only a perceived danger, the person can with repeated practise of the 4-7-8 technique restore the body more quickly to the PNS to calm itself (Thompson, 2019). According to Sharma *et al*. (2014:10-13), feeling in control of one's breathing can help to soothe stress and mental tensions. The physiological effect on the body is increased oxygen, which makes the body think that the mind is in a relaxed state and simultaneously lowers the heart rate. It is basically a command to the body to slow down all its functions.

B) Breathing regulates blood pressure

"Take a deep breath" is factual advice, especially when trying to keep one's blood pressure from spiking. While it is still unclear whether controlled breathing can entirely manage blood pressure, research done by Joseph *et al*. (2005:714-718) suggests that slow and controlled breathing increases "baroreflex sensitivity" which is the mechanism that regulates blood pressure via heart rate. Persistently exercising controlled breathing (to lower blood pressure and heart rate) may lower the risk of a stroke, cerebral aneurysm and decrease stress on blood vessels which is positive for cardiovascular health (Spicuzza *et al*., 2000:1495-1496; Goso *et al*., 2001:418-423; Bernardi *et al*., 2001:2221-2229; Bernardi *et al*., 2002:143-145).

C) Counting breaths taps into the brains' emotional control regions

A study, done by Herrero *et al*. (2018:145-159) notes that controlled (counting) breaths influence neuronal oscillations throughout the brain, particularly in brain regions related to emotions. Participants were asked to count their breaths over a two-minute period compelling them to closely pay attention to their breathing. When counted correctly, the brain activity (monitored by EEG) in regions related to emotion, memory, as well as awareness showed a more organised pattern against results normally experienced during a resting state. A study, conducted by Zelano *et al.* (2016:12448-12467) finds that there is a noteworthy difference in brain activity in the amygdala and hippocampus during inhalation compared with exhalation. The amygdala is strongly linked to emotional processing particularly fear-related emotions.

D) Controlled breathing may boost the immune system and improve energy metabolism

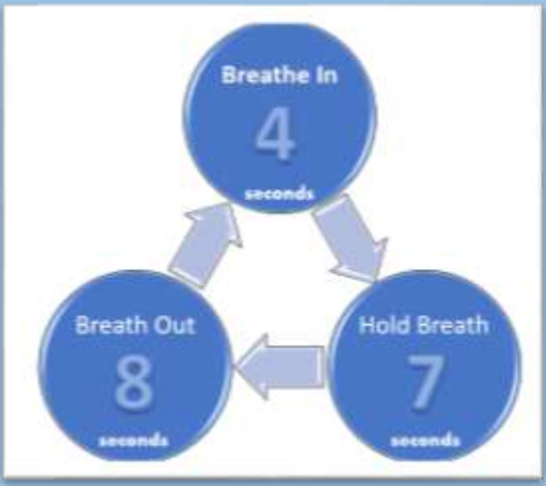
Bhasins *et al*. (2013:1-13) evaluate the relaxation response which refers to a method of engaging the parasympathetic nervous system to counter the sympathetic nervous system's fight or flight response to stress. According to the theory, controlled breathing triggers a parasympathetic response and may further improve immune system resiliency as a 'downstream health benefit'. In addition, the study notes energy metabolism improvements and more efficient insulin secretion, which results in improved blood sugar management. The results support the conclusion that controlled breathing can be a counterbalance to stress, as well as being important for overall health improvement. Other potential health benefits that deep breathing can have for IFCs include decreased fatigue, better stress management, reduced hypertension, reduced aggressive behaviour in adolescent males and improved migraine symptoms (Varvogli & Darviri, 2011).

As the caregiver must find a new normal and balance extra duties due to a cancer diagnosis and journey, there is little time and energy left to take care of the self. From the research it can be concluded that the "simple" task of breathing is highly recommended for IFCs, as steady and controlled breathing requires little input and effort but in return offers great health benefits. The technique recommended in this study, namely 4-7-8 breathing will be explained.

Box 23: 4-7-8 Breathing exercise

The 4-7-8 breathing technique was invented by Weil (2020), a world-renowned doctor focusing on holistic health. This technique focuses and calms the mind by helping to quieten thoughts like mindfulness meditation. Dr Weil (2020) refers to the technique as a natural tranquilizer for the nervous system.

Guide for the 4-7-8 breathing technique: 4-7-8 Breathing works in three ways



<table>
<tr><td colspan="3">Before starting the breathing pattern, adopt a comfortable upright sitting position and place the tip of the tongue on the tissue right behind the top front teeth.
Empty the lungs of all air and:</td></tr>
<tr><td>Inhale
1. close your mouth and inhale quietly through your nose to a mental count of four.</td><td>Hold your breath
2. hold for the count of 7.</td><td>Exhale
3. exhale completely through your mouth, making a whoosh sound to a count of eight.</td></tr>
<tr><td colspan="3">These three steps are one breath cycle. For best results, the cycle must be practised at least twice a day (or more), but never more than four breath cycles at a time for the first month. After the first month it can be increased to 8 breath cycles.
Please note: the technique may make some people feel light-headed (especially at first). A person who cannot hold their breath for long enough may try a shorter pattern instead, such as: inhale for 2 seconds; hold the breath for 3.5 seconds, exhale for 4 seconds (2: 3.5: 4)
<u>Video</u>: For a demonstration of the technique by Dr. Weil go to https://www.drweil.com/videos-features/videos/breathing-exercises-4-7-8-breath/.
<u>App</u>: 4:7:8 breathing app suitable for iPhone, iPad and Apple devices is available.</td></tr>
</table>

Source: Author compiled table from relevant literature

7.4 CYCLE OF WORKS vs CYCLE OF GRACE

The book, *The cycle of grace. Living in sacred balance* by Hudson and Haas (2012) is a powerful lesson from the life of Christ. The dynamic circle was first discovered and published by Lake[6] (Peters, 1989:132), who connected with Brunner (Hudson & Haas, 2012:13) to study the Gospels, asking, “Why did Jesus of Nazareth not show signs of emotional and spiritual burnout during His intense mission?” What they discovered was that Christ lived a life of dynamic balance of receiving grace and giving grace (Anon, 2018). A model named “the dynamic cycle” represents Lake’s (Peters, 1989:132) and Brunner’s (Hudson & Haas, 2012:13) attempts to connect the dynamics of a well-functioning personality with spiritual health that is grounded in the rhythms of Christ’s life (Hudson & Haas, 2012:13). The purpose of this model is to correlate the dynamics of relatively well-functioning personality and of spiritual health, in its formation and maintenance before it turns around into a condition where this integral wholeness is lost and replaced with anxiety, conflict, defences, distress, doubt and various other emotions (Peters, 1989:121). Using this model, the PC can guide IFCs through their journey with cancer and accompanying emotions to hope, acceptance and peace.

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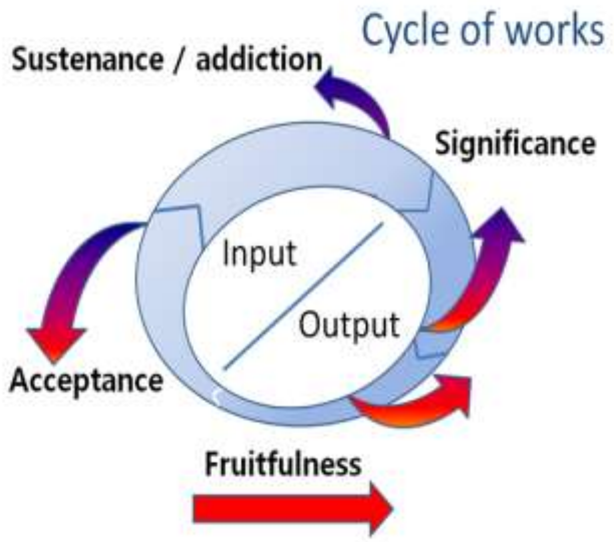
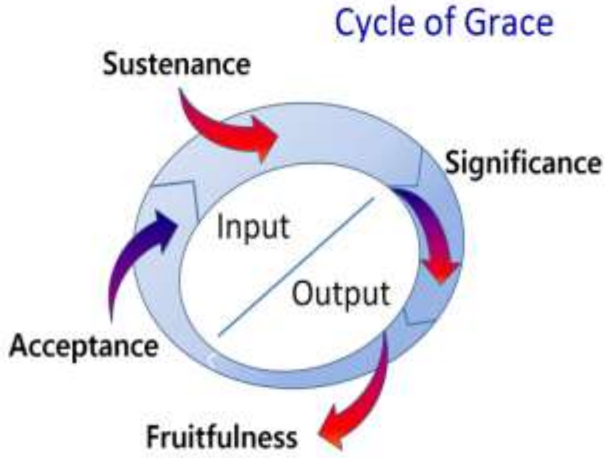
[6] Frank Lake book “Dynamic Circle”.1998. “Out of print”.



Source: *The cycle of grace. Living in sacred balance* by Hudson and Haas (2012)

Staying centred on God's loving acceptance the individuals' lives will bear fruit, but what happens when people follow their own movement?

The reverse of the biblical view (cycle of grace) is the cycle of works, also referred to as cycle of anti-grace which is followed in a quest to feel accepted and good enough, when people seek first to achieve, to be productive and fruitful (Hudson & Haas, 2012:47). By starting with achievement, the individual moves counter-clockwise, in other words against the flow of grace and becomes exhausted. From the world's point of view, the cycle of works / cycle of anti-grace will start with (i) achievement, which will give the individual the perception of (ii) significance, which then in turn (iii) sustains the person. Finally, if he or she succeeds through these three dimensions by their own efforts, they might have a chance to feel acceptance. Moving counter-clockwise conveys a false sense of security, because life is not without struggles and hardships and living in this way will sooner or later set one up for failure, making this type of life unsustainable and more difficult than it needs to be (Anon, 2020). IFCs will experience compassion fatigue if they operate from this cycle. Once immerged in the role of caregiving, IFCs tend to work tirelessly, putting their own needs and emotions second in order to first and foremost take care of the needs of the diagnosed loved one, which leads to burnout (cf.4.6). Striving to be the best caregiver and finding a new normal in a life turned upside down, IFCs lose connection with the self, their loved ones, the diagnosed person and with God, which can affect wellbeing both physically, emotionally and spiritually, leading to spiritual poverty.



Source: *The cycle of grace. Living in sacred balance* by Hudson and Haas (2012)

From a biblical view, the way into the cycle of grace is to begin with acceptance. About Christ's acceptance the gospel of Matthew says, "*And a voice from heaven said, this is my Son, whom I love; with him I am well pleased"* (Matthew 3:17 NIV). Because of Christ's finished work on the Cross, God's relationship with humankind was restored. God is the One who knitted everyone together in their mother's womb (Psalm 139:15). Even if rejected by fellow humans, God chose each person, adopting all as His own children (Psalm 27:10; John 1:12), which cost Him everything (John 3:16), providing all with a sense of being or belonging (Anon, 2020). The cycle of grace will empower IFCs to confidently and courageously take on the cancer journey and caregiving tasks, knowing that their worth and identity are secure in God. By following in Christ's footsteps and the rhythm of input and output that He set in place, IFCs will stay in balance on a physical, emotional and spiritual level (Anon, 2018). *"Come to me, all you who are weary and burdened, and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls. For my yoke is easy and my burden is light*" (Matthew 11:28-30 NIV).

By comparing the cycle of grace to the cycle of works, it becomes evident that burnout is not just physical, but also a spiritual matter. If one works for acceptance and to feel good enough as a caregiver, burnout becomes inevitable which can lead to spiritual poverty. If IFCs live in awareness of God's reality, trusting in God's loving acceptance, a different scenario will present itself leading into a fruitful life even during difficult times. The cycle of grace based on Christs' life has four dimensions namely acceptance, sustenance, significance and fruitfulness, which are placed within two dynamic phases that are the input phase and the output phase. The four movements will now be discussed.

7.4.1 Input phase: Acceptance

Divine acceptance comes in rare human relationships where one is fully known, valued and loved, "a relationship with a mutual sense of safety and trust" (Hudson & Haas, 2012:19). This kind of earthly relationship can be experienced through mentors (e.g. PC), family members and friends giving one the freedom to be oneself, share confidences, grieve losses and celebrate joys. Hudson and Haas (2012:19) refer to such a relationship as “divine acceptance” which can help IFCs to claim and reclaim their identity as a child of God even during hardships (cancer journey). Gods’ acceptance can be seen in the story of Jesus’ baptism before Christ started His ministry after He had received the acceptance and affirmation of His identity from His Father (Mark 1:11). Christ lived His life from the foundation of being God’s “*beloved Son”* with whom God is *“well pleased*” (Mark 1:11 ESV). Christ commenced His work with peace of heart, free from trying to please anyone, because He was secure in His identity and approval received as a gift of grace from God who loved Him (Anon, 2018). The New Testament highlights the truth that believers (IFCs) share this platform with Christ. Believers are regarded “*as God's chosen people, holy and dearly loved, clothe yourselves with compassion, kindness, humility, gentleness and patience”* (Colossians 3:12 NIV; Anon, 2018). Christ reflects God’s acceptance by mirroring it to others “o*ut of his fullness we have all received grace in place of grace already given”* (John 1:16 NIV), in other words the grace that Christ received became grace for all (Hudson & Haas, 2012:20). Many people find it difficult to accept God’s grace and to recognise that he or she is made in the image and likeness of God. Christ received and accepted grace and blessing by being anointed with oil by Mary (Mark 14:3-9; John 12:3). An example of Christ giving grace is when the child brought bread to share, Christ welcomed the gift and multiplied it (Mark 6:30-44). When Christ noticed Zacchaeus in the tree, He did not wait for an invitation but immediately accepted by saying “*Zacchaeus, come down immediately. I must stay at your house today*” (Luke 19:5). However reluctant IFCs may feel to receive God’s gift of acceptance, God will patiently welcome them into His loving embrace. God’s acceptance comes without long to-do-lists or strategies, as can also be seen in the story of the prodigal son who was unconditionally accepted back into his fathers’ house (Luke 15). “Acceptance ushers in a God-given identity, and God’s Spirit guides the coming encounters” (Hudson & Haas, 2012:21).

7.4.2 Input phase: Sustenance

The sustenance stage maintains the input where one is dependent on the continual input from outside sources. Christ was continuously sustained through God and the Holy Spirit (John 3:34; 5:20; 10:30). This is the root of wellbeing, where needs are met to give physical, mental and spiritual stability. God is the Preserver, the Protector (Psalm 12:15; Hebrews 12:1) and the Provider (Psalm 54:4; Ephesians 3:20; Anon, 2020). Hudson and Haas (2012:29) ask the question, ‘What are some of the ways that Jesus sustained his close relationship with God throughout His life?” Phrasing the question in this way, invites one to pay close attention to the life of Christ, not to merely imitate Christ, but to strengthen one’s own relationship with a loving Father God. To sustain His identity as God’s beloved Son, Christ regularly withdrew to spend time with His Father in prayer (cf.5.6.1, 5.6.2, 5.6.3), worship (cf. 5.6.4) and surrounding Himself with close friends who choose to believe in Him and who accepted the Word of God (cf. 2.9 theme 3c; Hudson & Haas, 2012:29).

> If we expect to enter wholeheartedly into the experience of the Spiritual Disciplines, we must understand clearly that these Disciplines open us to the Good Life. Their purpose is

> not to make life miserable but joyful, not to put us in bondage but to set us free, not to confine but to liberate us.

IFCs must come to understand the importance of sustaining practices to balance their lives. Myers (2003:87-88) writes that spiritual practices help one to understand that "grace is at work in the ordinary processes of daily activities as well as in the dramatic events of life". Practices of religious disciplines (cf. 5.6) are means to encounter the fractures of the human soul, not for the sole purpose of healing one's wounds, but to know Christ through them. It is an invitation to embrace suffering, value one's woundedness and entering an existential experience of trust and divine love (Sartor, 2003:250-253). Through solitude an open inner space is created through which God finds the believer (Foster, 1983). According to Myers (2003:87-88), the biggest challenge is often to "create theological space between justification and sanctification [to make] spiritual room for grace". In other words, developing spiritual practices involves theological as well as practical concerns, for example IFCs will have to find time in their daily schedules for quiet time where they wait on God to come to them, feed them and heal them. It is creating a space in daily lives and tasks where God can reach IFCs. To sustain grace means to actively pursue those activities necessary to keep one's faith alive. Grace will sustain IFCs if they allow it and grace will sustain IFCs through their joys, riches as well as hardships and challenges. Hudson and Haas (2012:30-31) teach that God is the source of all healing, and to be in a relationship with God is the highest good and main purpose of human existence. Therefore, the darkness of depression, chains of anxiety, fractured sense of reality and isolation of the cancer journey serve as the platform where Christs' mercy can be observed. Making the union with Christ through suffering IFCs' greatest hope and consolation (Sartor, 2003:250-253).

7.4.3 Output phase: Significance

In a materialistic culture emphasis falls on outward success and achievements, for example IFCs may feel that they must be strong, someone to count on and to be the best caregiver with the danger of taking on an identity of caregiver. In the third movement of the cycle of grace, the issue of identity resurfaces. Significance is the third stage where one finds true identity, value and worth in Christ. Every human has a God-given desire for significance (Hudson & Haas, 2012:37). On the worldly level, Christs' life seems insignificant in fact by the standards of the Roman Empire His life did not mean much (Hudson & Haas, 2012:37). Christ radically changes the measure of significance, showing through his life on earth that significance is a truth one bears, a witness made, a life lived before God and most of all desiring God. While many yearn for a life of significance, Hudson and Haas (2012:37) challenge the believer to ask, "What do I want my life to signify?" By asking the deeper question, IFCs must firstly explore who they are in Christ before, during and after their role as caregiver. Believers are encouraged to seek God's face (Psalm 27:8) and reflect His glory in one's very being (2 Corinthians 3:18). IFCs can grow in their God-given identity through the cancer journey to become symbols of God's love, which lies at the heart of everything (Hudson & Haas, 2012:38).

> The moment we say yes to God, we become bearers of God’s word. From the second we lower our defences – Here am I, the servant of the Lord; let it be with me according to your word – the Holy Spirit enters us, fills us, takes us over, changes everything about us, and, through us, the world in which we live (Dean & Foster, 1998:1).

In the gospel of John (14:6 NIV) Jesus clearly declares, *"I am the way and the truth and the life. No one comes to the Father except through me”*. This is the stage where Christ knew who He was, and this is the stage where IFCs will become aware of who they are in Christ (Anon, 2020). Christ understood His impact in God’s purpose. Before He followed God’s will, He accepted what He was meant to be in God’s will. Christ frequently referred to Himself as “*the Son of man*” (Daniel 7:13-14 NIV). Christ grasped what He was meant to be on earth, not just what He was meant to do. “He understood that more than doing things for God, He Himself was a sign of God’s grace to the world” (Anon, 2018).

7.4.4 Output: Fruitfulness

The fourth and final stage is fruitfulness where the awareness of the preceding stages gets into action. The cycle started by being rooted in God’s acceptance of humans. Individuals are then filled by God’s sustenance through practices and disciplines that strengthen faith. As Christ-followers, the believers flourish by becoming signs of grace as unique individuals achieving significance. In other words, the first three stages are discovering God, as IFCs become acquainted with God, learning His ways and becoming His friend, they find their identity as children of God “inward fellowship gives an inward knowledge of the ways of God” (Foster, 1983). At this stage IFCs are fruitful and can produce the fruit of love, joy, peace, patience, kindness, goodness, faithfulness, gentleness and self-control (Galatians 5:22-23). God’s grace in the last movement transforms into fruitfulness, as the believer shares God’s grace with others. The cycle of grace reflects Christ’s life and how grace flows through Him (Hudson & Haas, 2012:44). To mention a few of Christ’s fruitful actions that IFCs can represent during and after the cancer journey finding a new normal to their altered lives include to leave others (family, diagnosed loved one, close friends) feel valued, affirmed, loved and accepted when they are with the IFC. Teaching and guiding, offering love, giving hope and blessings to those who feel weary, giving redirection for a new normal and being courageous during and after the cancer journey (Hudson & Haas, 2012:44-45). The greatest fruit is the way in which Christ modelled an intimate relationship with God (cf. 5.4; 5.5), a relationship He encourages people to follow; an inner circle of God’s love and acceptance into which all are welcomed (Hudson & Haas, 2012:45) and a space that will become IFCs lifeline during their times of struggles. “The cycle of grace reflects God’s love moving outward, like ripples on a pond” (Hudson & Haas, 2012:46).

To live more consciously and in the moment (cf. 7.2) IFCs must be aware of their thinking patterns and consider and reconsider it (Jones *et al*., 2013:10). “We are positioned in particular discourses, which affect our preferred ways of being” (Els, 2000:149). For this reason, IFCs must look at and assess their discourses that are embedded in their thought processes. Among other practices mentioned in this study (cf. 5.6, 7.2, 7.3) this can also be done by walking a labyrinth.

7.5 MINDFUL LABYRINTH WALKING

Mindfulness can be cultivated through deliberate mental practices. The aim of mindful practices is not to empty the mind of thought, instead it involves training the mind to be aware of what it is always doing, together with being aware what one is thinking when one thinks (Siegel *et al*., 2008:1-28). The human mind consists of a joint effort between two distinct brains, namely the left hemisphere and the right hemisphere of which each hemisphere sees the world in vastly different ways. The left brain is concerned with logic, details and facts, while the right brain is based on feelings, emotions and imagination. Personality is determined and moulded by which hemisphere one allows to be dominant in daily life. Therapies, such as mindful labyrinth walking has proved to lessen the conflicts between the two hemispheres and coax left and right to work together in peace and harmony (Dudeja, 2018:666-673). Physical activity, such as walking has an impact on mood as it reduces activity in the sympathetic nervous system and the related hypothalamic-pituitary-adrenal axis responses in the brain (Rimmele *et al*., 2007:627-635). If a problem is contemplated during the labyrinth walk, it is possible that logic and emotional compromises will equally be mediated on. The labyrinth forces the two hemispheres to cooperate on a task where both left and right must learn to trust and compromise (Dudeja, 2018:666-673). As IFCs equally need a healthy balance between logic (daily caregiving tasks), emotions (unpredictability of cancer) and difficult theological questions (cf. 5.3.1.3), mindful labyrinth walking will be considered in this study to help IFCs cope with cancer related stress.

There are many different tales regarding the origin of the labyrinth, but what is clear is that Christians have been using the labyrinth as a spiritual tool dating back to Medieval times (Saward, 2018). Medieval labyrinths have a circular shape, the circle being a universal symbol of wholeness, completion and unity (Dedeja, 2018:666-673). The most famous labyrinth is the 11-circuit labyrinth of the Chartres Cathedral in France which dates to around 1205 (Ward, 2006:10). Classic labyrinth patterns vary from eleven to seven circuits depending on size, these patterns lead inward towards the centre and from the centre back out again. The circuitous journey to the centre is a representation of many turnings in the journey of life, a journey that requires Christ's guidance and support (Dudeja, 2018:666-673). From early on, Christians believed that walking the labyrinth symbolises the soul's journey to Christ (Schaper & Camp, 2012:8).

The labyrinth is a tool for both emotional and spiritual support used all over the world as a recreational and anti-stress resource to help one cope with hardships during the life journey (De Bellis *et al.*, 2001:552-557, Teicher *et al*., 2002:397-426; Sandor & Froman, 2006:103-110; Gersbach, 2008:77-80). A study comparing the effects of mindful labyrinth walking versus walking the labyrinth fast-paced on individuals with anxiety concluded that mindful walking is the preferred method of reducing anxiety (Edwards *et al*., 2018:691-704). Hospitals have been making use of labyrinths as a supporting tool for cancer cases (De Bellis *et al.*, 2001:552-557, Teicher *et al*., 2002:397-426; Sandor & Froman, 2006:103-110).

Mindful labyrinth walking can be used differently according to each unique personality and needs (Artress, 2006:7). It requires no training or any kind of extenuating physical movement and can thus be practised by persons of all ages, regardless of prior experience or fitness levels (Lizier, 2018:1-11). The aim of the walk is to improve mindfulness, install judgment-free awareness of the present moment and exercising the left and right brain hemispheres to work in harmony. The walk can be for personal, psychological or spiritual growth. A spiritual walk is completed in a prayerful meditative way or by having a specific question in mind. Walking the path in and out is with an attitude of devotion and openness to be enlightened during the process (Els, 2017:1-11). IFCs can, for example walk the path with a certain text in mind that has been studied during their *lectio divina* practice (cf. 5.6.1) or they can walk the labyrinth while struggling with certain difficult emotions, such as loneliness, loss of identity, feelings of depression and anxiety, dealing with RS (cf. 5.3.1.3.2) or asking the "Why?" questions (cf. 5.4, 5.5). By memorising scriptures during *lectio divina*, verses become rooted deeply in the inner mind of IFCs and begin to 'mould' and adjust their worldview almost without their realising it. As IFCs submit to the practice, God can reach them through His word at any given moment (Foster, 1983) in this case during the labyrinth walk of which there are three stages (Lizier *et al*., 2018:1-11).

Stage 1: Preparation (From entrance to centre): Deciding on the rhythm of the walk the labyrinth to the centre; slow paced or fast paced.

Stage 2: Illumination (Centre): At the centre deciding to sit or stand, finding the most comfortable position, with eyes open or closed.

Stage 3: Restoration (Centre back to entrance): Consist of walking back and towards the beginning.

The act of walking the labyrinth awakens the capacity for contemplation, reflection and transformation (De Bellis *et al.*, 2001:552-557, Teicher *et al*., 2002:397-426; Sandor & Froman, 2006:103-110). In early times believers walked the labyrinth tracing the path of a long and difficult earthly journey, beginning with birth at the entrance, death at the centre and the way out symbolises hope that a life well lived devoted to God will continue in heaven (Dudeja, 2018:666-673). With this example, IFCs can begin the walk by contemplating (cf. 7.2) the cancer diagnosis and difficult journey thereof (physically, emotionally and spiritually). At the centre, IFCs can reflect on the way they handle the circumstances and release themselves to God and giving up the cycle of works (cf. 7.3). Going out, IFCs can reflect on their transformation, committing to follow the cycle of grace and take on an identity given by God (cf.7.3).

Artress (1995) who studied and practised the labyrinth is a key promoter of the developing awareness of the mind-body connection, the impact of thoughts on peoples' lives and the importance of living with (self) compassion. Learning the skill of self-compassion (cf. 4.2.1) IFCs can give themselves permission to spend time to recuperate and draw strength from God with committed practices, such as *Lectio Divina* (cf. 5.6.1), centring prayer (cf. 5.6.2), serenity prayer (cf. 5.6.3), worship (cf. 5.6.4), breathing exercises and mindful labyrinth walking. By regularly and routinely following these practices, IFCs can gradually decipher how to become more mindful of thoughts, needs, emotions and find hope and purpose, even in the face of significant suffering.

7.6 THE MINDFUL COMPASSIONATE PC

Lakes' (Peters, 1989:104) driving motivation as pastoral counsellor was to

> … understand people's afflictions and suffering, and by taking them out of the torture of wasted lives, damaged emotions, frustrated ambitions and debilitating habits, to lead them to a position of well-being, peace and fulfilment. In other words, to a place of harmony internally, to wholeness psychologically and spiritually.

As an all-embracing and ongoing care approach, palliative care concepts should be introduced to the family shortly after the cancer diagnosis through treatment to remission or death till after the bereavement and adjustment period. Early integration of palliative care provides valuable opportunities to attend to the full impact of the cancer journey on IFCs psychological, developmental and spiritual wellness. For an effective family-centred care programme collaboration among professional providers, patient and family is important which involves clear and honest communication in a compassionate manner with mutual trust and respect between all parties concerned. This kind of collaborative approach to caregiving is called the collaborative person-centred practice (cf. 3.3). Pastoral care deals with a unique whole-person not merely a caregiver. A critical concept in whole-person pastoral care is the notion of healing as separate from cure. Whereas cure has a disease based focus, healing focuses on the whole person and how that individual can find peace, a sense of coherence, solace and meaning, especially when dealing with life threatening loss or disease, such as cancer. The cancer journey is a crisis that creates conflict on various levels which affects IFCs' being human and their search for meaning, yet the cancer journey can be transformed into an opportunity for growth, witnessing and deepening faith by finding meaning in suffering (cf. 7.2). Healing happens within IFCs who can use their own resources find inner peace. Evidence suggests that healing is facilitated within the presence of a compassionate PC and in the context of that professional friendship, also described as the "transformational potential of the healing relationship" (Puchalski *et al.*, 2009:885-904; Puchalski & Guenther, 2012:254-258). The PC thus needs to distinguish between the emotional (how IFCs feel), existential (how IFCs experience the world) and spiritual (IFCs God-image) dimensions of IFCs' distress (Balboni *et al*., 2014:1586-1598).

