

Participation and control experienced during animal-assisted activities by children hospitalised with cancer

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DECLARATION OF RESEARCHER

I, Monique Vicky Simon, hereby declare that the manuscript with the title *Participation and control experienced during animal-assisted activities by children hospitalised with cancer* is my own work and that I have not previously in its entirety or in part submitted at any other university in order to obtain a degree.

MV Simon

December 2014

DECLARATION OF TEXT EDITOR

Hereby I declare that I have language-edited and proof-read the thesis *Participation and control experienced during animal-assisted activities by children hospitalised with cancer* by Monique Vicky Simon for the degree MA Psychology. I am a full-time PhD student in the English Department at UCT as well as a freelance copy-editor and proof-reader.

A handwritten signature in black ink, appearing to read 'Joffe', written in a cursive style.

Daniela Franca Joffe [BA (*Hons*) Harvard University, MSt Oxford University]

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PREFACE

The candidate, Monique Vicky Simon, opted to write an article, with the support of her supervisor and co-supervisor. We, the supervisor and co-supervisor, hereby declare that the input and the effort of Monique Vicky Simon in writing this article, reflects research done by her on this topic. We hereby grant permission that she may submit this article for examination in fulfilment of the requirements for the Degree Magister Artrium in Psychology.

- The dissertation is presented in article format as indicated in Rule A.5.4.2.7 of the North-West University Potchefstroom Campus Yearbook.
- The dissertation consists of Section 1: Background to the study, Section 2: The article and Section 3: Critical reflections on the study.
- The article is intended to be submitted to the journal *Supportive Care in Cancer*
- In Section 2, which comprises the article, the researcher has followed the Harvard Method of referencing as well as the guidelines of the article format stipulated by *Multinational Association of Supportive Care in Cancer* (MASCC) As seen in the attached Author Guidelines (Addendum VIII) it, amongst other guidelines, specifies that sections should not be numbered
- Sections 1 and 3 have been referenced according to the North-West University's referencing manual: *NWU Referencing Guide*, Library Services, Potchefstroom Campus, 2012.

Suzette Weideman

Dr Zahraa McDonald

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SUMMARY

Children diagnosed and treated for cancer experience a profound life-transformation as they are confronted with unprecedented physical, psychosocial and emotional challenges. Children's experience of diagnosis and treatment is often accompanied by a lack of participation and reduced control.

Extensive research has been conducted on a variety of supportive interventions. Only a limited amount of research, however, has investigated the potential of animal-assisted activities (AAAs) to afford specialised support for the child hospitalised with cancer. Moreover, of this limited research, few studies explore AAAs in relation to participation and control. The purpose of this study was to explore and describe how participation and control are experienced during animal-assisted activities by children hospitalised with cancer.

Paediatric oncology patients between the ages of 8 and 14 with any type of cancer were offered the opportunity to participate in the study, which comprised of animal-assisted activities at the facility where patients received their medical care. Five children were included in the final sample. Data were gathered by means of non-participant observations, participant interviews, graphic questionnaires and field notes. Data were then analysed in accordance with steps proposed by Tesch (1990: 142-145), which involved coding according to categories and related themes.

Five major themes emerged, including (1) approach to animals, (2) body awareness, (3) level of engagement, (4) level of dependence and (5) communication. Nine sub-themes were derived from data analysis. Under "approach to animals", the sub-themes were (i) taking the lead, (ii) grooming and affection and (iii) laughter and spontaneity. The sub-themes of "body awareness" were (iv) protection of body and (v) comfort. The sub-themes of "level of engagement" were (vi) initiative and (vii) choice. Finally, the sub-themes of "communication" were (viii) verbal communication and (ix) non-verbal communication.

The study provides insight into the participation and control experienced during animal-assisted activities by children hospitalised with cancer. When the initial and final AAA sessions were compared, changes were noted in terms of the children's approaches to the dog, their body awareness, their level of engagement, their level of dependence and their communication. These changes are associated with an enhanced sense of participation and control, aspects that are often reported to be diminished in children who are diagnosed, treated and hospitalised with cancer. AAAs should therefore be considered an effective means of supporting children hospitalised with cancer.

KEY TERMS: animal-assisted activities; control; cancer, hospitalised children; participation; phenomenological investigation; supportive treatment.

OPSOMMING

Kinders wat met kanker gediagnoseer en behandel word, ervaar noemenswaardige verandering in hulle lewens aangesien hulle met fisiese, psigososiale en emosionele uitdagings gekonfronteer word. Kinders se belewenis van die diagnose- en behandelingsproses kan dikwels gepaardgaan met 'n verlies aan deelname en 'n gevoel van afname in beheer. Omvattende navorsing is reeds gedoen oor 'n verskeidenheid van ondersteunende intervensies. Beperkte navorsing ondersoek egter dier-gesteunde aktiwiteite (DGA) as moontlike ondersteuning, spesifiek vir die kind wat met kanker gehospitaliseer is. Verder, uit hierdie beperkte navorsing, ondersoek weinig studies DGA in verhouding met deelname en beheer. Die doel van hierdie studie was om te ondersoek en te beskryf hoe deelname en beheer tydens dier-gesteunde aktiwiteite ervaar word deur kinders wat gehospitaliseer is met kanker.

Pediatriese onkologie pasiënte tussen die ouderdom van agt en veertien jaar, met enige tipe kanker, is die geleentheid gegee om deel te neem aan die studie wat dier-gesteunde aktiwiteite behels het, by die instansie waar hulle mediese behandeling ontvang het. Vyf kinders is in die finale steekproef ingesluit. Data is ingesamel deur middel van nie-deelnemer observasies, deelnemer onderhoud, grafiese vraelyste en veldnotas. Die data is daarna ontleed volgens die stappe wat deur Tesch (1990:142-145) voorgestel word, wat kodering in terme van kategorieë en verwante temas behels.

Vyf hooftemas het navore gekom, insluitend (1) benadering tot diere, (2) liggaamsbewustheid, (3) vlak van betrokke wording, (4) vlak van afhanklikheid, en (5) kommunikasie. Nege sub-temas het uit die data-analise na vore gekom. Benadering tot diere het die neem van leiding, versorging en vertroeteling, asook lag en spontaniteit ingesluit. Die hooftema van liggaamsbewustheid, het beskerming van liggaam en gemak behels. Vlak van betrokke wording het inisiatief en keuse ingesluit, en laastens het verbale en nie-verbale kommunikasie die hooftema van kommunikasie uitgemaak.

Die studie verskaf insig in deelname en beheer wat die kind wat met kanker gehospitaliseer is beleef tydens dier-gesteunde aktiwiteite. 'n Vergelyking tussen aanvanklike en latere sessies het verandering gewys in terme van die kinders se benadering tot die hond, liggaamsbewustheid, vlak van betrokke wording, vlak van afhanklikheid, en kommunikasie. Hierdie veranderinge het gepaard gegaan met die toename in deelname en gevoel van beheer, wat aspekte is wat gereeld as verlaag gerapporteer word deur kinders wat gediagnoseer, behandel en gehospitaliseer word met kanker. DGA behoort dus as 'n effektiewe wyse oorweeg te word waarop kinders wat met kanker gehospitaliseer is ondersteun kan word.

SLEUTELTERME: dier-gesteunde aktiwiteite; beheer; kanker; gehospitaliseerde kinders; deelname; fenomenologiese ondersoek; ondersteunende behandeling.

SECTION A: BACKGROUND TO THE STUDY

PART 1: ORIENTATION TO THE RESEARCH

1. ORIENTATION AND PROBLEM STATEMENT

Children of all ages, races, genders and socio-economic aggregations, and their families, are affected by cancer every year (Children's Oncology Group, 2012). There are between 600 and 700 new cases annually of children diagnosed with malignancies in South Africa (Stefan & Stones, 2012:605) and, according to the Childhood Cancer Foundation of South Africa (2013), one in 600 children is affected by cancer before the age of 16. These childhood cancers are generally distinct from those that affect adults. The types of cancers that are most prevalent in children occur in the developing cells such as bone marrow, blood, kidneys and the nervous-system tissues (Childhood Cancer Foundation South Africa, 2012). Technological advances in the field of childhood cancer have led to an augmentation in survival rates and have meant that cancer is now more commonly conceptualised as a chronic illness (Johnson, Meadows, Haubner & Sevedge, 2003:56). Despite the improved prognosis, both diagnosis and subsequent treatment remain stressful and baleful experiences, particularly for children (Braun, Stangler, Narveson & Pettingell, 2009:105; Li, Chung & Chiu, 2010:47). Literature on the phenomenon has urged that a greater emphasis be placed on lived experiences, with a particular focus on ways in which children can be supported (Eiser, 1998:621).

Cancer can affect all aspects of the child's life including the physical, emotional and psychosocial aspects. Cancer itself can be physically painful: pain is often reported as one of the most prevalent features in paediatric oncology (Enskar & Von Essen, 2008:37; Hedstrom, Haglund, Skolin & von Essen, 2003:120; Van Cleve, Munoz, Savedra, Riggs, Bossert, Grant & Adlard, 2012:116). Many children fear pain as early as the initial time of diagnosis (Ljungman, Gordh, Sorensen & Kreuger, 2000:212). However, physical pain as the result of treatment is reported to be of greater concern (Hedstrom, *et al.*, 2003:124; Ljungman *et al.*, 2000:211). Treatment of cancer can include chemotherapy, surgery, radiotherapy and bone-marrow transplantation, alone or in combination (Li *et al.*, 2010:48; The Children's Oncology Group, 2011:51-58). A study conducted by Oberholzer, Nel, Myburgh and Poggenpoel (2011:7-8) further determined that children with cancer have various internal mind and body requirements such as the need to be supported with regard to disturbed sleep, eating problems attributed to nausea, and physical pain as the result of treatment. It is also common for children to realise their bodies are unhealthy and perceive them as vessels of pathology (American Cancer Society, 2013). This realisation can cause a shift in the way the child perceives and thinks about himself/herself, as well as in his/her interaction with the environment, and can exert an influence on the child's self-concept (Hymovich, 1995:51). According to Oberholzer *et al.* (2011:1) this shift elicits in the child a need to exert some control over the situation so as to feel less like a

victim and reduce the experience of negative emotions. Many studies support this notion of uncontrollability. Last and Grootenhuis (1998:171-175) state that “being confronted with cancer means being confronted with uncontrollability, which easily evokes feelings of helplessness” as well as feelings of anxiety, fear and depression. Woodgate (2008:233-234) adds that, besides a lack of control, children appraise cancer as threatening and numbing. Johnson *et al.*(2003:56) show that the participation in healthcare, autonomy and empowerment of these children may be compromised, affecting their overall quality of life and eliciting experiences of loss of control, disempowerment and disconnection from their bodies. Results from a study conducted by Hedstrom *et al.* (2003:124) suggest that confinement, alienation and worry, before medical procedures, are the emotional aspects that trouble children most. The most frequently mentioned aspect of emotional distress for children aged eight to 12 years was worry about death. This was supported by the findings of Li *et al.* (2010:50-52), in which children treated for cancer expressed feelings of sadness, anxiety, worry about death, loss of self-control and uncertainty.

It is therefore clear that cancer is not only challenging on a physical level but also associated with a fundamental alteration from former normal states and everyday life (Bjork, Wiebe & Hallstrom, 2005:269; Epstein, Orr & Stevens, 2004:3). The adjustment of children to their diagnosis of cancer can be strongly influenced by those around them, particularly the family (Patterson, Holm & Gurney, 2003:391; Robinson, Gerhardt, Vannatta & Noll, 2007:400). As social-ecological theories propose, an individual’s well-being is dependent on, among other elements, the social systems around them (Bronfenbrenner, 1979:97). The implications of cancer affect the child’s familial relationships and the family as a whole (Bjork *et al.*, 2005:265; Hymovich, 1995:51), and parental or familial distress has been found to be positively related to distress in children (Robinson *et al.*, 2007:401). Family members, including the child, often experience feelings of loss of control and powerlessness related to an inability to change the situation they are in (Bjork *et al.*, 2005:269-270). In a study conducted by Li *et al.* (2010:52) it was established that cancer treatment negatively affects children’s psychosocial well-being, with children reporting feeling confined, estranged and concerned about changes in their physical appearance. In addition, treatment may require that the child be hospitalised for extensive periods of time, which can involve separation from family and removal from the security of the home environment (Kurz, 1987:290). Reed, Smith, Fletcher and Bradding (2003:72) posit that, due to a lack of understanding and exclusion from decision-making, all children admitted to hospital could experience disempowerment and loss of control.

Oberholzer *et al.* (2011:3-5) have determined that children in a haematology-oncology unit have the following needs: support from parents, siblings and friends; assistance with school work; a need for information; normalisation of the environment; humour; trusting relationships; appreciation and encouragement; play and stimulation; and control. Schmidt, Peterson and Bullinger (2003:71) as well as Zwaanswijk, Tates, Van Dulmen, Hoogerbrugge, Kamps and Bensing (2007:1478) have identified an increased desire for participation with regards to medical decision-making in children

with chronic diseases. The Schmidt *et al.* (2003:71-72) study explicated that this notion of participation refers not only to compliance but also to the more active concept of exerting control. In addition, child participation in the decision-making process is imperative for psychological well-being (Coyne, O'Mathuna, Gibson, Shields & Sheaf, 2011:2; De Winter, Baerveldt & Kooistra, 1999:16). Children's participation in health issues has been found to augment the child's internal locus of control (Tiffenberg cited in Coyne *et al.*, 2011:2).

Social support is considered an imperative buffer during stressful life situations against the accompanying negative consequences (Brodie & Biley, 1999:332; Hart, 2010:62-65; Woodgate, 1999:201) and, as the social support of the child diagnosed with cancer is severely challenged, alternatives need to be identified. Supportive treatments within the context of oncology can be defined as those interventions concerned with physical, psychosocial and spiritual issues that affect both the individual diagnosed with cancer as well as the family, as a means to maximise quality of life (Berger, Portenoy & Weissman, 2007:xxv). The inception of the biopsychosocial paradigm in paediatric oncology has meant that supportive interventions that address physical, psychosocial and emotional needs are available (Armstrong, 2006:28). Armstrong (2006:22) and Abbate (2010:x) mention that initially supportive treatments strongly focus on the physical domain due to the nature of cancer. To this end, relaxation, guided-imagery and distraction techniques, among others, have been successfully utilised (Oberholzer *et al.*, 2011:7; Rehse & Pukrop, 2003:180). Support groups that foster social interaction are sometimes available, based on significant research in favour of social interactions among children with cancer, both with one another and with their healthy friends (Dowling, Hockenberry & Gregory, 2003:271; Ishibashi, 2001:64; Oberholzer *et al.*, 2011:7). Psychotherapeutic interventions include various kinds of psychotherapy and counselling, which can include eclectic therapeutic approaches (Rehse & Pukrop, 2003:180) such as art therapy. Education programmes provide medical and procedural information. It has been recognised that knowledge regarding cancer allows children to better cope with the life experiences associated with the disease (Dowling *et al.*, 2003:271).

However, supportive interventions that incorporate child participation and the associated concept of control are still lacking. Despite the evidence attesting to the benefits of child participation, this participation in practice remains limited (Coyne *et al.*, 2011:2; Tates & Meeuwesen, 2001:848; Young, Dixon-Woods, Windridge & Heney, 2003:1). According to Coyne *et al.* (2011:3), health professionals are uncertain about how to involve children. Furthermore, there is a lack of research on participation and shared decision-making in childhood cancer (Dixon-Woods, Young & Heney, 2005:153). There is, however, indication that children assisted by animals during their hospitalisation are offered opportunities to participate in decisions, which could contribute to a sense of control.

Of the existing research on supporting individuals hospitalised with cancer, few studies consider animal-assisted activities (AAAs) as a possible form of support (Moorhouse, 2009:26). The use of animals during supportive interventions was first formally organised in the United States of

America in 1942 at Pawling Air Force Convalescent Hospital between convalescing veteran soldiers and dogs (Netting, Wilson & New, 1987:60). Since then, expanding emphasis has been placed on the roles that animals can fulfil in supporting the health and emotional well-being of people in need (Jenkins, Ruehrdanz, McCullough, Casillas & Fluke, 2013:25). As such, animals involved in animal-assisted interventions (AAI) have become a familiar fixture in a variety of settings, including hospitals (Lefebvre, Peregrine, Golab, Gumley, Waltner-Toews & Weese, 2008:394) especially internationally. This is reflected by the more than 11,000 therapy-animal teams registered with Pet Partners (2012). This figure is in sharp contrast to the South African context, where there are only a few organisations that offer AAAs, such as Pets as Therapy and Paws for People, and even fewer that offer animal-assisted therapy (AAT), such as Top Dogs.

