



# **Faith communities' role in the pastoral support of children with life-threatening and/or life- limiting conditions: A pastoral study**

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## DECLARATION

I declare that **Faith communities' role in the pastoral support of children with life-threatening and/or life-limiting conditions: A pastoral study** is my work and that all the sources I have used or quoted have been indicated and acknowledged in the text and bibliography. I further declare that I have submitted this thesis to originality-checking software and that it falls within the accepted requirements for originality. I further declare that I have not previously submitted this work, or part of it, for examination at the NWU for another qualification or at any other higher education institution.



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## **DEDICATION**

“Blessed are those who mourn for they shall be comforted” (Matt 5:4, NIV).

“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” (Rev 21:4, NIV).

I dedicate this study to every child with a life-threatening and/or life-limiting condition. Children like Toni, a high-school friend who lived with cystic fibrosis before she passed away aged 17. These conditions affect the family and friends of the child; Jesus says the family who mourns are blessed because they will be comforted. Regardless of whether these children and their families receive this comfort on earth, they have the eternal assurance and hope that Jesus will wipe away their tears and pain in heaven.

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- To Jesus who died for us while we were still sinners. His example of true love and compassionate care in His earthly ministry inspires us today to reach the lost and vulnerable. I am thankful that Jesus tells us explicitly what He expects of us (Matt 25:31–46), so that we may know and honour Him in caring for the marginalised, such as children.
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## **ABSTRACT**

### **Faith communities' role in the pastoral support of children with life-threatening and/or life-limiting conditions: A pastoral study**

With a life-threatening and/or life-limiting condition, a child is confronted with unknown hospital environments and treatments, as well as with dealing with the illness or condition affecting their body. Without formal pastoral support systems, the child is often left seeking spiritual support from their direct family. The illness produces uncertainty and often fear in the child and their family. Pastoral support available to these children is often limited to church volunteers. There is a lack of pastoral care due to funding constraints, while healthcare workers and faith communities lack the necessary training to care for these children. By implication, there is no full-time pastoral support available to these children and their families.

It was hypothesised that there is limited pastoral support available to these children. The pastoral study set out to determine what pastoral support is available to children with life-threatening and/or life-limiting conditions. The study also aimed to use the pastoral strategies identified by the four pastoral caregivers in the empirical study, along with the other chapters, to create a pastoral strategy to inform faith communities and pastoral caregivers to provide more effective pastoral care to these children. Therefore, a synthesis of the findings of all the phases of the practical theological interpretation process is given.

#### **Key Words**

Faith communities

Pastoral support

Children

Paediatric palliative care

Life-limiting

Life-threatening

## **OPSOMMING**

### **Geloofsgemeenskappe se rol in die pastorale ondersteuning van kinders met lewensbedreigende en/of lewensbeperkende toestande: 'n Pastorale studie**

Met 'n lewensbedreigende en/of lewensbeperkende toestand word 'n kind gekonfronteer met onbekende hospitaalomgewings en behandelings asook die hantering van die siekte of toestand wat hul liggaam affekteer. Sonder formele pastorale ondersteuningstelsels waar die kind behandel word, word die kind dikwels gelaat op soek na geestelike ondersteuning van hul direkte familie. Die siekte veroorsaak onsekerheid en dikwels vrees by die kind en hul gesin. Pastorale ondersteuning wat vir hierdie kinders beskikbaar is, is dikwels beperk tot kerkvrywilligers. Daar is 'n gebrek aan pastorale sorg se erkenning en befondsing as 'n professionele veld, sowel as die opvoeding van geloofsgemeenskap en gesondheidsorgwerkers om hierdie kinders te besorg.

Die implikasie is dat daar geen voltydse pastorale ondersteuning vir hierdie kinders en hul gesinne beskikbaar is nie. Daar is veronderstel dat daar beperkte pastorale ondersteuning vir hierdie kinders beskikbaar is. Die pastorale studie het uiteengesit watter pastorale ondersteuning beskikbaar is vir kinders met lewensgevaarlike en/of lewensbeperkende toestande. Die studie het ook ten doel gehad om die pastorale strategieë wat deur die vier pastorale versorgers in die empiriese studie geïdentifiseer is saam met die ander hoofstukke te gebruik om 'n pastorale strategie te skep om geloofsgemeenskappe en pastorale versorgers in te lig om meer effektiewe pastorale sorg aan hierdie kinders te verskaf. Daarom is 'n opsomming van die bevindinge van al die fases van die praktiese teologiese interpretasieproses gegee.

#### **Sleutel woorde**

Geloofsgemeenskappe

Pastorale ondersteuning

Kinders

Pediatriese palliatiewe sorg

Lewensbeperkend

Lewensgevaarlik.

## LIST OF ABBREVIATIONS

ACE	Adverse Childhood Experiences
ACRP	Association of Christian Religious Practitioners
ACT	Association for Children with Terminal Conditions (UK)
BHF	The Board of Healthcare Funders in South Africa
CMT	Creative Movement Therapy
CPD	Continued Professional Development
CPSC	Council for Pastoral and Spiritual Counsellors
DMT	Dance Movement Therapy
EADMT	European Association of Dance Movement Therapy
EQ	Emotional Quotient
HPCA	Hospice Palliative Care Association of South Africa
HPCSA	Health Professions Council of South Africa
UFS	University of the Free State
UP	University of Pretoria
UNISA	University of South Africa
UWC	University of the Western Cape
ICPCN	International Children's Palliative Care Network
IQ	Intelligence Quotient
LCS	Living Conditions Survey
MODA	Multiple Overlapping Deprivation Analysis
MI	Michigan
NDOH	National Department of Health
NE	South African Nurse Educator's report
NHS	National Health Service

NIHR	National Institute for Health Research
NIV	New International Version
NWU	North-West University
NY	New York
PACE	Protective and compensatory experiences
PALPRAC	The Association of Palliative Care Practitioners of South Africa
PatchSA	Palliative Care for Children South Africa
RTHC	Road to Health Chart
SAAP	South Africa Association of Pastoral workers
SANC	South African Nursing Council
SAQA	South African Qualifications Authority
SU	Stellenbosch University
SQ	Spiritual Quotient
WASH	Water, Sanitation and Hygiene
WHO	World Health Organisation

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# CHAPTER 1

## INTRODUCTION

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This pastoral study focuses on faith communities' role in pastoral support of children with life-threatening and/or life-limiting conditions. Chapter 1 is the original research proposal that presents the introduction and a map for the rest of the study. Chapter 2 discusses the findings of the empirical study regarding what pastoral support is available to children with serious illnesses. The empirical study was conducted in January to February 2024. Chapter 3 unpacks scholarly articles to explain the findings of the empirical study. With the help of three pericopes in Matthew, Chapter 4 motivates pastoral care to sick children as part of God's heart. Using the ministering model, Chapter 5 portrays how pastoral care can be implemented by caregivers and faith communities to effectively support children with serious illnesses.

### 1.1 TITLE AND KEYWORDS

#### 1.1.1 Title

Faith communities' role in the pastoral support of children with life-threatening and/or life-limiting conditions: A pastoral study

### 1.2 CLARIFICATION OF TERMS AND CONCEPTS

#### 1.2.1 Faith communities

The Merriam-Webster dictionary (2024) defines community as "a group of people with common and especially professional interests scattered through a larger society". Therefore, faith communities can be understood as a network of like-minded individuals who share the same doctrines of religion or loyalty to God. In this study, faith communities refer to those who hold to the Christian doctrine.

Pastoral caregivers as discussed in this study are recognized as being members of faith communities and working with them to promote the well-being of the faith and outside communities.

#### 1.2.2 Pastoral support

Pastoral support falls under the umbrella term of practical theology (Louw, 2014a:47). Where pastoral theology addresses God's response of care and comfort in the face of death, suffering, illness and trauma, practical theology focuses more on interpreting the praxis of the church and how believers experience God within different contexts (Louw, 2014b:48). Pastoral care within practical theology ought to become more aware of the importance of healing the spirit. In other words, it should focus on

taking pastoral care in different contexts outside of the church, focusing on inner health and communal issues.

Magezi's (2019:11) recommendations for effective future pastoral care in an African context include giving a voice to marginalised groups, such as women and children, as well as shifting to public pastoral care. The word "pastoral" is derived from *pastorem*, meaning to mind the needs of the vulnerable (Magezi, 2019). Pastoral care also entails meeting people where they find themselves in their existential realities (Louw, 2014b:48). In South Africa, pastoral support in hospitals is often restricted to hospital hours (Oberholzer, 2017:121).

Holistic support is the belief that the parts of something are interconnected and can be explained only by reference to the whole (Merriam-Webster Inc, 2024). *Cura animarum*, according to Magezi (2019) describes the process of caring for human life because it was created by God. A holistic approach can be attained in some parts of South African healthcare where cultural practices and healthcare systems are combined with pastoral care strategies, for example, religion and prayer are encouraged by Christian care workers of HospiVision and some Netcare hospitals (Netcare, 2016). Ferngren (as quoted by Oberholzer, 2017:122) states that the purpose of medicine is to relieve suffering, while the purpose of religion is to explain suffering or to help us accept it.

Magezi (2012) believes that faith communities (religious institutions) can contribute to the holistic support of the healthcare system by providing hope, care and compassion in a time of confronting illness or death. Louw (2008:533) discusses death as an existential dilemma because the reality of death is unknown territory. Whenever we hear or read about death, it is always about someone else's experience. Louw (2008:534) concludes that most people are not spiritually, psychologically or emotionally prepared for the reality of death: he therefore believes that there should be a shift from a medical model where the focus is on the physical dimension to include all three dimensions of human beings (spirit, soul and body). Louw (2008:118–122 as cited in De La Porte, 2016) explains how a more holistic medical model affects patients practically because they are confronted with purposefulness and direction as the illness threatens the person's finiteness.

### **1.2.3 Paediatric palliative care**

The World Health Organisation (WHO; Benini *et al.*, 2022:532) defines palliative care as:

An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, through the prevention and relief of suffering utilising early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual.

Another WHO definition of palliative care for children (2023) is:

The active total care of the child's body, mind and spirit, and involves giving support to the

family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and even in children's homes.

Distinguishing between paediatric palliative care and illness in children is essential for this study. Illness can refer to simply having the flu, whereas children in paediatric palliative care are living with life-limiting and/or life-threatening diseases ranging from chronic diseases to cancer. Thus, paediatric palliative care refers to addressing the suffering and improving the care of children with life-limiting and/or life-threatening conditions (Moresco & Moore, 2021). This study will focus on faith communities' role in providing pastoral care to children with life-threatening and/or life-limiting conditions. According to Moresco and Moore (2021), palliative care includes symptom management, advance care planning, staff support, bereavement and end-of-life care.

The South African National Policy for Palliative Care (2017:15) uses the four categories of life-limiting conditions requiring paediatric palliative care given by the UK-based Association for Children with Terminal Conditions (ACT). The first ACT category consists of life-threatening conditions (leukaemia, malnutrition) where cure is a possibility, but where there is also a likelihood of failure. The second ACT category consists of children whose premature death is inevitable (cystic fibrosis), but where treatment is still available to ensure quality of life. The third ACT category comprises conditions for which there is no cure, such as inoperable congenital heart diseases. Unlike the third category, the final ACT category includes conditions which are non-progressive, such as Down syndrome and cerebral palsy.

### **1.3 BACKGROUND**

The primary reason for deciding on the theme, the role of faith communities in pastoral and spiritual support to children in paediatric palliative care, is twofold. Firstly, it was chosen due to practical, individual experience and secondly, to gain a better theoretical understanding of the topic.

The researcher has been part of her church's hospital ministry since 2019 and it is clear from her experience that Christian volunteers are welcomed and longed for, especially in South African state hospitals. During her ministry times, she often finds that nurses and patients are eager for prayer and someone to share their narratives with. The researcher does weekly outreaches to the Potchefstroom State Hospital with a team from various other churches.

To support her decision from a theoretical stance, the researcher agrees with De la Porte (2016) who emphasises the healthcare crisis in South Africa and explains that pastoral care can act as a national supporting resource for "healthcare, cost-effectiveness, spirituality, social change, reconciliation and multi-cultural application" in South African state hospitals. Research shows that only a few healthcare

givers are trained in spiritual care and support, even though they recognise its importance in promoting higher self-esteem, meaning and a sense of hope among patients (Robinson, 2018:73; Roger & Hatala, 2018:31).

Therefore, this study aims to investigate the role faith communities play in offering pastoral support to South African children with life-threatening and/or life-limiting conditions. Details about the empirical investigation are discussed later on.

The background of practical theological research is important as pastoral care falls under the umbrella of practical theology. As will be discussed in section 1.10, practical theology holds both praxis and theory in tension with one another. Thus, theory ought to guide practice, but practice also ought to encourage further investigation regarding practical theoretical research. This is recognised by Weyel (2022:222) who says that practical theology ought to hold relevance for its practitioners, while maintaining integrity with other academic fields. In terms of this study, the reality of children with life-threatening and/or life-limiting conditions needs to be understood, as well as the pastoral care available. Understanding the theoretical knowledge, as well as the reality of the support available and needed in South Africa, both practical theoretical knowledge and praxis can be further developed. This is unpacked using Osmer's tasks (2008:4), namely: the descriptive-empirical, the interpretative, normative and pragmatic tasks.

## **1.4 INTRODUCTION**

According to UNESCO's classification, children are considered as vulnerable. A Living Conditions Survey (LCS) of 2014/2015 done by Siebrits (as cited in Grobbelaar & Jones, 2020:210), highlights that 71.4% of South African children live in a household with five or more members, of which 35.9% households have two employed individuals, 33.7% have only one employed adult and 30.4% have no employed adults. Moreover, 87.6% of children do not have access to a medical aid, and 49.6% do not have access to a medical clinic within 2km of their home (Siebrits, 2020:212).

In South Africa, children in orphanages, broken homes and hospitals are considered even more vulnerable than children who grow up in households. Children are also often viewed as being innocent and lacking competence as they are not fully mature (Siebrits, 2020). Evidence of this problem of child vulnerability is a 2010 study done by Wall (as cited in Grobbelaar, 2020:15) who observes that 10 million children die annually of easily curable diseases or are used as human soldiers, trafficked, enjoy fewer rights than adults and are taught what mass media portrays as the truth. Similarly, Grobbelaar (2020:19) argues that South African children often suffer from abandonment issues and mistrust which stem from their families in which they are "not always welcome and welcomed" (Grobbelaar, 2020:19).

Another aspect is situational vulnerability, which is defined by Grobbelaar (2020:6) as a narrower view of vulnerability. This proposes that a certain situation may negatively impact a person's well-being, for

instance, children experience hospital admission as frightening. When a child has a life-threatening condition, this vulnerability can be further exacerbated by poverty, lack of cultural security, family instability and discrimination (Grobbelaar, 2020:15).

Furthermore, according to Meiring and Van Wyk (2013), South Africa has a shortage of nurses in the healthcare system. They emphasise that this is especially true in South Africa's rural areas. The South African Nurse Educator's (NE) report acknowledges that nursing schools lack the confidence to teach any form of pastoral care (Linda *et al.*, 2020). The report's authors attribute this to the lack of formal integration of pastoral support as part of holistic care in many South African nursing school curriculums. This affects not only educators' ability to teach students about spirituality, but also future nurses' ability to meet and address patients' spiritual needs (Linda *et al.*, 2020:1).

The Health Professions Council of South Africa (HPCSA) distinguishes between three primary palliative care organisations, namely the Association of Palliative Care Practitioners of South Africa (PALPRAC), Palliative Care for Children South Africa (PatchSA) and the Hospice Palliative Care Association of South Africa (HPCA). Each one of these three distinct palliative care organisations has their own unique purpose. Firstly, PALPRAC was established in 2018 and aims to provide quality care to all people with serious illness through its multi-disciplinary approach. Secondly, PatchSA has a narrower aim of advocating for the rights of every child and young adult in South Africa to receive quality palliative care treatment and train caregivers. Like PALPRAC, HPCA aims to provide excellent palliative care to people with cancer, as well as bereavement care.

## **1.5. PAEDIATRIC PALLIATIVE CARE**

The European regions' WHO estimates that 170,000 children in need in of palliative care die annually in Europe. Data indicates that palliative care is available in 20 countries, of which the majority is provided in high-income western European countries (WHO, 2023). A 2013 UN study reveals that between 20 and 21 million children require palliative care globally, of which 98% are situated in lower-income countries, such as those in sub-Saharan Africa (Sibomana *et al.*, 2019; Benini *et al.*, 2022). Regardless of this need, Sibomana *et al.* (2019:654) explain that only a shocking 1% of these children have access to palliative care. As a result, these children are confronted with life-threatening conditions, such as cancer, kidney and liver diseases, HIV and AIDS, neurological disorders, as well as neonatal conditions, all without receiving proper palliative care.

Oberholzer (2019a:1) highlights that early Christians made a point of caring for the sick. From 300 to 400 AD, after Christianity was legalised (313 AD), Christians established the first hospitals. Wyller (2022) points out that early hospitals in the Medieval Ages were often linked to religious institutions, such as monasteries. Later, with the move away from monastic hospitals after the Reformation, hospitals became part of "what later generations would label as secularisation, taken to mean

disconnecting from the ecclesial structure” (Wyller, 2022:317). In the 18<sup>th</sup> and 19<sup>th</sup> century, Protestant deacons came to the realisation that churches must operate missionally in alleviating the condition of the sick and poor (Wyller, 2022:318). Pleizier (2022:431) explains that pastoral prayer for the dying (palliative care) became more popular during the Reformation after the time of Calvin in Germany.

### **1.5.1 Pastoral care in general healthcare**

Mahilall and Swartz (2021:2918) comment that pastoral care combined with palliative care is a relatively new discipline in South Africa; it calls for healthcare workers to collaborate with pastoral counsellors and traditional healers to attend to the pastoral needs of patients in healthcare settings. HospiVision<sup>1</sup> and the Council for Pastoral and Spiritual Counsellors<sup>2</sup> (CPSC) are currently important contributors toward the goal of promoting pastoral care in South African healthcare (De la Porte, 2016; CPSC, 2023). The National Policy Framework and Strategy on Palliative Care (NDOH, 2017) notes that pastoral care in palliative-care settings is being provided by volunteers from NGOs or the community. Currently, HospiVision is presenting University of Pretoria- (UP) and CPSC-accredited courses to educate individuals to minister to sick and vulnerable children, as well as provide spiritual care to the sick. All volunteers of HospiVision are required to do a course, entitled *Spiritual care and counselling for the sick* (HospiVision, 2023). This ensures that everyone is equally equipped.

Du Plessis and Breed (2020) note that churches across the world often make the mistake of embracing crisis care instead of pastoral care. This means that pastoral care is limited to the pastor if there is a crisis in a faith community, instead of empowering the congregation to act as a body caring for itself and the broader community. This reflects the holistic ideal of “service is the task of every believer”, as seen in the National Policy Framework of Palliative Care (NDOH, 2017). Furthermore, the fact that pastoral care is limited points to the fact that pastoral care is often only available when an individual in a certain congregation experiences trauma. Therefore, general pastoral support is not readily available in the case of preventative care or within hospital settings.

### **1.5.2 Parental well-being**

The parents’ relationship with religion is important in how children’s relational consciousness with God is facilitated (Minor and Grant, 2014:214). Mayan *et al.* (2021:297) highlight that parents of hospitalised children are forced to assume the role of parent, patient and decision-maker. Furthermore,

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<sup>1</sup>HospiVision is a non-profit organisation whose vision is to touch the lives of sick people and give them hope through counselling, spiritual care and physical support. Their mission is also to facilitate the establishment of integrated support systems in service of the sick, where ownership is encouraged by community, family, church and individuals. HospiVision has a variety of training courses to equip individuals for pastoral and spiritual care.  
<sup>2</sup>The CPSC is the acronym for the Counsel for Pastoral and Spiritual Counsellors which oversees the ongoing professional development, registration and ethical conduct of pastoral counsellors. They function within the Association of Christian Religious Practitioners (ACRP). The South African Qualifications Authority (SAQA) recognises CPSC as a professional body for the professionalisation of Christian religious practitioners.

Mayan *et al.* (2021:297) explain that some of the negative effects of the demanding caretaker's role include negative emotions, such as stress, powerlessness and despair.

Parents' well-being is important since they are present at the time of their child's hospitalisation and are therefore affected emotionally; they are often expected to fulfil their child's social need for support (Oberholzer, 2016b:3). According to Beale *et al.* (2005), parents are often selective about which details they share with their child: "Their reluctance to be honest usually represents their own grief and struggle to accept their child's death" (Sahler *et al.*, 2000). Louw (2008:492) explains that dying children need their parents as their presence facilitates security. Moreover, children fear separation and abandonment more than death and therefore the parents' projections, which might instil fear in the child, need to be addressed through supporting the parents (Louw, 2008:492). Oberholzer (2016b:8) weighs the consequences of including the family in spiritual discussions. Beale *et al.* (2005) explain that paediatric oncology training programmes offer limited instruction as to how end-of-life communication should be conducted with the chronically ill child and their significant others. On the one hand, it can be positive as there can be honest discussions between the child and their parents. This might be good to eliminate the anxiety the child might pick up from their parents as Oberholzer (2016b:8) explains that children are sensitive to their parents' emotions. On the other hand, children might feel shy to discuss certain topics in front of their parents (Nash *et al.*, 2015:21–22).

### **1.5.3 Faith communities' role in palliative care**

Within the Christian worldview, faith communities refer to a group of people who share the same beliefs about the authority and doctrine of the Bible. Magezi (2008) explains that the church is a sub-system within communities to serve and support communities with their gifts and talents, including that of pastoral care and counselling.

Based on an international study, Selman *et al.* (2018:226; 2014:519) explain that most patients with life-limiting diseases experience spiritual distress and suffer unnecessarily due to hospital workers' limited knowledge about spiritual and palliative care. This limited knowledge is not always only applicable to medical staff; sometimes even pastoral caregivers can also be at fault by not knowing enough about palliative and end-of-life counselling. Some barriers identified to providing spiritual care include inadequate training, power inequality and framing illness as a punishment by God (Selman *et al.*, 2018:226).

Selman *et al.* (2018:221) refer to a patient they knew who experienced the stigma of someone from their church telling him that God gave him cancer because of his pride. This way of thinking can also be seen in biblical times when the disciples asked Jesus, "Rabbi, who sinned, this man or his parents, that he was born blind?" (John 9:2). People always try to find meaning or a reason for suffering. This emphasises the responsibility of pastoral caretakers and faith communities to frame sickness in an appropriate way.

Similarly, Robinson (2018:73) states that while the importance of care for the patients' spirit is often realised by healthcare givers, there are only a few who are trained to do so. Pastoral care for the spirit is a critical aspect of paediatric palliative care since it aims to decrease suffering by answering the patient's and family's existential questions that often arise during end-of-life care (Brelsford and Doheny, 2022:124). Ito *et al.* (2014) explain that children with an incurable paediatric condition, such as cancer, ought to receive a good death. A good death includes: "freedom from distressing symptoms; dying in a favourite place; good relationships with members and medical staff; a feeling that the dying person's life is complete; maintained dignity; preparation for death; and some form of contribution to others" (Ito *et al.*, 2014:349).

Roger and Hatala (2018:24) and Fitchett (2017:166) highlight the benefits of religion and spiritual support in health-promoting practices. Roger and Hatala (2018:31) find a positive correlation between increased spirituality and higher self-esteem, a sense of meaning and a sense of hope. Brelsford and Doheny (2022:120) explain that families can draw from positive religious coping mechanisms to attain a sense of hope and to assist in decision-making.

Sira *et al.* (2014:607) underline the importance of parents learning to cope with their child's illness in an effective manner since it holds a positive correlation with their child's state of mind and recovery rate. Faith communities have hope to offer, which Bronsema *et al.* (2022) show to be a critical unmet need of parents with a child in specialist paediatric palliative care. In fact, Grobbelaar (2020:24) argues that the church is called to be present with suffering children in South Africa – not only in our prayers and groanings, but also physically.

### **1.5.5 Challenges for pastoral support**

Addissie (2014:6) explains that one of the barriers to provide effective pastoral support in medical health institutions is politics and the "so-called ignorance of people". Firstly, the separation between state and church has impacted the relationship between civil and religious leaders (Addissie, 2014:6). Instead of working together, Winnial (as cited in Addissie, 2014:6) explains that doctors and theologians often work against each other: doctors within the confines of the physical and theologians within the confines of the spiritual. Winnial (2009) argues that religious leaders might experience confusion about how to practically facilitate their role of providing pastoral support outside the church building.

Secondly, the practitioners of modern medicine do not always acknowledge the belief systems of people. For example, Jehovah's witnesses do not believe that it is ethically right to accept blood transfusions. Therefore, in the case of blood loss, a medical practitioner might not know how to treat these patients without violating the Hippocratic oath or the beliefs of the patient. Oberholzer (2019a:1) advocates for the "restoration between the marriage of spirituality and healthcare". Public scientific healthcare and spiritual care each carry importance. Therefore, it is necessary that they should work together towards holistic support of individuals' well-being, spiritually, physically and psychologically.

This is important, especially in the context of palliative care for children.

Sibomana *et al.* (2019:670) state that the Kenyan Children's Act recognises every child's right to medical care and that the government and parents are held liable for providing such care. Similarly, the Children's Act (2006) in South Africa acknowledges giving holistic care (physical, spiritual and psychological) to children when they need it. However, Sibomana *et al.* (2019:671) explain that the South African Children's Act does not explicitly mention providing palliative care although it recognizes the right for necessary support services.

In fact, Sibomana *et al.* (2019:671) state that efforts to advance evidence-based research about interventions for palliative and hidden vulnerabilities in African children have so far been inadequate 'nationally and internationally' (Sibomana *et al.*, 2019: 671).

In the Spark Project<sup>3</sup>, Beresford (2022) identifies the shortcomings of the National Health Service (NHS) in the UK to provide spiritual care within palliative care services. The Spark Project is a research proposal funded by the National Institute for Health Research's Health and Delivery Service. It supports complete care to children and young people with life-threatening conditions. The focus is specifically on the pastoral, spiritual, religious needs and family support of such children. The Spark Project found that one barrier to providing spiritual care to children was health professionals' lack of awareness to identify spiritual needs and the contribution of chaplaincy services to end-of-life care (Beresford, 2022:10).

South Africa also lacks formalised spiritual care services. According to De La Porte (2016), there are limited statutory requirements or official systems in place for the certification of pastoral care in the healthcare context. Beresford's (2022) UK study seeks to understand the spiritual support needs of parents with children in palliative care. A similar study done in South Africa focusing on the pastoral needs of children from the perspective of pastoral caregivers could be insightful. Obstacles might also be identified during this study to formulate practical theological guidelines to support faith communities in their pastoral ministry to children needing palliative care.

Hospitalisation precipitates a security crisis for children and spiritual competence is often neglected by hospital staff (Louw, 2008:486). Louw (1994:150) criticises the misconception among pastors that sick children – in other words, children between the ages of three and 12 who are bedridden or in hospital – do not experience their illnesses as crises until they are teenagers. Besides experiencing illness as crisis, Oberholzer (2019b:1) explains that children can be disorientated regarding their own illness, pain and

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<sup>3</sup>The Spark Project is a study funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (NIHR128468). This study's research proposal was published in 2022 and will be conducted in the UK. The Spark Project focuses on supporting the complete care of children and young people with life-threatening or life-shortening conditions, as well as their families. It is a mixed-method study investigating pastoral, spiritual and religious needs, and support, as well as the role of chaplaincy services.

suffering (IPS).

Moreover, children might be more prone to believing the lie that their illness is a punishment for their sins (Oberholzer, 2019b:6). Oberholzer (2016a:1) asked children diagnosed with life-threatening illnesses to rank the importance of 19 resources for her research and found that children rated spiritual care fourth.

From this, it can be understood that children recognise the value of pastoral care during hospitalisation. However, pastors' inability to effectively communicate with sick children is often one of the primary reasons why their pastoral care is neglected (Louw, 1994:150). Moreover, Louw (2008:537) discusses that terminal patients have biological, physical, psychological, social and spiritual needs. The physical and biological needs have to do with the pain and discomfort experienced, whereas the psychological needs focus on the tension between attachment, separation and the helplessness of the child. There is also the social need for the nearness of loved ones since death is confronted individually. Louw (2008:538) posits that spiritual needs include the desire for human dignity, hope and meaningfulness. Doubt and despair are two of the primary emotions that contribute to a spiritual crisis.

Grobbelaar and Jones (2020:22) question the morality of the church in South Africa turning a blind eye to the suffering of vulnerable children. McCarthy (2005, as cited in Grobbelaar and Jones, 2020) suggests that we must be a "groaning church" for the suffering of children. To lament before God on behalf of children is part of what God's children are called to do (McCarthy, 2005). In Romans 8, the groaning of creation is described as creation waits its release from the sinful world which separates us from God.

The goal of pastoral care for the sick is to encourage the ill and hospitalised to rely on God's faithfulness, despite their suffering (Louw, 1994:72). This can be facilitated through intercession and discussions. "Likewise, the Spirit helps us in our weakness. For we do not know what to pray for as we ought, but the Spirit himself helps us with groanings too deep for words" (Rom 8:26).

What is already known in the field of ministering to sick children is that they experience a security crisis (Louw, 2008:486) and that these children have a need for spiritual support (Oberholzer, 2016a:2). It is also known that spiritual care towards children is a neglected area (Oberholzer, 2016a). One of the reasons for this neglect, according to Louw (2008:486), is that pastors lack the ability to communicate at a child's level. Oberholzer (2016a) addresses this lack of clarification of misconceptions children may hold regarding their illness and suffering.

### **1.5.6 Unique contribution of this study**

The unique contribution of this study is that firstly, it shows "what is going on" (Osmer, 2008) in the pastoral care of chronically ill children and why there is a need for faith communities and trained caregivers to be equipped to provide pastoral care to children with life-threatening and/or life-limiting

conditions. Secondly, the current practical support given by four pastoral caregivers will be discussed as part of this study. Its unique contribution is that it will highlight how theoretical pastoral care is applied practically by caregivers in supporting children with life-threatening and/or life-threatening conditions. It will show three types of practical approaches to support and how these can possibly be replicated in the future by pastoral caregivers and faith communities. The fact that pastoral caregivers in faith communities have theoretical and practical hope which surpasses what the material world can offer can be mobilised to support those who are confronted with death. Louw (2014a) identifies different functions of *cura animarum* (soul care), namely, healing, sustaining, guiding, reconciling, nurturing, liberating, empowering and interpreting. This study will aim to inform the what, why, ought to and how might we respond to Osmer's tasks (2008) and to apply these functions of *cura animarum* to each unique context of supporting a child with a life-threatening and/or life-limiting disease. The importance of biblical instruction regarding visiting the sick is part of the calling of Christians to provide comfort and hope through their message. Louw (2014a:102) highlights the role of biblical counselling in pastoral ministry.

Romans 5:3 states: "Not only that, but we rejoice in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not put us to shame, because God's love has been poured into our hearts through the Holy Spirit who has been given to us". The love and hope in and through Christ will be addressed as an important component of pastoral care since children have a need for safety and protection, according to Louw (2008:487). Oberholzer (2023), in discussing spiritual support for vulnerable children, underscores the importance of creating a familiar space for the child. This can be done through the love of familiar people, such as the pastor, pastoral caregiver and the child's family members.

## **1.6. PROBLEM STATEMENT**

Pastoral care given to children in palliative care needs to be re-evaluated as there is a lack of guidelines given to nursing students, pastoral caregivers and faith communities about how to support children spiritually in palliative care. Moreover, pastoral-care literature lacks practical case studies to examine regarding children in palliative care needing support. Faith communities have also not been directly involved in the support of children in palliative care. Oberholzer (2017) describes that visiting times often limit pastoral support. Furthermore, there may be a lack of knowledge in faith communities about the need to support families and children with life-threatening and/or life-limiting conditions.

## **1.7 RESEARCH QUESTIONS AND FURTHER QUESTIONS**

### **1.7.1 Research Question**

What pastoral strategy can be formulated to support faith communities in their pastoral ministry to

children with life-threatening and/or life-limiting conditions?

### **1.7.2 Further Questions arising from the research question**

- a) What can be learned from a descriptive-empirical research study about the current pastoral support given to children with life-threatening and/or life-limiting conditions?
- b) What can be learned from an interpretative study about the needs of children with life-threatening and/or life-limiting conditions and the support available to them?
- c) What can be learned from a normative (exegetical study) about faith communities' responsibility regarding providing pastoral support to children with life-threatening and/or life-limiting conditions?
- d) What pragmatic guidelines can be derived from caregivers who are providing spiritual care to children with life-threatening and/or life-limiting conditions to support faith communities in their pastoral ministry to children in palliative care?

## **1.8 RESEARCH AIM AND OBJECTIVES**

### **1.8.1 Aim**

This study aims to formulate a pastoral strategy to support faith communities in their pastoral ministry to children with life-threatening and/or life-limiting conditions.

### **1.8.2 Objectives**

To answer the aim and research question of this study, the following objectives are set:

- a) Descriptive-empirical task: To identify what the current pastoral needs of children with life-threatening and/or life-limiting conditions are (Chapter 2)
- b) Interpretative task: To describe why there is a need for the pastoral support to children with life-threatening and/or life-limiting conditions (Chapter 3)
- c) Normative task: To identify the norms prescribed by Scripture about faith communities' responsibility for providing pastoral support to children in palliative care (Chapter 4).
- d) Pragmatic task: To discuss pragmatic guidelines identified by caregivers who are providing pastoral support to children with life-threatening and/or life-limiting conditions (Chapter 5).

## **1.9. CENTRAL THEORETICAL ARGUMENT**

Faith communities can play an important role in the pastoral support of children with life-threatening and/or life-limiting conditions and can be equipped to fulfil this ministry with a contextual and biblical based pastoral strategy.

## **1.10 EPISTEMOLOGY OF THE STUDY**

A practical theological perspective is the guiding paradigm of this study. As mentioned under the clarification of definitions, pastoral care is a sub-division of practical theology. Dreyer (2012) includes both theory (academic knowledge) and practice as the ideal of practical theology. “In my view, both *episteme* and *phronesis* are important for practical theology” (Dreyer, 2012:50).

Practical theology (Swinton and Mowat, 2016) takes human experience seriously. Swinton and Mowat (2016:7) define practical theology as “critical, theological reflection on the practices of the church as they interact with the practices of the world, with a view to ensuring and enabling faithful participation in God’s redemptive practices in, to and for the world”.

According to Swinton (2022), theological knowledge is concerned about both theory and praxis. It “holds in tension the embodied nature of God’s love with the scholarly and prayerful task of understanding the revelation gifted to us” (Swinton, 2022:89).

There are three types of knowledge, namely, knowledge of the other, phenomena and reflexive knowledge. According to Swinton and Mowat (2016), all three types of knowledge are important for practical theology. All three may include observational, intellectual and experiential knowledge (Swinton, 2022:89). “Knowledge of the other” is when an individual explores another’s understanding of the world. This includes attaining intellectual knowledge by experiencing their understanding through observation and inquiries about and from them. Knowledge of the other includes the families and children with life-threatening and/or life-limiting conditions and how they view and interact with the world. Knowledge of phenomena, according to Swinton and Mowat (2016:33), investigates specific categories of an event.

Lastly, reflexivity as defined by Swinton and Mowat (2016) is concerned with how the researcher constructs the world and aims to say something new about the “shared or personal” world. This interacts with all three dynamics of theological knowing since the researcher uses introspection to observe how they understand, experience and observe the world around them. In terms of this study, reflexivity means it is important that the researcher is aware of how she perceives the world to prevent forcing her own preconceived understanding of the world onto participants’ constructions about a phenomenon.

Swinton and Mowat (2016:57) recognise that the researcher cannot objectively capture research from outside the research field; instead, the researcher ought to use personal reflexivity (reflecting on their own perceptions) and then integrate the knowledge discovered in a creative way.

This means the researcher discusses their knowledge from a place of self-awareness.

## **1.11 RESEARCH METHODOLOGY**

The research will be done through a literature and qualitative empirical study, according to the practical

theological interpretation model of Osmer. These four tasks will be utilised to organise the study, answering the research questions, aim and objectives (Osmer, 2008:4).

### **1.11.1 The descriptive-empirical task**

During the descriptive-empirical task, the researcher aims to identify what the current pastoral support to children in palliative care is. Osmer (2008:4) explains that the first task includes gathering information to help the researcher or individual comprehend “what is going on” and the function of this task can be described as priestly listening (Osmer, 2008:35).

As it is qualitative in nature, this study aims to capture the personal experiences of caregivers who are providing spiritual care to children with life-threatening and/or life-limiting conditions. The empirical study was done using semi-structured interviews and the participants were interviewed by the researcher in person at their place of work. The goal of the empirical study is to learn how the pastoral counsellors guide these children and the interviews started by inquiring about their guidance to these children and about what techniques and strategies they use.

Attending is a component highlighted on a continuum by Osmer (2008:37). Informal attending describes attending through active listening and attentiveness in daily conversations and encounters with people (Osmer, 2008:37). Semi-formal attending is when there is more structure to our attending. An example of this includes weekly staff meetings or pastoral meetings where people can reflect on events and people. Formal attending utilises empirical research to investigate contexts and situations. Through these attendings, spirituality of presence is an important focus as people are attended to and observed as representatives of God (Gen 1:27). It is to care about how others experience and see the world.

Swinton and Mowat (2016:28) explain that qualitative research assumes that individuals make sense of the world by interpreting it, instead of just discovering it, as quantitative research methodologies would assume. Swinton (2022) states that qualitative research is a subjective way of understanding the world and is often non-replicable. Swinton and Mowat (2016) compare qualitative research to a detective who gathers evidence about what happened and presents it to a judge. The aim is not to solve a problem, but merely to present as much evidence and stories as possible about the presenting case.

### **1.11.2 The interpretative task**

The researcher’s objective during the interpretative task is to describe why there is a need for the pastoral support of children with life-threatening and/or life-limiting conditions in palliative care contexts (Chapter 3). This task aims to learn from an interpretative study about the needs of children with life-threatening and/or life-limiting conditions and the support available to them. Wisdom guides this interpretative task, according to Osmer (2008:82), and lies on a continuum between thoughtfulness and theoretical interpretation. In the middle, wise judgement can be used to ascertain why a situation

has come about when both thoughtfulness and theoretical interpretation are considered. Thoughtfulness means to recognise when one has limited knowledge and use it as an opportunity to read and learn more. Theoretical interpretation refers to drawing on theories and science to understand why situations are a certain way and asks, “Why is it going on?” (Osmer, 2008:83). This task is useful to get a comprehensive understanding of a situation or a phenomenon since it aims to draw explanations from different sources to get an accurate, holistic understanding about a situation before moving on to the normative task.

Information on why the pastoral needs of children with life-threatening and/or life-limiting conditions and available support are limited will be gathered with the assistance of journals, books and articles through the NWU library, Google Scholar, ICPCN and HospiVision. The NWU library is comprised of around 317 databases – 21 of these databases fall under theology, nine fall under health sciences and 12 under humanities. The information contained in these three faculties is primarily of importance since this study is concerned about the pastoral care of children (theology) with life-threatening and/or life-limiting conditions (health sciences and humanities). ICPCN is defined as the International Children’s Palliative Care Network. This organisation aims to improve the access to research literature of more than 21 million children internationally.

### **1.11.3 The normative task**

The normative task aims to identify the norms prescribed by Scripture about faith communities’ responsibility to provide pastoral support to children with life-threatening and/or life-limiting conditions (Chapter 4). The third task by Osmer (2008) uses theological concepts to understand “what ought to be going on”. The normative task therefore looks at “good practice” to interpret situations or contexts in line with what the Word of God and what ethical norms prescribe.

Firstly, Osmer (2008:152) writes that normative guidance can be given by looking at a past or present model to reform faith communities’ present actions. Secondly, the normative task can be guided by revelation from God, the Christian life and social values beyond the current tradition. Prophetic discernment is the guiding principle of the normative task (Osmer, 2008:132).

The focus shifts to using Scripture as the measuring stick for what the norms should be regarding faith communities’ concern for the sick. This is appropriate since this study focuses on how faith communities can support children with life-threatening and/or life-limiting conditions. But before knowing how faith communities can do this, what Scripture expects from believers is important to understand. Below are two important biblical passages which discuss caring for the sick. Firstly, in Matthew 25:36, Jesus says to the righteous: “I was naked, and you clothed me, I was sick, and you visited me, I was in prison, and you came to me.”

The context of Matthew 25:31–46 is the end of time when the Son of God will separate people like a

shepherd separates sheep from goats. The righteous will ask God when they clothed or visited Him and He will reply (verse 40): “Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.” An exegetical study will therefore be conducted on Matthew 25:31–46 in Chapter 4 to identify how faith communities can take responsibility for pastoral care given to children with life-threatening and/or life-limiting conditions. Matthew 25:31 was chosen specifically because it shows the importance God places on loving others as a representative of Jesus. It can be said that Matthew 25:31 is an outward expression of the first and second commandment: to love God and to love people (Matthew 22:36–40).

Secondly, in Matthew 10:7–8 we can see that Jesus commands his disciples to go in search of “the lost sheep of Israel”. On finding them, they should proclaim, “The Kingdom of heaven has come near. Heal the sick, raise the dead, drive out demons. Freely you have received, freely give.” From this passage, we can see that Jesus commands his disciples to practise what He has modelled. He came to preach the good news firstly. Secondly, He healed the sick, drove out demons and raised the dead. Jesus modelled conveying the truth to His disciples, as well as the power of the Holy Spirit.

Both pericopes, Matthew 25:31 and Matthew 10:8 show how Jesus expects believers to serve one another. This power through the Holy Spirit also brings comfort. Exegesis will be done according to Klerk and Janse van Rensburg’s exegetical model as discussed in their book, *Conceiving a Sermon* (2015).

#### **1.11.4 The pragmatic task**

During the pragmatic task, the researcher will discuss pragmatic guidelines to support faith communities in their pastoral ministry to children with life-threatening and/or life-limiting conditions (Chapter 5). The last task by Osmer (2008) demands, “How might we respond?”. It aims to guide the researcher and faith communities towards an appropriate response which will positively influence contexts in which there may be room for improvement.

Besides the three types of leadership discussed by Osmer, namely task competence, transactional leadership and transforming leadership, servant leadership is the main determinant of effective, long-term change (Osmer, 2008:183).

Servant leadership can be seen through the example of Jesus as the suffering servant who “establishes God’s reign in healing the sick, welcoming social outcasts and calling for justice” (Osmer, 2008:186). This is of consequence to this study, since faith communities are called to follow the model of Jesus’ servant leadership. As a result, initiative should be taken to step out, serving the sick, outcasts and those experiencing injustice. Like Jesus, faith communities are called to serve in spaces like hospitals where there is a clear absence of pastoral support. Osmer (2008) posits that suffering should not be just for the

sake of suffering, but as a consequence of following one's calling as a kingdom-minded individual.

The pragmatic task aims to use the findings from the empirical study, as well as the previous tasks (Chapters 2, 3 and 4) to present a pastoral strategy to support faith communities in their pastoral ministry to children with life-threatening and/or life-limiting conditions.

## **1.12 ETHICAL CONSIDERATIONS**

The researcher has embarked on an empirical investigation and interviewed four caregivers who provide pastoral support to children with life-threatening and/or life-limiting conditions. When conducting empirical research, the following ethical considerations have been taken into consideration.

### **1.12.1 Population**

The researcher's supervisors contacted four caregivers providing pastoral care and support to children with life-threatening and/or life-limiting conditions. This population gave insight into the general pastoral support given to children in palliative care.

### **1.12.2 Population size**

The researcher worked with four participants using semi-structured interviews. The researcher is aware that it was a rather small sample size, but there is a limited number of caregivers providing spiritual care and support to children with life-threatening and/or life-limiting conditions. Dr Annemarie Oberholzer is currently the CEO of HospiVision and testified of the shortage of pastoral caregivers who work with children with life-threatening and/or life-limiting conditions in South Africa. The researcher and her two study leaders were nevertheless convinced that a small empirical research study was necessary to yield important insights into pastoral counselling, rather than only a literature review.

### **1.12.3 Sampling**

Purposive sampling was used to find appropriate participants which match the aim and objectives of this qualitative study. "This method of sampling is used in special situations where the sampling is done with a specific purpose in mind" (Maree and Pieterse, 2020:220). In this study, caregivers who have experience providing pastoral support to children with life-threatening and/or life-limiting conditions were included in the purposive sample. This was appropriate since this study aims to formulate practical theological guidelines to support faith communities in their pastoral ministry of children in the context of South African palliative care institutions.

#### *1.12.3.1 Inclusion criteria*

Only active caregivers providing spiritual care and support to children with life-threatening and/or life-limiting conditions were asked to participate in the study. Permission was given by Dr Oberholzer to interview caregivers she knows working in palliative care settings, such as CANSA and Hospice.

#### *1.12.3.2 Exclusion criteria*

No children or family members (significant others) of children with life-threatening and/or life-limiting conditions were directly included in the study due to the associated ethical risks. No hospital staff, such as doctors and nurses, were included in the participant list since their focus is predominantly on the physical health of patients in hospitals.

#### **1.12.4 Participant recruitment**

The researcher contacted Dr Oberholzer to gain permission to interview caregivers providing spiritual care and support to children with life-threatening and/or life-limiting conditions. The researcher emailed all the relevant information about the study to Dr Oberholzer. Therefore, Dr Oberholzer can be considered the gatekeeper who identified and contacted possible participants and obtained their consent to be part of the study. After ethical clearance and participants' consent was received, Dr Oberholzer made their details available to the researcher to continue with the empirical study.

#### **1.12.5 Probable experiences of the participants**

Every participant gave an hour to an hour-and-a-half of their time for the semi-structured interviews. The interviews were arranged ahead of time based on the participants' availability. Thereafter, no individual follow-up interviews were required. The researcher recorded the interviews. The recordings were destroyed after she transcribed the interviews. No one, apart from the researcher and supervisors, had access to the recordings as they were stored on the researcher's computer which is password protected.

#### **1.12.6 Estimated risk level**

There was a minimal estimated risk level for this study since the researcher did not interview significant others or children with life-threatening or life-limiting conditions. The participants were not exposed to more risk than what they usually experience in their daily work.

#### **1.12.7 Risks and precautions**

Possible risks associated with this study included:

- That the caretakers interviewed might not have the same training as one another or be registered with the same professional board. This could be a barrier towards getting a strong coherent theme to emerge from this study, since the sample size was small.
- There was a risk that the participants' trust and confidentiality could be broken by the researcher while sharing their experiences during the semi-structured interview questions.

The researcher took the following precautions during the empirical study:

- The researcher included only the caregivers identified by Dr Oberholzer and inquired about what relevant experience they have.

- The names of the participants have been kept anonymous. Trust and accountability between the participant and researcher are important. This anonymity also was likely to enhance the honesty of participants.

#### **1.12.8 Risk-to-benefit ratio analysis**

There was a minimal risk to participating in the study. The participants were asked about their personal experience in working with children with life-threatening and/or life-limiting conditions and about the models and resources they use in their pastoral work.

#### **1.12.9 Expertise, skills and legal competencies**

The researcher is registered as a level-5 pastoral counsellor under the CPSC scopes of practice with an honour's degree in psychology. Legally, the student is also aware of the POPI Act, as well as the participants' right to privacy and confidentiality.

#### **1.12.10 Facilities**

There were two physical facilities where the empirical research took place. The researcher collected data in person and communicated using a semi-structured question list. The participants needed to commute to their location of work (or previous work in the case of one participant) as these two locations were where the interviews were held.

#### **1.12.11 Legal authorisation**

This study firstly required the permission of the North-West University's Faculty of Theology research ethics committee before the empirical study was continued. Moreover, the confidentiality agreement in therapeutic relationships meant that the participants were volunteers and were not asked about any patient names or information that is confidential. Dr Oberholzer acted as gatekeeper and was responsible for recruiting participants for the study.

#### **1.12.12 Informed consent**

Dr Oberholzer sent an informed consent letter to each participant, detailing the nature of the study. The participant was able to freely choose whether they wanted to participate based on the information. The participants were also free to withdraw from the study at any time. If they had already been interviewed and then chose to withdraw, their information would also have been excluded from the study. However, there were no participants who withdrew.