The counselling process must strive to help IFCs achieve optimal levels of functioning despite hardships by growing through difficult experiences into sources of strength and wellbeing. Compassion stands central to the ethical practice of the healing professions, making compassion for the PC not a character trait, but a virtue with intellectual as well as emotional components. It is the habit that urges the PC to understand suffering and to do what can be done to lessen suffering without over identifying with suffering of others. To be with another is therefore a ministry of presence where the PC represents God and the faith community. “Presence implies availability and the creation of a space of intimacy”; it is the art of accepting IFCs unconditionally within the space they find themselves with their suffering (Louw, 2011a:241). The presence of the PC must convey to IFCs their uniqueness “a sense that they have been specially created by God” (Louw, 2011a:241). In many ways, compassion can be compared to a professional friendship that helps IFCs live through and talk through their experiences. It is a space where the PC offers divine consolation in that God promises in Christ to be with IFCs to be at their side and on their side, especially during hardships. “Consolation, true consolation, is not a matter of course” (Louw, 2011a:216). To ‘embrace’ IFCs so that the arms of God hold them is a task requiring giving of the self. It is the willingness of the PC to “wait with the love of God until … until the Word of God has an impact on the life of the sufferer” (Louw, 2011a:216). This is not an easy task especially if the PC has not yet experienced illness.

As a professional friend, the PC will equip IFCs with compassion by means of conversation. This form of conversation is not just any type of exchange, but a type of conversation that will meet the heart of IFCs, awaken them to the depths of God’s love and God’s truth by entering into intimate relationship with God. This kind of transformational teachings goes far beyond surface interactions, as it is entering the deep places where God breaks into the lives of IFCs making transformational change – it is a transformation from the inside out (cf. 4.5, 5.5). To be accepted and welcomed into the hearts and lives of IFCs are like walking on holy ground, it is a privilege to be invited into the conversations of IFCs at times of both pain and joy. Pastoral caregiving to IFCs can serve the purpose of life care and hope care. Pastoral care as life care (*cura vitae* and the healing of life; cf. 1.7, 5.1, 5.4.2). The beginning of psychology had a particular influence on pastoral care, especially on Rogers’ (1951:24) standpoint that people can be healed within an empathetic relation (acceptance), in which they can then be led to self-realisation. This standpoint had an influence on Hiltner (1958:23,55) who pursued the core of pastoral care in the shepherding perspective (cf. 5.7.3) believing that each person has their own unique abilities and potential; they do not need ‘fixing’ gives rise to a therapy of positive power (self-help as life care; Hiltner, 1985:151, 154). Hope (cf. 4.4.3, 4.5, 5.3.1.3, 5.4.2, 5.5) in hope care is not mere wishful thinking, but a new state of mind and being with the question of identity, who am I? in terms of the ontic reality of salvation (justification) and who can I become (sanctification)? (Louw, 2011a:220).

Lake (Peters, 1989:109) describes pastoral listening and dialogue as the very language of the Bible and the chosen method of Jesus Christ. Whole-person care involves being present to IFCs, listening to their story – the physical, emotional, social and spiritual story (Balboni *et al*., 2014:1586-1598). At the heart of Christ’s approach, lies His deep interest in people rather than in ideas, in fact more than half of His treatment of individuals (in times of His earthly ministry) were taken up by listening.

Lake (Peters, 1989:111) perceived the listener (PC) as Christs' representative which thus requires both great charity and great humility, "but when properly and effectively carried out, listening brings about ontological and theological results" (Peters, 1989:111). By emphasising the importance of non-directive client-orientated listening, Lake (Peters, 1989:112-113) used two main ideas: first, using the prophet Ezekiel as a model "*I sat where they sat*" (Ezekiel 3:15 KJV) to demonstrate his identification with the suffering person. Secondly, is the letting go of one's own personal identity in order to therapeutically help the person in need. Here the Pauline epistle refers to Christ Himself, writing, "*rather, he made himself nothing by taking the very nature of a servant, being made in human likeness. And being found in appearance as a man, he humbled himself by becoming obedient to death-- even death on a cross!"* (Philippians 2:7-8 NIV). This ultimate act of self-giving is something that the PC must practise. To establish a caring and accepting relationship with IFCs, the PC must be prepared to stay with the sufferer (IFCs) moving with them into difficult thoughts and feelings in a supportive, responsive and compassionate relationship allowing them to retain the steering wheel in the conversation. Within the professional friendship, both PC and IFCs may experience vulnerability, emotions and deep connections. In these moments of intense emotions, the aim is not to "fix" but rather accompany IFCs as they share their story (Balboni *et al.*, 2014:1586-1598). The mindful PC's agenda is one of "awareness and acceptance first, change second". From the mindfulness perspective, acceptance is a willingness to let things be as they are the moment the PC and IFCs become aware of it. Accepting both, joyful and painful experiences as they are (Germer, 2004).

Lake (Peters, 1989:112-113,118) advises the PC to step out of their role of professional superiority to stand with IFCs, before the cross, at the place of support suggesting that the PC must not attempt to lessen their own discomfort or anxiety by changing the direction of the conversation. The PC's emotional and behavioural problems can be amplified by an instinct effort to avoid discomfort by propelling themselves into change-seeking activity (Siegel *et al.*, 2008:1-28). In fact, avoiding psychological pain is built into the normal functions of human language itself, even if this process causes harm (Hayes & Shenk, 2004:249-254).

Providing compassionate care within the therapeutic setting by listening to the whole of IFCs story (physical, emotional, social and spiritual) must go beyond awareness, attention and remembering to include qualities of non-judgment and compassion (Siegel *et al.*, 2008:1-28). Baer (2003:125-143) defines mindfulness as "the non-judgmental observation of the ongoing stream of internal and external stimuli as they arise". Bishop *et al.* (2004:230-241) define the mindful caregiver as "self-regulation of attention so that it is maintained on immediate experience, thereby allowing for increased recognition of mental events in the present moment" and "adopting a particular orientation toward one's experience that is characterised by curiosity, openness and acceptance". The second part of the definition captures a vital emotional or intentional attitude of mindfulness within the pastoral caregiving setting. A short expression of therapeutic mindfulness, given by Siegel *et al. (*2008:5) is "affectionate awareness", "mindful acceptance", "openhearted presence" and "mindful compassion". Acceptance is an expansion of non-judgment, adding kindness or friendliness. The addition of acceptance to mindfulness caregiving is important, especially when IFCs are confronted with overwhelming traumatic circumstances of the cancer journey. It is essential for the PC to maintain an open compassionate and accepting attitude, together with empathy and positive regard (Elliott *et al*., 2018:399-410). The more intensely an individual suffers, it seems, the more he or she will need acceptance and compassion in order to be able to work with what is occurring in their lives.

Kindness without clear awareness is sympathy, which can lead to "sugar coating" the hardships of life that need to be addressed. Compassion is a form of empathy, a place where the PC comes to understand what IFCs are going through; it is to suffer with them, feel their pain, standing in their shoes. Offering helpful advice without first providing acceptance and compassion, IFCs can merely feel misunderstood (Siegel *et al*., 2008:1-28). Non-judgment therefore fosters mindfulness when the PC is dealing with difficult physical and emotional states. By not judging an experience, one will be more likely to observe it as it is. ACT is a well-established therapy for increasing psychological flexibility and helping individuals to achieve emotional balance by encouraging flexibility, creativity (cf. 4.4) and self-compassion (cf.4.2.1). At its core, ACT is about taking action of which compassion is an essential method for IFCs' healing process, fostering emotional balance through a mind-set of safety and interconnectedness and reducing feelings of threat and isolation. It is teaching IFCs to take good care of themselves, both short-term as well as long-term by being mindful (cf.7.2). This will be done by means of practising pastoral life coaching skills by incorporating the GROW and SMART practices (cf. 5.7.3). Whereas the pastoral caregiving process places focus and contemplates on the past (healing), pastoral life coaching reflects on the future (growth). Together the two methods lead to transformation and living the cycle of grace. The following is an example of a pastoral life coaching model, using Whitmore's concept of GROW (Viljoen and Lotter, 2018:1-10).

Box 24: Pastoral life coaching (cf.5.7.2)

Pastoral caregiving	**Goal**	**Reality**	**Opportunity**	**Way forward**
Healing Cure Resolving past issues Forgiveness	The issue that should be addressed. Challenges and concerns. What is important to IFCs.	Values, beliefs, attitudes, actions. Rethink reality and current situation. Issues that can influence the future. Rename current situation considering what is possible for God.	New options and opportunities for the future. Re-aligning goals and options. Future with relationship with God considered. Reality from a God perspective.	Implementing goals. How will actions look with God in mind. SMART goals (cf.5.7.2). Feedback.

Source: Author compiled table

The compassionate PC will ultimately rely on the love and power of God, making the point of departure the Word of God as the authoritative source for pastoral caregiving in order to build IFCs' ability to tolerate and transform difficult experiences in the short-term and long-term, encouraging awareness, mindfulness and self-compassion. Similarly, compassion and acceptance is also vital in the intrapersonal therapeutic relationship, the one the PC has with him- or herself (Siegel *et al.*, 2008:1-28). "Mindfulness has to be experienced to be known" (Germer, 2004).

Both, self-compassion and self-acceptance are skilful means for being aware under difficult circumstances. In order to have an open heart, the PC must have open eyes. Personally practising mindfulness and self-acceptance "is hopefully part of [the PC's] emotional landscape"; the professional friendship acceptance and compassion are essential for the pastoral caregiving process to be effective (Siegel *et al.*, 2008:1-28). In ACT the aim is for the PC to be fully present with IFCs with an authentic, mindful, compassionate and respectful attitude and in touch with own core values. ACT highly recommends before entering the therapeutic relationship with IFCs as fully and as deeply as the need demands that the PC must firstly and on an ongoing basis, personally practise ACT in order to enrich their personal lives and to resolve their own painful issues. ACT requires committed action that involves an active willingness to experience own undesirable private feelings and thoughts (cf. 4.5). Thus, the PC must practise self-care, before they can teach self-care to IFCs (cf. 4.6.2). They cannot help an anxious person to the peace of God, if that peace has not been given to the caregiver by the Holy Spirit. They cannot help the overwhelmed IFCs to handle their emotions before the cross, if the he or she has not learned to handle their own emotions consciously. They cannot help IFCs from feeling isolated and alone, if the PC is using his or her own profession to satisfy their need for attention; in other words, recognise, face and deal with their own erroneous thoughts and personal issues. In this way pastoral care is led by wounded healers.

Arising from the discussion on compassionate pastoral caregiving for IFCs, the PC supports IFCs in faith which is the process of understanding God in terms of suffering and distress as a result of the cancer journey, and personally exercising and demonstrating God's compassion and care through the Holy Spirit. The PC provides life care (*Cura Vitae*) in the form of non-directive-client-oriented listening as God's representative. Identifying with and staying with IFCs during their suffering (being present) in a supportive, responsive and accepting relationship and taking on the shepherding role believing in IFCs own resources. It's not a matter of 'fixing' but being with and staying with. The PC also provides hope care by empowering IFCs to take up their suffering in order to grow towards spiritual maturity (friendship with God) embracing characteristics of affectionate awareness, mindful acceptance, openhearted presence and mindful compassion. "The unique empowering character of pastoral [caregiving] is evident from the purpose of pastoral care which is love, trust and hope" (Louw, 2011a:253). Pastoral caregiving to IFCs is the work of the Holy Spirit.

Box 25: The pastoral encounter includes

Facilitating	The art of listening
Sustaining	The art of understanding
Guiding	The art of directing
Healing	The art of consoling
Nurturing	The art of caring
Reconciling	The art of witnessing

Source: Louw (2011a:253)

7.7 CONCLUSION

Together with human suffering that is universal and unavoidable comes emotional pain and struggles when confronted with hardships such as a cancer diagnosis of a loved one. To find a healthy way of living with the cancer journey reduces stress and sets the stage for positive personal transformation. This chapter proposes the practice of mindfulness. Rather than trying to escape the experiences that come with hardships, mindfulness practices can help IFCs to increase their capacity to bear it. Keeping in mind that IFCs may feel overwhelmed and distracted with time consuming caregiving tasks, it is possible to have mindful moments. For example, IFCs can momentarily disengage from their caregiving duties by taking a long, conscious breath, gathering their attention and asking themselves "What am I feeling right now?", "What am I doing right now?" What is most compelling to my awareness right now?" With the correct technique of mindfulness, IFCs can reach a state of physical relaxation and respiratory balance in a natural, spontaneous and time effective way. The 4-7-8 breathing technique is recognised as a "simple" time effective and beneficial practice. The silence and stillness acquired by being mindful induces a present-moment awareness of body, mind and soul expanding the moment in order to feel the presence of God. Learning how to regulate one's emotions through deep breathing and stillness can lead to unity with God and listening to God which will bring IFCs to deepen their relationship with self and God. From a Christian perspective mindful breathing is used to reflect on God, finding His loving presence and intention which can make IFCs more aware of their inner thoughts allowing the content of their thoughts to lead them to biblical truths as well as qualities of compassion and loving-kindness. In these small spaces taken throughout the day IFCs can find purpose, meaning and hope.

Living a mindful life striving to be in a relationship with God can be achieved by living the cycle of grace. The cycle of grace is a powerful lesson from the life of Christ and how He lived a life of dynamic balance of receiving grace and giving grace. By following in Christs' footsteps, living the rhythm of input and output that He sets in place IFCs will be empowered to confidently and courageously take on the caregiving tasks, knowing that their worth and identity is secure in God. The cycle of grace has four dimensions namely acceptance, sustenance, significance and fruitfulness which is placed within two dynamic phases that are the input phase and the output phase. Divine acceptance comes in rare human relationships such as mentors (PCs), family members and friendships where each person is fully known, valued and loved. In such a space IFCs will have the freedom to be themselves, to share their innermost emotions and experiences. With such a glimpse of divine acceptance the IFC can claim and reclaim his/her identity as a child of God during the cancer journey. The second input dimension is where Christ sustained his close relationship with God throughout His life on earth by regularly making time to spend with His Father by praying, worshiping and surrounding Himself with close friends. Developing spiritual practices involves theological and practical concerns, in other words IFCs must make time in their daily schedules for God to come to them, feed them and heal them. The third and fourth dimensions of the cycle of grace (output) ask the questions "Who am I called to be? and "What am I called to do?" Significance is a truth one bears, a witness made, a life lived before God and most of all desiring God. By asking the deeper questions IFCs must firstly explore who they are in Christ before, during and after their role as caregiver, anchoring their identity in God. God's grace in the last dimension transforms into fruitfulness as IFCs share God's grace with others. IFCs can represent God during and after the cancer journey by leaving others feeling valued, affirmed, loved and accepted, teaching and guiding, offering love, giving hope and blessings to those who feel weary, giving redirection for a new normal and being courageous during and after the cancer journey.

A practice for personal, psychological or spiritual support and growth that can be applied as an anti-stress resource in the sustenance dimension is for example mindful labyrinth walking. The aim of the walk is to improve mindfulness, install judgment-free awareness of the present moment and exercising the left and right brain hemispheres to work in harmony. Walking the labyrinth can awaken IFCs' capacity for contemplation, reflection and transformation. The PC can use a section of his or her office to tape the layout of a labyrinth to use in the therapeutic sessions to help IFCs work through their emotions.

Vital characteristics that the mindful PC must practise for successful therapeutic journey with IFCs include awareness of the present experience with acceptance and compassion without trying to solve problems or fix people. Although these are distinct components they are irreducibly intertwined in the therapeutic setting of the mindful and compassionate PC. All the components of mindfulness (awareness, present-centredness and acceptance) are required for a moment of mindfulness. In order to have an open heart the PC must have open eyes, putting it differently, to know mindfulness it must be practised. Entering the therapeutic relationship with IFCs as fully and as deeply as the need demands. It is therefore vital for the PC to personally practise (on an ongoing basis) compassion, self-acceptance and living the cycle of grace. In ACT the aim is for the PC to be fully present with IFCs with an authentic, mindful, compassionate and respectful attitude, be in touch with their own core values, work on resolving own painful issues with an active willingness to experience own undesirable private feelings and thoughts.

CHAPTER 8: MODEL TO HELP SIGNIFICANT OTHERS WITH CAREGIVER RELATED STRESS

8.1 INTRODUCTION

In this chapter the pragmatic task of Osmer's (2008) model will be used to find answers to the question of what kind of leadership model is open to the foundation Jesus laid, "How might we respond?" The previous chapters seek for a fitting response to the situation examined, developing and enacting strategies that will lead to change. This chapter aims to formulate a holistic Scripture based pastoral model in helping significant others to cope with caregiver related stress. All the findings of the previous chapters serve as building blocks in the compilation of the holistic Scripture based theological model to assist significant others cope with a cancer diagnosis in the family.

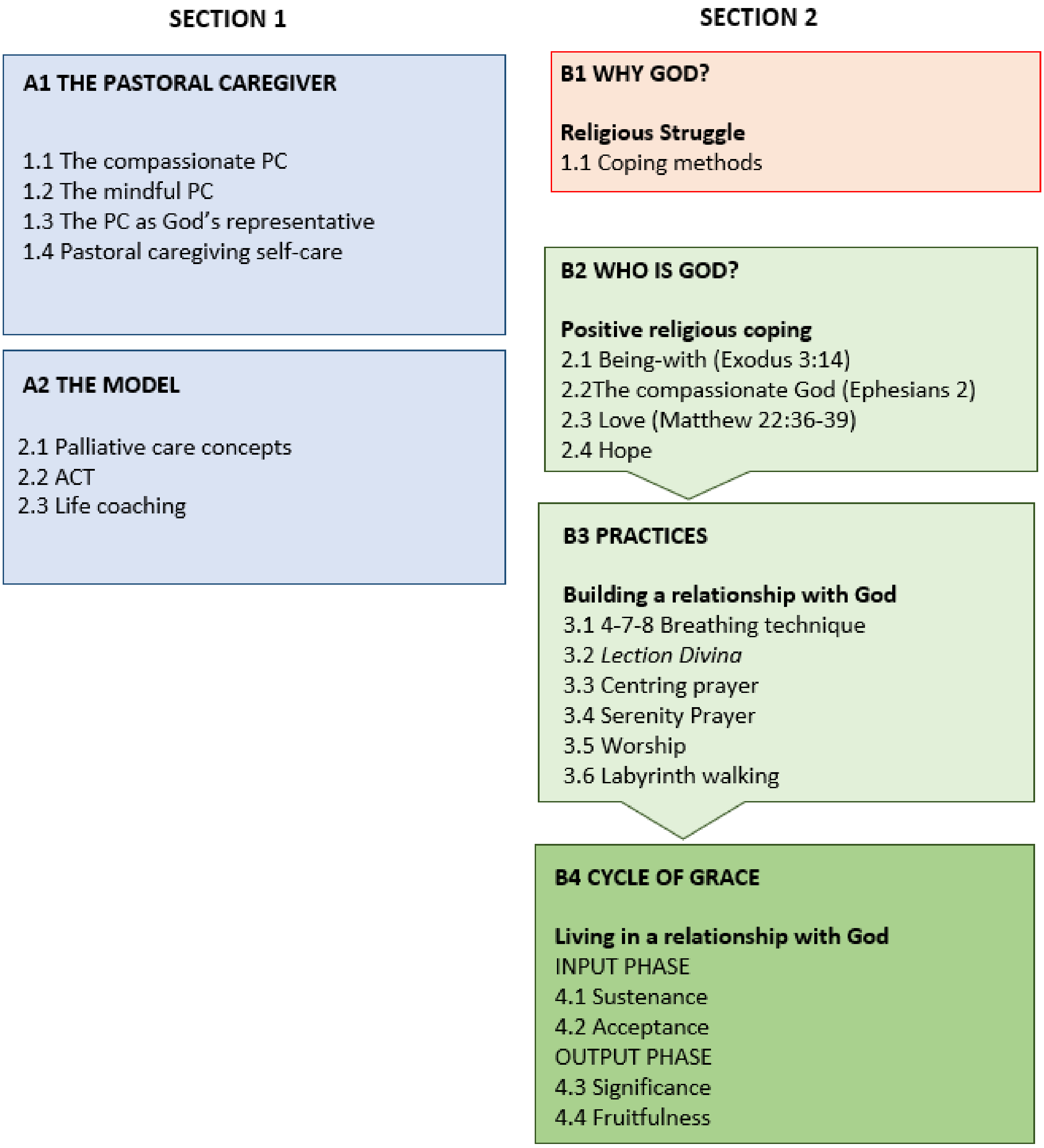
Within the Christian tradition, *Theodicy* is the effort to amend the perception of God's goodness with human suffering and to explain His love and grace in the light of evil. The PC strives to help IFCs achieve optimal levels of functioning, despite their current hardships due to the cancer journey by relying on their own resources to grow through the suffering into sources of strength and well-being. It is a privilege to be invited into the lives of IFCs and it is like walking on holy ground at times of both, anguished pain and celebrations. Engaging in deep conversations and meeting 'the heart' of the other, are at the core of pastoral caregiving. Pastoral caregiving is a professional relationship that reflects God's presence.

Pastoral caregiving for IFCs is not a task that the PC must take on lightly, as this caregiving confronts the PC with ambivalent issues. There will be many highs when everything seems good, but there will also be many lows when everything seems hopeless. Therefore, an undebatable factor of this proposed model is the PC must be fully committed to the journey of seeking meaning and purpose, to have hope and keep on hoping, even when hope seems elusive. The nurturing of hope is a goal of pastoral caregiving in general, for this reason one of the caregiving responsibilities is attending to thoughts about hope, knowing who God is and to trust in His unfailing omniscience and love.

This chapter will be divided into two main sections. As the characteristics, values and beliefs of the PC are key to a successful pastoral relationship and growth of IFCs, section 1 places focus on the compassionate dimension of the PC. Thereafter, section 2 focuses on the pastoral caregiving strategy to help IFCs to incorporate certain spiritual techniques or skills to grow into resilient individuals who can deal with caregiving related stress.

Section 1 will be divided into two sections. Firstly, the characteristics of the PC which include the compassionate PC, the mindful PC and the PC as God's representative. The PC must be sensitive to IFCs when they reach out for emotional support. As each case and individual are different, with unique emotions and perceptions, and although there is no "one-size-fits-all" formula in counselling, there are some vital components and methods, approaches and strategies that can be part of a transformational learning experience. Self-care as a coping skill for the PC will be discussed to create awareness of caregiving fatigue and techniques to alleviate and/or the prevention thereof. The second part of section 1 discusses the professional skills needed for the counselling process during the palliative care sessions, ACT and life coaching techniques.

Diagrammatic illustration of the proposed holistic Scripture based pastoral model[7] in helping significant others to cope with caregiver related stress:



SECTION 1

A1 THE PASTORAL CAREGIVER

1.1 The compassionate PC
1.2 The mindful PC
1.3 The PC as God's representative
1.4 Pastoral caregiving self-care

A2 THE MODEL

2.1 Palliative care concepts
2.2 ACT
2.3 Life coaching

SECTION 2

B1 WHY GOD?

Religious Struggle
1.1 Coping methods

B2 WHO IS GOD?

Positive religious coping
2.1 Being-with (Exodus 3:14)
2.2The compassionate God (Ephesians 2)
2.3 Love (Matthew 22:36-39)
2.4 Hope

B3 PRACTICES

Building a relationship with God
3.1 4-7-8 Breathing technique
3.2 *Lection Divina*
3.3 Centring prayer
3.4 Serenity Prayer
3.5 Worship
3.6 Labyrinth walking

B4 CYCLE OF GRACE

Living in a relationship with God
INPUT PHASE
4.1 Sustenance
4.2 Acceptance
OUTPUT PHASE
4.3 Significance
4.4 Fruitfulness

Source: Author

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[7] In discussing this model, the researcher will include the relevant tables (1-25) that were discussed in the previous chapters.

8.2 SECTION 1

A1 THE PC

Compassion and acceptance are demonstrated through non-directive client-orientated pastoral listening which is also the core language of the Bible and Jesus' chosen method. Whole-person care involves being present to IFCs, listening to their physical, emotional, social and spiritual story (cf. 7.6). Professional friendly conversation within the counselling space is essential for IFCs' development and growth on a cognitive, mental, emotional, interpersonal and spiritual dimension. This growth or empowerment is facilitated by a compassionate and mindful PC entering the space as God's representative while keeping him/herself healthy as a whole-person.

1.1 THE COMPASSIONATE PC

Self-compassion asks, "What do you need?" (cf.4.5). Compassion and acceptance for the PC must become a habit where the PC places him/herself "in the shoes of" IFCs without over identifying with their suffering (cf. 7.6). To demonstrate his/her identification with IFCs the PC can turn to Biblical examples, such as prophet Ezekiels' words *I sat where they sat* (Ezekiel 3:15, KJV). Another example that the PC can practise is letting go of his/her personal identity. This kind of letting go of personal identity refers to Christ Himself as Paul writes in Philippians 2:7-8. To establish a caring and accepting relationship with IFCs, the PC must furthermore be prepared to stay with them in their suffering, moving with them into difficult thoughts and feelings in a supportive, responsive and compassionate relationship allowing IFCs to steer the conversation (cf. 7.6).

Compassion refers to qualities associated with friendship, trust and compassion which foster acceptance. These qualities within the caregiving setting go beyond surface interactions. Compassion and self-compassion (cf. 4.2.1) must be practised both, on a short-term and long-term basis. In the short-term, the PC works on building IFCs' ability to tolerate and transform difficult experiences during the cancer journey. In the long-term, the PC encourages safe exposure and non-avoidance of hardships. This is done through transformational teaching, which is a specialised professional compassionate friendship consisting of deep conversations where IFCs are encouraged to express vulnerable thoughts (cf. 4.5; 5.5; 7.6). These conversations include thoughts of God and Scripture, recognising that God is present and working through the Holy Spirit (cf. 4.5). The caregiving setting becomes an experiential learning process through conversations in a space of compassion and acceptance, where IFCs can experience and reflect on their emotions and circumstances with the purpose of making meaning of and transforming these emotions and circumstances into knowledge. For the process to be empowered and thus changing participants from the inside out, equal participation is a requirement where both, the PC and IFCs must be prepared to open themselves up to think, feel and act differently making self-awareness, meaning and altered perspectives possible (cf. 4.5).

Creating awareness and space for reflection in such an environment, IFCs can start to grasp the dynamics of their journey with cancer, the many factors thereof that shape the way they understand and live out their faith, as well as current realities of their Christian experiences. A compassionate setting thus provides opportunities for meaningful rumination between past, present and future bringing about insight, fresh understanding and vision of the cancer journey.

In other words, providing compassionate pastoral care to the whole of IFCs' stories (physical, emotional, social and spiritual) goes beyond listening, awareness, attention, reflection and remembering. As a professional friend the compassionate PC will furthermore facilitate transformational conversations through the art of listening, utilising characteristics such as non-judgment, compassion, being fully present, contemplation and empathy (cf. 7.6). This will create a space where teaching will have the capacity to transform, incorporate, explore and speak to the realities of IFCs' lives (cf. 4.5) through sustaining (the art of understanding), guiding (the art of directing), healing (the art of consoling), nurturing (the art of caring) and reconciling (the art of witnessing).

Summary of the compassionate PC's characteristics and skills:

- Practise self-compassion (intellectually and emotionally)
- Constantly work on strengthening neurological capacity in order to feel greater compassion
- Be open to think, feel and act differently (self-awareness, process of meaning making, self-opening and altered perspectives)
- Truly understand suffering without over identifying
- Compassionate friendship through deep conversation within the pastoral setting (transformational teaching from the inside out)
- Compassionate communication which associates with friendship, trust, non-judgment and compassion that fosters acceptance
- Maintain mutual sensitivity and respect
- Have a deep interest in people (pastoral listening and conversation is the core of the Bible)
- Care for the whole person, be present, listen to IFCs' stories – the physical, emotional, social and spiritual stories
- Non-directive client-oriented listening skills – "I sat where they sat" (Ezekiel3:15)
- Let go of personal identity to pastorally help IFCs (practise the ultimate act of self-giving)
- Stay with IFCs in their suffering, move with them into difficult thoughts and feelings while being supportive and responsive
- Let IFCs steer the conversation
- Create awareness and space for reflection
- Provide opportunities for meaningful rumination between past, present and future
- God stands at the centre of the professional friendly compassionate conversations

1.2 THE MINDFUL PC

Mindfulness asks the question, “What are you experiencing?” (cf.4.5). Being mindful is to pay close attention to the here and now in a flexible, open and curious manner. It is more a process of being aware, than a thinking process. It is paying attention or bringing awareness to what is happening in the moment rather than getting caught up in thoughts. It is an attitude of openness and curiosity, even if the experience in the moment is difficult, painful or unpleasant; one can be open to hardships and curious about it, rather than running from it. It is the ability to consciously direct and broaden the focus of IFCs’ attention on different aspects of an experience (cf. 7.6).

Both, self-compassion and self-acceptance are skilful ways of being aware during difficult circumstances. In order to have an open heart, the PC must have open eyes which imply that the PC must personally practise mindfulness and self-acceptance in order for it to become a central part of the PC’s emotional landscape (cf. 7.6).