Based on the growing interest in AAIs, an umbrella term used to refer to different kinds of interventions utilising animals, studies have been done establishing the beneficial nature of various kinds of AAIs (Jenkins *et al.*, 2013:25; Kruger & Serpell, 2010:36). A very definite distinction is made in the literature between animal-assisted activities and animal-assisted therapy (Friesen, 2010:264; Kogan, Granger, Fitchett, Helmer & Young, 1999:106; Nimer & Lundahl, 2007:225; Odendaal, 1999:53). For the purpose of this study, the definitions used by Pet Partners (formerly known as the Delta Society) will be employed:

“Animal-assisted activity (AAA) provides opportunities for motivational, educational, recreational and/or therapeutic benefits to enhance quality of life. AAAs are delivered in a variety of environments by specially trained professionals, paraprofessionals and/or volunteers, in association with animals that meet specific criteria.” (Pet Partners, 2012)

AAAs are casual, support-based encounters involving activities that are applicable to a wide range of contexts and individuals. In AAA, animals, usually dogs (although other small pets can be used), are behaviourally assessed as a prerequisite to their interacting with ill and even bedridden patients (Arkow; Granger & Kogan cited in Abbate; Abbate, 2010:14). AAA is usually provided to inpatients on a weekly basis, although the nature of AAA dictates that the visits are generally unplanned and unstructured (Pet Partner, 2012). Typically during these sessions, a volunteer, usually the owner and/or handler of the dog/small animal, would accompany the animal into the ward and invite interested patients to interact with the animal, either individually or in groups (Abbate, 2010:28&35). The content, duration and nature of the sessions are directed by the child, as the volunteer/handler retreats into the background to allow for spontaneous interaction (Fine, O’Callaghan, Chandler & Pichot, 2010:195-196). It is, however, acceptable practice to initiate contact with the child by speaking “on behalf of” the dog, whispering in the dog’s ear, instructing the dog to perform tricks such as greeting or “talking” (barking), having the dog play with a ball or even reading a storybook to the dog (Fine, O’Callaghan, Schaffer, Pichot & Gimeno, 2010:203-204). These actions do not constitute therapeutic goals, though, as they do in the case of AAT. Rather, they serve to enhance

comfort and rapport, as well as trust in the process of AAA and in the animal itself (Fine, O'Callaghan, Schaffer *et al.*, 2010:199).

Besides the well-documented physical benefits of AAIs, such as a decrease in blood pressure, heart rate and cortisol levels (Odendaal, 2000:277-279), which are all commonly associated with stress due to hospitalisation (Katcher, Friedmann, Beck & Lynch cited in Jalongo, Astorino & Bomboy, 2004:9; Wu, Niedra, Pendergast & McCrindle, 2002:354&361), AAIs have additional psychosocial and emotional benefits (Jalongo *et al.*, 2004:12). According to Hart (2010:65) animals may fulfil a substitutive role for human social support, and strong attachment bonds can develop between humans and animals that are comparable to the bonds that develop between family and friends (Gerstman cited in Brodie & Biley, 1999:332). Additionally animals may function to enhance social interactions, facilitate conversations and extend one's social network (Cole, 2009:29; Hunt, Hart & Gomulkiewicz, 2001:245).

Specifically for children who have been hospitalised, the reported psychological and emotional benefits of AAI include a more positive affect and greater feelings of happiness (Budge, Spicer, Jones & St. George, 1998:229; Kaminski, Pellino & Wish, 2002:327; Sobo, Eng & Kassity-Kritch, 2006:56). Significant research findings (i.e. Brodie & Biley, 1999:334; Budge *et al.*, 1998:229; Hart, 2010:64 & 68; Smith, 2012:439-440) report that interactions with animals can lead to the alleviation of depression, loneliness, anxiety and distress. Further psychological benefits may derive from AAIs, offering the possibility for the patient to actively engage in his or her own health and fulfil the yearning to be contacted as a whole person (Johnson *et al.*, 2003:56). Whereas much of the hospital experience is focused on addressing physical needs, AAIs can assist in addressing the psychosocial and emotional aspects of the individual. AAIs may also provide patients with the opportunity to become equal and active partners in the process of their health and well-being as opposed to passive individuals to whom something is done (Johnson *et al.*, 2003:56). This partnership is achieved by providing the patient with an opportunity to participate in decisions regarding his/her health and well-being, which in turn contributes to a sense of control. This is in congruence with Davis (cited in Wu *et al.*, 2002:355) who notes that AAAs help to strengthen the hospitalised child's self-concept, which is often enervated due to constant engagement with authority figures. This can be linked to Erikson's stages of development (1968), according to which the child's sense of control and autonomy may be reinforced with the accomplishment of certain tasks (Abbate, 2010:3-4).

There have been an increasing number of research publications on the benefits of AAIs over the past four decades and, while some of this research has focused on child-specific AAIs in a hospital context, there is limited research on animal-assisted activities among cancer patients (Moorhouse, 2009:26). Of this limited research, few studies have explored how AAAs may address the psychosocial and emotional challenges associated with children hospitalised with cancer, particularly surrounding issues of participation and control. This research gap is confounded by the fact that most

research on childhood has its roots in developmental understandings of childhood, which then extends to research on paediatric cancer. The implications of this are that, in much of the research, children are conceptualised as “becoming adults” and are often not provided with a voice. A significant proportion of research on childhood cancer is attained from proxy accounts, from parental and medical staff reports, rather than from the children themselves (Dixon-Woods *et al.*, 2005:17). Dixon-Woods *et al.* (2005:17) also note that most of the research on childhood cancer is quantitative and psychological in nature and has been conducted in isolation, separate from other disciplines. They argue that it fails to consider a variety of research strategies and theoretical paradigms. The proposed study will therefore seek to address these aforementioned gaps in the research by assuming a qualitative phenomenological approach that explores and describes AAAs related to participation and control from the children’s own perspectives. This approach may also be a more appropriate research design to studying AAs, as it has been suggested that positivist quantitative research designs may not sufficiently capture results from AAs (Voelker, 1995:1898). Odendaal (1999:72) states that “the positivistic approach that only things that can be measured convince, or even worse exist, may be the wrong one in this field”.

The formulated research question is: How are participation and control experienced during animal-assisted activities by children hospitalised with cancer?

2. RESEARCH AIM

The aim of this study was to qualitatively, through the use of a phenomenological design, explore and describe the experiences of participation and control during animal-assisted activities by children hospitalised with cancer.

3. CONCEPT DEFINITIONS

3.1. Supportive interventions

In the context of oncology, the term “supportive interventions” can refer to those aspects of care that focus on the physical, psychosocial and spiritual issues that affect individuals with cancer, their families and their communities. Accordingly, supportive interventions are those used to support patients who experience the adverse effects of cancer treatments and therapies, as well as interventions that fall under the broader concept of palliative care, aimed at enhancing quality of life (Berger *et al.*, 2007:xxv). Berger *et al.* (2007:xxv) assert that although palliative care has traditionally been associated with enhancing quality of life and providing succour at the end-of-life stage of the cancer process, it can actually be applied much earlier on during active treatment. This broader

conceptualisation of palliative care is imperative because it incorporates a more holistic approach to the individual with cancer. Even when cancer can be treated effectively, there are always physical, psychosocial and spiritual concerns that need to be addressed in order to augment quality of life (Children's Oncology Group, 2012).

3.2. Animal-assisted interventions

Kruger and Serpell (2010:36) utilise the term animal-assisted interventions (AAIs), defining it as “any intervention that intentionally includes or incorporates animals as part of a therapeutic or ameliorative process or milieu”. It is therefore an overarching and broader term used to refer to both animal-assisted activities and animal-assisted therapy. Animal-assisted therapy and animal-assisted activities are the preferred terms used by Pet Partners because these terms suggest that the animal is the impetus that enhances treatment provided by a well-trained individual (Pet Partners, 2012).

3.2.1. Animal-assisted activities

Animal-assisted activities (AAAs) is the term used to refer to interventions that use animals to provide motivational, educational, recreational, and/or therapeutic benefits to augment quality of life. Based on this, AAAs tend to be more informal and can be conducted by trained professionals, paraprofessionals, and/or volunteers. Distinctive features of AAAs include the fact that the content of visits is generally spontaneous and that the activities can be applied to a variety of individuals in an array of contexts (Pet Partners, 2012).

3.2.2. Animal-assisted therapy

In an evaluation of literature, LaJoie (2003:3) details 20 disparate definitions of animal-assisted therapy (AAT) and a further 12 different terms for the same phenomenon, including pet therapy and pet-facilitated therapy (Friesen 2010:264; Odendaal, 1999:52). This inconsistency in the application of terms and definitions results in confusion both within and without the field of animal-assisted therapy (Kruger & Serpell, 2010:34) and despite the proliferation of research and literature on the subject, the term animal-assisted therapy continues to be applied to programmes that do not constitute therapy, or its real meaning. As a result, the International Association of Human-Animal Interaction Organizations formulated the IAHAIO White Paper (2014) as a means to consolidate these terms and reduce further confusion.

Pet Partners defines animal-assisted therapy as "a goal-directed intervention in which an animal that meets specific criteria is an integral part of the treatment process. AAT is directed and/or delivered by a health/human service professional with specialised expertise, and within the scope of practice of his/her profession. AAT is designed to promote improvement in human physical, social, emotional, and/or cognitive functioning. AAT is provided in a variety of settings and may be group or

individual in nature. This process is documented and evaluated" (Pet Partners, 2012). Thus, the defining features of animal-assisted therapy are the distinctive goals for each individual and the measurement of progress (Pet Partners, 2012).

3.3. Hospitalised children

Although seemingly obvious, definitions of the child are not entirely unequivocal (Qvortrup, 2009: xiv). Traditionally, childhood is conceptualised as a discernible phase in the human life-cycle. The dominant paradigm in studies of childhood assumes a developmental understanding of children as being in the process of becoming adult (Boyden, 2003:2; Qvortrup, 2009:2), rather than as individuals in their own right. Accordingly, children are believed to be dependent, illogical and inept, needing to master predetermined stages in order to achieve sagacity (Boyden, 2003:2; Dixon-Woods *et al.*, 2005:3; Mayall, 2008:110). However, more recently, this dominant paradigm has been disputed as being only one of numerous interpretations of childhood and the child; accordingly, there is a growing acknowledgment of the notion of many and varied childhoods (Dixon-Woods *et al.*, 2005:3; Moss, Dillon & Statham, 2000:235). There has therefore been a progression away from conceptualising children as solely a biologically constructed group with universal determinants, towards a social construction of childhood and the child. Dahlberg, Moss and Pence (2007:62) explicate that "images of what a child can be, is, or should be" are generated socially by both adults and children, thereby establishing the child as a co-constructor of information and identity.

Paediatric hospitalisation refers to the confinement of a child to hospital for diagnosis or treatment in an effort to restore the child to health and, on the whole, to recapture the individual's position in the world (Bsiri-Moghaddam, Basiri-Moghaddam; Sadeghmoghaddam & Ahmadi, 2011:201).

3.4. Cancer

Cancer is the broad name given to a group of diseases, comprised of over one hundred different types. Cancer occurs when abnormal cells divide uncontrollably and are able to invade other tissue (National Cancer Institute, 2013). Childhood cancers are generally distinct from those that affect adults. The types of cancers that are most prevalent in children occur in the developing cells such as bone marrow, kidneys and the nervous-system tissues (Childhood Cancer Foundation South Africa, 2013). Cancer in children can be divided into three primary types: leukaemias (cancers of the blood-forming cells), lymphomas (cancers of the lymphatic system) and solid tumours (cancers of the bone, brain, muscles, organs and other tissues) (Children's Oncology Group, 2012).

3.5. Participation and control

The concept of participation is complex and therefore challenging to define (Kirby & Woodhead, 2003:236). Polkki, Vornanen, Pursiainen and Riikonen (2012:108) suggest that participation can be broadly defined as “interaction, belonging and integration into and influence on society” while child participation specifically denotes the active involvement of children in decisions that affect their own lives, in addition to the lives of their families and communities (Ward, 2008:3). This is in line with the Convention on the Rights of the Child, which conceptualises participation as opportunities for children to engage in the world in which they are embedded as well as possibilities for children to be heard in more formal decision-making processes (Stephens cited in Ansell, 2005:233). Participation encourages children to cultivate their own plans for transformation and can be empowering for children, a means of augmenting control and autonomy over their own lives (Ansell, 2005:235,255; Hart, 1992:16).

The concept of control has enhanced understanding when contextualised in social-learning theory, as propounded by Rotter (1954). Control is related to the perception that individuals hold about the causation of personal consequences and other associated events (Engler, 2009:251). Individuals who have an internal locus of control perceive their own behaviours and actions as the primary cause of whatever happens to them. Conversely, individuals who have an external locus of control hold the conviction that consequences and events in their lives are controlled by external factors and are therefore not within their hands (Engler, 2009:251). De Winter *et al.* (1999:18) explicate that a sense of control over one’s own life-circumstances is essential for coping: “When people have the feeling that they themselves control circumstances and events (internal locus of control), they seem to be more inclined to adopt an active attitude with respect to any problems that may occur” (De Winter *et al.*, 1999:18). This obviously has relevance and applicability for children who are hospitalised with cancer. Participation in the medical decision-making process can result in children feeling more in control and can therefore help with their overall adjustment to hospitalisation (Coyne & Gallagher, 2011:2335; McCabe, 1996:506).

4. RESEARCH METHODOLOGY

4.1. Literature Review

Appropriate databases were consulted in order to conduct a review of the literature. This included the following electronic search engines: A-Z Journal List, Ebsco Host, Google Scholar, JSTOR and Sage Publications. The review included themes such as childhood cancer, paediatric oncology, child participation, control and animal-assisted activities. It is important to note that the review included additional themes such as animal-assisted interventions, animal-assisted therapy, pet-facilitated

therapy, pet therapy and other derivatives due to the somewhat inconsistent and interchangeable application of these terms in the literature.

4.2. Research design

For the purpose of this study, a qualitative approach was assumed in order to explore and describe the experiences of animal-assisted activities with children hospitalised with cancer. The research utilised a phenomenological design, which can be described as a study that endeavours to comprehend people's lived experiences of a particular phenomenon (Delpont, Fouché & Schurink, 2011:305). The intention of a phenomenological approach is to comprehend and describe the phenomenon as it is experienced by the subjects themselves (Bentz & Shapiro, 1998:96). Throughout the study, the researcher focused on the children's lived experience of participation and control in the context of the animal-assisted activities offered to them as part of their supportive treatment during hospitalisation, all the while bracketing her own preconceptions, as prescribed by Fouché and Schurink (2011:316).

4.3. Research method

4.3.1. Population

The population from which the researcher obtained the participants consisted of children hospitalised with cancer at a specific hospital in South Africa. Children were between the ages of eight and 14, since by middle childhood it is believed that children have mastered a relatively stable and comprehensive understanding of the self (Markus & Nurius, 1984:151) as well as the ability to generalise across concrete instances (Fischer & Bullock, 1984:74). Children were hospitalised, either on an inpatient or outpatient basis, in the oncology ward at the specific hospital.

4.3.2. Sampling

The selection of participants for the proposed study was based on the non-probability purposive sampling technique due to the qualitative nature of the research design (Strydom & Delpont, 2011:391; Babbie, 2007:187).

The following criteria were used to select participants:

- Children with any type of cancer were included in the sample. It was, however, essential to take into consideration the fact that AAAs were only offered to children who are able to interact and are therefore healthy enough to participate.
- AAAs that adhered to the organisation's protocol were offered to all children who indicated an interest in participating in the study by a suitably trained and experienced volunteer from the selected organisation for a period of two (2) months.

- The AAAs were offered to all children admitted into the oncology ward or receiving treatment at the oncology ward, during the two (2) month period.
- All children who had been participating in the AAAs were interviewed during the last week of the two-month period; regardless of how many sessions of AAA they had participated in.

4.3.3. Sampling size

According to Patton (2002:244-245), while there are no concrete rules pertaining to sample size, qualitative research is usually concerned with “the information richness of cases selected”. As such, sample size is generally premised on the notion of data saturation. Data saturation is defined as the point at which the same themes and notions continue to reoccur in the data and no further novel or significant information can be gleaned by increasing the size of the sample (Durrheim, 2006:50; Greeff, 2011:350; Kelly, 2006:289). Sample size is, however, also dependent on other factors, such as the procedures being followed by the hospital and by the organisation offering the supportive treatment, as well as the availability of the researcher’s time and resources (Patton, 2002:244). Thus taking into consideration both data saturation and the aforementioned factors, the final sample size included five children.

4.4. Data collection

4.4.1. Method of data collection

This study made use of observations, interviews, graphic questionnaires and field notes as multifarious means for data collection.

4.4.1.1. Non-participant observations

There are divergent definitions of observation and of the observer’s role in the literature. However, there seems to be consensus that observational methods can be classified along five dimensions, namely: disclosure, participation, setting, observational structure and reflexivity (Flick, 2009:222). Accordingly, observations for the proposed research were conducted in an overt manner, with the children fully aware of the researcher’s presence. The researcher assumed a non-participant approach thereby maintaining a more passive and distant position to the observational process. Observations occurred within the hospital context. Behaviours that occurred during the interactions between the child, the dog and the AAA-organisation volunteer were documented according to an observation schedule (Merriam, 1988) and as such were more systematic in nature (see addendum I). Behaviours that particularly revealed aspects of participation and control were focused on and noted. Behaviours related to participation included: communication by means of voicing one’s opinions (Stephens cited in Ansell, 2005:233) and expressing one’s self (Ansell, 2005:234); engagement through making and

contributing to decision that affect self (Ansell, 2005:236) as well as some degree of independence (Hart, 1992:5&6). Behaviours indicative of control include: enthusiasm, independence, self-confidence, assertiveness, acting deliberately and determined (Hersch & Scheibe cited in Lefcourt, 1982:176).

Observation is an essential first step in the data-gathering process because it provides the opportunity to comprehend nonverbal communication; this is of particular importance because AAAs are a nondirective approach (Ritchie, 2003:35). It also illuminates a contextual understanding of the phenomenon being studied, allowing the researcher to view the broader process of AAAs with children hospitalised with cancer (Ritchie, 2003:35). Observation also allowed the researcher to understand the hospital setting, which was fundamental to the research, considering the influence hospitalisation can exert on the child. Insights were gained through this method of data gathering that might otherwise have been overlooked (Strydom, 2011:329).