#### **1.12.13 Distribution of study results to participants**

After the dissertation has passed through the acceptance process, Dr Oberholzer and every participant will receive an electronic copy of the dissertation.

#### **1.12.14 Privacy and confidentiality**

To uphold the confidentiality and privacy of all participants, their names are expressed numerically (P 1,2,3,4) in the thematic analysis. The data collected was solely available to the researcher and her supervisors. The participant information was also kept on a password-protected laptop.

#### **1.12.15 Role of the researcher**

Mowat (2022) states that the researcher's role can be compared to the role of a quiltmaker who places pieces together to make a whole. Important skills required of a researcher include being interested in others' stories, having good listening and observational skills, being flexible in the data-collection process and not being stuck in preconceived ideas during the research process (Mowat, 2022:386). It is also the responsibility of the researcher to have a broader understanding of the research in question and to ensure the research is relevant.

### **1.13 CLASSIFICATION OF CHAPTERS**

Chapter 1: Introduction

Chapter 2: Findings of the descriptive-empirical research

Chapter 3: Needs and support of children with life-threatening and/or life-limiting conditions

Chapter 4: Normative aspects regarding pastoral care to children with life-threatening and/or life-limiting conditions

Chapter 5: Pragmatic guidelines to support faith communities in their care for children with life-threatening and/or life-limiting conditions

Chapter 6: Findings and recommendations

### **1.14 SCHEMATIC DIAGRAM**

<b>Faith communities' role in the pastoral support of children with life-threatening and/or life-limiting conditions: A pastoral study</b>
Research question: What pastoral strategy can be formulated to support faith communities in their pastoral ministry given to children living with life-threatening and/or life-limiting conditions?
This study aims to formulate a pastoral strategy to support faith communities in their pastoral ministry to children living with life-threatening and/or life-limiting conditions.

<p>What can be learned from a descriptive-empirical research study about the current pastoral support given to children living with life-threatening and/or life-limiting conditions?</p>	<p>To describe the current pastoral and spiritual support given to children with life-threatening and/or life-limiting conditions.</p>	<p>Chapter 2: Findings of the empirical study about current pastoral and spiritual support given to children living with life-threatening and/or life-limiting conditions.</p>
<p>What can be learned from an interpretative study about the needs of children living with life-threatening and/or life-limiting conditions and the support available to them?</p>	<p>To identify what the current pastoral needs of children living with life-threatening and/or life-limiting conditions are.</p>	<p>Chapter 3: Literature overview of a pastoral strategy to support faith communities in their pastoral ministry to children living with life-threatening and/or life-limiting conditions.</p>
<p>What can be learned from a normative study (exegetical study) about faith communities' responsibility to provide pastoral support to children living with life-threatening and/or life-limiting conditions?</p>	<p>To identify the norms prescribed by Scripture about faith communities' responsibility for providing pastoral support to children living with life-threatening and/or life-limiting conditions.</p>	<p>Chapter 4: Normative focus on the role of faith communities in their pastoral ministry to children living with life-threatening and/or life-limiting conditions.</p>
<p>What pragmatic guidelines can be derived to support faith communities in their pastoral ministry given to children living with life-threatening and/or life-limiting conditions?</p>	<p>To provide guidelines to support faith communities in their pastoral ministry to children living with life-threatening and/or life-limiting conditions.</p>	<p>Chapter 5: Pastoral strategy to support faith communities in their pastoral ministry to children living with life-threatening and/or life-limiting conditions.</p> <p>Chapter 6: Findings and recommendations .</p>

## **CHAPTER 2**

### **FINDINGS OF THE EMPIRICAL STUDY**

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#### **2.1 INTRODUCTION**

The empirical study was done with four pastoral caregivers who were interviewed to help the researcher understand “what is going on” in the lives of children with life-threatening and/or life-limiting conditions (Osmer, 2008:33). Life-threatening conditions refer to those in which a curative treatment is the focus. Life-limiting conditions, on the other hand, refer to conditions which cannot be cured and where treatment is focused on prolonging the child’s life. These may include conditions like cystic fibrosis and Duchenne muscular dystrophy where there is a greater likelihood of death during childhood. The participants in this study (P2, P3 and P4) had more experience working with children with life-threatening conditions like cancer, and thus feedback on supporting life-limiting conditions was limited.

Interview appointments were made with the guidance of Prof Du Plessis and Dr Oberholzer (the researcher’s supervisors) who acted as gatekeepers and gained informed consent from the participants. After setting a suitable date and time, the researcher travelled to conduct in-person interviews with the identified pastoral caregivers. These caregivers have vast experience in the field of supporting children who are dealing with loss, trauma and are facing life-threatening and/or life-limiting conditions, such as cancer. The aim was to gather information regarding their experiences and pastoral strategies. Based on the findings of this small empirical study, Chapter 2 aims to describe the current pastoral and spiritual support available to children with life-threatening and/or life-limiting conditions. These findings are relevant to this study’s eventual overall aim to formulate a pastoral strategy to support faith communities in their pastoral ministry to these children.

#### **2.2 METHODOLOGY**

The primary goal of the descriptive-empirical task in pastoral counselling is to discover “what is going on” in the relevant situation (Osmer, 2008:33). A qualitative research approach was used with the aim of understanding the actions and practices of pastoral caregivers working with children with life-threatening and/or life-limiting conditions. The meaning these caregivers attach to their caregiving experiences was also investigated (Osmer, 2008:50). Apart from the importance of gathering information, pastoral counsellors should pay close attention to people and events in their everyday life. Osmer (2008:33) calls this attention a spirituality of presence.

### **2.2.1 Spirituality of presence**

A spirituality of presence allows pastoral counsellors to attend to the situations and concerns of those around them, to become aware of what is happening in the lives of individuals, families and communities. Osmer (2008:34) emphasises openness, attentiveness and prayerfulness in working with others. By implication, a caregiver should not rush to judgement, listen half-heartedly or ignore suffering even when they are surrounded by it. This includes engaging with people at their level of understanding, regardless of whether they may seem different. As far as this study is concerned, a spirituality of presence means being present with a child with a life-threatening and/or life-limiting condition, to be approachable and bear Jesus' compassionate presence towards the child's family, to notice the pain of the parents, siblings and other extended family members and to intercede for the child and family like Jesus intercedes on behalf of all believers (Heb 7:25). Osmer (2008) warns those who do not practice this spirituality of presence not to be like the religious leaders of Jesus' time who were too busy with what they deemed important to notice the traveller in distress in the narrative of the Good Samaritan (Luke 10:29–37).

### **2.2.2 Priestly listening**

Intercessory prayer overflows from priestly listening; it involves a leader praying on behalf of others. This, Osmer (2008:35) notes, can only happen when a leader or pastoral counsellor is able to identify with others' needs. The pastoral counsellor's role should be to pray for the sick child, as well as the family's needs and concerns. Osmer (2008) uses Keck's twofold movement of intercessory prayer as a guideline for pastoral caregivers based on Jesus' model of the priestly office. First, they ought to present themselves and make contact by listening and empathetically using their imagination to try to understand the other person's situation. Next, they take their situation before God the Father. This can be seen in Jesus' life on earth in which he entered humanity's suffering and afterwards made an offering to God on humanity's behalf (Osmer, 2008:35).

Apart from leaders being called to model priestly listening, Osmer (2008:35) points out that the entire community ought to act as a holy priesthood. Hebrews 4:15 reminds people that Jesus is a high priest who is not unable to sympathise with humanity's weaknesses and temptations. Moreover, Scripture provides examples of how mothers and fathers react to their children being ill. For example, Naomi wanted to be called Mara because she felt bitter that her sons and husband had died (Ruth 1:20). Job's wife told him to curse God and die after their children were killed (Job 2:9). But instead of cursing God, Job (Job 1:20-22) reacted by tearing his robe, worshipping God and saying: "The Lord gave, and the Lord has taken away. Blessed be the name of the LORD." In all this, Job did not sin or accuse God of any wrongdoing. These examples underscore the importance of discerning what the counsellee is experiencing by exercising priestly listening.

Informal, semi-formal and formal attending are ways pastoral caregivers can carry the presence of Jesus and portray priestly listening to children and families of children with life-threatening and/or life-limiting conditions.

### **2.2.3 Ethical principles**

- *Non-maleficence and respect*

The principle of doing “no harm” was used to guide this empirical study. Non-maleficence was honoured by keeping the participants anonymous and getting their informed consent before the interviews were conducted. The researcher used eye contact, active listening and empathetic presence aimed at conveying respect towards the interviewees. The participants’ permission was asked before recording the interview sessions.

- *Honesty and transparency*

The researcher was honest in the process of this study. She was transparent towards the interviewees regarding the questions she asked and used the transcripts in the thematic analysis process. The researcher was honest about recording the interview session.

- *Informed Consent*

The participants were informed regarding the study’s purpose before consenting to the interview. The researcher also allowed the participants to inquire about the study if they had any questions.

- *Voluntary participation*

The participants were free to withdraw from the study at any time. No participants were forced to participate in the study.

## **2.3 BACKGROUND OF EMPIRICAL STUDY**

Osmer (2008:58) highlights the importance of accurately using the skills of describing, observing and interviewing in qualitative research. In empirical studies, the researcher is responsible for using the following three skills, namely describing, observing and interviewing (Osmer, 2008:58).

### **2.3.1 Describing**

Pastoral caregivers are often invited to speak to others about the situation and needs of children with life-threatening and life-limiting conditions. These people may include church congregants who want to support the sick child and their family or family members who may have spiritual questions or desire information regarding the medical procedure. During the interviews, the pastoral caregivers described their experiences working with children with life-threatening and/or life-limiting conditions to the researcher who is considered an “outsider”, according to Osmer (2008:59).

### **2.3.2 Observing**

Osmer (2008:60) highlights the importance of participating in the field which is being studied. Since the researcher interviewed participants who are actively involved in pastoral care with children with life-threatening and/or life-limiting conditions, the study provides insightful descriptions of their observations in the field. From their responses, the participants also became observers of their own behaviour when the researcher inquired about pastoral techniques they used and how children responded.

### **2.3.3 Interviewing**

An interview is described as a conversation between two individuals in which one is seeking information from the other regarding a topic or situation (Osmer, 2008:61). During an interview, the person seeking information asks questions to which the participant responds (Osmer, 2008:54).

In this study, the researcher interviewed pastoral caregivers working with children with life-threatening and/or life-limiting conditions in order to ascertain what pastoral support is available to these children. Researchers focus on active listening instead of talking, according to Osmer (2008:62). The researcher made use of probing in the forms of clarification, relevance and examples. Clarification is a technique in which the researcher asks the participant to elaborate, so that the researcher can better understand their answer. Relevance is highlighted when the researcher inquires about the relevance of the participants' statement with regards to the question asked. The participants were also asked to give examples of their experiences (Osmer, 2008:63).

### **2.3.4 Profile of participants**

The participants interviewed will be referred to as P1, P2 etc. to protect their true identities. Also, no names of children were discussed during the in-person interviews. Instead, cases of anonymous children were discussed between the participants and researcher. All four participants interviewed are female pastoral caregivers. P2 works as a pastoral counsellor at a non-profit organisation, moving between different hospitals in her area. P3 is a counsellor with around 15 years' experience who previously worked at a non-profit organisation. She currently works as a pastor and school counsellor. P1 is a pastoral play practitioner who works at a primary school in the mornings and at her own practice in the afternoons. P4 works as a paediatric oncology palliative counsellor and manager at a non-profit organisation. The researcher conducted in-person interviews in the Gauteng and North-West Provinces of South Africa.

### **2.3.5 Data collection methods**

The interviews were semi-structured in format and the same questions were asked to all four participants. The participants signed informed consent documents prior to the interviews.

List of questions:

- a) Can you please share some of the most effective pastoral techniques or strategies that you use working with children with life-threatening and/or life-limiting conditions?
- b) Do you follow the same strategy with all the children? Please elaborate.
- c) How do these children respond to your counselling?
- d) What advice would you give faith communities to effectively support children with life-threatening and/or life-limiting conditions?
- e) Do you work with the parents or other family members as well, maybe friends of the children?
- f) What do you think is the biggest need for this type of counselling?
- g) Is there other current pastoral support available to children with life-limiting conditions and/or life-threatening conditions that you are aware of?
- h) How do you care for yourself while working with these heartbreaking circumstances?

Besides recording the interviews, the researcher made use of active listening, clarification questions and asking spontaneous questions relevant to the answers and context of the participant being interviewed.

The data responses will be discussed in the form of themes after the data analysis is described under point 2.4.

## **2.4 DISCUSSION OF DATA**

In the process of analysing the data, the researcher first transcribed the participants' responses in English from the voice recordings. Then the researcher printed, highlighted and wrote the participants' responses. After arranging the participants' responses, certain themes started to emerge. The thematic analysis revealed two parts. Part 1 discusses pastoral techniques and strategies, whereas Part 2 consists of the participants' advice. Under Part 1, the importance of using expressive pastoral techniques (1.1) through play and drawing, empowering the child (1.2) through Scripture, choice and validation, introducing preventative support (1.3), as well as how pastoral caregivers use attending (1.4) were formed from the participants' responses. Under Part 2, the themes of relationship building (2.1), continued professional development (CPD) (2.2), contextual awareness (2.3) and self-care of the caregiver (2.4) came to the fore.

The researcher recognises that it is unusual to include academic publications in the discussion of the empirical study (Chapter 2). However, since the empirical study only included four participants, scholarly articles are integrated to enhance the understanding of knowledge in the field of pastoral support given to children with life-threatening and/or life-limiting conditions. The empirical study is useful because of the dearth of pastoral caregivers in this particular field.

Next, pastoral techniques used by the participants will be explored, as well as the rest of Part 1's themes. These include empowering, validating and supporting children with life-threatening diseases, using direct, indirect and avoidance approaches to implement preventative support and attending to the children, families and pastoral caregivers at informal, semi-formal and formal levels.

## **2.5 PART 1: PASTORAL TECHNIQUES AND STRATEGIES**

In the semi-structured interviews, the participants' pastoral strategies and experiences were discussed. From these, Theme 1.1: expressive pastoral techniques, Theme 1.2: empowering the child, Theme 1.3: preventative support and Theme 1.4: ways of attending, were recognised as important themes.

## **2.6 THEME 1.1: EXPRESSIVE PASTORAL TECHNIQUES**

The sub-themes drawn from Theme 1 include drawing, playing and ways P1 uses desensitisation to address traumatic experiences children may have had.



### **2.6.1 Drawing**

P1 uses Mark 4, the pericope about Jesus calming the storm, when she must counsel children who experience difficult circumstances. This technique is called the "storm technique" as it deals with linking the physical storm the disciples experienced to the storm of illness the child is facing. She starts her guidance with reading Mark 4, after which she explains the pericope at the child's level by dramatising her voice, gestures and facial expressions. For instance, she will talk about how big the boat was and about the Sea of Galilee. She will ask about storms in nature and the child's understanding of them (e.g., floods and hurricanes). After a while, P1 links physical storms to the challenge the child is experiencing and asks the child to share his/her "heart storm". The child can draw his/her storm in any way they like. The only prerequisite is that they should include themselves in the drawing. Afterwards, she asks the child to turn his/her page around and choose colours for basic emotions, like scared, sad, happy and angry, for instance, red for angry, blue for scared, black for sad, etc. The child must then draw a heart shape and colour it in with different colours according to what emotions he/she is experiencing at the time. The goal of this technique is that the child recognises the emotions he/she is feeling. Louw (2008:48) asserts that children may be prone to experiencing anguish in the face of chronic illness, as well as a loss of security. Moreover, these feelings can be magnified during treatment.




P1 uses various Scripture references in her guidance to children. The goal of this is to help children to know and trust God at a young age. Her motto is that the Bible is full of stories and children love stories. These stories can thus be a vehicle to trusting God. However, their stage of development also needs to be taken into consideration in understanding how children perceive God at different ages.

According to Fowler (1987:113), children aged six to 12 are in the mythic-literal faith development stage. During this stage, they perceive God to be reliable, caring and have a deeper understanding of cause and effect, as well as a strong sense of justice. This includes believing that good behaviour is rewarded and that bad deeds are punished. This may lead them to believe their illness is a punishment for something they did wrong.

A spiritual crisis might be triggered when they realise that bad things can happen to good people. In using the colour technique, P1 asks the child to choose a colour they think represents Jesus Christ and to draw Jesus where they think He is in the storm. It is important to note that P1 helps children deal with trauma in all its manifestations, such as being involved in a car accident or a parent committing suicide, as well as life-threatening illness. Image 8 (below) is an example of a boy's drawing of his storm. He drew where his dad hanged himself in front of him and his mum. P1 explored the boy's emotions on the other side of the page and was then asked to draw Jesus in his storm. He drew Jesus catching his dad when his dad kicked the bin from under himself. He also drew some yellow (Jesus) in his own heart.

Image 8 (Boy's drawing of his storm)	Image 10 (Jesus in my heart)
	

Below are more images of drawings by children during sessions with P1. Image 6–8 reveals how children can perceive and portray their storms and emotions differently.

Image 6: Storm technique drawing	Image 7: Another storm drawing	Image 9: Storm technique drawing when a child was involved in motor accident
		

Wass (1991:11) points out that adults often struggle to help children face death and their own mortality because they are apt to forget what their own childhood was like. Adults may think children are indifferent and unfeeling towards death (Wass, 1991:11). Alternatively, adults may fear talking about death to children, assuming that they are too fragile to cope (Wass 1991:12). In truth, children are resilient and determined to move from fear or trauma to healing.

From the above pictures, children clearly encounter and are aware of life's storms which can be processed using Christian terminology, expressive pastoral techniques and godly play. During hospital visits, P1 uses art techniques like sand-box therapy and drawing to help children face their storms and losses, so they can move on from fear towards healing and resilience.

## **2.6.2 Play techniques**

P4 makes use of drawing, wordplay and imaginary play to help children and their families process and prepare for the possible passing of their ill child. P4 encourages addressing possible separation anxiety the child may have and believes one does not need to explain death in elaborate detail to a child with words like one would with an adult. P4's primary tool in explaining concepts is the child's own imagination. The adventure technique and other imagination techniques aim to encourage the child to encounter and talk to Jesus. P4's techniques act as death-preparation techniques and help to include and create closure for the rest of the family members.

### *2.6.2.1 Pastoral play*

During hospital visits to children, P1 uses sand-box therapy to help children who experiencing trauma. She then acts out Psalm 23 with them. For example, the child is the shepherd who must protect the sheep from the wolf (played by P1). P1 then explains the deeper meaning of the metaphor behind the play technique. She also uses the metaphor of Psalm 91, linked with the play technique, for children who experience fear and anxiety during or after hospitalisation. Psalm 91 is about God being the child's shelter against fear.

Berryman (2013b:4) explains that learning the Christian language is often complex and contains four different genres, namely, sacred stories, parables, liturgical actions and contemplative silence. Godly Play<sup>4</sup> is a tool which assists children to learn the Christian language earlier, thus becoming artists in the Christian life. This creative way of learning the language also provides deeper meaning-making.

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<sup>4</sup> Godly Play was created by theologian Jerome Berryman and his wife (Berryman, 2013). It aims to teach children Christian language in their process of ongoing spiritual formation. Godly Play uses faith stories to connect children's innate sense of God's presence with their personal experiences through using wondering questions and silences (Godly Play UK, 2024).

Although differently presented, both the Montessorian<sup>5</sup> and Godly Play methods of presenting Christian education include the parables of the Good Shepherd, the mustard seed, the leaven and the great pearl to children aged three to six years (Berryman, 2013b:80).

Thus, from these two techniques, pastoral caregivers can be equipped to present the salvation history to children in a similar way to the Montessorian method. This method also guides children through narratives to seek the “elusive presence” of God as is common with Godly Play (Berryman, 2013b:81). Although not explicitly mentioned by P1, the foundation of systematic desensitisation can be seen in P1’s pastoral techniques to address traumatic experiences faced by children.

#### *2.6.2.2 Addressing trauma through systematic desensitisation*

Before explaining how P1 uses principles of systematic desensitisation in pastoral care, a brief description of what systematic desensitisation is may be necessary. Systematic desensitisation uses exposure to the feared stimulus, while educating the individual how to relax, despite the feared stimulus. P1 similarly helps children to overcome their trauma, fear stimulus and automatic arousal response by re-exposing them to the sensory components they initially experienced during the traumatic event.

However, this time the child is exposed to the same stimulus within a controlled environment. The end goal of this exposure is that they can reframe their negative experiences. P1 first makes children aware of their emotions using a tool like the heart-drawing technique. In addition, the child is encouraged and often plays out their traumatic experience in a sand box with as many sensory components (colours, characters, sound, etc.) as possible. Firstly, the child discusses what happened to the characters in the sand box and how the characters feel. Secondly, the counsellor asks the child what they think happened during their own trauma event by linking it to the scene in the sandbox, so that the child can connect the dots between their own trauma event and the scene. Lastly, when the child is able to link the dots and to help the characters in the sandbox to cope with their situation, the child is more readily able to positively reframe their own experience.






The importance of P1’s desensitising techniques is that the children’s emotions and thoughts are addressed in the process of addressing the trauma. To address these also communicates to the child that the caregiver cares about their thoughts and feelings. This in turn also subtly communicates to the child that Jesus cares about their emotions, since the caregiver is there to act as representative of Jesus.

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<sup>5</sup> The Montessorian model is a child-centred educational model developed by Maria Montessori in the 20<sup>th</sup> century. It focuses on igniting the child’s innate desire to attain knowledge and focuses on the holistic development of the child (South African Montessori Association, 2024).

Steele (2013:304) explains that pastoral counsellors must understand how children experience traumatic events before they can assign appropriate trauma-informed care. According to Steele (2013:3), pastoral counsellors must be aware of their own subjective experiences before they guide children to process their trauma and lead them to cognitively reframe the traumatic events using hope, resilience and strength. These new cognitive lenses will guide children in hospitals to re-instil trust in adults (Oberholzer, 2016b:6). P1 agrees with Steele (2013:305) that the incorporation of different sensory components that were part of the original trauma event help children recall the trauma, so that healing can take place. An example here is of the smell of medical disinfectant – when a child can smell the disinfectant in a safe space, they are able to become desensitised to the smell, so that they don't become anxious every time they encounter it.

Like P1's items pictured below, child-centred play therapy makes use of carefully selected toys in playrooms, so that children can express various emotions. A tote bag is recommended for caregivers and therapists as this allows them to be more mobile (Crenshaw & Steward, 2015: 9). Below are images of the items used by P1 during her play therapy with children.

<b><i>Image 1: Hospital 'doll' house</i></b>	<b><i>Image 2: Ambulance</i></b>	<b><i>Image 3: Hospital gown</i></b>
		
<b><i>Image 4: CT scanning machine</i></b>		<b><i>Image 5: Hospital bed toys</i></b>
		

P1 had to acquire hospital-themed toys to provide preventative and trauma support to children through play. P1 makes use of funzaroo.co.za to acquire these toys. Apart from the hospital toys P1 also has a wide array of other toys in her playroom.

The participants' use of narrative, validation and empowering children through choices will be discussed under Theme 1.2 below.

## **2.7 THEME 1.2: EMPOWER THE CHILD**

### **2.7.1 Bible stories**

While P1 uses Bible stories, such as Mark 4:35–41, as a prelude to her play therapy, P2 reads Bible stories to comfort children who have cancer. P2 was once asked by a child why God was angry at them. P2 responded by asking the child to show them in the Bible where God was angry at them. When the child did not respond, the counsellor said they read Scripture to children to comfort them, so that they know that God is not angry with them. The value of P2's technique is that she confronted the lie the child believed about God's anger toward them and replaced the lie with the truth of God's comfort through Scripture reading. According to P1, this means the child can die with peace in their hearts.

Scripture is a powerful tool to comfort and edify children. Their desire to be validated is also recognised from the empirical study's findings.

### **2.7.2 Validating the child**

When a child enters the playroom, P1 validates the child's negative lived experience by directly recalling the traumatic situation. For example, when a child's parent passes away, she will tell the child that she heard their mum or dad passed away. This, according to P1, gives the child permission to talk about anything regarding their painful situation. It communicates to the child that the pastoral caregiver cares about the child's experiences and feelings. This validation aims to empower children toward transparency, as well as to communicate trust and safety on the part of the pastoral caregiver. Steele (2013:310) explains that children do not show resistance; instead, whether they are willing to share their experiences or not relates to how safe they feel.

P3 shares the negative repercussions when a child is not validated at home. There was a case in which a child was living with their mother and her new husband. This living arrangement stressed the child and caused them to begin wetting themselves. The child's grandmother, who was a teacher at the school, became embarrassed about her grandchild's behaviour. When the child began to walk strangely, the grandmother took the child to the hospital. It then became apparent that the child had a brain tumour, which along with the stress of their living circumstances, caused the self-wetting. The child eventually passed away. P3 said this case shows the importance of being attentive to the child's behaviour and feelings and validating their experiences. As P3 expressed it, inquiring about what may be wrong when a child's behaviour is out of the ordinary is important.

When not given a choice, individuals may feel helpless and out of control. God never takes one's free will away; children who are ill need to be given a degree of choice to prevent a sense of helplessness and despair from setting in, bearing in mind that they have so little choice about their treatment and care.

### **2.7.3 Importance of choices**

It is critical that children's voices are respected. The way P2 and P3 allow children to exercise their will is by asking questions about what pastoral activities they want to do. This communicates to the child that their voice is important to the pastoral caregivers. When children are prevented from making choices, it often leads to anxiety and fear related to the treatment of their life-threatening and/or life-limiting condition. In a hospital setting, it is often subliminally communicated that the child's voice does not matter.

P1 visits children in hospital and uses play techniques to address the lack of control children experience when they are hospitalised. P1 explained that children more often than not are given no choice or control. The doctors and nurses just treat them in the manner they see fit – for example, draw blood, perform tests, give medication, switch on hospital lights, place other children in the same ward, etc.

One way which P1 aims to restore control is to take a teddy bear with a play stethoscope and other hospital items along with her, so that the child can use the bear as a hospital patient. The child then plays doctor with the bear, taking his blood and listening to his heartbeat. This example shows how a child can be preventatively desensitised from their fear of the hospital and any procedures they may have to undergo.

P2 and 3 use the technique of "inquiry" when working with children with life-threatening/life-limiting conditions. The pastoral value of the inquiry technique is that it empowers the child by providing them with a choice of which activity or play technique they want to do. Participants 2 and 3 explained that they unpack the options for children to read, listen to a story or sit quietly in the caregiver's presence. They also provide the option of receiving prayer or drawing with crayons.

Oberholzer (2011:3, 7–8) identifies that children have a need to have more control over their internal and external environments. This includes control over what they eat, control over procedures and some measure of control over their environment. The lack of control and a concomitant desire for choice by children was noted by P2, who said that children sometimes ask for refreshments, like Coke or sweets. Unfortunately, caregivers are strictly prohibited from giving children anything since their upcoming procedures might prohibit having fluids or solids in their system. The way that P2 deals with family

members drinking and eating in the presence of the child is to ask them to go to the kitchen where the child won't feel like they are missing out.

Kennedy and Howlin (2022:576) point out that pain and fasting are two topics parents find difficult to discuss with their children as part of hospital preparation. However, it's important to discuss these topics with children. Pastoral caregivers can facilitate these discussions as they may understand the negative impact of failing to fast before a procedure. Pastoral caregivers need to explain to those who are unfamiliar with hospital procedures, such as parents, what the child may be going through or alternatively ask a nurse to talk to the parents to explain the adverse impact of eating and drinking prior to an operation. Since children with trauma and illness may be triggered by unfamiliar or traumatic past experiences, it helps to use preventative support to prepare children for future experiences which might be unfamiliar and stressful to them. Preventative support may include proactive pastoral support, holistic pastoral support, pastoral counselling and crisis intervention, as well as community engagement and support groups (Ministry Brands, 2024; O'Neill, 2022). Preventative support will now be discussed as part of theme 1.3.

From the empirical study, direct, indirect and avoidance approaches to facilitating discussions about death with the child and their family can be navigated.

As part of preventative support, P1's approach to hospital preparation of the child will be discussed, which includes normalising the child's environment and addressing misconceptions. Because classically conditioned fears and anxiety are challenging to treat, preventative and informative sessions are recommended to reduce fear in hospital settings, like unexpected painful or frightening procedures (Walker *et al.*, 2012:97).

## **2.8 THEME 1.3: PREVENTATIVE SUPPORT**

Preventative support can be used to address the fear of cancer, trauma and death in children. P4 explained using direct, indirect and avoidance approaches to facilitate discussions about death to the sick child and their family. P4's pastoral approaches have the potential to prevent possible fears the child may have from being separated from their family and friends. The idea of death can be a source of sadness or terror for the child based on their beliefs about death. However, if they have no concept of death, they may not fear it at all. One first needs to check what the child's beliefs are about death before outlining what Scripture says about death.

P4 discussed using the direct approach (direct communication) to discuss death and trauma, as well as an indirect way of death preparation through storytelling to address separation anxiety. P4 also uses the avoidance approach to allow the family to guide the conversation.

## **2.8.1 Direct, avoidance and indirect approaches**

### *2.8.1.1 Direct approach*

Louw (2008) acknowledges the severe communication crisis regarding cancer since outsiders and the family find it difficult to talk about it. According to Louw (2008) the danger inherent in silence is that it can strain the child's relationship with adults due to the lack of honesty. In contrast, speaking honestly from the start about the uncomfortable can make the child feel safe, P1 believes. The participants have two different approaches regarding addressing death and trauma in children. P1 feels one should address the loss of the parent or family member directly with the child. She follows a direct approach as it is a way to establish trust and build a relationship with the child.

Although P1 believes a lot of people do not believe in talking directly with a suffering child about trauma, she believes this addresses the elephant in the room – for example, that one of the child's parents passed away recently. In addressing the situation directly, the child is given permission to talk freely about it, knowing it is a safe space to address hard feelings and thoughts. An example of how she would say this is: "I hear something terrible happened – your mother died."

P2 shared a case in which she discussed death with a child who was admitted at the same time (for different cancers) as another child who passed away. The boy asked her whether children die. This boy was unsure about what had happened because he and the other patient had played together for months, but according to P2, their mothers did not tell them they were dying. P2 strongly felt that people and children should be taught about cancer, TB and the possibility of death. P2 believes people have a misconception that one must be ill before one can die. A common question she's received in working in hospitals is inquiring whether a person was sick after news of their death.

"Even young people think they are not the dying type; they think they will only die in 40 years' time" (P2).

P2 says it is necessary to mentally prepare people for death, so that it does not destroy them when it happens. One way in which this mental preparation can be communicated is through pamphlets which can be handed out at hospitals and clinics. P2 also said that God conceals some matters (Proverbs 25:2), but the things that He has revealed should be conveyed to children, since although we don't know when we will die, we know we will die for certain. Another cultural misconception, according to P2, is the African belief that by discussing death with someone, one is wishing them to die; the topic is therefore

often avoided altogether. According to Berinyuu (as cited in Louw, 1994:21), it is critical to take the African systematic view on life into consideration when one is working with illness.

Louw (1994:24) recommends that caregivers include relationships affecting the patient when working with them since they will view illness personally and cosmically. In other words, the illness can be seen as a disturbance in balance and the imbalance needs to be identified and restored. For this model to be effective, the mystic dimension must also be considered (Louw, 1994:25). P2 said that she allows the family to go seek their own solutions from ancestors if they wish, but her door is open to discuss Scripture if the family returns. Although she is direct regarding death, she is sensitive to the family's own ideas, culture and religious views.

#### *2.8.1.2 Avoidance approach*

Using the avoidance approach, the topic of death and trauma is avoided consciously, says P2. She believes there is a misconception that discussing death might bring it upon the individual. These cases can be tricky since it might be offensive if the caregiver tries to address this misconception by bringing up the topic of death which evokes fear. In P2's experience, sometimes when someone dies next to a patient, the patient might wish to move to another bed because they think death is contagious. P2 says the best way to address this fear is through empowering people with the knowledge of the truth: a person will die when it's God's time for them to depart, instead of as a result of the death of another patient. However, the researcher must point out that Scripture also recognises that evil "comes to steal, kill and destroy", but that Christians should not fear the one who is only able to kill the body (Satan), but instead the One who is able to kill the "body and soul", namely God (Matt 10:28). At the end of one's life, the comfort exists in knowing that Jesus is ultimately in control and if one's soul is saved, one can rest in peace. Using the avoidance approach can be a good guideline for faith communities to not assume they know what the counsellee needs and should respect the views of the family. However, the faith community should not create the illusion that they condone views which oppose Scripture, such as ancestral worship or lying to the child or parents.

Instead of the direct or avoidance approach, P4 uses the indirect approach when addressing death and trauma. According to Erickson (1950), children aged three to five should be encouraged to take initiative or otherwise they may experience guilt. Prominent fears during preschool still include the separation from parents, as in previous age groups. Another fear includes mutilation of the body, darkness and monsters. Since preschool children in hospitalisation may undergo procedures involving medical equipment (needles and drips), this might aggravate the child's fear of mutilation.

Louw (2008: 341) explains that fear is a primary problem associated with cancer and that visualised fear can lead to people envisioning and fearing radiation, chemotherapy, disfigurement and alienation. In older individuals, this fear can also extend from separation anxiety to fear of death and the unknown.

### 2.8.1.3 *The indirect approaches*

The adventure, imagination and immigration pastoral techniques are examined as part of P4's indirect approaches to address death preparation with sick children and their families. According to P4, the adventure, imagination and immigration techniques are methods of assessing the spiritual readiness of the child, facilitating communication with Jesus and addressing separation anxiety the child may have from their parents. These techniques, which involve play and imagination, are also a great way for the whole family to connect. They can also prepare the family emotionally for the possible passing of their loved one.

- *Imagination technique*

P4 said that she has different ways of communicating death to individuals. Instead of going on an adventure with Jesus, the child imagines a conversation with Jesus. This technique helps the child register the fact that they are terminally ill, without directly saying so. When the participant has already walked a journey with a child and is aware that they have a relationship with Jesus, she can ask what they would ask Jesus if they could ask Him anything. She shared two cases of a boy and girl who asked Jesus what they'd want in their hypothetical room in heaven. The boy wanted his own room, everything in blue, games, an elephant and a speaking monkey. A striking question the boy asked during this process, without the participant even discussing heaven or death, was: "Do monkeys speak in heaven?". Afterwards, he told P4 he wanted to put the speaking monkey on top of the elephant. The child's statement, according to P4, suggested his spiritual readiness to pass away since the speaking monkey was in heaven and the elephant was in his room. This hypothesis was supported by the boy's own words: "Auntie, God is so good – I want to go." P4 expressed that children have an innate sense of when they are close to dying.

In another case, P4 spoke to a girl about what she wanted in her heavenly bedroom during the imagination technique. The girl shared that she wanted to become a designer. But everything she imagined putting inside her room was material in nature, rather than pointing towards a spiritual transition. P4 shared that this child's response related to her timeframe since there was still a period before the girl passed away. Thus, P4 got to have a follow-up session with her before she passed away. Interestingly, from these techniques, it can be discerned when a child has reached spiritual and emotional readiness prior to death; P4 believes one needs pastoral sensitivity to know when a child is preparing spiritually to die. This type of sensitivity assisted P4 to recognise when a little boy was "preparing his will"<sup>6</sup> by giving his teddy bear to his sister and so was able to assist the mother to help the boy prepare spiritually to meet Jesus.

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<sup>6</sup> See 2.7.2 Family

Through these examples, it can be seen faith communities and pastoral caregivers ministering to children facing death ought to be sensitive to the Holy Spirit's voice regarding what technique to apply to which child.

- *Adventure technique*

In preparing a child for death, P4 will take the sick child on an imaginary adventure in order to address separation anxiety and the fear of death. For example, she will tell a child that just like in the Disney film *Aladdin*, Jesus has a carpet. She then tells the children to climb on the carpet with their family. Then she asks the child to tell her where they would want to go with Jesus if they could go anywhere. After this, the child can directly ask Jesus if they could go there. Then the whole family will all put on their seatbelts and pretend to fly there. P4 will talk as they fly about how they are going to touch an eagle or fly across the ocean touching dolphins.

P4 never says that Jesus says yes during these exercises, but rather makes the child aware that they can ask Jesus anything in order to show them how easy it is to communicate with Him. Then when they arrive in a beautiful imaginary setting, she will ask the child if they want to stay. When the child says yes, the pastoral counsellor and family recognise together that the child's spirit has made that transition to be with Jesus, without discussing death directly. P4 says that when the child starts talking about what they will do when they are with Jesus, then the child has transitioned spiritually because of the Holy Spirit's facilitation of preparing for death.

P4 says that instead of the fear of death, children often deal with separation anxiety. P4 points out that the child's mum and dad are going to join them in heaven because they are part of Jesus' family. P4 concludes that the time when Jesus will take the child's mum and dad is irrelevant. She shares that no child has ever inquired about how long before they die. They immediately accept that mum and dad are also going to be with Jesus. This effectively addresses the separation anxiety children might experience. The second indirect technique P4 uses is an imagination technique.

The adventure technique that P4 employs includes the entire family on the imaginary adventure guided by the sick child. The whole family goes on this adventure together and P4 facilitates the exercise.

- *Immigration technique*

P4 compares the death of a child to immigration. She states that when someone immigrates, you cannot see that person any longer, but that does not mean the family won't see them again in the future. P4 conveys the hope to the Christian families she encounters that they will see their child in the future because their child is with Jesus. Using this analogy, P4 also highlights the necessity of having one's passport (salvation) to travel to the same destination as the child. This immigration technique can also be used to discuss older children's readiness to die.

From the above-mentioned techniques, it can be noted that the direct approaches are part of proactive preventative support. P1 and P2 encourage transparency with children to prevent doing harm by withholding information. The avoidance approaches can be described as holistic, preventative support techniques as P2 avoids discussing death in order to respect others' cultural perceptions of death. The indirect approaches are characterised by their holistic, pastoral support since they aim to prevent separation anxiety and also act as an engagement tool between family members.

Research indicates that preparing children for hospital mitigates feelings of anxiety and uncertainty (Taylor, 2013; Little Journey Limited, 2022). Kennedy and Howlin (2022) explain that parents are crucial in preparing children for elective<sup>7</sup> surgeries. Now that the value of preparing children for hospital has been discussed, P1's hospital preparation experiences will be examined.

## **2.8.2 Hospital preparation**

P1 shared her experience with a child who had a heart-valve condition during Covid-19 pandemic. P1 went to great measures to prepare the child for hospitalisation and the heart-valve operation. This was similar to the first technique of re-exposing children to the sensory components of their past traumatic experience. However, using this technique, P1 preventatively exposes the child to the sensations which they might detect during their operation, including their vision, hearing, touch, pressure, heat, cold, pain, smell and taste (Anon, 2024f). P1 prepares the child for what they might experience in the hospital to prepare the child's sub-conscious. P1 achieves this by buying a hospital gown and playing ICU noises in the background during the play-therapy session, so that the child will not be startled when waking up from the operation. Moreover, bowls of disinfectant are placed around the entire playroom and a rag doll is used as the patient to simulate what will happen during the procedure. The rag doll has clips covered in iodine (yellow), so that the child will be mentally prepared for the stitches and iodine they will receive during the operation.

### *2.8.2.1 Familiarising (normalising) the environment*

Because the heart procedure was done during lockdown, the child's parents were not allowed to stay with her in the hospital. Their absence created tension and anxiety for the child. P1 informed the parents that to help create a safe space for the child, they must leave something familiar behind, for example, a jersey to help the child smell their parent or a favourite teddy bear.

Accommodating family members and providing distractions for the child can assist in normalising the environment, according to Oberholzer *et al.* (2011:8). P4 noted the important impact which music can

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<sup>7</sup> "Non-emergency medical procedure and especially surgery that is planned in advance" (Merriam-Webster, 2024).

have in the hospital in providing support to the parents or family members. Oberholzer *et al.* (2011:8) recognises the importance of music, nature and animals in making children feel at home in haematology-oncology units. Music therapy has also proven effective in trauma and loss treatment (Malchiodi, 2020:66). P4 said that using music with parents in such a vulnerable context was difficult because each one might be in a different stage of processing their grief. More about how gospel music can be used in pastoral care as a means to connect with God will be shared in Chapter 3. Apart from the usefulness of music, dogs can be used to help children become more comfortable with an unfamiliar situation, according to P1.

#### *2.8.2.2 Animal-assisted techniques*

P1 has some experience with animal-assisted therapy. P1 shared how her play-therapy dog facilitated comfort to children working through shock or trauma. In one case, she went to greet a classroom of children and a boy with special needs did not get up to greet the dog like the other children. However, once he patted the dog, the dog reflected the boy's anxious emotions by shaking. Afterwards, the boy was comfortable with the dog. In other cases, children who are working through trauma will hold the dog during play or use the dog as a patient to simulate a procedure they are about to go through. Children who were molested can also be comforted by the presence of a dog who is there to provide a textile comfort which they can rub while talking and playing, according to P1. Animal-assisted activities have been proven to increase emotional comfort and decrease loneliness, while boosting independence and self-esteem (Oberholzer *et al.*, 2011:8). This can facilitate developing autonomy in a child between the ages of one and three (Erickson, 1950:222).

Lies and misconceptions lead children to having a warped view of God, others, themselves and the world. The importance of identifying lies and misconceptions will now be discussed.

#### **2.8.3 Addressing misconceptions**

The child that P1 worked with to prepare her for heart-valve surgery suffered from severe physical symptoms afterwards. For instance, she had slurred speech and her hand and foot turned in due to a shortage of oxygen. Interestingly, in P1's fourth or fifth session with her, the girl played in a hospital setting (Image 1) and operated on a doll who represented herself. P1 inquired about the play operation. The girl recalled that the doctors who cut open her chest, along with the hospital staff in the theatre, wore gowns, masks and caps. She believed they wore these gowns to prevent her blood from spraying on them when they cut her open. P1 corrected this misconception and said that they wore these outfits to protect her from germs. It is critical to correct misconceptions like this because they can become embedded in the child's mind, leading to emotional or spiritual pain in the future. Oberholzer (2016a:4) writes that although hospitalised children may be vulnerable to multiple misconceptions, care and sensitivity can make their experience positive.

P1 follows the principle of addressing misconceptions by working gently with the child at their own pace. The roots of the child's negative thoughts are primarily addressed, as these have the power to cause a pattern of negative thinking, as Hebrews 12:15 warns: "Be careful that no bitter root grows up to cause trouble and defile many." Any misconceptions or lies the child believes can be challenged with the truth of Scripture. Theme 4 will now investigate the participants' ways of attending to the sick child and their family.

## **2.9 THEME 1.4: ATTENDING**

The participants were asked how children respond to the pastoral techniques they apply. Based on the four participants' responses, the children responded mostly positively to their efforts. Osmer's (2008) description of the three types of attending, namely, informal, semi-formal and formal, will be used to guide Theme 4's discussion on attending in the context of children and those involved with serious illness and life-limiting conditions.

P4 mentioned that children might be hesitant to respond warmly to the caregiver's techniques due to uncertainty. This may be attributed to the child's uncertainty about the pastoral caregiver, as well as the destabilising process of illness and/or hospitalisation, according to P1. Thus, she advises two to three sessions of attending to the child to build a rapport with them and to encourage a relationship of trust. P1 also found that children respond well to a combination of play with Scripture. P3 said that one's attention as caregiver is an important component of relationship-building with the child since the child observes when the pastoral caregiver is interested in them and their stories. This describes attending as a spirituality of presence as defined by Osmer (2008:37).

### **2.9.1 Informal attending**

Informal attending describes daily attending through active listening and attentiveness in daily conversations and encounters with people, as was mentioned under spirituality of presence (Osmer, 2008:37). P2 and P3 demonstrate informal attending in their day-to-day visits to the oncology wards. These two participants encounter what Osmer calls the "beauty and tragedy" in everyday life. For the pastoral caregivers, this means encountering a child who is getting better and having a good discussion with a child or family member. However, this also includes encountering the tragedy of children frequently dying from cancer or experiencing trauma. P1 emphasises working at the child's pace when attending to them, since forcing the pastoral process of working through trauma might re-traumatise the child. Also, when one encounters the family outside of the formal pastoral care context, P3 recommends talking about topics other than the illness of the child to lend a sense of normality to their lives.

### **2.9.2 Semi-formal attending**

Semi-formal attending brings more structure to our attending. An example of this includes weekly meetings for pastoral sessions. P2 demonstrates semi-formal attending through meeting the mothers of children with cancer to do some crocheting together. These small groups are effective to help mothers process their experience and to speak with other women who are going through similar circumstances. P2 also uses these groups to introduce certain topics. This example of semi-formal attending is an illustration of community engagement, and a support group as discussed in the preventative support. Osmer (2008:38) also encourages journalling and small groups as a means of semi-formal attending which can help individuals to meet regularly, pay attention to their experience, as well as be able to verbalise their thoughts. P2 and P3 both endorse semi-formal attending. They believe that debriefing is necessary for those who minister to children with life-threatening and/or life-limiting conditions. These pastoral caregiver meetings can also help to discuss effective pastoral techniques and recent cases of children and families they worked with to provide a caregiver network.

### **2.9.3 Formal attending**

Formal attending utilises empirical research to investigate contexts and situations. Through these attendings, spirituality of presence is an important focus as people are attended to and observed as representatives of God (Gen 1:27). It is to care about how others experience and see the world. P4 notes that although children come in with anxiety and tension, they often leave with relief and happiness. Qualitative research (Osmer, 2008:39) is an effective way to attend to others by inquiring about their situations and contexts. The deepening of one's understanding regarding others' situations can be used in research to improve those situations through pastoral caregiving. Although research has the danger of objectifying those being studied, Osmer (2008:39) highlights the benefit of qualitative research as a vessel for portraying the spirituality of God's presence through formal attending. All the participants sometimes model formal attending by organising a meeting with the child or the child's family members. P4 shared having meetings with the child's parents before or after the death of their child to support them in processing their emotions. P1 also shows formal attending when planning a meeting beforehand with a child.

Theme 4 shows how children can respond positively to various ways of attending to them. Informal attending by the participants was displayed by informal daily or weekly visits to children in the oncology wards. Semi-formal attending was shown through weekly crochet meetings between the participants and mothers of the sick children. This support to the mothers would indirectly support the children since children are sensitive to their parents' well-being. Semi-formal debriefing groups can also be organised between pastoral caregivers to ensure they are encouraged to support children more effectively. This is critical in this field of care since one cannot show compassion when one is undergoing compassion fatigue. An example of formal attending was shown through the organised

interviews between the pastoral caregiving participants and the researcher. Through attending to the pastoral caregiver, the researcher was able to discover what advice they would give faith communities or other pastoral caregivers who have little experience working with seriously ill children.

Part 2 aims to unpack the participants' advice attained from the empirical interviews. As with Part 1, four themes will be discussed. However, these will focus less on specific pastoral techniques and more on how the pastoral caregiver who is part of a faith community can implement pastoral care.

## **2.10 PART 2: PARTICIPANTS' ADVICE**

The participants' counsel can be used to build healthy relationships with the children and their families (Theme 2.1). By focusing on continued professional development (Theme 2.2), they can inform themselves to work in a way that conveys contextual awareness (Theme 2.3). From their vast experience, their advice can also guide caregivers' self-care (Theme 2.4).

Attending and guiding (Osmer, 2008), unconditional acceptance (P3), continued professional development, managing one's expectations (P4) and the importance of checking the child's needs are some of the points of guidance the participants gave during the empirical study. Du Plessis (2021:8) encourages pastoral caregivers to work from a contextual hermeneutical paradigm and to be aware of the web of relationships, culture and contexts in which counselling takes place. To promote the art of "being with the other" in pastoral care, one can present an attitude of empathy through verbal and non-verbal communication, bearing hope, sensitivity, respect, discernment, wisdom and comfort. These positive attributes can also be used to provide guidance to the child and family in their time of uncertainty and illness.