Within the professional friendship, both the PC and IFCs will at some point feel vulnerable, have intense emotions and deep connections. In these moments, the PC must not attempt to ‘fix-it’, but instead just stay with IFCs on their journey. The mindful PC is primarily about awareness and acceptance, change is secondary. From the mindfulness perspective, acceptance is a willingness to let things be as they are in the moment (cf. 7.6).

Mindfulness is non-judgmental observation of the ongoing flow of internal and external stimuli as it happens and is summarised as affectionate awareness, mindful acceptance, openhearted presence and mindful compassion. Acceptance is an extension of non-judgment with the addition of kindness or friendliness. The PC must maintain an open compassionate and accepting attitude, together with empathy and positive regard. In order to be able to work through difficulties and the more IFCs suffer, the more they will need acceptance and compassion from the PC (cf. 7.6).

To offer advice without acceptance and compassion can leave IFCs feeling misunderstood. For this reason, showing kindness without having a clear awareness will come over as sympathy, which can lead to ‘sugar coating’ the IFCs’ circumstances. Compassion is a form of empathy, a place where the PC truly attempts to understand what IFCs are going through (cf. 7.6).

Summary of the mindful PC:

- Personally practise mindfulness
- Affectionate awareness
- Mindful acceptance
- Openhearted presence
- Mindful compassion
- Open compassionate and accepting attitude of what is happening in the moment
- Non-judgmental observation

- A presence of being-with; not attempting to “fix” people or situations
- Flexible, open and curious about the present moment (even if it is painful)
- Being aware of what is happening in the moment more than a thinking process

1.3 THE PC AS GOD’S REPRESENTATIVE

Pastoral care deals with the soul dimension, making the ‘what’ in pastoral caregiving the human soul. For this reason, it is not the ailment or illness (of the patient), nor the psyche of IFCs that become the focus, but the whole of the person as an ensouled body and an embodied soul (cf. 5.7.3). To share the space of someone else is therefore a ministry of presence where the PC represents God.

Pastoral caregiving must be practised in the shepherding perspective (cf. 5.7.3) with the belief that each person has their own unique abilities, potential and resources. IFCs do not need ‘fixing’, the caregiving setting is a space of empowerment. The PC must further be sensitive and responsive to warning signs of religious struggle (RS). Once RS is detected intervention can be initiated by the PC which is instrumental in preventing IFCs’ stress to escalate beyond the point of control and impacting IFCs’ meaning making of life (cf. 5.7.3). The PC must support IFCs in faith, which is the process of understanding God in terms of suffering and distress as a result of the cancer journey, and personally exercising and demonstrating God’s compassion and care through the Holy Spirit. The PC provides life care (*Cura Vitae*) in the form of non-directive-client-oriented listening, as God’s representative; identifying with and staying with IFCs during their suffering in a supportive, responsive and accepting relationship. In addition, taking on the shepherding role, believing in IFCs’ own resources, the PC also provides hope care by empowering IFCs to take up their suffering in order to grow towards spiritual maturity (friendship with God). Hope (cf. 4.4.3, 4.5, 5.3.1.3, 5.4.2, 5.5) care is not mere wishful thinking, but a new state of mind and being working with the question of identity “Who am I?”, in terms of the reality of salvation (justification) and “Who I can become?” (sanctification). The unique purpose of pastoral caregiving is love, trust and hope (cf. 7.6).

Critical theological questions that arise are, “Why did God allow this to happen?”, “What is the link between God and illness?” and “Why this illness?” Identifying God with suffering is mysterious; there is no logical explanation for the origin of suffering. There are no logical answers that the PC can offer to give comfort, and if logical answers are offered it will only settle IFCs’ doubts temporarily. God does not provide answers to the logical “why” questions, instead, in the midst of hardship, He proposes the “therefore” (the illogical reason of the cross). The PC must therefore change the logical “Why?” into the “therefore” by asking “To what purpose?” (cf. 5.4.2). The PC must remind IFCs that God does not provide solutions, He provides salvation. Explaining that in a sense, God was present in the suffering of Christ and His death on the cross, the PC can tell IFCs that God is present in their suffering. Fundamentally dealing with questions about attitude (ensoulment) and the quest for meaning in suffering, “Do you have grief?” or “Do you live your grief?” becomes the main question to work with. To merely have grief has the potential of bringing IFCs to the brink of destruction (cf. 5.4.2; 5.5).

To answer how God feels about human suffering the PC can use the following two examples (cf. 5.5):

Firstly, how Jesus responded to suffering: Jesus never said, “This is what God wants for your life” or “It is God’s will, accept it”. God shares suffering intimately, entering human grief and weeps with man as seen in the pericope (John 11:1-35) where Jesus was so deeply moved by the death of Lazarus that he wept (John 1:35). The story of Jesus’ weeping takes one into the suffering heart of God. Jesus was not weeping because of Lazarus’ death, but because of witnessing the pain of Mary and all the others around her. He did not condemn them. He did not tell them to cheer up or that everything was going to be all right. He entered their grief, shared their pain with them and wept with them. It is important for IFCs to understand that God, whom one meets in Jesus, does not cause suffering to teach lessons or because of disobedience. The PC must avoid phrases such as, “God always takes the best” or “It is God’s will”. Tragedy forms part of the broken nature of this world (cf. 5.5).

Secondly: The history of the cross: The cross does not only reveal God’s willingness to identify with humanity, but expresses the Trinity’s suffering with and for creation. Through the suffering of Jesus’ death, God will ultimately bring about redemption (cf. 5.5).

The explanation of how to answer the question, “Why did God allow this to happen?” may not entirely answer IFCs difficult questions, it cannot take away their pain, lessen their sorrow, relieve their grief or totally keep them from feeling that they are alone in their despair. However, the knowledge that God desires friendship and that He is a “co-sufferer” can give IFCs the strength to hold on to hope. The PC must understand and explain to IFCs that maintaining a relationship with God and having faith in His goodness in times of hardship is not easy (cf. 5.5).

Summary of the PC as God’s representative:

- PC must understand who God is in terms of suffering
- PC to demonstrate God’s compassion and care through the Holy Spirit
- PC takes on the role of shepherding
- PC deals with the human soul
- PC attends to the whole of the person as an ensouled body and an embodied soul
- PC must be sensitive and responsive to warning signs of religious struggle (RS)
- PC must not try to give logical answers to the “Why?” questions; there are no easy answers (or any at all).
- PC change question from “Who am I?” to “Who can I become?”
- PC changes the logical “Why?” into the “therefore” by asking “To what purpose?”
- PC reminds IFCs that God does not provide solutions, He provides salvation
- The main question to work with is “Do you have grief?” or “Do you live with grief?”
- Remind IFCs that Christian faith is essentially about knowing who God really is
- Teach IFCs to approach suffering and hard questions through the eyes of Jesus

1.4 PASTORAL SELF-CARE

Effective stress management has been identified as an ethical requirement amongst health professionals. Compassion fatigue has multifaceted effects on the PC including physical, emotional, social and intellectual. Besides these factors of exhaustion, caregiver fatigue in pastoral caregiving mainly describes spiritual exhaustion and its connection to depleted hope and an inappropriate theological framework of reference. Being continually exposed to suffering of others, will affect the PC's whole being, particularly attitude (*habitus*), internal make-up and cognitive framework. Internal confusion and over identification can lead to a kind of obsession to help and replace others' suffering. Working closely with IFCs, the PC will witness their emotional distress relating to their suffering in an empathic manner that may lead to increased negative effects, stirring up feelings of hopelessness, inadequacy, self-doubt, grief and fear causing the PC to question his/her professional competence (cf. 4.6.2).

This model suggests that important resources for the PC's well-being are personally practising mindfulness (cf. 8. B2.2), self-compassion (cf. 8. B2.3), ACT (cf. 8. A2.2), as well as all the practices suggested to IFCs (B3). Relating to the self with compassion is a promising method to promote self-care, professional well-being and resilience to stress. Self-compassion is a central mechanism by which mindfulness- and acceptance-based interventions influence psychological health. Practising ACT, self-compassion and mindfulness can help the PC to be emotionally balanced. The more these skills are practised, the more effective the PC will be in applying them to IFCs (cf. 4.6.2).

Another method to invest in a process of continuous healing is the ability to find positive aspects within a traumatic situation which relates to a sense of humour. It can be utilised to shift perspectives regarding stressful situations and to gain a sense of mastery. In this sense, humour is more than laughter, it is the ability to see situations from a different perspective understanding the relativity of life events. This model suggests affiliative and self-enhancing humour styles, which eases stress in a positive way. By using spontaneous jokes and funny anecdotes, the PC can facilitate relationship, minimise tension to give a more cheerful outlook on life with a tendency to be amused by inconsistencies that facilitates emotion regulation and coping with stress and misfortune (cf. 4.6.2).

Summary of self-care practices recommended for the PC:

- Regularly practise and incorporate mindfulness into PC's life personally and professionally
- Regularly practise and incorporate self-compassion into PC's life personally and professionally
- Regularly practise and incorporate ACT concepts into PC's life personally and professionally
- Take personal time to be with God using the same practices suggested to IFCs
- Utilising affiliative and self-enhancing humour styles into PC's life personally and professionally

A2 THE MODEL

Conversation in the pastoral setting creates a space where IFCs can identify and explore the state of their soul, personal beliefs, perspectives, attitudes, relationships, situation and circumstances (cancer journey), ideals and emotions. Conversational transformation involves deep internalised engagement with truth, reality and possibility which are navigated by the compassionate PC by utilising palliative care concepts, ACT model as well as life coaching techniques.

2.1 PALLIATIVE CARE CONCEPTS

As an all-embracing and ongoing care approach, palliative care concepts should be introduced to the family shortly after the cancer diagnosis through treatment to remission or death till after the bereavement and adjustment period (cf. 7.6). To effectively form a patient- and family-centred care programme four important elements come into play, which are (a) willingness to collaborate among health professionals, patient and family, (b) good communication, (c) mutual trust and (d) respect. Both, patient and their family members' quality of life can be improved through the prevention and alleviation of suffering through compassionate and honest communication and the psychosocial attentiveness incorporated by quality palliative care services (cf. 3.3). For an effective family-centred care programme, collaboration among professional providers, patient and family is important which involves clear and honest communication in a compassionate manner with mutual trust and respect between all parties concerned. This kind of collaborative approach to caregiving is called the collaborative person-centred practice (cf. 3.3).

Pastoral care deals with a unique whole-person and not merely an informal family caregiver. A critical concept in whole-person pastoral care is the notion of healing as separate from cure. Whereas cure has a disease based focus, healing focuses on the whole person and how that individual can find peace, a sense of coherence, solace and meaning, especially when dealing with life threatening loss or disease, such as cancer (cf. 7.5). Amid the journey of healing, the PC must be attentive to IFCs' different emotions. Herbst (2019:1-17) explains the emotions of IFCs as follows (cf. 4.5).

Box 9: Possible emotions in the IFC (Cf. 4.5)

Anger	They may for instance be angry with themselves, family members or sometimes even with the diagnosed person. Anger can be associated with fear, panic, worry, resentment and other emotions. If anger is detected the PC can use the emotion to help motivate the individual into self-exploration, action and constructive life changes.
Forgiveness	Another important construct to work on as an important act of self-love and support to others. The significant other can be encouraged to release thoughts about past or future by grounding the self in the present moment opening up to new possibilities (mindfulness).
Grief	In cases where the spouse has been diagnosed with cancer it is natural for the healthy spouse to mourn the loss of that loved one's health and life they had together before the diagnosis. Give space and permission to grieve the losses.

Guilt	This may include feelings that the significant other is not helping enough. Help the significant other identify and evaluate guilt and other associated emotions, in order to take control of it before they take control over the life of the significant other.
Anxiety and depression	Significant others may feel anxious and depressed about how they are coping. These feelings can be worsened by the impact of the illness on the cancer patient, the family and finances. Give space and show unconditional acceptance to the significant other to acknowledge these feelings and encourage them to continue with their counselling session.
Hope and hopelessness	These two emotions may be felt to different degrees. Whereas hope is having a vision toward what may change in time such as cure, comfort, peace, acceptance and even joy, hopelessness relates to anxiety, depression and feeling out of control.
Loneliness	Significant others often feel alone in their caregiving role. Feelings of isolation are the perception that others cannot understand what the IFC is going through. It may further be related to less time to socialise and previous routines. To lessen this feeling the PC can encourage the significant other to consciously make contact with others (Herbst, 2019:1-17) and remind them that others are in the same position (common humanity) (Neff & Dahm, 2013).
Stress	All the above emotions experienced by the significant other can become overwhelming making the IFC feel a loss of control. Stress is a response to any kind of demand for change and how the individual will respond to life. Teach the IFC about consequences and coping strategies, taking control and conquer stress and in the end negative influence.

Intense emotions do not only occur with death. It is the "little deaths" from the beginning of diagnosis, it is the loss and mourning of physical appearance, physical strength, roles played, social interaction, *et cetera* that bring about feelings of loss. Death is only the last phase of mourning and even in cases of recovery the family still endure and must work through the little deaths. This links to the five stages of grief from Kübler-Ross and Kessler (2014) that are denial, anger, bargaining, depression and acceptance.

To build good communication, mutual trust and respect, the compassionate PC entering in professional friendly conversations with IFCs, must keep in mind that in addition to treating each individual as a unique whole-person, there are also different communicating styles between males and females that must be kept in mind and be respected.

Box 2: Gender differences in caregiving (cf. 2.9a)

Males: Males *think* the cancer journey.	Females: Females *feel* the cancer journey.
vii. Reserved, keep thoughts and emotions to themselves.	vii. Emotional beings, comfortable in sharing and showing emotions.
viii. Cultural perception of "boys do not cry".	viii. Come across as emotionally stronger.
ix. Factual oriented, ask practical questions, need immediate answers and long-term plans, fixed on solutions.	ix. Reflect on medical information received and focus on immediate caregiving requirements.
x. More about coping than caregiving. Detach emotionally and physically.	x. Focussed on being the best caregiver. Stay connected emotionally and physically.

xi. Take a long time to build trust with counsellor.	xi. Establish trust relationship quickly with counsellor.
xii. Use more defence mechanisms such as creating emotional and physical distance, come across as irritable and rude, isolated and do not have the language to communicate their emotions.	xii. Comfortable in voicing, showing and sharing emotions.

Early integration of palliative care provides valuable opportunities to attend to the full impact of the cancer journey on IFCs' psychological, developmental and spiritual wellness (cf. 7.6). Parents, spouses, healthy siblings, grandparents, as well as extended family members often struggle with feelings of isolation due to the fear of becoming or being a burden to their support systems and experience a decrease of support over time. Encouraging the family to remember and speak about their deceased loved one, are often described as helping the family members cope with their pain. Palliative care concepts will have lasting effects throughout the cancer journey and help the family in finding a "new normal" after treatment or death and the bereavement period (cf. 3.3).

In the case of bereavement support, a crucial aspect of quality palliative care must be the well-being of IFCs in the years after their caregiving role. The result of the death of a loved one is often an extremely difficult time where IFCs can suddenly feel lost and alone, because so much of their sense of self came from being a caregiver that takes up the IFCs' whole identity. No longer under the pressure and demands of caregiving, IFCs can be left without a sense of purpose and usefulness (cf. 5.2). Questions that the PC can use to assist IFCs grow through their circumstances, while keeping in mind that answers are searched for within everyone's unique frame of reference, knowing that illness and caregiving are unique challenges to each individual sufferer (cf. 5.4.2).

Box 15: Examples of questions to be used by the PC (cf. 5.4.1.2)

Is it possible to live meaningfully and with hope, despite suffering, sickness and death?

Can hardship be experienced as a challenge and task to be wrestled with and worked through?

What is meant by acceptance of illness?

Is it possible that hardship in illness can create a passion for life and sense of victory?

The PC must also take into consideration the key risk factors for pre-loss risk that can lead to the development of prolonged grief (cf. 5.2a). The risk factors are presented in the following box.

Box 10: Key risk factors for complicated grief (cf. 5.2a)

Key risk factors for complicated grief
• Background factors

Close bond with the dying relative, especially loss of spouse or child.

Female gender, especially mothers.

Minority ethnic status.

Insecure attachment style.

High pre-loss marital dependence.

Religious (and spiritual) beliefs and practices.

(Religious/spiritual belief can result in lower levels of grief, and for others stronger faith can lead to more severe experiences of grief).

- Treatment-related factors

Aggressive medical intervention such as intensive care, ventilation, resuscitation.

Uncertainty regarding treatment.

Family conflict regarding treatment.

Economic hardship due to treatment.

Caregiving burden.

- Death-related factors

Bereavement overload (multiple losses in short period).

Low acceptance of impending death.

Violent death.

Finding or viewing the loved one’s body after a violent death.

Hospital death rather than home death.

Dissatisfaction with death notification.

As an all-embracing care approach, IFCs desperately need tangible support (for instance home visitations; cf. 3.3). The fact that pastoral caregiving goes beyond empathy, is what sets pastoral caregiving apart from all other disciplines. This implies that the PC does not wait for IFCs and patient to make an appointment, instead “the shepherd seeks out the sheep to care for them”. It is about meeting IFCs where they are (at home where caregiving takes place or at hospital where the patient is admitted) and not primarily in a counselling room. Pastoral care is about ‘being with’, deep concern and sincere empathy (cf. 5.7.3). Bereavement support standards recommended as a minimum level of bereavement support to be provided to IFCs by the PC are outlined in boxes 12 and 13.

Box 12: Principles of bereavement support by Hall *et al*. (2012; cf. 5.2c).

Principles of bereavement support

Bereavement support is delivered:

- In a targeted manner with those who would benefit the most from specialist interventions as identified through structured screening and assessments.
- Focussing on identifying the bereaved person's own resources and capacity that will improve their resilience.
- Spanning over a period from predeath to several months' post-death and beyond as required.
- Focussing not only on the primary caregiver but extending to all significant others (where sources allow).
- In a manner that will support the PC (palliative care staff) through processes such as death reviews, professional development and professional supervision.

Box 13: Methods to rebuild life after caregiving by Crossroad Hospice Charitable Foundation, (2016; cf. 5.2d).

COPING WITH GRIEF AND REBUILDING EMOTIONALLY AFTER CAREGIVING

- Use rituals as a tool to help cope with grief: Rituals can be any 'simple' act that brings the family member to a place of calm and remembrance of their loved one's memories. "If it brings you to a place of peace, embrace it and come back to it as often as you need to throughout your bereavement and journey of rediscovery of yourself" (CHCF, 2016).

- Allow all feelings: Grief is a unique journey for every person bringing with it a great range of emotions (some may be unexpected or confusing). Regardless of the type or intensity of the emotion, allow it to be felt. Being honest with self and emotions is crucial during the time of healing and recovery. "Grief does not follow a uniform path" (CHCF, 2016).

- Take time-outs from sadness: Franks (2016) states "as with physical exercise, constant grief exertion can be depleting". The joys of time outs, that take the mind away from grief (if only for a short time) must be pursued and embraced. These time outs can be going fishing, seeing a movie with family or friends, going for a walk, *et cetera*. "Grief takes a lot out of us" (CHCF, 2016).

- Seek professional help from a PC: The path toward healing and embracing a new normal is unique to each individual and can be an arduous journey. Seeking the help of a PC can be a valuable aid to the significant others' grief recovery. The expert insight and coping techniques offered by a PC can serve as a wealth of knowledge and understanding of what IFCs need during this time. "Grief recovery is never a display of weakness – you do not have to face this time of grief and mourning alone" (CHCF, 2016).

REBUILDING SOCIALLY AFTER CAREGIVING ENDS

Developing positive, meaningful relationships with others is very healing during grief recovery and self-discovery – particularly with others who also went through a cancer journey. The following guidelines are suggested to foster social connections.

- Begin reaching out to others: Re-establishing social connections does not have to happen all at once. Take small steps by for instance a phone call to a family member, coffee with friends, after-church brunch. All these small steps lay the foundation for reconnection with those who are important.

- Re-establish connections with church or community programmes: Due to the demands of caregiving activities requiring attendance away from the caregiving place (home) are eventually abandoned. Small interactions with others in the community (church) and just getting out of the house for a little while is the start for re-establishing positive social connections. “Now that the caregiving chapter in your life has passed, begin gradually involving yourself with the groups and missions you were once involved in” (CHCF, 2016).

- Lean on a support network of family, friends, or other former caregivers: Sharing the caregiver journey with people who truly care for one’s well-being is very important during the bereavement process. Family members are the most important source to lean on even though they may not be able to directly relate to the emotions. Their support and presence is a step towards the healing process.

REINVIGORATING THE PHYSICAL SELF AFTER CAREGIVING

Physical care is a very important component not to be overlooked assisting in the rediscovering of one’s identity “after setting aside the mantle of caregiving”.

- Daily exercise: Physical activity is a proven factor in relieving stress, boosting positive emotions and improving an overall life outlook.

- Adequate rest: Achieving truly restful sleep while in the caregiver role is never much of a reality while the brain is occupied with the next day’s events, worrying if one had done enough, general ever-present stress of caregiving makes restorative sleep near impossible. “Your body, mind and soul need rest to recover from the work of grief and rediscovering who you are beyond the role of caregiver” (CHCF, 2016).

- Practise daily meditation: “Meditation is the practice of bringing your mind to a state of calm, relieving you of the incessant activity of thoughts, fears, and stress” (CHCF, 2016).

Rebuilding a life after caregiving is crucial, after investing so much time and attention into the caregiving role, but turning focus on the self in an effort to deal with grief and personal loss generally brings on the perception of being secluded from society and “normal life” and feelings of selfishness. Here the PC can help the family members to allow themselves to take time and refocus, taking the love and attention they gave to their loved one and pouring it into the self (emotional, social, physical and spiritual levels; cf. 5.2).

Another concept that the PC must note is resilience. There are three requirements for resilience to happen which are, a situation of significant adversity, the presence of several resources that can face the hardship and assist with adaptation, and the avoidance of a negative outcome or a positive adjustment to a new situation. Within the cancer continuum resilience has been described as means that can promote positive growth. Resilience is therefore the ability to recover (return to a balanced emotional state) from harsh changes or hardships (cf. 5.2).

Box 11: Key attributes of resilient individuals (cf. 5.2b)

Key attributes of resilient individuals
Drawing on past experiences of loss survival.
Connecting with family and community for care.
Drawing on religious beliefs and practices.
Identifying internal and external strengths and resources.
Recreating a world of meaning and personal identity following a loss.
Drawing on the experience and support of fellow bereaved individuals.
Obtaining and accepting more practical support.
Holding onto a belief in a just world and acceptance of death.
Gaining comfort by talking and thinking about the deceased.

Summary of the palliative care concepts:

- Early integration of palliative care
- Encourage IFCs to take time for themselves to refocus
- Encourage IFCs to make use of their support structures
- Bereavement support in the years after the loss of a loved one is crucial
- Willingness to collaborate among health care workers, patient and family
- Compassionate, clear and honest communication among health care workers, patient and family
- Mutual trust and respect among health care workers, PC, patient and family
- Deal with a unique whole-person not merely a caregiver (psychological, developmental and spiritual wellness)
- Note gender differences
- Be aware of different emotions that IFCs go through
- Support healing focusing on how IFCs can find peace and meaning
- Be a support system
- Create a space for remembrance
- Lend tangible support such as home visitations

2.2 ACCEPTANCE AND COMMITMENT THERAPY (ACT)

ACT is based on a relational frame theory with six core processes that form the ACT *hexaflex*. These processes will help IFCs to accept painful experiences associated with the cancer journey instead of fighting to change, control or avoid unpleasant feelings and circumstances. It will further encourage IFCs to clarify their deepest values and to live by these values, also called committed action. The goal of ACT is to increase psychological flexibility, making the model a mindfulness, acceptance and values-based psychotherapy grounded in the behavioural and cognitive behavioural traditions. ACT for these reasons places focus on not only acceptance and mindfulness with cognitive defusion and psychological flexibility, but further also taking one's values or defining valued directions together with committed action. In short, ACT places focus on the process and function of IFCs' thoughts and feelings instead of their content. It further covers elements that go well together with a biblical worldview (cf. 4.4)

ACT offers life-changing answers to questions such as: "Why is it so hard to be happy?", "Why is life so difficult?", "Why do humans suffer so much?" and "What can people realistically do about it?"

<table>
<tr><th colspan="2">At its core ACT is therefore "about taking action" (Harris, 2009:2; cf. 4.4).</th></tr>
<tr><th>Values guided action</th><th>Mindful action</th></tr>
<tr><td>Values-guided action is the existential component asking IFCs:
• "What do you want to stand for in life?"
• "What really matters, deep in your heart?"

The PC asks IFCs to list values in different life domains for example family, intimate relationships, health, self-compassion, acceptance, spirituality, *et cetera*. Valued spiritual goals include walking with Christ, being like Christ and fulfilling specific callings in life (Cycle of Grace). These core values are used to guide, motivate and inspire behavioural changes.

By clarifying and embodying these values IFCs and PC can start to identify achievable goals. Concrete actions can be planned and taken in order to bring about these goals. Possible and specific barriers must also be identified in order to accomplish the identified actions.</td><td>This is conscious action where IFCs are being fully aware and open to life's experiences while being fully engaged in whatever they are doing in the present moment.</td></tr>
<tr><td colspan="2">The aim of ACT is therefore to help IFCs create a rich, full and meaningful life, while accepting the pain that it inevitably brings (Hayes *et al*., 2006:1-25; Harris, 2009:2).

ACT does this by teaching IFCs psychological skills to effectively handle their painful thoughts and feelings in such a way that these thoughts and feelings will have less impact and influence, known as mindfulness skills.

ACT furthermore helps IFCs clarify what is truly important and meaningful to them (clarifying values) and uses that knowledge to guide, inspire and motivate them to set goals and take action that will enrich their lives.

Mindful and values-congruent living is the desired outcome. In other words, ACT aims not to reduce IFCs' symptoms but to fundamentally change their relationships with their symptoms so that the symptoms can no longer hold them back from valued living. Reduction of symptoms is thus a "bonus" rather than the main point of therapy (cf. 4.4).</td></tr>
</table>

The goal of values guided action and mindful action is to achieve psychological flexibility and engaging in positive behaviours, rather than attempting to escape difficult experiences and emotions (the cancer journey and accompanying caregiving tasks). Psychological flexibility includes both, psychological flexibility and spirituality translating into psychospiritual flexibility. Psychospiritual flexibility stresses that IFCs' and PCs' spiritual understanding are involved and that the Holy Spirit is understood as to be active in the process of nurturing the moment-to-moment faith that is involved in following Christ. Psychological flexibility is therefore, the ability to stay in the present moment, being fully aware and open to one's experience and to act guided by one's values (cf. 4.4). Psychospiritual flexibility stands at the core of ACT where mindful, values-congruent living is the desired outcome, as well as fulfilment and hope (cf. 5.7.1.3).

2.2.1 Six core ACT processes (cf. 4.4.1)

The roots of self-compassion and compassion are developed from the six ACT core processes, also known as *hexaflex* processes. These six processes are both overlapping and interrelated where each supports the other and all focus on psychological flexibility. The six psychological skills are as follows (cf. 4.4.1).

i. Acceptance

- Flexible process: open up (cf. 4.4.1)

"You don't have to believe everything you think." Acceptance is opening and making space for painful feelings, sensations, urges and emotions; stop struggling with it, give it some breathing space and allow it to be as they are. Accepting one's situation and thoughts are also called behavioural willingness and psychological acceptance.

Values are the motivators of accepting the current situation and staying in contact with it, even if it is uncomfortable. It is not about liking or wanting the emotions, it simply means making room for them. For example, IFCs suffering from anxiety, concern, fear, *et cetera* is taught to experience it as a feeling, fully and without defence.

Willingness is the deliberate disengagement from the struggle to control private events (thoughts, images, memories) highlighting that acceptance involves an active process with a purpose. Whilst the effort to control private events narrows IFCs' range to only focus on the struggle, willingness extends the range of response alternatives so that additional outcomes can be followed. Seeing thoughts merely as thoughts can be a form of bringing them captive (2 Corinthians 10:5), in the sense that they are no longer controlling IFCs.

This is where the PC introduces mindfulness skills and exercises, not to free IFCs from the self, but to help them to be free to experience their thoughts and the environment as they are. Within the cancer journey IFCs can misperceive what God is doing in their lives. The IFC needs the flexibility to allow the thought that God is in control instead of clinging to emotions of fear, anxiety, worry and anger.

- Inflexibility process: Experiential avoidance (cf. 4.4.1).