4.4.1.2. *Interviews*

Following observation, one-on-one unstructured—also referred to as in-depth—interviews were intentionally utilised for the purposes of data collection (Greeff, 2011:342). The post-intervention interviews were aimed at gaining insight into the participants' experience of the AAAs and not of any particular aspect thereof, keeping the age of the participants in mind (See addendum II).

According to Greeff (2011:348) unstructured or in-depth interviews are simply extensions and formalisations of conversations. Smith and Bowers-Brown (2010:121) add that there may be some guidance from the researcher who may also have a vague schedule of issues to attend to. The aims of such interviews are to perceive the world through the eyes of the participants and to glean rich rigorous data that can assist the researcher in comprehending the participants' creations of knowledge and social realities (Maree, 2007:87). Based on these guidelines, the researcher immersed herself in the interview context by suspending any former knowledge and attitudes regarding AAAs, permitting the participant control of emerging information (Greeff, 2011:348) and challenging any lingering preconceptions the researcher may have inadvertently introduced into the interaction (May, 2011:136). The researcher employed several communication techniques during the interview process (Greeff, 2011:345):

- The researcher established a balance between minimal verbal responses and attentiveness to the participant.
- The researcher paraphrased what the participant said by stating it in her own language while retaining the original meaning.
- The researcher sought clarity in instances where she needed to ascertain more clearly what the participant meant.

- When the researcher needed the participant to expand upon a statement, she used the technique of reflection. Reflective summary was also used to determine if the researcher had understood correctly.
- The researcher use probing when she required more information in response to a question. This technique was used to elicit richer and deeper information from the participant.

Beginning the interviews with the open-ended question “*how was it for you?*” provided the children with an opportunity to reflect on the experience of the AAA sessions. Furthermore, it gave the participant a chance to talk about AAAs within his/her own frame of reference and assign meanings to events and relationships (May, 2011:136). This consequence of the study likely had particular relevance for the children themselves, who typically feel disempowered by a diagnosis of cancer eventhough this opportunity could not be maximised.

The interviews with the participants were recorded, provided permission was granted. Greeff (2011:359) and Kelly (2006:298) both suggest that the researcher audio-record the interviews as this fosters more complete, detailed and accurate accounts of the interviews. It also enables the researcher to focus more effectively on the interview rather than on note-taking.

4.4.1.3. *Graphic questionnaires*

Following observation of the AAA sessions and the individual interviews with each child, it was decided that an additional and supplementary form of data collection should be included. The decision to include graphic questionnaires was largely based on a dearth of usable data and verbal information that could be gleaned from the interviews. This was attributed to the temperament of many of the participants, most of the children were shy and reserved, as was observed during the AAA sessions. Moreover, for many of the children, English was not their first language and, despite them being competent in it, this factor proved to be an obstacle. The situation was compounded by the researcher’s inexperience in conducting one-on-one interviews. According to Booth and Booth (1996:67), “researchers should attend more to their deficiencies than to the limitations of their informants”.

The graphic questionnaires utilised for data collection were premised on research conducted by Rabiee, Sloper and Beresford (2005:385), who show how the views of children who do not utilise speech can be accessed during research. The fundamental aim of the research conducted by Rabiee *et al.*, is the participation of children, which therefore requires the development of communication methods that can augment children’s capacity to express themselves (Rabiee *et al.*, 2005:388). The graphic questionnaires were also developed based on the notion of Talking Mats® (Murphy, 1998), which is a visual framework utilising symbols to assist individuals with communicative problems to communicate. According to a study piloted by Murphy and Cameron (2008:232) into the

effectiveness of Talking Mats®, the quantity and quality in communication of those individuals who experience difficulty in expressing themselves can be greatly improved when using Talking Mats® concluding that this is an effective communication method . Some of the images utilised in the graphic questionnaires were also based on ‘the image vocabulary’ (Triangle/ NSPCC, 2001) an established communication tool used to support children in communicating complex issues. These images are componets of a larger project by the NSPCC which aimed to expand self-expression for children with communication difficulties using a range of relevant images (Triangle/ NSPCC, 2001). The graphic questionnaire is attached as addendum III.

4.4.1.4. *Field Notes*

Bogdan and Biklen (2003:110-111) define field notes as “the written account of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study”. They are either descriptive or reflective in nature and are compiled after each data collection session. Field notes can assume four possible roles (Bogdan & Biklen, 2003:115), all of which were relevant to this study:

- **Methodological role**

This provided an opportunity for the researcher to reflect on the procedures and strategies that were utilised in the research process. If the researcher experienced any challenges, she could reflect on these at this point.
- **Professional role**

Field notes allowed the researcher to reflect on her professional role, in the face of any ethical dilemmas she may have encountered.
- **Personal role**

The researcher reflected on her own manner of thinking. Although she endeavoured to suspend preconceived notions before entering the research field, it was impossible to separate herself entirely. Field notes allowed her to reflect on encounters that challenged her beliefs, assumptions and preconceptions.
- **Analytical role**

The researcher reflected on any themes that were beginning to emerge and connections between the data.

4.4.2. Process of data collection

A test study was conducted, as this allowed the researcher to face some of the practicalities of the research process. The test study involved a literature review that made the research more meaningful because the researcher was familiar with existing knowledge on the field of AAAs. The literature

review also revealed similar, previously conducted studies and therefore provided the researcher with invaluable information regarding the suitability of participants, the procedures and the possible challenges she could face (Strydom, 2011:237). The researcher incorporated the experience of experts in the field of AAAs into the test study by consulting them during her research. She also discussed the data-collection process with peers and supervisors (Strydom, 2011:238). The observation schedule was then adapted where necessary.

Imperative to the proposed study was the concept of mediators. Fouché and Schurink (2011:325) explain that a mediator is an individual with authority, formal or informal, who can grant the research access to the relevant research contexts and participants. Based on this, two key mediators—namely, the hospital itself and the selected AAA organisation—were identified. Approval and access was sought from both. The researcher therefore needed to provide the necessary organisations with a detailed proposal of the study outlining its aims and the manner in which it would be conducted, as well as the envisaged function of the results (Fouché & Schurink, 2011:325).

Once approval and access had been granted, the researcher identified those children who met the criteria for inclusion, provided them and their parents with detailed information about the study, and established whether they were willing to participate. After obtaining written informed consent from the agreeable parents and assent from the children themselves, the data-gathering processes began.

4.5. Data analysis

The researcher utilised the steps proposed by Tesch (1990:142-145) for “developing an organising system for unstructured qualitative data” as a framework for the data-analysis process.

- The researcher began by carefully reading through all the observation notes, interview transcripts, graphic questionnaires and field notes, sometimes several times, attempting to get a sense of the whole. She made informal notes about the data.
- The researcher then identified transitions from one topic to the next based on an exploration of what was indicated from graphic questionnaires distinguishing between content and topic. The research question was used to reduce the data step-by-step in order to systematically exclude all irrelevant data and to include only data that was relevant thereto. Behaviours indicative of participation and control were identified from the observation and field notes and broad topics relating to these two aspects were identified and noted.
- Following this, the researcher compiled a list of all the topics, looking for similarities between them. Similar topics were then arranged into groups by forming columns labelled: major topics, unique topics and leftovers.
- The topics were abbreviated as codes. The researcher then returned to the original data and wrote the codes next to the appropriate segment of text.

- Refinement to the organisation of the data took place by finding the most descriptive wording for the topics. These were then converted into categories. The aim was to reduce the total list of categories by grouping topics together that related to one another. Lines drawn between the categories indicated interrelationships of categories.
- The researcher then made a final decision on the abbreviation of each category name and alphabetised the codes. The researcher began the first complete coding session on all of the interview transcripts.
- Analysis took place by looking at the collection of material in one category at a time. At this stage in the data-analysis process, focusing on content was imperative. The researcher identified and summarised the content for each category.
- Lastly, recoding of the data was done where necessary. (Tesch, 1990:142-145).

4.6. Ethical aspects

The principles guiding ethical research were formalised in the Declaration of Helsinki (World Medical Association, 1964) and include the following: informed consent and voluntary participation; confidentiality and anonymity; and avoidance of harm. The proposed study was guided by these principles.

Informed consent and voluntary participation

The proposed study was designed to fall under the research project of the Centre for Child, Youth and Family Studies, a trans-disciplinary approach that has been registered with the Research Ethical Committee of North West University (ethics number: NWU-00082-12-A1). This project aims to develop sustainable support to enhance quality of life and well-being for children, youth and families in South Africa. The researcher was therefore required to obtain ethical approval from the relevant university authorities. Following this, she also needed to attain approval and permission from both the AAA organisation and the hospital, by providing them with a research proposal detailing the research process. The relevant hospital is an academic hospital and thus the researcher was required to obtain ethical approval from the Health Research Committee of the University of Stellenbosch (ethics number: S13/08145) as well as the hospital manager. Written informed consent from those children wanting to participate in the study was required (see addendum IV). The researcher therefore had the responsibility of providing all the necessary parties with a full and meaningful explanation of the research, including:

- The purpose and nature of the research;
- How the research would be disseminated;
- What was expected of the participants;

- The extent of confidentiality, including how confidentiality would be maintained and any exceptions thereof;
- The potential risks and benefits; and
- Other finer details such as the requirement to audio-record (Brinkmann & Kvale, 2008:266; Health Professions Act 56 of 1974; Strydom, 2011:115-117; Wassenaar, 2006:72).

It was also made evident to the participants that voluntary participation means they have the right to refuse to participate in the research and to withdraw at any time during the research process without any consequences (Strydom, 2011: 117).

Confidentiality and anonymity

The confidentiality of participants was ensured, with the effect that the researcher, despite being able to identify participants, refrained from revealing this information (Babbie, 2011:71). The researcher additionally took the following steps in order to maintain confidentiality:

- The personal details of the participants were not disclosed.
- Recordings were stored in numerical code.
- Anonymisation of data was used for removing identifying information and pseudonyms were used to disguise real names.
- Data was stored at the North-West University with restricted access and lock-up capability and was therefore secure.
- Electronic data was kept in a secure server environment and encrypted.
- Secure destruction of all personally identifiable or confidential information was undertaken as soon as possible (Toronto Academic Health Science Network Research Ethics Committee, 2013).

Avoidance of harm

Bearing in mind that the researcher was guided by the scope of practice for Registered Counsellors and the Health Professions Act (56 of 1974), she was required to assume all the essential steps of this practice in order to avoid harm. These included the following:

- Debriefing the participants after the research process if necessary (Strydom, 2011:122);
- Displaying honesty towards the participants in order to establish a trusting relationship (Punch, 2006:56); and
- Refraining from deceiving participants (Strydom, 2011:118-119).

4.7. Trustworthiness

Trustworthiness can be described as the degree of confidence that qualitative researchers have in their data (Pollit & Beck, 2008:768). It is therefore concerned with assuring the quality of qualitative research (Schurink, Fouché & De Vos, 2011:419). Trustworthiness is premised upon four epistemological edicts, namely: truth value, applicability, consistency and neutrality (Botma, Greeff, Mulaudzi & Wright, 2009:232). There are certain strategies and criteria that have been proposed as means to ensure that these epistemological edicts are met (Klopper, 2008:69-70).

4.7.1. Truth value – Credibility

Truth value is related to the extent to which the researcher has established confidence in the truth of the findings (Botma *et al.*, 2009:233). A correlation needs to exist between the originally constructed multiple realities of the participants and those realities, or reconstructions, which have been ascribed to the participants by the researcher (Babbie & Mouton, 2001:277; Lincoln & Guba, 1985:296). As such the researcher utilised the strategy of credibility, based on the following criteria, to ensure the truth value of the proposed study (Klopper, 2008:70):

- Prolonged engagement which involved persistent observation and investment of time by spending many hours in the pediatric oncology ward at the hospital. This time was often spent in the waiting area, allowing the researcher to become familiar with staff, patients and hospital procedures;
- Comprehensive, quality recordings of all information;
- The reflexivity of the researcher not only as prescribed by the methodology, but also continuously, during all stages of the study; and
- Peer examination, which was done extensively by the supervisor and co-supervisor of the study.

4.7.2. Applicability – Transferability

Applicability refers to how the findings from the study pertain to other contexts or other respondents (Babbie & Mouton, 2001:277; Lincoln & Guba, 1985:296-299). The researcher employed the strategy of transferability as a means to confirm applicability. This was achieved through the following criteria (Klopper, 2008:70):

- Participants who fulfilled all criteria for the study were selected.
- Data saturation was vigorously pursued, and various measures were put in place that contributed to this pursuit, including establishing a strong working relationship with the

academic hospital where the children were being treated in order to recruit enough participants; adapting the interview structure to overcome aforementioned challenges regarding language barriers and temperament and utilising different techniques, i.e. interviews, graphic questionnaires and field notes to gather rich descriptions of the participants' experiences.

- Thick descriptions were stimulated by using communication skills suggested by Greeff (2011:345).
- Information was contextualised when reporting on this study.
- Triangulation by using data from various sources (multiple participants and multiple data collection methods) as a means to substantiate the research in question (Schurink *et al.*, 2011:420).

4.7.3. Consistency – Dependability

Consistency implies that findings are stable over time; therefore the research should be consistent if repeated in the future, with comparable participants in a similar context (Botma, *et al.*, 2009:233). Consistency relies on the strategy of dependability and was attained through the use of the following criteria (Klopper, 2008:70):

- A clear, dependable trail of the ways and means in which the data was collected in order to ensure that it can be replicated;
- Thick and dense descriptions of the methodology;
- Triangulation of data, which is described by Babbie & Mouton (2001:277) as the collection of multifarious information from different participants through diverse means, was performed by comparing the data from the graphic questionnaires, observations and field notes; and
- Peer examination of the study, and co-coding of the data by the supervisor and co-supervisor of the study.

4.7.4. Neutrality – Confirmability

Neutrality refers to the degree to which the findings can be corroborated or confirmed by other individuals (Trochim, 2006) and the degree to which the findings are neutral and not a result of the biases of the researcher (Babbie & Mouton, 2001:278). As such, the researcher utilised the strategy of confirmability as a means to achieve neutrality. The following criteria were present in the proposed study (Klopper, 2008:70):

- Audit and audit trail;
- Triangulation; and

- Reflexivity.

5. CHOICE AND STRUCTURE OF RESEARCH ARTICLE

The dissertation follows the article format as prescribed by the North-West University and consists of the following:

SECTION A	
Part I	Orientation to the research (Harvard referencing style)
Part II	Literature review (Harvard referencing style)
SECTION B	Article: Participation and control experienced during animal-assisted activities by children hospitalised with cancer (Harvard referencing style)
SECTION C	Summary, evaluation, conclusions and recommendations
SECTION D	Addenda

Three possible journals for submission: Integrative Cancer Therapies, Supportive Care in Cancer Journal, South African Journal of Psychology.

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SECTION A: BACKGROUND TO THE STUDY

PART II: LITERATURE REVIEW

1. INTRODUCTION

There has been a proliferation of research establishing the multifarious benefits of animal-assisted interventions, an umbrella term used to refer to both animal-assisted therapy and animal-assisted activities (Jenkins *et al.*, 2013:25; Kruger & Serpell, 2010:36). Prominent physical benefits include a decrease in blood pressure, heart rate and cortisol levels (Odendaal, 2000:277-279), all common adverse effects of hospitalisation (Katcher *et al.* cited in Jalongo *et al.*, 2004:9; Wu *et al.*, 2002:354&361). AAIs additionally have psychosocial and emotional benefits (Jalongo *et al.*, 2004:12). Especially for hospitalised children, AAIs have reportedly resulted in a more positive affect, greater feelings of happiness (Budge *et al.*, 1998:229; Kaminski *et al.*, 2002:327; Sobo *et al.*, 2006:56) and a reduction of depression, loneliness and anxiety (Brodie & Biley, 1999:334; Budge *et al.*, 1998:229; Hart, 2010:64&68; Smith, 2012:439-440). While a significant proportion of the hospital experience is focused on addressing physical needs, AAIs can assist in addressing the psychosocial and emotional aspects of the individual. This may be achieved by providing the patient with the opportunity to actively participate in the decision-making process regarding their health and well-being (Johnson *et al.*, 2003:56).

Despite the increase in research focusing on the benefits of AAIs, there has been limited research into animal-assisted activities among cancer patients (Moorhouse, 2009:26). Of this limited research, few studies have explored how AAAs may address the psychosocial and emotional challenges associated with children hospitalised with cancer, particularly involving issues of participation and control. Dixon-Woods *et al.* (2005:17) report that much of the research on paediatric cancer is grounded in developmental understandings of childhood. Children are therefore conceptualised as being in the process of becoming adults and not as individuals in their own right. As such, this research tends to lack children's own voices and accounts, relying instead on proxy accounts.