### **2.10.1 Providing guidance**

Osmer (2008:40) describes leaders as interpretative guides: their role is to navigate people through unknown territory. This, in turn, means the interpretative guide ought to know what the territory entails before guiding people there. This is relevant for pastoral caregivers who guide families and churches across the unknown terrain they are facing with their child's illness. The pastoral caregiver ought to be informed regarding the possible questions and concerns the child and family might have regarding the child's life-threatening and/or life-limiting condition. This does not mean the pastoral counsellor might have information about the physical progression of the illness. However, they need to be able to guide the child and family through the faith journey that the illness presents. Osmer (2008:41) suggests investigating the empirical research of scholars as a way in which pastoral caregivers can inform themselves to attend and guide their counselees effectively. This was mentioned by P2 who recommends reading up on the procedures the child will undertake, as well as P1 who does research to

prepare children adequately for procedures. Drawing on research also applies to a pastoral caregiver studying anything they are unfamiliar with – be it a procedure, religious or cultural beliefs or pastoral techniques. The importance of this self-improvement will be discussed further under Theme 2.2. Firstly, the caregivers' advice on how to effectively build a good relationship with the child and their family will be discussed.

## **2.11 THEME 2.1: RELATIONSHIP-BUILDING**

### **2.11.1 Child**

Children want adults to approach them on their level, instead of as a parent with rules, according to P3. P1 agrees that caregivers lose a child's attention if they put themselves across a table from the child as one would with an adult. P1 argues that pastoral caregivers need to sit on the floor and interact with children. Moreover, P4 insists on communicating with the entire family at the child's level and avoids using medical terminology.

#### *2.11.1.1 Unconditional love and acceptance*

Unconditional acceptance is a way in which unconditional love is modelled (Hays-Grudo & Morris, 2020:25). Unconditional love means the child knows their caregiver or pastoral caregiver does not love them based on their conduct. P3 said it is important that pastoral caregivers do not show any judgement towards a child since they could be coming from a home where they were judged or mistreated. P3 shared the previously mentioned case of a child with a brain tumour who wet their bed because their living conditions distressed them so much. P3 advocates that because pastoral caregivers do not know where a child comes from that they show unconditional acceptance towards the child and their family. This attitude also helps to build trust with the child and family. Parental experiences of shock because of their child's illness can make them feel overwhelmed, which negatively impacts their ability to support the child's needs (Kennedy & Howlin, 2022:569). P4 therefore makes a point of treating parents who may be dealing with grief and shock with empathy and accepting them, regardless of their response to the stressful situation of having a child with a life-threatening and/or life-limiting condition. The impact of shock on the parents, as discussed in the participants' interviews, will now be dealt with as it directly impacts the child who is dependent on their parents' support.

#### *2.11.1.2 The impact of shock*

From the participants' responses, shock can have a wide-ranging impact on the sick child's family, often resulting in a state of denial. Interestingly, one of the participants from personal experience pointed out that shock can render one completely deaf. Therefore, P4 makes a point of talking in simple language with all the parents she works with in oncology settings. When her child was diagnosed with cancer, she had no hearing for a week. She said that the experience made her feel dumb and disorientated; she even spelled certificate as "PK973".

Because she knows that this phenomenon is a reality, P4 takes heed to ensure she stays sensitive to needs of the parents she encounters. She makes a point of repeating everything to parents and to talk in simple language which even children can understand. P4's mantra is: Never use terminology. She does this to treat parents who are illiterate and people who have doctorates the same. In one case, an educated parent confided in her and could share intimate details with her because she talked in such simple language.

Due to shock's impact, faith communities should be taught to speak in simple terms when ministering to parents in traumatic situations. P3 also said that it is important to realise that families might be undergoing denial. P3 shared a case of a mother who was using a facecloth to wash her boy who had passed away. She touched him and acted as if he was merely sleeping. This mother had not fully absorbed the reality of the situation. The news about the boy's passing had already been shared with her that morning. The mother also conveyed this information to the caregiver when she came to her. The caregiver's response was to ask the mother if she wanted prayer.

The mother was open to this. During prayer, the caregiver included the fact that God had taken the boy away, adding that His motive was love and that people have fixed dates to be born and to die. According to P2, the mom started to notice the boy was not there during prayer and she started to cry. This was an appropriate response to the reality of the situation, rather than denying that he was dead.

Those ministering to families should remember the myriad impacts of shock, including deep denial. Participants attributed parents' lack of honesty with their children to the fact that they were grappling with their children's condition, as reinforced by Sahler (2000) and Beale *et al.* (2005). Therefore, faith communities' response to shock and grief should be to talk sensitively to parents who struggle to convey this truth to their children, instead of thinking parents are just being unfair to keep their children in the dark about their condition. One way in which parents can be assisted is to receive training about the stage of denial in grief as part of their preparation for their child's eventual death.

#### *2.11.1.3 Culture of celebration*

P1 and P2 emphasised celebrating certain achievements or anniversaries, such as the anniversary of the child's heart operation or children who recover from cancer. The mother of the child that had a heart operation organised a one-year anniversary to celebrate her recovery. The pastoral caregiver and her husband were invited to this anniversary, and they celebrated together the "Jesus mark", as they called it.

There are non-profit organisations that have a ritual of bell ringing when somebody finishes their cancer treatment. This is a little celebration with friends and family which culminates in the child walking up to ring the bell. These are two examples of nurturing a culture of celebration for the difficult treatment children have to undergo, such as chemotherapy or medical procedure.

Since the child's family are intricately involved with the child's illness, the participants were asked whether they have experience working with the families of the children they counsel.

### **2.11.2 Family**

All participants (except P1) have experience interacting and working with parents, other family members or friends of the children. P3 discussed that it's important for any external persons not to treat the family and friends of the sick child as victims. Rather, they should separate them as individuals distinct from the condition, especially when encountering them outside of the hospital.

Stage 5 of Erickson's developmental theory explains that children undergo development of their identity from around 12 to 18 years of age (Louw & Louw, 2014; Erickson, 1950:227). If they are not able to affirm their identity, they may experience confusion. Also, between the ages of 13 to 18, adolescents start to critically reflect on and challenge their own beliefs and values. They develop new cognitive skills that enable them to take different perspectives into consideration and to form their own identity during the synthetic-conventional stage of faith development. Hospitalisation might challenge a child's identity since they might be tempted to assume a victim mentality. Pastoral caregivers can challenge children in this misconception that their illness does not define who they are. Pastoral caregivers can also equip the parents to pray for their children. P4 supports mothers by helping them to pray or she shares conversations with them while their children are in surgery or in a coma.

Kent *et al.* (2016) identify that parents, family members and friends act as informal caregivers. Treatment is often provided at home, while the continuum of cancer's development places different pressures in terms of the care burden on the family during diagnosis, treatment, transition from treatment, survivorship without treatment, secondary cancer and end-of-life care. Pastoral caregivers can empower parents by assisting them to foster positive caregiver-child relationships. This can be done through nurturing the child's attachment, balancing autonomy with connectedness and providing emotional coaching (Hays-Grudo & Morris, 2020:120).

P4 shared the story of guiding a mother to help her son prepare emotionally and spiritually to die. The pastoral caregiver used colouring pictures to achieve this. She sent the mother animated pictures of rockets. The boy had to choose which one God figuratively would use to come and fetch him. P4 encouraged the mother and son to dream what the rocket's colour would be and if it would require

stickers. Anning and Ring (2004:120) assert that drawing and colouring at home provides a great shared experience between parent and child.

Parents can also be empowered to show mindfulness in their parenting. According to Hays-Grudo and Morris (2020:117), mindfulness can help to heal the brain from trauma. They list five mindful dimensions concerning the parent-child relationship. These include listening with full attention, non-judgemental acceptance, showing self-regulation, emotional awareness and compassion in the caregiving relationship (Duncan, Coatsworth & Greenberg, 2009:258). Besides how the parent can effectively support the child, it is evident that the family needs pastoral support.

- *Pastoral support to family*

Besides these needs, it is clear that the parents, siblings and families need support due to the wide-ranging impacts of the child's life-threatening and/or life-limiting condition. P2 shared a story of a mother and father who dealt with the grief of losing their young child in different ways. P4 shared that in her experience, the dads would be more prone to cry while praying than when talking to the pastoral caregiver directly. The mother, however, might cry when talking to the pastoral caregiver. These responses by the parents are not set in stone, but pastoral caregivers need to be aware that the parents might respond differently. Abraham *et al.* (2014:9,795) recognise that mothers' and fathers' brain imaging shows a clear "parental caregiving network". This network is activated in engaged parents and involves brain structures linked with oxytocin (the bonding hormone). This proves that parents are sensitive to their child's experiences. As a result, both parents are negatively affected when their child is diagnosed with a life-threatening and/or life-limiting condition.

Therefore, empathy is important on the part of the caregiver toward the family of the child. Developmental science (Field & Behrman, 2003:29) ought to guide the care plan which has been tailored to the child and which lists the information and support available to the family. To identify the appropriate care plans and pastoral techniques for chronically ill children, the pastoral caregiver needs continued professional development.

## **2.12 THEME 2.2: CONTINUED PROFESSIONAL DEVELOPMENT**

P2 agrees with P3's stance that the pastoral caregivers working in oncology must have knowledge regarding what is going on in the ward and with the patients. For example, aside from knowledge on surgical procedures and treatment, the caregiver ought to know what stage of grief the child has reached, since children have an inner knowledge of death, according to Kübler Ross (as cited in Louw, 2008:492; Kübler Ross, 1991:155). CPD, through formal or informal pastoral education, includes developing knowledge of psychological phenomena, such as transference and countertransference, which will be discussed in more detail later on, and the different religious and cultural beliefs one might encounter in

supporting children with life-threatening and/or life limiting conditions. To attain knowledge about psychological phenomena, processes and other faiths and cultures, the caregiver needs to prioritise effective pastoral education.

### **2.12.1 Pastoral education**

P2 highlights that there is lack of pastoral training in this area. Pastoral education is required for caregivers to know how to build relationships with the sick child and family within their unique context. P2 said that ministers and nurses can be equipped to train others regarding pastoral support to these children and their families. Training ministers and nurses would be a means of filling the gap for hospitals who are not equipped with structured support. It is only among some non-profit organisations that there is pastoral care available (P2). Since nurses are always doing rounds in the hospital, it can also be effective to introduce them to effective pastoral support. Also, government funds and support are needed to provide pastoral caregivers for every hospital (P2). Besides the need for pastoral support for sick children in hospitals and homes, P1 also identified the need to support impoverished communities. The call to be intercessors is just as important as being informed and present with the children.

### **2.12.2 Intercession**

P2 recommends that a pastoral caregiver must be present in the wards like the doctors and nurses. This ensures that there is pastoral and emotional support available to the sick children and their families. Moreover, the caregivers can act like pastoral intercessors since our “struggle is not against flesh and blood, but against the rulers, against the authorities, against the powers of this dark world and against the spiritual forces of evil in the heavenly realms” (Eph 6:12). Therefore, the caregivers can intercede for the children. The caregiver is not only pleading for the child’s physical healing, but often for their spiritual well-being as well. P2 shared a story about a child who was angry with her because she refused to give him something to drink, and this perceived rejection affected his body negatively. He died a week later, angry with everyone, and he turned his back against the caregiver. Louw (1994:151) explains that unpleasant sensations and unsatisfied immediate needs often lead to extreme frustration in children. As a pastoral caregiver, part of effective practical support is knowing how one ought to self-regulate to help foster calmness in the child and to help the child trust that one is constant and accepting, despite the child’s negative behaviour. Hays-Grudo and Morris (2020:116) highlight the impact which self-regulation has on healing from adverse childhood experiences (ACEs) and trauma. Thus, pastoral caregivers ought to stay calm in their interactions with children and regulate their own emotions and responses. P2 always leaves children who want to be left alone and thus models’ self-regulation. Other ways of practically supporting the child will now be discussed.

### **2.12.3 Practical support**

Part of CPD as a pastoral caregiver is to expose oneself to the difficulties present in the care and support of the ill child, as well as in the family dynamics. If the caregivers are in the wards more often, they are able to build a deeper relationship with the child and can support both the child and their parents (P2). An example of this, mentioned by Kennedy and Howlin (2022:576), is to support the child with topics the family might find difficult to understand or address, such as pain and fasting. P2 said that if caregivers were in the wards more often, they would be able to enforce rules regarding families eating and drinking in the wards. P2 expressed how parents were encouraged to tell families to eat and drink in the kitchen since some of the children undergoing treatment had to fast for treatment and then the temptation around them was difficult and discouraging for those child patients.

P2 says that pastoral caregivers need to educate themselves regarding the procedures the child will undergo. P2 noted that pastors sometimes struggle with medical terminology and that they needed to study the procedures to open discussions with the family. Although medical terminology is important to understand, P4 feels strongly about not being the one who uses them in front of parents. Because the focus is on the CPD of pastoral caregivers, a medical outline of what cancer will be given.

### **2.12.4 Medical diagnoses and treatment**

#### *2.12.4.1 Cancer*

To be informed regarding procedures, a brief explanation of cancer and its impact on the patient will now be given. Louw (1994:114) explains that tumours form when the cell-growth process goes wrong. These tumours are malignant, meaning that they invade normal tissue or may return after removal. It is argued that stress is a causative factor of cancer, although other factors may include chemicals, viruses and hereditary factors (Louw, 1994:114). When undergoing chemotherapy, many patients experience nausea and vomiting. To support children experiencing these side effects, relaxation and guided imagery is often used to assist them (Oberholzer *et al.*, 2011:7). Although the caregiver does not automatically have to know everything about the physical well-being of the child, they can inquire from nurses, doctors and journals about diagnoses, such as cancer. But the pastoral caregiver's primary role remains to provide pastoral support to the child and family.

### **2.12.5 Caregiver role**

For pastoral caregivers and family members, it is necessary to know what caregiving for the sick child entails. Kent *et al.* (2016) explain that the role of caregiving is usually a family affair: it may involve all family members and friends who can provide care to the patient and who help with the performance of various tasks that can be physically, spiritually, emotionally or financially draining. The caregiver ought to be present, informed and attend to the patient and family, as well as set boundaries in

caregiving. Hays-Grudo and Morris (2020:117) encourage mindful caregiving as part of the caregivers' role. Mindfulness helps caregivers regulate their own emotions and to move their interactions with the child and family from "brainstem" reactions (fight, flight or freeze) to more intentional behaviours, which include listening with attention and non-judgemental acceptance of the child (P3). Caregivers need to continually be mindful of the values they portray to the children and families they work with as these communicate something about who they are and who they represent in the workplace.

#### 2.12.5.1 Values

From the empirical study, unconditional acceptance, respect and compassion were shown to be actively practised by all participants.

- *Respect*

The participants model respect, compassionate care and dignity to every patient they encounter. The pastoral caregivers meet the needs of the sick child and their family in the best way they know how.

- *Unconditional acceptance*

P2 and P3 said that children need to be accepted, regardless of who they are or the physical state they are in. They need to feel that the pastoral caregiver is willing to love and play with them. P2 also stated that parents need to know that the pastoral caregivers are non-judgemental towards them, despite their choices of treatment for the child. To be non-judgemental opens pastoral caregivers up to be curious and aware about the contexts of others and helps them minister to others according to their needs.

## 2. 13 THEME 2.3: CONTEXTUAL AWARENESS

All the participants gave examples of practising contextual awareness in their work. P1 makes it clear that she works from a Christian perspective. Families who have different religious beliefs do not often contact her to receive grief or death counselling for their children. P2 shows respect towards others by not forcing any child or parent to talk to her when doing hospital rounds.

Pastoral caregivers need to be aware that they might encounter situations, values and cultures which they are unfamiliar with. The necessity for contextual awareness comes from the realisation that pastoral care is heavily influenced by context (Magezi, 2019:2). He notes that from the early 20<sup>th</sup> century, there has been a call to return to the theology of the Reformation and the Bible (Magezi, 2019:2). During the missionary era, African peoples' cultures and worldviews were neglected, which led to African theological intellectualism. Today there is no longer just the challenge of attempting to apply Western practices in the African context, as was done in the missionaries' era. Now the challenge emerges to bring African independent churches' (AIC) personal theologies (often informed by subjective experiences) into conversation with scholarly engagement (Magezi, 2019:3). Thus, to be contextually relevant, pastoral care needs to consider African people's lived experiences. Examining the context of

people whose faith and culture is different will help pastoral caregivers to better manage their expectations. Some of these lived experiences include African patients' superstitious beliefs, according to P3. When a patient passed away in the bed next to a child, the child might fear that they are next in line (P3).

### **2.13.1 Diverse strategies**

The participants unanimously agreed that they do not have the same strategy for all the children because it depends on the child, religion, culture and situation. P2 said that the children she counsels are not always Christian and then she has to adapt her strategy to build a relationship with the child regardless of their religion. P1 also said that her strategy depends on the problem the child is dealing with. She previously has had children with eye problems, so she made feeling a bigger component of play. Similarly, she has counselled children who struggle to hear and has therefore made seeing a larger component of their play therapy. P4 said that as a caregiver, one is very reliant on the Holy Spirit's guidance and must prayerfully choose a strategy for each child. As a general guideline, P1 mostly uses a combination of play and Bible stories for children's recovery from trauma. However, for hospital preparation, she uses a completely different approach.

P3's strategy is to familiarise herself with each child individually. She interacts with them and inquiries about how they are. She also states the importance of accepting each child the way they are. From participants' responses, it is apparent that all participants allow the child and situation to determine what approach they will take. All apply their Christian worldview and virtues of love to each unique situation. However, with non-Christians, they do not force their worldview but instead discuss the individuals' experience. The pastoral caregivers were asked how children responded to the diverse strategies they use as pastoral techniques to promote children's inner healing. This is discussed under attending (1.4). In providing pastoral support, it is important that caregivers manage their expectations regarding the child and their family.

### **2.13.2 Managing expectations**

Managing one's expectations when ministering to children is important (P2). P2 shared her experience of pastors coming to pray, expecting the child to be healed instead of being open to the possibility that it's God's will and timing for the child to die. According to P2, this misconception regarding prayer and healing impacts the way that the congregation responds to those who reach out to provide pastoral support. She shared about pastors who experience negative reactions because they prayed for people who did not get healed but instead passed away.

Secondly, pastoral caregivers must be informed to recognise their own feelings of sadness when people pass away<sup>8</sup> Lastly, P2 emphasises not promising healing which one cannot deliver. She reminds congregations that God is the healer and that humans are just vessels who pray for others in their time of need. A key component of contextual awareness is to be aware of the cultures and religions of non-Christians to be able to provide effective caregiving when ministering to other faiths.

### **2.13.3 Ministering to non-Christians**

P2 went to pray for children in a particular hospital and encountered a Muslim mother with her baby. She prayed for another family nearby and then approached the Muslim mother. The Muslim mother rejected her offer for prayer due to her difference in religious beliefs. The pastoral caregiver, however, still engaged with her and asked her about her experience at the hospital. This opened a door for some relationship-building to occur, despite religious differences. When the other baby P2 prayed for got better, the Muslim mother came in search of the pastoral caregiver, so that she could also receive prayer for her baby.

In another case, P4 befriended a Muslim mother and then because of the family were extremists, they forbade the mother and child to have further interaction with the caregiver since they feared the child would be led away from their faith in the afterlife. In this case, the child died without the mother being present. This reinforces why sagely wisdom is critical<sup>9</sup>. The examples provided by P2 and P4 show that South African hospitals cater to different types of cultures and religions which pastoral caregivers should be aware of.

Sagely wisdom means the pastoral caregiver as interpretative guide must be wise in discerning which theoretical map will be most helpful to apply to the counselee (Osmer, 2008:81). Ancestral worship is another topic which was discussed during the empirical interviews. This also requires knowledge on the part of the pastoral caregiver regarding what is believed according to the descriptive task and how one should handle it using sagely wisdom (Osmer, 2008:81).

### **2.13.4 Ministering according to needs**

It is important for faith communities to minister according to the needs of those they encounter. P4 has experienced many individuals assuming what to bring to children dealing with life-threatening and/or life-threatening conditions. The problem with assuming the child's needs is that the child's actual needs and desires might not be met. For example, P4 stated that a lot of people bring colouring books, crayons and cupcakes for the children. But a 16-year-old patient may not want to colour in. Too much sugar

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<sup>8</sup> See 2.2.3.7. Compassion fatigue in Caregivers.

<sup>9</sup> Compare with Chapter 3: Children in palliative care

also makes the children who are on chemo treatment nauseous. Instead, P4 encourages people take blank paper and pens so that any age can benefit from the exercise. P4 also recommends that church groups inquire before they do an outreach to visit children with life-threatening and/or life-limiting conditions. Asking beforehand will force faith communities to be more practical in the tools they bring with them in relation to the needs of the children and adolescents.

Hays-Grudo and Morris (2020:115) support P4's explanation that adolescents have different developmental needs than those of children. Adolescents can be supported by respecting their need for autonomy, while also encouraging parents' involvement. It has been proven that parents' involvement predicts youth's academic success and acts as a protective factor from negative peer influence (Hays-Grudo and Morris, 2020:115). Parental support through regular communication between parents and adolescents, as well as communication with external faith communities, is critical to meet the needs of sick children and adolescents (Hays-Grudo & Morris, 2020:116).

- *Impoverished community support*

P1 highlights that impoverished communities need pastoral support. P1 identified a big need for faith communities to go to state hospitals to work with some of the children who come from informal areas. She said this is a massive gap which churches can fill since they have access to hospitals to work with those children. P1 also believes that there is a need for pastors to be trained in townships to support and empower the parents of such children who don't have money for other forms of counselling.

The final theme which will be addressed is what pastoral caregivers can do to practise self-care in the face of working with sick, vulnerable and at times impoverished children.

## **2.14 THEME 2.4: SELF-CARE**

From the empirical study, expressive pastoral techniques, preventative support, having diverse strategies at hand, use of informal and formal attending (Osmer, 2008), as well as using contextual awareness to support the child's and the family's pastoral needs are all important. Apart from effective pastoral support of others, the participants also recommend self-care to prevent burnout and compassion fatigue.

### **2.14.1 Debriefing**

P1, who works with childhood trauma, walks her dogs every day and goes to debrief with someone every three months. P1 says it is critical to debrief and talk through her tough cases with another counsellor because she sometimes ends up carrying burdens for others from her pastoral work. In some cases, P1 experienced being haunted by a child's story, even though it may have been less severe than

another child's case she worked with. She attributes this to one's spirit as a counsellor connecting with the child's spirit. Debriefing helps one to disconnect from the child (P1). P1 also believes creativity helps to deal with emotional pain and therefore she does mosaics during the holidays.

P3's demeanour changed as she shared her experience regarding her self-care. She became sad as she shared that there used to be a place where she and the other pastoral caregivers unpacked, called "Caring for the caregivers". However, later they were short-staffed when the original founders of the organisation left. Thereafter, they could no longer afford taking the time to care for one another as the needs of others were too big. P3 shared that a nurse once requested that she come in on a day when she was sick and on leave. She forced herself out of bed to meet the patient because it seemed urgent. On the positive side, this shows that there was a good relationship between the caregiver and patient and that the nurses trusted her to help (P3). However, on the negative side, it shows that there was a shortage of pastoral caregivers available to care for patients in distress. P3 attributed this experience to a possible "obsession" that she had to go to the hospital instead of prioritising taking care of herself first. This is an example of the danger of taking patients' burdens on oneself as caregiver (burden-bearing), especially when there is a shortage of caregivers. Pastoral caregivers also need to be cautious not to develop a saviour complex. A saviour complex is a psychological attitude, fuelled by empathetic episodes, in which the person believes they are solely responsible for assisting other people. A person with a saviour complex believes it is noble to help others at the expense of their own health (Benton, 2017). Benton (2017) recommends individuals trapped in a saviour complex set clear boundaries, redefining what helping means, slowing down and assessing before saying yes.

P4 views her relationship with a child in need a bit differently from P1. How P4 connects with children will now be discussed as part of a bigger discussion regarding caregiver self-care since the degree to which a caregiver builds a good relationship with a child may inevitably affect her own well-being.

#### **2.14.2 Relationship with children**

To cope with the heartache of connecting with children who will possibly pass away, P4 has developed her own coping strategy: she distances herself from sick children by not memorising their names. Since hospital rotations are high, it is virtually impossible to remember all the children's names, she said. P4 personally believes she will recall the names she is supposed to remember. P4 also does not attend all the funerals of the children she has ministered to, but instead only attends the funerals of those whom she has connected with at a deeper emotional level.

P4 talks to Jesus about the connections and losses she has formed with children. She does not believe she would be able to debrief with an individual because she explains that one can only find one's peace talking to Jesus. P4 believes that a caregiver who has only had one or two experiences working with

children who have died will not be able to relate to her experience of treating over a thousand children who passed away in the 27 years she has worked in the field of oncology. Instead, P4 draws on religion as her primary source of comfort.

### **2.14.3 Religion**

P4 explicitly mentioned religion by debriefing through her talks with Jesus about her positive and negative experiences. In this way, having a relationship with God and significant others is one way in which caregivers can practise self-care. P2 and P3 make use of talking to fellow caregivers as a way of processing their experiences and reminding one another about God's truth. This highlights the importance of using Scripture to make sense of the pain and suffering encountered in these pastoral-care contexts. Besides religious relationships, boundaries are also important.

### **2.14.4 Setting boundaries**

The necessity of work (ministry) boundaries becomes clear in light of P3's experience of feeling obligated to support someone else on her day off. As a pastoral caregiver, clear boundaries should be communicated beforehand to oneself, the organisation (church or NGO) and patients. Boundaries are important so that pastoral caregivers can establish safe boundaries for the counsellor-client relationship. P4's negative experience of connecting personally with some clients at the start of her career and then feeling used when they leave the relationship shows the importance of protecting oneself and the client from transference and countertransference. Boundaries in the client-counsellor relationship help to maintain trust, uphold objectivity and promote good ethical practices, as discussed under point 2.2.3 (Hutchison, 2021).

Boundaries also protect pastoral counsellors from over-involvement in their clients' lives. Hutchison (2021) asserts that caregivers are better equipped to manage their emotional resources and maintain a professional distance which protects them from burnout, vicarious trauma and compassion fatigue. Leisure-time activities will be discussed next as they form an important part of caregivers' self-care.

### **2.14.5 Recreational activities**

These refer to activities which serve to alleviate stress, enhance well-being and provide enjoyment to the individual. Some recreational activities already mentioned include creative outlets, such as arts and crafts (mosaics), journalling and prayer (P4), and engaging in physical activities like going for walk with loved ones and/or pets (P1). From the positive impact of music mentioned by P4, it could also be suggested that worship could be an effective means for pastoral caregivers to fill up their spiritual tank during their time off.

The primary advice, taken from the four themes under Part 2, includes how effective relationship-building can be facilitated between caregiver and child (Theme 2.1), how the pastoral caregiver can be encouraged to focus on continued professional development (Theme 2.2) and cultivating contextual awareness (Theme 2.3) in one's work. The final theme which was discussed was participants' advice on nurturing their own self-care (Theme 2.4).

## **2.15 CONCLUSION**

Chapter 2 aimed to give insight regarding the nature of the work undertaken by the four participants. From the interviews, several themes emerged. The researcher noted the value of the participants' pastoral techniques to empower the child, as well as the effective preventative support they offered. Informal, semi-formal, and formal manners of attending (Osmer, 2008) were also used to organise the participants' experiences of attending to sick children and their parents. The participants' advice extended to four themes, including relationship-building, continued professional development, contextual awareness and how pastoral caregivers can practise self-care.

Chapter 2 included some sources since the empirical study was limited in scope, but Chapter 3 will be more focused on reviewing literature to identify "why it is going on", according to Osmer's model (2008). This will inform the reason behind pastoral care offered to seriously ill children being the way it is, as evidenced in the empirical study.

# CHAPTER 3

## CHILDREN IN PALLIATIVE CARE: A RATIONAL FOR PASTORAL CARE

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### 3.1 INTRODUCTION

Chapter 3 will focus on providing a deeper understanding of why pastoral care of children in palliative care is necessary. Chapter 2 reflected on current pastoral care interventions that are available to children with life-threatening and/or life-limiting conditions in South Africa from an empirical and a literature review paradigm. This chapter will investigate why pastoral support is necessary in various facets of these children's lives. Religion, spirituality and pastoral care will be defined, as well as what the needs of children with life-limiting and/or life-threatening conditions are. An emphasis will be placed on *why* it is necessary to focus on the holistic (physical, emotional and pastoral) needs of children according to their developmental stages. The needs of the parents and siblings will be discussed, as well as barriers to providing effective pastoral care to these children. The pastoral techniques utilised by the participants in the empirical study, alongside pastoral techniques which were not discussed in Chapter 2, will now be examined. Importantly, the term caregiver refers to pastoral caregivers in this context and not to the child's primary caregivers. Osmer (2008:83) posits that sagely wisdom in theoretical and practical knowledge of different types of situations is especially important during the interpretative task.

#### 3.1.1 Osmer's spirituality of sagely wisdom

Thoughtfulness and theoretical interpretation are at opposite ends of Osmer's spirituality of sagely wisdom. Wise judgement is centred exactly between the two extremes (Osmer, 2008:82). Pastoral caregivers are encouraged to grow in thoughtfulness, which includes putting oneself in the shoes of another to reflect and try to understand what they are going through. This is like contextual awareness in which the pastoral caregiver seeks to be relevant given the situation at hand. The caregiver looks for ways to become necessary by observing what the situation and family requires and meeting that need.

Thoughtfulness also helps caregivers understand why people react the way they do (Osmer, 2008:83). The next part of sagely wisdom is theoretical interpretation that draws on existing theories to make sense of life experiences and situations. Osmer (2008:83) notes that it is important to learn from such theories, but also to criticise theory, realising that it was constructed by human reason and offers but an approximation of the truth, not truth itself. The researcher will discuss the childhood developmental theories of Erickson, Bowlby and Fowler with the aim of providing some explanation as to why children may have diverse needs based on their psycho-social stage of physical and faith development.

Wise judgement is placed between thoughtfulness and theoretical interpretation as two ends of the same continuum. Wise judgement is divided into three steps (Osmer, 2008:84). Firstly, Osmer (2008:84) encourages caregivers to recognise the relevant event; secondly, to discern the moral stakes; and thirdly, to determine the most effective means to achieve the goal the caregiver has in mind.

Osmer (2008:82) urges ministers to stay intellectually curious in the face of reaching the limits of their own understanding. Instead of just referring the individual to another health practitioner or caregiver, one should reach towards the unknown to equip oneself, but never at the expense of another.

### **3.1.2 Contextual awareness**

Situational awareness enables pastoral caregivers to practise non-maleficence (“do no harm”). An example of why situational awareness is important is when children must not eat before an operation to avoid aspiration (food or liquid going into their airways). The caregiver needs to be aware of the child’s physical and emotional state in such a situation. When the caregiver considers that the child is not allowed to eat anything, while others might be eating around them, then they can show empathy and intervene in the situation.

Another example is when P2 modelled awareness to a child who was fasting, but he perceived it as being rude to him. Instead of being impatient or irritated with the child, P2 was calm and carefully explained to the child the importance of not eating or drinking before an operation. The information calmed the child, thus bringing him to a calm physical and psychological state.

In reference to ministering to non-Christians, P4 highlighted why it so important to discern the moral stakes of one’s actions as a pastoral caregiver. She shared about a Muslim family who isolated their child from their mother because she had befriended the Christian pastoral caregiver (P4). The family feared that the child could be influenced by the mother who was friends with the Christian caregiver (P4). This why a pastoral caregiver must be aware of other religious and cultural views. Caregivers ought to be considerate and thoughtful in their responses by developing a theoretical understanding of the family’s views.

In their actions of thoughtfulness to gain insight into a counselee’s situation, caregivers may seek theoretical interpretation about the child’s medical and spiritual condition. They may also use wise judgement to respond appropriately, allowing the counselee to experience comfort in their situation (Osmer, 2008:82). Caregivers can effectively convey wisdom and hope through their own faith conviction and through Scripture. 1 Peter 3:15 encourages believers to always be ready to give an answer for the hope they have in Jesus through His resurrection life (Osmer, 2008:82). However, this

sharing of the gospel should always be done in a way that is respectful to patients from all religious beliefs and practices. Religion will now be discussed, and a distinction will be made between spiritual and pastoral care, as well as the benefits of such care.

## **3.2 RELIGION**

Walsh (2012:347) explains that religion is defined as an organised, institutionalized faith system with shared traditions, doctrine, practices and a community of believers. Religion impacts personal virtues, relational conduct and family life because believers' faith encompasses their complete being. Furthermore, being affiliated to a congregation provides the benefits of leadership guidance, a like-minded faith community and support in times of need (Walsh, 2012:348).

Barlow (2011:1) defines religion as the adherence to the practice of a particular faith, tradition or sect. Adherence refers to devotion to a particular faith's manner of thinking and behaving. As far as this study is concerned, understanding religion helps us comprehend why all Christians, regardless of their denomination, are called to adhere to Jesus' words by caring for others of the same faith, as well as those who are not part of the faith community, but need support, as stated in Matthew 25:31–46.

Barnum (2011) points out that not all people follow religion for its spiritual expression and not all who are spiritual express it through religion. Therefore, not all people who believe in God are practising it in a faith community. This is mentioned since those individuals who do not consider themselves to be part of a faith community are not excluded in the call by Jesus to show care for the sick.

### **3.2.1 Spiritual care and pastoral support**

Spirituality is an umbrella term which refers to transcendent beliefs and practices. According to Walsh (2012:348), spirituality is the heartbeat of religion as it can be seen as a human expression which exists independently of religious structures. Barnum (2011:19) makes the distinction that spirituality is more focused on individuality, whereas religion is built on the foundation of shared beliefs. Nye (2009:5) explains theologians define spirituality as our search for God in response to God's search for us. Psychologists define spirituality as an awareness, a response or an ability to reflect on areas which are beyond an individual's grasp (Nye, 2009:5), while educators define spirituality as a heightened awareness and a response of awe and wonder, as well as a sense of divine presence (Nye, 2009:5).

Van Rensburg (2014:134) identifies spirituality as being more inclusive than religion, since it includes individuals who believe their spirituality gives them meaning apart from religious groups or views. A beautiful, simplified definition of Christian spirituality, given by Nye (2009:5) is: "God's ways of being with children and children's ways of being with God."

Practical theology can be broken down into four interpretative tasks, the descriptive-empirical, the interpretative, the normative and pragmatic tasks (Osmer, 2008:4). These guide how professional pastoral support can be practically implemented in different contexts. This makes these interpretative tasks appropriate for this study of pastoral support to sick children.

Carey and Cohen (2015:2) state that although both pastoral and spiritual care have a long-established history, pastoral care is theologically more grounded, whereas spiritual care has a broader definition. Spiritual care includes both spiritual practices and traditional religious beliefs (Carey & Cohen, 2015:2). By comparison, pastoral care has a normative aspect and accepts the Bible as an authoritative source for human experiences. Because spirituality is a wider concept than religious or pastoral care, the Bible is not necessarily viewed as an authoritative normative source.

Pastoral care gives clear guidelines by which a child's experience of God can be measured against Scripture's explanation of God's character. For example, if a child has a negative experience, then they may form a misconception about God. Thus, pastoral care facilitates conversations about an individual's experiences and God's involvement in their situation of suffering.

Not all spiritual care is pastoral care since it might not be in line with Scripture. Although pastoral support includes spiritual experiences, pastoral care will be the primary focus of Chapter 3. However, when spiritual care is discussed, it is intended to submit to Scripture, just as pastoral care aims to have the Bible guide the actions of the caregiver's and faith community. Pastoral care given to children with life-threatening and/or life-limiting conditions needs to effectively support children holistically in their different stages of development.

### **3.2.2 Benefits of spiritual and pastoral support**

Spiritual care (Beresford, 2022:8) is a critical aspect of paediatric palliative care since it aims to decrease suffering by answering the family's existential questions which often arise during end-of-life care. Selman *et al.* (2018: 226) agree that there has been a lack of attention to spiritual care needs, but that it is necessary in palliative care as it produces resilience against trauma in children (Allen *et al.*, 2020:132).

Bryan-Davis (as cited in Allen *et al.*, 2020:141–142) asserts that spiritual coping mechanisms “contribute to decreased depressive symptoms, greater self-esteem and overall greater life-satisfaction”. Moreover, ministry to children creates a bridge between their existing spirituality to their current life experiences which helps promote resilience.

De la Porte (2018:70) underscores the importance of spirituality in holistic healthcare. He states that non-profit and faith-based organisations should play a prominent role in developing guidelines and strategies providing effective spiritual care tailored to the South African context. Van Rensburg (2014:133) states that 72% of psychiatrists are more likely to encounter spiritual and religious issues in

practice but explains that psychiatrists are also less religious than other specialists. Moreover, it is believed that religious physicians are less likely to refer patients to psychiatrists, which may explain the gap between religious and psychiatric treatment.

Roger and Hatala (2018:24) and Fitchett (2017:166) highlight the benefits of religion and spirituality in health-promoting practices, such as physical healing facilitated by doctors. Rogers and Hatala (2018:31) saw a positive correlation between increased spirituality and a higher self-esteem, sense of meaning in life and a sense of hope. Furthermore, Beresford (2022:7) explains that families often draw on spiritual and faith beliefs to attain a sense of hope and to assist in decision-making. Sira *et al.* (2014:607) highlight the importance of parents coping with their child's illness in an effective manner, since it holds a positive correlation with their child's recovery rate. Limited research has been conducted into how illness in childhood impacts a child's spirituality (Nash *et al.*, 2013:149). However, Nash *et al.* (2013:155) stress how spiritual care can affirm sick children's identity through encouraging positive self-regard. Osmer (2008:86) also emphasises that people need spiritual guides who are thoughtful to point them towards hope.

Spiritual care creates a space where trust and meaning making can take place between the child and caregiver, leading to more effective pastoral care (Nash *et al.*, 2013:157). An outsider, like a chaplain or pastoral counsellor, can earn the child's trust by not invading their personal space, compared to, for instance, the medical staff who physically treat them with drips, pills and medicine. Community is another vital component of spiritual support, according to Nash *et al.* (2013:157), as this facilitates a psychological sense of community as well as a "new home".

According to a 2005 US study by Flannelly *et al.*, a chaplain's role in supporting families during end-of-life care, prayer and emotional support was rated important by directors of medicine, nursing staff, pastoral counsellors and social workers. This shows that the contribution of pastoral support is recognised by hospitals in the US. Cadge *et al.* (2011) explain that both medical staff and chaplains agree on the role chaplaincy plays in emotional support, as well as end-of-life care. In South Africa, pastoral support in hospitals is often restricted to visiting hours (Oberholzer, 2016b:10). Moreover, although children highly value spiritual support, research is limited on this subject (Oberholzer, 2016a).

Allen *et al.* (2020:129) discuss how environments can shape a child's spirituality. They discuss that children's faith, hope and religious belief systems promote resilience in children who encounter hardship. Religion, faith, hope, belief, prayer and spiritual support are some of the caring factors which help children recover from trauma (Allen *et al.*, 2020:130). Developing theories are useful to assist pastoral caregivers to understand children's ongoing developmental needs.

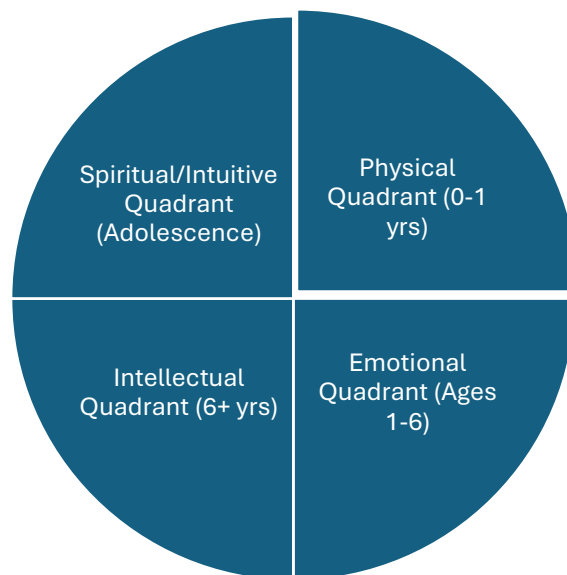
### 3.3 THE DEVELOPING CHILD

Children have spiritual, social, psychological and physical developmental needs (Oberholzer, 2016b:3; Louw, 2008:537). Children’s overarching development can be better understood by considering developmental theories expounded by Kübler- Ross, Erickson, Kohlberg, Fowler, Bowlby, Ainsworth and Nagy. These scholars demonstrate that children go through various stages of development – for example, Erickson’s theory of psycho-social development and Kohlberg’s theory of moral development. Fowler’s theory is useful for breaking down the stages of children’s faith development and Bowlby and Ainsworth did groundbreaking work into understanding children’s attachment styles. Nagy’s theory of understanding death is crucial for this study as a child’s perception of death impacts their well-being. Kübler-Ross’ four quadrants of human well-being will now be discussed as it gives insight into the physical, spiritual, intellectual and emotional development of a child.

#### 3.3.1 Elizabeth Kübler-Ross

The Swiss psychologist Kübler-Ross (1991:147) notes that medicine is beginning to recognise the importance of including the physical, emotional, intellectual and spiritual quadrants of human beings. The spiritual develops automatically when the other three (physical, intellectual and emotional) are balanced and if the individual is honest with themselves.

3.3.1.1 Fig 1: Four quadrants of human well-being



- *Physical Quadrant*

Kübler-Ross (1991:147) notes the importance of caring for an infant’s physical well-being during their first year of life, which is similar to Erickson’s eight stages of psycho-social development. Taking care

of an infant means physical touch, which includes hugs, kisses, and touches (Kübler-Ross, 1991:147). Physical contact and care influence the emotional quadrant.

- *Emotional Quadrant*

Between the ages of one to six, the emotional quadrant develops in response to the physical contact and love received in a child's first year of life (Kübler-Ross, 1991:149). Kübler-Ross hypothesises that most unnatural fears are developed during this age because of the suppression of emotions. Kübler-Ross (1991:149) argues that only two fears are natural and necessary for survival – the fear of loud noises and the fear of falling. Distorted emotions which develop from unnatural fears include the fear of failure, rejection, self-pity, prolonged anger, envy and conditional love.

- *Spiritual Quadrant*

In a similar vein to the theory of relational consciousness which was first proposed by Rebecca Nye (1998), Kübler-Ross (1991:154) believes that spirituality is part of human beings' natural design to connect with others (Hay & Nye, 2006:111; Wills, 2012:51). It is also the most important quadrant, according to Kübler-Ross, and is nurtured through unconditional love during a child's early life. When children have a normal upbringing, their spiritual quadrant will emerge during adolescence. Individuals with a balanced spiritual quadrant are more certain about their calling and career and have a bigger likelihood of living a meaningful life, instead of being bound by bitterness which may be a protective factor against regret at the end of their life (Kübler-Ross, 1991:154). Since spirituality helps give meaning to suffering, it is an important factor to consider for those working with children who have life-threatening and/or life-limiting conditions (Kübler-Ross, 1991: 155).

### **3.3.2 Erickson: Eight stages of psycho-social development**

Erickson's theory shows that children and adults develop in a sequence of stages in which each stage is defined by a unique crisis or challenge which they need to overcome (Erickson, 1950; Louw and Louw, 2014). During the eight stages of man, the ego develops a number of virtues, namely, hope (ages 0–2), will (2–6), purpose (2–6), competence (7–12), fidelity (13–21), love (21–35), care (35–60) and wisdom (60+) (Erickson, 1950:221, Fowler, 1981:52).

#### *3.3.2.1 Trust vs mistrust*

From birth to the age of one, basic social trust versus mistrust is learned by the infant based on their interaction with their caregiver. Erickson (1950:221) explains that a good quality relationship with the mother is a prominent influence which instils trust and sense of personal worth in the child. When more trust than mistrust is experienced by the infant, then hope emerges as a strength in the ego (Fowler, 1981:55).

### 3.3.2.2 *Autonomy vs shame*

From ages one to three, the child practises autonomy or develops shame in the face of not developing a sense of an independent will. The tension between holding on and letting go is emphasised in this stage of anal-muscular maturation (Erickson, 1950:222). Caregivers and pastoral caregivers can practise giving choices to children with life-threatening and/or life-limiting conditions to facilitate the development of autonomy and give them some form of control. P1 practised allowing children to choose which hospital toys to play with to promote their having a voice, while P4 gave children a choice in the sentences and thoughts they used in facilitating conversations with God. These techniques give no room for shame, since the child has a choice within the structure of play or prayer. Outer control by parents, caregivers and nurses ought to be reassuring in nature, otherwise shame can be experienced as rage against oneself (Erickson, 1950:223).

### 3.3.2.3 *Initiative vs guilt*

Between three to six years, children go through the psycho-social stage of initiative versus guilt. Their challenge during this stage is to develop a willingness to try new things, while at the same time learn to handle failure (Louw & Louw, 2014). Erickson (1950:225) differentiates between autonomy and initiative. Autonomy is focused on keeping potential rivals out, whereas initiative anticipates rivalry and acts to promote oneself to gain favour. Parents can be educated by pastoral caregivers to anticipate that there may be sibling rivalry during this stage or a sense of wanting to attempt new things. The parents can also act as comforters if the child failed to achieve the goals they envisioned. By handling children's failure and anxiety in a way that communicates unconditional acceptance, parents can protect them from feelings of inferiority in the next stage.

### 3.3.2.4 *Industry vs inferiority*

Children between the age of six to adolescence undergo the psycho-social challenge of industry versus inferiority. Erickson (1950:226) describes this as the child wanting to win recognition by producing things. During this phase, it is important for children to learn basic skills and to work with others (Louw & Louw, 2014: 22). If a child between the ages of seven to 13 fails to learn basic skills in school and work with their peers, it might lead to feelings of inferiority. Fowler (1981:67) encourages providing uninterrupted learning opportunities and growth for the child to help instil a sense of their own competence.

Although challenging, doing schoolwork while in hospital can be encouraged by parents of children with life-threatening and/or life-limiting conditions. Oberholzer *et al.* (2011:8) explain that if parents allow children to fall behind with their schoolwork, it might evoke more stress as they might start to feel inferior, and the hidden message may be that tomorrow is not important. Before hospitalisation, the child might consistently have done their homework. However, there is a risk of parents becoming more

lenient towards schoolwork during hospitalisation. Since children focus on being industrious between the ages of seven and 13 (Erickson, 1950:227), the lack of status among “tool-partners” may contribute to feeling incompetent or inferior in comparison to schoolmates. This may be regarding sport, culture or academics, which the ill child misses out on because of their condition. Based on the expected fears at different ages, which was discussed by Louw and Louw (2014:186), school performance can also be a fear for children between the ages of nine and twelve. Therefore, to instil a feeling of industry instead of inferiority, parents must encourage children with life-threatening and/or life-limiting conditions to do schoolwork, so that they can have consistency.

#### *3.3.2.5 Identity vs role diffusion*

Socially, children have a need to experience their family’s and friends’ support (Oberholzer *et al.*, 2011:7). Having family and friends to alleviate the isolation and loneliness sick children encounter also facilitates in normalising their environment.

Erickson (1950:228) hypothesises that adolescents, in the fight between identity and role diffusion, refight the battles of earlier years. During this time, adolescents may ascribe roles for people. For example, well-meaning people may suddenly become enemies and they may choose ideals as their final identity. It is important for parents and caregivers to address and affirm the child’s God-given identity at this age.

To avoid role confusion, adults can support adolescents in establishing good personal relationships, so that the teenager feels safe in their own identity to commit to relationships with others (Fowler, 1981:77). When this safety in relationship and identity is established, then fidelity to religious or other ideological visions will be established (Fowler, 1981:77). This is how human connection can facilitate a healthy God connection for teenagers with life-threatening and/or life-limiting conditions. As with an internal desire, children also have an external desire for religious engagement (Oberholzer, 2011; Zohar & Marshall, 2000).

### **3.3.3 Kohlberg: Moral development**

Moral development is important as it helps children to distinguish between right from wrong, learn ethical values and can influence socialisation behaviours. Kohlberg’s theory demonstrates how moral reasoning develops from a self-centred stance to one in which a child can make decisions which reflect justice and empathy.

Children undergo six stages of moral development (Kohlberg, 1974:7; Louw & Louw, 2014:290). Kohlberg outlines three stages and two sub-stages of development. The pre-conventional stage comprises

Stage 1 and 2. The conventional stage consists of Stage 3 and 4, while the post-conventional stage includes Stage 5 and 6.

### *3.3.3.1 Pre-conventional stage*

Kohlberg (1974:7) explains that the basis of the child's moral judgement lies in quasi-physical needs. This refers to needs that arise in specific situations and are not fundamental in nature. Thus, external, social factors, such as what other children or family members do or do not have, can influence the quasi-physical needs of the child.