Is an unwillingness to remain in contact with one's private experiences. The effort to control private events narrows IFCs' range to only focus on the hardships of the cancer journey.

ii. *Cognitive defusion*

- Flexible process: watch your thinking (cf. 4.4.2)

The PC can ask, “what if life is about following Christ, in the midst of pain, rather than waiting for the symptoms to go away?” Defusion is learning to step back and separate or detach from thoughts, images and memories, it is to recognise one’s thoughts in real time. Instead of getting caught up in thoughts or being pushed around by it, IFCs allow it to come and go stepping back and watching the thinking process instead of getting entangled. Cognition is not inherent, rather it is contextually learned. Defusion is to see thoughts for what they are, nothing more or less than words or pictures.

- Inflexibility process: Cognitive fusion (cf. 4.4.2)

Cognitive fusion means entanglement with verbal or cognitive processes to the point of dominating one’s awareness and greatly influences behaviour. Cognitive fusion is when IFCs’ thoughts determine who they are, “you are not a good enough caregiver”. With fusion IFCs become trapped because they fuse with the content of their cognition.

iii. *Being present*

- Flexible process: be here now (cf. 4.4.3)

“Letting go and letting God”, “Watch and pray”. Being present in the here and now places emphasis on present moment awareness. It is the ongoing, non-judgmental contact with environmental events that appear within and outside of the self. Being present is to be psychologically present, consciously connecting with and engaging in whatever is happening now. The PC teaches IFCs that contacting the present moment is to bring awareness to either their physical world or their psychological world within, or to both at the same time. It further means consciously paying attention to the here-and-now experience. The goal of being present is to help IFCs experience the world more directly so that behaviour becomes more flexible and in so doing their actions become more consistent with their values.

IFCs must be made aware that they must not be passive in regard to their thoughts, but to bring their thoughts to Jesus so that each thought can be brought captive under His control (2 Corinthians 10:5). IFCs thus learn to “watch and pray” (Matthews 26:41) implying that the content of IFCs’ thoughts are important because the biblical truth is crucial in right thinking that affects feelings and actions (Romans 12:2; Philippians 4:8). Monitoring thoughts instead of clinging to them is a way of bringing thoughts under control. This includes having hope for the future because of eternal life in Christ and Heaven to come (Romans 8:18; 2 Corinthians 4:17-18). Being mindful of the moment or being contemplative can be practised through centring prayer, *Lectio Divina*, Serenity prayer, worship and labyrinth walking (cf. B3).

- Inflexibility process: Experiential avoidance (cf. 4.4.4).

Experiential avoidance or fusion of thoughts is wandering thoughts or getting absorbed in thoughts about past or future; operating on automatic pilot (just going through the motions).

iv. *Self-as-Context*

- Flexible process: pure awareness (cf. 4.4.4)

"Looking from the self, instead of at the self." Self-as-context is a way of learning to attend to where one is at any given moment without evaluating a conceptualised self. The PC can use the example, Romans 7 where Paul reflects on the conflict between his desires and his actual behaviour; he is free to see the conflict between his goals and actual behaviour. This is important for effective counselling as IFCs discover how to observe the war within instead of getting caught up in fighting it. By focussing on the self-as-context (I am here and now instead of there and then), can loosen IFCs from spiritual rigidity, making it a place of perspective. Self-as-context thus proposes that the PC must understand IFCs as experiencing life instead of as a source of experiences such as thoughts, emotions and memories. There are two distinct elements of the mind namely, the thinking self and the observing self.

- The familiar 'thinking self' generates thoughts, beliefs, memories, judgments, fantasies, plans *et cetera*.
- The less familiar 'observing self' or pure awareness consists of the aspect of the individual that is aware of whatever he or she is thinking, feeling, sensing or doing at any given moment. The technical ACT term is self-as-context.

Self-as-context is important because it will make IFCs aware of their flow of experiences without attaching to them, thus fostering defusion and acceptance.

- Inflexibility process: Attachment to the conceptualised self cf. 4.4.4).

IFCs might have the thought of "I am not a good enough caregiver" and hold on to this thought as objective truth instead of simply as a thought that most IFCs occasionally have.

v. *Defining valued directions*

- Flexible process: know what matters (cf. 4.4.5)

"Values must be turned into action." One of the primary reasons that avoidance, escape and fusion cause problems is that it is a distraction from constructive direction in life. For IFCs clarifying values is an essential psychological skill in creating a meaningful life, also referred to as "chosen life directions" and frequently compared to a compass because they give direction and guide the ongoing journey.

Although values do not need to be religious, for Christians they often are. It is the things that give meaning to life and losing one's values that will affect IFCs greatly; for Christians "to do what matters" (engage in committed action). This implies following Jesus as disciples becoming transformed into the image of Christ; living the cycle of grace (cf. B3.6). Living the cycle of grace is committed action which is a step-by-step process of acting to create a whole life. Values should be linked to IFCs' ongoing daily life with all its ups and downs.

- Inflexibility process: A life disconnected from chosen meaning and purpose (cf. 4.4.5).

Tension may arise when a Christian client has values that stand inconsistently with biblical values to which IFCs ideally should be directed.

vi. *Building patterns of committed action*

- Flexible process: do what it takes (cf. 4.4.6)

To do what it takes is taking effective action, guided by one's values. It is good for IFCs to know what their values are, but it is only via an ongoing values-congruent action that life becomes rich, full and meaningful. Values-guided action opens a wide range of thoughts and feelings (both pleasant and unpleasant, pleasurable and painful). Committed action therefore means doing what it takes to live by one's values even if that brings pain and discomfort.

The acronym for ACT that sums up the entire model is:

A = Accept your thoughts and feelings, and be present
C = Choose a valued direction
T = Take action

Summary of the six flexibility processes and their inflexible counterparts

Box 8: Six core ACT processes (cf. 4.4.1)

Target problem: Area of rigidity/inflexibility	**ACT intervention:** Process to increase flexibility
Experiential avoidance; unnecessarily running away or escaping from emotions and thoughts, even when that creates behavioural harm	Acceptance
Fusion with the mind; arguing with the mind; believing the mind	Defusion
Living in the past or worrying about the future; lack of self-knowledge	Flexible contact with the present moment
Attachment to the conceptualised self	Self-as-context: perspective taking; conscious awareness *per se*; experiencer versus the experienced
A life disconnected from chosen meaning and purpose	Values: chosen qualities of being and doing
Inaction and or avoidance persistence	Committed action: making and keeping behavioural commitments that exemplify chosen values

⇩	⇩
Psychological inflexibility	Psychological flexibility

2.2.2 ACT and the PC

In ACT the aim is for PCs to be fully present with IFCs with an authentic, mindful, compassionate and respectful attitude. Before PCs can enter the pastoral relationship as fully and deeply as the need demands, they must firstly get to know and stay in touch with their own core values, on an ongoing basis practise mindfulness, as well as personally practising ACT in order to enrich their personal lives and to resolve their own painful issues. In this way pastoral care is led by “wounded healers” (cf. 4.5 1), who personally also qualify for counselling, by being in contact with their own suffering and hardships. The best way to learn and become familiar with ACT is to personally practise it. PCs must take time to identify what they fuse with, what they avoid, what values they lose touch with and what ineffective actions they succumb to (cf. 4.5.1). They must practise self-care, before they can teach self-care (cf. 4.6.2). PCs cannot help an anxious person to the peace of God, if that peace has not been given to the caregiver by the Holy Spirit. PCs cannot help the overwhelmed IFCs to handle their emotions, if they themselves have not learned to handle their own emotions consciously. PCs cannot help IFCs from feeling isolated and alone, if they are using their own profession to satisfy their need of attention. The more this model is applied to the self and own issues and observing how it works in personal life, the more experience can be drawn into the pastoral setting (cf. 4.5.1).

Being respectful to IFCs, the PCs must repeatedly ask IFCs’ permission to begin and/or to go on with exercises. Similarly, during an exercise where IFCs are in touch with strong emotions, PCs can ask, “I’m just checking if it is okay if we keep going with this? I don’t want you to feel in any way coerced, we can stop at any point”.

Flexibility is a crucial aspect when leading these exercises, making it longer or shorter as required, changing words to suit one’s own style and adapt them for IFCs. In addition, the PC must be creative, incorporating thoughts, feelings, comments or metaphors that IFCs have made in the current or previous sessions. Metaphors and exercises must be directly relevant to the issue being dealt with in the session (cf. 4.5.1).

The PC must further be sensitive to how IFCs use their words. An example of a language convention includes the words ‘but’ and ‘and’. Everything following ‘but’ contradicts what went before the word, meaning there are two things that are inconsistent and at war with each other. The PC must replace the word with ‘and’ whenever possible. This will reduce the psychological sense that something is wrong and needs changing whenever literally contradicting reactions are noticed (cf. 4.5.1).

The PC can boost the counselling process by merging the life coaching processes (GROW and SMART) into the ACT model, thus ensuring that the PC (who is not always a trained life coach as well) can still add value to the counselling process by placing focus on the past (healing) and the future (growth; cf. 5.7.3).

Summary of ACT and pastoral caregiving:

- PC must get to know and stay in touch with own values
- PC must learn to handle their own emotions consciously
- PC must hold IFCs accountable for value-congruent patterns of action
- PC must maintain a compassionate yet challenging approach towards IFCs
- PC must create a safe context for IFCs without being judgmental or evaluative
- PC must NOT try to “fix” IFCs
- PC must ask IFCs’ permission before commencing with exercises
- PC must be flexible and creative with exercises; structuring it according to IFCs’ situation / needs
- Where possible replace the word but with and

2.3 LIFE COACHING

This model calls attention to a more holistic approach considering not only past experiences, but also the future. For deep joy and well-being, one must have “psychic strength” which contains a strong sense of self-identity (rooted in the past), as well as an equally strong power of self-transcendence (directed to the future). For this reason, this model combines life coaching principles and concepts with pastoral counselling, making it possible for the PC to holistically assist IFCs through the cancer journey.

In the pastoral caregiving context, the PC as the carer for the soul places focus on assisting IFCs to deal with and heal from the consequences brought about by past events. While, in the context of life coaching the PC aims to guide IFCs through a process that will empower them to set clear and specific future goals (cf. 5.7). The essence of life coaching involves three parts namely, understanding where the individual is at present, focusing on what the individual wants in the future and finding the means to get there (cf. 5.7.2).

Fullness of life must be seen in the context of the right relationship with God. Life coaching can contribute to this relationship by assisting IFCs to restructure their lives according to a new relationship with God through Christ (cf. 5.7.1.1). Another important context is the hermeneutical focus. For a hermeneutical focus, four pastoral theological guidelines come into play namely *Cura Animarum*, new focus on Christology and eschatology, Christian spirituality and human flourishing.

a) Care of the human soul. Life coaching is about new (soulful) attitudes where IFCs’ life approach will be influenced by their relationship with God for both in this life and the afterlife (eschatology). In the life coaching context *Cura animarum* incorporates healing, growing and flourishing (cf. 5.7.1.1).

b) New focus on Christology and eschatology. Applying life coaching skills can motivate IFCs to act and plan goals for a new life according to their status as a child of God (Romans 8:14-17) forming a Christ like identity (cf. 5.7.1.2).

c) Christian spirituality is being capable of experiencing the presence and movement of the Spirit in the current moment. Within pastoral caregiving Christian spirituality is primarily the work of the Holy Spirit guiding IFCs in heart and mind by means of motivation and teaching as well as placing emphasis on grace, forgiveness, reconciliation, resurrection and hope supported by fellowship, service and sacrament (cf. 5.7.1.3).

d) Human flourishing within pastoral caregiving can be linked to the biblical concept of abundance as found in John 10:10. It is through Christ's death and resurrection that humans receive life in its fullness (cf. 5.7.1.4).

It is important to note that coaching and counselling cannot be combined in one session. After a first evaluation, the PC makes an informed decision of which method to start with. The IFC must be notified of which method (counselling or coaching) will be used with each appointment (cf. 5.7). The following box is a summary of pastoral life coaching.

Box 24: Pastoral life coaching (cf. 5.7.2; 7.6.1)

Pastoral caregiving	**Goal**	**Reality**	**Opportunity**	**Way forward**
Healing Cure Resolving past issues Forgiveness	The issue that should be addressed. Challenges and concerns. What is important to IFCs.	Values, beliefs, attitudes, actions. Rethink reality and current situation. Issues that can influence the future. Rename current situation considering what is possible for God.	New options and opportunities for the future. Re-aligning goals and options. Future with relationship with God considered. Reality from a God perspective.	Implementing goals. How will actions look with God in mind. SMART goals (cf.5.7.2). Feedback.

Life coaching is about enhancing IFCs' purpose and personal performance, developing skills by means of effective questions and active listening skills within a context of awareness and responsibility. Life coaching is about teaching IFCs to take good care of themselves, both short-term as well as long-term by being mindful (cf. 7.2; 7.6). Enhancing IFCs' purpose and personal performance, developing skills, teaching IFCs to take care of themselves and being mindful can be achieved by means of practising pastoral life coaching skills by incorporating the GROW and SMART practices (cf. 5.7.3).

Box 22: GROW model and SMART model (cf. 5.7.2)

Whitmore's model **GROW**	**Doran's model** **SMART**
• G oals Goals can be short, medium or long-term. Goals is a twofold process: -goals for each session -goals for the whole coaching process • R eality Refers to how IFCs feel about the reality of the current situation and future predictions. The purpose of this point is to clarify goals because it can focus on sources of motivation and dissatisfaction. • O pportunity Alternative options that IFCs can choose when planning goals. The aim is to create possible alternative actions and evaluate them instead of finding immediate solutions. • W ay forward Refers to the way forward allowing IFCs to identify and agree on specific actions and plans to reach set goals. This final stage involves the headway from discussing options to decision and specific actions.	Goal setting is done with the SMART model by Doran (1981:35-36) which brings focus and measurement to goal setting. • S pecific • M easurable • A greed • R ealistic • T ime-framed

It is further very important that the PC allocates time for reflection in the beginning of each session (cf. 2.9b).

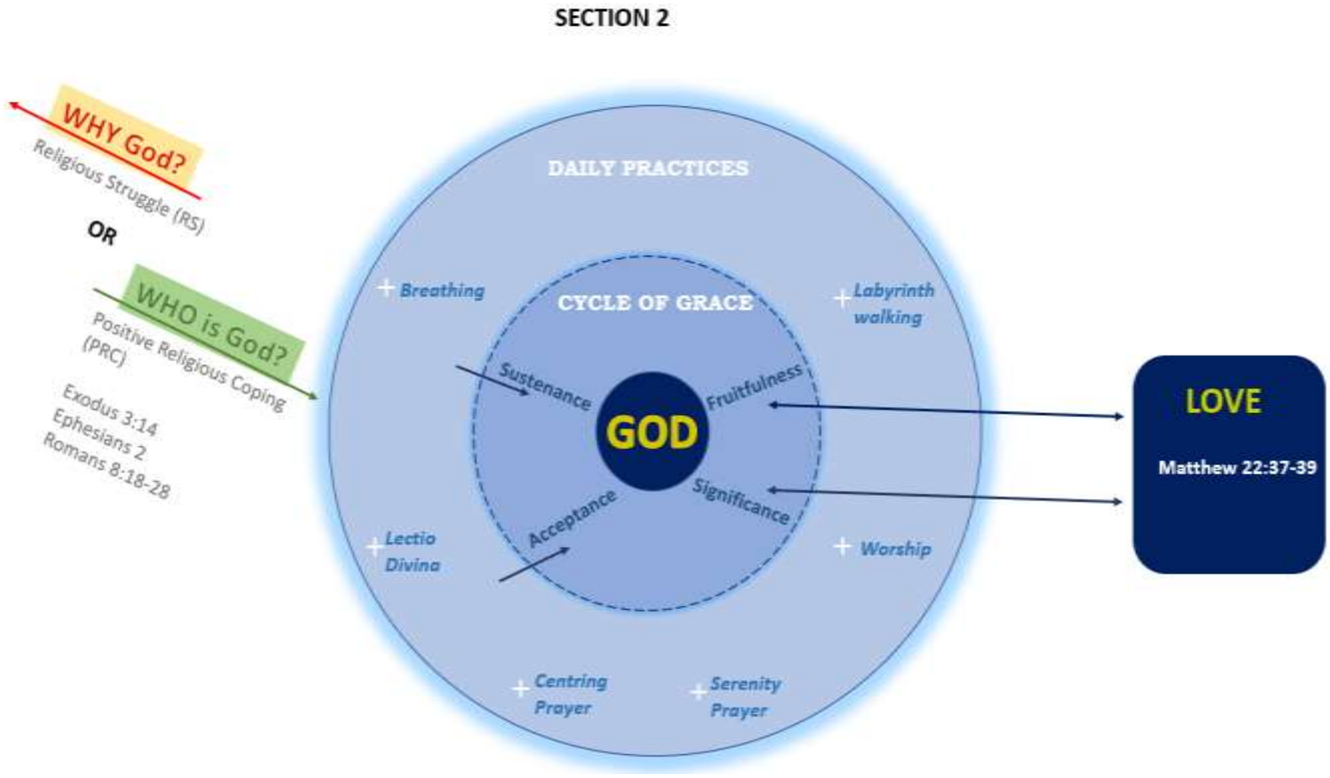
Box 4: Feedback questions (cf. 2.9b)

Feedback: Reflecting on exercises
"What worked for you?" "How did you perceive the exercise?" "How did it make you feel?" "What emotions came up?" "What is different today compared to last week?" "How do you feel hearing your answers?" "How are your emotions changing (what is new, different)?"

In summary, the PC must distinguish between the emotional (how IFCs feel), existential (how IFCs experience the world) and spiritual (IFCs God-image) dimensions of IFCs' distress. Within the pastoral process the PC must strive to help IFCs achieve optimal levels of functioning, despite IFCs' hardships by growing through difficult experiences into sources of strength and wellbeing (cf. 7.6). Pastoral caregiving is a special preparatory and preventative task of sustaining, assisting and preparing the patient and IFCs for the general problems of cancer such as inability to cope with the illness, fear of suffering (witnessing suffering) and anxieties about end of life. Helping the patient and IFCs on “how to be sick” even before the sickness comes about, “how to die” before death by focussing on the creative powers in life and faith and not on pathology. It is a process of empowerment where the PC motivates IFCs to rely on their own resources believing that each person has strengths, capabilities and resources (cf. 5.4.2).

8.3 SECTION 2

The point of feeling utterly lonely is where the true quest for meaning and for God starts, questioning whether cancer is a fate to be endured alone (Why God?) or if this path of suffering (physically, emotionally, spiritually) also runs through God’s heart (Who is God?). To this effect giving meaning to suffering is complex. The quest for meaning is not about what meaning life has for the individual, but the meaning one gives to life (cf. 5.3).



B1 WHY GOD?

When the connection between God and suffering becomes so problematic that IFCs' understanding of God is inappropriate, then suffering becomes a theological problem. With suffering to such an extent that IFCs' God-image becomes so harmful that it can effect the process of healing, also referred to as "spiritual trauma of pain" (cf. 5.4.1).

Facing uncertainties in a complex world and the mystery of God, IFCs must understand that the goal of questioning is not to find answers, but to "ask, seek and knock". IFCs must not expect that a relationship with God entails getting what they want when praying, because there will always be hardships to be endured during the earthly journey that simply cannot be understood, but nevertheless still must be worked through. What is known is that God desires a relationship with everyone and created humans for this end (cf. 5.4.1).

During the cancer journey, the patient and IFCs can harden themselves, becoming embittered or simply submitting to a destiny of hardship. In an embittered frame of mind, life becomes meaningless with perceptions such as no life expectations, pessimism and despair which darken their outlook on existence. It is the PC's task to help IFCs understand how their God-image (perceptions and concepts of God) play a role in the way they interpret the cancer journey. This does not imply that there is a correct or incorrect concept of God. The task of the PC is to determine whether IFCs' God-image is disruptive and destabilised (standing still at the "why God?" question) or whether their God-image plays a constructive role with a positive influence on IFCs' origin of faith and emotions (working with the question "who is God?"; cf. 5.4.1).

The questions to be asked by the PC are, "How does IFCs' concept of God function?" and "What effect does it have on faith behaviour?" (cf. 5.7.3). In the quest for the answers to these questions the PC can use the four different coping methods of stress, FICA and God-image table.

1.1 COPING METHODS

The IFCs can have different forms op coping, namely:

- Problem-focused coping. Active coping where IFCs will attempt to constructively change or eliminate the source of stress (cf. 5.3.1).
- Emotion-focused coping. The use of social support where IFCs will attempt to work through their emotional distress with the intention of minimising the impact of the stressor and maintain emotional stability (cf. 5.3.2).
- Avoidant focused coping. This is denial where IFCs often represent a psychological defence against difficult realities such as a cancer journey. This coping style does not address the cause or the effects of the stress also referred to as denial. IFCs pretend not to feel sorrow, withdraw from the challenge of suffering and seem to accept the journey but in fact lost all hope and joy in life (cf. 5.3.3).

Among cancer cases, problem- and emotion focused coping have been positively associated with improved psychological adjustment, mental health and quality of life. Avoidant coping on the other hand has been negatively associated with these outcomes.

- Religion as a coping mechanism. Religious coping (RC) is not simply a defence mechanism, it is actively and dynamically involved in each stage of the coping process to help IFCs find, maintain and transform significance (cf. 5.3.4). RC is the way in which IFCs will cope with the trauma, adversities, or stressful events due to the cancer journey by finding comfort in their religious practices (cf. 5.3.4.1). Religion can provide a set of beliefs to help IFCs find meaning and purpose during hardships, as well as providing hope, order and coherence that help with the process of acceptance and adjustment of the cancer journey. Religion can thus be a major coping resource for IFCs facing serious illnesses such as cancer (cf. 5.3.4.1).
- Of particular importance to this model is the type of religious coping. Depending on its use and interpretation, religion could have two outcomes. Generally, religion is applied in a positive manner (PRC) as a great source of coping. In contrast religious struggle (RS) has been associated with negative outcomes, such as mortality and worse mental health (cf. 5.3.4.1).

1.1.1 Religious struggle (RS)

Major life stressors, such as a cancer diagnosis and death not only affect the cancer patient, but the lives of their spouses, preadolescent / adolescent, parents, friends and others in their social networks which can have a profound effect on the family's belief system leading to religious struggle. RS is a set of strategies or negative God-images that regards God as a punishing God accompanied with feelings of abandonment by God, insecure relationship with God, pessimistic worldview and doubt in one's religious beliefs (cf. 5.3.4.3).

The PC can use the acronym, FICA developed by Christina Pulchalski (1998:970-974; 2000:129-137) to assess IFCs current spiritual position (cf. 2.8.2).

Box 1: FICA (cf. 2.8.2)

Faith	**Importance and Influence**	**Community**	**Application**
"What do you believe in that gives meaning to your life?" Do you consider yourself to be a religious or spiritual person?" This is an important question because the individual may relate to one and take offence at	"How important is your faith (religion or spirituality) to you?" Hearing that the individual is religious or spiritual tells the counsellor little. The counsellor needs to find out by asking, "How is this important?" There is a big difference between for instance a Catholic	"Are you a part of a religious of spiritual community?" For those who participate in an organised religion community it often forms a central part of their spiritual and social experience. This community often becomes more important during the cancer journey	"How would you like me to address these issues in your health care?" "How might these things apply to your current situation?" "How can I assist you in your spiritual care?" Patients and family often feel better because they have been given the

the other. The answer to this question tells the counsellor something about the individual but needs exploration of what the terms mean to them.	who has been to Mass sporadically and one who attends Mass daily.	especially as death approaches.	permission to share their beliefs

IFCs' God-images will play a role in the way they will perceive suffering (the cancer journey). Van der Ven (1990) and Louw (2012) give an indication of the variety of ways in which IFCs' relationship with God could be interpreted by describing different God-images in crisis behaviour (cf. 5.4.1). The way IFCs will approach the cancer journey depends on their framework of meaning, perception of life and how they understand God (their God-image; cf. 5.3.4.3).

Box 14: God-images by Van der Ven and Louw (5.4.1)

Theological symbols which play a role in the concept of suffering by Van der Ven (1990:209-210)
• **Apathy:** Suffering does not really affect God; it leaves Him cold. • **Retribution:** Suffering is a way of God's punishment. • **Providence and dispensation:** Suffering is God's will and there is a purpose and plan with it. • **Purification:** God uses suffering as a means of purification and education in one's faith. • **Compassion:** The suffering God has compassion with the sufferer. • **Substitution:** In the light of God's grace, He strengthens people to exchange places with others and help others with sacrificial service, as Christ suffered for humans. • **Mystical unification:** Through suffering the suffering comes in direct contact with God; humanity suffers in unity with God.
Four possible God-images by Louw (2012:159)
• **God as Lord:** Represented as a king who is in control of life, whose wisdom is a guideline. "Through faith one can rely on the faithfulness of God despite the prevailing crisis." • **God as soulmate, partner for life**: Represented as the one identifying with human suffering of which the cross is the representation of God's woundedness and vulnerability. "God does not always provide a solution to a crisis, but indeed offers salvation (grace) despite our human predicament." • **God as parent**: Represented as a caring parent showing compassion and nurturing one in suffering. Within this relationship one is open to His embracement. • **God as judge:** Represented as a God of justice, judging injustice and evil, dealing with guilt in a fair and just way. In this regard reprimands become a means to a constructive end for example converting people to and instructing them in a new life mode to a lifestyle imitating justice and reconciliation
The theological centre of these symbols and groups is primarily determined by two concepts namely, God's faithfulness and his suffering. The PC must make sure to communicate these two faith perspectives to IFCs (Louw, 2011a:229-230)
• IFCs can rely on God because He is faithful. • In Christ IFCs must realise that God is part of their suffering and suffers "sym-pathetically" with them.

To lessen IFCs' sense of confusion and to improve their sense of hopefulness, the PC can increase IFCs' awareness by reminding them that although negative religious coping strategies predict both, short- and longterm negative outcomes, it can also be a path of healing. IFCs must be reminded that they should not cover up their pain and true feelings, not feel guilty about negative feelings toward God but to weep, grieve and even rage if needed. The PC will help IFCs to work through all their emotions with hope because of the knowledge that God weeps with the suffering, shares their grief and understands the rage. More than this is to remember that the God who came to earth in Jesus is the same God who raised His Son from the grave (cf. 5.5). A crisis of faith may over the long-term serve as a powerful motivation to finding a deeper sense of meaning or valued commitments.

Box 3: Questions regularly asked. Answers and recommended Bible verses (cf. 2.9d)

Regular questions asked are	Replies on these questions	Bible verses recommended
iv. Why does my loved one have to suffer? v. Why is God doing this? vi. Why does God cure some people and not others?	v. To simply and honestly state that one does not have all the answers. vi. How and what can you learn from this journey? vii. How can you get deeper personal insight? viii. How can you experience God differently?	vii. To explain deterioration of the body – 2 Corinthians 4:16 viii. "Thorn in my flesh" can be cancer - 2 Corinthians 12:1-10 ix. There is so much better to come – Romans 8:18 x. Message of comfort – Revelation 21:4 xi. Social support systems –Galatians 6:2 xii. Staying in God's presence –Philippians 4:6-7

While suffering does not come from God, it must at times be accepted. Practising the art of coping with illness involves putting meaning into suffering, trusting while everything seems futile and living in the face of death (cf. 5.4.1).

The death of a loved one is a primary stressor (illness of a family member) triggering a religious secondary stressor on happiness and depressive symptoms. Being confronted by both stressors simultaneously is overwhelming and compromises the resources IFCs might typically rely on. Under such circumstances IFCs must search outside themselves for sustenance. One place IFCs might look for support is from God relying on a sense of religious hope to carry them through the cancer journey (cf. 5.3.4.3).

1.1.2 Positive religious coping (PRC)

Individuals using religion as a coping mechanism during illness generally rely on PRC, characterised by constructive reliance on faith to promote healthy adaptation. PRC has the potential to offer the cancer family a sense of meaning, purpose, altered priorities, closer relationships, comfort, control and personal growth, a deeper appreciation for life and bringing about better coping with stress, giving social support, encouraging human virtues, increasing positive emotions such as peace (cf. 5.3.4.1; 5.3.4.2). These outcomes are referred to as post-traumatic growth and perspective transformation (cf. 5.3.4.2). Benefits that are experienced as a direct result of becoming an IFC, include post-traumatic growth, benefit finding, optimism, positive effects, hope, and finding meaning in life (cf. 4.6.1).

Peace and meaning highly correlate with quality of life. Meaning is an important element of religion, because it addresses issues such as what in life is important, the purposes for living and what the nature of the human experience is. Peace is as a kind of acceptance of one's circumstances without being fatalistic (cf. 5.3.4.2).

Both, RS and PRC consider God to be in control of one's fate, but holding different views on God's will, for example RS maintains an attitude of "God has forsaken me", getting stuck in the "Why God?" questions, holding negative outcomes on religious beliefs and well-being. PRC journeys with the attitude of "God has called upon me", working on the "Who is God?" questions, in order to grow into an intimate relationship with God through daily spiritual practices with the ultimate goal of living the cycle of grace (cf. 5.3.4.3).

B2 WHO IS GOD?