2. CHILDREN HOSPITALISED WITH CANCER

Cancer can affect all aspects of the child's life including the physical, emotional and psychosocial aspects. Cancer itself can be physically painful: pain is often reported as one of the most prevalent features in paediatric oncology (Enskar & Von Essen, 2008:37; Hedstrom *et al.*, 2003:120; Van Cleve

et al., 2012:116). Many children fear pain as early as the initial time of diagnosis (Ljungman *et al.*, 2000:212). However, physical pain as the result of treatment is reported to be of greater concern (Hedstrom *et al.*, 2003:124; Ljungman *et al.*, 2000:211). Treatment of cancer can include chemotherapy, surgery, radiotherapy, and bone-marrow transplantation, alone or in combination (Li *et al.*, 2010:48; The Children's Oncology Group, 2011:51-58). A study conducted by Oberholzer *et al.*, (2011:7-8) also determined that children with cancer have various internal mind and body requirements such as the need to be supported with regard to disturbed sleep, eating problems attributed to nausea, and physical pain as the result of treatment. It is common for children to realise their bodies are unhealthy and perceive them as vessels of pathology (American Cancer Society, 2013). This realisation can cause a shift in the way the child perceives and thinks about himself/herself, as well as in his/her interaction with the environment, and can exert an influence on the child's self-concept (Hymovich, 1995:51). According to Oberholzer *et al.* (2011:1) this shift elicits in the child the need to exert some control over the situation so as to feel less like a victim and reduce the experience of negative emotions. Many studies support this notion of uncontrollability including Last and Grootenhuis (1998:171-175), who state that "being confronted with cancer means being confronted with uncontrollability, which easily evokes feelings of helplessness". This experience of uncontrollability may also elicit feelings of anxiety, fear and depression. Woodgate (2008:233-234) adds that, besides a lack of control, children appraise cancer as threatening and numbing. Johnson *et al.*, (2003: 56) show that the participation, autonomy and empowerment of these children may be compromised, affecting their overall quality of life, and eliciting feelings of loss-of-control, disempowerment and disconnection from their bodies. Results from a study conducted by Hedstrom *et al.* (2003:124) suggest that confinement, alienation and worry, before medical procedures, are the emotional aspects that trouble children most. The most frequently mentioned aspect of emotional distress for children aged eight to 12 years was worry about death. This was supported by the findings of Li *et al.* (2010:50-52), in which children treated for cancer expressed feelings of sadness, anxiety, worry about death, loss of self-control and uncertainty.

It is therefore clear that cancer is not only challenging on a physical level but also associated with a fundamental alteration from former normal states and everyday life (Bjork *et al.*, 2005:269; Epstein *et al.*, 2004:3). The adjustment of children to their diagnosis of cancer can be strongly influenced by those around them, particularly the family (Patterson *et al.*, 2003:391; Robinson *et al.*, 2007:400). As social-ecologic powerlessness theories propose, an individual's well-being is dependent on, among other elements, the social systems around them (Bronfenbrenner, 1979:97). The implications of cancer affect the child's familial relationships and the family as a whole (Bjork *et al.*, 2005:265; Hymovich, 1995:51), and parental or familial distress has been found to be positively related to distress in children (Robinson *et al.*, 2007:401). Family members, including the child, often experience feelings of loss of control and powerlessness related to their inability to change the situation they are in (Bjork *et al.*, 2005:269-270). In a study conducted by Li *et al.* (2010:52), it was

established that cancer treatment negatively affects children’s psychosocial well-being, with children reporting feeling confined, estranged and concerned about changes in their physical appearance. In addition to this, treatment may require that the child be hospitalised for extensive periods of time, which can involve separation from family and removal from the security of the home environment (Kurz, 1987:290). Reed *et al.* (2003:72) mention that, due to both a lack of understanding and exclusion from decision-making, all children admitted to hospital could experience disempowerment and loss of control.

3. SUPPORTIVE TREATMENTS

Fawzy, Fawzy, Arndt & Pasnau (1995:100) note that, as a result of the rise in cancer-survival rates, there has been an increased focus on supportive interventions that assist cancer patients with both diagnosis and the ensuing treatment. Relatedly, Hughes, Ladas, Rooney and Kelly (2008:431) mention that, because children diagnosed with cancer have to cope with a variety of stressors, there is greater recognition of the need for supportive interventions to improve overall quality of life. The table below is a summary of some of the various supportive interventions available to children with cancer. A caveat regarding the table below is that, while comprehensive, it is not exhaustive.

		Traditional	Non-traditional
Physical	Primary (cancer itself)	<ul style="list-style-type: none"> - Chemotherapy - Adjuvant chemotherapy - Surgery - Radiotherapy - Novel drugs 	<ul style="list-style-type: none"> - CAM: <ul style="list-style-type: none"> • Natural products • Mind-body interventions: <ul style="list-style-type: none"> ▪ hypnotherapy ▪ yoga

	Secondary (side effects from treatment)	<ul style="list-style-type: none"> - Pharmacology: anaesthetics, nausea- reducing drugs and antibiotics - Behaviour therapeutic techniques 	<ul style="list-style-type: none"> ▪ meditation • Manipulative and body- based practices - CAM: <ul style="list-style-type: none"> • Natural products • Mind-body interventions • Manipulative and body- based practices • Expressive and creative psychosocial interventions <ul style="list-style-type: none"> ▪ Fantasy ▪ Art therapies - AAA & AAT
Psychosocial Emotional		<ul style="list-style-type: none"> - Psychosocial intervention model - Individual therapy - Group therapy 	<ul style="list-style-type: none"> - CAM: <ul style="list-style-type: none"> • Mind-body interventions • Manipulative and body- based practices • Expressive and creative psychosocial interventions <ul style="list-style-type: none"> ▪ Fantasy ▪ Art therapies - AAA & AAT

Table 1. *Supportive intervention available to children with cancer*

3.1 Traditional – Physical – Primary

The cancers encountered in children are differentiated from those that occur in adults based on the fact that they tend to manifest in the tissues and organs that propagate most quickly during embryogenesis and the postnatal period. As such, the majority of cancers in children cannot be prevented, are not presaged by overt pre-malignant lesions and are not susceptible to early diagnosis (Izraeli & Rechavi, 2012:3). The most common childhood cancers involve the lymphoid system, particularly acute lymphoblastic leukaemia; the nervous system; and disparate tumours of the

musculoskeletal and soft tissues (Izraeli & Rechavi, 2012:3-4). Traditional treatment of the aforementioned types of cancer includes chemotherapy, adjuvant chemotherapy, surgery and radiotherapy. Moreover, remarkable technological, biological and diagnostic progress in the field of oncology has meant the introduction of new, targeted therapies for children with cancer and the possibility of treatment being personalised (Izraeli & Rechavi, 2012:5).

3.2 Traditional – Physical – Secondary

3.2.1 Pharmacology

A range of analgesic and sedating medications are available as a means to reduce pain, anxiety, nausea and vomiting, among other side effects of cancer treatment. One of the most common side effects of chemotherapy is neutropenia. A child with neutropenia is susceptible to potentially life-threatening infections. As such, antibiotics and antifungals can be administered to prevent such infections (National Collaborating Centre for Cancer, 2005:52-53).

3.2.2 Behaviour therapeutic techniques

The learning principles of the behavioural approach have proved valuable to the child with cancer in their addressing of treatment-induced anxiety and pain (Last & Grootenhuis, 2012:97). The primary techniques that are utilised can include pre-exposure, positive reinforcement, relaxation and breathing exercises, modelling, systematic desensitisation and guided imagery. Pre-exposure can be utilised as a method of preparation and involves exposing the child to possible anxiety-provoking stimuli while the child is calm and relaxed. For example, the child can be shown the room where treatment will occur (Last & Grootenhuis, 2012:97). Positive reinforcement by parents, primary caregivers or medical staff can encourage cooperation on the part of the child. One such method of positive reinforcement is to provide material reinforcers to the child following treatment. Relaxation and breathing exercises are helpful in calming the sympathetic and motor-nervous system in stressful situations. Modelling is often achieved through modelling videos that impart information to the child regarding medical procedures. These videos can also teach the child various relaxation or distraction techniques that help the child remain in control during medical procedures (Last & Grootenhuis, 2012:98). Systematic desensitisation is premised on the notion that the child will gradually be exposed to a hierarchy of increasing anxiety-inducing stimuli while simultaneously undergoing relaxation. In this way the child's level of anxiety can be reduced and therefore helps with avoidant behaviours (Last & Grootenhuis, 2012:98). Lastly, guided imagery involves distracting the child's attention away from the painful medical procedure by means of a fantasy story. This technique is particularly useful for those children who are sensitive to suggestions (Last & Grootenhuis, 2012:98). In practice these behavioural techniques are generally used in combination with one another as opposed to in isolation.

3.3 Traditional – Psychosocial and emotional

The increased survival rates of childhood cancer, due to profound advances in the field of pediatric oncology, have resulted in a greater requirement to focus on the psychological aspects of cancer, particularly the psychosocial aspects (Anholt, Fritz & Keener, 1993:2; Artherholt & Fann, 2011:23; Kazak, Rourke, Alderfer, Pai, Reilly & Meadows, 2007:1099). One of the difficulties in providing psychosocial interventions involves a lack of standardisation, with great variability between and even within institutions (Kazak *et al.*, 2007:1099; Mechnert & Koch, 2005:579).

Additionally, a critical debate exists in the literature regarding the psychosocial impact that cancer can exert on children and their families. Some researchers contend that a cancer diagnosis can exert negative psychosocial effects on both the child who has been diagnosed and the child's family (Holland, 2003:260; Hughes *et al.*, 2008:431; Seitz, Besier & Goldbeck, 2008:683; Telch & Telch, 1986:802). This goes against the position of other researchers, such as Kazak *et al.* (2007:1100), Anholt *et al.* (1993:1) and Last and Grootenhuis (1998:169), who assert that recent research conducted on the psychosocial needs of children with cancer, as well as their families, has tended to sunder the notion that these children and their families have a propensity for psychopathology or other adverse psychosocial effects. It is important to consider, however, that the results from these latter studies may possibly be attributed to the inappropriateness of the instruments used (Last & Grootenhuis, 1998:169). The variability in results upon which this debate is premised could also be due to a lack of standardisation. Nevertheless, Kazak *et al.* (2007:1099) believe that the competence-grounded reconceptualisation of responses to cancer implores a corresponding adaptation in the interventions provided. They also mention that, while some children and families display resilience, others may be at greater risk for developing maladaptive psychosocial effects. As a result, they propose an intervention model that fosters the existing competencies in children and families who do not display potential risks, while identifying those children and families who may be at greater risk and providing appropriate psychosocial interventions based on their needs (Kazak *et al.*, 2007:1100). This thinking is in line with Last and Grootenhuis (2012:98), who propose that the psychosocial intervention model be initiated if control deteriorates and the child and/or family consequently require support in reconstructing their defences or diminishing/eradicating unpleasant behavioural responses.

Previous literature reviews indicate that psychosocial interventions can assist cancer patients, *inter alia*, in some of the following ways: an increase in knowledge about cancer and treatment that helps clarify any misconceptions; an improvement in emotional adjustment by reducing feelings of alienation, isolation, helplessness and hopelessness; an increase in quality of life and coping abilities, as well as contentment with care, through talking to others in a similar situation (Newell, Sanson-Fisher & Savolainen, 2002:558; Holland cited in Fawzy *et al.*, 2005:100). Traditional psychosocial interventions may include the following: education, the aforementioned behavioural techniques, individual psychotherapy and group interventions (Fawzy *et al.*, 2005:100).

3.3.1 Education

The broad aim of education for individuals diagnosed with cancer is a reduction in feelings of helplessness and incapacity that come as a result of confusion and lack of knowledge. Education aims to supplant helplessness with feelings of mastery and control. It can include specialised information regarding diagnosis and treatment as well as information about emotional issues associated with cancer and about ways of coping (Fawzy *et al.*, 1995:100-101). This educational approach is in line with a study conducted by Hymovich (1995:56), who asserts that one of the most integral interventions available to children with cancer should be the provision of developmentally appropriate information, because this facilitates the child's understanding and coping. Hymovich (1995:56) also notes that children often derive their meaning of cancer from the response of significant others, and that education and information-provision should therefore extend to parents, siblings and peers.

3.3.2 Individual psychotherapy

Individual psychotherapy can be utilised to ameliorate the anguish and disturbance that accompanies a diagnosis of cancer. Individual psychotherapy is premised on support, compassion and empathy (Fawzy *et al.*, 1995:104).

3.3.3 Group interventions

Other common names for group interventions include support groups, group therapy and group psychotherapy, among others (American Cancer Society, 2013). Support groups can be described as therapy groups that provide a safe space in which members can share their experiences of cancer as well as experience a sense of communion and mutuality with other members. Moreover, support groups provide information regarding both the diagnosis and the treatment of cancer. When the group consists of children, the information must be adjusted so as to be applicable and understandable to the children. The group also provides support, teaches coping skills and assists in reducing anxiety (American Cancer Society, 2013). Preliminary research has indicated that support groups can be beneficial in improving quality of life in patients with cancer, although this finding is still tentative (American Cancer Society, 2013). With specific reference to children with cancer, it is imperative to acknowledge that the degree of social support available to the child from parents, siblings and friends may assist them in dealing with cancer (Woodgate, 1999:201).

3.4 Non-traditional – Physical, psychosocial and emotional

3.4.1 Complementary and alternative medicine

Research has indicated that the implementation of complementary and alternative medicine (CAM) is frequent among adults and children for preventing cancer, curtailing cancer advancement and

ameliorating the symptoms and side effects of cancer treatment (Evans, Cousins & Zeltzer, 2012:135). CAM can be categorised as “a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine” (National Centre for Complementary and Alternative Medicine, 2014). However, it must be stressed that what falls into the category of CAM is often in flux; therapies that, over time, prove safe and effective become amalgamated into conventional medicine (Evans *et al.*, 2014:135). CAM therapies can be grouped into four comprehensive types which include natural products, mind-body medicine, manipulative and body-based practices, and other CAM practices (National Centre for Complementary and Alternative Medicine, 2014).

3.4.2 Expressive and creative psychosocial interventions

Expressive and creative psychosocial interventions can include, *inter alia*, fantasy involvement and various art therapies. During fantasy the child is asked to imagine some kind of experience, object, event or situation. It is possible to engage all of the child’s senses and not focus solely on visual sensations (Kreitler, Oppenheim & Segev-Shoham, 2012:143). The primary aims of guided imagery and fantasy are decreasing anxiety, encouraging positive emotions and sometimes “fighting cancer (i.e. promoting healing)” (Kreitler *et al.*, 2012:144).

The three pillars of art therapies are the therapist, the patient and the image, with the art therapist often fulfilling three roles: artist, teacher and therapist (Kreitler *et al.*, 2012:145). Three dimensions comprise art therapies. The first is the expressive-creative dimension, which is premised on the relationship between the patient and the image. The therapist functions as a facilitator in this dimension. The next dimension is that of the cognitive-symbolic, which is based on the relationship between the therapist and the patient “through and about the produced image” (Kreitler *et al.*, 2012:145). In this dimension, the therapist assists the patient in understanding the image that he/she has produced. The final dimension is the interactive-analytic dimension, which is premised on the candid communication between therapist and patient. Here the therapist assists the patient, through communicating with him/her, in gaining a greater understanding of self (Kreitler *et al.*, 2012:145).

3.4.3 Animal-assisted interventions

Based on the growing interest in animal-assisted interventions (AAIs), studies have been done to establish the beneficial nature of various kinds of AAIs, an umbrella term used to refer to different kinds of interventions that utilise animals (Jenkins *et al.*, 2013:25; Kruger & Serpell, 2010:36). A very definite distinction is made in the literature between animal-assisted activities and animal-assisted therapy (Friesen, 2010:264; Kogan *et al.*, 1999:106; Nimer & Lundahl, 2007:225; Odendaal, 1999:53). For the purpose of this study, Pet Partners’ (formerly known as the Delta Society) definitions will be employed:

“Animal-assisted activity (AAA) provides opportunities for motivational, educational, recreational and/or therapeutic benefits to enhance quality of life. AAAs are delivered in a variety of environments by specially trained professionals, paraprofessionals and/or volunteers, in association with animals that meet specific criteria.” (Pet Partners, 2012)

AAAs are casual, support-based encounters involving activities that are applicable to a wide range of individuals and contexts. In AAA, animals, usually dogs (although other small pets can be used), are behaviourally assessed as a prerequisite to their interacting with ill and even bedridden patients (Arkow *et al.* cited in Abbate, 2010:14). AAA is usually provided to inpatients on a weekly basis, although the nature of AAA dictates that the visits are generally unplanned and unstructured. Typically, during these sessions, a volunteer, usually the owner and/or handler of the dog/small animal, accompanies the animal into the ward and invites interested patients to interact with the animal, either individually or in groups (Abbate, 2010:28&35). The content, duration and nature of the sessions are directed by the child, as the volunteer/handler retreats into the background and allows for spontaneous interaction (Fine, O’Callaghan, Chandler *et al.*, 2010:195-196). It is, however, acceptable practice for the volunteer to initiate contact with the child by speaking “on behalf of” the dog, whispering in the dog’s ear, instructing the dog to perform tricks such as greeting or “talking” (barking), having the dog play with a ball or even reading a storybook to the dog (Fine, O’Callaghan, Schaffer *et al.*, 2010:203-204). These actions do not constitute therapeutic goals, though, as they do in the case of AAT. Rather, they serve to enhance comfort and rapport, as well as trust in the process of AAA and in the animal itself (Fine, O’Callaghan, Schaffer *et al.*, 2010:199).

Besides the well-documented physical benefits of AAIs, such as a decrease in blood pressure, heart rate and cortisol levels (Odendaal, 2000:277-279), which are all commonly associated with stress due to hospitalisation (Katcher *et al.* cited in Jalongo *et al.*, 2004:9; Wu *et al.*, 2002:354&361), AAIs have additional psychosocial and emotional benefits (Jalongo *et al.*, 2004:12). According to Hart (2010:65), animals may fulfil a substitutive role for human social support, and strong attachment bonds can develop between humans and animals that are comparable to the bonds that develop between family and friends (Gerstman cited in Brodie & Biley, 1999:332). Additionally animals may function to enhance social interactions, facilitate conversations and extend one’s social network (Cole, 2009:29; Hunt *et al.*, 2001:245).