- *Stage 1*

The child wrestles with obedience versus punishment. Instead of considering the motives of parents or others who instil boundaries in the child's life, they adjust their behaviour at this stage to avoid punishment (Kohlberg, 1974:7). One-way P2 and P3 took advantage of this stage with younger children who wanted sweets or drinks was to say that they couldn't give them otherwise the doctor would scold them. This is language children understand as they want to avoid trouble.

- *Stage 2*

During this stage, children develop awareness of themselves (individualism) and that others may have different viewpoints. They might act in their own self-interest, even if the caregiver or parent disagrees. This was seen in Chapter 2 when a boy wanted something to drink and became angry that neither the parent nor pastoral caregiver would give it to him.

### *3.3.3.2 Conventional stage*

In the sub-stages 3 and 4 (conventional stage), conformity, authority and social order are important for the child.

- *Stage 3*

The child is concerned about pleasing others and thus pastoral caregivers should be sensitive to not manipulate children to receive salvation or unconsciously take away the child's will in any way.

- *Stage 4*

During this stage, a child learns to abide by the laws that society has determined. For example, an adolescent knows the consequences of not doing their homework and will do it if they are internally motivated to avoid punishment and gain the reward of knowledge.

### *3.3.3.3 Post-conventional stage*

The final level includes Stage 5 (social contract) and Stage 6 (universal ethical principles).

- *Stage 5*

Relativistic thoughts can be seen to emerge during this stage when the child has become an adult. They can identify that some values and rules can be changed based on a particular group of people.

- *Stage 6*

The person develops and follows the ethical principles they personally agree with (Kohlberg, 1974:7; Louw & Louw, 2014:292). Fowler's theory of faith development gives insight into how a person develops their faith based on their cognitive ability and life phases.

### **3.3.4 Fowler: Faith Development**

There are seven stages of faith development which give insight to children's spiritual development (Fowler, 1981:121; Browning, 1987).

#### *3.3.4.1 Stage 0: Undifferentiated faith stage*

The undifferentiated stage of faith development in children is from birth to two years old (infancy). During this phase, Fowler's theory overlaps with that of Erickson's, emphasising the necessity for children to develop basic trust with their caregivers since this indirectly affects their trust in God (Oberholzer, 2023). Caregivers are thus a tangible way in which they can understand God. During the undifferentiated faith stage of development, trust, courage, hope and love grow. Fowler (1981:121) explains that when an infant has not received consistent caregiving, they may be tempted to develop fears of abandonment and deprivation.

#### *3.3.4.2 Stage 1: Intuitive-projective faith*

Pre-school children between the ages of three to seven go through the intuitive-projective development of faith stage in which a child responds spontaneously to stories and dreams. The child can be powerfully influenced by stories and examples of faith. During this stage of development, children lack reversibility of thoughts, as well as structured logic. Thus, these children often believe their experiences and perceptions are the only perspective there is (Fowler, 1981:123). According to Oberholzer (2023:7), children enjoy stories which clearly define good and evil, as well as religious symbols and visual images that connect with their faith. In supporting their faith development, caregivers should also be aware that children before the age of seven are unable to grasp abstract spiritual concepts and can thus support them spiritually by using simple terms they can understand. Children during this stage of faith experience self-awareness (Fowler, 1981:133). Since imagination is the strength of children in early childhood, it should be directed towards God.

#### *3.3.4.3 Stage 2: Mystic-literal faith*

From ages seven to 12, children undergo the faith stage of mythic-literal faith (Fowler, 1981:136). Children in this stage believe goodness is rewarded, whereas badness is punished (Browning, 1987; Oberholzer, 2023). These children may have a faith crisis when they realise that bad things can happen to good people. But since children have a big interest in narrative during their primary-school years (Fowler, 1981:136), Bible and other stories can be used as a vehicle to confront their fears. However, it should be noted that during the intuitive-projective stage, children may not automatically draw real-life

meaning from the narratives yet, so these must first be explained (Fowler, 1981:137). Consequently, caregivers can comprehend why children may have a faith crisis between the ages of seven to 12. Children during this age need stories that represent their own religious and moral views (Oberholzer, 2023).

#### *3.3.4.4 Stage 3: Synthetic-conventional faith*

The third stage is the synthetic-conventional stage of faith development (Fowler, 1981:151; Browning, 1987) which starts in adolescence (ages 13 to 18). During this stage, teenagers can challenge their own faith assumptions and develop new cognitive skills that enable them to take other perspectives into consideration during their identity formation; this was similarly recognised by Erickson in the eight stages of psycho-social development (Erickson, 1950; Oberholzer, 2023). Unlike children during the mythic-literal stage, adolescents in the synthetic-conventional stage have a capacity to reflect on their thoughts. The adolescent can draw patterns of meaning from narratives and, what Fowler calls, “the story of our stories” (1981:152). Adolescents sometimes develop a sense of dread of possible future insignificance or fear of being invisible. This is something pastoral caregivers need to be aware of and address. Consequently, teenagers need a positive mirror as to how their loved ones’ view them in their formation of identity and faith (Fowler, 1981:153).

#### *3.3.4.5 Stage 4: Individuate-reflective faith*

In the fourth stage, people question the assumptions they have around their faith and greater maturity becomes possible. However, Oberholzer (2023) highlights that not everyone reaches this stage and that some may be in Stage 3 of faith development for their entire life. Fowler (1981:182) explains that this stage demands that the person take responsibility for their commitments, beliefs, attitudes and individuality. Fowler says this stage can occur in late adolescence or in later adulthood (30s to 40s). Parents or family members of children with a life-threatening or life-limiting condition may be going through this stage in shaping a new lifestyle to cope with the situation. Stage 5 (conjunctive faith) and Stage 6 (universalised faith) will not be discussed as they are more relevant for mid-life and later adulthood faith development, which is not the focus of this study. Bowlby’s attachment theory will now be investigated as attachment impacts children’s brain development, relationship development and emotional regulation (Dozier *et al.*, 2008).

### **3.3.5 Bowlby’s Attachment styles**

Bowlby (1988:140) proposed four attachment styles, namely, secure, anxious-resistant, anxious-avoidant and disorganised. Attachment styles are based on the interactions between children and their caregivers. The caregiver acts as a secure base from which the infant explores the world (Counted, 2015:4).

Bowlby explains that babies whose mothers responded more during their first year of life cry less and are more cooperative to their parents' wishes in their second year than those of babies whose mothers were less responsive (Ainsworth *et al.*, 2015; Bowlby, 1988:10). From this, one can see that the interaction between the caregiver and infant determines which attachment will form.

#### *3.3.5.1 Secure attachment*

In this attachment type, the child has a trusting relationship with their caregiver. The child is confident that the parent will be available and responsive if a frightening situation presents itself. This knowledge of parents' availability leads to the child being bold in their exploration (Bowlby, 1988:140).

#### *3.3.5.2 Anxious-resistant*

This attachment style describes a child who is fearful of rejection and may be needy towards their caregivers. Unlike the securely attached child, the anxious-resistant child is unsure whether their parents will be available or responsive when called upon (Bowlby, 1988:140). This evokes anxiety about exploring the world.

#### *3.3.5.3 Anxious-avoidant attachment*

This attachment style can be observed in children who avoid intimacy with others. Bowlby (1988:140) explains that these children expect to be refused when seeking help. This child tries to be self-sufficient emotionally and may be vulnerable to being diagnosed with narcissistic disorder (Bowlby, 1988).

#### *3.3.5.4 Disorganised attachment*

The studies of Main (Bowlby, 1988:141) describe disorganised attachment as children portraying a mix of the previous three attachment styles. This attachment could have resulted from trauma or grief the parent was dealing with, which directly influenced the way the parents interacted with their child. Disorganised attachment is of clinical concern since the child shows no consistency between their behaviours and emotions.

#### *3.3.5.5 Value of attachment styles*

Being informed about attachment styles will help the child and family to deal with the child's illness and meet their needs more appropriately. The parent needs to be aware of the child's attachment style, as well as of their own attachment style. If the adult is insecure in their attachment and the child perceives the hospitalisation as rejection by their parents, then the parents might want to pull back from the child. Moreover, if the parent hears about the child's diagnosis and is insecure in their attachment, then it may create a barrier of self-protection for the parent at the cost of intimacy with the child. Oberholzer (2023:35) has attested to the fact that children closely observe their parents' behaviour and respond accordingly. If the parent is anxious and unable to cope, then the child will also struggle to regulate their emotions.

Ainsworth's strange situation experiment, developed in the 1970s, highlights the impact caregiving can have on the quality of relationships, as evidenced between a parent and child (Ainsworth *et al.*, 2015:37). This can be helpful for pastoral caregivers to understand the interactions between families and children better.

### **3.3.6 Ainsworth: Strange situation**

The strange situation tests how young children react to the presence and absence of their mother when they are placed in an unfamiliar environment. The strange situation is comprised of eight episodes which illustrated the different attachment styles of children (Ainsworth *et al.*, 2015:37). How the episodes were structured will now be unpacked. Episode 1 lasted 30 seconds: the mother, child and observer were placed in an experimental room. Episode two is three minutes' long: just the mother and baby are placed in the room to watch a baby's exploration. In episode three, a stranger enters the room for three minutes. The fourth episode involves the stranger and baby interacting, while the mother leaves. The fifth episode is the first reunion between mother and baby after the stranger leaves. After the reunion, the child is left alone in the sixth episode. The stranger re-enters the room in the seventh episode and in the final episode the mother and child have their second reunion after the stranger leaves. In the above-mentioned episodes children reacted in different ways which gave insight into their attachment styles. Some children explored the room, others held back, other started crying or befriended the stranger.

Although Ainsworth rightly hypothesises that infants will react warily to the stranger in Episode 3, she points out that stranger anxiety was not as intense as Spitz claimed in 1965. Ainsworth *et al.* (2015:254) believe that Spitz might have confused stranger anxiety with separation anxiety since he tested when the mother was absent. From this, pastoral caregivers are encouraged to engage with younger children when their mothers are present, so that this phenomenon of "stranger danger" may be avoided in pastoral caregiving to children with life-threatening and/or life-limiting conditions.

#### *3.3.6.1 Behavioural systems*

The interplay between two behavioural systems needs to be considered by pastoral caregivers. From the stranger situation, Ainsworth *et al.* (2015:14) note that a one-year-old child may be conflicted: they may want to explore the room and approach the stranger or hold back and avoid the stranger. Pastoral caregivers can use Ainsworth *et al.*'s (2015:15) study to discern what attachment style the child is displaying (Bowlby, 1988), wary/fearful behaviour, exploratory conduct, or sociable behaviour towards the pastoral caregiver/stranger. The pastoral caregiver can respond accordingly to the behavioural cues given by the child. If the child is presenting reserved behaviour (smiling and looking away), then the pastoral caregiver might win the child's sociable system over with play and expressive pastoral techniques. P2 makes sure to read the child's behavioural and emotional cues to see whether to approach

or respect the child's desire to be alone. Another therapy that is valuable for this study is Frankl's logotherapy as it articulates people's innate desire to find meaning.

### **3.3.7 Frankl and meaning**

Logotherapy recognises people's freedom of will, will find meaning and be meaningful in life.

#### *3.3.7.1 Freedom of will*

The freedom to choose is what can empower individuals to withstand suffering (Frankl, 2004:111). Therefore, pastoral caregivers need to recognise children's freedom of choice, despite external limitations placed on them through necessary treatment measures. Recognising their freedom of will enables children to build resilience (Madeson, 2020; Frankl, 2004).

#### *3.3.7.2 Will to meaning*

When humans are unable to find meaning, it often leads to frustration and other negative feelings, such as aggression and depression (Madeson, 2020). Frankl (2004:104) asserts that the primary motivator of people is the pursuit of meaning, rather than pleasure.

#### *3.3.7.3 Meaning in life*

Like pastoral caregivers who submit to Scripture, Frankl believes meaning is an objective reality instead of a subjective perception. In this way, children can be guided to comprehend the objective realities of Christianity to attain comfort and understanding in the face of serious illness. The fact that one can choose this objective meaning guides children to recognise responsibility and freedom to choose (Madeson, 2020; Frankl, 2004:113).

#### *3.3.7.4 Background*

The search for meaning is the primary motivator in people's lives (Zohar & Marshall, 2000). Victor Frankl, an Austrian Holocaust survivor, asserts that the search for meaning is what motivates humankind (Frankl, 2004:105). Frankl created a psychotherapy called logotherapy. The word "logos" is derived from the Greek word "meaning" and focuses helping individuals find meaning in their lives (Frankl, 2004:104). Through a public poll, Frankl (2004:105) found 89% out of thousands of people interviewed in France admitted that humankind needs something to live for. In a repeated study using hospital staff and patients in Vienna, Frankl discovered the results to be only different by two percent. Frankl also argues that people can be moved towards meaning when confronted by a hopeless situation, such as an incurable disease (Frankl, 2004:116).

Logotherapy guides individuals to gain meaning from unavoidable suffering; although they cannot change the situation, they are challenged to change themselves and how they view the situation (Frankl, 2004:118). This resonates with Romans 5:3: "Not only that, but we also rejoice in our sufferings,

because we know that suffering produces perseverance; perseverance, character and character, hope. And hope does not disappoint us, because God has poured out His love into our hearts through the Holy Spirit, whom He has given us.” Romans 5 highlights the hope and meaning Christians have through their faith in God to rejoice in suffering (physical illness or emotional despair), knowing that God can use it to produce perseverance, character and hope. Jesus, as the Prince of Peace (Isa 9:6), can be demonstrated through the child’s relational consciousness.

### 3.3.7.5 *Relevance to this study*

The search for meaning is a clear need in children with life-threatening and/or life-limiting illnesses because the meaning and hopes they hold for the future are being threatened by their illness. The fear of death might allude to the necessity for meaning (Zohar & Marshall, 2000). This fear needs to be recognised as a need the sick child may have. Viewed in a positive light, children have a high SQ<sup>10</sup> which can be seen in their openness to asking “why” questions. Zohar and Marshall (2000) recognise that people have spiritual intelligence (SQ), just like emotional (EQ) and thinking intelligence (IQ) Allen *et al.* (2020:134) explain that children attempt to understand both what is happening to them, as well as why. In trying to discern what is happening to them, they often recall previous religious life experiences “in order to” make sense of their current situation. Frankl (2004:123) talks about drawing on a patient’s spiritual resources to gain super-meaning (meaning beyond human understanding) – in other words, what one learns in this life for the hereafter. How God preserves ones’ tears in a bottle is written of in the Psalms: sanctification occurs through suffering (Frankl, 2004:123). Frankl believes that super-meaning cannot always be attained, and he uses a story of an interaction with his daughter to convey this. He says that it was the Good Lord who made her well from her measles, to which she replied that it was also God who caused it and therefore one cannot always know the specific reason for why one must suffer (Frankl, 2004:124).

If children who are suffering have been taught a higher power protects them, they may experience “spiritual dissonance”, according to Allen *et al.* (2020:134). Since children don’t have the same cognitive abilities as adults, they need an adult to explain the situation (their illness) to them. Allen *et al.* (2020:135) explain that parents can be an essential support system for a child who is undergoing loss or trauma. However, when their parents are also affected by trauma, as in the case of the child’s illness, the child may not receive the spiritual support they need from their parents. The spiritual support children receive impacts the child’s social connection with others. Maria Nagy (1948) identifies three stages of development which children undergo in their perception of death. Parents and pastoral

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<sup>10</sup> Spiritual Intelligence is defined by Zohar (2000) as: “The intelligence with which we address and solve problems of meaning and value, the intelligence with which we can place our actions and our lives in a wider, richer, meaning-giving context...”

caregivers can more readily support children to cope with death when they understand how children perceive death.

### **3.3.8 Maria Nagy: Understanding death**

Nagy (1948:3–27) hypothesises that children go through three phases of understanding death.

#### *3.3.8.1 Stage 1*

In the first stage (three to five years), children deny the finality of death. Instead, they believe death is like falling asleep and that one can wake up again. Krepia *et al.* (2017:2) attribute this belief that death is reversible to children's cognitive developmental stage. They argue that children might be innately curious about death. However, environmental factors, such as their parents' and teachers' attitudes, may lead to fear and sorrow associated with death (Krepia *et al.*, 2017:1).

#### *3.3.8.2 Stage 2*

Between the ages of five to nine, children come to grips with the fact that someone else can die, but they only believe they can die from age 10 (Grollman, 1991:5). They also believe they can escape death if they are clever enough (Krepia *et al.*, 2017:2).

#### *3.3.8.3 Stage 3*

From age nine onwards, children know that death is certain for all people. There are various contributing factors that influence how death is perceived (Krepia *et al.*, 2017:3).

The factors include age, cognitive development, experiences of death, sex, emotional development and social environment. The age of children plays a role in whether the child views death as final or reversible. Piaget's cognitive developmental stages (sensorimotor, pre-operational, concrete-operational and formal-operational) describe at what ages can children understand increasingly more complex thought processes and comprehend abstract concepts (Krepia *et al.*, 2017:3).

The Stanford Medicine of Children's Health (2024a) briefly discusses children's understanding of death. They explain that babies have no concept of death and recommend a consistent routine between the caregiver and the terminally ill baby. Similar to the explanation given by Krepia *et al.* (2017), toddlers do not understand death but instead react to the emotions of adults around them. Pre-school children cannot grasp the permanence of death; in fact, many pre-school children experience shame and guilt because they blame themselves for the sadness in their family (Stanford Medicine of Children's Health, 2024a). Pre-school children might also battle to understand why their parents cannot protect them when they fall ill.

Children and teens have a more realistic view of death. Teens may believe they are exempt from death. This means caregivers and parents need to support their identity and self-image development since a serious illness may challenge these (Stanford Medicine of Children’s Health, 2024a). Kübler-Ross (1991:155) emphasises that children are not born with the fear of death, but instead they may fear being buried. From this, the necessity to explain death to children can be seen.

#### *3.3.8.4 Explaining death to children*

The fear of death may have crept in from children’s exposure to television programmes, cartoons, movies, video games or books (Stanford Medicine of Children’s Health, 2024a). Kübler-Ross (1991:155) creates a model to explain death to children. The physical body is seen as a cocoon and represents what we look like. Then at death (regardless of how death occurred), the cocoon opens and releases the individual’s “butterfly”. This butterfly is more beautiful and freer. When the cocoon is buried, it does not contain the butterfly. This may ease the child’s worries of wondering if the person may struggle to breathe underground or suffer. Instead, death can be seen to be a natural part of life.

Parents need to realise that children of different ages may respond differently to death and that they need to be there to listen to the child’s thoughts and address their fears (Stanford Medicine of Children’s Health, 2024a). Supporting a child with serious illness requires a multi-faceted approach. It requires the parent and pastoral caregiver to be sensitive to the child’s need for spiritual, social, emotional and physical support.

### **3.4 HOLISTIC SUPPORT**

The participants in the empirical study explained how children can be spiritually supported through Bible stories, socially supported through hospital visits, emotionally supported through listening and physically supported by ensuring that the environment is normalised, while providing comfort. The spiritual, social, emotional and physical support will be outlined from an academically informed standpoint as well.

#### **3.4.1 Spiritual support**

Hospitalisation creates a security crisis for children (Louw, 1994:150). Children’s routine, sense of safety at home, as well as their perceived sense of protection from their parents can be misunderstood as rejection by their parents (Louw, 1994:151). This is supported by Ray and Landreth (2015:5) who advocate the importance of child-centred play therapy. They argue that children have a self-actualising tendency. Moreover, when children are placed in environments they perceive as threatening, their emotions and behaviours may change to promote self-protection. Ray and Landreth (2015:8) believe the counsellor should create a safe relationship and environment wherein the child can see their actualising potential again. This includes removing barriers to growth. The participants in Chapter 2

applied the principle of removing barriers to children by explaining things to them that they do not understand and allowing them to choose within the boundaries of what they are allowed to do in the hospital and with the aim of supporting the child's inner self.

Oberholzer (2016b:4) unpacks children's three interacting dimensions, namely, body, soul and spirit, and emphasises the importance of treating the individual holistically. This links to the biblical description in 1 Thessalonians 5:23: "May God himself, the God of peace, sanctify you through and through. May your whole spirit, soul and body be kept blameless at the coming of our Lord Jesus Christ." Oberholzer (2016a:4; 2016b:6) and Oberholzer *et al.* (2011:7) explain that when children experience terror in a hospital setting, it is important to provide them with spiritual and emotional support. This support will help the child develop a secure attachment to their parents and pastoral counsellor (Bowlby, 1988). To provide spiritual support includes bringing the Prince of Peace (Isa 9:6) into the child's context of confusion and fear because believers have the hope that out of suffering, God can bring perseverance, which produces character (Rom 5:3).

They highlight the "God spot" in the brain which is activated while discussing spiritual topics and which is located among neural connections in the temporal lobes. SQ is used to cope with existential crises and becomes fully developed among those who have known pain, suffering and loss and have made peace with it (Zohar & Marshall, 2000:1). Khumalo *et al.* (2020:244–245) assert that positive youth development is correlated with spiritual development; they state that a sense of meaning and social relationships can reduce stress and help people become more resilient. Benson (2006, as cited in Khumalo *et al.*, 2020:245) indicates a gap in research on spiritual development and that it ought to be given recognition, just as cognitive, social, emotional and moral development is recognised. Allen *et al.* (2020:135–138) identify different practices to foster spirituality in children who are experiencing grief, loss or trauma, such as reading books to children to combat the misconceptions they may have about God, like feeling unworthy of God's help or that God is testing them. One recommendation is that the child should write a letter to God about the questions or disappointments they have. Next, social support as a vehicle for the spiritual support of children will be discussed.

### **3.4.2 Social support**

Children are sensitive to their parents' emotions (Oberholzer, 2016b:8); if their parents are fearful, they might not want to share their own anxieties with their parents. Accordingly, Oberholzer (2016b:8) suggests that having open discussions with the family could be good for transparency. However, Nash *et al.* (2015:23) note that children may not want to open about certain topics in front of their parents. Allen *et al.* (2020:138) suggest that the child could process trauma by speaking to other children who share similar experiences. In this case, it may be a good idea to start a support group for children with life-limiting and/or life-threatening conditions. Caregivers are necessary to facilitate these types of

practices at a time when their parents are also probably experiencing a crisis and confronting the fear of losing their child.

Relational consciousness assumes that children have a sense of connection with people and God. Through the connection built between humans (for example, between a pastoral caregiver and child), our connection with God can also be manifested. The pastoral caregiver can investigate why the child may not have this connection with God by analysing whether the six conditions for relational consciousness are present in the sick child (Minor & Grant, 2014: 214). Space, process, imagination, relationship, intimacy and trust are the six conditions which nurture relational consciousness (Minor & Grant, 2014:214).

It's important for the pastoral caregiver to know what the child's needs are when faced with a life-threatening or life-limiting illness. Life-limiting conditions include cystic fibrosis and Duchenne muscular dystrophy. Life-threatening conditions include cerebral palsy and cancer (Crowe, 2003:6, 25). While cancer may involve curative treatment, life-threatening conditions include complexities, such as intellectual and physical disabilities, premature death and no cure available (Crowe, 2003:5). This means that these children have unique needs which were not really considered in the empirical study as most of the participants worked in oncology settings (P2, P3 and P4).

According to a study by Donnelly *et al.* (2005), the needs of children with life-limiting conditions were rated according to importance (where 1 is relatively unimportant and 5 is extremely important) by professionals in the field of paediatric and palliative care. The findings reflected the need for pain management (4.90), decision making (4.30), medical access and quality (4.14), respect (4.14), family-centred care (4.11), spiritual support (4,11) and psycho-social support (3,96) (Donnelly *et al.*, 2005:263–264).

Moreover, some of the needs observed by Oberholzer *et al.* (2011) in the haematology-oncology children's unit additionally include social factors. Oberholzer *et al.* (2011:3) divide the needs into external and internal dimensions as defined by the theory of health promotion in the nursing profession. The theory states that these dimensions are continually interacting with one another: the internal dimension comprises the body, mind and psyche, while the external comprises the physical, social and spiritual. Practically, this means that children have an internal need for support during their treatment's side effects, but also need external support through some predictable structures, like their family and being able to express their experiences through story or play (Louw, 2008:488–490). Attachment styles (Bowlby, 1988:8) between a child and their primary caregiver influence the child's internal and external social needs (Oberholzer *et al.*, 2011:3). In Chapter 4, the positive impact of Jesus' presence in blessing

children shows why social support is necessary as it indirectly provides emotional support to the mother and child.

### **3.4.3 Emotional support**

Children are transparent about their emotions and need effective caregiver socialisation strategies to develop emotional competence (Saarni & Camras, 2022). Careful caregiver socialisation strategies may facilitate effective emotional regulation in children who are in stressful situations like serious illness. Examples of supportive socialisation strategies by parents include: (a) acknowledging the child's emotion and validating it as a legitimate reaction to a stressful event, (b) providing comfort to the child and (c) equipping the child to cope with the stressful stimulus (Saarni & Camras, 2022:5).

The need for emotional control can also be identified as an internal need for children (Oberholzer *et al.*, 2011). The exposure to unfamiliar situations could amplify a child's existing fears (Oberholzer *et al.*, 2011) and this could contribute to a child's feeling of helplessness in the hospital and hence the need to regain some emotional control. But there are not always people to provide pastoral care to children to address these feelings of helplessness. Louw (1994:155) says that the lack of pastoral care to children might be based on the misconception that children between three to 12 years are immune to experiencing crises. The child's ability to verbalise their feelings is also a contributing factor (Louw, 1994:152). Battles and Wiener (2002 as cited in Oberholzer *et al.*, 2011) emphasise the stress children with chronic illness experience, having to endure invasive procedures, side effects and repeated exposure to the process of hospitalisation. This need can be alleviated through providing spiritual support by introducing children to how they can give their worries to the One who is in control over everything. As 1 Peter 5:7 states: "Cast all your anxiety on him because he cares for you."

#### *3.4.3.1 Impact of trauma*

Levine and Kline (2007:197) highlight the detrimental effects which a lack of physical and emotional support during hospitalisation can have on a child later in life. They share the story of Jeff Dahmer who had a traumatic hospital experience at age four. Despite his resistance, he was strapped to a hospital table. Afterwards, he became secretive and depressed, and later the serial killer he is infamous for. Theodore Kaczynski is another example of the impact hospitalisation trauma can have on a child. At the age of nine months, he was isolated from his mother for seven days and was strapped to a paediatric examination table for a rash he had. Afterwards, his mother said he never really bonded with anyone and later became a university and airline bomber, known as "Unabomber" (Levine & Kline, 2007:184). The physical impact this trauma can have on children may include "acting in" and "acting out" (Levine & Kline, 2007:185). "Acting in" is explained as a child's internalisation of trauma, which can later present through anxiety and body pains, whereas "acting out" can present through hyperactivity and aggression.

P3 explained how a child wet their bed because of family trauma and how his grandmother scolded him for embarrassing her. Levine and Kline (2007) highlight how children who are treated insensitively in the face of their trauma can develop hypersensitivity, fearful or clinging behaviour, bed-wetting or become aggressive and bully others. To avoid such outcomes and instead promote physical support of children during hospitalisation, Levine and Kline (2007) recommend that medical professionals and caregivers should be sensitive to the needs of these children. P2 did communicate the doctors' acknowledgement of their role as pastoral caregivers and those doctors entrusted them to convey certain messages to the child's family, such as disappointing news, knowing that the caregivers were equipped to communicate in a sensitive manner. For pastoral caregivers to communicate information regarding the child's illness or passing can cause grief for the family of the child with a life-threatening and/or life-limiting condition. Accordingly, caregivers need to understand the process of grief in order to better support the child's family. The ill child may also grieve and the caregiver should support the child during their phase of mourning.

#### 3.4.3.2 *Grief*

Louw (2008:491) explains that a child may either mourn over a short period or the child may have difficulty expressing their grief. Consequently, it is important to have an understanding of the stages of grief to identify why a child may react in a certain manner and respond appropriately.

- *Stages of grief*

Kübler-Ross's stages of grief include denial, anger, bargaining, depression and acceptance (Kübler-Ross & Kessler, 2014). Grollman (1991:4) presents guidelines to help deal with children's grief and address death. Grollman encourages schools and churches to discuss death and to allow children to experience emotions associated with grief. P1 openly allows a child to feel anything by directly asking the child if they know why their parents brought them to her for counselling. Grollman (1991:4) is opposed to discussing death through half-truths to children by saying, for example, that a dead person is "sleeping". P2 said it was confusing when a child's culture did not allow her to discuss the death of her brother. The role of the child should also not be altered to become like adults. This can be applied to the sick child's siblings who may be told to "be brave" for their parents' sake (Grollman, 1991:5). The child ought to be allowed to process their grief in their own way and to be spoken to at a level they can understand.

#### 3.4.3.3 *Fears*

Children have an emotional need to have their fears addressed (Louw & Louw, 2014:186). Most fears, Kübler-Ross (1991:149) argues, are unnatural and caused by the suppression of children's emotions. The ICARE model (Hays-Grudo & Morris, 2020:67) shows the impact adverse childhood experiences (ACEs) and protective and compensatory experiences (PACEs) can have on a child who is exposed to

stress. The boy who drew his father hanging himself in Chapter 2 is an example of a traumatic event or ACE which occurs between birth to 17 years of age (Centres for Disease Control and Prevention, 2024). According to research on ACEs, early death can be an eventual result, as traumatised patients who, for instance, witness a suicide might adopt risky behaviour as a short-term solution which damages their health (Hays-Grudo & Morris, 2020:47). Instability due to divorce can also negatively impact the child's sense of safety and ability to bond (Centres for Disease Control and Prevention, 2024). By contrast, the positive social support received by the child can buffer them from the adverse impact trauma can have on their body, soul and mind.

Regarding childhood fears, Louw and Louw (2014:186) argue that these may differ based on context, temperament, experience and age. Children may also mimic their parents' fears. The fears children experience at different ages will now be discussed, as they can act as a guide to understanding the emotional support they might need. According to Louw and Louw (2014:186), children between birth and six months might fear loss of support as this is the time of building basic trust (Erickson, 1950:219); loud sounds can also startle them. Between seven to 12 months, strangers, unexpected objects and heights are believed to instil fear in infants (Louw & Louw, 2014:186).

From one to six years, separation from parents is an expected fear in children (Louw & Louw, 2014). From ages two to 12, the dark can stimulate fear, while older children may fear "bad people" and supernatural creatures (Louw & Louw, 2014). Physical injury is an important fear from ages six to 12; hospitalisation might further aggravate this fear (Oberholzer, 2016a). Between ages nine to 12, tests, exams and school performance can be experienced as fears by children (Louw & Louw, 2014: 186). Oberholzer (2016a:6) proposes Chapman and Campbell's five love languages (2016) to promote the spiritual and emotional care of children diagnosed with cancer. The five love languages are physical touch, words of affirmation, quality time, gifts and acts of service (Chapman & Campbell, 2016). These acts are all ways in which Jesus' unconditional love can be communicated with children.

#### *3.4.3.4 Anger*

Louw (2020:2) describes that when a person is frustrated, they might blame another for it. Sometimes with angry patients, God might be accused of treating them unfairly. Behind this anger may be frustration, fear, anxiety, hopelessness, loneliness or despair. The child can be assisted to verbalise their anger when the pastoral caregiver first understands the four basic issues in relationships which may be behind the anger.

The child might have unfulfilled needs, including the need for intimacy or unconditional acceptance which is not yet met (Louw, 2020:4). Secondly, the child may have unrealistic expectations and disappointment, which fuels their angry responses. In addition, the child might feel that there are too

many external demands, which might make them believe that they are not good enough or a failure. Lastly, Louw (2020:4) believes negative feedback from others may break down a child's sense of value. Pastoral caregivers are encouraged to approach the patient as someone who is presenting with anger, instead of viewing them as an angry patient, as this labels them with an angry identity.

Spiritual and emotional needs can be positively or negatively impacted by the physical support given to the child and their family. This is illustrated by Bronfenbrenner's ecological model in the next section.

#### **3.4.4 Physical support**

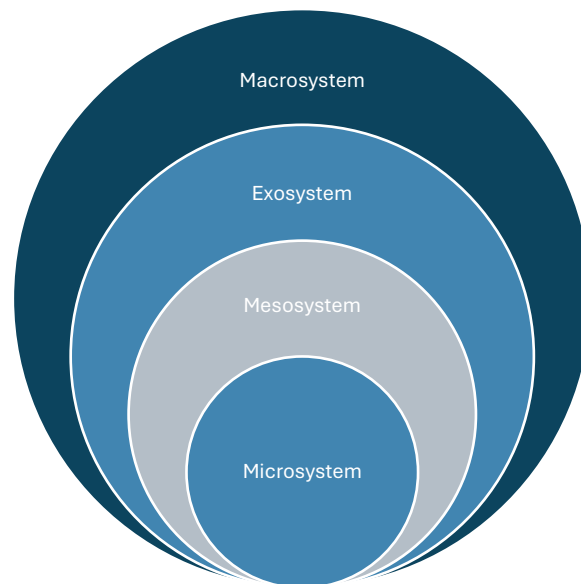
Moving to the external environment, children have a physical need to normalise their environment by reducing negative stimulation. Physically, Levine and Kline (2007:186) encourage parents to be proactive in supporting children and minimising the physical discomfort the child might be experiencing in hospital. P2 modelled this by asking the family members to eat in the kitchen, instead of the ward where the sick children were. This was to ease discomfort for the child who was not allowed to eat or drink anything before a medical procedure.

Many children receiving palliative care from diagnosis to death are at risk of inadequate physical pain management (ICPCN, 2022). This can be attributed to limited access to medicine, age-related factors and lack of knowledge regarding how to treat the pain effectively (ICPCN, 2022). In upholding Hippocrates' edict to doctors to "first do no harm", the pastoral counsellor can learn from other practitioners' writings on working with children. Lampert (2004:2) encourages healthcare workers to proceed slowly, watchfully and to be sensitive. She provides two examples where caution must be taken to do no harm unconsciously. Children who have been sexually assaulted (like some children P1 works with) may be fearful of sexual assault when the pastoral caregiver intends only to give a friendly hug. Another way children can be physically and emotionally supported is to use humour sparingly since the child may misinterpret it as the adult laughing at them, especially when the child is used to cruel criticisms at school or in other contexts. Language may also be a barrier in this respect as humour may be lost on children speaking a second language.

The ICARE model highlights how environmental stressors increase a child's stress levels, negatively affecting their physiological systems (neurologic, immunologic, metabolic and endocrine), which may lead to impaired developmental systems and negative health outcomes (Hays-Grudo & Morris, 2020:67). The lack of protection for the child from environmental stressors might lead to hypervigilance, a lack of social connection and a lack of emotional regulation (Hays-Grudo & Morris, 2020:67). If parents provide adequate physical support to children, children can experience support in

other facets of their lives. But for parents to effectively support their children physically, emotionally, socially and spiritually, they also need to ensure that their internal and external needs are met.

- *Fig 4: Bronfenbrenner's ecological model*



#### *3.4.4.1 Bronfenbrenner's ecological model*

Bronfenbrenner (1981:21) explains the two-directional impact which the external environment and the person can have on one another. Hence, the person's development is not only influenced by their environment, but they are also believed to restructure and impact their environment. The environment which impacts the child extends beyond their direct environment (Bronfenbrenner, 1981:22). In other words, the micro-, meso-, exo- and macrosystems are concentric structures within each other as seen in Fig. 4. Similar to Erickson's theory of the eight stages of psycho-social development (1950:119–234), this ecological model considers the continuing development of a person within their context.

- *Microsystem*

The microsystem is defined as the 'pattern of activities, roles and interpersonal relations experienced by the developing person' (Bronfenbrenner, 1981:22). This includes the direct impact which the role of being a child and having an illness has on a child and their family. The interactions which the parents and siblings have with the child also form part of the child's microsystem. The patterns of activity, including school, play, eating, treatment and sleep, have impacted the child's routine and development and directly involve the child.

Children can be empowered to cope with the side effects of cancer treatment through visual pictures and books. The CANSA non-governmental organisation creates visual story books to address frequently asked questions and issues related to cancer (CANSA, 2023).

- *Mesosystem*

The mesosystem describes the interactions between participants (secondary links) in which the participant (primary link) is involved. Bronfenbrenner (1981:210) explains that this includes the settings the child is involved in, for example, the parent and teacher who interact with one another. It is important for pastoral caregivers to understand how the interactions between doctors, nurses, pastoral caregivers and parents can have an impact on the sick child.

- *Exosystem*

The exosystem refers to the environments which indirectly impact the child (Bronfenbrenner, 1981:236). These include the parent's work environment which the child does not enter, but which still affects the child since the work directly impacts the child's well-being through financial support and the parents' work stability. A life-threatening and/or life-limiting condition puts a lot of financial pressure on parents. They may need to take time off from work to take care of the child or to find and possibly fund a caregiver. Access to healthcare also impacts South African children, as Maluleke (2020) attests that many children are far from healthcare centres.

- *Macrosystem*

The macrosystem describes the broader social, political and cultural structures and contexts and how they impact a person's development. Bronfenbrenner (1981:258) explains that studying the macrosystem of an individual helps to understand their ethnic and cultural differences in socialisation practices and outcomes. Thus, the macrosystem helps pastoral caregivers to comprehend the different families they come across and to keep different cultures and styles of child-rearing in mind (Bronfenbrenner 1981:258). Bronfenbrenner's ecological model can be used as a roadmap to investigate the child's micro-, meso-, exo- and macrosystem and to understand and treat them more holistically. It can also be used to prepare the child for what will happen next, as they don't react well to medical surprises or dishonesty about the treatment (Levine & Kline, 2007:189). P1 modelled this with the child with the heart condition by preparing them for hospital noises, environment and smells beforehand by "playing" hospital. Levine and Kline (2007) recommend that parents organise a time when the child can meet the surgeon before they wear their surgical garb and mask. In this way, any misconceptions that the doctor is a monster can be avoided. To keep the holistic perspective of supporting these children in mind, pastoral caregivers can use practical techniques which are recognised in academic literature to provide continued professional pastoral support to children with serious illnesses.

#### 3.4.4.2 *External pastoral resources*

Oberholzer *et al.* (2011:3) describe therapeutic resources which can be used to meet the external needs of children in haematology-oncology units. Psychoeducation is a tool used to inform a person about their condition and then equipping them with the knowledge of how to cope with it. Children have social, spiritual, and physical external needs (Oberholzer, 2011:3). Physically, children have a need to

reduce negative sensory stimulation and to normalise their environment. Borrowing from occupational therapy, pastoral caregivers can include sensory integration into their therapeutic resources to facilitate pastoral care in normalising the child's environment. In addition, Oberholzer (2023) encourages taking the child's own blanket, pillow and some familiar toys to the hospital to make the environment more familiar for the child. Externally, children also have a need for spiritual support and religious activities. Oberholzer (2011:7) states that mealtime and bedtime prayers and Bible study should be upheld as part of the child's routine during hospitalisation. Moreover, a child's fear of punishment by God or their parents for perceived wrongdoing can be addressed through religious participation. Oberholzer (2016b:9) emphasises the importance of a caring presence, as well as finding meaning through therapeutic play, show-and-tell and the use of a prayer tree to promote religious participation.

Socially, children have a need to establish a trusting relationship (Oberholzer, 2011:3). This can be done through the support of a caregiver, parents and friends of the child. To establish such secure connections will help children to form healthy attachments to those around them. Expressive pastoral techniques, empowerment-focused techniques, godly play and other pastoral techniques will now be explored as ways to build a relationship with a child.

### **3.5 PASTORAL TECHNIQUES**

Louw (1994:152) explains that pastoral techniques which are used to build a relationship with a sick child can range from inquiry about the child's interests and immediate environment to using hand puppets or art to meet a child's need to be creative (Louw, 1994:153). Grobbelaar (2020) notes the low and high view of childhood in shaping theology conveyed to children. This is an important point, as how one views a child as a caregiver will also impact the way pastoral techniques are applied.

Other techniques, such as logotherapy, puppets, play, storytelling, the discussion of God images, doxology and expressive therapy can be used as means to draw the child and family back to the centre of meaning, which is ultimately to have eternal life in the presence of God. In the face of this, the worries of the present life fade away. Pastoral techniques refer to ways pastoral care is facilitated between the caregiver and counselee. Expressive therapeutic techniques used by the participants and other general techniques, including storytelling and drawing, will now be discussed. Thereafter, preventative support techniques and ways to actively empower the child through various pastoral techniques will be examined.

#### **3.5.1 Expressive pastoral techniques**

P1 and P4 make use of drawing and play techniques to address current and past fears and traumatic experiences the child may carry. P1 uses the storm technique, along with colours representing different emotions to help the child identify difficulties in their life, the emotions around the experience and

where Jesus is in their storm, as inspired by Mark 4. P4 makes use of wordplay and imagination techniques to convey meaning and encourage children to communicate with Jesus through play. P4 says her goal is to show children how easy it is to talk to God. She uses the child's imagination and adventure techniques discussed under death preparation in Chapter 2 to address possible separation anxiety children might face when separated from their parents. The way P4 does this is to take the child on an imaginary adventure and to ask questions that the child would have to ask Jesus. This teaches the child to talk to and listen to the Holy Spirit. This technique achieves security in being with Jesus, which removes separation anxiety as the child realises their parents are there with them and Jesus (P4).

Du Plessis and Breed (2020:3) note expressive pastoral techniques' close association with African cultures since Africans are innately more expressive than Western cultures. The chosen medium through which an African individual expresses themselves (art, dance or song) becomes the "co-caregiver" in the healing process. However, the caregiver ought to feel comfortable with the way the child chooses to express themselves. For example, if a child expresses their emotions in a loud manner because of their cultural upbringing, the Western caregiver should be able to respond appropriately. Importantly, the counsellor must not assume the role of interpreting the art but instead use it to inquire regarding its meaning (Du Plessis & Breed, 2020:4). P1 said if a child draws snakes, one should not just assume there is something wrong in their lives as snakes are usually associated with evil. The simple explanation may be that the child's family has pet snakes. Thus, the child's art and play can be used as vehicles towards personal and communal healing in contextual pastoral care.

### *3.5.1.1 Using play*

Play is an effective technique which can be integrated with theology, as evidenced in P1's play therapy. Children use play to process their thoughts and emotions in times of crises and thus, pastors and caregivers can meet children in this way at their level of communication (Louw, 1994:152). Oberholzer (2023:36) promotes play as a way for the child to cope with stressful situations and familiarise themselves with a new environment. Play is beneficial as it creates new cerebral maps with emotional regulation (Brown, 2015: xii). Clinicians see the benefit this has for a child's development in terms of their flexibility and adaptability. These are important for a child, especially when they are confronted with an unfamiliar environment. Louw and Louw (2014:191) highlight the importance for children to develop emotional regulation since it helps them to connect and respond appropriately to their own and others' emotions. Both Louw (2008:448) and Crenshaw and Stewart (2015)'s work highlight the benefits of play in helping children process their thoughts and emotions during a crisis.

Crenshaw and Stewart (2015:1) recognise the different psychological models which apply play therapy differently. Child-centred play therapy focuses on the relationship between counsellor and child as it is believed to be fundamental in the child's healing process and recognises that play is the appropriate

developmental way to connect with children (Ray and Landreth, 2015:1). These Rogerian principles can be seen to be effective when meeting children for the first time – both P1 and P2 conveyed the importance of relationship-building with children and accepting them as they are. Ray and Landreth (2015:6) emphasise the non-judgemental, consistent acceptance of the child for them to move towards free expression of what they feel, think and do. The caregiver needs to be aware of the danger of humanism inherent in Roger’s theory of caregiving. This means the caregiver should link the child to God and Scripture, instead of either being their saviour or creating the idea that the child can empower themselves (client-centred) by looking inward to their human resources available.

P4 uses death-preparation techniques which address the separation anxiety many children feel before they die. Louw (1994:151) explains that when smaller children are removed from their safe home environments, one of their emotional reactions may be to experience extreme separation anxiety since these smaller children have a higher need for acceptance and security. Therefore, with younger children, P4 addresses separation anxiety to restore a sense of safety, instead of directly addressing fear of death as one may be inclined to do with an adult patient. Imagination is often an important component of expressive pastoral techniques as children often express that which they conjure up in their imagination.

### *3.5.1.2 Storytelling*

The benefit of utilising storytelling is that stories stimulate a child’s imagination and can be used to convey God’s presence during suffering through biblical narratives. Richard Gardner (Louw, 1994:153) uses a story-telling technique which invites children to participate in a make-believe radio broadcast. Adults start by inviting the child to tell a story and then ask what lesson the story conveys. Thereafter, the adult uses the same characters as the child but can convey different events to reach a similar or different ending with a moral lesson (Louw, 1994:154).

Bible stories can be used to remind people of God’s active presence in human history. Louw (2014a) recalls the example of the phrase “I am the Lord your God who brought you out of the land of slavery” which was used to comfort Israel at times of great suffering. The aim of this refrain was to remind the Israelites of God as their King and Saviour. Narrative can especially be used to promote pastoral care to children since they are invited to communicate their experiences. These experiences can then be cleverly linked to stories in Scripture (Louw, 2014a:125). Within contextual pastoral counselling, storytelling is a tool to identify peoples’ needs within their current environment and worldview (Du Plessis & Breed, 2020:3). Gospel music and dance movement therapy are useful to assist children to connect with themselves and others.

### 3.5.1.3 Gospel music

Gospel describes a popular genre of Christian music. The benefit of using Christian children's music is that it is catchy or "sticky", plants a seed in the child's heart and teaches a child how to worship God (Richmond, 2022). Psalm 8:1–2 forcefully conveys the power of children's praise to Jesus: "From the mouths of children and infants You have ordained praise on account of Your adversaries, to silence the enemy and avenger." Ellicott's commentary (Ellicott, 2024) explains that this psalm highlights the innocent wonder of a child as the truest form of worship unto God, especially compared to the religion of the Pharisees of Jesus' time. Age-appropriate Christian music can be used to teach children the gospel and wonder of God. Similarly, dance is another a way to use music to facilitate fun and healing among children.

### 3.5.1.4 Dance movement therapy

Also known as creative movement therapy (CMT), dance movement therapy (DMT) utilises bodily movement to facilitate healing and self-expression (Vardhan *et al.*, 2022). Koch *et al.* (2019) found that applying DMT decreases depression and anxiety, increases cognitive and interpersonal skills, and improves the quality of life of the individual. The European Association of Dance Movement Therapy (EADMT) defines DMT as: "the therapeutic use of movement to further the emotional, cognitive, physical and social integration of the individual" (EADMT, 2021). In 1999, Mendelsohn said that movement could help minimise the trauma, stress and suffering children may undergo during hospitalisation (Mendelsohn, 1999: 65). Dance or movement can achieve this by promoting contact, communication and expression of physical and emotional needs. This suggests that pastoral caregivers can use dance and movement to promote the child's self-image. Goodill and Morningstar (1993:24) believe the child's self-image is threatened by illness and hospitalisation which often directs the child's attention to their body parts affected by the illness. Even though DMT was already researched in the 1990s and known for its healing benefits, it is still an underutilised technique in 2019 paediatric oncology settings (Tortora, 2019:1). All four participants in the empirical study did not make mention of DMT as one of their pastoral techniques, which would suggest that it is not used in their places of work. Tortora (2019) asserts that DMT could restore children's innate sense of playful, spontaneous physical activity and help them regain a sense of control, which is so often compromised in children undergoing oncology treatments. It however must be recognized that dancing in a hospital might have some obstacles, like hospital equipment, beds and other patients which need to be considered. Using art and puppet dolls will now be explored as a pastoral technique as these are ways children can express their stories and emotions.

### 3.5.1.5 Puppets and art techniques

The benefit of using puppet dolls is that children feel more comfortable with them than they would with an adult stranger (Louw, 1994:153). Drawings can reveal a child's immediate perceptions and hidden

feelings, as well as diagnose a child's comprehension of God, other family members and their hospital experience. The benefit of using art, such as drawing or painting, with sick children is that it helps overcome the obstacles of communicating with a child who has a limited ability to verbalise their feelings (Louw, 1994). In Chapter 2, it was mentioned that P1 uses a combination of Bible stories and play in her pastoral techniques in working with children affected by trauma. The benefits of play therapy as an effective pastoral technique will now be discussed as this can assist caregivers and faith communities in ministering to children with life-threatening and/or life-limiting conditions, such as cancer.