It is normal for IFCs to feel overwhelmed which includes emotions such as a sense of anxiety or not coping due to prolonged levels of high stress, which can eventually lead to physical and emotional burnout (cf. 4.6; 6.2). The PC must explain to IFCs that feeling overwhelmed is not a sign of failure, not being good enough or even a lack of faith during times of RS. It is a natural human response to a drastic changing environment due to hardships. The cancer journey can make IFCs aware of their own inabilities and shortcomings, mostly because they struggle to get control over their own emotions (inner world) and environment (outer world). The overwhelmed soul is overcome with feelings of helplessness and uncertainty, causing an urgency to be freed from hardship, a plea to be loved, led and revived (cf. 6.2).

The PC can use King David's Psalm 143 when IFCs feel overwhelmed. Psalm 143 teaches that the believer can freely confess their need for God, reminding themselves of Gods faithfulness throughout history. The burdened IFCs can ask God to remind them of His compassion and love, to lead them in His light and breathe life into their soul, giving them hope (cf. 6.2). From feeling hopeless, the cancer journey can be transformed into an opportunity for growth, witnessing and deepening faith by finding meaning in suffering (cf. 7.2). In this space, the PC can provide a theological understanding of the significance of God's presence within the context of caregiver related stress (cf. 6.1) by means of the following four examples of Scriptures that the PC can use to help IFCs through difficult questions and come to a place of peace within the moment and filled with hope for the future.

2.1 BEING-WITH (EXODUS 3:14)

In Exodus 3:14 God reveals His name to Moses with the words "*I AM*" and "*to you*". "*I am who I am*" of Exodus 3:14 means, "I will be present (in a dynamic, active sense) wherever, whenever, and to whomever I will be present". When God says, "*I am who I am*" He does not merely indicate to His existence but rather to His gracious presence (cf. 6.3). With the words "*I AM*" God says that He is with IFCs and their diagnosed loved one, bestowing grace and having mercy on them throughout their lives. Being-with is thus a boundless and unending being-with – past, present and future (cf. 6.3).

From the verse in Exodus 3:12(NIV) "*And God said, 'I will be with you'*" can be interpreted that God is there for His people to overcome all their fears and to take away every doubt. It does not matter who Moses is or what strengths he has - God is his leader. In these words, IFCs are taught that even when overwhelmed with their own weaknesses, it must be kept in mind that God is there with and for His people (cf. 6.3). Therefore, when IFCs experience hardships they must magnify the power of God, knowing that God is with them deeply rooted in their hearts. God teaches Moses that He alone is worthy of the most Holy Name and that Moses must not doubt overcoming all things under God's guidance (cf. 6.3).

God only seeks good for His people, seeking to help His people to live for more than this fragile earthly life, but for the life of the world to come. Exodus 3:12 *"I will be with you*" are words of promised aid and freedom (Exodus 3:7-10). The announcement is to be taken as a promise, indicating God's compassion in interventions to come. It is God's way to open an unpredictable future yet guaranteed divine assistance (cf. 6.3).

The concept "*I am who I am*" is one of the most insightful statements concerning God's being and essence. From this IFCs can receive comfort that God is a unique kind of deity and that He will always be with His people wherever they are. Exodus 3:14 can be viewed as the basis of a spirituality of hope and a theological understanding of the spirit of compassion as started by the compassionate being of God with the suffering of His people which will be discussed in the following section.

2.2 THE COMPASSIONATE GOD (EPHESIANS 2)

The word compassion can be given as an answer to the questions "How might one speak of God during suffering and what kind of God fashions and participates in pain, suffering and death?" Ephesians 2 defines God as the vulnerable God, the kenotic Creator, the compassionate God and the Triune God.

The core problem of mankind is that they do not have a relationship with God, because they are alienated from God by sin. It has nothing to do with the way people live, it has to do with the fact that they are dead, even while physically alive. In other words, people are spiritually dead while being physically alive. By being dead to God, the individual is equally dead to spiritual life, truth, righteousness, inner peace and happiness. God longs to be re-joined with His people, which He made in His image and for

His glory. A God that is fundamentally kind, merciful and loving reaches out to condemned human beings offering them salvation and all the eternal blessings it brings (cf. 6.4).

In Ephesians 2 Paul connects the ideas of Christ's great love and His sacrificial death. The PC can bring it under IFCs attention that the story of the crucified Christ is not only about a bloody Christ, the important point of the crucified Christ is about love – sacrificial, giving and saving love. Jesus' dying on the cross as a guilty sinner in the place of guilty sinners, brings the believer closer to God (cf. 6.4). Romans 8:2 (NIV) "*because through Christ Jesus the law of the Spirit who gives life has set you free from the law of sin and death*".

There is a creative self-emptying and self-offering (a kenosis) side of God, a sharing in the suffering of His people. This sharing in the suffering is a display of the suffering love primarily in and through Jesus Christs' life, suffering, death and resurrection. Thus the pain, suffering and death that affect IFCs and their families must be regarded as affecting God. The suffering of Christ is not the only display of divine love. The Christ event also shows that God not only experienced suffering and death on the cross, but importantly overcomes suffering and death through the resurrection. While God does not prevent pain, suffering and death throughout the life journey, He also does not intend that pain, suffering and death should endure or triumph. IFCs can find comfort in the fact that suffering and death are not final but lead to new life within the embrace of God's love. 2 Corinthians 5:21(NIV) says, "*God made him who had no sin to be sin for us*" which implies that God shares in the pain of humans to become their "co-sufferer" (cf. 6.4). Therefore, in Christ, God becomes and is the diagnosed loved one. The meaning of the concept "the suffering God" is that God personally identifies with human suffering. God turns suffering around to become an element for the growth of faith and hope. God the Saviour / Redeemer, co-sufferer, friend and partner for life will support, sustain and assist the sufferer (cf. 6.4).

2.3 SELF-COMPASSION THROUGH LOVE (MATTHEW 22:36-39)

Self-compassion through love is especially directed toward IFCs, making it an important factor for the well-being on physical, emotional and spiritual levels. Love for God, the neighbour and self-love are addressed in Matthew 22:36-39. Moses summed up all the rules in ten commands, Christ brings the ten to two in Matthew 22, love to God and love to the neighbour therefore love is the fulfilling of the law. The commandments of the law and the teaching of the prophets cannot be fulfilled separate from the twofold love commandment which can be seen in Matthew 7:12(NIV) "… *for this sums up the Law and the Prophets*" and Romans 13:10 (NIV) "…*love is the fulfilment of the law*". The love commandments thus belong together, enfolding IFCs vertical relationship with God and the horizontal relationship with self and others. The first leads to the second and the second requires and depends on the first (cf. 6.5).

The law supposes that one should love the self or otherwise they will not be able to love their neighbour "*as thyself*" – so that we may love the self. This explains that the Scriptures teach self-denial, but it does not teach self-annihilation. It forbids selfishness, but does not forbid self-love. Thus IFCs should love their neighbour not as they love themsleves but as they ought to love themselves; not to the same degree, but after the same manner, which is freely and readily, sincerely and unfeignedly, tenderly and compassionately, constantly and perseveringly available. With this, IFCs can come to understand that love is the first thing that God demands from His people and for this reason the first thing that IFCs should devote to Him as their Creator, Owner and Ruler, is to love Him with one's whole heart, soul and mind. To love one's neighbour (patient, family and others) is the second great commandment (v.39). IFCs must therefore not feel selfish or ashamed to take time care of themselves and love themselves but learn that self-love is natural and the rule of the greatest duty which must be preserved and sanctified. This kind of self-love is to have regard for the welfare of one's soul and body which is one of the most important aspects during the caregiving journey.

2. 4 HOPE (ROMANS 8:18-28)

Romans 8:24-25 highlights the importance of hope and the Spirit mediating for Christs' followers with the message of hope that all things work together for good to them who loves God and lives according to His gracious purpose, bringing mankind to eternal glory. IFCs can feel secure that while they hold onto their faith, God gives the promise that nothing can separate them from His love (cf. 6.6).

Hope can empower IFCs to have enough trust to move out of the present into the future, inciting them to commit themselves in both, thought and deed to the incomprehensible mystery of God. Hope is a theological virtue, established on the premise that one's daily commitments and decisions are of vital importance. This requires that IFCs must surrender themselves to God and understand that despair comes partly because of the refusal to abandon the self to the unpredictable and the uncontrollable. The full meaning of "*having the spirit of Christ*" (Romans 8:9) means that it is not merely receiving the Spirit, nor merely a sustained quality of conduct and lifestyle (v.14), but an entire life in the course of which the death of Christ achieves full expression (cf. 6.6).

Hope is forward looking and forward moving and therefore also transforming the present. Yet this hope does not suppress or avoid the unpleasant realities of life. Death is real, death and suffering remains, even for the believer, there are no ready-made answers. Faith does not overstep hardships into a heavenly utopia and does not wish itself into a different reality. Hope relates to "what is". It does not cause IFCs to deny their reality. In fact, hope provides the courage to face hardships during the life journey. Hope does not avoid the pain felt during hard times nor is it naïve about suffering. The key event in the Christian story which must speak to IFCs during the cancer journey is the crucifixion where God embraces suffering as a reality of human existence. By the cross IFCs are reminded that nothing "*neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord*" (Romans 8:39 NIV). Through the resurrection IFCs thus find hope and comfort (cf. 6.6).

Hope is an important factor to work on because it has to do with the psychological event of anticipation and moving forward versus regression. It touches IFCs awareness of the future. Past and present therefore cannot be separated from the future. The ties between the future and the present are patience, perseverance and endurance. A vital part of hope is the tension between the future and the present "*For in this hope we were saved. But hope that is seen is no hope at all. Who hopes for what they already have? But if we hope for what we do not yet have, we wait for it patiently*" (Romans 8:24-25 NIV; cf. 6.6).

Having discussions on who God truly is this new relationship with God or new God-image must continue to be nourished and grow. This can be done by the following practices that the PC must introduce to IFCs and encourage them to frequently and continuously practise it. Reminding IFCs that self-love is crucial just as fostering and holding on to hope.

B3 PRACTICES

BUILDING A RELATIONSHIP WITH GOD

Though IFCs can be shaken by a cancer diagnosis and journey thereof, religious practices can provide them and their families with a set of potential resources that can be accessed in order to help deal with the trauma. In the context of the cancer journey, religious beliefs, behaviours and experiences can be important resources and valuable when dealing with the physical, mental and social challenges of the journey (cf. 5.6).

The PC must keep in mind that adapting to a new routine after a cancer diagnosis, IFCs can have a difficult time to break away from the caregiving tasks and extra daily chores to spend time with God in solitude and silence. By introducing spiritual practices to IFCs, the PC can remind them that these practices hold the potential of managing their stress related to cancer with the purpose of reducing negative outcomes such as depression, anxiety, worry, poor quality of life, and disrupted relations with family and friends. Together with better coping skills these practices furthermore will bring IFCs to a closer relationship with God (cf. 5.6).

The model suggests the following spiritual practices to both, the PC and IFCs: the 4-7-8 breathing technique, a unique way of reading Scripture (Lectio Devina), followed by two types of prayer, centring prayer and Serenity Prayer, as well as the effects of gospel music and labyrinth walking.

3.1 BREATHING

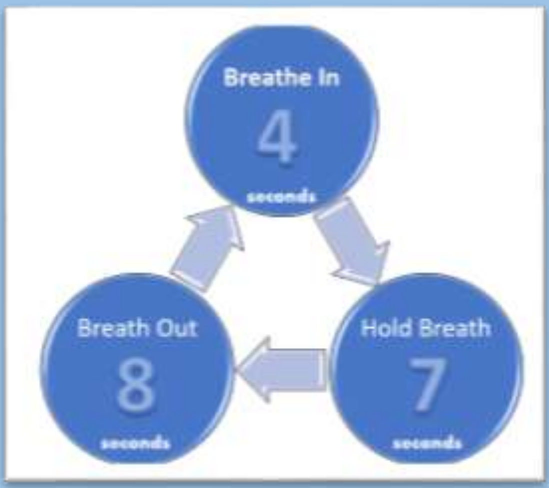
As IFCs must find a new normal and balance extra duties due to caregiving duties, there is little time and energy left to take care of the self. From the research done in this study it can be concluded that the "simple" task of breathing is highly recommended for IFCs, as steady and controlled breathing requires little input and effort but in return offers great health benefits. Breathing is a technique not interupting daily tasks and chores, it can be practised throughout the day without taking time from commitments. IFCs can teach it to their family and diagnosed loved one to be practised alone or together through especially hard days. Both PC and IFCs can start and end each session with the breathing technique to ancor them in the moment at the beginning and release them to carry on with the day in a calm and mindful manner.

The technique recommended is the 4-7-8 breathing technique. This technique focuses and calms the mind by helping to quieten thoughts like mindfulness meditation also referred to as a natural tranquilizer for the nervous system (cf. 7.3.2). From the evidence from the study it is strongly advised that IFCs start with mindfulness meditation (cf. 7.4) as soon as possible before caregiver fatigue sets in (cf. 7.3.2).

Box 23: 4-7-8 Breathing exercise (cf. 7.2.2)

The 4-7-8 breathing technique was invented by Weil (2020), a world-renowned doctor focussing on holistic health. This technique focuses and calms the mind by helping to quieten thoughts like mindfulness meditation. Dr Weil (2020) refers to the technique as a natural tranquilizer for the nervous system.

Guide for the 4-7-8 breathing technique: 4-7-8 Breathing works in three ways



Before starting the breathing pattern, adopt a comfortable upright sitting position and place the tip of the tongue on the tissue right behind the top front teeth.

Empty the lungs of all air and:

Inhale	**Hold your breath**	**Exhale**
1. close your mouth and inhale quietly through your nose to a mental count of four.	2. hold for the count of 7.	3. exhale completely through your mouth, making a whoosh sound to a count of eight.

These three steps are one breath cycle. For best results, the cycle must be practised at least twice a day (or more), but never more than four breath cycles at a time for the first month. After the first month it can be increased to 8 breath cycles.

Please note: the technique may make some people feel light-headed (especially at first). A person who cannot hold their breath for long enough may try a shorter pattern instead, such as: inhale for 2 seconds; hold the breath for 3.5 seconds, exhale for 4 seconds (2: 3.5: 4)

Video: For a demonstration of the technique by Dr. Weil go to https://www.drweil.com/videos-features/videos/breathing-exercises-4-7-8-breath/.

App: 4:7:8 breathing app suitable for iPhone, iPad and Apple devices is available.

3.2 LECTIO DIVINA

Divine reading, in Latin *Lectio Divina,* is an ancient spiritual practice, placing focus on developing a heightened awareness and self-reflection by meditative reading of biblical texts. It is the skill of listening to God's word as if in conversation with Christ where He suggests the topics to be discussed. This daily encounter with Christ and reflecting on texts lead beyond mere acquaintanceship to a space of trust, love and friendship – also referred to as resting in God. Lectio Divina can be practised alone or IFCs can share this experience with their diagnosed loved one. *Lectio,* involves only a few verses that are read repeatedly, slowly and contemplatively while reflecting on each word and phrase which will allow IFCs and their loved ones to become still and aware of God's presence opening to the possibility of God speaking to them through the text while being mindful of the impact that the words have on their hearts. This can become a sacred shared experience between IFCs and the loved one; resting in God together can bring them closer to each other and to God. In this way suffering and hardship become a space of love, growth and transformation.

Lectio Divina consists of four phases (cf.5.6.1):

- *Oratio*: calling on the Divine
- *Lectio*: reading a text
- *Meditatio*: contemplate on the text
- *Contemplatio*: practise listening, becoming one with the text

In this practice the PC must teach IFCs that they must firstly make a conscious effort to engage with the sentences through listening or contemplation, and secondly allow the texts to speak to their hearts. The texts discussed with IFCs regarding "Who is God?" can be carried on within this practice connecting deeper and journeying with it in an effort to find meaning and hope.

The practice of *Lectio* exercise requires a specific way of reading the Bible "that involves listening with the heart". Instead of studying Scripture with the intention of understanding the meaning of the text, *Lectio* studies the reader. In other words, IFCs are "praying the Scriptures" (cf. 5.6.1). Texts to be recommended are Exodus 3:14, Ephesians 2, Matthew 22:36-39 and Romans 8:18-28.

Box 17: Nine steps of Lectio Divina by Smith (2009:109; cf. 5.6.1)

Nine steps of *Lectio Divina*

PHASE 1: *Oratio* - calling on the Divine

Step 1: Select a passage from the Bible.

Step 2: Take a few minutes to relax while breathing deeply.

PHASE 2: *Lectio* - reading a text

Step 3: First reading.

- Read the selected passage slowly, pausing between phrases.
- Be silent for a few minutes.

Step 4: Second reading.

- Read the selected passage again slowly using longer pauses between phrases.
- Be mindful of any of the words or phrases that stand out.
- Make mental notes of those words or phrases.
- Write the selected words or phrases down.

Step 5: Third reading.

- Have a second look at the word or phrase up to the part that stood out.
- Stop there and repeat those words or phrase a few times.

PHASE 3: *Meditatio* - contemplate on the text

Step 6: Pondering.

- Reflect on the chosen words or phrases.
- Repeat the words or phrases a few times to allow it to interact with thoughts and memories or any other Bible passages that come to mind.
- Let it touch the heart, desires as well as fears.
- Begin to wonder, “What might God want to say to me specifically?”

PHASE 4: IV *Contemplatio* - practise listening, becoming one with the text

Step 7: Prayer.

- Turn above question into a prayer asking God: “What is the word you have for me in this passage, God?” / “Is there anything you want to say to me today?”
- Listen and write anything that God might be answering down.

Step 8: Rest: (the step from doing to being).

- Be still and silent for a moment.
- Take God’s presence in.

Step 9: Response.

- Ask self and God, “What am I being called to do as a result of the word I have been given?”

In how to grow in a new and strong relationship with God, this model uses the work from Hudson who suggests three gospel addresses. Firstly, and the most basic but also continuous and everlasting activity is learning how to pray. Together with the second activity to be on a mission of getting to know God through the gospels. The third activity is to finding soul-friends to join IFCs on their thoughts and journey of the spiritual practices and when IFCs are ready to bravely and compassionately open their hearts to fellow sufferers (cf. 5.6c).

The purpose of prayer, apart form growing a relationship with God, is listening to His message and finding peace prayer further bringing about positive effects, personal integration and well-balanced self-expression, also countering depressive feelings and easing stress (cf. 5.6c). After explaining the purpose and effect of prayer to IFCs the PC can introduce and teach Centring prayer and Serenity Prayer.

3.3 CENTRING PRAYER

This model uses Centring prayer as described by Keating which aims to bring unity with God in order to improve the ability to be silent, hear God and be filled with the Spirit (cf. 5.6.2). The prayer is about opening to God, surrendering and declaring "Here I am, fill me". Centring prayer can help IFCs to relate differently to distressing inner experiences such as anxiety, fear, anger, and questions by learning to sit at the feet of Christ (Luke 10:38-42).

Centring prayer built around a relationship with God is a responsive way of surrendering to God's loving presence and healing action within. It is a way that IFCs can divert attention from the ordinary flow of thoughts (whether a body sensation, feeling, emotion, image, memory, plan, concept, reflection), in order to awaken faith (psychological breakthrough or spiritual experience). Centring prayer thus goes beyond thoughts, words and emotions. It also opens the mind and heart (the whole being of a person) to God (cf.5.6.2).

The PC must teach IFCs that the battle during early stages of contemplative prayer will be within their thoughts. For this reason, it is important that IFCs must find quiet and alone times of the day away from distractions and foreseeable interruptions. Although one wants to be quiet, wandering thoughts form part of nature, it will happen. IFCs must expect and accept it knowing the thoughts will come. When distracted with a thought or feeling, they must simply acknowledge the experience and gently return focus back to their sacred word (cf. 5.6.2).

The sacred word stands for the symbol of IFCs' intention to surrender to God. The word must be one to two syllable(s) long, meaningful and sacred such as "Jesus", "Peace" or "Yes". It is important to understand that the solution is not a blank mind or using the sacred word as a mantra to achieve an enlightened state. IFCs must merely gently return to their sacred word reaffirming their will to converse with God and to be united with Him. This does not demand effort but surrender done without exasperation or desperation. The sacred word represents the willingness to focus on God, letting go of own efforts to understand Him through cognition and effect. The aim is to learn in time to rest in God's presence, finding comfort during this time with Him and letting go of the tendency to chase or push distressing thoughts, feelings and sensations away especially the uncertainty, doubt, worry and anxiety IFCs may experience during a cancer journey.

On the question "Are you your thoughts and feelings?" This model suggests that people are not their thoughts and feelings. Instead this question is changed to a statement from "God, I am anxious" to statements of "I have a feeling that I am anxious, and, in my anxiousness, I worship God" (cf. 5.6.2).

Box 18: Guidelines for Centring Prayer (cf. 5.6.2)

The method of Centring Prayer

Be still and know that I am God (Psalm 46:10)

Four guidelines

V. Sacred word	VI. Surrender	VII. Focus	VIII. Remain in silence
Choose a sacred word as the symbol of the intention to surrender to God's presence and work within.	Sit comfortably; close the eyes; settle briefly and silently introduce the sacred word as the symbol of surrendering to God's presence and action within.	When one become aware of thoughts, gently return to the sacred word.	Remain in silence at the end of the prayer with closed eyes for a couple of minutes

Explanation of the four guidelines

V. Sacred word

- Using a sacred word shows the aim of being in God's presence and surrendering to divine action.
- Choose the sacred word during a brief prayer asking the Holy Spirit for inspiration. Examples of sacred words include: Lord, Jesus, Abba, Father, Love, Peace.
- Do not change the sacred word once it has been chosen.

VI. Surrender

- Sitting comfortably enough to avoid feeling uncomfortable during the time of prayer, but not so comfortable to encourage sleep.
- The back must be straight regardless the sitting position.
- In case of falling asleep, continue the prayer for a few minutes when awake (if time permits).
- Close the eyes and let go of activity around and within.
- Gently introduce the sacred word inwardly.

VII. Focus

- Thoughts are a normal part of Centring prayer which includes all perceptions for instance sense perceptions, feelings, images, memories, reflections and commentaries.
- During Centring prayer, the only activity initiated is "returning ever-so-gently to the sacred word".
- While praying, the sacred word can become vague or even disappear.

VIII. Remain in silence

- At the end of the prayer time an additional 2 to 3 minutes must be allowed in order for the psyche to readjust to the external senses and enable the person to bring the atmosphere of silence into their daily life.

(Keating, 2007).

Practical points of Centring prayer

- The minimum time for the prayer is 20 minutes.
- Two periods each day are recommended, one first thing in the morning, and the other during afternoon or early evening.
- The end of the prayer time can be indicated by a timer (avoid audible tick sounds or a loud sound when it goes off).

(Keating, 2007).

Centring prayer can help accomplish two imporant tasks

In an effort to relate differently to worry and anxiety centring prayer can:

> Firstly: Assist in letting go of own efforts to get certainty which can escalate worry and anxiety.
> Secondly: Assist in finding rest, learning to trust in God, acknowledging and surrendering to God's active presence.

In summary centring prayer can help with the improvement of both psychological and spiritual functioning as one gains greater awareness of God's active, loving presence from moment to moment. Consistent with Jesus' teachings on worry in Matthew 6:25-34, IFCs will turn their focus on God in the present moment, who will sustain them and carry them along their paths of life.

(Knabb & Frederick, 2017:4),18.

Centring prayer is NOT	**Centring prayer IS**
During the prayer avoid analysing the experience, harbour expectations or aim at specific goals such as: • Making the mind blank. • Achieving a spiritual experience. • Having no thoughts. • Feeling peaceful or consoled. It is not a: • technique. • form of self-hypnosis. • para-psychological phenomenon. • discursive meditation or affective prayer. • relaxation exercise. • charismatic gift. The effectiveness of the prayer does not depend on how distinctly the sacred word is said or how often repeated, but rather on the gentleness with which it is introduced in the beginning and the promptness with which one returns to it when mentally or emotionally engaging with thoughts. (Keating, 2006:120;122; 2007).	• About trusting in God's active, loving presence, beyond words. • Surrendering to God, letting go of own efforts. • A symbol of willingness to consent to God in the present moment, focusing exclusively on Him in the here and now. Staying rooted in the present moment. • Developing the ability to spend time with God in solitude, without using words, thoughts, images and emotions to guide the relationship with Him. • Finding rest in God, despite an uncertain future. • Reaching out to God in love instead of knowledge. • Letting go of own attempts to dictate God's pace and timing, own efforts to reach God instead trusting God's mercy and grace. (Knabb & Frederick, 2017:71). • A relationship with God and a discipline to foster that relationship. • An exercise of faith, hope and love. • Orientating the self to God's language which is silence.

	• A method of directing one's attention "from the particular to the general, from the concrete to the formless". (Keating, 2006:120-122).

3.4 SERENITY PRAYER

God grant me the serenity to accept the things I cannot change;
courage to change the things I can;
and wisdom to know the difference.
Living one day at a time;
enjoying one moment at a time;
accepting hardships as the pathway to peace;
taking, as He did, this sinful world as it is, not as I would have it;
trusting that He will make all things right if I surrender to His Will;
that I may be reasonably happy in this life and supremely happy with Him forever in the next.
Amen.

The Serenity Prayer can assist IFCs to manage their caregiving role more effectively by recognising what can change (their reaction to stressful situations during the cancer journey), cannot change (cancer diagnosis and the progression of the illness), how to deal with the cancer journey and their emotions, as well as where they stand in their religion and build a relationship with God. In other words, IFCs are taught that although they may not be able to control the diagnosis and progression of the illness (primary control), they can control their cognitions and emotions (secondary control). The Serenity Prayer can also be beneficial to the PC, where especially the third section "and the wisdom to know the difference" can prevent burnout (cf. 5.6.3).

The PC can introduce and teach IFCs the value of the Serenity Prayer (Box 19) by using Hudson's guidelines and how to apply three truths from the Bible (Box 20).

Box 19: The Serenity Prayer explained by Hudson (2012; cf. 5.6.3a)

God, grant me the serenity
The word serenity goes far beyond being happy or having peace of mind or knowing inner contentment or not experiencing conflict. It is a peace that only God can give, a spiritual peace that lasts and cannot be taken away through hardship, providing an inner assurance that ultimately all will be well. Therefore, "God's peace is a peace that goes beyond all human understanding, it cannot be grasped by the intellect alone but must be experienced in our hearts" (Hudson, 2012:26). In order to receive the gift of peace from God IFCs must enter into a trusting relationship with God, only then will the gift of peace be planted within like a seed by praying the Serenity Prayer. According to Uwineza, (2018:76), "human beings have an orientation towards God, the Absolute, the Ultimate, and this is what offers them the possibility of hearing and participating in God's revelation". This does not mean that IFCs will instantly be filled with a deep and inner peace. Practising the Serenity Prayer will require IFCs to face their journey with cancer (sources of un-peace), changing their thinking processes and lives while working for peace in the practical realities of their daily lives living with cancer.

The depth of this peace can is seen in John 14:27(NIV) in Jesus' words to His followers just before He was put to death.

Peace I leave with you; my peace I give you. I do not give to you as the world gives. Do not let your hearts be troubled and do not be afraid.

To accept the things, I cannot change

A cancer diagnosis is an example of a situation that cannot be changed leaving the diagnosed person and significant others powerless over it. The first request of the Serenity Prayer is acceptance, a kind of acceptance that seldom comes easily. For this kind of acceptance, IFCs will need all the grace, help and power that God can give. During the cancer journey the Serenity Prayer can "become a close friend". Praying it during times of fear, anger, regret and loss is not denying one's emotions or pretending to be calm. Emotions need to be acknowledged and felt; losses need to be mourned. "Befriending" these emotions can lead IFCs on a healing path towards a deeper peace.

(Hudson, 2012:29-35).

Courage to change the things I can

Inner change can only happen once IFCs face what need to be changed. Examples of what can possibly rob IFCs of their serenity during the cancer journey are the desire to always be in control, to be a perfect caregiver. Wanting everything to be perfect and planned out is not realistic while trying to find a "new normal" and living with the unpredicted ableness of the illness and effects of the treatment. Until IFCs can overcome the deep-seated tendencies to deny their shortcomings (being in control, being perfect, not asking for help, not accepting their emotions) they will not be able to experience inner change. The journey to self-honesty entails a few steps that IFCs can embark on:

- Being quiet on a regular basis, asking God to search their hearts.
- Reflecting on instant reactions towards self and others (especially those actions that can be harmful).
- Searching for what aspects of self and others are criticised.
- Asking loved ones and friends how they changed during the cancer journey.

This inner change can only happen through the work of the Holy Spirit. Ridding the self of possible defects requires special effort from IFCs without doing God's job for Him. IFCs must acknowledge what aspects of the self require change and express to God the desire to change. Only God can be IFCs' "heart transformer".

(Husdon, 2012:37-43).