Specifically for children who have been hospitalised, the reported psychological and emotional benefits of AAI include a more positive affect and greater feelings of happiness (Budge *et al.*, 1998:229; Kaminski *et al.*, 2002:327; Sobo *et al.*, 2006:56). Significant research findings (i.e. Brodie & Biley, 1999:334; Budge *et al.*, 1998:229; Hart, 2010:64 & 68; Smith, 2012:439-440) report that interactions with animals can lead to the alleviation of depression, loneliness, anxiety and distress. Further psychological benefits that may derive from AAIs include the possibility of the

patient actively engaging in his or her own health, and fulfilling the need to be contacted as a whole person (Johnson *et al.*, 2003:56). Whereas much of the hospital experience is focused on addressing physical needs, AAI can assist in addressing the psychosocial and emotional aspects of the individual. AAI may also provide patients with the opportunity to become equal and active partners in the process of their health and well-being as opposed to passive individuals to whom something is done (Johnson *et al.*, 2003:56). This partnership is achieved by providing the patient with an opportunity to participate in decisions regarding his/her health and well-being, which in turn contributes to a sense of control. This is in congruence with Davis (cited in Wu *et al.*, 2002:355), who notes that AAI help to strengthen the hospitalised child's self-concept, which is often enervated due to constant engagement with authority figures. This can be linked to Erikson's stages of development (1968), according to which the child's sense of control and autonomy may be reinforced with the accomplishment of certain tasks (Abbate, 2010:3-4).

There have been an increasing number of research publications on the benefits of AAI over the past four decades and, while some of this research has focused on child-specific AAI in a hospital context, there is limited research on animal-assisted activities among cancer patients (Moorhouse, 2009:26). Of this limited research, few studies have explored how AAI may address the psychosocial and emotional challenges experienced by children hospitalised with cancer, particularly surrounding issues of participation and control. This research gap is confounded by the fact that most research on childhood has its roots in developmental understandings of childhood, which is then extended to research on paediatric cancer. The implications of this extension are that children are conceptualised as "becoming adults" and, in much of the research, are often not provided with a voice. Rather, a significant proportion of research on childhood cancer is derived from proxy accounts, from parental and medical staff reports, and not from the children themselves (Dixon-Woods *et al.*, 2005:17). Dixon-Woods *et al.* (2005:17) also note that most of the research on childhood cancer is quantitative and psychological in nature, and has been conducted in isolation, separate from other disciplines, and that it therefore fails to consider a variety of research strategies and theoretical paradigms. The proposed study will seek to address these aforementioned gaps in the research by assuming a qualitative phenomenological approach that explores and describes AAI related to participation and control from the children's own perspectives. This approach may in fact be a more appropriate research design for studying AAI, as it has been suggested that traditional research designs may not sufficiently capture results from AAI (Voelker, 1995:1898). Odendaal (1999:72) states that "the positivistic approach that only things that can be measured convince, or even worse exist, may be the wrong one in this field".

4. PARTICIPATION AND CONTROL IN THE CHILD HOSPITALISED WITH CANCER

Internationally there has been a growing acceptance and recognition of children's rights to participate and be heard as well as of their ability to contribute to society in valuable ways (Alderson, 2007:2276; Coyne, 2006:61; Coyne & Gallagher, 2011:2334; Coyne & Kirwan, 2012:293; Gibson, Richardson, Hey, Horstman & O'Leary, 2005:4). This is evidenced in the United Nation's Convention on the Rights of the Child (1989), which stipulates the importance of a child's right to participate and engage in the world in which they are embedded and have a voice in more formal decision-making processes (Stephens in Ansell, 2005:233). It is important to note, though, that the United Nation's Convention on the Rights of the Child (1989) does not provide children with complete autonomy or control in all decisions that affect their lives. It does, however, present a fundamental contestation to traditional approaches, which assume that children should be seen and not heard (Lansdown, 2001:2). This growing recognition of children's participatory rights is also exhibited within the South African context: the Children's Act 38 of 2005 explicitly states in Section 10 that "Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration".

According to Kirby and Woodhead (2003:236) the notion of participation is variegated. Polkki *et al.* (2012:108) maintain that participation can be broadly defined as "interaction, belonging and integration into and influence on society" while child participation specifically denotes the active involvement of children in decisions that affect their own lives, in addition to the lives of their families and communities (Ward, 2008:3). Several authors point out that children's participation is an imperative factor for health and well-being (Coyne & Gallagher, 2011:2335; De Winter *et al.*, 1999:16) and there is a substantial amount of research advocating the numerous benefits of children's participation, particularly in medical decision-making. Such benefits may include: improved dissemination of information, leading to an enhanced comprehension of both the diagnostic and treatment aspects of illness (Coyne, 2006:65; Coyne & Kirwan, 2012:300; Tiffenberg, Wood, Alonso, Tossutti & Vicente, 2000:292); the possibility of expressing one's emotions and developing confidence and competence; greater compliance with medical care (Coyne & Gallagher, 2011:2335; Sloper & Lightfoot, 2008:18); development of a child's sense of self (Hallstrom & Elander, 2004:374); feeling valued and appreciated (Coyne & Gallagher, 2011:2335; Dixon-Woods, Anwar, Young & Brooke, 2002:506); reduced anxiety based on feelings of being prepared (Coyne, 2006:65; Justus, Wyles, Wilson, Rode, Walther & Lim-Sulit, 2006:40-41); reduction of psychosocial problems (De Winter *et al.*, 1999:16); and the increased possibility of fulfilling developmental tasks associated

with childhood (Alderson cited in Hallstrom & Elander, 2004:368; De Winter *et al.*, 1999:17; Runeson, Hallstrom, Elander & Hermeren, 2002:584).

According to Coyne (2006:68), illness can fracture a child's sense of well-being and hospitalisation may impede a child's independence and self-control. Indeed, hospitalised children have reported loss of control and increased dependence as possible sources of stress (Johnson *et al.*, 2003:56; Last & Grootenhuis, 1998:171-175; May & Sparks, 1989:118; Oberholzer *et al.*, 2011:1; Woodgate, 2008:233-234). Important for control acquisition is a paper authored by McCabe (1996:506) that states that children's participation may foster a sense of control, which subsequently may be related to positive adjustment. When individuals feel that they are in control over situations and events, termed an internal locus of control, they are more likely to adopt an active attitude to any difficulties they may encounter. Alternatively, when individuals feel that they have little or no control over situations and events, termed an external locus of control, they tend to demonstrate more passive behaviour in the face of adversity (De Winter *et al.*, 1999:18). This notion is supported by results from a study conducted by Coyne (2006:68) that found that the provision of information made children feel more actively involved in their treatment and consequently assisted them in experiencing greater control. This is consistent with several other authors who maintain that children's sense of control over their own lives is augmented and enhanced when they are involved and participate in the medical decision-making process, (Alderson, 2008:211; Ansell, 2005:225; May & Sparks, 1989:121; Runeson *et al.*, 2002:584; Tiffenberg *et al.*, 2000:281-293).

On this point, however, a debate exists in the literature. Other scholars argue that participation in the decision-making process may at times lead to negative effects in so far as children may feel deserted or stressed as a result of increased responsibility (Alderson, 2007:2277; Deatrick, 1984 cited in Coyne & Gallagher, 2011:2335). Additionally, Coyne and Gallagher (2011:2335) note that there is limited evidence regarding the health and social improvements associated with children's participation. In response to the argument that participation detracts from childhood, Ansell (2005:235) maintains that this argument is very much built on Western notions of the adult versus child distinction. Kirby and Woodhead (2003:236) highlight that the debate pertaining to children's participation all too easily becomes polarised. At the one extreme are those who subscribe to the traditional view that adults should be responsible and in control of making decisions for children, while at the other extreme are the child liberationists (Ansell, 2005:226; Kirby & Woodhead, 2003:236).

Historically, the medical model and an exceedingly paternalistic perception of patients, particularly children, have dominated the field of healthcare, with compliance as opposed to autonomy typically expected of children (Alderson, 2007:2273; Harrison, Kenny, Sidarous & Rowell, 1997:823; Runeson *et al.*, 2002:583). Traditionally, childhood has been associated with cognitive inadequacies, emotional inconsistencies and an inability to communicate articulately (Ansell, 2005:226-227; Dixon-Woods *et al.*, 2005:8-9; Roche, 1999:476). This is in contrast to adulthood,

which traditionally has been concomitant with rationality, maturity and competencies (Ansell, 2005:235). These perceptions, coupled with the conviction that increased participation has negative effects on children, have often been the justification utilised by healthcare professionals for excluding children in the medical decision-making process. Alderson (2007:2277) explicates that attempts to ‘protect’ children from having to decide about treatment and participate in the healthcare process may preserve adult power as much as children’s welfare. In a previous study, Alderson (1993:143) includes the following excerpt from discussions with a healthcare professional:

“But are you going to lay on children the weight of their future? Perhaps let them make a decision that could lead to their death? These are impossible questions, but hospital staff have to find the answers. Am I big enough to say, ‘Whatever you choose will be valued, even if you decide against the tide; okay, you’ve made that decision, I’ll do all I can to support you, and we’ll go forward together?’ It’s such a big step for the adult to surrender power to the child.”

Such rigid thinking proves to be problematic since children can often be sagacious and adults can often be imprudent (Alderson, 2007:2276; Boyden, 2003:15). Additionally, children are often more competent than is expected (Ansell, 2005:235). In fact, several studies underscore children’s abilities to actively participate and negotiate during their interactions with adults (Elbers, 1996:283-285; Tates *et al.*, 2002:291) and comprehend medical issues (Alderson & Montgomery, 1996 cited in Tates *et al.*, 2002:282; Holzheimer, Mohay & Masters, 1998:88).

McCabe (1996:508) postulates that children’s participation in medical decision-making occurs along a continuum encompassing three levels of involvement. The first level provides children with information about their illness, including information pertaining to diagnosis and subsequent treatment. The second level is a collaborative effort involving shared decision-making between children and parents, guardians or caregivers. The third and final level is based on autonomous decision-making. This is similar to the four levels of decision-making proposed by Alderson and Montgomery (1996:66), namely: to be informed, to express an informed opinion, to have that view taken into consideration when decisions are made, and to be the primary decision-maker about proposed interventions, if competent to do so, and potentially subject to supervision of others.

Often, however, there is a fissure between theory and practice, and implementing child participation in the medical decision-making process is often difficult and sometimes problematic (Ansell, 2005:235; Coyne, 2006:62; Coyne & Gallagher, 2011:2335; Dixon-Woods *et al.*, 1999:778; Roche, 1999:478). In general, children are frequently silenced and rendered invisible (Roche, 1999:478). They are conceptualised primarily as passive rather than active participants during the medical decision-making process (Tates & Meeuwesen, 2001:839). Several studies on children’s experiences in the healthcare context report that children of all ages, even older children, were habitually excluded from discussions and given limited autonomy (Carter, 2002:36-37; Dixon-Woods *et al.*, 2002:506; Freemon, Negrete, Davis & Korsch 1971:300; Nova & Vegni, 2005:327; Tates *et al.*,

2002: 291; Van Dulmen, 1998:566-567). Especially relevant to children who are hospitalised, Tates, Meeuwesen, Bensing & Elbers (2002:291) found that child participation is moderately limited within the healthcare context. In a study conducted by Coyne and Gallagher (2011:2340) it was established that, although children had differing experiences of participation, the majority of the children included in the study encountered obstacles to participating in discussions and the decision-making process, which finding agrees with Runeson *et al* (2002:593). Likewise, Coyne and Kirwan (2012:300) established that, although some positive statements about the healthcare professionals were made, many of the children felt that their own voices were impeded. It has been proposed that excluding children from participating in the decision-making process can have potentially negative consequences (Runeson *et al.*, 2002:584).

5. CONCLUSION

In recent decades, there has been a substantial proliferation of literature on the many benefits of animal-assisted interventions and, more specific to the purposes of study, of animal-assisted activities (Moorhouse, 2009:26). Such benefits span the physical, psychosocial and emotional spheres (Budge *et al.*, 1998:229; Hart, 2010:65; Odendaal, 2000:277-279). However, despite this, research on animal-assisted activities with children hospitalised with cancer remains limited, particularly research that explores the notions of participation and control. Children, who are diagnosed, treated and therefore at some point hospitalised with cancer face many challenges. In terms of physical distress, cancer itself can be extremely painful: however, pain that arises as a result of treatment is reported to be a greater concern (Hedstrom *et al.*, 2003:124; Ljungman *et al.*, 2000:211). Psychosocial and emotional challenges are often premised upon a complete change to the child's normal equilibrium and can include separation from family, friends and the school environment (Kurz, 1987:290). Children may also experience anxiety, worry and depression as well as apprehension based on increased dependence (Johnson *et al.*, 2003:56; Last & Grootenhuis, 1998:171-175; Li *et al.*, 2010:52; May & Sparks, 1989:118; Oberholzer *et al.*, 2011:1; Woodgate, 2008:233-234).

Moreover, children who are hospitalised with cancer tend to become disempowered and experience a loss of control. This may be in response to exclusion from the decision-making process and a lack of understanding with regards to their cancer diagnosis (Reed *et al.*, 2003:72). According to Coyne (2006:68), illness can fracture a child's sense of well-being and thus hospitalisation may impinge upon a child's independence and self-control. Traditionally, children have been conceptualised as passive recipients as opposed to active participants during the medical decision-making process and therefore often experience limited autonomy (Dixon-Woods *et al.*, 2002:506; Freemon *et al.*, 1971:300; Nova & Vegni, 2005:327; Strong, 1979:9; Tates & Meeuwesen, 2001:839). There are a variety of both traditional and non-traditional supportive interventions available to children who are diagnosed and treated for cancer, including animal-assisted activities (AAAs).

AAAs offer the possibility of enhancing participation and control-acquisition because they can provide patients with the opportunity to become equal and active partners in the process of their health and well-being as opposed to passive individuals to whom something is done (Johnson *et al.*, 2003:56). This partnership is achieved by providing the patient with an opportunity to participate in decisions regarding their health and well-being, which in turn contributes to a sense of control, participation and overall empowerment.

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SECTION B: ARTICLE - PARTICIPATION AND CONTROL EXPERIENCED DURING ANIMAL-ASSISTED ACTIVITIES BY CHILDREN HOSPITALISED WITH CANCER

ARTICLE	
Title:	Participation and control experienced during animal-assisted activities by children hospitalised with cancer
Aim:	The aim of this article is to identify and discuss the experiences of participation and control during animal-assisted activities by children hospitalised with cancer.
Journal:	<i>Supportive Care in Cancer</i>

PARTICIPATION AND CONTROL EXPERIENCED DURING ANIMAL-ASSISTED ACTIVITIES BY CHILDREN HOSPITALISED WITH CANCER

Monique Vicky Simon, Suzette Weideman, Zahraa McDonald and Cristina Stefan

ABSTRACT

Purpose

Children diagnosed and treated for cancer experience a profound life-transformation as they are confronted with unprecedented physical, psychosocial and emotional challenges. Children's experience of diagnosis and treatment is often accompanied by a lack of participation and reduced control.

Extensive research has been conducted on a variety of supportive interventions. Only a limited amount of research, however, has investigated the potential of animal-assisted activities (AAAs) to afford specialised support for the child hospitalised with cancer. Moreover, of this limited research, few studies explore AAAs in relation to participation and control. The purpose of this study was to explore and describe how participation and control are experienced during animal-assisted activities by children hospitalised with cancer.

Methods

Paediatric oncology patients between the ages of 8 and 14 with any type of cancer were offered the opportunity to participate in the study, which comprised of animal-assisted activities at the facility where patients received their medical care. Five children were included in the final sample. Data were gathered by means of non-participant observations, participant interviews, graphic questionnaires and field notes. Data were then analysed in accordance with steps proposed by Tesch (1990:142-145), which involved coding according to categories and related themes.

Results

Five major themes emerged, including (1) approach to animals, (2) body awareness, (3) level of engagement, (4) level of dependence and (5) communication. Nine sub-themes were derived from data analysis. Under "approach to animals", the sub-themes were (i) taking the lead, (ii) grooming and affection and (iii) laughter and spontaneity. The sub-themes of "body awareness" were (iv) protection of body and (v) comfort. The sub-themes of "level of engagement" were (vi) initiative and (vii) choice. Finally, the sub-themes of "communication" were (viii) verbal communication and (ix) non-verbal communication.

Conclusions

The study provides insight into the participation and control experienced during animal-assisted activities by children hospitalised with cancer. When the initial and final AAA sessions were compared, changes were noted in terms of the children's approaches to the dog, their body awareness, their level of engagement, their level of dependence and their communication. These changes were associated with an enhanced sense of participation and control, aspects that are often reported to be diminished in children who are diagnosed, treated and hospitalised with cancer. AAAs should therefore be considered an effective means of supporting children hospitalised with cancer.

Key words animal-assisted activities; control; cancer; hospitalised children; participation; supportive treatment.

INTRODUCTION

Cancer does not discriminate. Children of all ages, races, genders and socio-economic classes—and their families—are affected by cancer every year (Children’s Oncology Group, 2012). In South Africa, there are between 600 and 700 new cases annually of children diagnosed with malignancies (Stefan & Stones, 2012:605). Survival rates among paediatric cancer patients have improved significantly over the last decade, with cancer now more commonly conceptualised as a chronic illness (Johnson *et al.*, 2003:56).