### **3.5.2 Preventative support techniques**

In her pastoral work, P1 sometimes focuses on hospital preparation for children. As mentioned in Chapter 2, P1 simulates the scenario which the child is likely to encounter in hospital by familiarising the child's sub-conscious to what they might see, hear, taste and touch. To prevent fear which an unfamiliar environment might instil in a child, P1 teaches parents how they can normalise a hospital environment by bringing something with from home, such as a teddy bear or a parent's jersey. Other preventative pastoral techniques which can be implemented include non-judgemental attitudes to promote emotional support to the family and child. Bible teachings, prayers and godly play rituals can be used to create structure, an atmosphere of spiritual guidance and support to the child to make sense of their situation. Finally, crises can be averted by pastoral caregivers asking the right questions to make the logistics easier for families to navigate. For example, the pastoral caregiver can inquire about who in the community can help with shopping, looking after other siblings, etc. Next, pastoral techniques aimed at empowering these children will be discussed.

### **3.5.3 Empowerment-focused pastoral techniques**

All four participants model empowering children with serious illnesses by asking them which activity they would like to do. P2 and P3 give the children in oncology wards a choice between what pastoral activities they would like to do, such as reading, being quiet, storytelling and play. During the imaginative play exercises P4 uses, she asks the child questions to teach them to communicate directly with God. Other pastoral techniques will now be discussed, since they could be useful contributions to the practical field of pastoral care to children with life-threatening and/or life-limiting conditions.

Oberholzer (2011:3) identifies three main internal environmental needs in children. These include the child's mind (volition, emotion and intellect), spirit and body. Regarding the intellectual, internal needs of children, the parents can be informed that the child may need their support in keeping up with schoolwork, as well clearing up any misconceptions they may have (Oberholzer, 2011:3). Emotionally, resources which can be equipped to meet this internal need include using humour, play interventions, music, literature, tokens of appreciation and electronic devices (Oberholzer, 2011:3). Volition refers to

the mind and children's need for control. Control can be promoted by choosing to give it to God freely, knowing that He is in control. This can be linked to God images the child already has; Scripture can then be used to form new revelations of God in the child's mind. P4 shared that she has tried laugh therapy before and that music is an excellent way to get people who are going through something difficult to connect and heal. However, P4 found that laugh therapy was challenging to apply in oncology settings since each family member that attended was in a different situation than the person next to them.

Frankl's theory of meaning was described under the developing child. Now it will be explored as a pastoral strategy.

### **3.5.4 Logotherapy as a pastoral technique**

Frankl (2004:108) argues that diagnosing a patient who experiences existential distress with a mental disorder often causes doctors to bury their patients under drugs, which tranquilise the patient's despair. Instead, Frankl (2004:108) believes the "pilot should be piloted" through their existential crisis toward growth. Inner conflict does not equal neurosis, but instead is healthy when it leads towards suffering, which is rooted in existential frustration over life's worthwhileness. Therefore, unlike the psychoanalytic school of thought, logotherapy encourages the tension created in man's search for meaning because "when man has a why to live for, he can bear almost with any how" (Nietzsche as quoted by Frankl, 2004:109). Thus, logotherapy aims to assist people in their wrestling to find life's why (2004:108).

### **3.5.5 Gestalt therapy**

Gestalt therapy was first developed by Fritz and Laura Perls in the 1940s. Gestalt therapy is a form of psychotherapy where self-acceptance and self-awareness are vital to personal growth. Gestalt play therapy was further explored in the 1970s by Violet Oaklander who combined the principles of gestalt therapy with play therapy (Oaklander, 2001:46). Similar to P1's Christian play therapy, Oaklander uses creative play tools, such as drawing, a sand tray, puppets and clay. Lampert (2003:12) is a gestalt therapist who uses storytelling as part of her method to bring healing to hurting children. She explains that her motive is to validate the child's phenomenology (way of viewing the world). But when the child's stories are morbid, she uses honesty to suggest other possibilities to them.

Lampert shared a case in which an eight-year-old child told a sombre story of a baby being left alone on an island. It turned out she was kidnapped six years before. Lampert asked the child if someone came to help the baby, to which she replied that no one did. The therapist responded by saying that it made her feel terrible. The child said that perhaps "a nice old lady and nice old man could come to take care of her". After this therapy session, both the child's parents were unable to take care of her and her

grandparents ended up caring for the child. Lampert (2008:13) attributes the child's "knowing" during the therapy to perhaps a prophecy of the future. Pastoral caregivers might also call this type of "internal knowing" a revelation by the Holy Spirit which gives the child a sense of hope and peace (John 14:26–27). P4 shared examples of this internal knowing in which children knew they were going to die before their parents did.

Contact and resistance are crucial terms which will not be unpacked fully at this stage. However, the importance of respecting children's cues of resistance are important for caregivers to remember as these are ways of coping. First, the child should be allowed to feel safe to be honest and work with the caregiver at their own pace, as P1 indicated. Oaklander (2001:49) agrees that children know when they can handle the material beyond their resistance. Intense emotions like anger can be normalised through gestalt play therapy by using projective techniques, such as play, drawing and creative drama (Oaklander, 2001:51).

Having identified the benefit of expressive and gestalt play techniques, godly play can be seen to be a useful pastoral technique to teach children to recognise God, His presence and voice. Prophetic awareness can be seen in Scripture when prophets knew of future events before they occurred. Jesus knew the details of His death, as can be seen in the gospels when Jesus prayed in the Garden of Gethsemane and told Judas at the Last Supper that he should do what was in his heart. The Godly Play model will now be discussed.

### **3.5.6 Godly Play**

Berryman (1991:61) is recognised as the founder of Godly Play and attributes its roots to storytelling and the educational theory of Maria Montessori (Berryman, 2009:23). Six factors to effectively learn religious language will be examined (Berryman, 1991:61). These include wonder, play, community (ethics), the creative process, the structure of the religious language system and existential limits (Berryman, 1991:62). The religious language system gives Godly Play structure to learn the Christian language system, including sacred stories and parables (Berryman, 1991:62).

Montessori (Gentaz & Richard, 2022:1, Berryman, 2009) encourages children to be active interpreters of their learning and promotes their intrinsic motivation and curiosity to learn. Berryman was mentored by Sofia Cavalletti, whom he describes as a third-generation Montessori religious educator (Berryman, 2013:56). Although she was Berryman's mentor, Berryman and his wife Thea moved away from the initial ideas purported by Montessori educational worldview (Berryman, 2013:78). In a godly playroom, Berryman believes there are four primary languages: the language of sacred stories, parables, liturgy and silence (2008:12).

Minor and Campbell (2016:39) describe Godly Play as a Christian approach to children's spiritual formation. Godly Play is effective as it aims to give children a vocabulary to express their experience of God and to make meaning of their lives. Although it was originally intended for Christian churches, it is now used for day schools, hospitals, homes and nursing homes.

#### *3.5.6.1 Identifying Godly Play*

Berryman (2009:116) explains that Godly Play can be distinguished from other forms of theological education in that God's presence is welcomed, usually in a setting of a small group of children playing together. Berryman advocates using a living spiral curriculum. The living spiral curriculum involves three characteristics, which include the three generating circles, the three steps to conscious language systems and the three cycles of three years (Berryman, 2009:119). These characteristics of threes guide the adult mentors through the child's developmental phases. Learning the living spiral curriculum can help caregivers working with sick children to be cognisant of the age of the child and using the time of year to use the Christian language system to build a relationship with the child. For example, if the caregiver meets a five-year-old boy during Passover time, the caregiver can use the story of Jesus to bring meaning to the child's illness or limitation.

#### *3.5.6.2 Three generating circles*

The Godly Play spiral moves through early, middle and late childhood. There are also three generating circles, which include the circle of the child's creative process, the circle of class dynamics and the circle of the turning of the church year (Berryman, 2009:119).

#### *3.7.6.3 Three steps to a conscious language system*

The layout of the Godly playroom embodies the Christian language system (Berryman, 2009:122). The mentors assist children to form this consciousness about the language system from what Berryman adopted from Montessori. It is called a "three-period lesson". The first step of this three-part lesson occurs when the storyteller shows the child a shelf with names on it (Berryman, 2009:122–123). Typically, Godly playrooms will look the same because certain lessons are always packed on certain shelves. The caregiver will show the child the shelf or lesson to familiarise the child with the content and room.

The second step occurs when the storyteller states the name and asks the children where the lesson or shelves are in the room. Thirdly, the storyteller points to a lesson or shelf and asks the children to discuss that story or shelf unit. This technique helps children move from unconscious intuition to consciousness (Berryman, 2009:123), as vague understanding progresses towards the child's own grounded and functioning understanding of how the Christian language system works.

#### *3.5.6.4 Three cycles of three years*

Children are divided into three cycles of three years. From ages three to six, children are taught how the class works, the different parts of the classroom/curriculum and core lessons (Berryman, 2009:125). From the ages of six to nine, the spiral widens, and the core lessons are presented again. This is the time where some children may be frustrated by the repetition and Berryman (2009:125) attributes this to a failure of imagination to go deeper into the lesson. The mentor aims to challenge the children to seek more in each lesson than the previous year. The fruit of deeper imagining will be seen in children's expressive art, wondering and private conversations shared between the mentor and children. For children in the third cycle from ages nine to 12, they continue to become more conscious about the community of children, the lessons and classroom organisation. Berryman (2009:126) points out that this is the reason for children's increasing interest in church and the people at church. These lessons of the third cycle include worship in the tabernacle, synagogue and church, as well as lessons about communion (Berryman, 2009:126). The goal of Godly Play is for children to have an internalised Christian language system by the time they reach adolescence (Berryman, 2009:138).

#### *3.5.6.5 Dynamics of a Godly Play session*

There are two primary adult figures, called the storyteller and door person, who work together to help the children enter the room, listen attentively and help contribute to the community of children. The storyteller sits at the focal point where they can be seen from the doorway. Meanwhile, the door person is at the door which is important at the beginning and end of the class. The door person also fulfils the roles of greeting the children by name, helping them cross the threshold, assisting the children during response time, guiding children to deliver "the feast" (snack time) and maintaining the threshold and interpreting it to the parents at the door (Berryman, 2009: 29). Godly Play assumes that God is present and thus there is room for God to reveal himself (Berryman, 2009:116). Since the way one views God affects one's behaviour, God images will now be discussed.

### **3.5.7 The discussion of God images**

God images are set ideas which one has about God's attributes. These images or metaphors are important for individuals to understand God and His identification with human needs and suffering within pastoral care (Louw, 2014:58). The benefit of God images is that they convey meaning to the suffering by communicating God's compassion and involvement in our crises. Thus, the image of God as shepherd, servant, judge, king and saviour can be useful metaphors to incorporate into pastoral techniques to restore the child's understanding of who God is and what His role is in their present challenging circumstances. P1 uses play therapy with a shepherd, wolf and sheep toys to convey the message to children that Jesus is the Good Shepherd who protects His sheep (John 10:11-15). The child is the sheep in the analogy and so the child gains the understanding that God will protect them in real

life, just as He protected the sheep during play therapy with the caregiver against the toy wolf (played by the caregiver).

The Good Shepherd image helps children understand God's protection and care for them (Psalm 23). The servant metaphor promotes the idea of Jesus identifying with human suffering and that Jesus was punished for others' sins, gaining salvation for the sinful who fall short of God's glory. God as judge conveys the importance of God's justice against all sin. This can be comforting when parents lose a child. Then the parents can know that Jesus died for our illnesses on the cross and thus, they will one day see their child again, despite the temporary earthly loss – although the Word does teach us that there will not be relationships in heaven as we have on earth (Matthew 22:27-30). The parents' hope is therefore not so much in the reunion of the parent-child relationship, as in their hope of everlasting life with God.

However, Louw (2014:78–80) emphasises the importance of discerning which God image to use in what context since it may promote anxiety and guilt in the listener if they think, for example, that God is only a Judge, and the caregiver emphasises only this characteristic of God. God as King and Ruler conveys His power and control over everything. The impact which this can have, is to empower the counsellor, knowing they belong to the Kingdom which will not end (Luke 1:33). This promotes a sense of belonging and safety with Jesus who is the victor over death. P4 indirectly promotes the God image of Jesus as Ruler by guiding the child to communicate with Jesus about what they want in His Kingdom and where they want to go with Him. The God image of Saviour communicates comfort, compassion and freedom from sin and pain to the child and their family. Louw (2014:81) emphasises the importance of having an appropriate image of God to suit the child, even though it may not be dogmatically correct. The goal is not to correct any dogmatic theory, but to let the child feels safe in the presence of God.

This means the child and their family can be vulnerable towards Jesus who is the Redeemer of their being. God images can be conveyed through puppets, art, storytelling or through play to expand the child's understanding of God in their life and in their crisis, promoting inner healing and peace. Counted (2015:4) argues that God images are born out of the parent-child attachment. Thus, the parent-child relationship is an important influence on the child's attachment to God.

### **3.5.8 Doxology**

Doxology is an awareness of the gift of life and an expression of gratitude to God, despite the experience of suffering (Louw, 2014c:5). Doxology can be promoted through practising gratitude with children who have life-threatening and/or life-limiting conditions. Music, which conveys praise and gratitude to God, can be used as a pastoral technique to encourage doxology. Prayer is also a form of doxology in which God can be praised.

A discussion of the SOZO<sup>11</sup> prayer ministry follows, as it shares similarities with the imagination techniques used by P4 in her work with sick children.

### **3.5.9 Prayer ministry**

SOZO ministries was started in Bethel Church in the USA in 1997 (SOZO SA, 2024b). It is a prayer ministry which expanded to South Africa; it requires that two prayer ministers act as vessels of intercession to have the counsellee encounter the Father, Jesus and Holy Spirit in their imagination. This Spirit-led interaction aims to identify wounds and lies an individual believes and to facilitate inner healing. This ministry is a powerful technique to provide relational awareness of God in a safe space mediated by trained counsellors.

*Sozo* is a Greek word meaning “saved, healed, delivered” which occurs 110 times in the New Testament. Sozo refers to the finished work of Jesus at the cross (SOZO SA, 2024b). This is relevant for people’s salvation (Rom 10:9), for their healing (Matt 9:22) and for their deliverance (Luke 8:36). SOZO for Kids was created to minister to children and youth, aged five to 14. This course teaches children about forgiveness and bitterness and helps children to build a relationship with Jesus (SOZO SA, 2024b). The heart behind this children’s ministry is to model Proverbs 22:6: “Start children off in the way they should go and when they are old, they will not turn from it.”

Nye (2009:60) explains that encouraging children to use their imagination when they pray can help them understand that prayer can be an informal conversation with God. This was modelled well by P4’s imagination exercises to encourage children to talk to Jesus. She asks children questions and then she nudges them to ask Jesus directly through prayer and use their imagination. Free-flowing use of imagination, as well as structure, can be taught to children in their prayer life (Nye, 2009:61). Relationship can be the vessel used to teach children about prayer, just as Jesus, out of His relationship with His disciples, taught them the Lord’s prayer. Use of imagination is also part of building a child’s relational consciousness (Nye, 2009:56).

## **3.6 PARENTS’ NEEDS**

### **3.6.1 Support system**

Spiritual needs which parents may have include the need for intimacy, freedom, hope, fulfilment of life competencies and support (Louw, 2008:290). The need for intimacy means that parents may have

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<sup>11</sup> SOZO is a prayer ministry focused on addressing spiritual “roots” or ties which hinder an individual’s connection with God. Lies, wounds, unforgiveness and sin are renounced in the inner healing process of SOZO (Bethel SOZO SA, 2024).

expectations that the pastoral caregiver must show them the same unconditional acceptance given to the child.

Freedom is presented by the pastoral caregiver to help the parents deal with any guilt, self-blame and unforgiveness they may be struggling with. Hope is presented through ministering life to them, bringing them back to the good news of the gospel, as well as helping parents to overcome any existential frustrations they might have regarding their child's situation (Louw, 2008: 290). Parents also have a need for a support system to help them cope with feelings of helplessness and hopelessness. If the pastoral counsellor specialises in working with children only, they must refer the parents to colleagues who can assist them with pastoral counselling.

Children often respond to their parents' emotions, especially if they are unable to grasp the impact of illness and thus it is important for parents to have access to pastoral support (Louw, 2008:491). Louw (2008:491) describes parents feeling that they might betray their child by leaving them in hospital, just as the child may feel rejected when their parent leaves. Louw (2008:491) emphasises the need for support from a pastoral figure, so that parents' sense of guilt and the weight of their child's illness does not drive a wedge between the parents as they try to process their emotions in isolation.

#### *3.6.1.1 Providing support*

Parents have a need for different kinds of support, for instance, logistical support, financial support, reassurance and connection to the outside world (Douma *et al.*, 2020:1244; Dorman, 2024; Toalson & Wiederholt, 2023). Logistical support may include meal preparations (such as mealtrain.com) and lifting other siblings. Financial support may include helping families set up a crowdfunding project to help with the costs of the medical treatment needed for the child (Dorman, 2024).

Friends and family of the sick child can provide emotional support through reassuring the parents that they are doing the best they can. The illness may cause the parents to split up the family tasks, which could lead them to feel overwhelmed and guilty for not being everywhere at the same time (Dorman, 2024).

#### **3.6.2 Familial stressors**

Battles and Wiener (2002:48) identify familial stressors common to chronic illness in childhood: the diagnosis and management of the disease; differential treatment of the chronically ill child with healthy siblings; high rates of school absence; the potential disruption of developmentally appropriate socialisation experiences; increased dependency; fears associated with the child's future; and for many families, the emotional and financial stress associated with having to travel great distances to participate in available clinical trials. Black (1991:141) describes that life-threatening illnesses often put strain on

marriages, work and finances. Black (1991:140) attests that all life-threatening illnesses affect the entire family and their social relationships. Children with life-limiting illnesses have higher concerns about death and perceive themselves to be isolated (Black, 1991:141). Moreover, children with leukaemia are known to be less open with their families and have a higher incidence of behavioural problems. Also, childhood cancer survivors are more prone to psychological secondary conditions (Black, 1991:141).

### **3.6.3 Access to information**

P2 noted the importance of informing parents about what is going on with their children. Similarly, P4 makes a point of reiterating information to parents who are experiencing shock and grief and may not always be able to grasp medical information concerning their child's illness. The International Children's Palliative Care Network (ICPCN, 2021) provides paediatric palliative care training for families through free e-learning courses. The training includes an introduction to palliative care, communicating with children about emotional issues, child development and play, symptoms other than pain in paediatric palliative care and end of life care (ICPCN, 2021).

### **3.6.4 Managing cancer treatments' side effects**

Although this study is not primarily focused on children with cancer, it is a dominant theme in the pastoral caregivers' work, as seen in the empirical study, and will therefore be discussed. B-well<sup>12</sup> sponsors booklets to educate parents about the side effects of cancer treatment and the dietary needs of children diagnosed with cancer. This booklet explains what nausea and emesis (vomiting) associated with chemotherapy treatment are. Since P2 identified that medical knowledge is important, the three stages of emesis related to chemotherapy treatment will be briefly discussed.

- *Acute emesis*

This can be expected right after chemotherapy treatment, usually one to two hours after treatment and then starts to decrease after four to six hours.

- *Delayed emesis*

This develops after 24 hours and then gets better a few days after chemotherapy treatment begins.

- *Anticipatory emesis*

This often develops as a learned response in patients who have had severe nausea and vomiting with previous rounds of chemotherapy (CANSA, 2024a; Schoeman & Pentz-Kluyts, 2023). Although P2 warned not to give children with life-threatening and/or life-limiting conditions fluids before some operations, before chemotherapy, fluids are highly recommended. The B-Well booklet encourages parents to give children and teenagers water, clear apple juice, rooibos tea and even carbonated drinks

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<sup>12</sup> B-well is a South African food brand that carries CANSA's smart food choice "seal of recognition". This endorsement aims to promote healthy lifestyles and reduce exposure to carcinogens and other risk factors (CANSA, 2024a).

to prevent dehydration during treatment. Ice cubes are also suggested as way to prevent nausea and increase hydration (CANSA, 2024a; Schoeman & Pentz-Kluyts, 2023:4).

- *Stimulating the child's appetite*

Parents can be taught to stimulate a child's appetite undergoing treatment by washing their face before a meal, rinsing their mouth with water, doing light exercising and enjoying a meal in a relaxed environment together as a family. Other tips mentioned in the B-Well booklet include allowing the child to drink clear apple juice and giving them food that looks appealing (CANSA, 2024a; Schoeman & Pentz-Kluyts, 2023:4). However, it should be remembered that supporting the siblings of the sick child is just as crucial as providing support to the parents of the child.

### **3.6.5 Support to siblings**

Lamb (1982:4) notes that siblings are important agents of socialisation. Although family influences have primarily focused on mother-father-child relationships, in families with more than one sibling, each person in the family may influence every other member directly or indirectly (Lamb, 1982:4). Families who are supporting the parents of the sick child need to consider the well-being of the siblings as well. Toalson and Wiederholt (2023) explain that the siblings of the ill child have a need to exist outside of the medical context. Toalson & Wiederholt (2023) also advise those supporting the family to consider bringing a gift to the sibling when they are taking one to the ill child.

## **3.7 SIBLING NEEDS**

Significant stress is experienced by the siblings of the child who is diagnosed with cancer. They are also at risk of poor psycho-social outcomes when their sibling passes away (Kenney *et al.*, 2021:230)

### **3.7.1 Psychological well-being and coping**

Siblings of children who die often develop behavioural problems and 75% develop psychological disorders (Black, 1991:140). These studies have not shown the best therapeutic interventions to help children with life-threatening conditions, as well as the morbidity experienced by their families. The poor coping mechanisms presented by the sibling may be attributed to the siblings' unmet needs, as well as their intense feelings which are played out as emotional turmoil (Tay *et al.*, 2022:525).

Tay *et al.* (2021:518) explain that research is mostly focused on the child with a life-threatening and/or life-limiting condition, while the child's siblings are "forgotten mourners". The unhappy siblings often silently suffer as the parents are too preoccupied with their own grief (Farrant, 1998:41). Siblings' lack of personal power after the loss of a brother or sister with life-threatening and/or life-limiting condition is noted by Farrant (1998:97). Siblings also need to know that they do not have to take responsibility by keeping their emotions together during times of crisis or loss (Farrant, 1998:87–99).

### 3.7.2 Siblings' grieving

Apart from Kubler-Ross's stages of grief, Grollman (1991:6) mentions that children grieving the loss of someone like their sibling may experience various emotions and physical symptoms. The child's anxiety may be experienced physically. They may complain of having a stomach or headache (Grollman, 1991:6). Emotions ranging from anger, guilt, jealousy, shock and denial to fear may be experienced by the grieving sibling. The sibling might also feel sad and alone in the absence of their playmate. On the other hand, some siblings reported post-traumatic growth after their siblings' passing, especially those who got to say goodbye to their ill siblings (Kenney *et al.* 2022:231, 235). Post-traumatic growth can be seen as individuals' positive growth in spirituality as a result of significant loss (Louw, 1994:189).

During grief, siblings might respond in various ways (Farrant, 1998). The sibling might attempt to substitute the dead sibling through impersonation of their dead sibling's mannerisms. Farrant (1998:10) shares the story of J.M. Barrie, author of *Peter Pan*, who wore his dead brother's clothes and learned to whistle like him to comfort their mother. Other siblings battle with "survivor guilt", as the parents might recall only the good qualities of the child who passed away. This may lead the living sibling to feel they should have been the one to have died instead. The way parents can reduce these feelings include discussing the good and bad of the child who died, instead of just idealising them (Farrant, 1998:15). Since children are egocentric, they might carry guilt which has not been apportioned to them, according to Farrant (1998:53).

### 3.7.3 Family dynamics

Disruption of the family's usual routine, changes in the family environment and changes in family relationships can distinctly impact the family's functioning when their child is diagnosed with a life-threatening and/or life-limiting condition (Tay *et al.*, 2022:521). Since the child requires intensive support, the parents need to adjust their roles and times to meet the ill child's needs.

This often leads to lack of time spent with the ill child's siblings (Tay *et al.*, 2022:522). The siblings also said that it was difficult for them that the family was often scattered since their sibling (ill child) was often hospitalized. Besides for this change in the family environment, the siblings also wrestled with the changing relationship dynamics within the family. With the parents' attention focused on the child with a life-threatening and/or life-limiting condition, the other siblings can end up feeling neglected. Regarding their parents, the siblings recall their mothers being more emotional, while their fathers seem more short-tempered (Tay *et al.*, 2022:522). Lamb *et al.* (2010:3) point out that in parental dynamics, the fathers consistently fulfil the role of playing with the child, while the mother specialises in caregiving and nurturing, especially with younger children. Although the mother does play with the child, the father is known for more "boisterous, stimulating, emotional arousing play" (Lamb *et al.*, 2010). The father also indirectly impacts the child through his financial support, while the mother

influences the child through her emotional support (Lamb *et al.*, 201:9). Life-threatening and/or life-limiting conditions can be expensive and thus father's financial support and the mother's emotional support play a crucial role in the child's emotional well-being. Lamb *et al.* (2010:11) emphasise that fathers play multi-faceted roles in their children's lives and therefore one should not magnify only one facet of a father's influence in understanding their role in the family's dynamics.

Freeks (2013:19) argues that the father's role includes accountability before God, as the father is to lead the family with love and is responsible to keep the family healthy. Moreover, the father carries authority in parenting and models Christ to his family. The earthly father should also protect his wife and children. He is also to provide financially and emotionally through showing intimacy and love to his family. The father's guidance should also be tangible. These spiritual principles can be taught to fathers with ill children, so that they can lead their family with God's Word, demonstrate love to their wives in the trying time of illness and sincerely love their children, both the sick child and their siblings. Tay *et al.* (2022:527) recommend future studies to consider the role of the extended family, such as grandparents or the community, in supporting the siblings of ill children. It is clear from these findings that there is theoretical and practical pastoral care needed to support the siblings of children with a life-threatening and/or life-limiting condition.

### **3.8 BARRIERS TO SOUTH AFRICAN PASTORAL SUPPORT**

Selman *et al.* (2018:226) identify the barriers that exist to providing pastoral support to the families of seriously ill children, such as inadequate training and education, lack of funding and not recognising the benefit of religious and spiritual support for a child's socialisation process (Louw & Louw, 2014:295). While these factors are common the world over, in South Africa there are other factors to consider – the impact of state corruption, the lack of practical education in facilitating pastoral care and the high degree of poverty, which means many families do not have access to physical or pastoral care for their children.

#### **3.8.1 Lack of recognition**

Many theorists have been critical of the benefit which spirituality and religious support could have on children (Wilber, 2000; Piaget, 1968; Goldman, 1965). Hart (2005:163) says theorists like Wilber, Piaget and Goldman view children as developmentally immature and unable to understand meaningful reflection. They argue that children may not have the psychological and cognitive capacity to understand spiritual concepts (Louw & Louw, 2014:295). P2 mentioned how children would be excused from discussing death with their family when the pastor arrived. Instead, they would be sent to their rooms or the neighbour's house, even though the pastoral support could have been a source of comfort to the child.

The importance of spiritual care is highlighted by Oberholzer (2011:7) who explains that children rate spiritual support fourth in importance out of 19 resources they would like during repeated hospitalisation and after receiving a life-threatening diagnosis. Although there is lack of recognition of its importance to children among theorists, religious support is nevertheless a prominent need.

### **3.8.2 Lack of funding**

General funding for emotional and pastoral care has been identified by P1 to be a barrier, since there are no toys for children in state hospitals. However, P1 also stated why there is no real barrier for faith communities to get involved, since these children do not expect expensive toys and are happy with anything. Moreover, P2 said that the government ought to fund pastoral caregivers, just as nurses are funded, so that there can be pastoral care available to cancer patients.

- *Lack of prioritisation of pastoral care*

The Board of Healthcare Funders in South Africa (BHF) does not financially support the religious practitioner boards in South Africa and thus there is a lack of funding for pastoral support. Meyer (2020:4) points out that this is because the BHF does not recognise the Association of Christian Religious Practitioners (ACRP) as a regulatory body. Regulatory bodies act in the interest of the public by ensuring the ethical conduct of professional bodies.

- *Corruption*

Rheeder (2021) explains that corruption in public and private healthcare is also a contributing issue towards lack of funding in South Africa. Corruption is defined as “the abuse of resources, power and/or connections for private gain” (Rheeder, 2021:84). Vorster (2012) defines corruption as the misuse of office or authority for personal, social or material gain at the expense of other people.

Du Plessis and Breed (2013:1) highlight the annual loss of R30 billion due to corruption and bribery in South Africa. According to a recent report (Transparency International, 2023), South Africa had a corruption index of 41 in 2023. This score has dropped two points since 2022, which means corruption has increased. They further discuss how the church is called to servant leadership to stand against corruption which impacts the poor and vulnerable (Du Plessis & Breed, 2013).

- *Awareness of needs*

Vorster (2012) encourages the church to be ethically aware and to remind society of the needs of the poor. Due to corruption, medical resources are often stolen, meaning those who cannot afford expensive treatment are denied it (Vorster, 2012:139). This shows the deficiency in medical care available, although it is supposed to be a human right in South Africa. Ninety percent of sub-Saharan Africa falls below the 50% mark on the 2023 corruption perceptions index, where 0 is highly corrupt and 100 very clean (Transparency International, 2023). South Africa received 41% on this index which indicates

corruption. The report faults decades of continued underfunding in the public sector, which has led to increased difficulty for the most vulnerable in sub-Saharan countries, such as the disabled, women and children (Transparency International, 2023:18). This will be further discussed in 3.8.4 under impoverished communities. Aside from the impact of corruption, disregard for people's needs and a lack of prioritisation to fund pastoral caregiving, there is also a lack of education regarding spiritual care for healthcare practitioners.

### **3.8.3 Lack of education**

#### *3.8.3.1 Healthcare practitioners*

Including spiritual care in the curricula of doctors, nurses and other healthcare practitioners is an important facet missing in healthcare training (Meyer, 2020). This is necessary because environments of illness and suffering impact people's concepts regarding meaning and purpose. People can only be healthy when they are treated holistically (bio-psycho-social-spiritual) (Meyer, 2020:9).

Linda *et al.* (2020) note the gap in nursing schools' commitment to educate their students on spiritual care to provide holistic care to patients. Although the South African Nursing Council (SANC) advocates holistic nursing, they don't clarify where spiritual care fits into patients' holistic care. Moreover, Linda *et al.* (2020) highlight the lack of spiritual care guidelines in nursing curricula. Concern by nursing educators has been raised regarding the lack of interpersonal skills and care applied by nursing students. The study recommends that South African nursing programmes should include guidelines regarding spiritual care facilitated by nurses to support those coping with illness. On the other hand, Van Rensburg (2014:137) asserts that doctors and medical students should not be expected to provide spiritual care like a spiritual caregiver would, since this may create an unfair power balance between doctor and a patient.

Chandramohan and Bhagwan (2015:3) point out the lack of spiritual care literature in South Africa and they assert that nurses should be empowered to provide spiritual care to patients, since patients rely on spirituality more in cases of HIV/AIDS and cancer, according to Koenig (2009:283). Nurses also indicate a desire for workshops and seminars on spiritual care, as 69% of the study's participants believe terminally ill patients search for meaning and 82% believe spiritual participation could protect patients from depression (Chandramohan & Bhagwan, 2015:5).

The distinction between religion and psychotherapy (Frankl, 1986 as cited in Van Rensburg, 2014:135) has important implications in the academic and practical training of specialists who need to be culturally and spiritually competent, although they are not primary pastoral caregivers. Frankl states that where psychotherapy aims to heal the soul, religion aims to save the soul (Van Rensburg, 2014:135).

Therefore, practical education needs to clearly construct the aims of the curriculum in equipping practitioners to support patients who are critically ill. This practical education should include informing practitioners and caregivers about African cultural beliefs.

Van Rensburg (2014:135) says patients from African backgrounds may experience more existential and spiritual issues and may have a need to discuss these concerns with their doctors and psychiatrists. The Traditional Health Practitioners Act of 2007 is important for practitioners and caregivers to take heed of since it includes indigenous healthcare practices, such as ancestral practices and traditional medicine. Chapter 2 highlights that there may be stigmatisation from practitioners who place higher value on Western medicinal practices than on traditional African practices. P2 noted that this could convey a feeling of judgement from the practitioner to the patient or the family when they take the child to a traditional healer rather than a medical doctor. Therefore, practitioners should read up about African practices to avoid what Louw (2008:147) calls “the problem paradigm”. The problem paradigm is the automatic association of Africa with problems such as HIV/AIDS, a dysfunctional education system, failing infrastructure and corruption. This negative association might guide people who uphold a medical model to think they have a superior response to illness and health. When the African model is viewed as inferior to the Western model, it can bring a disconnect between the caregiver and patient (Louw, 2008:180). Instead, the caregiver should recognise the importance of their relationship with the patient. Thereafter, religious matters can be communicated to the patient from a place of relationship.

### 3.8.3.2. *Pastoral workers*

The lack of training and registration of pastoral workers is a barrier to the provision of pastoral care to children with life-threatening and/or life-limiting conditions.

- *Training*

According to Meyer (2020:2), pastoral training is currently presented through general ministerial training by six well-known South African universities. These include the University of South Africa (UNISA), the University of Pretoria (UP), the North-West University (NWU), the University of the Free State (UFS), Stellenbosch University (SU) and the University of the Western Cape (UWC). The problem with this ministerial training, however, is the lack of pastoral modules produced by their regulatory body. Meyer (2020:2) notes that in the five years of pastoral training, students are exposed to only three pastoral care and training modules. Training is essential to meet the practical daily pastoral needs in South Africa. For effective pastoral caregiving in the future, Magezi (2019:10) states there is a need for pastoral reflection, balanced with attention to pastoral praxis. Intellectual theories and pastoral praxis are equally important to providing professional pastoral care. There are both internal and external barriers in pastoral caregiving in South Africa. Externally, pastoral caregiving is not recognised by all psychological services to be professional (Louw & Dames, 2021:106).

- *South African context*

Ma Mpolo (2013 as cited in Magezi, 2019:8) describes the *homo Africanus* elements which are important for pastoral caregivers to understand African people's unique identity. These elements incorporate African people's sanctity of life; the relation between illness, misfortune and sin; spirits and ancestors in the life of the community; and life experienced as a whole (Magezi, 2019:10).

Although the *homo Africanus* elements identified by Ma Mpolo (2013) are important to understand African people, Magezi (2019:10) implores pastoral care in Africa to consider modern and technological advances to provide effective contextual pastoral care. The modern era and technological advances create pastoral needs which the *homo Africanus* elements fail to address, including holistic protection and pastoral sensitivity regarding the tension between the individual and the community, as well as empowering the marginalised.

Integration of technical life skills, sincere compassion, pastoral preparation for local and international migration and public pastoral care are important pastoral care needs, according to Magezi (2019:11). Relevant daily issues ought to be addressed, including empowering people to promote holistic protection in all spheres of their lives and to address people's fears (Magezi, 2019:12). Pastoral care in Africa has more complex issues than other places (Magezi (2019:12). Since there are a lot of complex life issues which need to be addressed in African pastoral care, there are also requirements for effective training to attain the diverse skills for the vocation of pastoral caregiving. Apart from the expansion of pastoral caregiving to address the internal needs of Africa, pastoral care's professionalism is another contributing barrier to the provision of effective pastoral care to children with life-threatening and/or life-limiting conditions.

- *Professional discipline*

Louw and Dames (2021:104) highlight some challenges faced by pastoral care's identity in the area of ministry. One theme observed is that the church-based ministry of pastoral care is not considered as professional as psychological services by the world. On the other hand, a move towards a more professional service risks the "psychologisation" of practical theology, including pastoral caregiving.

Conversely, the collaboration between healthcare and church institutions might spark the necessary reflection towards authentic theological praxis (Agbiji, 2014:2). 1 Peter 3:5 tells Christians to be ready to give an answer for the faith they hold. Thus, the integration of disciplines will allow pastoral caregivers working alongside other practitioners to think about the rationality of their beliefs and actions (Agbiji, 2014:2). Louw and Dames (2021:106), however, describe tension between pastoral care workers and psychological professionals in South Africa. Pastoral care's professionalism has been doubted by the psychological practices, according to Louw and Dames (2021:106), based on their

resistance to include these pastoral services under the Health Professions Council for South Africa (HPCSA) (Meyer, 2020:3). Meyer (2020:3) points out that the South African Qualifications Authority (SAQA), as a legal entity or “juristic person”, recognised the South African Association of Pastoral workers (SAAP) as a professional body under the Association of Christian Religious Practitioners (ACRP) in 2017. SAAP has since joined the Council for Pastoral and Spiritual Caregivers (CPSC) and is recognised as a professional body to promote the educational regulation of the pastoral care profession (Meyer, 2020:3). The HPCSA, which is the largest regulatory body for control and regulation of 12 health-related professions, enforces the standards for these professional practices. Unlike the HPCSA, the CPSC does not influence the curricula for pastoral caregiving education.

Meyer (2020:3) believes that the CPSC ought to develop pastoral therapy programmes for universities which can benefit students in practice in the future. The CPSC does not warrant registration with them, like the HPCSA who have the Health Professions Act behind them. This act states that it is a criminal offence not to register with the council when practising in the healthcare profession. Because the CPSC is not supported by the government, they do not provide practice numbers to their practitioners. This means that medical aid schemes do not cover the clients of pastoral caregivers. As a result, there is an absence of statutory regulation to prevent unethical conduct in the practice of pastoral caregiving (Meyer, 2020:4) Therefore, it may be harder to get clients as a pastoral caregiver than a psychologist who has a practice number. The education and registration of pastoral caregivers is a barrier to producing more caregivers who can support children with life-threatening and/or life-limiting conditions. Agbiji (2014:2) notes that for pastoral caregivers to work alongside hospital teams, there is a need to legitimise pastoral care as a professional discipline first.

Aside the lack of pastoral care training, as well as its lack of recognition as a professional discipline, the lack of pastoral care to impoverished communities is also a problem.

### **3.8.4 Impoverished communities**

P1 identified that impoverished communities have a “massive” gap in pastoral support, especially to children. Maluleke (2020) highlights that children from impoverished communities are more prone to not receiving physical and pastoral support. According to the government report by Maluleke (2020), a child’s poverty is measured based on a Multiple Overlapping Deprivation Analysis (MODA), which has seven dimensions. These include housing, protection, nutrition, health, information, WASH (drinking water, sanitation and water disposal), as well as the child’s development and education. A child is classified as poor if they are deprived of three of the seven above-mentioned elements.

Shockingly, the report found that 62% of South African children from birth to the age of 17 are multi-dimensionally poor, while most suffered from four to seven deprivations instead of just seven

(Maluleke, 2020). For children from birth to four years old, health (54%), housing, development and WASH were the highest deprivation rates in their multi-dimensional poverty. Moreover, 53% of these children live more than 5km away from a healthcare centre and 12% of parents lack a road-to-health chart (RTHC). This chart is used in South African healthcare to monitor children's health and development, including their immunisation schedule.

For children aged five to 12, health (53%) was the primary deprivation dimension, with more than five out of 10 children needing to travel more than 5km to their nearest healthcare centre. Over 52% of children between the ages of 13 to 17 are also deprived of proximity to a healthcare centre. Because more than half of all South African children live far from healthcare centres, they do not have direct access to pastoral, psychological or medical services. Poverty presents physical barriers to these services. Because these children come from poor families where nutrition, education, information, housing and WASH are some of the areas of deprivation, they may not have the funding to pay for general healthcare services (physical, psychological and pastoral support), especially if the family has many children and the parents are unemployed (Maluleke, 2020). Regardless of whether pastoral caregivers work with children in impoverished communities or better equipped hospitals, their self-care remains critical to continue to offer effective pastoral support to others.

### **3.9 IMPORTANCE OF CAREGIVERS' SELF-CARE**

In Chapter 2, the importance of self-care for pastoral caregivers was highlighted, especially to prevent compassion fatigue, burnout and to have good boundaries. This protects caregivers from falling into the trap that they are obliged to care and fix others. Awareness of transference and countertransference, as well as practising debriefing, are important elements to consider for pastoral caregivers.

#### **3.9.1 Transference and countertransference**

Transference is when the repressed past becomes conscious (Racker, 2007:725). In other words, the client transfers past feelings or memories into the present onto the counsellor to rectify "pathological decisions and destinies" (Racker, 2007:725; Gibson *et al.*, 2003: 52). Countertransference occurs when emotions are evoked in a pastoral caregiver in their work with their client (Gibson *et al.*, 2003: 54). This, according to Racker (2007:725), can interfere with the analyst's objectivity of the patient's situation and past experiences.

##### *3.9.1.1 Children's transference and countertransference*

Lampert (2003:16) notes that transference is less frequently observed with children than with adults, although the child may wish the pastoral caregiver to be all-powerful and may be disappointed and angry when they see the pastoral caregiver is not. This is apparent from P2's example when a boy patient was disappointed that the pastoral caregiver followed his mother's example by refusing to give

him something to drink. Although transference may enter, what Oaklander (2001:46) calls the “I/Thou relationship” between the therapist (pastoral caregiver) and child should be discouraged. Instead, the pastoral caregiver should have boundaries which set them apart from the child’s parents, so that the child does not view them as like their parents (Oaklander, 2001:47).

Pastoral caregivers need to be alert of countertransference in cases where the child reminds them of their own children, as well as where the child reminds the caregiver of themselves as a child (Lampert, 2003:16). The practitioner may have a love/hate emotional reaction toward the child who reminds the pastoral caregiver of themselves. Both reactions can negatively interfere with the pastoral support process. When a child reminds the pastoral caregiver of their own child, it can evoke fear in the caregiver that illness or trauma might affect their own child. The primary problem with these instances of countertransference is that they may result in the pastoral caregiver pitying the child and wanting to rescue them. Lampert (2003:16) rightly observes that this may create the false promise that the pastoral caregiver will be there for the child whatever happens. Instead, Lampert recommends caregivers help children build an internal safe place where they can withstand what she calls the “huffing and puffing of an unfair world”, like the third piggy in the story of *The Three Pigs*. Similarly, pastoral caregivers should help children build their lives on the rock of Christ, instead of on the sand of them as a pastoral caregiver (Matthew 7:24–27).

### *3.9.1.2 Adult transference and countertransference*

P4 shared experiences in which families that she worked with used her as a crutch. P4 said that they can be extremely dependent on the caregiver during the vulnerable time when the child’s treatment is completed or when their child passes away. This is an example of transference by the counselees in which they transfer their emotions onto the pastoral counsellor, seeking extensive comfort or friendship from them.

P4 shared that afterwards the counselees may disregard their relationship with the caregiver because they associated her with a difficult period in their lives and want to leave it behind them. P4 recalled that in the beginning, she felt rejected because she had grown close to the families, perceiving friendship with some of the mothers who came to see her. This is an example of countertransference on the part of the pastoral caregiver (Racker, 2007:728, 775). Counter-transference can present itself as feelings of frustration when the client does not show transference towards the pastoral counsellor but instead focuses on their own past or childhood. Racker (2007:775) gives an example of a counsellor who was frustrated when the client was excessively focused on their childhood and the counsellor felt transference would further the treatment. However, the reality was that the counsellor felt frustrated because they wanted the client to show interest in them (Racker, 2007:775).

Similarly, pastoral counsellors should be wary to protect their hearts above all else, as Proverbs 4:27 warns, so that they will be able to objectively bring God's perspective and comfort to the families of children with life-threatening and/or life-limiting conditions. From her experience working with mothers of seriously ill children, P4 warns pastoral caregivers against experiencing chronic rejection when one is under the illusion of friendship with a client. According to P4, the way pastoral caregivers can prevent and deal with this is to become emotionally mature and realise that the discarding of the therapeutic relationship has nothing directly to do with them. Instead, pastoral counsellors ought to allow God to use them as a vessel for His glory. Pastoral caregivers should inform those they are working with about their role to ensure the counselees are able to manage their expectations.

Similarly, when trained to work with families of children with life-threatening and/or life-limiting conditions, P2 encourages pastoral caregivers to be informed that Jesus Christ should be the focal point of all emotional healing. Thus, pastoral caregivers must ensure to not become the perceived healer or develop a need to be needed. Lastly, P2 warns against making promises of healing, since the caregiver cannot guarantee the patient's healing. The cost of caregiving will now be investigated.

### **3.9.2 Cost of caring**

The cost of pastoral care for ill children may include burnout, compassion fatigue or transference/countertransference. Psychological debriefing has been deemed necessary by those involved in healthcare to combat the above-mentioned symptoms of caring.

#### *3.9.2.1 Debriefing*

Gibson *et al.* (2003:71–72) believe there is no strong scientific evidence supporting debriefing. Instead, they hypothesise that the popularity of debriefing may be a defence mechanism as people wish there was a package which could prevent the overwhelming effects trauma might have. P4 considers debriefing only necessary through discussion with Jesus, although she seemed sad that she was unable to share her work with her close loved ones, since they seemed uninterested to discuss the losses she has experienced. P1, P2 and P3, on the other hand, consider debriefing to be a vital component of working with children with life-threatening and/or life-limiting conditions.

#### *3.9.2.2 Burnout*

Burnout is described as an exhaustion experienced by caregivers in their professional identity (Louw, 2008:135). Feelings of incompetence have been reported with regards to burnout; the caregiver may no longer feel any empathy towards their clients and may consider changing their career (Louw, 2008:135). Because the participants in the empirical study are continually exposed to brokenness and adversity, it is important to understand the role resilience and hope play in their lives.

### 3.9.2.3 *Compassion fatigue*

Another cost of caring is compassion fatigue: this is due to overexposure to people's suffering and trauma, in turn "traumatizing" the caregiver (Louw, 2008:135). This exhaustion is caused by activity, empathy and input by the caregiver, which was experienced by P3 when she was called to visit a patient in hospital at a time when she herself was ill. She could not bring herself to say no, even though she had flu; her compassion fatigue was possibly rooted in a liberator complex. The phenomenon of continuing to give oneself despite an awareness of being unable to balance a healthy lifestyle and objectivity is a symptom of compassion fatigue (Louw, 2008:135).

Caregivers ought to practice self-care to prevent developing burnout or compassion fatigue in the face of working with children with life-threatening and/or life-limiting conditions. Through self-care, resilience and hope can also be produced as caregivers rely on God for strength. Resilience is defined as positive outcomes, despite exposure to significant adversity, which typically exerts major assaults on biological and psychological development (Nel *et al.*, 2020:136). Walsh (2012:149) describes family resilience as the family's ability to "withstand and rebound from disruptive life challenges, strengthened and more resourceful". In a study, Teti *et al.* (2012:526) highlight five main forms of resilience, namely, perseverance, commitment to learning from hardship, reflecting and refocusing to address stressors, creating a supportive environment and drawing on religion and spirituality for support.

Through debriefing, P1 can refocus and address stressors from therapy, while P4 does not debrief and at the time of the interview said she was experiencing burnout. In Chapter 2, it was noted that individuals working with children who are dying are more at risk of burnout (Oberholzer & Doolittle, 2024:2). P3 noted that being understaffed at the non-profit organisation where she works contributed to her experience of burnout. All participants drew on their relationship with Jesus (religion) for support and believed that it helped.

### 3.9.2.4 *Secondary trauma*

Self-care is necessary, especially when the pastoral caregiver has secondary traumatisation. Secondary trauma can be acquired through repeated hearing of events which, according to Gibson *et al.* (2003:68) may lead one to question life's meaning and feel detached from other people. Pastoral caregivers who help children traumatised by hospitalisation, medical procedures or cancer treatment are especially at risk of secondary trauma. Secondary trauma can also be caused by the caregiver's feelings of helplessness in the face of those they desire to help.

### 3.9.3 Self-Care

#### 3.9.3.1 Coping with feelings

Pastoral caregivers need time to reflect and understand their own feelings. This means they need a “container” which can help them hold their feelings until they are able to come to terms with them. Gibson *et al.* (2003:43) explain that it is crucial for caregivers to know their own feelings to be able to understand the feelings of those they work with. SOZO Ministry uses a jar imagination exercise: the person can put all their negative emotions into a jar and give it to Jesus. This is similar to how P4 is open with Jesus about her own negative emotions. When the emotions of the child or family overwhelm the pastoral caregiver, it can be useful to use another therapist or colleague as a sounding board (Gibson *et al.*, 2003:44). Caregivers are also encouraged to have a container (person/God/journal) to help them be aware of blind spots (feelings that are difficult to talk about), transference and countertransference (Gibson *et al.*, 2003:62).