Wisdom to know the difference

Especially during hardships finding the best way forward is not easy. During these times one needs wisdom, which is exactly what the Serenity Prayer invites one to pray for. The wisdom needed during a cancer journey goes deeper than knowledge. Cambridge dictionary (2020) defines knowledge as "understanding of or information about a subject that you get by experience or study". Wisdom is defined as "the ability to use your knowledge and experience to make good decisions and judgments".

Becoming wiser entails, a three-step process of discernment:

Ask God:

Wisdom is a gift from God, something one needs to pray for. James 1:5 (NIV) *If any of you lacks wisdom, you should ask God, who gives generously to all without finding fault, and it will be given to you*. This guidance in question usually comes gradually, "God gives us just enough light to keep us walking" (Hudson, 2012:49).

Listen to thoughts and feelings:

Consciously pay attention to what goes on in one's life, mind and heart. Write it down and reflect on it. God's voice usually comes through by inner promptings, so unless one listens carefully to what happens within the whispering of the Spirit can be lost to inner noise. Repeat the prayer and continually remind the self that, "God is totally good, totally loving, and totally competent" (Hudson, 2012:50).

Decide:

Imagine seeing the self-making one possible decision.

- Envision the self-continuing to live in the current situation without changing anything. Hold this image for a few moments and let it fade. As it fades become aware of emotions.
- Next, imagine pursuing a different way by trying to change the situation in some way. Imagine the self-trying utmost best to make some sort of difference. Hold the picture before letting it fade and again monitor the response. Is it feelings of peace, anxiousness or uneasiness?

A deeper peace will rest on the decision that God wants one to make coming through as a “quiet steady peace of serenity” no excitement or thrills.

Living one day at a time

The nightly review is a habit that can help IFCs live one day at a time.

Step 1: Make time to be quiet for a few moments.
Take a few deep breaths to settle down.
Invite God to be with you and to shed light on the past day.

Step 2: Ask God to recall one moment of the day for which you can be most grateful, the moment that gave the most of life or when you received or gave the most love.
If one moment of the day can be recaptured, which one would it be?
Relive this moment.
Breathe in the gratitude you felt and thank God for it.

Step 3: Ask God to recall the least grateful moment, the most draining moment or moment that one received or gave the least love.
Reflect on what was said and done that made the moment so hard.
Acknowledge your emotions about the experience.
Refrain from judging the self.
Share these emotions with God and let God’s love fill you again.

Consistently practising the night review can help IFCs embark more creatively on their caregiving tasks and the cancer journey helping them to live one day at a time. Although the Serenity Prayer teaches one to live just for today it does not suggest that IFCs stop setting goals or that they must quit planning for the future. It simply expresses the desire to focus on the present day allowing one to absorb most of one’s energy, effort and interest. When IFCs start to live in the present moment they will be able to build better foundations for the future, as well as knowing that the past has been lived well.
(Hudson, 2012:55-61).

Enjoying one moment at a time

Asking God to help one to live one moment at a time is an invitation to savour the present moment, immersing the self in it and living it to the fullest. It is a reminder that living with a sense of immediacy, there are gifts to be discovered, and one of these gifts is God’s peace. “Enjoyment of the present moment and the genuinely peaceful heart go together.”

The importance of the here and now:

It is all that one has. The past can be remembered and future imagined, but one cannot live in either. It is within the present moment that life connects with life making the present moment precious. For IFCs to be preoccupied with the “what ifs” of the past and dwelling on the future they disconnect themselves from the present moment where their loved one is still with them, missing opportunities to build memories and treasure moments.

The here and now is the place where God meets His people. “We encounter God in the present, or we don’t encounter God at all”. The gift of peace is received only in the immediacy of the present moment, whatever that moment may be like (glad or sad, high or low, difficult or easy). One can only be in God’s presence in the here and now.

God wants to bestow His gift of peace on His people, but to receive it one must slow down, live gratefully and accept that there is only one life to live. The Bible encourages its readers to see their physical lives as *a mist that appears for a little while and then vanishes* (James 4:14 NIV.)
(Hudson, 2012:63-70).

Accepting hardships as the pathway to peace

Life can be hard, a place where no one can escape pain, grief or loneliness. Sooner or later troubles come to all in the shape of external difficulties (cancer journey) as well as internal difficulties (depression, anxiety, fear, anger). There is one of two choices to be made. On the one hand avoidance and on the other hand acceptance (Serenity Prayer).

The encouraging news is that God is deeply present in all the facets of life, especially during hardship. The Bible teaches that there is *one God and Father of all, who is over all and through all and in all* (Ephesians 4:6 NIV). There is no fear, loss, grief, loneliness, despair or suffering that God does not intimately share in. God is continually present and reaching out in whatever circumstances one may be going through at this

moment. Knowing that God is with them (even when their worlds are falling apart) IFCs can find the strength to face the pain of the situation with hope and courage. The Serenity Prayer encourages people not to run away from hardship because it is in this space that the suffering God draws close to the person. In trying to escape hardship one can easily miss the gifts God so generously wants to bestow upon people such as peace, serenity and growth. IFCs must learn to be gentle with themselves asking God for the strength to take constructive and creative action in those moments when they are tempted to give up. These acts can be ordinary and small such as walking around the block, having a cup of tea in a quiet place of the garden or phoning a good friend (passive diversions like reading or watching television is not enough to rouse from the darkness). (Hudson, 2012:71-78).
Taking as He did, the sinful world as it is, not as I would have it
This part of the prayer begins by acknowledging the reality of a sinful world. It also proposes that one should adopt an attitude toward it (as God relates to the world). When faced with evil and hardship one can learn to reflect God’s attitude. God accepts human beings unconditionally, discerns between the sinner and the sin, and desires that as much goodness as possible be infused into human life. As one follows God’s attitude and example one takes the world as it is and not as one would want it to be. (Hudson, 2012:79-87).
Trusting that He will make all things right
Even through hardship like a cancer journey, IFCs can become whole and fruitful again with the help of God. *And we know that in all things God works for the good of those who love him, who have been called according to his purpose* (Romans 8:28). God wants to take everything that has happened and use it for good, even the painful times like a cancer diagnosis and the journey thereof. Every detail given to God can be reworked into something beautiful. The Serenity Prayer challenges IFCs to take this promise seriously, asking them to live each day to the fullest trusting that God will make everything all right. This is not easy though, there are strong forces in an around one’s life that work against having a genuine, confident trust in God. In the end IFCs must realise that authentic faith comes as a gift from God. With this they must place themselves on the path of trust. This can be accomplished with three steps: Learn who God really is (God image): To commit to God whole-heatedly IFCs must first truly believe that God is good and trustworthy. Pârvan and McCormack (2017:1-25) describe the nature of God “as a particular kind of love”. *God is love* stands on its own in 1 John 4:16 (NIV) as a description of God’s nature (an identity statement). Paul teaches in Philippians 2:7 that this kind of love is a self-giving and self-emptying love (Pârvan & McCormack, 2017:1-25). Spend time with other believers: By connecting with other trustees (family members, friends, cell groups, prayer groups, and church communities), IFCs will discover that trust produces trust. At times where the flame of faith starts to flicker and sometimes even go out IFCs must spend time with others who have also walked through dark valleys and kept their trust in God. Act: Have daily conversations with God about concerning issues that cause anxiety. Experiencing God’s help in these situations deepens one’s trust in God. Regularly meditate on some of the ideas Jesus teaches about God. For example, dwell on the fact that God loves humans unconditionally, centring prayer. Over time (weeks, even months) this truth will sink deep into one’s heart to become a real part of one’s life. (Hudson, 2012:89-96).
If I surrender to His will
To receive God’s gift of peace IFCs must find and do God’s will. Everyone has been created with certain gifts (one’s uniqueness) placed within by God the Creator. Finding and doing God’s will consist of two elements: 1. God’s will for humankind is to live a full, loving and as honest as possible life. This involves using and developing one’s gifts, giving love priority and walking in the light. The Bible teaches that God is both love and light (1 John 1:5)

2. Personal calling is a lifetime adventure because it changes with the different seasons of one’s life. Finding God’s will assumes a living relationship with God. Finding God’s will not only nourish the individual but also enriches the lives of people around one (a season of IFCs life for example is being a caregiver for a loved one during a cancer journey).

Walking closely with God through the cancer journey, living in the present and finding one’s unique gifts will not only nourish IFCs during their caregiving duties but also the diagnosed loved one and rest of family.

(Hudson, 2012:97-106).

That I may be reasonably happy in this life

The line about being reasonably happy follows - trusting that He will make all things right if I surrender to His will. This sequence suggests that the more one trusts that God can bring good from hardship and the more one surrenders the self to God’s purpose, the happier one will be.

According to Hudson (2012:107), one of the most important questions one can ask is “How happy am I?” and to others “How happy are you?” The pursuit of happiness is universal, through the ages is has been maintained that God created humans to be happy. Happiness in this regard refers to a “deep sense of inner well-being and contentment, the experience of being fully alive to ourselves, to others, and to God” (Hudson, 2012:107). Fretheim, (2012:5-38) also addresses happiness, stating that happiness is a gift from God to human beings. The most evident example is humans as created in God’s image. “Because God’s life is characterised by happiness, those made in God’s image are also so gifted”, for this reason it is God’s will for humans to be happy (Ecclesiastes 5:18-20). According to Peterson (2017:71-74) “our very existence, begins and ends with joy. And between the beginning and the conclusion there is joy”. Jesus said it in John 15:11 and Paul wrote to the Philippians (1:25) about what he called *joy in the faith* (NIV). The book of Ecclesiastes teaches about joy as God’s creation and gift. For Peterson (2017:71-74) “the foundational human appetite is for God”.

According to Hudson (2012:109), one of the biggest mistakes people make in their search for happiness is always the insistence on being happy at all costs and all the time. Once people realise that it is unrealistic to be happy all the time it encourages them to pray for reasonable happiness in this life. There is a time and place for happiness and sorrow, for laughter and joy, but also for tears and sadness. God’s work turning hardship into something good can take away sorrows, cares and, broken-heartedness, so that happiness can include healing (Fretheim, 2012:5-38). Fretheim, (2012:5-38) further notes that it is not helpful to speak of total or perfect happiness. Although humans are gifted with happiness it can never be fulfilled or totalised in this lifetime.

Happiness just like serenity originates within the self. Although external factors do influence people for better or worse, it is temporary. To find enduring happiness one must take a deep look at what happens on the inside. During a cancer journey IFCs often feel ambushed by feelings and emotions that threaten to destroy their happiness. For reasonable happiness in this life, they will have to deal with these emotions as creatively and responsibly as possible. Instead of feeling overwhelmed with emotions or avoiding those IFCs need to identify and name them. Then they need to share these emotions with God and ask God to teach them how to live best with it.

True happiness is another gift from God “a freely given by-product of a particular way of life that comes to us when we stop seeking it”.

(Hudson, 2012:107-114).

And supremely happy with Him forever

Ideas about death and what comes after death are critical. These perceptions have an effect on one’s life in this world. The Serenity Prayer offers three important thoughts about what life in heaven will be like:

> In heaven a depth of happiness will be experienced beyond all comprehension, enjoying supreme happiness, hearing Jesus’s words *Come and share your master’s happiness* (Matthew 25:21 NIV).
>
> In heaven one will be with God, there will be no isolation.
>
> In heaven one will become an unceasing spiritual being.

(Hudson, 2012:115-121).

Box 20: Applying three truths from the Bible compiled and edited by Crosswalk.com (2017; cf. 5.6.3)

Three biblical truths that can be applied to the short version of the Serenity Prayer	
“God grant me the serenity to accept the things I cannot change.”	When life feels out of control due to a cancer diagnosis of a loved one, it is easy for IFCs to take charge and control the situation. The other extreme is to avoid the situation and choose not to be part of the cancer journey (cf. 5.3). Peace and serenity will continue to move further from IFCs life if choosing these negative methods to manage the stress of a cancer journey. Accepting, submitting and committing to God’s plan (cf. 5.2.1.3) for one’s life journey is the only way to find peace during hardships. Although God’s plan is not always clear IFCs can let go of trying to be in control and let God work through them. God promises a supernatural peace when worries and concerns are brought to Him in prayer. • Phillippians 4:7(NIV) *And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus*. • Psalm 46:10(NIV) *Be still and know that I am God.*
“the courage to change the things I can,”	Once IFCs have accepted Jesus Christ as their saviour, they receive the power of the Holy Spirit. Through the Holy Spirit IFCs will receive the courage to follow and act upon God’s plan for the situation. Instead of fearfully ignoring hard decisions or running from difficult situations IFCs can call upon God’s power. • Deuteronomy 31:6 (NIV) *Be strong and courageous. Do not be afraid or terrified because of them, for the LORD your God goes with you; he will never leave you nor forsake you.* • 2 Timothy 1:7 (NIV) *For the Spirit God gave us does not make us timid, but gives us power, love and self-discipline.* • Proverbs 3:5-6 (NIV) *Trust in the LORD with all your heart and lean not on your own understanding; in all your ways submit to him, and he will make your paths straight.*
“**and, the wisdom to know the difference”.**	Wisdom is a gift from God to those who ask for it. More wisdom is sustained each day with the wiser decision-making process as IFCs spend time with God by reading the Bible, praying and worship. God gives answers through the Bible or prayers, when to accept circumstances and when to be courageous to change it. • James 1:5 (NIV) *If any of you lacks wisdom, you should ask God, who gives generously to all without finding fault, and it will be given to you.* • 2 Timothy 3:15-17 (NIV) *and how from infancy you have known the Holy Scriptures, which are able to make you wise for salvation through faith in Christ Jesus. All Scripture is God-breathed and is useful for teaching, rebuking, correcting and training in righteousness, so that the servant of God may be thoroughly equipped for every good work.*

The following section will focus on the power of music as a gift from God and the possible benefits that music can have on IFCs to help them cope with cancer related stress.

3.5 WORSHIP

The combinations of music individuals are exposed to are endless depending on family background, culture, religion, personal preferences, different seasons of one's life, *et cetera*. Because of this, the music IFCs enjoy, either by listening to or actively playing, will differ greatly. Despite these differences the PC can introduce music in order to provide and provoke a response, which is universal, ingrained into mankind's evolutionary development with the ability to cause noteworthy changes in emotions (cf. 5.6.4).

As to the benefits of listening to music the PC can explain the impact of music on the IFCs' brain. Introducing and using it as a therapy method and a means of accessing and stimulating specific cerebral circuits in the brain (cf. 5.6.4). As with the breathing exercise music can also be enjoyed as a non-interuppted practice together with the diagnosed loved one or alone. Soothing music can play through the house during the day. It is recommended that IFCs learn the words by heart in order to really connect with the song awakening emotions and opening up to the Spirit.

The researcher supplies a list of music that helped her through her cancer journey of a loved one. This list is only a suggestion that the PC can use. As stated, the choice of music is individualistic. IFCs must be encouraged to find and listen to gospel music that will touch their hearts. This list serves as suggestions of songs that may help encourage IFCs to find some peace during the caregiving season.

Box 21: Playlist for IFCs

Song	**Album**	**Artist**
All that I'm after	Faultlines.	Kalley
Blessings	Laura story blessings	Laura Story
Even if	Lifer	MercyMe
Even now	Speed of light	Philippa Hanna
Faultlines II	Faultlines	Kalley
Guardian God	Faultlines	Kalley
It is well	Speed of light	Philippa Hanna
Let you lead	Speed of light	Philippa Hanna
Rescue	Look up child	Lauren Daigle
Run to you	Speed of light	Philippa Hanna
Sanctuary	Faultlines	Kalley
The Hero	Come back fighting	Philippa Hanna
Trust in you	How can it be	Lauren Daigle
Vow	Faultlines	Kalley
You say	Look up child	Lauren Daigle

3.6 LABYRINTH WALKING

As seen in the previous five practices, mindfulness can be cultivated through deliberate mental practices. The aim of mindful practices introduced in this model is not to empty the mind of thought, instead it involves training the mind to be aware of what it is always doing, together with being aware what IFC are thinking while they are thinking. The PC can explain to IFCs that their mind consists of a joint effort between two distinct brains, namely the left hemisphere and the right hemisphere of which each hemisphere sees the world in a vastly different way. The left brain is concerned with logic, details and facts, while the right brain is based on feelings, emotions and imagination. Personality is determined and moulded by which hemisphere one allows to be dominant in daily life. Practices, such as mindful labyrinth walking have proved to lessen the conflicts between the two hemispheres and coax left and right to work together in peace and harmony. If a problem is contemplated during the labyrinth walk, it is possible that logic and emotional compromises will equally be meditated on. The labyrinth forces the two hemispheres to cooperate on a task where both left and right must learn to trust and compromise. As IFCs equally need a healthy balance between logic (daily caregiving tasks), emotions (unpredictability of cancer) and difficult theological questions (cf. 5.3.1.3), mindful labyrinth walking can be introduced by the PC to help IFCs cope with cancer related stress (cf. 7.5). The aim of the walk is thus to improve mindfulness, install judgment-free awareness of the present moment and exercising the left and right brain hemispheres to work in harmony.

Slowed pace mindful walking is the preferred method of reducing anxiety. Mindful labyrinth walking can be used differently according to each IFC's personality and needs. It requires no training or any kind of extenuating physical movement and can thus be practised by persons of all ages, regardless of prior experience or fitness levels. The walk can be for personal, psychological or spiritual growth. A spiritual walk is completed in a prayerful meditative way or by having a specific question in mind. Walking the path in and out is with an attitude of devotion and openness to be enlightened during the process. IFCs can, for example walk the path with a certain text in mind that has been studied during their *Lectio* practice (cf. 5.6.1) or they can walk the labyrinth while struggling with certain difficult emotions, such as loneliness, loss of identity, feelings of depression and anxiety, dealing with RS (cf. 5.3.1.3.2) or asking the "Why?" questions (cf. 5.4, 5.5). By memorising scriptures during *Lectio* verses and listening to gospel music these texts and words become rooted deeply in the inner mind of IFCs and begin to 'mould' and adjust their worldview almost without their realising it.

Box: Labyrinth walking (cf. 7.5)

Stage 1 Preparation From entrance to centre	Decide on the rhythm of the walk; slow paced or fast paced (advise slow pace for mindful mediation). Decide on the question, word or text that will be contemplated on.
Stage 2 Illumination Centre	At the centre decide to: • sit or stand • find a comfortable position • eyes open or closed • allocate a time to meditate

Stage 3 Restoration Centre to entrance	Mindfully walking back and towards the beginning.

Walking the labyrinth awakens the potential for contemplation, reflection and transformation. To introduce the labyrinth walking to IFCs, he/she can explain to IFCs that during early times believers walked the labyrinth tracing the path of a long and difficult earthly journey, beginning with birth at the entrance, death at the centre and the way out symbolises hope that a life well lived devoted to God will continue in heaven. With this example, IFCs can begin the walk by contemplating (cf. 7.2) the cancer diagnosis and difficult journey thereof (physically, emotionally and spiritually). At the centre, IFCs can reflect on the way they handle the circumstances and release themselves to God and giving up the cycle of works (cf. 7.3). Going out, IFCs can reflect on their transformation, committing to follow the cycle of grace and take on an identity given by God (cf.7.3).

If space allows it the PC can designate an area inside his/her office or more preferably outside and tape a labyrinth path. IFCs can in the same way do this at their home. The labyrinth walking can then be used as an exercise in the pastoral setting as well as in between sessions.

The labyrinth is a key promoter to develop awareness of the mind-body connection, the impact of thoughts on IFCs' lives and the importance of living with (self) compassion and love (self-love). Learning the skill of self-compassion (cf. 4.2.1) IFCs can give themselves permission to spend time to recuperate and draw strength from God with the suggested practices. By regularly and routinely following these practices, IFCs can gradually decipher how to become more mindful of thoughts, needs, emotions and find hope and purpose, even in the face of significant suffering.

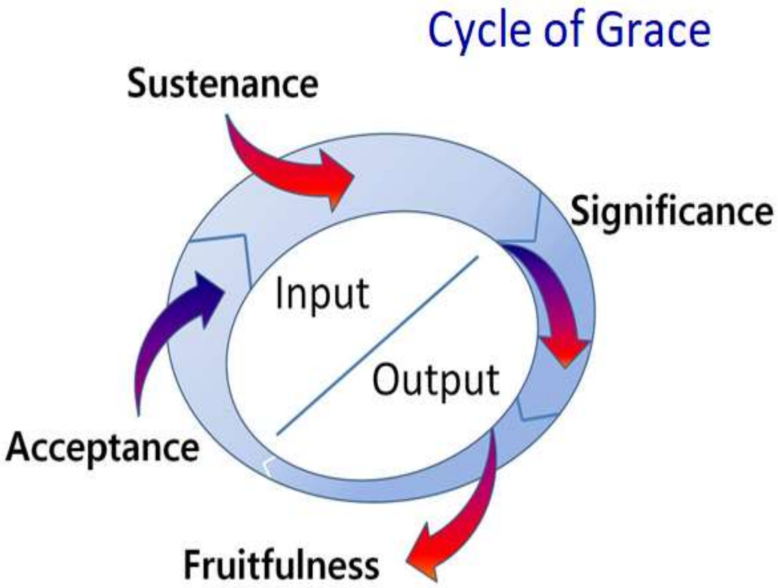
The last section and what the study worked towards is to live in a relationship with God through the Cycle of Grace.

B4 THE CYCLE OF GRACE

LIVING IN A RELATIONSHIP WITH GOD

To help IFCs alleviate stress caused by the cancer journey (in agreement of IFCs) the aim for both PC and IFCs are to work towards connecting the dynamics of a well-functioning personality with spiritual health that is grounded on the rhythms of Christ's life. The purpose of this model is to correlate the dynamics of relatively well-functioning personality and of spiritual health in its formation and maintenance before it turns around into a condition where this integral wholeness is lost and replaced with anxiety, conflict, defences, distress, doubt and various other emotions (cf. 7.4).

The cycle of grace, based on Christs' life, has four dimensions namely acceptance, sustenance, significance and fruitfulness, which are placed within two dynamic phases and those are the input phase and the output phase.



INPUT PHASE

4.1 ACCEPTANCE

Divine acceptance comes in those special human relationships where there is a sense of mutual safety and trust where one is fully known, valued and loved. It is a safe space where IFCs have the security and freedom to be their selves, share confidences, discuss difficult questions, grieve losses (the little deaths) and celebrate joys. This kind of earthly relationship can be experienced through mentors (e.g. PCs), family members and special friends. Such a relationship is also referred to as “divine acceptance” which can help IFCs to claim and reclaim their identity as a child of God even during hardships (cf. 7.4.1).

On this level the PC can explain to IFCs that Christ lived His life from the foundation of being God’s “*beloved Son”* with whom God is *“well pleased*” (Mark 1:11 ESV). Christ began His work with peace of heart, free from trying to please anyone, because He was secure in His identity and approval received as a gift of grace from God who loved Him. The New Testament highlights the truth that believers share this platform with Christ regarded “*as God's chosen people, holy and dearly loved, clothe yourselves with compassion, kindness, humility, gentleness and patience”* (Colossians 3:12 NIV). Christ reflects God’s acceptance by mirroring it to others “o*ut of his fullness we have all received grace in place of grace already given”* (John 1:16 NIV), in other words the grace that Christ received became grace for all. Acceptance will lead to a God-given identity, and the Holy Spirit will guide the future (cf. 7.4.1).

During the cancer journey IFCs can become consumed in the caregiving tasks. Life changes in totality, new normal must be negotiated and re-negotiated often unexpected and suddenly. Some IFCs become a fulltime caregiver deciding (or forced) to quit their jobs. The caregiving role is time consuming and within these circumstances IFCs often lose their identity in the caregiving role. There is seldom time for themselves accompanied with a sense of guilt if they should take moments for themselves. Friendships change and often dwindle to mere acquaintances. It is crucial that the PC enquires about IFCs friendships encouraging them to nurture divine friendships or if there are none to seek and grow a divine earthly relationship.

4.2 SUSTENANCE

The sustenance stage maintains the input where IFCs are dependent on the continual input from outside sources as Christ was continuously sustained through God and the Holy Spirit (John 3:34; 5:20; 10:30). This is the root of wellbeing, where needs are met to give physical, mental and spiritual stability (cf. 7.4.2).

The PC must help IFCs realise the importance of sustaining practices (B3) to balance their lives. Spiritual practices can help IFCs understand that grace is at work in ordinary daily routines as well as in the dramatic events of life such as the cancer journey they are going through. Practices of religious disciplines are means to encounter the fractures of the human soul, not for the sole purpose of answering questions or healing one's wounds, but to know Christ through them (cf. 7.4.2). Through solitude an open inner space is created through which God can find IFCs.

Developing and regularly practising spiritual practices involve both a theological and practical matters, for example IFCs will have to create space (allocate a time and location that is quiet, peaceful and comfortable) in their daily schedules for quiet time where they wait on God to come to them, feed them and heal them. It is creating a space in daily lives and tasks where God can reach IFCs. To sustain grace means to actively pursue those activities necessary to keep one's faith alive. Grace will sustain IFCs if they allow it and grace will sustain IFCs through their joys, riches as well as hardships and challenges (cf. 7.4.2).

The cycle of Grace is based on Hudson and Haas' teachings. The PC can ask the question, 'What are some of the ways that Jesus sustained His close relationship with God throughout His life?" Phrasing the question in this way, invites IFCs to pay close attention to the life of Christ, not to merely imitate Christ, but to strengthen their own relationship with God. To sustain His identity as God's beloved Son, Christ regularly withdrew to spend time with His Father in prayer and worship, surrounding Himself with close friends who chose to believe in Him and who accepted the Word of God (cf. 7.4.2).

OUTPUT PHASE

4.3 SIGNIFICANCE

Significance is the stage where IFCs will find their true identity, value and worth in Christ. In the gospel of John (14:6 NIV) Jesus clearly declares, *"I am the way and the truth and the life. No one comes to the*

Father except through me". This is the stage where Christ knew who He was, and this is the stage where IFCs will become aware of who they are in Christ

Christ radically changes the measure of significance, showing through His life on earth that significance is a truth one bears, a witness made, a life lived before God and most of all desiring God. While many yearn for a life of significance, the PC can challenge IFCs to ask themselves, "What do I want my life to signify?" By asking the deeper question, IFCs must firstly explore who they are in Christ before, during and after their role as caregiver. Believers are encouraged to seek God's face (Psalm 27:8) and reflect His glory in their very being (2 Corinthians 3:18). IFCs can grow in their God-given identity through the cancer journey to become symbols of God's love, which lies at the heart of everything (cf. 7.4.3).

4.4 FRUITFULNESS

During the final stage awareness of the first three stages turns into action. The cycle started by being rooted in God's acceptance of IFCs through the divine acceptance of special earthly relationships. IFCs are then filled by God's sustenance through practices and disciplines that strengthen their faith. As Christ-followers, IFCs flourish by becoming signs of grace as unique individuals achieving significance. In other words, the first three stages are discovering Who God is; as IFCs become acquainted with God, learning His ways and becoming His friend they find their identity as children of God (cf. 7.4.4).

At this last stage IFCs are fruitful and can produce the fruit of love, joy, peace, patience, kindness, goodness, faithfulness, gentleness and self-control (Galatians 5:22-23). God's grace in the last movement transforms into fruitfulness, as IFCs share God's grace with others. To mention a few of Christ's fruitful actions that IFCs can represent during and after the cancer journey finding a new normal to their altered lives, including to leave others (family, diagnosed loved one, close friends) feeling valued, affirmed, loved and accepted when they are with the IFC. Teaching and guiding, offering love, giving hope and blessings to those who feel weary, giving redirection for a new normal and being courageous during and after the cancer journey.

The greatest fruit is the way in which Christ modelled an intimate relationship with God, a relationship He encourages people to follow; an inner circle of God's love and acceptance into which all are welcomed and a space that will become IFCs' lifeline during their times of struggle. The PC can use the following metaphor to explain the process of the cycle of grace "The cycle of grace reflects God's love moving outward, like ripples on a pond" (cf. 7.44).

The cycle of grace will empower IFCs to confidently and courageously take on the cancer journey and caregiving tasks, knowing that their worth and identity are secure in God. By following in Christ's footsteps and the rhythm of input and output that He set in place, IFCs will stay in balance on a physical, emotional and spiritual level.

During the cancer journey and adjusting to a new normal after the illness whether remission period or bereavement period IFCs can move around in these four spaces. The cycle of grace is never completed it remains a earthly journey in itself moving between spaces always with the aim to reach and remain as long as possible in the fruitful stage. It is natural and human to ask the “why” question. The aim is to never stay in the “why” but always turn to one’s true identity in God, remembering “who” God is and entering His light and grace with hope and endurance knowing that there is more to come after the journey on earth. Within the cycle of grace, the IFC must also practise self-compassion and self-love, it is not a journey to enforce on the self, again it is letting go and letting God.