Despite this improved prognosis, both diagnosis and subsequent treatment remain stressful and hostile experiences, particularly for children (Braun *et al.*, 2009:105; Li *et al.*, 2010:47). They can impinge upon all aspects of a child’s life, including the physical, emotional and psychosocial aspects. Coyne (2006:68) states that illness can fracture a child’s sense of well-being, and that resultant hospitalisation may impede a child’s sense of independence and self-control. Indeed, loss of control and increased dependence have been reported as possible sources of stress among hospitalised children (Johnson *et al.*, 2003:56; Last & Grootenhuis, 1998:171-175; May & Sparks, 1989:118; Woodgate, 2008:233-234). Many studies support the notion of uncontrollability, including Last and Grootenhuis (1998:171-175) who state that “being confronted with cancer means being confronted with uncontrollability, which easily evokes feelings of helplessness”. Johnson *et al.*, (2003:56) show that the participation, autonomy and empowerment of these children may be compromised by cancer, affecting their overall quality of life and eliciting experiences of loss of control, disempowerment and disconnection from their bodies. Participation encourages children to cultivate their own plans for transformation and can be empowering for children, in addition to augmenting their sense of control and autonomy over their own lives (Ansell, 2005:235, 255; Hart, 1992:16).

Although contemporary research affirms the benefits of children’s participation in the medical decision-making process (Tates & Meeuwesen, 2001:848; Young *et al.*, 2003:1; Coyne, *et al.*, 2011:2), there is often a fissure between theory and practice. As such, efforts at implementing children’s participation tend to be dubious and sometimes problematic (Ansell, 2005:235; Coyne, 2006:62; Dixon-Woods *et al.*, 1999:778). Children are frequently silenced and rendered invisible (Roche, 1999:478) and are primarily conceptualised as passive as opposed to active participants in the medical decision-making process (Tates & Meeuwesen, 2001:839).

A wide range of supportive treatments are available for addressing the aforementioned challenges associated with paediatric cancer. Of the existing research on supporting individuals hospitalised with cancer, however, few studies consider animal-assisted interventions (AAIs), an umbrella term used to refer to various kinds of interventions utilising animals, as a possible form of support (Moorhouse, 2009:26). Numerous studies—though few relating to cancer—have established the benefits of several kinds of AAIs (Jenkins *et al.*, 2013:25; Kruger & Serpell, 2010:36).

Animal-assisted interventions (AAI) can be divided into two separate categories: animal-assisted activities (AAAs) and animal-assisted therapy (AAT). AAAs can be defined as providing “opportunities for motivational, educational, recreational and/or therapeutic benefits to enhance quality of life. AAAs are delivered in a variety of environments by specially trained professionals, paraprofessionals and/or volunteers, in association with animals that meet specific criteria” (Pet Partners, 2012). Besides the well-documented physical benefits of AAIs, such as a decrease in blood pressure, heart rate and cortisol levels (Odendaal, 2000:277-279), factors commonly associated with stress due to hospitalisation (Katcher *et al.* cited in Jalongo *et al.*, 2004:9; Wu *et al.*, 2002:354&361), AAIs have additional psychosocial and emotional benefits (Jalongo *et al.*, 2004:12). According to Hart (2010:65) animals may fulfil a substitutive role for human social support, with animals functioning to enhance social interactions, facilitate conversations and extend one’s social network (Cole, 2009:29; Hunt *et al.*, 2001:245).

Specifically for children who have been hospitalised, the reported psychological and emotional benefits of AAI include a more positive affect and greater feelings of happiness (Budge *et al.*, 1998:229; Kaminski *et al.*, 2002:327; Sobo *et al.*, 2006:56). Significant research findings (i.e. Brodie & Biley, 1999:334; Budge *et al.*, 1998:229; Hart, 2010:64 & 68; Smith, 2012:439-440) report that interactions with animals can lead to the alleviation of depression, loneliness, anxiety and distress. There are indications that children, while being assisted by animals during hospitalisation, are afforded opportunities to participate in decisions pertaining to the AAAs, which could contribute to a sense of control (Abbate, 2010:4,249; Kaminski, *et al.*, 2002:321-322). Furthermore, AAIs may intensify participation by providing patients with the opportunity to become equal and active partners in the process of their health and well-being, as opposed to passive individuals to whom something is done (Johnson *et al.*, 2003:56).

The multitudinous benefits of AAAs have been amply established (Jenkins *et al.*, 2013:25; Kruger & Serpell, 2010:36). However, in spite of this, research often fails to consider AAA as a possible form of support particularly for individuals hospitalised with cancer (Moorhouse, 2009:26). Of this limited research, few studies consider the ways in which AAA may be utilised to support *children* hospitalised with cancer (Gagnon, Bouchard, Landry, Belles-Isles, Fortier & Fillion, 2004:217,220), especially as a means to enhance participation and control, which can be diminished as a result of the diagnosis and treatment of cancer. These gaps in existing research are reflected in the South African context, where there is a paucity of context-specific research on AAA in general (Weideman, 2007:177) and on AAA and childhood cancer specifically. There is also insufficient implementation of AAA. Against this background, the present study set out to explore the following question: How are participation and control experienced during animal-assisted activities by children hospitalised with cancer?

METHOD

Design

This study assumed a qualitative research design focusing on exploring and describing the participation and control experienced during animal-assisted activities by children hospitalised with cancer. Qualitative research focuses on the social constructions of phenomena, since these constructions are what provide form and content to an individual's comprehension of the world (Ashworth, 2008:4). Importantly, Ashworth (2008:4-5) asserts that a focus on the social constructions of reality does not necessarily preclude a focus on the individual's subjective world, since qualitative research aims to consider the perceptions or meanings of an individual's world "whether socially shared or idiosyncratic". The phenomenological paradigm can therefore be placed within the context of qualitative research as it endeavours to comprehend people's lived experiences of a particular phenomenon (Delpont *et al.*, 2011:305). The intention of a phenomenological approach is to comprehend and describe the phenomenon as it is experienced by the subjects themselves (Bentz & Shapiro, 1998:96). This is in line with the aim of this research, as the researcher was focused on the children's lived experience of participation and control in the context of the animal-assisted activities offered to them as part of their supportive treatment during hospitalisation.

Participants

Paediatric oncology patients were recruited from a government-funded hospital in the Western Cape, South Africa. Non-probability purposive sampling (Strydom & Delpont, 2011:391) was utilised due to the qualitative nature of the study. Children between the pre-adolescent ages of 8 and 14 who were diagnosed with any type and stage of cancer were eligible for the study. Children were excluded, however, if their physician deemed them too unhealthy to interact with the dogs during the AAA sessions. Children included in the sample often oscillated between being inpatients and outpatients due to the nature of their illness, which required that each participant be hospitalised at least once during the data-collection process. All AAA sessions coincided with treatments received at the oncology ward.

Due to the qualitative nature of the study, the sample size was not predetermined but rather dependent on a number of factors, such as the protocols followed by the hospital and by the selected organisation offering AAA, as well as the availability of the researcher's and the volunteers' resources and time (Patton, 2002:244). This situation was compounded by the limited number of children who met the inclusion criteria, because a large portion of the population was younger than the required age, while many others were deemed too unhealthy to participate. The unpredictable reality of the illness also affected the sample size, in terms of the reliability of participants and their parents/guardians.

Five participants participated in the research, including four boys and one girl. A total of 13 AAA sessions were observed. Participants *a*, *c* and *e* each had five sessions, participant *b* had six sessions, and participant *d* had three sessions. The majority of the 13 AAA sessions occurred in a group context with two or more participants at a time. There were, however, five individual sessions: participants *b* and *c* had two individual sessions each, while participant *d* had a single individual session.

Child *a*

Child *a* was the only female participant, aged 14. She was observed to be physically emaciated and frail. She experienced difficulty with mobility, had a trachea in her throat and was one of only a few girls in the ward. She was shy, introverted and not comfortable or confident with verbal communication, but quite expressive non-verbally.

Child *b*

Child *b* was a 9-year-old male and observed to be an introverted and shy boy. Although he did not necessarily appear sick, he did have a swollen face as the result of his chemotherapy treatment. He was from an economically disadvantaged background and had never owned a dog as a pet nor had exposure to dogs in that context.

Child *c*

Unlike the majority of children receiving treatment at the government hospital, child *c*, an 11-year-old male, was from a middle-class environment. He had two pet dogs at home and this familiarity translated clearly into his first session with the volunteer dogs. He was quite confident and was comfortable with verbal communication.

Child *d*

Child *d*, an 8-year-old male, probably had the most extroverted and gregarious personality of all the participants. He spoke a great deal about his dogs at home and his love for them. Again, because of previous exposure, pet ownership and a familiarity with dogs, child *d* was immediately comfortable with the volunteer dogs.

Child *e*

Although child *e*, a 12-year-old male, had been away from home for a sustained amount of time, he had been exposed to dogs on the farm where he lived and thus had familiarity with them. Again, like the other child participants who owned dogs or had been exposed to them, child *e* showed no fear or hesitation during his first AAA session. He immediately began playing with the dogs and bent down in order to be on the same level as them. Although comfortable with the dogs, he was introverted and struggled to communicate verbally with others.

Ethical issues

Those children who met the inclusion criteria and showed an interest in participating were provided with an information letter containing details about the procedure and aim of the study. The letter was made appropriate for and applicable to the children through the use of language that the children would be able to understand. The researcher ensured that consent forms were signed and completed by the parents/guardians, and assent forms by the child participants, as suggested by Wassenaar (2006:72). This study was approved by the Health Research Ethics Committee of Stellenbosch University as well as the Ethics Committee of the North-West University. Permission was also obtained from the animal organisation to conduct the research in conjunction with their volunteers and dogs and was therefore in line with the organisation's guidelines and policies. The study was also guided by the principles outlined in the Declaration of Helsinki (World Medical Association, 1964), which include the following: informed consent and voluntary participation; confidentiality and anonymity; and avoidance of harm. Based on this, precautions were established in order to ensure the physical well-being of participants. This included consulting with, and obtaining authorization from, several ward doctors as to the physical health of each participant prior to every AAA session. Moreover, the integrity of the medical equipment was preserved by means of adhering to hospital procedures and standards. For example, drips were locked and IVs were secured by a nurse at the ward prior to each session. In addition to these general ethical considerations, specific considerations pertaining to animals were considered in order to ensure the safety and well-being of both children and animal. Reliability, predictability and controllability in terms of the interactions between volunteer and animal were maximised through volunteer experience, the assessment and training of the animal.

Data collection

Non-participant, or simple, observation (Strydom, 2011:329) together with one-on-one unstructured interviews, graphic questionnaires and field notes were utilised for the purposes of data collection. The use of numerous data-collection methods resulted in the attainment of various forms of

information from different participants, which is also referred to as triangulation (Babbie & Mouton, 2001:277).

During the non-participant observations (Ritchie, 2003:35), interactions between the child, the dog and the AAA-organisation volunteer were documented according to an observation schedule (Merriam, 1988), in order to render the observations systematic. The sessions occurred on the hospital premises but not in the paediatric oncology ward. An organisation for childhood cancer has a lodge on the hospital premises for children and parents who require frequent treatment but live too far from the hospital for convenient commuting. The lodge was identified as the most suitable location for the sessions as it has a large enclosed garden that is the ideal space for the volunteers, dogs and participants to engage with one another. The observation of sessions at the lodge also restricted contact to children who wanted to participate and did not impose contact on the other children in the oncology ward.

Following a two-month period in which children engaged in AAA, one-on-one unstructured interviews were conducted with each of the five participants in order to garner the children's perspectives directly. Beginning interviews with the open-ended question "How was it for you?" provide each child with an opportunity to reflect on the AAAs within his/her own frame of reference, allowing the meanings that the child assigned to events and relationships to be understood on his/her own terms (May, 2011:136). Three of the interviews were conducted in the hospital ward's conference room, one in the child's hospital room and another at the child's home. All interviews were audio recorded and later professionally transcribed. An external coder was also utilised for the data analysis to facilitate greater trustworthiness.

The decision to include graphic questionnaires (see Table 1 for examples) was made following the insufficient amount of data gathered from the interviews with the children; the qualitative nature of the research allowed for flexibility in this regard. The lack of rich data can be attributed to the researcher's inexperience in conducting one-on-one interviews with children in particular or to language barriers, as the majority of the children did not speak first-language English, though they could communicate in English adequately. Additionally, most of the children exhibited a preference for communicating non-verbally; therefore, direct verbal communication in the context of one-on-one interviews proved challenging. The development of the graphic questionnaire was based partly on the notion of "talking mats" (Murphy, 1998), which is a visual framework that uses symbols to facilitate communication among individuals who have problems communicating. It was also based on the notion of "the image vocabulary" (Triangle/NSPCC, 2001), which is a communication tool that supports children in communicating complex issues. The emphasis was on the participation of children and on utilising data-collection methods that would enhance the children's capacity to express themselves (Rabiee *et al.*, 2005:388).

Field notes were utilised as a means of enriching the observed data. Field notes were completed as soon after each AAA session as possible. The field notes consisted of a reflective

account of what the researcher experienced during each AAA session (Bogdan & Biklen, 2003:110-111).






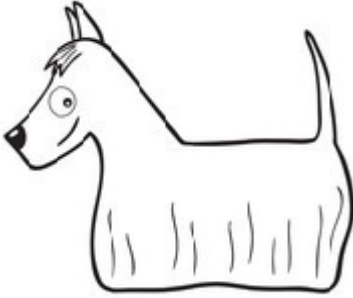

My visits with the dog made me think about myself...		
<p>As happy, strong and believing in myself</p> 	<p>As sad, not strong and like I can't do things</p> 	<p>As no differently than before they came to visit me</p> 
My visits with the dog made me think about my body and health...		
<p>As all right and okay</p> 	<p>As not alright and not okay</p> 	<p>As no differently than before they came to visit me</p>
I think the dog coming to visit me was...		
<p>Helpful</p> 	<p>Not helpful</p> 	<p>So so</p> <p>I don't know</p> <p>Kind of</p>

Table 1 Example of graphic questionnaire

Data analysis

Data analysis was based on the steps proposed by Tesch (1990:142-145) for “developing an organising system for unstructured qualitative data”. The analysis began by obtaining a comprehensive overview of all the data, which was read through several times. Topics were then identified, and similarities were noted and arranged into groups, with the following columns: major topics, unique topics and left-overs. Topics were then abbreviated as codes and the original data

reanalysed according to these developed codes. The data were refined by finding the most descriptive wording for the topics, which were then converted into broader categories. The aim was to reduce the total list of categories by grouping related topics with one another. Lines drawn between the categories indicated the interrelationships of categories. Once each category name was abbreviated and the codes were alphabetised, the researcher began the first complete coding session, which focused on the identification and summarisation of content for each category. Lastly, recording of the data was completed where necessary. This same analysis process was conducted independently by another researcher with experience in qualitative research, to ensure the consistency and dependability of data (Tesch, 1990:142-145).

Trustworthiness

Trustworthiness can be described as the degree of confidence that qualitative researchers have in their data (Pollit & Beck, 2008:768) and is concerned with the quality of the research (Schurink *et al.*, 2011:419). Trustworthiness generally includes credibility, transferability and dependability (Botma *et al.*, 2009:232).

Credibility is related to the extent to which the researcher has established confidence in the truth of the findings (Botma *et al.*, 2009:233). A correlation needs to exist between the originally constructed multiple realities of the participants and those realities, or reconstructions, which have been ascribed to the participants by the researcher (Babbie & Mouton, 2001:277; Lincoln & Guba, 1985:296). Transferability refers to how the findings from the study pertain to other contexts or other respondents (Babbie & Mouton, 2001:277; Lincoln & Guba, 1985:296-299). Dependability implies that findings are stable over time: the research should be consistent if repeated in the future, with comparable participants in a similar context (Botma *et al.*, 2009:233). Credibility, transferability and dependability were ensured in this study by means of the following measures (Klopper, 2008:70):

- Prolonged engagement, which involved persistent observation and investment of time on the part of the researcher through spending many hours in the pediatric oncology ward at the hospital. This time was often spent in the waiting area, allowing the researcher to become familiar with staff, patients and hospital procedures;
- Peer examination, which was done extensively by the supervisor and co-supervisor of the study;
- Thick and dense descriptions of the methodology such that the ways and means in which data were collected can be replicated;
- Triangulation of data, which is described by Babbie & Mouton (2001:277) as the collection of multifarious information from different participants through diverse means, was performed by comparing the data from the graphic questionnaires, observations and field notes.

RESULTS

The themes that emerged from the data were strongly associated with time, as comparisons were made between initial to later sessions, and definitive changes in all participants were observed. The first differences observed in the participants' reactions from the initial to the final sessions were in their approach to and interaction with the animals, including taking the lead, grooming and showing affection, as well as laughing and acting spontaneously. The second set of changes occurred in their body awareness, specifically concerning the protection of their bodies and the level of comfort they experienced. The third mode of differences involved the children's level of engagement during the sessions, often indicated by initiative and choice. The fourth progression was in their level of independence. The fifth and final set of changes was in the children's communication, including the content of their verbal conversations, as well as their non-verbal communication. (See Table 2.)