#### 3.9.3.2 Unburdening

Elijah House<sup>13</sup> ministry explains that people who are empathetic might end up carrying the burdens of others. Although this can happen, the idea is to give these burdens over to Jesus through intercession, instead of carrying it alone. In 1 Peter 5:7, God tells us to cast our cares on Him because He cares for us. In psychology, this phenomenon of burden bearing is also recognised where counsellors and care-workers end up carrying the distressing feelings of their clients (Gibson *et al.*, 2003:93).

#### 3.9.3.3 Fillers

Pastoral caregivers might have different things which fill their emotional, psychological, spiritual and physical tanks. For one caregiver, her filler might be running; for another, it may be a drainer. But generally, from the responses of the participants in the empirical study, fillers include walking with dogs (P1), art through mosaic (P1) and prayer (P4). The five forms of resilience (Teti *et al.*, 2012) can be used to inspire self-care fillers. Reflection through journalling might help to address stressors and learn from hardship. Pastoral caregivers can also surround themselves with a faith community and close loved ones who form part of their supportive environment. They can also practise faith disciplines, such as prayer and fasting, as seen in the book of Daniel, to deal with hardship and confusion by drawing on religion and spirituality for support. Authors like Schwartz (2020), who wrote *Post-traumatic Growth Guidebook*, and Bessel van der Kolk, author of *Your Body Keeps the Score*, would encourage yoga as a source of healing. But from Schwartz’s book (2020:144,151), there are clear roots in the Buddhist religion where healing is sought. Pastoral caregivers should not seek for healing in other religious

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<sup>13</sup> Elijah House is a prayer and teaching ministry which was started by John and Paula Sandford. Their mandate is to restore the hearts of the fathers to the children and the children to the father (Mal 4:5–6). To accomplish this mandate, Christians are equipped with biblical tools for discerning the root issues in the lives of people (Elijahsa.za.org, 2024).

practices like those who believe one can “guide oneself to bloom”. Instead, pastoral caregivers should not navel-gaze at their shortcomings but instead trust Jesus to finish the good work He started in them (Phil 1:6). To navel-gaze means to look inwardly at what is wrong with oneself, striving to be better out of your own strength. Doing this may lead to feelings of unworthiness and discrediting oneself for the ministry pastoral caregivers are called to.

#### *3.9.3.4 Leave it at the office*

Tiegreen and Newman (as cited in Norcross & Guy, 2007) give a few practical self-care tools for practitioners to leave their work at the office. They share a moving story of a colleague who works with children and families with life-limiting conditions, such as cancer. The colleague had recurring nightmares. The nightmare started with him standing in line for a roller coaster, surrounded by bald or bewigged children he recognised as previous patients who passed away. There in line is a sign warning that 40% of riders fall to their deaths. He climbs in and secures his safety bar but realises others have not. As the ride continues, every time it emerges from a strobe light, there are more empty seats in front of him. Tiegreen and Newman (2007:42) share this as a reminder of the patients who die because of illness or suicide that counsellors were unable to reach. Strikingly, they title these encounters and disappointments as “sandpaper on the soul”, even though the counsellor may wish to forget these negative experiences. Pastoral caregivers working with children suffering from life-threatening and/or life-limiting conditions often encounter heartache and loss; they need healthy tools to enable them to leave death and disappointment “at the office”. Tiegreen and Newman (2007:21) explain that these practical tools include refocusing on the rewards, recognising the hazards, minding the body, nurturing relationships, sustaining healthy escapes, and cultivating spirituality and mission (Norcross & Guy, 2007:21). Some of the rewards they mention include the satisfaction of helping others, as well as the variety of experiences gained from interacting with a wide range of individuals (Norcross and Guy, 2007:21). Emotional growth can also be a reward from counselling.

Theoretical interpretation was applied by conveying various pastoral techniques and developmental theories, so that pastoral caregivers can practise in a more thoughtful manner, as Osmer (2008:82) suggests.

### **3.10 CONCLUSION**

After investigating what pastoral care is available in Chapter 2, the interpretative task focused on seeking sagely wisdom to identify why children with life-threatening and/or life-limiting conditions need pastoral care. The benefit of pastoral support was highlighted, as well as children’s need for spiritual, social and emotional support. Children’s feelings of grief and fear have been recognised by theorists, such as Kübler-Ross (1991) and the ICARE model (Hays-Grudo & Morris, 2020:67). The need for pastoral support for parents (Louw, 2008; Black, 1991) was identified as an indirect support to

sick children. Barriers to effective pastoral support in South Africa include lack of funding, registration and practical education on pastoral care. Poverty also plays a role in South Africa where many communities have a high need for better healthcare services, offering physical, spiritual and emotional support. As palliative care includes the holistic support of children suffering from serious illness, pastoral support should also be available to these children in South Africa. Therapeutic techniques to meet the internal and external needs of such children can include play, storytelling, expressive pastoral techniques and Godly Play. Chapter 4 will discuss what ought to be done for these children according to Scripture, based on Osmer's normative task. Matthew 25:31–46, Matthew 10:8 and Matthew 19:14 will be studied using Rousseau's exegetical steps.

## CHAPTER 4

# NORMATIVE PERSPECTIVE ON MINISTERING TO CHILDREN WITH LIFE-THREATENING AND/OR LIFE- LIMITING CONDITIONS

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### 4.1 INTRODUCTION

Chapters 1 and 2 discussed the theoretical and practical components of “what is going on” in the lives of children with life-threatening and/or life-limiting conditions (Osmer, 2008). The interpretative task (Chapter 3) highlighted important principles for pastoral support to these children in hospitals. The next step is the normative task. The focus of this chapter is to firstly examine aspects of God’s heart towards caring for children and secondly, to discuss how pastoral caregivers can apply Scripture, which is the objective voice. Scripture is the measuring stick which guides how pastoral caregivers can respond appropriately to the suffering experienced by children with life-threatening and/or life-limiting conditions. Osmer (2008:173) explains that normative theological perspectives provide interpretative guides in understanding how people ought to respond to difficult situations. Instead of guiding a person to get to the end goal, Osmer (2008) believes the normative task helps to answer what a person ought to do. This chapter will establish the “what ought to be going on” (Osmer, 2008). In Chapter 5, the pragmatic task will emphasise how to apply the task mentioned in the previous chapters effectively. The historical-grammatical exegetical model will be used in the process of uncovering the intended meanings of three pericopes, namely Matthew 10:8, Matthew 19:14 and Matthew 25:31–46. The researcher chose these passages because in them, Jesus’ character and discipleship are foregrounded, especially His care and love for children.

#### 4.1.1 Definitions for exegesis

Exegesis can be described as the interpretation of a pericope – the original meaning is literally to “lead out” or “*exégeomai* -to show the way” of a passage’s intended meaning (Strong’s Greek, 2021). A pericope is defined as a coherent scriptural passage. The opposite of exegesis is eisegesis and refers to the reader’s own interpretation – in other words, to read a certain message in a text that the text may not contain (Merriam-Webster Inc, 2024).

Good practice, prophetic discernment and ethical discernment provide normative guidance to help determine what “ought to” be accomplished in the relevant area of concern and how one can implement

God's Word to address the area of pastoral concern (Osmer, 2008:132). In this case, the three identified pericopes aim to discern how faith communities (pastoral caregivers) can best facilitate pastoral support to children with life-threatening and/or life-limiting conditions.

#### **4.1.2 Prophetic discernment**

In the Old Testament, a prophet was seen as somebody who acted as God's messenger; directly translated, the word prophet means mouthpiece (Osmer, 2008:132). They reminded Israel of how God graciously set them free from slavery (Exodus). God made a covenant with Abraham and called His descendants to live as His people. Prophets reminded Israel of God's judgement and love (Osmer, 2008:132). As messengers of God, prophets brought a divine message to their people, understanding their unique culture and context; they showed understanding for the time they were living in. Osmer (2008) describes the interaction between divine disclosure and human shaping thereof as prophetic discernment. The prophetic office aims to interpret God's Word to the covenant people in a particular socio-historical context. For the modern pastoral caregiver, prophetic discernment means being able to distinguish God's Word from the falsehood which has shaped the culture or beliefs of individuals and communities. To be able to discern means they can also be bearers of the truth for children and families of children with life-threatening and/or life-limiting conditions who may be "poor in spirit" (Matt 5:3) or have difficulty hearing God's voice. Hebrews 5:14 explains this well: mature food (spiritual food) is for those who have trained themselves to distinguish good from evil. Pastoral caregivers are called to have prophetic discernment. Prophets draw on specific theological traditions to critique popular beliefs and other theologies justified by false doctrines (Osmer, 2008:135). Good practice and its importance as a normative guideline will now be discussed.

#### **4.1.3 Good practice**

Good is defined as ἀγαθός, ἡ, ὄν (*agathós*) in Greek and is described as "inherently (intrinsically) good; as to the believer, *agathós* describes what originates from God and is empowered by Him in their life through faith" (Strong's, 2024).

Good practice is the practice of finding a model which provides normative guidance to the congregation's present actions. Good practice also provides normative guidance to a community by generating new understandings about God, the Christian walk and social values. This may challenge existing traditions (Osmer, 2008:152). Osmer (2008:152) recommends churches take time to observe other congregations to gain normative guidance in the area where they are seeking good practice models. In Chapter 2, good practice was observed in the interviews with the pastoral caregivers. Chapter 4 will also investigate good practices of showing care to the sick and vulnerable and what God thinks about modelling compassion (Matt 25:31–46). Applying moral principles to pastoral care practices in the field of caring for sick children is significant and will now be discussed.

#### **4.1.4 Ethical interpretation**

Ethical principles are important to guide human choices and behaviour (Osmer, 2008:147). Browning (1983:39) highlights the importance of using application from the beginning of interpretation to the end. Since application affects interpretation, a model of practice-theory-practice best describes practical theological interpretation (Browning, 1983:39). In other words, one confronts a problem in practice, which prompts research to seek a solution to the problem. Importantly, Browning recognises that the current praxis already has existing values and norms. This means one cannot just apply a new set of ethics to a situation without taking the existing norms into consideration. Instead, Browning states that the interpretative task is crucial in guiding the development of ethical values which inform norms.

Normative guidelines offer a model which pastoral caregivers and believers can follow to discover what God's will is. These guidelines include good practice, prophetic discernment and ethical discernment (Osmer, 2008:132–153). Normative reflection encourages new understandings of God and the Christian life (Osmer, 2008:152). Along with Osmer's valuable normative guidelines, Stein's grammatical-historical methodology is applied to this pastoral study's exegetical process (Stein, 2011).

## **4.2 METHODOLOGY**

Keeping the above-mentioned principles of prophetic discernment, good practice and ethical interpretation in mind, effective exegesis can be applied to the current pastoral issue by asking: "What does Scripture teach us about ministering to sick children?" A balanced pastoral strategy needs to be built on a biblical foundation. This biblical underpinning needs to consider the context of the events of the time and can then effectively cross the hermeneutical bridge to provide normative principles which can be applied to the modern context and pastoral issues of today. Stein (2011:19) and Rousseau's (2009:33) hermeneutical components will now be examined before looking at the chosen pericopes.

## **4.3 GRAMMATICAL-HISTORICAL HERMENEUTICS**

Hermeneutics is derived from the Greek word *hermēneuein* which is defined as the explanation or interpretation of something (Stein, 2011:5). The author, text and reader (or the coder, code and decoder) are the three distinct components involved in the communication process in biblical hermeneutics (Stein, 2011:6). Using a grammatical-historical approach prevents either an under- or over-exposure of the New Testament text (Rousseau, 1985:93). Using a one-mode approach over-emphasises either the theological-philosophical, historical or linguistic literary components at the expense of the other modes, which in turn distorts the author's intended message (Rousseau, 1985:93).

## **4.4 SIX EXEGETICAL STEPS**

Rousseau (2009:33) developed a grammatical-historical model which can be used for biblical exegesis. There are six critical questions he considers important to ask during the process of exegesis. These six questions fall into two categories. The first three questions give insight into the specific book of the Bible. The last three questions help the reader understand the specific text. The first question inquires who the author of the text is. The second question asks to whom the text was written (in other words, the original audience). The third question is why the text was written. The fourth question asks what is written, while the fifth wants to know what it meant to the original audience. The final question asks what the message and application are for today (Rousseau, 2009:33).

Each of these steps will be investigated and applied to the book of Matthew since the three pericopes are all derived from it.

### **Texts that will be used in this study**

- Matt 10:5–15 (Jesus' call to heal).
- Matt 19:13–15 (Jesus' call to children).
- Matt 25:31–46 (Jesus' call to care).

#### **4.4.1 Aspect 1: The author**

To know who wrote a book in the Bible and to whom it was written gives insight to the biblical scholar about the true intention and context of the author and thus assists in eventually crossing the hermeneutical bridge towards the modern reader.

According to early church tradition, the Christian leader Papias, who was Bishop of Heropolis (circa 60 to 130 AD), attributed an early Christian writing of the gospel to Matthew (Hays & Duvall, 2011:491–492). Matthew became one of Jesus' twelve disciples and is the only gospel where Matthew's career as a tax collector is recalled (Matt 10:3). Other confirmations of Matthew being the author, as identified by Hays and Duvall (2011:492), include the emphasis on financial topics which verify his identity. Finally, because of Matthew's background as a tax collector, early Christians would not have been proud to ascribe him as the author, unless it were probably true (Hays & Duvall, 2011:492).

#### **4.4.2 Aspect 2: Original audience**

The gospel of Matthew is written to the Jews (Hays & Duvall, 2011:492). This is clear from the Jewish customs Matthew refers to without explanation, expecting that the readers were accustomed to them from the Old Testament (Matt 15:2, 17:4, 23:5). Interestingly, Matthew is organised into five discourses, which Hays and Duvall (2011:492) believe is a reminder to the original Jewish audience of

the Pentateuch. The genre of a book in the Bible additionally gives the modern-day reader insight into how the original audience would have understood the author's message.

#### 4.4.2.1 Genre of Matthew

The book of Matthew is a theological biography, namely a gospel. Matthew is the first gospel which gives an account of the ministry and life of Jesus (Hays & Duvall, 2011:493). Voorwinde (2011:57) describes Matthew as the most Jewish of the four gospels. This can be seen from the rich Old Testament language which Matthew utilises to point out the fulfilment of Old Testament prophecies and symbols in Jesus' life and ministry. By doing so, Matthew strengthens the argument for the fulfilment and faithfulness of God's covenant promises to Israel through Jesus. Matthew succeeds in pointing to Jesus as the fulfilment of Israel's Jewish Messiah by writing a genealogy from Abraham to David to Joseph's line.

Gospel is translated from the Greek word *evangelion*, meaning good news (Hays & Duvall, 2011:485). Matthew, Mark, Luke and John are the first four books of the New Testament that reveal the narrative of Jesus' life and ministry. Matthew, Mark and Luke are titled the "synoptic gospels" (i.e. viewed together) since they recall similar stories of Jesus' life, whereas the Gospel of John has unique content about Jesus (Strauss, 2011:485). Matthew therefore wanted to reassure the Jewish audience that God's people are followers of Jesus and thus, they can break with the strict adherence to the law since Jesus fulfilled God's promises (Hays & Duvall, 2011:493).

The literary context refers to the literary function and placement of the text, as well as details regarding the author and the social and geographical setting. Chapters 1 to 4 of Matthew cover the narrative of Jesus' birth and early life, as well as a genealogy of Jesus. Chapters 5 to 25 report on the ministry of Jesus (Smith, 2013).

#### 4.4.2.2 Genre of pericopes

- *Pericope 1 (Matt 10:7–8)*

Using a narrative style, Jesus instructs his disciples by sending them out on a mission to preach the gospel. Matthew 10 is a didactic narrative as it instructs the reader through Jesus' teachings and commands (Precept Austin, 2022).

- *Pericope 2 (Matt 19:13–14)*

Matthew uses a narrative and instructional style in Matthew 19 to convey Jesus' moral and theological lessons (Constable, 2012).

- *Pericope 3 (Matt 25:31–46)*

Jesus uses parables in the text, leading up to the Day of Judgement described in the Olivet Discourse. Jesus uses parables to create urgency in being watchful for His return.

To give context to the three pericopes, the Old Testament background will first be investigated.

#### *4.4.2.3 Old Testament background*

Each area and city in Israel have roots in the Old Testament. Everywhere Jesus travelled and everything He said was strategic. Thus, some texts need to be taken from the Old Testament to understand Jesus' words and actions more comprehensively in the book of Matthew. Such an Old Testament example can be found in the book of Daniel. Daniel prophesied about Jesus' identity and inheritance long before it was written down in Matthew. Both Daniel and Matthew point to Jesus' identity as the Son of Man who is given the power to judge and rule by "the Ancient of Days" which refers to God the Father (Tsarfati & Yohn, 2024:136). In Daniel's vision in Daniel 7:15, the kingdom is given to "the most holy people of the Most High". This is confirmed in Matthew 25:46 when Jesus says the righteous will be given life and a reward "blessed of my Father".

The Book of Daniel moves from historical narrative (Chapters 1 to 6) to discussing apocalyptic visions from chapter 7 to 12 (Tsarfati & Yohn, 2024:132). The vision about the Son of Man coming back as Judge is echoed by Matthew 25. This is significant because Daniel prophesied about Jesus being led into the Father's presence before Jesus even came to earth. This was to fulfil the promises God made to Abraham that He would uphold a covenant with Israel. The fact that the first coming of Jesus was fulfilled increases the reliability of Jesus' second return as described in Daniel 7 and Matthew 25. Daniel 7:13 says: "In my vision in the night I continued to watch, and I saw One like the Son of Man coming with the clouds of heaven. He approached the Ancient of Days and was led into His presence. And He was given dominion, glory and kingship, that the people of every nation and language should serve Him. His dominion is an everlasting dominion that will not pass away, and His kingdom is one that will never be destroyed."

Taking Jesus' background and position into consideration is relevant to this study because if He considers visiting the sick to be important and He is the Son of God, then all followers of Christ ought to listen and do the same.

#### **4.4.3 Aspect 3: Why the text was written**

Exigency refers to the events which led to the creation of the book. The key verse in the gospel of Matthew is helpful to identify the "need" which prompted the Holy Spirit to inspire the author to address certain topics, since all Scripture is God-breathed and useful to teach believers how they should live (Kleingeld, 2024:171; 2 Tim 3:16).

Matthew was specifically written with the intention of confirming Jesus’ identity as the true awaited Jewish Messiah (Hays & Duvall, 2011:493). The key verse, which can support the importance for this book, is verse 1:1. Matt 1:1 trace Jesus’ genealogy back to the line of David and Abraham, supporting his identity as the true Messiah (Matt 1:1). The exigency of Matthew was recognising the need to encourage Christians who had to endure persecution in the early church (Hays & Duvall, 2011:493).

#### 4.4.4 Aspect 4: What is written

To truly understand what the book and pericopes are saying, the pericopes must be discussed in the language of the time (Kleingeld, 2024:171).

Pericope 1	Pericope 2	Pericope 3
• Matt 10:5–15	• Matt 19:13–15	• Matt 25:31–46
• Call to heal	• Call to children	• Call to care

##### 4.4.4.1 Pericope 1: Call to heal (Matt 10:7–8)

“The kingdom of heaven has come near. Heal the sick, raise the dead, cleanse those who have leprosy, drive out demons. Freely you have received; freely give” (Matt 10:7–8).

An extract of Matt 10:7–8 will be given below from the New King James Version (NKJV) and from the New International Version (NIV). The NIV is a dynamic equivalence translation, whereas the NKJV is a formal equivalence translation.

A dynamic equivalence translation is focused more on conveying the meaning of the text, rather than strictly adhering to the wording of the original language. A formal equivalence translation aims to stay as close to the original structure of the wording as possible (Stewart, 2024).

NIV (Dynamic equivalence)	NKJV (Formal equivalence)	Greek (NASB lexicon)
7 The kingdom of heaven has come near. 8 Heal the sick, raise the dead, cleanse those who have leprosy, drive out demons. Freely you have received; freely give.	7 And as you go, preach, saying, “The kingdom of heaven [c]is at hand.” 8 Heal the sick, [d]cleanse the lepers, [e]raise the dead, cast out demons. Freely you have received, freely give.	Κηρύσσετε/kērussete: “preach”. Defined: To be a herald.  Βασιλεία/basileia: “the kingdom”. Definition: The kingdom, sovereignty, royal power.  ἤγγικεν/ēngiken: “is at hand”. Definition: To make near/to come near.

		<p>Θεραπεύετε/therapeuete: “heal”. Definition: To serve, cure.</p> <p>Θεραπευετε/therapeuo: “wait upon menially”, i.e. (figuratively) to adore (God), or (specially) to relieve (of disease) – cure, heal, worship.</p> <p>ἐγείρετε/ egeirete: “raise”. Definition: To waken, to raise up.</p> <p>ἐκβάλλετε/ekballete: “Cast”. Definition: To expel, to drive, cast or send out.</p> <p>δωρεὰν/dōrean: “Freely”. Definition: As a gift.</p>
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#### 4.4.4.2 Text limits

To make sure that one does not take a biblical passage out of context, it is necessary to see what occurs in the text before and after each pericope.

- *Chapters before Pericope 1*

In Matthew 9, Jesus heals a paralytic man, a woman suffering from bleeding and a blind man; He also raises a girl from the dead and casts out a mute spirit. From Matthew 9, Jesus is seen operating from the authority that God has given Him (Hays & Duvall, 2011:507). Some of the people respond by saying: “Nothing like this has ever been seen in Israel!” (Matt 9:33). On the other hand, the Pharisees accuse Jesus of being “the prince of demons, who drives out demons” (Matt 12:22-45). After Jesus models God’s authority, Matthew 10 starts with Jesus giving the disciples authority over unclean spirits, sickness and disease. Thereafter, Jesus instructs the disciples to go and preach to the lost sheep of Israel (unsaved Jews). In Matthew 10:1, Jesus calls his twelve disciples to be apostles and gives them authority over the sick, oppressed and dead. Apostles are individuals who are sent as authorised representatives of another (Hays & Duvall, 2011:512).

In Matt 10:5–15, the twelve disciples are given their ministry instructions by Jesus. In Matthew 10:8 (Pericope 1), the apostles are told to go out to proclaim that God’s kingdom is near to “the lost sheep of Israel.” The apostles are given divine power and are instructed to go out and represent God’s kingdom.

- *Chapters after Pericope 1*

Matthew 10:9 continues with Jesus’ instructions regarding the disciples’ specific mission on how to minister to the lost sheep of Israel (Hays & Duvall, 2011:511). On the short-term mission, Jesus tells his apostles to take no extra clothes and provisions with them, but instead to find homes worthy of them. In Matthew 10:16–39, the apostles are encouraged to fear God alone. The expectations and cost of following Jesus are also described. In Matthew 10:40, the reward of serving Jesus is expressed. Jesus says that those who take care of Jesus’ disciples will not lose their reward. Verse 40 links to Pericope 3 (Matthew 25) in which Jesus shows His care for His followers, clearly stating: “He who receives you (disciples) receives Me (Jesus)”. This reward for serving God’s servants can also be seen in 2 Kings 4:8–17 in which the Shunammite woman was rewarded by conceiving a son after taking Elisha, the prophet of God, into her home. The above-mentioned Old Testament example is given to show the unchanging nature of God’s love for those who trust in Him and show care to one another. This care should extend to children, as recognised in Matthew 19.

#### 4.4.4.3 Linguistic aspects (important words and concepts)

- *Jesus gave authority (Matt 10:1)*

Constable (2023) notes the authority Jesus delegates to his disciples. This confirms Jesus’ identity, since no other prophet had delegated his powers to his disciples while alive. Importantly, the disciples did not heal the sick or drive out demons before Jesus’ delegation of His power to do so.

- *Apostles (Matt 10:2–4)*

From Matthew 10:2–4, the disciples are now called apostles. The word apostles is derived from the Greek word *apostello*, which means “to send” (Constable, 2023). This is fitting, since they are sent to the lost sheep of Israel in verses five to six.

- *Go to the lost sheep of Israel (Matt 10:6)*

The lost sheep refer to the Jews in Galilee: the apostles were thus excluded from going to the Samaritans on this mission. Constable (2023) notes the three aims of the apostles’ ministry to the Jews. First, they were to communicate the Jewish Messiah’s appearance; then, they were to announce the arrival of God’s kingdom. Finally, they were to provide signs confirming the authority they had been given.

- *Kingdom of heaven has come near (Matt 10:7)*

This verse means that the kingdom of heaven was about to begin, and thus, the apostles were to proclaim the good news of Jesus and to be travelling preachers like John and Jesus were (Constable, 2023).

- *Heal the sick... drive out demons (Matt 10:8)*

Since Jesus delegated His authority to His apostles, they were to heal the sick and free people from demonic oppression in the same manner Jesus did.

- *Freely you have received, freely give (10:8)*

Since the apostles received this divine authority and grace freely through their salvation, Jesus said they were to also freely give it to others.

#### 4.4.4.4 Pericope 2: Call to children (Matt 19:13–14)

“Let the little children come to me, and do not hinder them, for the kingdom of heaven belongs to such as these” (Matt 19:14).

An extract of Matthew 19:13–14 will be given below, again from the New King James Version (NKJV) and the New International Version (NIV).

<b>NIV (Dynamic equivalence model)</b>	<b>NKJV (Formal equivalence)</b>	<b>Greek (NASB lexicon)</b>
<p>13 Then people brought little children to Jesus for him to place his hands on them and pray for them. But the disciples rebuked them.</p> <p>14 Jesus said, “Let the little children come to me, and do not hinder them, for the kingdom of heaven belongs to such as these.”</p>	<p>13 Then little children were brought to Him that He might put His hands on them and pray, but the disciples rebuked them.</p> <p>14 But Jesus said, “Let the little children come to Me, and do not forbid them; for of such is the kingdom of heaven.”</p>	<p>Προσηνέχθησαν/ prosēnechthēsan. “Were brought”. Definition: To bring, to offer.</p> <p>Προσηνεχθη/prosphero. Definition: To bear towards, i.e. lead to, tender (especially to God), treat – bring (to, unto), deal with, do, offer (unto, up), present unto, put to.</p> <p>ἐπετίμησαν/epetimēsan. “Rebuked”. Definition: To censure, express disapproval.</p>

		<p>ἄφετε/aphete. “Let”. Definition: Leave alone, permit.</p> <p>Παιδία/paidia. “The children”. Definition: A young child.</p> <p>Βασιλεία/basileia. “To Me, for the kingdom”. Definition: Kingdom, sovereignty, royal power.</p> <p>ἐστί “Belongs”. Definition: I exist, I am. To such as these.</p>
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#### 4.4.4.5 Text limits

- *Chapters before Pericope 2*

Jesus teaches about what it means to be His followers from Matthew 19:1–20. Before Jesus teaches that His kingdom belongs to the childlike, He first answers the Pharisees’ question about divorce (Matt 19:1–12). After Jesus’ teachings on God’s original design for marriage between a man and a woman, Jesus starts to bless the children (Hays & Duvall, 2011:531).

As part of Jesus’ discourse on what it means to follow him, He uses the disciples’ irritation at the children’s interruption to teach the disciples that a person needs to be childlike to enter God’s kingdom.

- *Chapters after Pericope 2*

Having rebuked the Pharisees and disciples in Matthew 19:1–15, Jesus goes on to teach a rich young man how he can obtain eternal life (Matt 19:16–26) and then discusses the eternal rewards for following Him in Matthew 19:27–30.

#### 4.4.4.6 Linguistic aspects (important words and concepts)

- *Brought little children to Jesus*

The fact that the parents or other family members brought the children to Jesus reveals their respect for Him (Benson, 2024). It points to the obedience of the children to come, as well as the gentleness and approachability of Jesus (Adeney, 2024).

- *Placed his hands on them and prayed for them*

Constable notes (2023) the tradition of hand-placing reflected in the Bible: Genesis 48:14, Numbers 27:18 and Acts 6:6. In Genesis 48:14, Israel shows the tradition of a father blessing his children by usually placing his right hand on the eldest and his left on the youngest, although Israel placed his right hand on the youngest in this passage. In Numbers 27:18, Moses blesses Joshua in a similar fashion to Genesis 48:14, but at the same time inaugurated Joshua into Moses' office. Lastly, in Acts 6:6, the apostles laid their hands on seven men chosen for prayer and ministry of the Word. These verses show the contextual significance of Jesus placing His hands on children to bless them. Jesus shows the value of this benediction. Although Jewish people loved their children, they still viewed the children's role as having to listen, learn and show respect (Constable, 2023).

Although the disciples' reason for prohibiting the children from approaching Jesus is not explicitly mentioned, the disciples are confronted by Jesus who is more welcoming to the children than to them (Matt 19:13). Benson (2024) argues that the disciples believed the blessing of these children was beneath their master's dignity, since it was customary for fathers to bless their children by placing their hand on the heads of their children (Gen 48:14–20). Besides wanting to protect their master, Adeney (2024) believes the disciples wanted to keep Christ for themselves.

- *Do not hinder them, for the kingdom of heaven belongs to such as these.*

The kingdom of heaven refers to the invisible church of God (MacDonald, 2024). Pericope 2 communicates that the kingdom of heaven belongs to those who are childlike because they have the right humble attitude God desires (NIV, 2011: 1573). This contrasts with Jesus's response to those who used religion and law to justify themselves before God, like the Pharisees. Instead, Jesus emphasises the naïve faith of children to teach adults. Jesus' actions towards children prove that He believes the children's innocence entitles them to affection from those who are older (Benson, 2024).

Constable (2023) points out that the children in this passage also symbolise the adults who approach Jesus in a childlike manner. Jesus says that adults who act in this manner are the receivers of the kingdom of heaven. Jesus' attitude towards these children reflects the way Jesus challenged the other social norms of the time: by eating with a tax collector, talking with a Samaritan woman and healing lepers – all of whom were outcasts. It was frowned upon by the Jews who excluded tax collectors, Samaritans and lepers as part of Jewish society. Jesus thus came to lift the social status of the needy, humble, vulnerable and those trusting in Him. This can be seen from the story of the woman caught in adultery who was to be stoned, the children He welcomed and adults like Nicodemus the Pharisee who was curious about Jesus but was not socially welcome in Jesus' presence. Thus, Jesus demonstrated including the excluded, just as people today may exclude children with life-threatening and/or life-limiting conditions from pastoral support because of the uncertainty regarding how to approach and minister to these children.

4.4.4.7 Pericope 3: Call to care (Matt 25:31–46)

“When the Son of Man comes in His glory... and these will go away into everlasting punishment, but the righteous into eternal life” (Matt 25:46).

An extract from Matt 25:31–46 will be given below from the New King James Version (NKJV) and from the New International Version (NIV).

<b>NIV (Dynamic equivalence model)</b>	<b>NKJV (Formal equivalence)</b>	<b>Greek (NASB lexicon)</b>
31 “When the Son of Man comes in his glory, and all the angels with him, he will sit on his glorious throne.	31 “When the Son of Man comes in His glory, and all the holy angels with Him, then He will sit on the throne of His glory.	ἔθνη/ethne: “nations”. Definition: A race, a nation, pl. the nations (as distinct from Israel). Significance: Everyone outside of Israel (all/ ἅντα) will stand before Jesus’ judgement seat.
32 All the nations will be gathered before him, and he will separate the people one from another as a shepherd separates the sheep from the goats.	32 All the nations will be gathered before Him, and He will separate them one from another, as a shepherd divides his sheep from the goats.	ἀφορίσει/ apherisei: “Him and He will separate”. Definition: To mark off by boundaries from, i.e. set apart.
33 He will put the sheep on his right and the goats on his left.	33 And He will set the sheep on His right hand, but the goats on the left.	Significance: ἅγιος, ἱά, ον means hagios/sacred/holy. This means to be set apart by (or for) God.
34 “Then the King will say to those on his right, “Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. 35 For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, 36 I needed clothes and you clothed me, I was sick and you looked after	34 Then the King will say to those on His right hand, “Come, you blessed of My Father, inherit the kingdom prepared for you from the foundation of the world: 35 for I was hungry and you gave Me food; I was thirsty and you gave Me drink; I was a stranger and you took Me in; 36 I was naked and you clothed Me; I was sick and you visited	Therefore, those who are set apart for God (holy) are separated from those who are the same as the world and hence enemies of God (Jas 4:4). Ἡσθένησα: “Me; I was sick” Definition: To be weak, feeble (Matt 25:36). Significance: Originates from ‘asthenés’, meaning “without strength” when they were

<p>me, I was in prison and you came to visit me.”</p> <p>37 “Then the righteous will answer him, ‘Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? 38 When did we see you a stranger and invite you in, or needing clothes and clothe you? 39 When did we see you sick or in prison and go to visit you?’</p> <p>40 “The King will reply, ‘Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.’</p> <p>41 “Then he will say to those on his left, ‘Depart from me, you who are cursed, into the eternal fire prepared for the devil and his angels. 42 For I was hungry, and you gave me nothing to eat, I was thirsty and you gave me nothing to drink,</p> <p>43 I was a stranger, and you did not invite me in, I needed clothes and you did not clothe me, I was sick and in prison and you did not look after me.’</p> <p>44 “They also will answer, ‘Lord, when did we see you hungry or thirsty or a stranger or</p>	<p>Me; I was in prison and you came to Me.”</p> <p>37 “Then the righteous will answer Him, saying, ‘Lord, when did we see You hungry and feed You, or thirsty and give You drink? 38 Then did we see You a stranger and take You in, or naked and clothe You?’</p> <p>39 Or when did we see You sick, or in prison, and come to You?’</p> <p>40 “And the King will answer and say to them, ‘Assuredly, I say to you, inasmuch as you did it to one of the least of these My brethren, you did it to Me.’</p> <p>41 “Then He will also say to those on the left hand, ‘Depart from Me, you cursed, into the everlasting fire prepared for the devil and his angels: 42 for I was hungry and you gave Me no food; I was thirsty and you gave Me no drink; 43 I was a stranger, and you did not take Me in, naked and you did not clothe Me, sick and in prison and you did not visit Me.’ 44 “Then they also will answer Him, saying, ‘Lord, when did we see You hungry or</p>	<p>visited by the righteous who ‘zoomed in’/<i>skopos</i> and visited them.</p> <p>Συνηγάγομεν: “And invite” Definition: To bring together, entertain (Matt 25:38). Significance: Originates from word ‘ago’, meaning ‘to bring or carry’ (Strongs Greek, 2021). Thus, by inviting a stranger one is in a sense carrying them physically/emotionally.</p> <p>Ἀποκριθεὶς: “Will answer” (Matt. 25:40). Definition: To answer Significance: It is the King who answers, and the Greek will answer ‘Ἀποκριθεὶς’, originates from <i>ansapo and krinó</i>, which means ‘to judge’. This means He the King has the final say in the matter and has the authority to judge.</p> <p>Κατηραμένοι: “From Me, accursed” (Matt 25:41). Definition: To curse. Significance: It originates from the word <i>katara</i>, meaning a doomed one. This gives insight to the reader about the destination of those who stood on His left in this passage.</p> <p>Κόλασιν: “punishment”. Definition: “Correction”.</p>
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<p>needing clothes or sick or in prison, and did not help you?’</p> <p>45 “He will reply, ‘Truly I tell you, whatever you did not do for one of the least of these, you did not do for me.’</p> <p>46 “Then they will go away to eternal punishment, but the righteous to eternal life.”</p>	<p>thirsty or a stranger or naked or sick or in prison, and did not minister to You?’ 45 Then He will answer them, saying, ‘Assuredly, I say to you, inasmuch as you did not do it to one of the least of these, you did not do it to Me.’</p> <p>46 And these will go away into everlasting punishment, but the righteous into eternal life.”</p>	<p>Significance: It originates from the word <i>kolazó</i>, meaning to chastize/cause to be punished (Matt 25:46).</p> <p>On the other hand, the righteous are sent to eternal life.</p> <p>Ζωήν: “Life”</p> <p>Definition: “life”.</p> <p>Significance: This word originates from the word <i>zaó</i>, meaning ‘I live’, am alive. This fate of the righteous is the opposite of the chastisement inflicted on the unrighteous who are curse.</p>
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#### 4.4.4.8 Text limits

- *Chapters before Pericope 3*

In Matthew 23:37–39, Jesus laments over Jerusalem’s unwillingness to accept Him as God’s Messiah (Hays and Duvall, 2011:539). Later, in Matthew 24, Jesus begins the fifth discourse, namely the Mount of Olives Discourse (Matt 24:1–25:46). Before Pericope 3, Jesus predicts the temple’s destruction (Matt 24:1–3), answers the disciples’ questions (Matt 24:4–35) and warns his disciples about Jerusalem’s destruction (Matt 24:15–20). Then Jesus describes a time in the future of great tribulation when false messiahs and false prophets will appear to deceive God’s people (Matt 24:21–48). Hays and Duvall (2011:541) explain that Jesus will return in the Second Coming with power and glory after the time of tribulation. Jesus states that He could return at any moment (Matt 24:32–35) and that it is necessary to be prepared (Matt 24:36–25,46). Jesus warns his disciples to be watchful and alert (Matt 24:42) and then speaks about parables on watchfulness from Matthew 24:43 to Matthew 25:30 (Hays and Duvall, 2011:542).

- *Chapters after Pericope 3*

Matthew goes on to discuss the crucifixion, resurrection and great commission from Matthew 26 to Matthew 28:20. It starts with the plot to kill Jesus in Matthew 26:1–5 and then Jesus’ Last Supper in Matt 26:17–30. The Last Supper is also the first communion which symbolises Jesus delivering his followers from sin and spiritual death through His blood (the wine) and broken body (the bread). With Jesus’ crucifixion, He refused the drugged wine and bore the full weight of suffering (Hays & Duvall, 2011:545,551). This means Jesus can relate to children suffering from serious illness. Because of Jesus’

resurrection, these children do not have to fear death, but instead can look forward to eternal life with Him (Matt 28:1–15). The crux of the message of the book of Matthew is that Jesus can tell his followers what to do (the Great Commission) since all authority on heaven and on earth has been delegated to Him (Hays & Duvall, 2011:554). Jesus tells his disciples to invite people to have a relationship with Him and to disciple people to grow in that relationship.

At the end of Matthew’s gospel, the importance of the Final Judgement is highlighted (Matt 25) which should stir believers to realise the urgency of applying the Great Commission (Matt 28:16–20). The linguistic aspects of Matthew 25 will be unpacked next. In God’s kingdom, Jesus is highlighted as the Judge (Matt 25:31–46) who separates His followers (the sheep) from non-believers (goats).

#### 4.4.4.9 Linguistic aspects (*important words and concepts*)

The understanding of Greek words is important in exegesis since their grammar may differ from the English translation. Therefore, the NASB lexicon (Biblehub.com) and Louw and Nida’s text was used to get an understanding of the original Greek words.

- *Son of Man*

Broadly speaking, the communicational goal of Matthew is to affirm Jesus as the fulfilment of the Messianic predictions of the Old Testament prophets (International Standard Bible Encyclopaedia, 2023). The theological significance of the phrase “Son of Man” is that it emphasises Jesus’ full humanity, divine authority and his Messianic role.

From the surface, Son of Man (which Jesus uses 88 times to refer to Himself in the New Testament) refers to Jesus’ full humanity, that He is the son of an earthly man, Joseph. But John Piper (2008) points out that those who began to see Jesus’ identity as the Son of God might have noticed that this phrase refers back to Daniel 7:13–14 (Daniel’s apocalyptic vision) in which the Son of Man refers to an exalted figure. Jesus might have used this phrase, instead of Son of God, to hinder offending the Sanhedrin, until it was His time to be crucified (Piper, 2008). Therefore, Son of Man, according to Piper (2008)’s analysis of the phrase, explains that Jesus wanted to communicate that He is fully human, as well as the exalted heavenly one who would fulfil Daniel’s prophecy (Dan 7). Although Ezekiel the prophet was also called “son of man” in the Old Testament (Ez. 33:7-33), Jesus’ use of the phrase includes the definite article “the”. The use of this article implies that Jesus is the only one who is fully human, but without sin (Anon, 2024).

The fact that Jesus’ humanity is emphasised means that He can relate to humans, showing compassion in their suffering. But although Jesus has humanity, He is also powerful, as noted in Daniel’s vision in which the Son of Man is given authority. This is attested by other Old Testament prophecies which Jesus fulfilled. Isaiah 7:4 predicts a virgin birth; Psalm 22 presents a crucifixion prophecy which Jesus

quotes while on the cross (Matt 27); Micah 5:2 prophesies about a Bethlehem birth; Hosea says the Messiah will end up in Egypt (Hos 11:1) and Isaiah 9:2 prophesies about a Wonderful Counsellor.

Isaiah prophesied that Jesus' ministry would start in Galilee (Isa. 9:1). This is fulfilled in Matthew 4:12–17 when Jesus began to preach in Galilee, saying, “Repent for the kingdom of heaven has come near.”

In Psalm 78:1–2, it is prophesied that Jesus will speak using parables (Matt 13:34–35). This can clearly be seen in Pericope 3 in which Jesus tells a parable of ten virgins and a parable of bags of gold (Matt 25). Overall, there are 23 parables in the book of Matthew.

All the above-mentioned Old Testament prophesies are fulfilled in the book of Matthew, which affirms Jesus as the Son of God and awaited Messiah. Lastly, besides being fully human and the powerful Son of God, Jesus also fulfilled the messianic mission to save humanity.

- *He will sit on his glorious throne*

“He” refers to Jesus who is addressed as the Son of Man. The throne is His and the fact that it is described as glorious underscores His place of position and authority. In Colossians 3:1, Mark 16:19 and 1 Peter 3:22, Jesus is given a place of honour on the right hand of God after He conquered death. Therefore, Jesus comes back as a Judge (Acts 10:42) of the living and dead. Osmer (2008:135) describes Jesus as not only the prophet who is God's mouthpiece, but instead as the true Word of God (John 1:1).

- *I was sick, and you looked after me, I was in prison, and you came to visit me*

The Son of Man identifies with those who are in need (hungry, sick and in jail) by using the personal pronoun “I”. Jesus' compassion goes out to those who are vulnerable. Jesus modelled compassion in his care of others: Matthew 9:35 says: “When he saw the crowds, he had compassion on them, because they were harassed and helpless, like sheep without a shepherd.” To understand Jesus' feelings of compassion it is helpful to first understand divine pathos (Osmer, 2008:136).

- *Splanchnizomai*

*Splanchnizomai* is defined as “to be moved in the inward parts (intestines)” (Krause, 2019; Strong's concordance, 2021). Louw (2011:11) calls God's compassion the theology of the intestines, which places the emphasis on God as the “covenantal and faithful God”. *The Blue Letter Bible* (2024) describes this compassion as “to be moved as to one's bowels” since the bowels were believed to represent the seat of love and pity.

The fact that Jesus had *splanchnizomai* on the crowd (Matt 9:36) means Jesus did not show an artificial feeling but instead was deeply moved physically (Krause 2019:4). In the parable of the Good Samaritan, *splanchnizomai* models the willingness to use all resources, time and strength to help someone in need (Krause, 2019:10). This is mentioned since Jesus is the Good Samaritan in the story and modelled what

he expects from His disciples. Voorwinde (2011:9) highlights Jesus' humanity through his emotions. Matthew uses 10 references to Jesus' emotions. These capture Jesus' feelings of astonishment (Matt 8:10), sternness (Matt 9:30), compassion (Matt 9:36; Matt 14:14; Matt 15:32; Matt 20:32) and sorrow (Matt 26:37,38; Matt 27:47). Jesus as compassionate king is noted four times in Matthew's gospel (Voorwinde, 2011:24). The Greek word *splanchnizomai* is the original verb used, referring to having great affection and compassion for someone (Louw & Nida, 1988:295).

Since this verb is only used in the synoptics to refer to Jesus and a few other saint-like figures (such as the father of Prodigal Son, the master of the unmerciful servant and the Good Samaritan), it can be argued that this use of compassion describes Jesus' attitude and His divine nature (Voorwinde, 2011:24). Moreover, besides revealing something about Jesus' character as God, His compassion is directed at crowds in need in the book of Matthew (Voorwinde, 2011:26).

Children with life-threatening and/or life-limiting conditions can be compared to sheep without a shepherd to guide them through their fears and difficulties. In the next verse, Jesus states: "The harvest is plentiful, but the workers are few" (Matt 9:37). Jesus not only sees the need for a Good Shepherd in verses 35 to 36, but He sees that the crowds have potential to be part of God's kingdom (Voorwinde, 2011:27). The extract in Matthew 9:36 highlights how Jesus perceived others: He stepped in to be the shepherd who cares for them. In the same way, it can be argued that Jesus expects His disciples to care for those who are suffering because they are sheep without a shepherd and since He delegated His power to them in Matthew 10.

- *Lord...when did we see you sick...?*

In Matthew 25:37, the righteous (sheep) and in verse 44, the cursed (goats) question Jesus about His identification with those in need, since they do not recall either providing for or ignoring Jesus.

Jesus responds by saying that actions of charity or compassion reveal true faith in Him. This is supported by James 2:14–17 in which the relationship between faith and deeds are discussed. James explains that it is of no use when someone claims to have faith but does not portray deeds. "Can such faith save him?, 'Go in peace; stay warm and well fed,' but does not provide for his physical needs, what good is that? " This passage addresses the action of serving others with words only, which has no impact of blessing the other person. Jesus blesses those who care for those in need and with whom He identifies with, while He curses and dismisses those who did not answer the call to care for those in need (Matt 25:41).

The missionary-encouragement perception of Matthew 25 (Gibbs, 2018) states that serving the needy is not merely about serving everyone, as the social-ministry interpretation discusses, but the sense of "brother" relates to Jesus' disciples and, in the case of Matthew 18:5, receiving children. When one uses the social-ministry interpretation in isolation, one is in danger of gearing one's works toward others

as the basis for “eschatological judgement”. Instead, Gibbs (2018:1346) states that to merely provide for the physical needs of the world is not supported by the rest of the chapters of Matthew.

Turner (2008) agrees with the missionary-encouragement reading on Matthew, stating that although Jesus modelled caring for the needy, the rest of Matthew does not exegetically support just caring for every needy individual (Keener, 1999 as cited in Turner 2008:604). Gibbs (2018:1353) explains that the missionary-encouragement stance explains Jesus’ “brothers” as His disciples. The idea that Jesus’ disciples are brothers is supported by Matthew 18:15 and Matthew 21:35; only one is to be referred to as “Father” above them in Matthew 23:8–9. Moreover, Gibbs (2018:1356) points out that the righteous refer to those who welcome the messengers of Christ, since it indicates they are welcoming the message and hence “Christ himself” (Matt 10:40).

At the time of Jesus’ discussion in Matthew 25:31–46, Jesus had not died and been resurrected. Gibbs (2018:1352) unpacks the eschatological perception (starting in Matt 24:1-26) using the missionary - encouragement reading. Jesus explains how the post-Easter mission has been completed and how humanity will be separated into those who received or rejected Jesus’ “brothers” (Matt 25:4). Gibbs (2018:1351) describes the four scenes Jesus sketches, which take place in Matthew 25:31–46. In the first scene from verse 31 to 33, Jesus arrives and separates the righteous (Jesus’ disciples) from the wicked (unsaved). Then, from verses 34 to 40, Jesus invites the righteous from the previous scene to receive the blessings of the Father’s reign and clarifies their query regarding serving Jesus by serving those in need. Scene 3 (verse 41-45) explains the fate of those who rejected serving Jesus’ “brothers”. Gibbs (2018:1351) explains Jesus’ concluding words in verse 46, which emphasises Jesus’ final words about the outcomes of the righteous and the wicked.

- *Righteous and unrighteous*

All three translations (Greek, NIV and NKJV) convey the same message that the righteous (sheep) are blessed by God the Father and that they will receive an inheritance (the kingdom/eternal life) which has been prepared from the beginning of the world. All three translations clearly convey the separation of the righteous and unrighteous on the grounds of their actions towards caring for their brothers as if caring for Christ Himself. On the other hand, the unrighteous (who are not in right standing with God) are called “cursed” by Jesus and receive eternal punishment. It can be understood that there are heavenly rewards for good earthly deeds for those who are in right standing with Jesus.