8.4 CONCLUSION

The compassionate PC first and foremost relies on the love and power of God, making the point of departure the Word of God as the authoritative source for pastoral caregiving in order to build IFCs’ ability to tolerate and transform difficult experiences in the short-term and long-term, encouraging awareness, mindfulness and self-compassion. The PC as a professional friend has a source of knowledge and experience that is of direct use to IFCs in dealing with the journey of cancer. Compassion stands central to the ethical practice of the healing professions. In this regard it is not simply the ability to understand suffering but includes an intelligent understanding of the suffering linking it to knowledge of the causes and possible remedies thereof. Compassion is furthermore the quality to understand each individual as unique with their perceptions and within their unique situations. Through mindful conversation the PC provides the theoretical framework as well as practical methodological dynamics for IFCs’ personal and social awakening, knowing, learning and personal growth. Conversation between PC and IFCs creates a space where IFCs can identify and explore the state of their soul, personal beliefs, perspectives, attitudes, relationships, situation and circumstances, ideals and emotions. The PC navigates this conversational transformation by utilising palliative care concepts, the ACT model as well as life coaching techniques.

Early integration of palliative care provides valuable opportunities to attend to the full impact of the cancer journey on IFCs’ psychological, developmental and spiritual wellness making palliative care an all-embracing and ongoing care approach of the unique whole-person. Palliative care should be introduced to the family shortly after the cancer diagnosis through treatment to remission or death till after the bereavement and adjustment period. Within this process it is important that there is collaboration among health professionals, patient and family, upholding clear and honest communication in a compassionate manner endorsing mutual trust and respect between all parties concerned also called the collaborative person-centred practice. As an all-embracing care approach, the tangible support (for instance home visitations) is an important aspect. The fact that pastoral caregiving goes beyond empathy is what sets pastoral caregiving apart from all other disciplines. This implies that the PC does not wait for IFCs and patient to make an appointment, instead the shepherd seeks out the sheep to care for them.

ACT is a well-established therapy for increasing psychological flexibility that can help IFCs achieve emotional balance by encouraging flexibility, creativity and self-compassion. At its core, ACT is about taking action of which compassion is an essential method for IFCs' healing process, fostering emotional balance through a mind-set of safety and interconnectedness and reducing feelings of threat and isolation. ACT consists of six core processes known as *hexaflex* that will help IFCs accept painful experiences associated with the cancer journey instead of fighting to change, control or avoid it. ACT offers life-changing answers to questions such as: "Why is it so hard to be happy?", "Why is life so difficult?", "Why do humans suffer so much?", "What can people realistically do about it?" It will further encourage IFCs to clarify their core values and to live by them. ACT is a good "fit" for Christians both in terms of its ends and its means offering a view of life that is about pursuing valued ends that include more than merely getting over unpleasant life events (emotions). ACT acknowledges inevitable suffering in life and argues that suffering is not to put IFCs off from reaching their goals. The power lies within each individual to make changes once he or she experiences acceptance. In short, ACT places focus on the process and function of IFCs' thoughts and feelings instead of their content teaching IFCs that they are not their thoughts.

Life coaching is about improving IFCs' purpose and personal performance, developing skills, teaching IFCs to take care of themselves in the short- and long-term and being mindful. This can be achieved by means of practising pastoral life coaching skills by means of effective questions and active listening skills within a context of awareness and responsibility as well as incorporating the GROW and SMART practices. Whereas the pastoral caregiving process places focus on and contemplates the past (healing), pastoral life coaching reflects on the future (growth).

The point of feeling utterly lonely is where the true quest for meaning and God starts, questioning whether cancer is a fate to be endured alone (Why God?) or if this path of suffering (physically, emotionally, spiritually) also runs through God's heart (Who is God?). To this effect giving meaning to suffering is complex. IFCs' image of God is very important in how they will perceive, react to and act upon the cancer journey. The PC must turn the "Why?" questions into asking IFCs "To what purpose?" Instead of asking "Why God?" IFCs must ask, "Who is God" journeying with the "Who is God?" question IFCs will get to know God, build a friendship with God through Christ. The "Who" question can be explored through four suggested texts.

Gods' words to Moses "*I am who I am*" in Exodus 3:14 are of the most insightful statements concerning God's being and essence. This statement by God can be a source of comfort to IFCs' learning that God is a unique kind of deity and that He will always be with His people wherever they are. God is the same God yesterday, today and tomorrow; throughout time God will be with His people.

The difficult question "How might one speak of God during suffering and what kind of God fashions and participates in pain, suffering and death?" can be answered with the word compassion as described in Ephesians 2 about Christ's great love and His sacrificial death. God suffers in and through Christ's' earthly life and death. The story of the cross is not the only display of divine love, it also shows IFCs that God not only experienced suffering and death on the cross, but importantly overcomes suffering and death through the resurrection. While God does not prevent the cancer journey accompanied with pain, suffering and possible death of a loved one, He also does not intend that this pain, suffering and death should endure or triumph. IFCs can find comfort that hardships during the life journey are not final but lead to new life within the embrace of God's love.

To teach IFCs self-compassion through love the PC can work through Matthew 22:36-39 where Christ brings the ten commands to two namely, love to God and love to the neighbour therefore love is the fulfilling of the law. The love commandments belong together where the vertical relationship is with God and the horizontal relationship with others and self. During a time where IFCs often neglect their own health (emotional, physical and spiritual) it is important that the PC reminds them to practise self-compassion. "*As thyself*" - loving the self as Scriptures teach self-denial, but it does not teach self-annihilation. It speaks against selfishness, but does not forbid self-love. IFCs should love their loved ones and others not as they love themselves but as they ought to love themselves; not in the same degree, but after the same manner, which is unconditionally, wholeheartedly, readily, sincerely, tenderly and compassionately. This kind of self-love is not only natural but crucial for the welfare of IFCs' souls and bodies which is one of the most important aspects during the caregiving journey.

Keeping hope is another important element that the PC must keep alight within IFCs during the cancer journey. This can be done by working through Romans 8:18-28. Hope relates to "what is"; it is not about denying the reality of the cancer journey. In fact, hope will give IFCs the courage to face hardships during the cancer journey. Hope is not avoiding the pain felt during the cancer journey nor is it naïve about suffering. The key event in the Christian story which must speak to IFCs during their hardship is the crucifixion where God embraces suffering as a reality of human existence. Through the resurrection IFCs can find hope and comfort.

To grow and strengthen a relationship with God the PC must introduce religious practices to IFCs that can provide them with a set of potential resources that can be accessed in order to help deal with the trauma. The PC must keep in mind that adapting to a new routine after a cancer diagnosis IFCs can have a difficult time to break away from the caregiving tasks and extra daily chores to spend time with God in solitude and silence. The PC can reinforce the time allocated to their soul by explaining that time with God is valuable in helping with cancer related stress and that inner peace is nurtured and grown by daily spending time with God through the following six practices. The aim of these practices is to grow into a relationship with God, by getting to know Who God is through Christ.

Finding a new normal and balance due to extra duties and caregiving leaves IFCs with little time and energy to take care of themselves. The PC can make IFCs aware of the "simple" task of breathing as steady and controlled breathing requires little input and effort (it can consistently be done during caregiving tasks without disrupting daily routines and tasks) but in return offers great health benefits.

Lectio Divina places focus on developing a heightened awareness and self-reflection by meditative reading of biblical texts. Here the PC teaches IFCs that they must firstly make a conscious effort to engage with the sentences through listening or contemplation, and secondly allow the texts to speak to their hearts, "listening with their heart". The four texts regarding "Who is God?" can be carried on with in this practice connecting deeper and journeying with it in an effort to find meaning and hope. This daily encounter with Christ and reflecting on texts lead beyond mere acquaintanceship to a space of trust, love and friendship – also referred to as "resting in God."

Centring prayer aims to bring unity with God in order to improve the ability to be silent, hear God and be filled with the Spirit. The prayer is about opening to God, surrendering and declaring "Here I am, fill me". The purpose of this prayer is to help IFCs relate differently to their distressing inner experiences such as anxiety, fear, anger, and questions by learning to sit at the feet of Jesus. It is a way of diverting attention from the ordinary flow of thoughts, in order to awaken faith. As IFCs will battle during early stages of contemplative prayer with their thoughts the PC must clearly explain to IFCs that quiet times of the day away from distractions and foreseeable interruptions are very important for this as well as all the recommended practices.

The aim of the Serenity Prayer is to help IFCs manage their caregiving role more effectively by recognising what can change (their reaction to stressful situations during the cancer journey), cannot change (cancer diagnosis and the progression of the illness), how to deal with the cancer journey and their emotions, as well as where they stand in their religion and to build a relationship with God. The PC can explain to IFCs that although IFCs may not be able to control the diagnosis and progression of cancer (primary control), they can control their cognitions and emotions (secondary control). The Serenity Prayer can also be beneficial to the PC, where especially the third section "and the wisdom to know the difference" can prevent burnout.

Just as breathing, listening to gospel music requires little input and effort (music can be enjoyed throughout the day while doing tasks as well as enjoying and sharing the meaning of the words with the diagnosed loved one) but in return offers great health benefits with noteworthy positive changes in emotions. The PC can recommend a list of songs to help IFCs cope with anxiety, feeling overwhelmed and/or sad. Listening to and feeling God's promise, giving hope and courage to grow through the cancer journey.

The labyrinth is a tool for both emotional and spiritual support used as a recreational and anti-stress resource to help IFCs cope with the cancer journey. Mindfulness can be cultivated through deliberate mental practices such as the labyrinth walking. The aim of slow mindful walking is not for IFCs to empty their minds of thought, instead it involves training their minds to be aware of what processes their minds are following and what they are thinking. As IFCs equally need a healthy balance between logic (daily caregiving tasks), emotions (unpredictability of cancer) and difficult theological questions, the PC can introduce mindful labyrinth walking to help IFCs cope with cancer related stress.

For the PC to help IFCs with caregiver related stress the PC must start with his/her personal life journey learning to grow through his/her hardships by regularly practising characteristics such as mindfulness, compassion and acceptance. Actively and continuously practising the ACT model, learning what he/she fuses with and working to be in a relationship with God by personally practising the recommended practices. By "walking the talk" as a wounded healer the PC can take on the shepherding role. It becomes a matter of professional friendship having deep and meaningful conversations with IFCs without sugar coating the situation or attempting to give easy (or any) answers to difficult questions. Working from a holistically healthy platform in an ever-growing relationship with God the PC can engage with IFCs being with them through the cancer journey. Palliative care, ACT model, life coaching and religious practices are all very important building blocks of PRC preparing IFCs to develop and grow a deep and intimate relationship with God. The cycle of grace is based on Christs' life consisting of four dimensions namely acceptance, sustenance, significance and fruitfulness, which are placed within two dynamic phases which are the input phase and the output phase.

The first input phase is acceptance. The cycle starts by being rooted in God's acceptance of humans through the divine acceptance of special relationships also referred to as "divine acceptance." IFCs must be reminded of the importance of such deep friendships during palliative care. Divine acceptance comes in those special human relationships where there is a sense of mutual safety and trust where IFCs are fully known, valued and loved. It is a safe space where they have the security and freedom to be their selves, share confidences, discuss difficult questions, grieve losses (the little deaths) and celebrate joys. These deep friendships can help IFCs to claim and reclaim their identity as children of God even during hardships.

In the second input phase IFCs are filled by God's sustenance through practices and disciplines that strengthen their faith. Working on the question "Who is God?' the PC can ask, "What are some of the ways that Jesus sustained His close relationship with God throughout His life?" Phrasing the question in this way, invites IFCs to pay close attention to the life of Christ, not to merely imitate Christ, but to strengthen their own relationship with God. As Christ was continuously sustained through God and the Holy Spirit so are IFCs dependent on the continual input from outside sources. The suggested outside sources will be the six religious practices. These practices form the root of wellbeing, where needs are met to give physical, mental and spiritual stability, to balance IFCs' lives and help IFCs understand that grace is at work in their ordinary daily routines as well as in the dramatic events of life such as the cancer journey.

As Christ-followers, IFCs flourish by becoming signs of grace as unique individuals achieving significance in the first output stage where IFCs will find their true identity, value and worth in Christ. Here the ACT model and pastoral life coaching come into play where IFCs must identify their values and put it into dynamic action. The PC can ask IFCs, "What do you want your life to signify?" By asking the deeper question, IFCs must firstly explore who they are in Christ before, during and after their role as caregiver. The PC encourages IFCs to seek God’s face (Psalm 27:8) and reflect His glory in their very being (2 Corinthians 3:18). IFCs can grow in their God-given identity through the cancer journey to become symbols of God’s love, which lies at the heart of everything.

The second output and final phase is fruitfulness. During this stage awareness of the first three stages turns into action. In other words, the first three stages are discovering God, as IFCs become acquainted with God, learning His ways and becoming His friend they find their identity as children of God. At this last stage IFCs truly live the fruit of love, joy, peace, patience, kindness, goodness, faithfulness, gentleness and self-control (Galatians 5:22-23). God’s grace in the last movement transforms into fruitfulness, as IFCs share God’s grace with others such as making others (family, diagnosed loved one, close friends) feel valued, affirmed, loved and accepted when they are with the IFC. Teaching and guiding, offering love, giving hope and blessings to those who feel weary, giving redirection for a new normal and being courageous during and after the cancer journey. “The cycle of grace reflects God’s love moving outward, like ripples on a pond”.

CHAPTER 9: SUMMARY AND RECOMMENDATIONS

This chapter will be an individual summary of each chapter. Recommendations regarding future topic related research will also be considered. By providing the summaries of each chapter, the researcher wants to show how the research question and aim for the study were met.

9.1 SUMMARY CHAPTER ONE

Chapter one is an introduction to the subject of helping significant others cope with cancer related stress. The entire family system is affected by a cancer diagnosis, the treatment thereof and threat of recurrence where the impact of the illness holds long-term consequences on the inner balance of the family. Knowledge on how families respond to a cancer diagnosis and the journey thereof has become a research priority as adjusting to altered health circumstances influences the dynamics of how the family members will adapt to the emotional, logistical and interpersonal demands that come together with a cancer diagnosis. The question to be answered by this study is “What will a holistic Scriptural based pastoral model through which significant others can be helped to cope with cancer related stress, look like?” The aim of this study is thus to obtain a deeper insight into the impact of cancer related stress on IFCs with the goal of assisting them to adapt to the circumstances in a well-balanced and healthy manner in order to support the diagnosed loved one.

The epistemology of the study is from a pastoral care paradigm, as a subdivision of practical theology. Hardships during the life journey studied in theology and ethical discussions often call for a reassessment of perceptions, as well as the practice of theology. As the aim is to find a holistic Scripture based model it is important to find a balance between spiritual, academic, ministerial and personal dimensions. Osmers’ model was used to answer the aim of the study. The approach of the descriptive empirical task is twofold. Firstly, a qualitative empirical study in the form of semi-structured face-to-face interviews to explore current guidelines used by professionals to gain insight into methods or guidelines that successfully relieve caregiver related stress. The second part of the descriptive empirical task is an objective and in-depth literature review to systematically gather information with the purpose of understanding different types of caregiver related stress. The first part of the interpretative task draws on a literature study from multi-disciplinary sciences discussing the Christian version of ACT, mindfulness, compassion, the neurological connection with mindfulness and the role of the pastoral counsellor. The second part of the interpretative task places focus on the theological implications of coping with illness by focussing on the work of Louw and Hudson as well as practices of spiritual disciplines in the form of centring prayer, serenity prayer, *Lectio Devina* and worship. The normative task is firstly to gain a deep theological understanding of the significance of God’s presence within the context of caregiver related stress by means of a theological word study. The second part of the normative task focuses on the pastoral theology viewpoint by means of “The cycle of Grace” and labyrinth walking to discover God within. The pragmatic task utilises all the findings gathered in the study that serve as building blocks for a theological model to compile a holistic Scripture based model to assist significant others cope with cancer diagnosis in the family.

9.2 REFLECTIONS ON THE DESCRIPTIVE TASK: EMPIRICAL STUDY

The first part of the descriptive empirical study is presented by means of a summary of the findings. In order to obtain rich data, the researcher selected participants with ample experience and insight into the cancer journey. The relevant professional groups identified and interviewed for this study consisted of a small sample of eight participants in the fields of social workers, counsellors, pastors, hospice representatives and occupational therapists. The qualitative empirical study explored the current guidelines used by these professionals because they represent a variety of multi-discipline counselling methods.

The interest of the study is to gain an understanding of subjective experiences allowing the researcher to see things through the eyes of the participants, offering the chance to grasp the what, why and how of the context. To understand the activities and practices IFCs engage in and the meaning they attribute to their experiences, the first part of the descriptive task was done by means of qualitative non-numerical data collection. The qualitative data collection for this study was done by using semi-structured face-to-face interviews with a predetermined set of questions in a specific order, while being flexible and open to deviate from the order if the participant spontaneously should move into an area to be covered at a later point.

Reflecting on the findings of the interviews, the following observations were made. To effectively deal with the tremendous stress of a cancer journey the family members must engage both internal (religion, emotions such as doubts, anger, *et cetera*) and external (counselling) practical adjustments to settle into a new normal. Most families appear to adjust well reporting emotional and spiritual growth. Potential resiliency factors include strong support systems, palliative care, good communication with the medical team, solving problems purposefully, emotion-focused coping such as breathing, and living mindfully. The most important IFC needs were related to patient care and emotional well-being, honest, clear, age and circumstance appropriate information, and the least important was the health of the IFC. Focus is thus entirely on the patient. Prolonged distress shows to have a negative impact on IFCs' quality of life, mental and physical health factors and religious struggles unable to move from the "Why God?" questions.

All the participants emphasised the value and respect of the uniqueness of not only each case but each individual within a family. There is consensus among all participants that the empowerment of both patient and IFC is the main aim of sessions. All participants stated that social support can help the family to weather periods of stress or change in their lives. These support systems mostly comprise of key family members, close friends and their pastor.

In the palliative caring environment, the cancer patient and family members cannot be seen as separate entities, they are interconnected. Patient and family will be encountered in hospital as well as home visitations where conversation topics commonly addressed include diagnosis, cancer treatment, medication, caregiving support, important end of life decisions, emotional well-being and theological questions. For this reason, counselling must deviate from the norm of counselling from a set location (office). IFCs do not have the time nor energy to seek counselling and on top of the time constraints feelings of guilt will keep them from any activity they perceive as spending time on themselves. For these reasons the PC must reach out to the family, meeting them at locations and times most suited to IFCs.

It is further concluded that psychologists do not play a large part in the cancer journey. Possible reasons given are that IFCs do not see the need for psychological help. They are homebound due to caregiving tasks. They do not have the time and energy to leave the bedside of their diagnosed loved one. They feel guilty to spend time on themselves. Psychologists further do not have insight into the physical space the cancer occupies. These include practical variables such as the layout of the house, the energy in the house, family dynamics, routines of the house, beloved pets and the role they play in the family dynamics. This space as experienced by the participants is ‘sacred’ and ‘holy’. The PC must physically be there, spend time with the family in their space to really grasp the situation.

The variable which mostly influence acceptance of the diagnosis and cancer journey is the age of diagnosis. If the “turn back” period of remembrance is short the cancer journey will be difficult to accept because a long road was still imagined with the diagnosed loved one. The circle of life is a strong cultural assumption that the young will bury their elders. Paediatric cancer diagnosis and young couples thus will need more counselling to help them come to terms with the diagnosis. From the qualitative interviews the researcher concludes that the cancer journey is a choice of attitude (towards God, cancer journey and caregiving role) and being mindful of emotions. The main task to empower the family and help them cope with cancer related stress appears to be to help them feel, understand and accept their emotions towards all the variables mentioned in the interview questions within the uniqueness of each individual.

9.3 REFLECTIONS ON THE DESCRIPTIVE TASK: LITERATURE REVIEW

The second part of the descriptive task is in the form of a literature review from a multi-disciplinary focus with the purpose of discussing the impact of cancer on the family system to systematically gather information in order to understand different types of stress. By understanding the families’ responses and reasons for conflict and adjustment issues the PC can identify which family subsystem is at risk and build interventions to target at risk relationships and strengthen families by providing effective family-centred, multidimensional methods. Family is considered as a system consisting of multiple interrelated parts including both the individuals and the relationships between individuals. For this reason the study placed a fivefold focus on how a cancer diagnosis affects the healthy spouse, parent with a child with cancer, preadolescent/adolescent with a parent with cancer, healthy sibling with a brother or sister with cancer and grandparents with grandchildren diagnosed with cancer.

Spouse: literature shows that both spouse and patient are equally distressed, and that their distress is connected, terming it the “we-illness”. The chapter accentuates the importance of showing concern and support for the spousal caregiver, because their mental- and physical statuses affect their capacity as the caregiver to the diagnosed spouse.

Parent with child with cancer: this chapter notes that parents’ ability to adapt to their child’s cancer diagnosis and accompanying challenges has an influence on the diagnosed child’s quality of life. Also, how parents choose to adjust to the cancer diagnosis will have an influence on the diagnosed child’s coping mechanisms. Both interviews and literature have shown that the parents of paediatric cancer patients are uncomfortable to admit that they need relief from the caregiving role and day-to-day tasks. Asking for support will require of the parents to share personal information about their own struggles with coping with the diagnosis and treatment. The PC must actively work on building a safe environment where the parents can learn to give themselves permission to ask for help. The trauma of having a child diagnosed with cancer affects the whole family unit with a great impact on the relationships within the family system. Paediatric cancer is also a highly stressful event with serious social and emotional impacts on all involved.

Preadolescent/adolescent with a parent with cancer: preadolescent/adolescents are especially vulnerable because they are dependent on their parents’ care and support, and as a result they have limited capacity to cope with a life-altering situation such as a parent being diagnosed with cancer. Studies show that a cancer diagnosis of a parent affects the preadolescent/adolescents on behavioural-, emotional- and physical functioning as well as school performance and social adaptation. Age and gender are highlighted as significant factors to play a role in helping the preadolescent/adolescent adjust and/or cope with parental cancer.

Healthy siblings with a brother/sister with cancer: with a paediatric cancer diagnosis, family life is turned upside down. Siblings are exposed to significant stress when a brother or sister is diagnosed with cancer. A variety of difficult emotions were noted in the healthy siblings which include shock, fear and uncertainty, especially at the time of diagnosis. Healthy siblings often express strong negative feelings, such as, anger, jealousy and anxiety. Concern about the ill sibling, disruptions in family roles and routines, taking on additional responsibilities and roles within the family, decrease contact with family members (especially the parents), and additional demands for caregiving are common stressors endured by the healthy siblings. As the diagnosed child becomes the focus of the parents’ attention the healthy siblings often feel like the “invisible children”. The healthy siblings often take on added chores to lessen family stress. These increased responsibilities in the house strip the healthy sibling of their childhood forcing them to grow up fast. A number of siblings voiced a need to be included in the care of the sick sibling, needing more information about the cancer diagnosis, treatment plan, and basic health information and generally be kept up to date throughout the cancer journey. Providing age appropriate information about the cancer diagnosis and expected journey thereof eases healthy siblings’ fears, as well as correcting any misconceptions about the diagnosis and process, suggesting that positive family environments and support systems can increase resiliency in the healthy siblings.

Grandparents with grandchildren with cancer: the involved grandparents can be an irreplaceable source of informal support to the family and improve family closeness by providing emotional comfort and practical support. The PC must be mindful of the fact that these grandparents tend to withhold their own emotions believing that their distress is uncalled for in the context of their own son’s or daughter’s and grandchildrens' distress. Whereas in fact the grandparents suffer with double the emotions, firstly feeling for their son/daughter and secondly having great concern for their grandchildren (diagnosed and healthy). Withholding their emotions can lead to feelings of helplessness, guilt and isolation during the treatment; furthermore, feeling removed from the direct care and treatment decisions concerning their grandchild’s cancer despite the vital role they play in supporting the family through the cancer diagnosis.

Families living with a cancer diagnosis of a loved one and the journey thereof often struggle with feelings of isolation due to fear of burdening their support systems with their ongoing pain and experience a decrease of support over time. Palliative care is the support of the whole-person-whole-family regardless of the anticipated cancer outcome. Effective communication between all parties involves the cancer patient, family members of the cancer patient, PC, social workers, clinicians and shared decision making in palliative care. Palliative care as a standard of care in the cancer journey has the potential to foster improved quality across the cancer trajectory for the cancer patients as well as their family members with lasting effects throughout the cancer journey and can help the family find a “new normal” after treatment or death. The early integration of palliative care by the PC will provide meaningful opportunities to attend to the full impact of the illness on IFCs’ psychological, developmental and spiritual wellness.

9.4 REFLECTIONS ON THE INTERPRETATIVE TASK: LITERATURE STUDY (AUXILIARY)

The first part of the interpretative task was a study of literature from different arts and sciences in working towards a holistic model to help IFCs increase their self-awareness and improve harmony between mind, body, emotions and spirit in the ever-changing environment of cancer.

To reach a state of such harmony and wellbeing IFCs must start with the activation of their inner caregiver by means of self-compassion. This chapter provides a compelling argument for the use of self-compassion as an important means to help IFCs develop emotional resilience and well-being. Self-compassion simply is compassion directed inwards, thus being kind toward the self as imperfect human and discovering how to be present within struggles of life with greater ease. Just as IFCs feel compassion towards their diagnosed loved one, they can extend that compassion towards themselves. In order to treat the self with compassion, IFCs must learn to turn toward, acknowledge and accept personal suffering, meaning that mindfulness is a core element of self-compassion. For this reason, self-compassion has been described as a double-edged sword, meaning it cuts through the pain of the present as it opens the pain of the past, making it both a challenge and opportunity for growth towards holistic well-being. It involves offering non-judgmental understanding to own pain and failures seeing these experiences as part of the larger human experience. To understand why self-compassion creates a positive mind-set while simultaneously improving negative mind-states it is useful to think of the three key features of self-compassion in terms of loving kindness, connectedness through common humanity and being present through mindfulness. Self-compassion is thus a central concept by which mindfulness-based and acceptance-based interventions influence psychological health.

Self-compassion is associated with ACT constructs such as acceptance, perspective taking and psychological flexibility. Furthermore, a significant development that has grown exponentially is the use of ACT in religious contexts, bridging psychological and spiritual care. The emphasis on values and committed action resonates well with Christian teachings. For these reasons, in the spirit of providing compassionate, effective, caregiver-centred care to IFCs, this study proposes that the PC integrates ACT and religion. ACT uses four mindfulness-based processes (accepting emotions, defusion from thoughts, observing inner states from a safe distance and passing values and committed action) together with two values-based processes (values and committed action). ACT is a behaviourally oriented psychotherapy addressing the relationship to cognitions, emotions, sensations and memories in order to help vitality and meaningful participation in life through creating psychological flexibility, which involves openness, centredness and a deeper engagement with life. Psychological flexibility will encourage IFCs to change their relationship with their emotions and cognitions through cultivating mindfulness (a present moment, non-judgmental form of awareness). ACT leans into suffering instead of promoting avoidance. Happiness is thus not a goal of ACT but is replaced with acceptance. ACT further promotes awareness of values and living in ways that demonstrate commitment to those values. ACT allows IFCs the space and time to step into the present moment, encountering the self in a mindful, compassionate and accepting way. This moment of radical acceptance and love is perhaps the greatest common ground between self-compassion and ACT. Using ACT, the compassionate PC will be able to assist IFCs in accepting their internal experiences such as thoughts, emotions, sensations, images and memories. Merging acceptance and behavioural action helps IFCs to move forward guided by their values despite unpleasant emotions that have the potential of sending them into a contradictory life direction of fear.

Pastoral conversation is an extraordinary gift where the PC is invited into the IFCs’ most intimate space where they discuss the very nature of their being human, sharing their joy and pain. Compassion in pastoral caregiving is about showing *ta splanchna* where the PC is moved by suffering of others within a spiritual awareness of God’s *ta splanchna* (the theological motive in compassion). Apart from characteristics such as effective communication skills to draw out and understand the IFC's situation, experiences, hopes, values and preferences, accurate listening skills, visualising others' perspectives, empathic concern and non-judgemental attitude, the PC must be aware of any personal subconscious biases and triggers, self-other boundary awareness and the ability to regulate their own emotions.

In many ways compassion was shown to be more like friendship than anything else. This friendship occurs on a professional rather than personal level where the PC is like a professional friend. This form of conversation awakens IFCs to the depths of God's love and God's truth. Taking part in deep conversations as a professional friend meeting the heart of the other is the core of pastoral caregiving also referred to as transformational teaching. In other words, it goes beyond surface interaction to help IFCs enter their core where God starts working in and through them. Through conversation the PC provides the theoretical framework as well as practical methodological dynamics for IFCs' personal and social awakening, knowing, learning and personal growth, bringing awareness, insight, fresh understanding and vision of the cancer journey. This type of compassion stands central to the ethical practice of the healing professions. In this regard it is not simply the ability to understand suffering of others but to furthermore have understanding with a scientific component placing the IFC's story within a paradigmatic context of others in the same situation. Mindfulness asks the question "What are you experiencing?" and self-compassion asks, "What do you need?" During hardship IFCs often find it difficult to know what they need or to show kindness towards the self, in such cases the PC must keep these questions in mind until IFCs can do it for themselves. It is concluded that conversation is essential for IFCs' development and growth on a cognitive, mental, emotional, interpersonal and spiritual dimension.