Theme	Sub-theme
1. Approach to animals	1.1 Taking the lead
	1.2 Grooming and affection
	1.3 Laughter and spontaneity
2. Body awareness	2.1 Protection of body
	2.2 Comfort
3. Level of engagement	3.1 Initiative
	3.2 Choice
4. Level of dependence	
5. Communication	5.1 Verbal communication
	5.2 Non-verbal communication

Table 2 Themes and sub-themes

Theme 1: Approach to animals

Children's engagement with the animals and their initial reactions in the sessions can be divided into two groups, with one group of children displaying fear and hesitation when introduced to the dogs and the other group immediately comfortable and confident. Children *c*, *d* and *e* had their own dogs and constituted the group of children who were comfortable and confident, while children *a* and *b* did not have dogs as pets and comprised the latter group. It can therefore be deduced that previous exposure to a dog (the animal of choice in this study) could have a great impact on the child participating in

AAAs, at least initially, which is in line with the findings of Fine, O'Callaghan, Chandler *et al.* (2010:197).

1.1. Taking the lead

Over time, many of the participants actively exerted control over the situation and participated freely in the activities. This tendency was demonstrated clearly by child *a*, who had no previous exposure to dogs. Initially, she was nervous and fearful. However, once the volunteer explained that the dogs would not hurt her and demonstrated petting them, her whole demeanour changed. She began smiling, actively engaging with the dogs by petting them and became involved in all of the activities. In the final session, she immediately began interacting with the dog without any fear or hesitation, as evidenced by her body language, which was open. She was able to maintain good eye contact with the dog and also got down to the level of the dog when necessary. She was spontaneous in her interactions with the dog when feeding her treats and led the dog around holding the lead, assuming a leadership role and asserting herself when required.

Although neither child *c* nor child *e* displayed fear in their approaches to the dog, they did require a significant amount of coaxing and encouragement from their mothers as well as from the volunteer in order to engage physically during the initial sessions. This is in contrast to their final sessions, in which both of them displayed confidence, comfort and involvement in the activities, showing a marked increase in participation. Child *e* also appeared to become more self-assured in his interactions with the volunteer and the researcher.

All of the children, regardless of whether fear was present or absent in their initial approaches to the dog, showed improvement in their approaches to the dog, exemplified in their greater self-confidence. Urichuk and Anderson (2003:71) explain that greater self-confidence can be achieved through earning the respect and trust of the dog. Furthermore, through the graphic questionnaires, participants reported greater self-confidence insofar as the sessions with the dogs made them think about themselves as “happy, strong and believing in myself” and also assisted them in thinking of their bodies as “alright and okay”. Children participating in the study also managed to achieve both the respect and trust of the dog, especially in the later AAA sessions, as seen in the dogs’ compliance with the children’s instructions. This was particularly noticeable in the session where each child had the opportunity to tell the dog to lie down and then roll over, with the dog responding positively to each child’s instructions. In this way the children were able to visibly witness the control they could exert over the dog.

1.2. Grooming and affection

According to Melson (2003:36), the desire to nurture others is a basic human need, with Odendaal (2000:276) elaborating that the need for positive interactions, such as nurturing, is ingrained in the

behaviour of many living organisms and that animals can fulfil this need in humans. The researcher observed that some children did experience feelings of responsibility toward the animal over the course of the AAA sessions: for example, child *b* brought his own ball to the second session so that he could play with the dog. This was his own initiative and affirmed his sense of responsibility for the dog. Child *b* also brought along a picture that he had drawn to session four, depicting his interactions with the dog. Again, because he initiated this himself, it showed a sense of responsibility in his relationship with the dog.

An exemplary instance of affection between dog and child occurred when child *a*, who initially maintained distance between herself and the dog, grabbed the dog's face and began kissing her on the mouth. All of the children exhibited nurturing and caring for the dog in terms of grooming with a brush. Child *a* showed particular vehemence for brushing the dog and after some time in her first session she began brushing the dog all over his body, including his feet, which no other child did. She continued this enthusiasm for brushing the dog into the fourth session where she also brushed the dog's tail. Another instance of nurturing occurred when child *c* began massaging the dog in the third session. During the second session with child *d* the dog dug a big hole in the garden and the dog's face was covered in dirt. The volunteer then asked child *d* if he would clean the dog's face and give her some water. Child *d* wiped the dog's face gently with a tissue and bent down on one knee to get to the dog's level. Many of the children showed an enriched sense of purpose, which may be achieved through animal-assisted activities if children experience feelings of responsibility toward the animal or provide some sort of care (Urichuk & Anderson, 2003:70). Moreover, children *a*, *c* and *e* indicated on the graphic questionnaires that their favourite activity was brushing the dog which denotes the affection these children especially had for the dogs.

1.3. Laughter and spontaneity

Spontaneity, including human expressions of laughter and joy, as observed in child *a*'s later approaches with the dog, have been shown to positively impact on a child's quality of life (Cousins, 1989:132). This is in line with research conducted by Dowling *et al.* (2003:271) that established a direct positive relationship between sense of humour and adjustment to cancer. As such, engaging with the dog during the AAA sessions created opportunities for the children to experience laughter and joy, with all of the children reporting in the graphic questionnaires that they enjoyed the sessions and that provided them with an opportunity to experience joy and happiness. A specific moment of shared laughter and joy occurred when the volunteer put one of the small dogs in the swing. She then attempted to put the bigger dog in the swing, which all of the children found hilarious. Child *b* showed delight and responded with a hug when the dog spontaneously licked his face. These

improved approaches to the dog over the course of the sessions can be attributed to an enhancement of overall quality of life as a result of engaging in AAAs.

The mutual giving and receiving of affection is an essential tenet of the human-animal bond, and in cases where children have the opportunity to nurture a dog, such as during AAA sessions, the bi-directional affection and nurturing can contribute to an increased sense of purpose, making the children feel valued (Urichuk & Anderson, 2003:76). To this end, it is important that children perceive the mutuality of the relationship between themselves and the dog. Participation can be increased on the basis of this mutuality as it functions as a form of positive reinforcement. According to Nebbe (1994, cited in Urichuk & Anderson, 2003:82) animal-assisted activities offer a realistic foundation for individuals to exercise control, whether it be internal, external or self-control. One of the ways in which control can be enhanced comprehensively is through a sense of purpose (Owusu-Ansah, 2008:63). Children diagnosed with cancer can experience loss of control and a lack of purpose as the result of being transposed from their regular home and school contexts to the hospital environment. This can be addressed, however, by providing children with the opportunity to care for a dog during the AAA sessions, because having a sense of purpose is positively correlated with feelings of control and overall well-being (Owusu-Ansah, 2008:63-64).

Theme 2: Body awareness

The researcher observed a general pattern in the majority of children in relation to their body awareness. Initially some of the participants indicated heightened awareness and at times even protection towards their bodies. It was also observed that some of the participants were aware of the limitations, abnormalities or restrictions imposed by their bodies. Later, however, they became more comfortable, relaxed and oblivious. All children participating in the study indicated on the graphic questionnaires that the AAA sessions assisted them in thinking about their bodies and their health as “alright and okay”, consolidating their improvement in self-confidence.

2.1. Protection of body

The participants made certain decisions regarding their own health and well-being by concealing or covering up various features of their bodies (mouth and tracheostomy, IV hand, hair loss) less and less over the course of the sessions, and by displaying an ever-decreasing awareness of these features, which was indicative of a growing sense of control over their bodies and environments. Furthermore, they participated in animal-assisted activities and engaged in decision-making, which seemed to enhance their overall well-being, in line with the findings of Jenkins *et al.* (2013:25), Coyne and Gallagher (2011:2335), and De Winter *et al.* (1999:16).

For example, initially child *a* insisted that her tracheostomy be covered before leaving the ward, and en route to the first AAA session she covered her mouth with her hand when exposed to the

outside environment. Moreover, her body movements revealed that she was acutely aware of her trachea and it looked like she was both concerned and constrained by it. However this aspect of her demeanour gradually changed over time. For example, during her initial session, as a result of her physical condition, the volunteer provided her with a chair so that she could sit down while brushing the dogs. In the second session she no longer covered her mouth when exiting the hospital. During the third session she asked her mother to wrap a pink scarf around her trachea while in session number four she no longer covered her trachea at all. At this point child *a* had also lost all of her hair as the result of her chemotherapy treatment but she did not make any attempt to conceal her hair loss. Finally, in her last session she sat on the ground with her legs outstretched in front of her, her body language indicating relaxation, and her interactions during this session were no longer dictated or constrained by her body.

Although child *c* was observed to be the most comfortable conversing and interacting with the volunteer, dogs and researcher throughout the study, at the start of the AAA sessions he had already experienced hair loss as a result of the stage of cancer treatment he was receiving. He participated in five AAA sessions in total and during the first four sessions he made a purposeful effort to conceal this hair loss by wearing a hat at all times. This effort to conceal his body and the side effects of treatment gradually changed such that in the final AAA session child *c* did not wear any head covering and exposed his body and hair loss fully. He later reported in the interview that by this stage his hair loss did not concern him.

This was also demonstrated by child *d* who had expressed that he was extremely concerned about the IV inserted in his arm, for easy administration of chemotherapy. He asked the nurse if she could please bandage it a second time for reassurance. This was an overt attempt at concealing the body and protecting it. During his initial AAA session although he actively engaged and participated in all of the activities, it was observed that he refrained from using his hand that had the IV inserted, more so when petting the dogs. However, his awareness progressively changed over time such that in the final session, child *d* insisted on completing a drawing with this hand, utilising it fully and comfortably. During the AAA sessions children *a*, *c* and *d* would all exert control over the dog when necessary, pulling the lead and directing the dog by making use of their bodies.

2.2. Comfort

Similarly, there was a discernible relaxation in child *a*'s body movements, which initially were stiff and restricted as a result of the trachea. In the final session, she managed to sit down on the ground and stretch her legs out in front of her. Fine and Beck (2010:7) refer to Dr Creagan's conviction that interactions with animals can help establish equilibrium between body and mind. Thus, attending to the body and providing individuals with an opportunity to utilise their bodies in a new way can assist with their psychological health. Child *a* also required a wheelchair to get from the hospital to her first session but chose not to rely on it for all of the subsequent sessions. The wheelchair is particularly

important for the conceptualisation of participation and control, because the child wanted to exert control over her own body and exercise her ability to use her legs and walk.

During sessions the children would use their bodies to participate by getting physically close to the dogs, touching, brushing, holding and hugging them. There is a substantial amount of literature on the physical benefits of animal-assisted interventions, which include, *inter alia*, a decrease in blood pressure, heart rate and cortisol levels (Odendaal, 2000:277-279). Indeed, a host of research findings have established that AAIs have the potential to reduce both anxiety and stress levels (Brodie & Biley, 1999:334; Hart, 2010:64 & 68; Odendaal, 2000:277-279; Smith, 2012:439-440). These benefits imply that children can participate more significantly in their own health and well-being, with anxiety and stress no longer forming additional obstacles.

The data related to this sub-theme reflect the researchers' observations and field notes during the AAA sessions. Although they show a clear reduction in the participants' levels of anxiety, stress and possibly also the physical effects thereof, it is not clear whether this reduction had a generalised impact and whether the effect was lasting and carried over to other contexts. This could indicate an area of further enquiry.

Theme 3: Level of engagement

Many factors could have interfered with the participants' levels of engagement, for example the side effects of treatment and general pain levels. Nonetheless, there was an overall observable pattern of enhancement in children's levels of engagement over time. Children self-initiated more readily and exercised greater choice.

3.1 Initiative

Comparing the initial and final sessions of all participants—especially child *a*, *d* and *e*—the researcher observed a heightened level of engagement, not only with the dogs, but also with the volunteer. In earlier sessions the children had to be coaxed and instructed, but later they took initiative and even demonstrated activities to one another. Even when child *d* was not very physically active he still managed to engage with the dog in a seated position. He initiated calling out to the dog, followed by petting and grooming. During the sessions, participants gave the dogs treats, played fetch with them and took them on treasure hunts. All activities were addressed with greater enthusiasm and vigour in later sessions, and were often self-initiated, which could be indicative of an increase in the participants' sense of well-being as participation and control increased. For example, both children *a* and *b* were initially fearful of feeding the dog treats and threw them on the ground for the dog to pick up and eat. However, in later sessions, both were able to engage more significantly with the dog as they overcame their fears and allowed the dog to eat the treats directly from their hands. A further increase in engagement was observed in the fact that both child *a* and *b* eventually initiated treat-

feeding themselves and rapidly repeated this activity. Whereas child *a* initially found it challenging to brush the dog, requiring that the dog sit on a chair to make the activity easier, in session four she bent down and brushed the dog of her own accord.

These increasing levels of engagement, and particularly initiative, can be linked to Erikson's (1968) stages of development whereby a child's sense of control and autonomy may be reinforced with the accomplishment of certain tasks (Abbate, 2010:3-4). Therefore if the child is more engaged, more active and participating more fully in the AAA session, he/she has a greater opportunity to experience a sense of accomplishment. All of the children exhibited a similar response when getting the dog to do a trick: they all smiled at their success in getting the dog to sit, lie down and roll over. Completing a task or activity in the AAA session can be imperative because "control is related to the perception that individuals maintain about the causation of personal consequences and other associated events" (Engler, 2009:251).

3.2 Choice

During AAA sessions the participants were allowed to engage in the activities according to their own needs and wants when provided with a choice by the volunteer. This meant that they were able to engage on their own terms and make the activity or the interaction their own. This approach facilitates assimilation, as opposed to the child simply consuming the whole, and is far more meaningful (Bringuier & Piaget, 1989:42-43). Child *a*, although not confident or comfortable with verbal communication, when provided with choice was able to express her preference, and in this way engage on her own terms. The volunteer asked whether she would like to take the dog off the leash and lead him around the garden, to which child *a* responded, "No, I want to keep walking him like this." This is an example of child *a* cultivating her own way of being and participating in the world. Similarly, child *c* was observed to participate in several sessions on his own terms by choosing which activities he would prefer to be involved in. Child *e* was admitted as an inpatient to the oncology ward during the research period and there were some discrepancies among the hospital staff and doctors about whether he should participate in certain AAA sessions. The researcher, with permission, decided to ask child *e* directly whether he felt able enough to participate, to which he responded yes. By providing him with choice, he was able to participate fully in that particular AAA session on his own terms. Interestingly, this was one of the sessions where his activity level was at its greatest.

When individuals feel that they have little or no control over situations they tend to demonstrate more passive behaviour (De Winter *et al.*, 1999:18). Consequently, greater levels of activity during the AAA sessions could be indicative of children experiencing greater control. If the children observe that their actions can have direct results, this may strengthen their sense of control over a situation, and thus reinforce their internal locus of control, even if only contextually specific.

Theme 4: Level of dependence

While a natural state of dependence or independence may be a feature of a child's personality and/or developmental level, from observation it was evident that the children could be placed on a continuum that reflected varying levels of dependence. Children *a*, *b* and *c* tended towards the more dependent end of the continuum, and at the initial sessions appeared more reliant on either a parent or the volunteer. However, all the participants seemed to grow more independent over the course of the AAA sessions.

Dependence on a parent was marked by maintaining close physical space to the parent, continually trying to establish eye contact while looking to the parent for support and reassurance, requiring encouragement from the parent and letting the parent assume the child's position in the session. These markers were most evident in the first session with child *c* and his mother: she became very involved, continually encouraging him with statements such as "Come on my boy". In other instances, the children exhibited dependence on the volunteer, initially requiring coaxing, support and encouragement to participate and engage in the activities fully. The children sometimes also needed a demonstration from the volunteer, as in the case of child *b* who relied heavily on the volunteer to show him how to interact with the dog in his first session.

This dependence gradually transformed over time, and changes became evident in some of the children's behaviours and interactions with the dog. For example, child *a* clipped the dog's leash on by herself and started walking the dog, and in the second session she separated herself from the volunteer and began walking the dog on her own, later rejoining the volunteer. Similarly, the researcher observed child *e* exerting his independence, walking the dog on his own during his final session. In session one, child *b* relied heavily on the volunteer to direct him, provide demonstrations and encourage his participation. By the following session he could follow the directions given to him by the volunteer without needing a demonstration for each activity. He also looked less to his mother for reassurance and began making more eye contact with the dog. Importantly, in this session, he assumed a leadership role in relation to child *c* and was the more dominant child. In the fourth session he progressed to the point of asking the volunteer if he could push the dog in the swing, therefore initiating an activity of his choice himself. Although child *c* was initially comfortable with the dogs and was therefore able to maintain considerably stable interactions with the dog over the course of the sessions, his activity level seemed to increase over time in sync with an increase in independence. He progressed from not being physically active during the first two sessions to becoming far more physically active in the later sessions.

According to Endenburg and Van Lith (2011:209), child development encompasses a combination of social and emotional development, which can be measured by positive self-esteem and social proclivity, as well as cognitive development. Animals have been shown to influence child development by augmenting self-esteem, autonomy, social competence and cognitive development

(Wilks, 1999; McNicholas & Collis, 2000; Poresky & Hendrix, 1988, all cited in Endenburg & Van Lith, 2011:210). Many children diagnosed with cancer suffer from low self-esteem, but this can be addressed through the inimitable medium of animals, who display unconditionally positive behaviour and unequivocal acceptance towards people (Urichuk & Anderson, 2003:69). Moreover, animal-assisted activities provide children with opportunities to increase their self-esteem by either learning a new skill or recognising their own progress (Urichuk & Anderson, 2003:69). All of the children in the study learnt a new skill when the volunteer demonstrated how to instruct the dog to lie down and roll over. Moreover, many of them were able to recognise their own success in getting the dog to roll over as was indicated by their smiles and laughter.