#### 4.4.4.10 Word study on goats and sheep

- *Goats*

Those who did not take care of Jesus’ brothers are referred to as goats. In Scripture, Jesus quotes the Old Testament many times as He came to fulfil these prophecies. Thus, the Old Testament is quoted to emphasise the impact of Jesus’ words as a fulfilment of the Law in the New Testament, which attests

to Jesus' identity as God. Jesus also uses words the Jews could comprehend. The Jews knew about the role a goat played as a sin offering, since they abided by the Levitical laws. Leviticus 16:5-22 states: "The goat will carry on itself all their sins to a remote place; and the man shall release it in the wilderness." In this passage, two goats were sacrificed on the Day of Atonement. The first was sacrificed for the people's sins, while the second was sent into the desert, symbolising the removal of the people's guilt which is sent away through the scapegoat.

In the New Testament, Hebrews 9 refers to Jesus' ultimate sacrifice on the cross, so that the people no longer had to practise the sacrifice of goats on the Day of Atonement. Hebrews 9:12 says: "He did not enter by means of the blood of goats and calves; but he entered the most holy place once for all by his own blood, thus obtaining eternal redemption." This passage refers to Jesus who by His own blood functioned as the final, pure lamb who took away the sins of the world in order that people could be restored to a covenant relationship with God. This means that people can finally enter God's presence with boldness by the grace of Jesus (Heb 4:16). Although people externally "clean" themselves, Jesus' offer cleans people internally. This means sick individuals, like the children in this study, have an eternal hope of being in Jesus' presence when they die because of Jesus' offering.

Hebrews 9:13-14 states: "The blood of goats and bulls and the ashes of a heifer sprinkled on those who are ceremonially unclean sanctify them so that they are outwardly clean. How much more, then, will the blood of Christ, who through the eternal Spirit offered himself unblemished to God, cleanse our consciences from acts that lead to death, so that we may serve the living God."

This passage refers to the Old Testament (Lev 16) and New Testament (Heb 9) covenants. Thus, Jesus' blood cleanses people internally, so that they may be considered sheep at the Final Judgement (Matt 25:31-46), instead of having to bear their own sins like the scapegoats in Leviticus 16 who were sent away into the wilderness. Matthew 25:46 says: "Then they will go away to eternal punishment, but the righteous to eternal life." The sheep will enter God's presence because they accepted the blood of Jesus' offering on the cross, while the goats are unsaved and unholy, meaning they cannot be in God's presence.

- *Sheep*

Importantly, the theme of God's justice is already communicated in Ezekiel 34:17: "I will shepherd the flock with justice". Matthew 25:31-46 is not the first time the analogy between sheep and goats is used in Scripture. It is also used in Ezekiel 34 to address the rich who oppress the poor. Ezekiel 34:17 will be quoted with the purpose of reading and analysing the Scripture in context.

Ezekiel 34:17 states: “As for you, my flock, this is what the Sovereign LORD says: I will judge between one sheep and another, and between rams and goats.” Instead of linking this passage with the separation which takes place in Matthew 25:31–46, this separation is argued to be between the rich and the poor. God is addressing the rich who oppress the poor, even though they have enough to provide for them. God scolds those who do not take care of the flock: “You have not strengthened the weak or healed the sick or bound the injured.” The God image of God as Judge can be seen in both Ezekiel 34:17 and Matthew 25:31–46.

#### **4.4.5 Aspect 5: What it means to the original audience**

The social-historical context of the original audience is crucial to understanding the book before a modern application can be achieved (Kleingeld, 2024:172). Thus, to give an oversight of the Old and New Testament background, a historical, geographical and political context background will be given.

##### *4.4.5.1 Old and New Testament background*

Jesus relives Israel’s history in the first seven chapters of Matthew (Bordow, 2005). Like Israel, Jesus was persecuted as a baby and was led into and out of Egypt (Matt 2:13-23). From Matthew 3:1–12, John the Baptist prepares the Jewish people for Jesus’ ministry by teaching them to repent and be baptised in the Jordan River (Hays & Duvall, 2011:497). Then, again like Israel who wandered in the desert for 40 years, Jesus was tested in the wilderness for 40 days (Matt 4). Matthew 5 describes Jesus’ famous Sermon on the Mount in which Jesus models a kind of “new Moses” who climbs a mountain and delivers God’s revelation to the people (Bordow, 2005). These links between the Old Testament and Jesus’ life on earth highlight the importance of the geographical context as the places Jesus travelled to during his public ministry had their roots in the Old Testament. Thus, the geographical, historical and political context of Jesus’ time will be discussed.

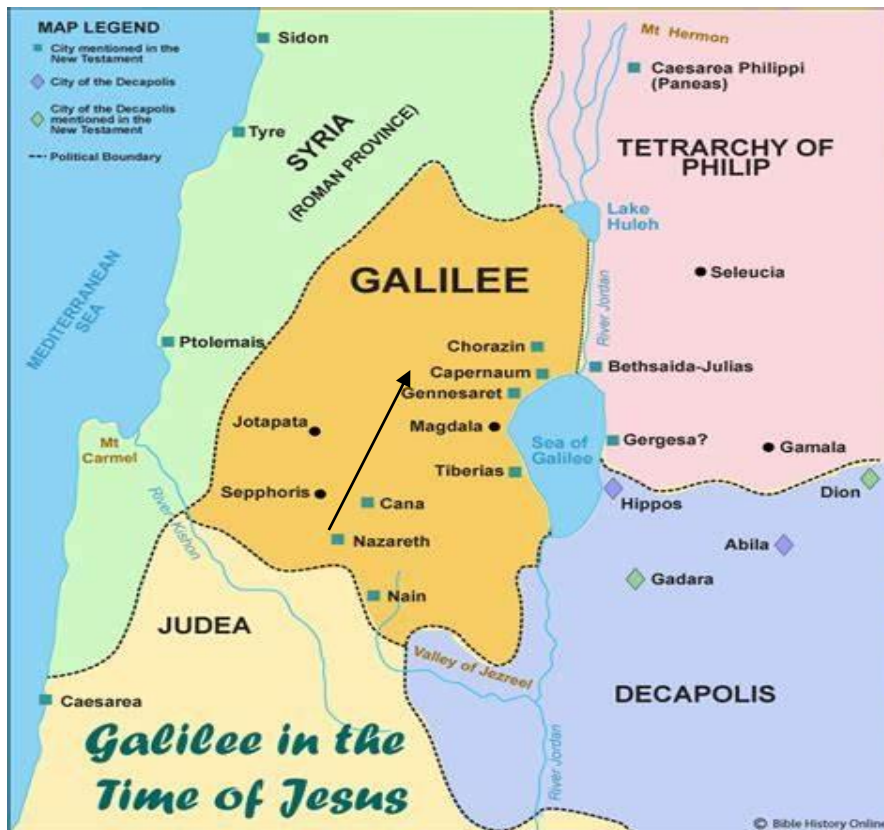
##### *4.4.5.2 Historical context*

Historical context includes a description of a specific place’s existing social, political, geographical and economic conditions. All three pericopes come from the book of Matthew and thus, they take place under similar historical conditions during Jesus’ earthly ministry. Existing Jewish cultural norms are prominent in the book without the author explicitly explaining them to his readers.

The gospel of Matthew unfolds during the time of the Roman empire (63 BC to 135 AD). Although the Jews were allowed certain religious freedoms, they were frustrated under Roman reign and were expecting a warrior saviour who would set them free from Roman rule. When Jesus’ ministry began, the Jews did not want to accept Him as their Messiah. His agenda did not meet their expectations of what their Saviour would do (Bible, 2011:1519; Hays & Duvall, 2011:497). Geographically, the events in the book of Matthew unfold in Jerusalem, Judea, Samaria and the other occupied lands of the Greco-Roman empire (Mackie & Collins, 2024; Hays & Duvall, 2011:479–484).

#### 4.4.5.3 Geographical context

Figure 1: Map of Galilee (Anon, 2024).



The arrow on the map (Fig 1) indicates Jesus' journey from Nazareth where He was rejected by His own people (Matt 13:53–58) to the area of Capernaum where He spent most of His time ministering. Bordow (2005) calls this fishing village Jesus' adopted hometown and the headquarters of his ministry. From this home base, Jesus the Messiah proclaimed a new covenant and warned about His Second Coming, requiring a decision about either following or rejecting God's kingdom (Hays & Duvall, 2011:497).

#### 4.4.5.4 Political context

- *Roman rulership*

During the intertestamental period, Judaism changed from a temple-centred hierarchical religion to a more democratic religion with synagogues for worship and teaching (Osborne, 2011:471). The Herodian family was at the top of the Roman political ladder. Herod the Great brought peace to the land but also built Roman temples which contributed to bringing Hellenistic cultural influences to Palestine. After the death of Herod, the Great (circa 4 BC), his sons Archelaus, Antipas and Philip ruled his kingdom. Osborne (2011:472) describes that Archelaus was known for being brutal and was replaced by prefects. Antipas, his second son, was less brutal than Archelaus. However, he was known for the execution of John the Baptist and for participating in Jesus' trial.

- *Jewish rulership*

During this time of the Roman rule, there was the Sanhedrin, which was comprised of 71 members who acted as the congress and supreme court of the Jewish people. There existed two primary Jewish factions in the Sanhedrin, namely, the Scribes (Pharisees/legalists) and the Sadducees, who were the aristocrats of the time (Osborne, 2011:472). The Romans delegated the Sanhedrin with the responsibility to decide religious, political and civic issues concerning the Jewish people, although they legally had little authority over the area of Galilee (Osborne, 2011:473). Because the Sanhedrin had little authority over Galilee, Jesus ministered there for a significant portion of His public ministry since it was safer.

- *Jesus' rulership*

Because Jesus healed the sick, forgave sins and spoke with authority, Jesus drew attention as a possible Jewish king since the people at times regarded Him highly. The Sadducees feared Jesus' popularity would put the Jews under threat and they would lose the privileges bestowed to them by the Roman empire. The Romans would not allow another king to threaten their empire (Bible, 2011:1519). The Pharisees and Sadducees agreed that Jesus needed to die since he broke the laws and blasphemed, claiming to be the Son of God who had the ability to forgive sins.

Now that the author, text and original audience have been studied, the exegete can proceed towards applying the text to the modern reader.

#### **4.4.6 Aspect 6: Modern-day application**

Kleingeld (2024:172) asserts that application is built on the foundation of interpretation. Therefore, the researcher needs to ensure that her interpretation is in line with the first five steps before applying it to the theme, since the caregiver has a responsibility to convey God's heart correctly. Each pericope's revelation and application will be investigated as it is necessary to understand what the text is revealing about God and how it is relevant to the modern reader.

Matthew points out the Gentile thread in the gospel which builds toward the Great Commission in Matthew 28:18–20. This thread reveals God's action towards fulfilling the Abrahamic covenant. Moreover, the establishment of Jesus' eternal kingdom fulfils the Davidic covenant and ultimately Jesus' shedding of His blood replaces the Mosaic covenant (Voorwinde, 2011:58). The revelation can be determined from the larger salvation-historical context of Scripture. The salvation-historical context refers to the history of God's unfolding of His covenant promises to man from the Old to the New Testament. Key events in this timeline include the creation of man, the fall, the exodus from Egypt, the exile of the Israelites in Babylon, the birth of Christ, His crucifixion, His resurrection, His ascension, Pentecost and the Second Coming of Christ.

Revelation refers to what is revealed about God in the passage. Christians believe there are three persons in the godhead, namely God the Father, Jesus the Son and the Holy Spirit. Thus, what is revealed about God, Jesus and the Holy Spirit will be investigated in the passage.

#### *4.4.6.1 Revelation of Pericope 1*

- *God*

From Matthew 10:7–8, the absolute authority and power of God the Father is revealed. He is the origin of the power which is delegated to Jesus and which Jesus delegates to His apostles.

Practically, this delegation means that God’s power and His presence (kingdom) is near to humanity through the finished work of Jesus on the cross. Thus, pastoral caregivers have access to the throne room of grace to intercede on behalf of sick children and their families, as Jesus intercedes for all humanity (Heb 4:16; Rom 8:34). Pastoral caregivers also do not need to see the Father to believe in the power of Jesus (John 14:7). Although God is Holy, caregivers can approach Him when they are in Jesus, since He paid for their sins and God sees them through the grace of Jesus (Jas 5:13–17).

- *Jesus*

Jesus’ position as God’s Son is revealed prominently in the book of Matthew (Matt 28:18). This is made clear from Jesus’ divine conception, birth and the fact that Jesus performs miracles, is crucified, gives up his own spirit and then defeats physical and spiritual death. In Matthew, Jesus expounds a principle which reflects something of the character He modelled on earth. He says that the disciples should feely give what they’ve received. This refers to the fact that they’ve received salvation, Jesus’ presence and His spiritual gifts freely. Because they’ve received all this, Jesus says “go” to encourage His representative to go and preach the nearness of His kingdom, to heal the sick, raise the dead and drive out demons (Matt 10:7–8). They should give freely to others their time, love and spiritual gifts (Constable, 2023). The apostles had spiritual freedom through Jesus’ salvation to offer physical and psychological freedom from earthly ailments and oppression.

- *Holy Spirit*

The Holy Spirit came down like a dove on Jesus when He was baptised (Matt 3:16) right before Jesus’ public ministry began (Matt 4). God’s voice also came out of heaven, saying, “This is my beloved son, whom I love; with him I am well pleased.” These two manifestations revealed that firstly, Jesus is the Son of God and secondly, that He was empowered by the Holy Spirit to minister to others. Through the power of the Holy Spirit, Jesus’ followers can be “shrewd and innocent” at the same time (Matt 10:16). This is the same Holy Spirit whom Jesus promised to His believers when he ascended into heaven: “If I go, I will send Him to you” (John 16:7). Later, the disciples had to wait in the upper room for the Holy

Spirit to empower them (Acts 2:2). Similarly, pastoral caregivers ought to wait on the Holy Spirit to empower them with wisdom and the right words to minister to sick children and their families.

#### *4.4.6.2 Application of Pericope 1*

Faith communities and pastoral caregivers are clearly called to minister to others and to follow the example of Jesus. In the final pericope (Matt 25:31–46), Jesus places loving God and others as the most important commandments. Crossing the hermeneutical bridge, it is important for pastoral caregivers and Christians in the 21<sup>st</sup> century to serve one another, just as they were called to serve one another in the time of Jesus, as demonstrated in Acts 5:12–16. Voorwinde (2011:28) points out that Jesus' compassion towards crowds was one of the major motivators of Jesus' ministry in the gospel of Matthew. Although Jesus was mourning his cousin John's death at the time, he was moved with compassion when he saw the 5,000 people waiting for him and healed those who were r sick among them (Matt 14:14).

The themes which can be identified from Matthew 10:1–42 include:

- Commission
- Authority
- Persecution
- Commitment and fearlessness

The disciples are commissioned by God, then given authority to represent Jesus through miracles and healing. However, Jesus cautions them about the persecution they will face and calls them to prioritise mission over comfort. Persecution will come because they are devoted to Jesus (Hays & Duvall, 2011:513). Jesus encourages them to fear God and not man, since God's providence and protection are with them. Similarly, pastoral caregivers are commissioned by Jesus to serve in a certain setting and are given the authority to operate from the truth of His Word. They are also to be aware that the world might not always be open to their message and that their caregiving may result in their own pain. Caregivers still need to commit and operate fearlessly, even though they might experience the emotional pain of children suffering from serious illness. Jesus demonstrated His love and care for children in Matthew 19:13–14 and calls His followers to do the same.

#### *4.4.6.3 Revelation of Pericope 2*

Like Matthew 10 and Matthew 25, Matthew 19 takes place before the crucifixion of Jesus, but after His birth. The difference between Jesus and other famous ministers are highlighted from passages like Matthew 19. Constable (2023) notes that it is next to impossible to meet with famous preachers and evangelists. By contrast, Jesus eschews His disciples' instincts to protect Him from the ill, the hopeless, the weary, outcasts and children. Jesus' presence was one of openness to the humble, as well as to young children. In Matthew 19:14–15, Jesus reveals the importance of childlike humility in the hearts of His

disciples. What this reveals about God the Father, Jesus and the Holy Spirit is that “God opposes the proud, but gives grace to the humble” (Jas 4:6). Therefore, knowing God’s character, one should strive to humble oneself before Him.

- *God*

God’s love for children is revealed in this passage. The fact that Jesus is God’s representative and willingly blesses children highlights God’s grace towards them. Humility and dependence on God are emphasised by the words “for the kingdom of heaven belong to such as these” (Matt 19:13–14).

- *Jesus*

Jesus’ compassion towards children, despite his disciples’ expectations, is noteworthy. This action of welcoming children is another example of Jesus confounding societal expectations to include and be accessible to those whom society excludes, such as lepers, Samaritan women and tax collectors (Mark 1:40; John 4:4; Mark 2:16). Jesus ultimately models to his disciples the principle that spiritual maturity means one ought to have childlike faith.

- *Holy Spirit*

This childlike faith and dependence on God can only be achieved through the sanctification work of the Holy Spirit, and so this passage encourages Christians to invite the Holy Spirit to transform their faith.

#### *4.4.6.4 Application of Pericope 2*

Based on Matthew 19:14, Jesus has a high regard for children and adults who show childlike faith. This links to Matthew 18:1–5, a passage in which Jesus says that children are the greatest in the kingdom of heaven. He tells Christians that they ought to become like little children to enter the kingdom. Jesus also says that those who welcome a child in His name welcome Him. Therefore, pastoral counsellors ought to meet children at their level and represent Jesus by visiting them. They ought to welcome those who are childlike in faith, whom Jesus considers to be His brothers and sisters, such as those in prison or who are suffering from illness. The implication Pericope 2 has for pastoral counsellors and faith communities is to examine whether they are childlike in faith themselves and whether they are providing support to families and children who are undergoing illness. To be theologically grounded, caregivers also ought to be able to interact with non-Christian doctrines they might be confronted with. These may include philosophies like humanism, other religions and cultural practices.

#### *4.4.6.5 Revelation of Pericope 3*

Similar in nature to Pericope 1, Pericope 3 confronts Christians with the spoken expectations of Jesus. God sent Jesus to represent His will, which He modelled to His disciples and taught them to walk in (Matt 10 and 19) by spreading the news of His kingdom to the lost sheep of Israel. Moreover, the weight of Jesus’ expectation for His followers is to walk in His ways, as embodied by Matthew 25:31–46. In this passage, the consequences of either caring for or not caring for the sick and vulnerable are clearly

outlined. The consequences for the sheep and goats reflect God's just character in rewarding the righteous and punishing the wicked.

- *God*

Periscope 2 shows how God values humility and dependence on Him. These values are also emphasised in Matthew 25:31–46. It matters to God how people treat one another. God values it when the marginalised are treated with compassion.

- *Jesus*

In Matthew 24 to 25, the audience learns three primary things about Jesus. Firstly, from Matthew 24:44, it is apparent that Jesus will arrive at an hour when He is not expected. This means His followers need to be ready at all times. Secondly, when He returns, He will be accompanied by all the angels around Him and thirdly, as the Son of Man, He will sit on His glorious throne.

Matthew intended to prove that Jesus is the promised Messiah (Easten's Bible Dictionary, 2023). This means that the ancient prophecies in the Tanakh have been fulfilled through Jesus. This theme pervades the revelation of God in the book of Matthew, that Jesus "has not come to destroy, but to fulfil" (Biblehub, 2023). The revelation about God in Matthew incorporates that Jesus is God among His people and that He is the beloved Son of God who has all authority, as stated in Matthew 10. Therefore, Jesus is equal to the Father, as testified by John 14:9 (Viljoen, 2016). Viljoen (2024) describes Jesus as the personified wisdom of God, as well as being the messenger of this wisdom.

True faith in Jesus is shown by actions of serving and love, as modelled by the Son of Man to "the least of these". This is expected from the Father since Jesus does everything the Father does (John 5:19).

Voorwinde (2011:58) describes the significance of Jesus' compassion for the covenant people through His actions of healing the sick, feeding the hungry and restoring sight to the blind. These actions Voorwinde (2011:58) suggests point to the covenant's renewal. However, this renewal cost Jesus His own blood and overwhelmed Him with grief in the Garden of Gethsemane. Because of the suffering He endured on the cross, Jesus can sympathise with human beings in every way (Hebrews 4:15). Children and families confronted with life-threatening and/or life-limiting conditions are invited to boldly enter the throne room of grace where they can find help in their time of need because of what Jesus did (Heb 4:16). Just as Jesus was God's representative on earth, so the Holy Spirit represents Jesus' presence to Christians today.

- *Holy Spirit*

Serving, loving and caring for the marginalised is only possible through the empowering work of the Holy Spirit. Christians are dependent on Him to follow Jesus' teachings (Matt 10; Matt 19; Matt 25). Viljoen (2016) explains that in contrast to Josephus' teachings, Matthew taught that the Pharisees are not the most accurate interpreters of the Torah. Instead, Matthew points out that Jesus is the

representative of God who is greater than the temple, which was central to Israel's religious traditions. Viljoen (2016:2) posits that Jesus became the *shekinah* (presence) of God among His people, just as God did through the pillar of fire and cloud during the exodus from Egypt. This links to Isaiah 11:2, which states that the Spirit of God will rest on Jesus. Viljoen (2016) emphasises the manner which Jesus acted with God-given authority, being the Son of God. Practically, this means Christians bearing the Holy Spirit should walk with the God-given authority they have access to.

#### 4.4.6.6 Application of Pericope 3

Pericope 3 conveys four important points which readers can implement practically in their lives today. The first point is realising Jesus is available through His Spirit and that His people are bearers of God's presence. Secondly, this realisation ought to spur believers on to minister to the body of Christ. Thirdly, the warning of the rejection of the goats should stir urgency among believers to examine their hearts' attitude toward the needy, knowing that Jesus could return at any time. But this also ought to stir hope in believers' hearts. Fourthly, believers need to stay faithful to the Word of God. This is important for pastoral caregivers who predominantly use Scripture to teach and comfort seriously ill children.

- *Stirred to serve*

Viljoen's (2016) discussion on God's presence relates to the presence people carry today through the same Spirit of Jesus, namely the Holy Spirit. Therefore, people's response ought to be to serve those who bear the presence of Jesus, as Gibbs discusses under the missionary-encouragement interpretation (Gibbs, 2018). Those who are sent on mission can be encouraged that Jesus is going with them (Gibbs, 2018:1361; Matt 28:18,20). The next communicational goal for the pericope of Matthew 25 is for every believer to realise that the gospel comes through human means and that these messengers of the Word ought to be supported by believers (Gibbs, 2018:1360).

- *Ministering to the sick*

Jesus demonstrated healing every sick individual who crossed His path (Matt 4:24; Luke 6:19). Jesus' example showcases that God's will is to restore individuals, according to his redemptive plan in human history.

Romans 8:38–39 is a reminder to the sick and vulnerable that nothing can separate them from God's love. This means God is present in difficult circumstances and that He works through individuals like pastoral caregivers who are called to be present like He is. James 5:14 highlights the importance of the involvement of the church in helping the sick. James wrote that elders are to anoint and pray for the sick since the oil symbolises the presence of the Holy Spirit (James 5:14).

- *Urgency and hope*

Under the social-ministry interpretation, the "sheep and goats" analogy in Matthew 25:31 encourages Jesus' disciples to take their calling of caring for the needy seriously (Gibbs, 2018:1339). Moreover, this confirms the double-love command (Viljoen, 2015:9) in which Jesus commands believers to love

God and love your neighbour (Matt 22:36–40). This is the social responsibility of the church to minister to the sick and needy: the love of God functions on a vertical relationship with Him and loving people as a horizontal outflow thereof. In Matthew 10:40, Jesus states that those who welcome His disciples welcome Him. Furthermore, He says love for God is demonstrated through feeding the poor and caring for the sick, as stated in Matthew 25:31–46 (Viljoen, 2015:7). Das (2016:81) confirms that one of the marks of being Jesus’ followers, part of the *missio Dei* (mission of God), is whether one is compassionate and generous to the needy. In addition, Jesus’ disciples will be judged whether they care for the poor or not (Matt 25:31–46). Furthermore, the fact that Jesus will exercise His authority in judgement and salvation ought to encourage Jesus’ disciples to look forward to His coming with godly fear and hope (Gibbs, 2018:1360).

- *Faithful to the Word*

Those who are sent ought to bear humility as they determine whether they have remained faithful to the message of Christ or not (Gibbs, 2018:1361). Moreover, Osmer (2008) states that Jesus is the Word of God, which needs to be listened to and interpreted according to the author’s intent and then made applicable to the congregation to promote accurate prophetic discernment. Prophetic discernment ought to be a combination of divine revelation and the human interpretation thereof. Concerning sick children, pastoral caregivers can use Scripture to comfort by conveying the truth about eternal life through faith in Christ Jesus. The caregivers can also confront fears and misconceptions the children and family might have concerned the Word of God. To empathise with the child’s vulnerable situation, the pastoral caregiver needs to be willing to suffer alongside them.

- *Willing to suffer*

A sobering statement Gibbs (2018:1361) makes is that those who are sent must be willing to “be hungry and thirsty and naked and sick and in prison for the sake of the gospel”. In other words, followers of Christ ought to be willing to sacrifice earthly comfort for the sake of furthering God’s kingdom. From the participant interviews, it is clear the pastoral caregivers are willing to give up their physical and emotional comfort zones to encounter the pain and suffering of families whose children have a life-threatening and/or life-limiting condition. From the empirical study, the pastoral caregivers were clearly confronted with the pain and death of children suffering from cancer.

#### **4.5 THEMES IDENTIFIED FROM PERICOPES**

From the discourses described in Matthew, it is apparent what it means to be a follower of Jesus today (Hays & Duvall, 2011:55). God expects Christians to be mission-driven (Matt 10), kingdom-centred (Matt 13), treating one another with humility and faithfulness (Matt 18) and expectant for Jesus’ return (Matt 24–25).

The kingdom of heaven and Jesus' role as judge and compassionate king is highlighted in the pericopes, as well as the new commandment Jesus gave his followers to "love one another" (John 13:34-35). Jesus taught his disciples to pray that His Kingdom come, and His will be done "on earth as it is in heaven" (Matt 6:5-15). This means followers of Jesus ought to represent God's Kingdom on earth, as well as to be bearers of His love to others.

#### **4.5.1 Kingdom of heaven**

"Kingdom" is used 28 times in the book of Matthew and is accordingly a key theme. The kingdom of heaven is an irreplaceable theme in these pericopes. Jesus is established as the judge and king of the kingdom (Matt 25) to whom all authority has been given (Matt 28:17). The kingdom is proclaimed to be near (Matt 10:7-8) and is said to belong to the children/the humble (Matt 5; Matt 18:1-5; Matt 19:13-14). The kingdom is near physically since Jesus gave the Holy Spirit (John 14:16) and therefore He is with us "always, even to the very end of the age" (Matt 28:20).

From these three pericopes, the kingdom of heaven belongs to those who answer the call to care for those Jesus identifies with (Matt 25:31-46), who serve others spiritually, psychologically or physically (Matt 10:7-8) through the presence and power of Jesus, who is close through the Holy Spirit (John 14-15).

Moreover, there is the call for believers to walk in childlike humility and faith through the example which was set by children in Matthew 19:13-14, leading children to know Christ. *Missio Dei* refers to God's mission. This is part of God's character, working through humans' "indwelling essence", the way God uses humans to bring His creation back into the kingdom of God and under His authority (Thinane, 2024:1, 6). Mackie and Collins (2024) also identify hope and life within the messianic kingdom of God as a key theme in the book of Matthew.

The nature of God's kingdom is clearly one where love and service are valued, according to Matthew 25, where healing and restoration are possible (Matt 10:7-8) and where childlike faith is welcomed and the marginalised are included (Matt 19:13-14).

#### **4.5.2 Obedience and service**

John 13:34-35 states: "A new command I give you: Love one another. As I have loved you, so you must love one another. By this everyone will know that you are my disciples if you love one another." Under the new covenant of Jesus, He expects Christians to love one another as representatives of Himself.

Thus, faith communities are called to love others in different contexts because where two or more are gathered in His name, there He is in the midst of them (Matt 18:20). Du Plessis (2021) agrees that pastoral care is a ministry in which believers are called to love both within the church and the broader community. Pastoral caregivers ought to be a voice to those who have none, such as children. This is in fulfilment of the love command which enables the “least of these” to be shown compassion (Matt 25:45).

To proclaim the truth about life after physical death (Rom 8:2) means to proclaim freedom (John 8:31–32) to those who might be captives to despair, such as families and children with life-threatening and/or life-limiting conditions. Isaiah 58:7–9 emphasises the fruit of a church which shares food with the needy and looks after their own flesh and blood. The result of such actions, according to Isaiah 58:7–9, is that the church will receive healing and God’s glory will accompany them.

God’s closeness to His people is a key theme in Matthew (Mackie & Collins, 2024). Das (2016) explores the connection between caring for the needy and God’s presence becoming more real to those who step out to help the broken. Galatians 2:9 highlights the importance of Christians showing compassion and care for the poor, since it communicates God as redeemer (Das, 2016). Das (2016) points out that the church has always preached the compassion and redemption of God but has nevertheless battled to embody these characteristics of God. The danger of this struggle is that the church becomes an inward-looking force, which has lost sight of God’s mission to reach other communities. Chapter 5 will focus on how faith communities, such as churches and pastoral caregivers, can support children with life-threatening and/or life-limiting conditions as part of the pragmatic task (Osmer, 2008).

The call to serve in God’s kingdom is reflected in all three pericopes in this study: Matthew 10:7–8 instructs Christians to freely give what they have received. In Matthew 19:13–14, Jesus models a humility and openness to children who are vulnerable and dependent in society. When Christians, including pastoral caregivers, are obedient, they will act as servants in God’s kingdom, meaning they will be active carriers of Jesus’ presence through the Holy Spirit. Matthew 25:31–46 show that those who are considered righteous are praised for their acts of kindness which Jesus associates with serving Him.

#### **4.5.3 Carriers of His presence**

These pericopes instruct Christians how to be carriers of God’s presence. Firstly, in Matthew 10:7–8, the disciples are commissioned to carry His presence to others. Matthew 10:40 further instructs the disciples to be active carriers, knowing that those who welcome them, also welcomes Jesus Himself. This links well with Matthew 25, which will be touched on again after Matthew 19 in which the importance of serving children is conveyed. In Matthew 19:13–14, Jesus includes children as part of

His audience who are worthy of His attention. In Matthew 25:31–46, the seriousness of serving the brothers of Christ is conveyed, since it is as if they are serving Jesus (Matt 10).

The fact that believers are carriers of His presence means there will be accountability for their actions. This is recognised in Matthew 25, in which individuals are judged for their actions, while in Matthew 10, there is a responsibility to act on behalf of others in proclaiming the good news. In Matthew 19, Jesus rebukes His disciples' attitude towards children. Thus, there are clear guidelines and implications for those who carry His presence from the example Jesus Himself set.

#### **4.5.4 Implication for Christians**

- Jesus modelled selfless service to others.
- As the Son of Man, Jesus modelled compassion, identifying with the suffering of humans.
- Jesus' role as the Son of Man offers hope to believers of salvation and eternal life.

The implications of Jesus' selfless service, compassion and hope show how He brought the kingdom of heaven to earth by delegating His authority to His disciples. Jesus expects obedience from His followers since He gave clear commands to this effect. Jesus made His presence and power available through the Holy Spirit to make the Great Commission to make disciples possible.

#### **4.6 CONCLUSION**

These pericopes point out the responsibility that pastoral caregivers must study the Word to be able to draw out the intended meaning of the author to comfort children. The three pericopes clearly convey why ministering to sick children is part of the Father heart of God, since Christians are given the authority to proclaim the nearness of His kingdom (Matt 10), are called to bless children (Matt 19:13–14) and, at the Final Judgement, will have to account for their compassion or lack thereof (Matt 25:31–46). Chapter 5 will give practical guidelines as to how pastoral caregivers and faith communities can provide effective pastoral care to children with life-threatening and/or life-limiting conditions.

## CHAPTER 5

# PRAGMATIC PASTORAL STRATEGY TO MINISTERING TO THESE CHILDREN

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### 5.1 INTRODUCTION

This chapter provides the researcher's own pastoral guidelines for effective ministry to children with life-threatening and/or life-limiting conditions. Some of the themes and guidelines identified in the empirical study (Chapter 2) and the interdisciplinary theories identified in Chapter 3 highlight the importance of integrating theory and praxis in the pastoral care to these children. Since the Bible is the measuring stick which ought to guide Christians' conduct, Chapter 4 investigates what God's Word says regarding providing pastoral support to children with life-threatening and/or life-limiting conditions. Chapter 4 focused on biblical evidence from the book of Matthew, calling Christians to support those who are vulnerable and suffering. Chapter 5 aims to provide practical pastoral guidelines for faith communities to effectively support children with life-limiting and/or life-threatening conditions.

Faith communities need training to minister to sick children and their families since there are many factors involved, such as contextual (culture and religions), developmental and parental responses which need to be considered. The descriptive-empirical, interpretative and normative tasks have been discussed in the previous chapters. With these tasks in mind, this chapter will focus on the pragmatic task (Osmer, 2008).

#### 5.1.1 Pragmatic task

The aim of the pragmatic task is to create strategies for action to influence events positively. This study aims to formulate a pastoral strategy to support faith communities in their pastoral ministry to children with life-threatening and/or life-limiting conditions. The pragmatic task includes task competence, transactional leadership and transforming leadership as the three forms of task leadership (Osmer, 2008:178).

##### 5.1.1.1 *Task competence*

The pragmatic task aims to perform pastoral care leadership tasks thoroughly. Colossians 3:23–24 says one ought to work as if to the Lord and not to men. This means that anyone ministering to ill children ought to develop task competence.

### ***5.1.1.2 Transactional leadership***

This describes influencing others through a process of interchanges. Osmer (2008:176) explains that transactional leadership has two parts. The first part is to meet the needs of those involved in the organisation in return for their contribution. The second part is comprised of making political trade-offs to deal with different agendas in an organisation, so that it can accomplish its ultimate purpose.

Transactional leadership applies to pastoral caregivers involved in organisations who provide pastoral care to children with life-threatening and/or life-limiting conditions.

The second part of transactional leadership can be seen in voluntary organisations like faith communities. Individuals who are part of these communities can be given a chance to give back to society through their support of pastoral caregivers and families whose children are dealing with serious illness. Transactional leadership can be seen practically, since Christians volunteer their time to serving others and experience meaning making and God's kingdom purpose in return. This underscores why providing pastoral support to sick children should be prioritised by pastoral caregivers and faith communities.

### ***5.1.1.3 Transforming leadership***

A certain calibre of leadership is required which would produce the accessibility of pastoral caregivers to sick children. Some of the practical obstacles which faith communities can address include training individuals to effectively support children with life-threatening and/or life-limiting conditions by developing pastoral guidelines, donating appropriate toys and addressing assumptions about what the family and children need.

The motive to care for sick children is clear from Chapter 4. This normative guideline explored the biblical mandate of the call to obedience and caring for other Christians, as well as the vulnerable in prison, the homeless, the sick, orphans and widows. These mandates are supported by Matthew 25:31–46 in which Jesus returns as a judge separating the sheep (His followers) from the goats (the unbelievers). Religion the Father considers pure is to care for orphans and widows, as stated in James 1:26. Jesus as the compassionate king (Chapter 4) calls the church to represent Himself on earth. This call to care means the church ought to respond by caring for sick children and their families and to help these children to know Jesus, just as Jesus encouraged His disciples to do (Matt 19:14).

Pastoral preparation is required to ensure the pastoral caregiver is trained, focused on continued professional development and acts respectfully to the socio-cultural context (Chapters 2 and 3). This inward reflection of the caregiver's abilities and attitude is critical before an external focus of helping the sick child and developing a relationship with them can be made. The most effective pastoral

preparation incorporates implementing spiritual disciplines because counsellors cannot preach something they are not practising first.

## **5.2 PASTORAL PREPARATION**

For pastoral caregivers and Christians to be effective ministers to children with life-threatening and/or life-limiting conditions, it is critical to continually practise spiritual disciplines to keep them rooted in Christ. To be able to be representatives of Christ, they need to grow spiritually in their faith through different spiritual disciplines, such as prayer, Bible meditation, resting, fellowship and worship.

1 Timothy 4:7–8 says: “Train yourself in godliness... godliness is valuable in every way, holding promise for the present life, and the life to come.” This statement contains hope which pastoral caregivers ministering to sick children can convey – the hope for the life to come after death through eternal life through Jesus Christ.

### **5.2.1 Prayer and fasting**

The power of prayer can be seen in Chapter 2 (P3, cf. 2.11.1.2; P4, cf. 2.11.2). Prayer is a way in which pastoral caregivers can be strengthened to comfort sick children, according to the promise in 1 Corinthians 1:4. Matthew 6:16-18 uses the term “*when* you fast”, instead of “*if* you fast”. This means that it is expected of Christians to fast as it makes them more dependent on God and less dependent on the world’s resources.

### **5.2.2 Word**

2 Timothy 3:16–17 teaches pastoral caregivers the importance of equipping themselves with the Word of God to be able to teach, rebuke, correct and train others in righteousness. By having a healthy discipline of meditating and studying Scripture, pastoral caregivers can be equipped for every good work, which includes ministering to sick children.

Pastoral caregivers can use the pericopes in Chapter 4 to teach and motivate faith community members and other caregivers to care for seriously ill children. Each of the three pericopes has hermeneutical significance regarding this topic.

Matt 10:5–15 encourages Jesus’ disciples to know that the kingdom of God is near. They are also commanded to use the authority given to them to heal the sick, raise the dead, cleanse the lepers and drive out demons. This passage gives pastoral caregivers comfort in knowing they are not operating alone, but instead have the authority given to them by Jesus.

Matt 19:13–15 emphasises God’s heart for children to know Him and for Christians to carry humility and childlike faith. From this passage, pastoral caregivers can do introspection to determine whether they are carrying this humility and faith in their ministry.

In Matthew 25:31–46, Jesus underscores the consequences of not caring for those God cares about, such as the marginalised. From this passage, pastoral caregivers can train others in why it is important to care for sick children as representatives of Jesus.

### **5.2.3 Resting (Sabbath)**

The necessity of self-care to prevent burnout and compassion fatigue were discussed in Chapter 2 (cf. 2.14). As part of preventative care, pastoral caregivers need to prioritise rest, according to Mark 2:27. Resting means to fill oneself with the spiritual disciplines seen in Scripture, namely meditating on the Word (Ps 1:2), prayer (1 Thess 5:17), worship (Ps 149:3), fasting (Matt 6:16–18) and community interaction (Heb 10:25).

### **5.2.4 Recreational activities**

Pastoral caregivers need activities which refill their spiritual and soul tanks (cf. 2.14.5). Depending on the pastoral caregiver’s likes and dislikes, these fillers can include exercise, sleep, arts and crafts, worship, journalling and prayer (cf. 3.9.3.3). These recreational activities provide a break from the illness and sorrow they are continually confronted with. This is also an effective way to prevent burnout.

### **5.2.7 Bias check**

In preparation to facilitate caregiving which does no harm, the pastoral caregiver needs to do introspection about their attitude toward other cultures, values and religions. The pastoral caregiver can have a journal to write down their thoughts and then measure these against Scripture.

### **5.2.8 Community**

The empirical study showed that the practice of debriefing with other pastoral caregivers is another important aspect of self-care. This is an important reminder to pastoral caregivers to be part of a community in which they can be supported in dealing with the suffering they are faced with. The absence of family support in P4’s life is evident because she does not have anyone close that she can talk to. After pastoral preparation (Word, prayer and recreational activities), the pastoral caregiver can start thinking about how they can effectively support children whose development has been seriously affected by disease.

### **5.2.9 Interacting with non-Christian doctrines**

Pastoral caregivers need prophetic discernment and ethical principles to identify philosophies, such as humanism or other faiths. From the above-mentioned pericopes, similar exegetical studies could be

done by pastoral caregivers to interact respectfully with others whose beliefs may differ from Christian doctrines.

### **5.2.9.1 Humanism**

Humanism is a philosophy which advocates against supernaturalism and stresses an individual's dignity and worth for self-realization through reason (Merriam-Webster Inc, 2024). This philosophy advocates that humans are innately good and thus the good needs to be encouraged. Unlike the *agathós* described in good practice which originates from God (Strong's concordance, 2024), this "innate goodness and worth" is believed to exist apart from God. But in Mark 10:18, Jesus makes it clear that humans cannot be good by themselves: "Why do you call me good?" Jesus answered. "No one is good – except God alone" (Mark 10:18).

Humanism places the individual at the centre and the godhead is discarded. This is mentioned as non-believer caregivers may promote this philosophy to comfort the child and family. However, no higher power is appealed to for hope and instead, the person's own human resources are sought to empower themselves. When discussing good practice and prophetic discernment, pastoral caregivers need to be sensitive to know what other faiths believe to show respect towards them. In the empirical study, two participants mentioned encounters with Muslim individuals. Thus, it is worth mentioning for pastoral caregivers to develop a normative guideline from the theoretical understanding of other faiths and belief systems.

### **5.2.9.2 Other faiths and cultural practices**

The participants discussed encounters with women of the Muslim faith. It is one of the religions Christianity may be confronted with when caring for the sick in a South African context. Caregivers can support Muslim families by inquiring about their experience and building relationships to support the family emotionally. Hays and Duvall (2011:513) speak about Jesus' followers facing persecution from family members when they convert from a religion like Muslim to Christianity. The pericopes which were previously discussed encourage Jesus' followers to persevere (Matt 10:22–23).

As well as encountering other faiths, pastoral caregivers may also come across different cultural norms, such as ancestral worship.

When encountering such cultural practices, pastoral counsellors may disagree about communication between the living and the dead, as they believe that Jesus is the only mediator between God and humanity.

### **5.2.9.3 Christian response**

After using prophetic discernment to identify other faiths, one ought to know how to engage in the manner Jesus taught.

1. Identify religion/cultural practice/philosophy
2. Inquire/read about it
3. Do exegetical study to see whether the cultural practice is opposing Christians scriptural norms.

Children and families with life-threatening and/or life-limiting conditions ought to be guided towards a direct personal relationship with Jesus, as P4 advocates, as Jesus is the only way to a spiritual life with the Father. The child does not need a deceased ancestor to fight on their behalf through the prayers of a medium (Deut 18:10–12). Consulting the dead is detestable to God as Deuteronomy 18 describes because those who practise it seek divine guidance from the dead, rather than Him. This renounces the sovereign and living God (Bae & Van der Merwe, 2008:1304). It also denies the exclusive relationship between Israel and God, as stated in Exodus 19:5.

Humanism is flawed in accordance with the truth of Scripture that all men have fallen short of the glory of God (Rom 3:23). The response to an awareness of one's sins should be repentance (Acts 3:19) and faith in Jesus to receive salvation, instead of striving to produce good works based on a misconception that one is innately good. Moreover, Christian caregivers ought to bear love towards all religions, such as the Muslim faith. Thus, they can show the same compassion Jesus modelled in Scripture. Since the Muslim faith is also a monotheistic religion, caregivers can still extend prayer as a means of connecting with the child patient and their family.

Themes were identified to assist pastoral caregivers and faith communities to find connections across the pericopes to inform their application of pastoral care to seriously ill children and their families. These themes aim to simplify the important exegetical findings, while providing deeper insight into Scripture. The primary themes identified include the kingdom of heaven, obedience and the importance of carrying the essence of His presence.

## **5.3 MINDING THE MULTI-FACETED CHILD**

Individuals are comprised of spirit, soul and body. Even before the relationship-building process takes place, the caregiver needs to be cognisant of the child's interconnected developmental processes (cf. 3.3). This means caregivers needs to remind themselves of the theories of Erickson, Piaget and Bronfenbrenner to correctly identify and meet the child's needs (cf. 3.3, 3.4.4).

### **5.3.1 Developmental theories**

In Chapter 3, developing theories of the child (cf. 3.3) was discussed in more depth. A brief overview will be given below for pastoral counsellors to refer to.

#### **5.3.1.1 Kübler-Ross**

The four quadrants of human well-being, namely the physical, emotional, spiritual and intellectual, all interact and influence one another (cf. 3.3.1.1). This division is useful when the pastoral caregiver needs to identify how these facets influence one another and how each one can be nurtured individually to create a healthier, holistic individual.

Kübler-Ross also developed the well-known stages of grief, which include denial, anger, bargaining, depression and acceptance (cf. 3, 3.4.3.2, Kübler-Ross & Kessler, 2014). These can be of help to understand the behaviour and emotions of the sick child and their family, such as grieving due to the child's hair falling out because of cancer treatment or the eventual death of the child.

#### **5.3.1.2 Erickson**

The psycho-social theory describes the challenges children face in developing the ego's virtues of hope, will, purpose, love, care and wisdom (cf. 3.3.1.2). This theory is useful to determine what psycho-social challenges the child might be experiencing at any given time.

#### **5.3.1.3 Kohlberg**

This moral development theory helps to see children's development of moral reasoning (cf. 3.3.1.3). It may be useful in cases in which the caregiver needs to understand the child's moral reasoning, especially in instances such as P2 encountered when a pastoral caregiver needs to explain to a child that they are not allowed to eat or drink anything before a procedure (cf. 3.1.2).

#### **5.3.1.4 Fowler**

His faith development theory has seven stages, which give insight into children's faith development (cf. 3.3.1.4). This can be helpful for pastoral counsellors to gain a deeper understanding of where the child is at in their faith journey. This will assist the caregiver to effectively build a relationship with the sick child.

#### **5.3.1.5 Bowlby and Ainsworth**

Attachment theory was advanced through the work of Bowlby and Ainsworth. Bowlby's (cf. 3.3.1.5) theory describes the secure, anxious-resistant, anxious-avoidant and disorganised attachment styles. The child's behaviour might reveal which attachment style they have with their primary caregiver (cf. 3.3.1.6). This could provide a foundation to use Scripture to address attachments which involve fear or avoidance to reveal God's heart towards the child.

### 5.3.1.5 Frankl

Logotherapy was founded by Victor Frankl in order to create a therapy which describes people's desire for meaning making. This theory is useful to understand children's will to meaning and freedom to will and how strength and meaning can be drawn from one's faith in the midst of suffering.

### 5.3.1.6 Nagy

Maria Nagy's theory hypothesises that children go through three stages of understanding death. This includes feelings of denial (ages three to five), feelings of some comprehension (ages five to nine) and feelings of complete comprehension over the certainty of death (ages nine and older). This theory can be of assistance for pastoral caregivers to understand how to address children on this topic.

### 5.3.1.7 Bronfenbrenner

The ecological model (Chapter 3, Fig 4) was developed by Bronfenbrenner. This describes individuals as being interconnected with a micro-, meso-, and macro-system (cf. 3.4.4). This theory is helpful to understand how the child is part of a complex, interconnected system which affects them and can be used to reflect on how the child can be physically supported by those around them (cf. 3.4.4).

Below is a table pastoral caregivers can refer to in order to identify which theory would be useful for them based on the child's context.

<b>Theorist</b>	<b>Name of theory</b>	<b>What is it?</b>	<b>When to use it?</b>
Kübler Ross	Four quadrants of human well-being  Stages of grief	They give insight to cognitive, spiritual, psychological and physical needs.  The stages show the process of grief.	These two theories can be investigated when the caregiver needs to implement or understand the interaction of the child's well-being and/or their stage of grief.
Erickson	Psycho-social theory	It describes basic conflicts at different ages. Trust vs mistrust (from birth to age one), autonomy vs shame (ages one to three), initiative vs	It could be useful to review this theory to understand what psycho-social conflict and virtue (Chapter 3, 3.3.1.2) the child is

		guilt (ages three to six), industry vs inferiority (ages seven to 11) and identity vs confusion (ages 12 to 18).	developing. To be aware of this may help the caregiver assist the child to overcome their conflict.
Kohlberg	Moral reasoning	It describes the development of moral reasoning in children.	It can be useful for pastoral caregivers to know at what age to convey information to a child based on their ability to understand.
Fowler	Faith development	It explains the development of a child's faith understanding.	Before offering biblical support, the child's age and faith development needs should be considered.
Bowlby and Ainsworth	Attachment theory (Bowlby)  Strange situation (Ainsworth)	Attachment styles were introduced by Bowlby.  Ainsworth shows the impact attachment style has on the relationship between the primary caregiver and the child.	Understanding the child's attachment style will help the caregiver know how to approach the child in the relationship-building process.
Frankl	Logotherapy	This is a model of therapy focused on meaning-making.	This therapy may be useful when the child and/or family is feeling hopeless during the child's illness journey.
Nagy	Understanding death	It describes the three stages children	This theory can be useful to refer to

		undergo to understand death.	when the caregiver needs to explain death to a sick child.
Bronfenbrenner	Ecological model	Bronfenbrenner's theory describes the impact the environment can have on a child.	The ecological theory is handy to reflect on the multi-faceted environmental and social factors which could positively or negatively impact the child.