Regarding ACT and the PC, ACT recognises that the PC also endures difficult times and suffering in this way pastoral caregiving is led by "wounded healers", who personally also qualify for counselling by being in contact with their own experiences of misery, doubt, suffering and helplessness. The PC must take time to identify what he or she fuses with, what he or she avoids, what values he or she loses touch with and what ineffective actions are taken. The more this model is applied to the self and own issues and observing how it works in personal life, the more experience can be drawn into the therapy setting.

Self-compassion is further an inner resource that relieves caregiver fatigue for both IFCs and PC. Being able to cope with the stresses of being in a caregiver role is part of the art of caregiving. Caregiving fatigue occurs when an individual takes on the pain and suffering of another. To remain healthy in order to continue with the caregiver role, both IFCs and PC must be able to recognise own limitations and learn to care for the self. Regulation of emotions, self-compassion, self-care, reflection and other resilience-promoting attributes and skills are shown as important factors for well-being. Coping is categorised into two types namely self-compassion and mindfulness to resolve the stressful role of caregiving.

9.5 REFLECTIONS ON THE INTERPRETATIVE TASK: *CURA VITAE*

Religion as a practice of coping represents a crucial resource for this study. An important belief system frequently relied on during stressful times and uncertainty, including that of caregiving, is religion. In the second half of the interpretive task, chapter five discusses the link between religion and psychosocial adaption, the theological implications of coping with cancer and the practices of religious disciplines in order to provide pastoral caregiving to IFCs.

This chapter turned its focus on educating the PC on how to understand IFCs in order to help them navigate a world turned upside down searching for meaning and purpose. Beliefs are the blueprint of who an individual is, making habitual thought patterns a powerful construct. The energy behind beliefs drives decisions, attitudes, feelings, coping patterns, life choices and more. Studies show that religious coping offers the cancer family a sense of purpose, meaning, comfort, altered priorities, control, personal growth and a deeper appreciation of life. These outcomes are referred to as “post-traumatic growth” and “perspective transformation”.

Particularly of importance to this study is the type of religious coping. Religious coping methods were grouped into two broad categories, positive (PRC) and negative (RS). Generally, religion is applied in a positive manner (PRC), as a great source of coping. In contrast RS has been associated with negative outcomes, such as mortality and worse mental health. Religious coping is not simply a defence mechanism, it is actively and dynamically involved in each stage of the coping process to help IFCs find, maintain and transform significance and meaning.

The manner in which IFCs approach cancer depends on their framework of meaning, perception of life and how they understand God (their God-image). Work from Louw was introduced to explain the concepts of God-images and how cancer can be used as an opportunity to grow closer to God. From this work the PC will be able to help mend the perception of God’s goodness with human suffering and to explain His love and grace in the light of hardship. From a mended God-image the PC can move on to the work of Hudson on how to grow a friendship with God with the purpose to reach a deeper meaning of life and the purpose thereof amidst hardship.

One of the key attributes of resilient individuals is to draw upon religious beliefs and practices. The goal of the PC is to empower IFCs giving them meaning and peace that will help them to cope, promote well-being and quality of life. To keep growing in a relationship with God, coming to an understanding of who God is (God-image) practical guidelines were suggested on how to nurture a friendship with God by means of religious practices. Four practices were introduced and discussed.

Firstly, Centring prayer is summarised as a process of inner purification leading to divine union where one consents to God’s presence and action within. It is a responsive model built around a relationship with God where one surrenders to God’s loving presence and healing action. It is a method to divert attention from the ordinary flow of thoughts in order to awaken faith. This prayer goes beyond thoughts, words and emotions by opening the mind and heart (the whole being of a person) to God.

Secondly, Serenity prayer can assist IFCs to manage their caregiving role more effectively by recognising what can change (their reaction to stressful situations during the cancer journey), cannot change (cancer diagnosis and the progression of the illness), how to deal with the cancer journey and their emotions, as well as where they stand in their religion and to build a relationship with God. In other words, although IFCs may not be able to control the diagnosis and progression of the illness (primary control), they can control their cognitions and emotions (secondary control). The third section "and the wisdom to know the difference" is an important part for both PC and IFCs in the prevention of burnout.

Thirdly is *Lectio Divina* as an ancient spiritual practice with the focus on developing a heightened awareness and self-reflection by meditative reading of biblical texts. It is the skill of listening to God's word as if in conversation with Christ where He suggests the topics to be discussed. The purpose of divine reading is to come to a point where one understands Scripture at the level of both the heart and mind.

The last practice is music described as a gift from God which has the power to bring a calm and joyful nature to the worshipper and for this reason music provides and provokes a response, which is universal, ingrained into mankind's evolutionary development with the ability to cause noteworthy changes in emotions. With regards to the impact of music on the brain, neuroscience teaches that music is a therapy method and a means of accessing that stimulate specific cerebral circuits which are viewed to stimulate the brain. As a significant other herself the researcher compiled a list of songs that helped her through her journey with cancer

In combination with ACT pastoral care and life coaching were introduced as techniques to utilise to assist IFCs on both a historical directed (counselling) level as well as taking action, future directed (life coaching). The customary understanding of pastoral caregiving is that it is a process focusing on assisting a person dealing with and healing from the consequences brought about by past events. Life coaching aims to guide the individual through a process that will empower them to set clear and specific future goals. The 21st century's approach to well-being calls attention to a more holistic approach considering not only past experiences, but also the future. For this reason, this study incorporates life coaching principles within the context of pastoral caregiving.

9.6 REFLECTIONS ON THE NORMATIVE TASK: THE THEOLOGICAL CONCEPT OF COMPASSION

Chapter six is a discussion of the first part of the normative task with the purpose of gaining a deep theological understanding of the significance of God's presence within the context of caregiver related stress by means of a theological word study on four chosen texts. The unique feature of caregiving consists of two basic entities namely, comfort and compassion. As a result of the interrelatedness between comfort and compassion, the passion in compassion gives rise to more than feeling, it is an existential category of being-with. Comfort is in essence a spiritual category linked to the theological dimension of the Christian faith. At heart comfort is an exemplification and embodiment of the passion and suffering of Christ.

Exodus 3:14, “being-with”. In Exodus 3:14 God reveals His name to Moses with the words “I AM” and “to you”. Through this identity revelation comes a promise that God will be with His people, that He seeks a deep, personal and loving relationship with His people, bestowing grace and having mercy on them throughout time. God, being with His people is a divine presence making it boundless and unending throughout time. Being in a relationship with God IFCs can thus truly know that others before them have walked the same path and those to come will follow on the same path. “I AM”, is as unchangeable today as all those generations ago. To be able to hope in this promise can make it easier for IFCs to endure the cancer journey. IFCs get hope by knowing that “I AM”, “to you” will be with them yesterday, today and tomorrow. They can reflect on God’s faithfulness and His forever-enduring love being-with them.

Ephesians 2, “the compassionate God”. In Ephesians 2 the Apostle Paul connects Christ’s great love and His sacrificial death, teaching the people about God’s desire to be re-joined with mankind, made in His image and for His glory. God is defined as self-offering love in the self-limitation which was His incarnation in Jesus Christ and in the self-offering of Jesus’ human life for condemned mankind. That is why pain, suffering and death of humanity are also regarded as influencing God. This self-emptying and self-offering (a kenosis) of God, a sharing in the suffering of His people demonstrates the suffering love primarily in and through Jesus Christs’ life, suffering, death and resurrection. God essentially kind, merciful and loving reaches out in love to humans who are condemned offering them salvation and all the eternal blessings that come with it.

Matthew 22:36-39, “self-compassion through love”. Concerning the great commandment of the law in the Gospel of Matthew 22:36-39, the evangelist highlights that Christ’s Great Commandment contains two requirements both equally important. This double commandment is to love God and one’s neighbour. Christ brings the Ten Commandments to love for God and love for neighbour. All the law is thus fulfilled in one word namely love. This law assumes that IFCs should love themselves (be self-compassionate) or otherwise they will not be able to love others. The love commandments cannot be separated; they belong together embracing the vertical relationship with God and the horizontal relationship with others and self. It is revealed that those who love God will love themselves without being selfish. The Bible forbids selfishness but does not forbid self-love. “As thyself” therefore means that IFCs may (must) love themselves and take care of themselves. In fact, IFCs must not love others the same way they love themselves but as they ought to love themselves; not to the same degree, but after the same manner, which is freely and readily, sincerely and unfeignedly, tenderly and compassionately, constantly and perseveringly.

Romans 8:18-23, “hope”. These verses teach about hope. God became mankind’s “co-sufferer” through His incarnation in Jesus Christ and in the self-offering of Jesus’ human life. The Christ event shows that God not only experienced suffering and death on the cross, but importantly overcame suffering and death through the resurrection. The destruction of sin and death and the victory of God’s goodness in giving life to those who have put their faith in Christ are the things that IFCs must put their hope on.

A cancer journey brings painful losses or “little deaths” throughout the journey, for example the loss of familiar routines, the loss of health and sometimes the loss of life itself. For healing IFCs must mourn all the “little deaths” throughout the journey. This process of grieving will allow their hearts to acknowledge the pain and trauma finding hope in the fact that God is love, He is compassionate and with His people through all the seasons of their earthly journey and beyond. God being-there, being-with and being-for His people.

The loving, self-emptying God only seeks good for His people, wanting His people to live for more than this fragile earthly life. The vulnerable God, Kenotic creator, compassionate God, God the Triune seeks a deep, personal, loving relationship with mankind.

9.7 REFLECTIONS ON THE PASTORAL CONCEPT OF MINDFULNESS

For the PC to promote IFCs’ stress resilience and wellbeing in a positive, integrated and sustainable way the second part of the normative task discussed the relevance of mindfulness for both IFCs and the PC. This study worked towards the point of finding a model to help IFCs with caregiving related stress. The heart of this study’s questions about meaning during suffering, “Who is God?” and “To what purpose?” are answered in chapter seven by means of the cycle of grace.

Together with human suffering that is universal and unavoidable comes emotional pain and struggles when confronted with hardships such as a cancer diagnosis of a loved one. This chapter proposes the practice of mindfulness to find a healthy way of living with the cancer journey reducing stress and setting the stage for positive personal transformation. Rather than trying to escape the experiences that come with hardships, mindfulness practices can help IFCs to increase their capacity to bear it. The aim of mindfulness as used in this study is for IFCs to no longer ask, “Why?” and “For what reason / purpose?” but to find meaningful acceptance of suffering and hardships. From God’s mercy and faithfulness, these questions will be replaced with “To what purpose?” Asking “To what purpose?” does not imply that IFCs will receive answers and reasons but instead to find God’s faithfulness within their pain and confusion. Hardships and suffering must not be seen as God’s will, it is more about the possibility of personal growth through hardships. The core of the question of meaning is therefore not what happens to IFCs but what can happen in and through them. God is interested in how IFCs react during hardships and their spiritual growth through suffering.

Keeping in mind that IFCs may feel overwhelmed and distracted with time consuming caregiving tasks, it is possible to have mindful moments. For example, IFCs can momentarily disengage from their caregiving duties by taking a long, conscious breath, gathering their attention and asking themselves "What am I feeling right now?", "What am I doing right now?" What is most compelling to my awareness right now?" With the correct technique of mindfulness, IFCs can reach a state of physical relaxation and respiratory balance in a natural, spontaneous and time effective way. The 4-7-8 breathing technique recognised as a 'simple' time effective and beneficial practice was introduced. The silence and stillness acquired by being mindful induces a present-moment awareness of body, mind and soul expanding the moment in order to feel the presence of God. Learning how to regulate one's emotions through deep breathing and stillness can lead to unity with God and listening to God which will bring IFCs to deepen their relationship with self and God. From a Christian perspective mindful breathing is used to reflect on God, finding His loving presence and intention which can make IFCs more aware of their inner thoughts allowing the content of their thoughts to lead them to biblical truths as well as qualities of compassion and loving-kindness. In these small spaces taken throughout the day IFCs can find purpose, meaning and hope.

This study suggests that living a mindful life, striving to be in a relationship with God, can be achieved by living the cycle of grace. The cycle of grace is a powerful lesson from the life of Christ and how He lived a life of dynamic balance of receiving grace and giving grace. By following in Christs' footsteps living the rhythm of input and output that He set in place IFCs will be empowered to confidently and courageously take on the caregiving tasks, knowing that their worth and identity is secure in God. The four dimensions of the cycle are discussed namely acceptance, sustenance, significance and fruitfulness which are placed within two dynamic phases that are the input phase and the output phase. Divine acceptance comes in rare human relationships such as mentors (PCs), family members and friendships where each person is fully known, valued and loved. In such a space IFCs will have the freedom to be themselves, to share their innermost emotions and experiences. With such a glimpse of divine acceptance they can claim and reclaim their identity as a child of God during the cancer journey. The second input dimension is where Christ sustained His close relationship with God throughout His life on earth by regularly making time to spend with His Father by praying, worshipping and surrounding Himself with close friends. Developing spiritual practices involves theological and practical concerns, in other words IFCs must make time in their daily schedules for God to come to them, feed them and heal them. The third and fourth dimensions of the cycle of grace (output) ask the questions "Who am I called to be? and "What am I called to do?" Significance is a truth one bears, a witness made, a life lived before God and most of all desiring God. By asking the deeper questions IFCs must firstly explore who they are in Christ before, during and after their role as caregiver, anchoring their identity in God. God's grace in the last dimension transforms into fruitfulness as IFCs share God's grace with others. IFCs can represent God during and after the cancer journey by leaving others feeling valued, affirmed, loved and accepted, teaching and guiding, offering love, giving hope and blessings to those who feel weary, giving redirection for a new normal and being courageous during and after the cancer journey.

Mindful labyrinth walking is introduced as a practice for personal, psychological or spiritual support and growth that can be applied as an anti-stress resource in the sustenance dimension. The aim of the walk is to improve mindfulness, install judgment-free awareness of the present moment and exercising the left and right brain hemispheres to work in harmony. Walking the labyrinth can awaken IFCs' capacity for contemplation, reflection and transformation.

Vital characteristics that the mindful PC must practise for a successful caregiving journey with IFCs include awareness of the present experience with acceptance and compassion without trying to solve problems or fix people. Although these are distinct components, they are irreducibly intertwined in the caregiving setting of the mindful and compassionate PC. All the components of mindfulness (awareness, present-centredness and acceptance) are required for a moment of mindfulness. In order to have an open heart the PC must have open eyes, putting it differently, to know mindfulness it must be practised. Entering the caregiving relationship with IFCs as fully and as deeply as the need demands it is vital for the PC to personally practise (on an ongoing basis) compassion, self-acceptance and living the cycle of grace. In ACT the aim is for the PC to be fully present with IFCs with an authentic, mindful, compassionate and respectful attitude, be in touch with their own core values, work on resolving own painful issues with an active willingness to experience own undesirable private feelings and thoughts.

9.8 CONCLUSION REGARDING GUIDELINES FOR THE COUNSELLING PROCESS

For the pragmatic task all the findings of the previous chapters serve as building blocks for the compilation of the holistic Scripture based theological model.

Pastoral caregiving must include actions that can support IFCs' spiritual, physical, emotional and social well-being to help them cope with the full impact of the cancer journey delivering lasting psychological, developmental and spiritual wellness. The model is divided into two main sections. As the characteristics, values and beliefs of the PC are key to a successful pastoral relationship and growth of IFCs, the first part places focus on the compassionate dimension of the PC. An undebatable factor of the model is that the PC must be fully committed to the journey of seeking meaning and purpose, to have hope and keep on hoping, even when hope seems elusive. The nurturing of hope is a goal of pastoral caregiving in general, for this reason one of the caregiving responsibilities is attending to thoughts about hope, knowing who God is and to trust in His unfailing omniscience and love. The model suggests that the PC gets acquainted with the suggested practices by personally and regularly practising it; become one with it. "Walking the talk" as a wounded healer the PC then takes on the shepherding role. It becomes a matter of professional friendship having deep and meaningful conversations with IFCs without sugar coating the situation or attempting to give easy (or any) answers to the difficult questions asked. It is a matter of humbly being-with / sitting-with IFCs in acceptance, compassion and hope. As each case and individual are different, with unique emotions and perceptions, and although there is no “one-size-fits-all” formula in counselling there are some vital components and methods, approaches and strategies that can be part of a transformational learning experience. The compassionate PC first and foremost relies on the love and power of God, making the point of departure the Word of God as the authoritative source for pastoral caregiving in order to build IFCs’ ability to tolerate and transform difficult experiences in the short-term and long-term, encouraging awareness, mindfulness and self-compassion. The PC navigates this conversational transformation by utilising palliative care concepts, the ACT model as well as life coaching techniques.

The point of feeling utterly lonely is where the true quest for meaning and God starts, questioning whether cancer is a fate to be endured alone (Why God?) or if this path of suffering (physically, emotionally, spiritually) also runs through God’s heart (Who is God?). The second part of the model focuses on the pastoral caregiving strategy to help IFCs to incorporate certain spiritual techniques or skills to grow into resilient individuals who can deal with caregiving related stress. Through hard times such as a cancer journey difficult questions are asked, seeking for answers to understand pain and suffering. IFCs’ image of God is very important in how they will perceive, react to and act upon the cancer journey. The PC must turn the “Why?” questions into asking IFCs “To what purpose?” Instead of asking “Why God?” IFCs must ask, “Who is God” journeying with the “Who is God?” question IFCs will get to know God, build a friendship with God through Christ. Four texts were proposed to work with: Exodus 3:14, “being-with”. This verse finds the priority of compassion specifically regarding the act of divine presence described as boundless and unending being-with. Ephesians 2, the compassionate God. With reference to the suffering God and the theology of the cross as the framework of the *theopaschitic* approach (passion of Christ). Matthew 22:36-39, self-compassion through love. As part of the greatest commandment. Romans 8:8-28, hope. By means of the power and love of God in the midst of suffering.

These verses are enforced through practices such as mindful breathing, centring prayer, serenity prayer, worship and labyrinth walking. For example, the “simple” task of breathing is highly recommended for IFCs, as steady and controlled breathing requires little input and effort but in return offers great health benefits. *Lectio Divina* focuses on refining awareness and self-reflection by meditative reading of biblical texts. Centring prayer and Serenity prayer bring unison with God in order to improve the ability to be silent, hear God and be filled with the Spirit. Music described as a gift from God has the power to bring a calm and joyful nature to the worshipper. For mind-body connection IFCs can become aware of their thoughts and exercise self-compassion by means of the Labyrinth slow paced mindful walking.

These practices must be done mindfully and they teach IFCs self-compassion. The researcher believes that when IFCs commit to these spiritual practices, they will grow and find hope in their relationship with God and will therefore be able deal with caregiver related stress.

The model starting at equipping the PC for the caregiving task to suggesting texts to meditate on and religious practices to encourage and grow a relationship with God all work towards the heart of the model which is living according to the cycle of grace. Here IFCs go through four stages of finding spiritual earthly friendships, spending time with God on a daily basis, finding an identity as given by God and the last step, fruitfulness where IFCs start to live and share the fruit of the Spirit.

9.9 FINAL CONCLUSION

The impact of a cancer diagnosis can be compared to the effect of dropping a stone in a pond. In other words, cancer causes a ripple effect resulting in changes to IFCs' identity, roles and daily activities. Cancer is a life-changing illness along with a high degree of uncertainty that goes along with equally high caregiving demands where IFCs are exposed to multiple challenges during the treatment continuing through the remission period or death and bereavement. Confronted with the challenge of balancing the term "we-disease" IFCs will find themselves in situations of multidimensional adjustments and sometimes to a point where their own self is at risk of compassion fatigue that holds physical, emotional, social, spiritual and professional implications. For this reason, the IFC must be approached as a unique whole-person (physical, emotional and spiritual) within a unique situation during all the phases of the illness.

The concept of mindfulness was used for IFCs no longer to ask, "Why?" and "For what reason / purpose?" but to find meaningful acceptance of suffering. From God's mercy and faithfulness, these questions were replaced with "To what purpose?" The "Where to?" question does not imply that IFCs will receive answers and reasons. It means that IFCs discover God's faithfulness within their pain and confusion. This was done through Scripture and practices of religious disciplines with the purpose of managing stress, illness demands, and life events specifically related to cancer with the aim of lessening negative outcomes such as depression, anxiety, worry, poor quality of life, and disrupted relations with family and friends. The purpose of these exercises is not only for the holistic wellbeing of both the PC and IFCs but more importantly to develop and grow a deep and intimate relationship with God. By meditating on and working through the question "Who is God?" both PC and IFCs can come to a point of living the cycle of grace.

Instead of assuming that IFCs need to reduce their symptoms in order to lead a better life, this study promotes a mindful, value-congruent living as the desired outcome by means of the model ACT, palliative care concepts as well as life coaching techniques that work towards a fundamental change within IFCs' way of dealing with their symptoms (such as stress) so that the symptoms can no longer hold them back from valued living (purpose and meaning).

The impact of a cancer diagnosis is compared to the effect of dropping a stone in a pond. Chapters one to six demonstrate the means and ways on how cancer causes a ripple effect resulting in changes to IFCs identity, roles and daily activities. To answer the question that this study set out to answer "What will a holistic Scriptural based pastoral model through which significant others can be helped to cope with cancer related stress, look like?" the study formulates such a model where IFC's come to know who God is. Through Scripture and religious practices, the PC walks with IFCs to a place of empowerment where they start to live a life according to the cycle of grace. The cycle of grace reflects God's love moving outward, like ripples on a pond.

"Come to me, all you who are weary and burdened, and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls. For my yoke is easy and my burden is light" (Matthew 11:28-30 NIV).

9.10 RECOMMENDATIONS

The following areas for further research are suggested:

- The PC must have specialised training and understanding of the cancer journey. Experience in working with serious, chronic illness (cancer) is important as well as ongoing training and support in order to provide ethically appropriate treatment of the IFC.

  Bereavement follow-up programmes and formal intervention in support of the families need to be recognised more.

  Pastoral caregiving to IFCs must deviate from the norm of counselling from a set location (office), to counselling at homes or hospitals.
- Collaboration requires an intentional partnership between professional disciplines wherein mutual valuing, respect for different skills and scope for practise, accountability, appropriate communication around consent and treatment, and shared goals for the family form the cornerstone. In order to enhance the experience of the family the PC must work closely with social workers, hospice representatives, nurses, and occupational therapists building strong relations with one another in order to refer the family members.

  Psychosocial providers should have access to medical records and relevant reports should be shared with psychological report interpretation.
- Healthy siblings are a psychosocial at-risk group and should be provided with appropriate and supportive care from healthcare professionals. Healthcare professionals together with parents of the healthy siblings should be advised about ways to anticipate and meet these siblings' needs.

  As the "invisible children" more focus must be turned towards the healthy siblings.
- Medical centres can:

  Provide training for oncology nurses on how to effectively support the cancer patient and their families, for example, training on family centred care, empathic listening skills, open, clear and honest communication, child development, and problem solving skills.

Build a strong referral basis within the community through community support agencies, such as PCs, social workers, hospice representatives directing cancer patient and family to these trained professionals.

Appoint a staff member to oversee palliative care for IFCs and facilitate referrals.

Provide access to appropriate multimedia resources for cancer patients as well as IFCs. Books and videos should normalise the cancer experience and feelings associated with the different stages of cancer.

- Studies with the focus on the difficulty people might encounter in terms of religious coping (e.g. negative religious coping) and critical reflection about problematic concepts in theology/pastoral care can also be recommended as further research on this theme.

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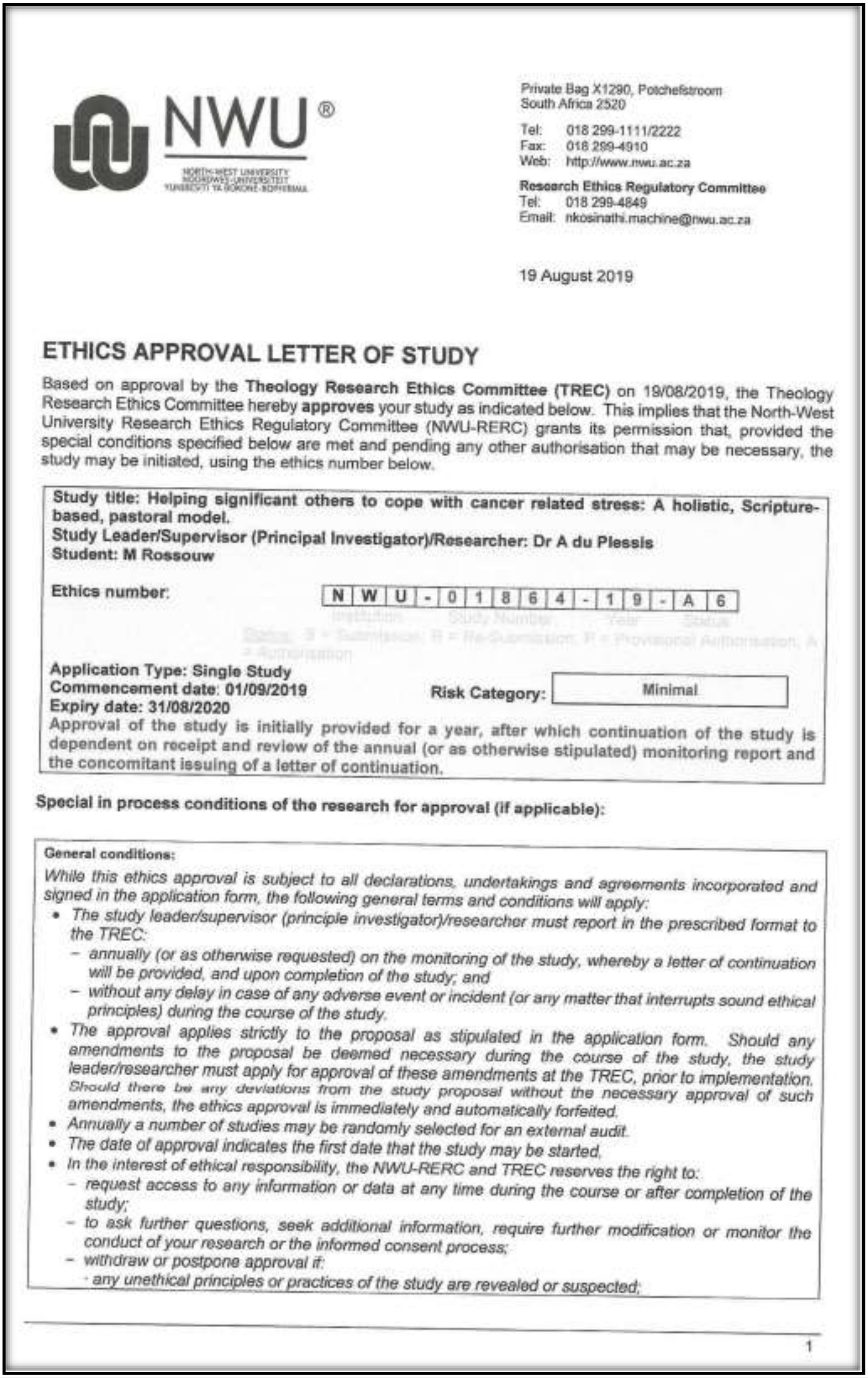
ADDENDUM



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19 August 2019

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the **Theology Research Ethics Committee (TREC)** on 19/08/2019, the Theology Research Ethics Committee hereby **approves** your study as indicated below. This implies that the North-West University Research Ethics Regulatory Committee (NWU-RERC) grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Helping significant others to cope with cancer related stress: A holistic, Scripture-based, pastoral model.
Study Leader/Supervisor (Principal Investigator)/Researcher: Dr A du Plessis
Student: M Rossouw

Ethics number: N W U - 0 1 8 6 4 - 1 9 - A 6
Institution Study Number Year Status
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Application Type: Single Study
Commencement date: 01/09/2019
Expiry date: 31/08/2020
Risk Category: Minimal

Approval of the study is initially provided for a year, after which continuation of the study is dependent on receipt and review of the annual (or as otherwise stipulated) monitoring report and the concomitant issuing of a letter of continuation.

Special in process conditions of the research for approval (if applicable):

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

- *The study leader/supervisor (principle investigator)/researcher must report in the prescribed format to the TREC:*
  - *annually (or as otherwise requested) on the monitoring of the study, whereby a letter of continuation will be provided, and upon completion of the study; and*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the study leader/researcher must apply for approval of these amendments at the TREC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*
- *Annually a number of studies may be randomly selected for an external audit.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-RERC and TREC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the study are revealed or suspected;*

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