Table 1: Pastoral caregiver's guide to using developmental theories

When the caregiver has a cognitive and psychological understanding of the multi-faceted child, they can plan what is needed for effective relationship-building with the child. Pastoral caregivers are expected to have fundamental knowledge about children's social, emotional and spiritual needs. A pastoral care strategy that includes these different needs will be suggested as a framework for caregivers and other Christians in providing effective pastoral support to sick children. But before such support can be provided, it is crucial for the caregiver to first ensure that a trusting relationship is built.

### 5.3.2 GENERAL PRESUPPOSITIONS

Below are some simplified general presuppositions for faith communities and pastoral counsellors to follow when ministering to sick children. These presuppositions carry twofold importance. Firstly, they ensure that caregivers and faith communities uphold professional conduct, prevent non-maleficence and promote sensitivity while ministering. Secondly, they make sure caregivers and faith communities have access to the same ministering principles to facilitate effective relationship-building between the pastoral caregiver and child. In answering the call to care for the sick and vulnerable, it also became apparent from the empirical study that there are certain do's and don'ts when ministering to children.

Do's	Don'ts
<ul style="list-style-type: none"> <li>Respect religious and cultural beliefs and build relationship.</li> </ul>	<ul style="list-style-type: none"> <li>Don't "Bible bash". This refers to the practice of initiating or participating in aggressive or unwelcome religious debates.</li> </ul>
<ul style="list-style-type: none"> <li>Educate yourself about the child's sickness.</li> </ul>	<ul style="list-style-type: none"> <li>Do not assume you know what the child or family needs.</li> </ul>
<ul style="list-style-type: none"> <li>Do not serve from an "empty cup" as a caregiver.</li> </ul>	<ul style="list-style-type: none"> <li>Do not forget it is <i>only</i> God who can heal them and don't make empty promises.</li> </ul>
<ul style="list-style-type: none"> <li>Actively debrief and fill your "cup" by having creative outlets.</li> </ul>	<ul style="list-style-type: none"> <li>Be aware of isolating yourself too much as a caregiver.</li> </ul>
<ul style="list-style-type: none"> <li>Speak using simplified terminology.</li> </ul>	<ul style="list-style-type: none"> <li>Do not use complicated terminology.</li> </ul>
<ul style="list-style-type: none"> <li>Prayerfully minister.</li> </ul>	<ul style="list-style-type: none"> <li>Do not assume what the child's or parents' needs are.</li> </ul>
<ul style="list-style-type: none"> <li>Take the child's developmental age into consideration.</li> </ul>	<ul style="list-style-type: none"> <li>Do not judge the parents.</li> </ul>
<ul style="list-style-type: none"> <li>Be sensitive to the impact of trauma, shock or denial in families.</li> </ul>	
<ul style="list-style-type: none"> <li>Respect parents and include them in the child's therapy.</li> </ul>	
<ul style="list-style-type: none"> <li>Get on the child's level (sit on the floor, speak simply, joke with them, etc).</li> </ul>	
<ul style="list-style-type: none"> <li>Be a public church, reaching out towards strangers.</li> </ul>	
<ul style="list-style-type: none"> <li>Be part of a faith community where you can get support.</li> </ul>	
<ul style="list-style-type: none"> <li>Practice Continued Professional Development: Inform yourself regarding procedures, body memory, the impact of trauma, etc.</li> </ul>	
<ul style="list-style-type: none"> <li>React sensitively towards parents, being aware of their stage of grief.</li> </ul>	
<ul style="list-style-type: none"> <li>Practise the same compassion of Christ.</li> </ul>	
<ul style="list-style-type: none"> <li>Be aware of compassion fatigue.</li> </ul>	

## **5.4 RELATIONSHIP-BUILDING**

The pastoral caregiver must have a holistic awareness of where the child is at developmentally. Thereafter, the process of caregiving can develop into thoughts of how to engage with the child.

The importance of ensuring that the child feels safe, unpressured and trusting of the pastoral caregiver has been recognised in the previous chapters (P1, P2, cf. 2.8.3, 2.9.1, 2.12.2). Pastoral strategies will now be discussed to help caregivers create a safe space for the child they are ministering to. Modelling trustworthiness and helping to create a safe space will lead to positive relationships being built. Apart from these important principles, the caregiver can also use their senses to meet the child where they are at.

### **5.4.1 Trustworthiness**

The pastoral caregiver ought to show that they are trustworthy to the child. A simple way in which the pastoral caregiver can do this is by keeping their promises to the child. The pastoral caregiver must always keep their word to build trust with the child.

### **5.4.2 Creating a safe space**

Pastoral caregivers working with sick children can allow children to take control over certain situations to help them feel safer in their immediate environment, especially if they are away from home. For instance, they could give the child two choices and allow them to pick whatever activity they would enjoy doing the most, such as colouring in or reading. These activities might include traditions from home to help the child feel safer.

### **5.4.3 Sense making**

The pastoral caregiver can use their senses (sight, touch, smell and taste) with a twofold purpose. Firstly, they use their senses to put themselves in the child's shoes and remind themselves of what the child might be experiencing. This is the way that Jesus showed compassion to people and children (cf. 4). Secondly, pastoral caregivers can use their senses to recognise any negative sensations the child might be experiencing.

#### ***5.4.3.1 Sight***

Surgical garb, a mask and stethoscope are examples of hospital equipment which can be used to help the child make sense of what they are likely to see in the hospital (cf. 3.4.4).

#### ***5.4.3.2 Taste***

Homecooked food could be brought to the hospital to make the environment feel more familiar to the child (cf. 3.5.2). Food that looks appealing can also stimulate the child's appetite, especially if they are undergoing chemotherapy which is known to inhibit the appetite (cf. 3.6.4).

### **5.4.3.3 Touch**

Jesus modelled blessing children in Matthew 19 with His touch (cf. 4). In Chapter 3, Kübler Ross's theories were discussed, which include the importance of physical touch as part of taking care. This physical contact can positively impact the child's emotional quadrant (cf. 3, 3.3.1).

### **5.4.3.4 Smell**

As demonstrated by P1 (cf. 3, 3.4.4), the pastoral caregiver can play hospital with the child to familiarise them with possible smells they might encounter in the hospital. For example, the pastoral caregiver can put disinfectant in bowls around the playroom (cf. 2, 2.6.2.2).

### **5.4.3.5 Hearing**

One way in which a child can be prepared through hearing is by playing noises which the caregiver anticipates the child will hear in hospital. P1 played one child ICU sounds to prepare their subconscious for a procedure, so that when they woke up from the general anaesthetic, they would not be startled (cf. 3).

## **5.5 PASTORAL TOOLKIT**

The pastoral caregiver is encouraged to have a file at hand with printouts of exercises and games. This could include paper plates with different coloured pencils and crayons to draw the faces of characters to be discussed later (cf. 5.6.1.1, cf. 5.6.1.2 and cf. 5.7.1). A light soccer ball can also be kept in the caregiver's ministry bag to play the throw-a-question game (cf. 5.7.2.1).

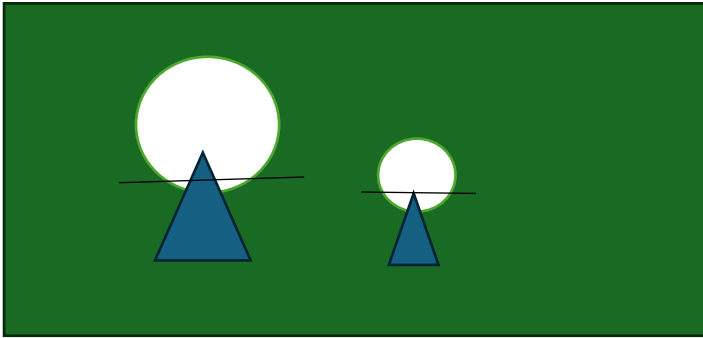
## **5.6 PASTORAL SUPPORT**

To effectively provide pastoral support, the pastoral caregiver uses Scripture in multi-faceted ways to address misconceptions and fears, as well as promote feelings of hope and resilience in the child.

### **5.7.1 Pastoral care support activities**

The pastoral care activities focus on the spiritual support of children with serious illnesses. The perceiving-Jesus-and-myself activity allows the pastoral caregiver to see how the child views Jesus and themselves. This gives the caregiver the opportunity to use Bible narratives to address any misconceptions and fears the child may have about Jesus or themselves.

### 5.7.1.1 Perceiving Jesus

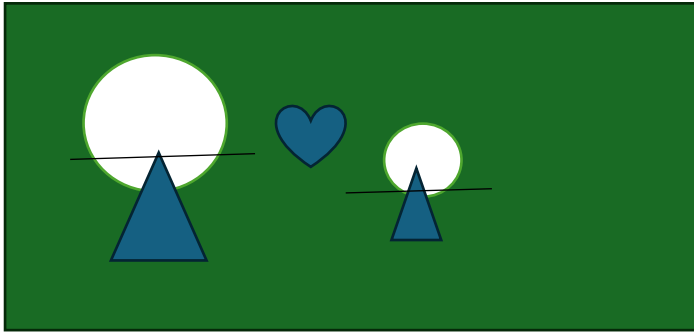


*Jesus on the left and the child pictured on the left*

The pastoral caregiver gives the child a drawing representing Jesus and themselves. The pastoral caregiver then gives the child crayons and asks the child to draw Jesus' face, as well as the child's face. After the child has filled these in, the pastoral caregiver will ask the child questions about why the child filled in the faces the way they did. The pastoral caregiver will also inquire whether the child wants to draw anything else on the picture.

After the child has drawn Jesus and their own facial expressions, the pastoral caregiver could read Matthew 19:13–15 to them. The caregiver could also explain to the child that Jesus wants them to come to Him. The child can then be given a second picture, similar to the first, but with the child now holding the heart (as seen in the figure below). The caregiver now uses colours (similar to P1's technique, cf. 2.6.1) and allows the child to attach emotions to each colour (yellow being happy, red being angry, etc.). The child then fills in the picture "perceiving myself" with the colours they've chosen. Afterwards, the caregiver can ask them appropriate questions, such as why their heart is happy, sad or angry based on the colours the child has chosen. If the child coloured the heart with an emotion, then the caregiver can guide the child to give that emotion to Jesus and to ask Jesus what emotion He wants to give to them in return for their negative emotion. The first exercise is necessary to first determine what the child's relationship with Jesus is before introducing the second exercise. If the child does not know Jesus, then the second exercise can be used to explain how one accepts Jesus as their Savior by giving their heart to Him.

### 5.7.1.2 Perceiving myself



*(Jesus on the left and the child pictured on the left)*

McMinn (1996:269) talks about the multi-tasking counsellor. This includes a counsellor who considers psychology, theology and spirituality in treating the client from within (present in the relationship), while being able to view the client's problems from an objective (outside) point of view. This need for presence in the relationship, as well as growing one's own spiritual disciplines as a caregiver, are important. P3 said that one cannot give when one is empty, and this is critical for faith communities and pastoral caregivers to remember. Those who are going to minister to seriously ill children have the privilege of offering eternal hope to them through their pastoral care. Spiritual care and physical and emotional training guidelines will now be discussed for faith communities to enrich themselves in the process of supporting children with life-threatening and/or life-limiting conditions.

## 5.8 EMOTIONAL SUPPORT

By helping children identify and talk about their emotions, they can develop emotional intelligence and coping skills.

### 5.8.1 Recognising emotions

Children who are sick may undergo an array of emotions, including fear, anxiety, sadness and anger. Pastoral caregivers can take paper plates with crayons to help the child to become aware of their emotions. The pastoral caregiver can help the child draw a happy, sad, angry, fearful or anxious face. Then the pastoral caregiver can use the plates to play out a narrative with the child who is sick and leave a space in the dialogue for the child to express how they are feeling. For instance, the pastoral caregiver can say, "Once upon a time there was a child. How do you think the child felt?"

The sick child can be encouraged to take a paper plate to draw the emotion of the child in the story. Then the pastoral caregiver can ask why the child is feeling that way (happy or sad). The caregiver can use this pastoral technique to validate the child's feelings and to encourage them to move towards a positive emotion if they described a negative emotion. The pastoral caregiver can ask: "How can we

make the child feel less sad, angry or frustrated?” Then, based on the child’s reply, the caregiver can offer social, pastoral or physical support.

If the caregiver has a device, they could watch the movie “*Inside out*” with the child/children to expose them to emotions.

### **5.8.2 Facilitating open communication**

Open communication with the sick children leads to trust and empowering them to choose (P1, P2, P3, cf. 2.7.2, 2.7.3). Introducing a question game with children may facilitate open communication about their thoughts and feelings.

#### **5.8.2.1 *Throw-a-question game***

The pastoral caregiver can take a soccer ball and have some children sit in a circle. Every time a child catches the ball, they need to answer a question asked by the person who threw it. After answering the question, they become the person who throws the ball. In this way, open communication can be encouraged by playing this game. The pastoral caregiver can ask each child about their emotions or well-being every time they throw the ball. For instance, “What makes you happy?” or “What makes you sad?” Regular social interaction is important for sick children to prevent feelings of loneliness, help them learn social cues and form healthy relationships.

## **5.9 SOCIAL SUPPORT**

Pastoral caregivers can involve their local faith community to provide additional social support to the ill child, especially if the child is in the same faith community. The caregiver can also encourage the family of the child to involve their own faith community and organise play dates with the child’s friends if they are already at school. Similar to the throw-a-question game, the pastoral caregiver can encourage social engagement by teaching children who are in the same hospital ward a game, so that they can interact with one another.

### **5.9.1 Creating a comforting environment**

If the child is hospitalised, the family members can buy a toy at the hospital’s gifts store to make the strange environment feel more comfortable. Comfort items from home can also strengthen the trust between the child and family members (P1, cf. 2, 2.8.2.1).

### **5.9.2 Family socialisation**

The pastoral caregiver needs to be sensitive to when the child needs quality time alone with their family and respect that. But at other times, the pastoral caregiver can introduce prayer time with the entire family and child to bring Jesus into their vulnerable situation.

## **5.10 PHYSICAL GAMES**

Games are useful to provide distraction and restore joy to sick children. More game ideas which require more physical exertion will be listed below. Physical exercise is useful to improve people's mood by releasing endorphins (Nuffield Health, 2024). These games need to be used with caution in case the child is feeling ill from chemo or another form of treatment.

### **5.10.1 Party-freeze game**

On Spotify, YouTube or Apple Music, pastoral caregivers can find the party-freeze dance song by The Kiboomers. This is a catchy song which children can dance to by listening to the words which first tell the children to "dance all around", then to freeze, then to hop, freeze, skip and freeze. This is a playful way the pastoral caregiver can interact with the children. If a child forgets to freeze, the caregiver can playfully chase after them.

### **5.10.2 Bible charades**

This game is suitable for children who are capable of understanding and miming out Bible characters. The child, family members (optional) and caregiver can each write the names of a few Bible characters down on small pieces of paper and put them in the centre of the circle. Then each person can have a turn to pick a piece of paper and mime the Bible character. Having a point system and time limit for playing out the character is up to the caregiver, family and child.

### **5.10.3 Doctoring teddy bears**

If the child has a teddy bear or other soft toys, then they can play out doctoring the soft toy with the caregiver. The caregiver can play along and is encouraged to keep a soft toy in the ministering toolkit bag in case the child wants to doctor a teddy bear. This game is a useful tool to teach the child about hospital and other procedures they may have to undergo and prepare them for it (P1, cf. 2.7.3).

After effective pastoral preparation has been achieved, effective caregiving can be facilitated to the multifaceted child. Thereafter the pastoral caregiver needs to also equip themselves to be able to support the family of the sick child since they form an important part of the child's wellbeing and support system.

## **5.11 SUPPORTING THE FAMILY UNIT**

Although the family unit is not the primary focus for this study, the pastoral caregiver needs to be cognisant of the fact that the parents and siblings of the sick child may also require pastoral support (cf. 2.11.2). This is important since the parents' well-being impacts the child's well-being (cf. 1.5.2, 2.9.3, 2.11.1.1, 3.7.3). As a result, the pastoral caregiver needs to be able to respond with appropriate pastoral techniques to support the family of the sick child.

### **5.11.1 Pastoral techniques and discussions for the family unit**

Techniques which were predominantly discussed in Chapter 3 to provide support to the sick child can also be applied to the family unit. Some of the pastoral techniques include prayer ministry (SOZO), God images, meaning making through a logotherapy approach and doxology (cf. 3.5.4, 3.5.7, 3.5.8,3.5.9).

#### ***5.11.1.1 Prayer support***

From the previous chapters, it is clear that there are various ways in which the pastoral caregiver can use prayer to provide support to the seriously ill child and their family. By simply praying and thanking God for the life of the child who had passed away, the mother was able to step out of denying that her child had passed away (cf. 2.11.1.2). In the experience of P4 (cf. 2.11.2), the effectiveness of prayer to help fathers express their sorrow was highlighted. The indirect approaches (imagination, adventure and immigration) are examples of how the entire family can be drawn into the process of coming to terms with the possible passing of a sick child (cf. 2.8.1.3). Other more structured ways in which pastoral caregivers can provide prayer ministry to family units may include techniques proposed by SOZO and Elijah House Ministries, which can help to unburden from negative feelings (cf. 3.5.9, 3.9.3.2). In SOZO, the God images (cf. 3.5.7) of the parents and siblings, in other words, how the individual relates to the Father, Son and Holy Spirit, will become clear.

#### ***5.11.1.2 God images***

From talking and praying with the individuals, the pastoral caregiver can identify whether they automatically perceive God to be more of a judge, shepherd, king or servant or whether they have other God images (cf. 3.5.7). From identifying their God image, follow-up questions can be asked and possible lies and misconceptions detected which are contrary to Scripture. These can then be discussed and addressed by the pastoral caregiver. For example, if the parent sees God as a judge, the pastoral caregiver can inquire what the root is of their God image. Any misconceptions about God's character associated with that specific God image can then be challenged by gently guiding the parent to see an example where God portrays another God image to help them broaden their understanding about God's character. For example, if a parent believes their child is sick because God is angry at them, then the caregiver might highlight other stories where a child or adult was sick, and Jesus showed love and compassion (cf. 3.4.1).

#### ***5.11.1.3 Logotherapy***

In the face of suffering, meaning making is crucial. Instead of following the avoidance approach (cf. 2.8.1.2), the pastoral caregiver can use more of a direct approach to help parents create meaning-making in the face of their child's suffering. The pastoral caregiver can directly ask the parent what is detracting from their meaning and how they can appeal to their available resources to create meaning. Just as P1 used the direct approach to make children feel comfortable to discuss and process death, so the pastoral

caregiver can address topics and questions which may be subconsciously bothering the parents, so that they can learn to cope with it.

#### ***5.11.1.4 Doxology***

One way in which the parents and siblings can be guided to view their situation more positively is to introduce the concept of praise and gratitude, instead of just focusing on the negatives (cf. 3.5.8). In this way, the parent and sibling can renew their mind to think about things that are more beautiful as Scripture instructs (Rom 12:2, Phil 4:8).

### **5.11.2 Parental support**

#### ***5.11.2.1 Information***

Parents have a need for access to information (cf. 3, 3.6.3). Therefore, it may be useful for pastoral caregivers to build a referral network which they can use when the parent needs information the pastoral caregiver is not specialised in. Examples of referrals may include to online training platforms (cf. 3.6.3), in-person discussions with doctors or other healthcare practitioners like dietitians for the child's dietary needs specific to their condition (cf. 3.6.4). At the same time, the pastoral caregiver needs to remember the negative impact shock can have on the parent's ability to process information (cf. 2.11.1.2). It is therefore recommended that pastoral caregivers avoid technical language.

#### ***5.11.2.2 Pastoral support***

The pastoral caregiver can be sure to expect that the parents of the child may desire support to deal with their grief, theological questions or just want company while their child is undergoing a procedure (cf. 2.11.2). The caregiver can respond to these needs by equipping themselves with grief-support resources, as well as answering the parents' theological questions. The pastoral caregiver can also use their knowledge of the child's development to help facilitate the relationship between the primary caregiver (parents) and the sick child (cf. 3.3, 5.3.1).

#### ***5.11.2.3 Community support***

The pastoral caregiver can recommend the parents develop a support system to assist them with logistical support, including meal preparations, transporting other siblings and social support to give the parents a break to go home if the child is hospitalised for a prolonged time (cf. 3.6.1.1). Other community support may include helping the family start a fundraising project to help financially with medical bills, such as GoFundMe.

### **5.11.3 Sibling support**

Knowing that siblings may experience various physical symptoms, such as stomach ache due to the stress and uncertainty they face, as well as emotions like anger and sadness in their process of grieving (cf. 3.7.2), it might be useful for pastoral caregivers to be attentive in supporting the siblings of an ill

child. Feelings of shame or survivors' guilt also need to be addressed through the Word of God to reassure the child's identity in Christ and bring comfort about their ill or passed sibling.

## **5.12 OVERCOMING BARRIERS TO PASTORAL COUNSELLING**

Lack of recognition, funding and education are some of the obstacles to providing pastoral counselling in South Africa (cf. 3.8). These barriers also feed into the lack of pastoral support available to children with life-threatening and/or life-limiting conditions (cf. 1.5.6, 1.6). The question remains how the pastoral caregiver can overcome these barriers to be able to provide pastoral support to these children.

### **5.12.1 Lack of recognition**

#### ***5.12.1.1 Problem***

The positive impact pastoral care could have in supporting children has not always been recognised (cf. 3.8.1).

#### ***5.12.1.2 Positive response***

However, the participants' responses showed that the nurses recognised their contribution and called them when emotional support was necessary. The participants are also willing to be involved with non-profit organisations, despite the lack of official recognition. Therefore, pastoral caregivers are encouraged to be bearers of God's message to those who do not know Jesus, just as the disciples went to preach the nearness of God's kingdom in Matthew 10.

### **5.12.2 Funding**

#### ***5.12.2.1 Problem***

The lack of recognition of the importance of pastoral care may lead to the lack of financial support from organisations funded by the state, such as government hospitals and schools (cf. 3.8.2).

#### ***5.12.2.2 Solution***

As stated by P1 (cf. 3.8.2), this should not be a barrier to pastoral caregivers who realise that children just need someone to be present and that the toys used by the caregiver need not be expensive. From the example of P1 and the theological significance of Matthew 10, pastoral caregivers' response can be to freely give as they've freely received wherever possible. This means hospital visits to sick children can be done using a "tent-making" approach.<sup>14</sup>

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<sup>14</sup> A tentmaker is a dedicated, Christian who views work in light of the Great Commission and as an opportunity to serve the Kingdom of God (Worldwide Tentmakers, 2024).

### **5.12.3 Education**

#### ***5.12.3.1 Problem***

In addition to a lack of pastoral and nursing education on this topic, there is a lack of training on spiritual support that can be given to these children (cf. 3.8.3). Moreover, the lack of recognition of pastoral workers by registration bodies creates a barrier to pastoral support to these children.

#### ***5.12.3.2 Solution***

Pastoral caregivers can register with existing bodies like the CPSC to ensure their professional status is upheld. Pastoral caregivers can also continue to grow in their professional development by doing short courses offered by non-profit organisations like HospiVision.

### **5.13 CONCLUSION**

A pastoral strategy was formed with the guidance of Osmer's pragmatic task. Through pastoral preparation which includes spiritual disciplines like prayer and reading the Word, pastoral caregivers can carry out their tasks competently in their work environment. Moreover, caregivers are encouraged to be mindful of various developmental theories to enrich their understanding in working with seriously sick children. Important facets in the relationship-building process included the facilitation of open communication, creating a safe environment and introducing physical games with the child. The parents and siblings can also be supported by showing care and providing information to them. Lastly, it was discussed how the barriers to the lack of pastoral support could possibly be overcome with regards to the recognition, funding and education of professional pastoral care in South Africa.

Chapter 6 will revise this study's chapters and discussions.

# **CHAPTER 6**

## **FINDINGS AND RECOMMENDATIONS**

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### **INTRODUCTION**

This pastoral study focused on identifying pastoral support that is available to children in South Africa with life-threatening and/or life-limiting conditions. Osmer's framework was used to structure this study. Chapter 2 asked: "What is going on?", while Chapter 3 posed the question: "Why is it going on?" Chapter 4 asked, "What ought to be going on?" and Chapter 5 examined how we should respond. The study concludes with this chapter which summarises each chapter's thought process and findings. It also provides recommendations for further studies in the field of pastoral care.

### **6.1 CHAPTER 1**

Chapter 1 identified what pastoral support is available to seriously ill children in South Africa. The aim of chapter 1 was to act as a roadmap for the rest of the study. Research shows that pastoral support to children with life-threatening and/or life-limiting conditions is lacking in South Africa. Osmer's model (2008) was identified to structure the study according to his four tasks of practical theology. The study's research questions, aim and objective, epistemology, paradigm and methodology were identified.

The unique contribution this study offers is to show why there is limited pastoral support to children with life-threatening and/or life-limiting conditions. The fact that only four participants were interviewed supports the research in Chapter 1 which shows that there is limited pastoral support to children with life-threatening and/or life-limiting conditions. Moreover, only two of the participants are currently working specifically with these children, which highlights the need for more trained caregivers in this field. Research found that there are few contributing factors to the lack of pastoral support to these children. It was identified that pastoral care in end-of-life care is a relatively new theme within pastoral ministry, which means that there is a lot of practical work, theoretical research and equipping of caregivers that need to take place. Fortunately, however, it was noted that HospiVision and the CPSC are two organisations which help to promote the advancement of pastoral care in South Africa.

The lack of collaboration between theologians and medical practitioners is one of the challenges faced by pastoral care. The medical personnel also might not acknowledge the belief systems of the patient. In Chapter 1, an example was mentioned about how the medical personnel might not understand Jehovah Witnesses' objection to blood transfusion (cf. 1.5.5). This might leave the nurses and doctors at a loss as to how to treat the patient without violating the Hippocratic oath. By contrast, the interviewees pointed out (P2) the other side, too, in which the family felt judged by some medical

personnel because they had visited a traditional healer based on their African culture before visiting a medical doctor. Overall, this highlights the necessity for pastoral caregivers to act as mediators between the family and the medical personnel in the case of emotionally and spiritually sensitive topics. Pastoral caregivers can help the child and family rely on God, despite the physical, spiritual and emotional suffering they may be going through.

## **6.2 CHAPTER 2**

Four pastoral caregivers (P1 to P4) who minister to children were interviewed in the qualitative empirical study. P1 specialises in working mostly with children who are traumatised by a medical procedure (reactive). She also works proactively by using preventative play techniques to help children prepare for upcoming procedures. The other participants' primarily work with children in paediatric oncology settings (P2 to P4). The empirical study was of hermeneutical significance since it provided practical insight to the researcher with regards to what pastoral support is available to these children. The descriptive-empirical task by Osmer (2008) was used to structure Chapter 2. The aim of this task was to identify "what is going on" in a certain situation. From the interviews, the openness, attentiveness and prayerfulness of the pastoral caregivers were noted. Osmer calls these the spirituality of presence (2008). Besides being present as a pastoral caregiver in another's situation, priestly listening and intercessory prayer on behalf of others are also important aspects of the descriptive-empirical task.

The findings from the empirical study will now be discussed.

### **6.2.1 Findings**

#### *6.2.1.1 Part 1 (Themes 1.1, 1.2, 1.3, 1.4)*

From the interviews, the researcher learnt about insightful, expressive pastoral techniques (Theme 1.1). It was discovered that effective pastoral techniques for children include activities, such as drawing and playing, since children express themselves naturally through these, even though they may lack the vocabulary to accurately express themselves in words. Expressive pastoral techniques provide a way in which children can become aware of their emotions (cf. 2.6). Play techniques are useful to confront separation anxiety and grief in the case of death preparation with the ill child (cf. 2.6.2). Similarly, pastoral play was shown to be a good tool to bring comfort through combining Scripture and play (cf. 2.6.2.1). As one of the participants works with children who are traumatised, effective pastoral techniques to address trauma were also discussed. It was found that systematic desensitisation works well for children who have been traumatised by a negative hospital experience. Through re-exposure to the triggering stimuli, healing is made possible by also confronting misconceptions which accompanied those triggers. Bible stories were found to validate the child's negative lived experiences, while the importance of giving children a choice in an environment where they have few choices was found to be

crucial to their empowerment (Theme 1.2). Ways to preventatively support the child (Theme 1.3) include direct, indirect and avoidance approaches. These three approaches were applied depending on the context of the child and family.

It was discovered that directly discussing death with one child might be helpful to develop trust between the caregiver and child, whereas with another family, it could be considered disrespectful as it might imply that the caregiver is “wishing death” on them by talking about it. The indirect approaches were helpful in death preparation by addressing the anxiety the child may have at the idea of being separated from their parents. Informal, semi-formal and formal attending could be observed through the participants’ ways of ministering to children. Effective ways to apply informal attending were through casual daily visits to the wards by P2 and P3. Some of the mothers of the sick children were attended to in semi-formal ways by having weekly meetings to do an activity like crocheting together. This was found to be productive in getting mothers together who are going through similar circumstances to build fellowship with one another. The participants were attended to formally by the researcher who sat with them and asked semi-structured questions to gain insights into their pastoral care to children with life-threatening and/or life-limiting conditions. Their responses were useful to inform the advancement of the theoretical research on the topic of providing pastoral care to these children. It was found that the children responded positively to the variety of pastoral care techniques applied by the four participants (Theme 1.4).

#### *6.2.1.2 Part 2 (Themes 2.1, 2.2, 2.3, 2.4)*

Part 2 was comprised of four themes which were primarily focused on discussing the participants’ advice to faith communities and pastoral caregivers. Theme 2.1 unpacked how the caregiver can build healthy relationships with the client (child and family of the child). It was recognised that conveying unconditional acceptance, instead of judgement, promoted relationship-building between the pastoral caregiver and the child, as well as with their family. Moreover, the caregiver needs to be sensitive to the impact shock has on the family when building a relationship with them. Also, promoting a culture of celebration will help the family to connect positively with one another. As well as promoting a culture of celebration, the pastoral caregiver can also equip the parents to help the child through spiritual difficulties when the pastoral caregiver is not there. Giving their full attention, non-judgemental acceptance, emotion-coaching and doing a shared activity to prepare for death were a few examples of how the parent can be equipped to support their ill child (cf. 2.11.2). As a result, it was identified that the family of the child also needs pastoral support since they have more responsibility for the financial, emotional and physical care of the sick child. Developmental science could empower the parents and caregiver to effectively support the child because they can understand the child’s phase of life.

CPD of pastoral support was identified as Theme 2.2. Continued professional development can be promoted through pastoral education, practical support and being available to intercede for the child

and family in the wards. The necessity for the pastoral caregiver to have knowledge of medical terminology has also been recognised (cf. 2.12.3) to understand what treatment the child will receive and how it will affect them.

Contextual awareness is another important part of professional pastoral care to seriously ill children (Theme 2.3). This is crucial because the pastoral caregiver can expect to encounter different people and should be flexible in adjusting their strategy to meet the unique context of the child and their family. Caregivers are also cautioned to manage their expectations around what they think the process and outcome of the ministry to the child will look like. When ministering to non-Christians, the caregivers should respect the family's cultural beliefs and religion.

Lastly, in relation to Theme 2.3, it was found that faith communities can minister more effectively to these children by first inquiring what the ages and needs of the children are before doing an outreach to them. Contextual awareness also means faith communities need to realise that there is a need for pastoral caregivers to support impoverished communities in South Africa. Theme 2.4 was titled self-care as the pastoral caregiver's self-care forms an important part of their ministry to these children. The process of relationship-building and hearing children's stories has an impact on the participants' well-being. Because these caregivers work with vulnerability, illness and death, debriefing through talking and reactional activities forms an important component of their well-being. Boundaries are necessary for healthy counsellor-child relationships (cf. 2.14.4).

Chapter 2's pastoral techniques formed the basis for researching and discussing why the pastoral techniques practised are useful and what other pastoral techniques might be of use to implement in praxis.

## **6.3 CHAPTER 3**

The interpretative task is Chapter 3's primary task (Osmer, 2008). Sagely wisdom is a necessary task which ought to be practised by pastoral caregivers by balancing thoughtfulness and theoretical interpretation. Chapter 3 discussed developmental theories of the developing child and pastoral techniques by the caregivers in the empirical study, as well as other useful pastoral techniques. The identified barriers to pastoral support in South Africa were investigated, as well as the importance of caregivers' self-care.

### **6.3.1 Findings**

Pastoral care plays an irreplaceable role in being messengers of meaning for families who are facing suffering and existential questions regarding the child's illness or condition (cf. 3.2.2). Interestingly, it was noted that an increase in spirituality meant an increase in hope, self-esteem and meaning. This

finding is echoed by Frankl's logotherapy which promotes meaning making as a way to promote spiritual support and healing. It was discovered that a holistic approach to the developing child is necessary to meet their physical, spiritual, social and psychological needs.

#### *6.3.1.1 Developmental theories*

Similar to Erickson's psycho-social theory, Kübler-Ross encourages physical touch in the first year of life to enhance trust and the child's positive development in the emotional quadrant between the ages of one to six. The spiritual quadrant was shown to have the potential to be a protective agent against bitterness later in life. Erickson's theory is useful to apply (cf. 5) when the child is undergoing a developmental crisis. This theory states what values the child should be developing given their age. Kolberg's moral development was found to be useful to analyse the reasoning of the sick child and how they view themselves, others, justice and empathy. Similarly, Fowler's faith development theory reflects at what level children are able to grasp theological concepts regarding faith.

Although it may not always be applicable when working with seriously ill children, Bowlby and Ainsworth's attachment and strange situation theories are useful to explain children's way of relating to others, especially their primary caregiver (parent). Prompted by the discussion with P2 about the significance of explaining death to children, Mari Nagy's theory was discovered. This theory is useful to explain to the caregiver how a child understands death and at what age a child is able to understand its finality. The fear of death, whether by the parents or the child themselves, is something pastoral caregivers can expect to come across in the ministry of paediatric palliative care. Moreover, it was discovered that a child can be holistically supported by addressing different needs in their lives, namely, spiritual, social and physical.

The counsellor's relationship with the child is key in making the child feel safe to open up to receive spiritual support. Moreover, the parents are important agents of the child's social and emotional support. In addition to the positive ways in which children can be supported, the far-reaching impact of trauma and negative emotions were discussed in Chapter 3. The child can be physically supported to build internal and external resources to combat these negative emotions through pastoral techniques.

#### *6.3.1.2 Pastoral techniques*

The pastoral techniques which can have a positive impact on seriously ill children based on research include the use of gospel music, dance movement therapy and Godly Play. These are all intended to bring comfort and joy to the sick child. The power of prayer ministry, thanksgiving (doxology) and God images were discussed. These were shown to help children, and their families renew their minds to see God for who He truly is and not in the negative way in which circumstances may have framed Him.

### *6.3.1.3 Familial needs*

Parents need pastoral caregivers to treat them with respect and acceptance. They also need a social, emotional and physical support system. It was found that parents desire access to information about their child's care and that siblings of the sick child also needs support since the parents have a lot more obligations between their own work and taking care of the sick child.

### *6.3.1.4 Barriers to pastoral care*

As recognized in Chapter 1, barriers of providing pastoral care in South African healthcare include lack of training, funding and formal recognition of pastoral care as a professional discipline.

### *6.3.1.5 Self-care*

Building on the identified need for pastoral caregivers to prioritise self-care, Chapter 3 discussed that the cost to caring (cf. 3.9.2) might include burnout, compassion fatigue and transference and/or countertransference. Therefore, the pastoral caregiver is cautioned to be aware of these phenomena when ministering to sick children and their families. Unburdening, knowing what your fillers are, as well as having healthy boundaries between work and one's personal life were encouraged for the well-being of the pastoral caregivers.

## **6.4 CHAPTER 4**

Three pericopes from the book of Matthew were studied to motivate how caring for the sick and vulnerable is commanded by Scripture. Matthew 25:31–46, Matthew 10:7–8 and Matthew 19:13–14 gave insight into Jesus' perspective on caring for sick children. The normative task by Osmer (2008), as well as the grammatical-historical exegetical model, guided Chapter 4. This task included using prophetic discernment, good practice and ethical interpretation.

### **6.4.1 Findings**

#### *6.4.1.1 Grammatical-historical model*

The purpose of the book of Matthew is to prove that Jesus is the awaited Messiah. Matthew, the disciple of Jesus, is the most likely author and the book was written to the Jews in 60 to 65 AD. The genre of Matthew is a theological biography about the life of Jesus. Rousseau's grammatical-historical model was used to structure this chapter. This gave insight into who the author was, its original audience, the author's intention, as well as how the text is relevant to a modern audience today.

In Matthew 10:7–8, Jesus commands His disciples to heal the sick, raise the dead and tell others about the nearness of God's kingdom. Similarly, this means that Jesus' representatives ought to take the authority He delegated to them to make a difference on earth using His kingdom principles. For this study, the pericope of Matthew 19:13–14 was highly relevant as it communicates the heart of Jesus to allow children to come near to Him, so that He can bless them. Jesus sets the children's faith as the

standard by which all people's faith should look like. Matthew 25:31–46 aims to stir a sense of urgency in its readers about what it means to be a true follower of Jesus. It also communicates the authority of Jesus as judge in the end times. This means Jesus' command to be His representatives is important.

In summary, these pericopes call Jesus' followers to heal (Matt 10) and to care for sick children (Matt 19; Matt 25). These pericopes give the normative guidelines for what Christians' response ought to look like with regards to visiting the sick and how Jesus expects children to be treated.

With regards to this study's investigation into what faith communities' role is in giving pastoral support to children with life-threatening and/or life-limiting conditions, this chapter clearly shows that faith communities have an obligation to care for the sick and to guide children to know Jesus.

## **6.5 CHAPTER 5**

How Christians should respond based on the pastoral problem which was identified in Chapter 1 was this chapter's focus. The primary task was the pragmatic task, which included task competence, transactional leadership and transforming leadership, as well as practical activities and suggestions. Task competence means pastoral caregivers ought to do their task well, while transactional leadership means that pastoral caregivers can work with everyone in the child's direct and indirect environment to effectively supporting the child. Transforming leadership means deep change toward removing barriers to provide effective care to children with serious and/or life-limiting conditions.

### **6.5.1 Findings**

There clearly is a place for pastoral caregivers and faith communities to respond to the need for pastoral support for these children in a way that reflects excellent practice. To do this, however, pastoral caregivers need to consider all the study's findings. Thus, this chapter aimed to reflect about what the caregiver needs to know about preparation beforehand, such as the child's development and the family's needs.

#### *6.5.1.1 Preparation*

Pastoral preparation includes taking note of spiritual disciplines to practise self-care and having an awareness of other cultures and religions. This promotes introspection regarding one's response to encountering people who hold different views to one's Christian beliefs. Moreover, pastoral preparation also requires the caregiver to have knowledge about the child's stage of development, as these inform the child's possible needs. General presuppositions to uphold are non-maleficence in practice (as seen in Chapter 5 based on the participants' responses) and scholarly information (as seen in Chapter 3).

#### *6.5.1.2 Relationship-building*

Conveying trust and creating a safe space will help in building a relationship with the child and their family. The caregiver can also effectively support the child by using their senses to help them understand their circumstances (their sickness or hospital preparation). These include techniques involving their sight, taste, touch, smell and hearing.

#### *6.5.1.3 Pastoral support activities*

The researcher developed activities which can be done with the child to help them to reflect on how they see themselves and Jesus. These enable the pastoral caregiver to know which lies, fears and misconceptions need to be addressed with the Word of God. From this, other social, emotional and physical support activities were discussed with the intention of providing holistic pastoral support to the child.

#### *6.5.1.4 Overcoming barriers*

Since Chapter 1, there were clear barriers mentioned about providing pastoral care to these children. These included the lack of pastoral care as a professional discipline in health environments, the lack of funding and the fact that there is a lack of education of nurses and pastoral students on this topic. However, Chapter 5 focused on providing solutions to overcoming these obstacles in order to be obedient to Jesus' call to care for the vulnerable, sick and children.

Chapter 5 provides appropriate pastoral guidelines informed by the participants, as well as scholarly information, which makes these guidelines dependable for working with children with life-threatening and/or life-limiting conditions.

## **6.6 CHAPTER 6**

The findings of each chapter have been discussed. The significance of each chapter will now be summarised and recommendations for further study discussed (6.8). Chapter 1 mapped the study. Chapter 2 highlighted what practical pastoral support is available to children in South Africa with serious illness, according to the four participants' interviews. Chapter 3 drew from the caregivers' interviews and other theories to explain why there is limited pastoral care available to these children in South Africa. What developmental and pastoral theories are useful to integrate into the practical care of children with illness were also investigated. Scripture was then unpacked in Chapter 4 as the measuring stick for pastoral caregivers to realise the hermeneutical significance and commandments to care for the sick, one's brothers in Christ and allowing children to draw near to Him. Chapter 5 provided pastoral guidelines for effective ministry to children who have life-threatening and/or life-limiting conditions.

The golden thread identified from Chapter 1 to Chapter 5 is that children with life-threatening illnesses have a need for pastoral support. This support, however, is currently limited, as noted from Chapter 2 and Chapter 3. This can also be seen from the small sample of pastoral caregivers who specialise in caring for these children in the empirical study. Chapter 3 also unpacked the barriers of lack of training and financial support to implement pastoral support to these children in South Africa. Knowing there is a lack of care ought to stir urgency to provide this care, as evidenced by Chapter 4, which points out Jesus' clear commands to care for the sick and help children know Him, especially before they pass away.

Based on the need for pastoral support and training of caregivers and faith communities, Chapter 5 provided a pastoral strategy which is built on the shared information of the participants and additional research.

## 6.7 OVERALL SUMMARY

The critical role of pastoral care is recognised. However, there still remains a need for the implementation and professionalisation of pastoral support to children with life-threatening and/or life-limiting conditions in South Africa. Pastoral caregivers can assist these children to navigate the difficulties presented by illness and hospitalisation. This pastoral study's methodology utilises Osmer's descriptive, interpretative, normative and pragmatic tasks. The six chapters were structured according to these above-mentioned tasks. Chapter 1 describes the foundation of pastoral care and proposes an empirical study to investigate what pastoral care is offered to these children in South Africa.

There are many vulnerable<sup>15</sup> children in South Africa, 87,6% of whom do not have access to medical aid. Their physical circumstances are made worse by the fact that pastoral care in general healthcare is relatively new in South Africa and not equipped to meet the high needs of these vulnerable children. Faith communities and pastoral caregivers ought to support children with serious illness, since nurses are not trained to support patients from a pastoral paradigm. Barriers to provide this service include the lack of collaboration between medical practitioners and theologians, as well as a lack of recognition of the need for this service. During the empirical study, the researcher aimed to get insights into what pastoral support is available to seriously ill children in South Africa. From the participants' responses, eight themes were identified, which were divided into two primary parts with four themes each. The first part's themes discuss the pastoral techniques and strategies utilised by the pastoral caregivers in ministering to these children. The second part focused on the advice the participants gave to build effective relationships with the family, keep up with CPD, show contextual awareness and prioritise self-care.

After the empirical study, the study aimed to elaborate on why pastoral support is of practical value and importance in the field of caring for these children. Developmental science, pastoral techniques and knowing the child and family's needs were discussed, as awareness precedes why meeting those needs is important. The barriers help to explain why there is a lack of pastoral support to these children when there is clearly a need. These barriers include lack of recognition, lack of training and lack of funding. The adverse impact of neglecting self-care by caregivers could lead to compassion fatigue, burnout, transference/countertransference and secondary trauma.

Guided by the normative task, Rousseau's grammatical-historical model for exegesis was used on the relevant pericopes in the book of Matthew. The six steps in this model included discussing the author (Matthew), original audience (Jews), motivation for writing the book, discussing the linguistic

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<sup>15</sup> Vulnerable children are those who face poverty, a lack of basic medical services, societal issues and negative caregiver capability in South Africa.

characteristics, the original meaning, as well as the modern application of the text. The three pericopes of hermeneutical significance include Matthew 10:5–15, Matthew 19:13–15 and Matthew 25:31–46. These motivate why Jesus calls Christians to be instruments of healing to the sick and to invite children to know Jesus and His kingdom.

Chapter 5 was the pinnacle of the study as it considered all the information and aimed to inform pastoral caregivers how they can respond in the best interests of the child and their family. Pastoral preparation, through practising spiritual disciplines and self-care, is necessary for the caregiver to be a healthy vessel for the Holy Spirit to work through effectively.

## **6.8 RECOMMENDATIONS FOR FURTHER RESEARCH THEMES**

This pastoral study points to the clear need for pastoral support to children with illness in South Africa. This study aimed to identify how pastoral support can be provided to children with severe illness and life-limiting conditions. From the scholarly articles and the empirical study, it also became clear that the pastoral caregivers need support, as well as the family of the sick child. These three research themes will be explored as probable future studies.

### **6.8.1 Caregiver support**

A future recommendation is a study which explores effective ways for practising caregivers to debrief. This recommendation is based on the participants' responses to Question 8: "How do you care for yourself while working in these heartbreaking circumstances?" Although there have been multiple studies done on caring for caregivers, such as *Trauma stewardship* by Lipsky *et al.* (2009); *Caring for joy* by Moschella (2016); *Caring for caregivers and patients* by Kent *et al.* (2016), it is clear from the participants' responses that the support of caregivers working with serious illnesses like cancer is not always applied in practice. P4 felt that she was more experienced than anyone who could debrief her. Therefore, in practice, caregivers might benefit from compulsory debriefing sessions.

### **6.8.2 Sibling support**

The researcher recommends a further study into the impact that sickness and death have on siblings in South Africa. Siblings often feel a variety of emotions when their brother or sister is ill. Field and Behrman (2004:161) suggest that siblings should also receive therapy since they may deal with misconceptions regarding their brother or sister's illness, fears, anticipatory grief and feel isolated as their parents are frequently supporting their ill sibling. Other ways siblings can be supported include through their school and other relatives and for parents to include the sibling in the care and support of the ill child (Field and Behrman, 2004:161). Caregivers can make sure to spend undistracted time with the sibling of the sick child and provide an environment where the sibling's emotions can be shared without judgement (Grollman, 1991:6). Pastoral caregivers and parents can inquire to make sure the

sibling is not bearing any misplaced burden of guilt since children are egocentric<sup>16</sup> and may believe their siblings' illness or death is their fault. Farrant (1998:89) recommends that children be given an opportunity to express their emotions before and/or after the death of a sibling. In emphasising speaking the truth to children (P1 to P4), Bowlby's advice is of value: "Only, indeed, when he is given true information, and the sympathy and support to bear it, can a child or adolescent be expected to respond to his loss with any degree of realism" (1980). This will assist the child to go through denial and disbelief and to get rid of imaginary scenarios which the sibling might have fantasised about, but which have no real basis (Farrant, 1998:16,89). Grieving siblings' health can be promoted through positive parent-child relationships, expression and validation of grief and healthy coping skills (McNiel and Gabbay, 2018: 91–99).

### **6.8.3 Parental support to parents with a sick child**

This study recognises that parents are important agents in meeting the sick child's financial, physical, spiritual, social and emotional needs. The well-being of the parent also directly impacts the child's well-being since they are sensitive to their parents' emotions and state of mind. Further research could be done on how to provide effective pastoral support to the parents of children with life-threatening and/or life-limiting conditions which would indirectly provide support to the child.

### **6.8.4 Pastoral needs of children**

As mentioned earlier, a similar study done in South Africa focusing on the pastoral needs of children from the perspective of pastoral caregivers could be valuable to identify barriers to effective caregiving to these children.

## **CONCLUSION**

All six chapters were revisited in this chapter. This study contributes to the body of knowledge in practical theology by offering an investigation into what the role of faith communities is in providing pastoral support to children with life-threatening and/or life-limiting conditions.

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<sup>16</sup> See Chapter 3: Sibling grieving

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