All of the children participating in the study indicated in the graphic questionnaires that the AAA sessions assisted them in believing in themselves and thinking about themselves as happy and strong. An increase in self-esteem as the result of earning the dog's affection and interacting positively with the dog during animal-assisted activities has been found to heighten an individual's sense of independence (Kaminski *et al.*, 2002:322; Urichuk & Anderson, 2003:71). Growing independence is linked to enhanced control because, rather than the children following someone else's (the volunteer's) lead, they had the opportunity to take the lead themselves.

Theme 5: Communication

One of the most prevalent features of the data-collection process was the fact that very few of the children were comfortable, confident and assured with verbal communication. Of all the child participants, only children *c* and *d* exhibited confidence in their verbal communication, visible through the medium of their body language: for example, they made and sustained eye contact when speaking to the volunteer. While both child *c* and *d* were content to answer questions, child *c* was observed to be more self-assured, posing questions to the volunteer. The remaining participants displayed a greater propensity towards, and reliance upon, non-verbal communication and gestures: for example, nodding of the head to indicate a positive response, shaking of the head to indicate a negative response and smiling to indicate agreement or enjoyment. Children *a*, *b* and *e* would occasionally respond verbally, but the responses were passive.

According to Oren and Parish-Plass (2013:5) communication “involves different actions, the central ones being expression, transmission, comprehension/listening, deciphering, pausing (experiencing), giving of meaning, reaction, and expression of that reaction”, such that these actions enhance the communication process. AAAs as an approach recognises the need for supplementary and/or complementary non-verbal mediums when verbal communication is constrained, as a means to facilitate communication and achieve change (Oren & Parish-Plass, 2013:5). The effect thereof was witnessed throughout the current study.

5.1. Verbal communication

It seems especially important to mention those moments when the children who relied more heavily on non-verbal communication and body language did utilise speech. For example, child *a* spoke only a few times throughout the observation stage of the data-collection process. In her first session, child *a* softly said “paw” after the volunteer demonstrated how to ask the dog for her paw. She spoke a second time during this session, responding to the choice of putting the dog on the leash with the statement “No, I want to keep on walking him”, as discussed above. This was a crucial moment because, despite her speech being passive and soft, child *a* was able to express her needs and wants. In the fourth session, child *a* made even more progress in communicating verbally, calling the dog by its name and of her own accord for the first time during her AAA sessions. In her final session, child *a* was comfortable enough to answer several of the volunteer’s questions and was verbally responsive to the volunteer throughout. At one point child *a* assertively commanded the dog, stating, “Rosie, down!” in response to the volunteer’s direction.

Child *b* was another child who displayed a greater propensity towards non-verbal communication and made use of his body instead of talking. In the first half of the initial session, child *b* relied exclusively on hand gestures to communicate with the dog and volunteer, gradually using a few verbal statements towards the end of the session. In the third session he was able to instruct the dogs to sit, although the instruction was not delivered in an assertive or commanding manner. The following session saw child *b* speaking more, and speaking with greater confidence. In his final session, child *b* asked the volunteer, “Can I put the dog in the swing?”, which was important, as he initiated this verbal communication on his own without needing to be prompted or coaxed.

Much like the other two children, child *e* tended to be shy and introverted and was therefore uncomfortable with verbal communication. Despite the volunteer and child *e* sharing Afrikaans as a first language, he remained noticeably uncomfortable in his few verbal interactions with her and, although he was responsive to her questions and instructions, relied more heavily on his body as a medium for communication when he could. In the subsequent session, when the volunteer asked child *e* whether he would like to take the dog for a walk, he responded both verbally and non-verbally in an enthusiastic manner. However, it was observed that there was far less verbal communication between the volunteer and child *e* in this session than in the previous one. As discussed previously, prior to the third session the researcher asked child *e* directly whether he felt well enough and wanted to participate in that day’s session, a matter his various doctors had been debating. His response was verbal and again conveyed enthusiasm despite being somewhat quiet, shy and passive. In the actual session, an accompanying volunteer began asking child *e* a lot of questions that he was clearly reluctant to answer, therefore relying exclusively on body language and covering his mouth with the sleeve of his top. In his final session, child *e* was able to instruct the dog in an assertive manner and was also able to verbally respond to the volunteer when she provided him with choices of activities.

He overtly responded more verbally than non-verbally to both the volunteer and the dog in this session, despite primarily using yes and no answers.

Based on these observations, there were clear changes that occurred in some of the children's verbal communication with both the volunteer and the dog, which is in line with Urichuk and Anderson (2003:244) who note that AAA can lead to improved communication. Verbally, children progressed in terms of being able to express their wants and needs, and in subsequently witnessing these wants and needs being met, which was demonstrative of enhanced control. Children participated more fully in the following ways: calling the dog by its name, initiating calling the dog by themselves without having the volunteer encourage or direct them, and commanding the dog in an assertive and instructional rather than passive manner. These were critical instances, as the overall progression from resisting verbal communication and relying almost exclusively on non-verbal bodily communication towards greater verbal communication highlighted more confidence and self-assuredness. The child's ability to command the dog in an assertive manner especially revealed an ability to assume leadership over the dog, exert control and participate more independently.

5.2. Non-verbal communication

Talking is an obvious medium of self-expression that conveys the content of people's cognitive and emotional state. However, this is not always the case, as many people experience barriers to verbal communication (Oren & Parish-Plass, 2013:7). This is particularly true of children, who generally do not respond well to direct verbal communication, as evinced by most of the children participating in the study. Non-verbal communication, through the medium of body language, can function as an ingress to the child's inner world, facilitating expression either consciously or unconsciously (Oren & Parish-Plass, 2013:8). According to theories on animal-assisted activities, animals may function as a unique medium for facilitating communication, especially non-verbal communication, because the presence of animals establishes a range of simultaneously emotional, genuine and unprompted expressions that transcend certain barriers to verbal communication (Oren & Parish-Plass, 2013:11) and that thereby help expose the child's inner world. This result was particularly evident in the spontaneous actions of the children, such as their expressions of joy and laughter.

Where children exhibit barriers to verbal communication during AAA sessions, the dog may serve as an object for the children's projections of their own emotions and cognitions, or as an object of transference or deflection of their emotions onto another being (Oren & Parish-Plass, 2013:13). For example, child *a*, who showed especial fervour in her affection with the dog, could have been projecting her own need for affection and nurturance during the challenging time of treatment onto the dog. While verbal communication is a more concrete medium for what is occurring in the here and now of the AAA session—for the children's comments on the dog's behaviour, for instance—non-verbal communication may reveal aspects of the inner world of the child via the child's emotional

reaction to the dog. According to Oren and Parish-Plass (2013:17), a child who interprets aspects of the dog's behaviour such as open mouth, eye contact, wagging of tail and barking as threatening is transferring feelings from a previous situation or person onto the dog. Alternatively, the same behaviour in the dog may be interpreted as non-threatening, with positive associations or feelings being transferred onto the dog. Based on Oren and Parish-Plass' elucidation (2013), and on an examination of the children's initial non-verbal reactions to the dog—such as restricted body movement, lack of eye contact and avoidance of physical contact—children *a* and *b* could have been transferring negative feelings or experiences onto the dog.

Consequently, enhancing a child's use of the medium of communication, often non-verbal, through interaction with animals may reduce disparities between inner and outer realities (Milner cited in Oren & Parish-Plass, 2013:9). In this way children's sense of control and participation may be enhanced as they witness their ability to shape the world within which they exist (Oren & Parish-Plass, 2013:9). This dynamic was evident when children in the study instructed the dog and then saw the dog comply with their instructions, as well as when they exerted choices in terms of which activity they would prefer to engage in. Communication during AAA sessions, because it centres on non-goal-directed activities, can be used to open up communication in general, because it appears to be less confrontational for the children. For example, while brushing the dog, child *c* noticed a scar on the dog's back; when the volunteer explained that the scar was the result of a life-threatening illness the dog had overcome, child *c* likened it to his challenge of overcoming cancer, stating, "Like me". In addition, the content of conversations may be used to increase control and participation, through inclusion of issues that are pertinent to the children. Being "heard", whether verbal or non-verbal, is an essential component of participating in one's life as well as in the medical decision-making process. Providing children with the opportunity to express themselves and participate in this manner may result in a greater sense of control.

CONCLUSION

It became clear that the children's approaches to the animals changed over the course of the AAA sessions, which significantly contributed to their sense of well-being. Spontaneity, including joy and laughter, has been shown to enhance quality of life and assist with the adjustment to cancer, as evidenced by the children's improved approaches with the dog. Their self-confidence and self-assuredness increased, as they earned the trust and respect of the dog over time. This was perceivable during observations and also reported in the graphic questionnaires. Children experienced an increase in control as they were able to see the dog comply with their instructions. Moreover, children's participation tended to increase, with their participation positively reinforced through the reciprocity of the animal-child relationship.

Changes in the children's demeanour were also seen through their awareness of their bodies. As the result of arduous cancer treatment, all of the children experienced physical side effects that manifested in their bodies in differing ways. In the initial sessions, most of the children showed a propensity towards protecting their bodies and an acute awareness of the ways in which their bodies were negatively affected as the result of treatment. These children showed a progression from protecting their bodies towards "exposing" their bodies, no longer making efforts to conceal the side effects of treatment. This progression is probably linked to an accompanying reduction in their awareness of their bodies. Convincing evidence has shown that engaging in animal-assisted activities can have physical benefits, including reduced stress and anxiety levels. It is likely that, while the children were interacting with the dogs during sessions, they were experiencing the physical benefits of AAA, which therefore led to a reduced body awareness and more relaxed body movements over time. In this way children were able to participate more fully in AAA sessions and also experience a sense of control over their bodies—a sense of control that is atypical of the cancer experience.

Children's levels of engagement, including their initiative and choice, were also seen to increase over time, with most children requiring increasingly less encouragement or coaxing from the volunteer or parent. In later sessions, most children managed to overcome their initial fears or challenges and started engaging in activities of their own accord with enthusiasm and self-initiative, evident in the often rapid repetition of an activity, such as feeding the dog treats. Physical activity also tended to increase; however, there were a few exceptional instances, which could possibly be attributed to the physical side effects of cancer treatment. Engaging with the dog could assist children in achieving various stages in their development, particularly with regard to autonomy and control. A greater sense of control may be derived from accomplishing developmental tasks through the AAA medium with the use of the dog. Moreover, when children were provided with choices in AAA sessions, such as which activity they wanted to engage in, they demonstrated the ability to engage in sessions according to their own wants and needs. Shaping sessions and making them their own can only be achieved if children are constantly provided with choices throughout the AAA experience. This lends itself to enhanced control, engagement and overall participation.

The children's development was further observed in the progression in their levels of dependence, with a movement away from being dependent on the volunteer or parent in the sessions, towards greater independence. Animals have been shown to facilitate children's development across a range of dimensions, with self-esteem particularly pertinent for this study, considering that a diagnosis of cancer is often accompanied by a drop in self-esteem. AAA provides children with opportunities to augment their self-esteem by either learning a new skill or recognising their own progress. Self-esteem may also be increased through the inherent nature of dogs, who demonstrate unconditionally positive behaviour and non-judgemental acceptance of people. The shifts in levels of dependence therefore signalled a change in how the children perceived themselves; with greater self-esteem they could begin to assume more leadership in the sessions and so exert more control over their situation.

Lastly, those children who initially showed an aversion to verbal communication did tend to improve in this regard, commanding the dog in a more assertive manner over the course of the sessions. The children's ability to command the dog assertively, as opposed to passively, suggested an increase in the children's levels of control and participation during the AAA sessions. On the other hand, non-verbal communication, mainly via body language, can provide insight into the child's inner world. Using a child's preferred medium of communication—often non-verbal—has been shown to reduce disparities between a child's inner and outer worlds. Thus, employing the non-directive medium of AAA could have permitted some of the children a medium through which to express their inner worlds outwardly, an expression often achieved through transference. The dog may therefore have functioned as the object of transference for the children, allowing them to work through emotional difficulties or express themselves in an alternative manner to verbal communication. In this way, children's control and participation were enhanced as they experienced an increase in self-expression.

In spite of the children's aforementioned approaches to the animals changing over the duration of the AAA sessions, it must be mentioned that a limitation of the study is the inability to generalise enhanced participation and control reported during the AAA sessions to other aspects of the children's lives, particularly the hospital ward.

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SECTION C: SUMMARY, CONCLUSION AND RECOMMENDATIONS

1. INTRODUCTION

This section of the report provides a summary of the research problem, followed by a summary of the methodology that was used and of the deductions and conclusions that were attained from the literature review and the qualitative research. Recommendations are made regarding the implementation of AAAs in practice and the provision of support for children hospitalised with cancer. The discussion also includes suggestions for future research. Following this, various limitations of the study are considered and a reflection on the overall research process is offered. Finally, a general conclusion completes the section.

2. SUMMARY OF RESEARCH PROBLEM

Cancer can affect children of all ages, races, genders and socio-economic levels, as well as their families (Children's Oncology Group, 2012). While childhood cancer is relatively rare (Stones, de Bruin, Esterhuizen & Stefan, 2014:501), and while advances in this field have augmented survival rates (Johnson et al., 2003:56; Stones *et al.*, 2014:501), this is not necessarily the case in South Africa. Cancer survival is less likely in South Africa, a developing country, than in its developed counterparts (Stones *et al.*, 2014:501) due to the variety of obstacles to early diagnosis and effective treatment (Stones *et al.*, 2014:501).

Childhood cancers have a propensity for growing fast; consequently children are usually administered higher doses of treatment in a shorter amount of time, as compared to adults (Abbate, 2010:204). These factors cause the diagnosis and treatment of cancer to be stressful and hostile experiences, particularly for children (Li *et al.*, 2010:47), with all aspects of children's lives affected, including the physical, psychosocial and emotional aspects. This situation demands that a greater emphasis be placed on the lived experiences of children with cancer and on the ways in which children can be supported (Eiser, 1998:621).

Cancer is associated with a fundamental break with former normal states and everyday life (Bjork et al., 2005:269; Epstein *et al.*, 2004:3). Reed *et al.* (2003:72) posit that children admitted to hospital could experience disempowerment and loss of control. Children typically experience a loss of control as they realise their bodies are unhealthy and begin to perceive them as vessels of pathology (American Cancer Society, 2013). Last and Grootenhuis (1998:171-175) state that "being confronted with cancer means being confronted with uncontrollability". Moreover, Johnson *et al.* (2003:56) show that the autonomy and empowerment of children with cancer are often compromised, which affects their overall quality of life and elicits feelings of loss of control, disempowerment and disconnection in relation to their bodies.

The lack of participation and control experienced as a result of cancer diagnosis and treatment can be addressed by having children participate in the medical decision-making process, the benefits of which have been established by substantial literature. Child participation in the medical decision-making process has been shown to be imperative for psychological well-being (Coyne *et al.*, 2011:2; De Winter *et al.*, 1999:16) and is particularly necessary for augmenting the child's internal locus of control (Tiffenberg cited in Coyne, *et al.*, 2011:2). However, a fissure seems to exist between theory and practice. Despite the established benefits of child participation, children are often deemed too young, too immature or too incompetent to express themselves adequately and, on this basis, they are not included (Boyden cited in Ansell, 2005:235).

Though exclusion from the decision-making process remains a real issue, there is still a range of supportive interventions available to children hospitalised with cancer, with the aim of addressing the physical, psychosocial and emotional challenges they face. Interventions comprise both traditional and non-traditional varieties, including complementary and alternative medicine (CAM), of which animal-assisted interventions (AAIs) are considered one type. There have been an increasing number of research publications on the benefits of AAIs over the past four decades and, while some of this research has focused on child-specific AAIs in a hospital context, there is limited research on animal-assisted activities (AAAs) among cancer patients (Moorhouse, 2009:26). Of this limited research, few studies have explored how AAAs may address the psychosocial and emotional challenges associated with children hospitalised with cancer, particularly surrounding the pertinent issues of participation and control.

These gaps in the literature are exacerbated by the reality of the South African context, with individuals diagnosed with cancer generally not afforded opportunities to engage in AAAs. This reality is most likely the result of a combination of factors including South African hospitals' general nonreceptiveness to having animals in the hospital environment, the lack of research on AAAs in South African hospitals specifically, inadequate knowledge about AAAs in South Africa, and the shortage of local organisations offering AAIs. With these conditions in mind, this study posed the following research question: How are participation and control experienced during animal-assisted activities by children hospitalised with cancer? It aimed to explore and describe these experiences.

3. SUMMARY OF METHODOLOGY

The empirical investigation appeared to be successful in ensuring that the specific aim of the research was achieved: namely, to qualitatively explore and describe, through the use of a phenomenological design, the experiences of participation and control during animal-assisted activities of children hospitalised with cancer. A non-probability purposive sampling method was used to select the participants for the study. Sample size was dependent on factors, such as the procedures followed by

the hospital and the organisation offering the animal-assisted activities, as well as the availability of the researcher's time and resources. The final sample size included five children, with any type of cancer and during any phase of cancer, who were hospitalised for any period during the duration of the study, with the prerequisite that the child was healthy enough to interact with the dogs.

Data collection included observations, one-on-one interviews, graphic questionnaires and field notes. The researcher noted behaviours that occurred during the interactions between the child, the dog and the AAA-organisation volunteer and documented them according to an observation schedule, to ensure that they were systematic. A special focus was maintained on behaviours related to participation and control. Behaviours related to participation included communication through voicing one's opinions (Stephens cited in Ansell, 2005:233); communication through expressing one's self (Ansell, 2005:234); engagement through making and contributing to decisions that affect one's self (Ansell, 2005:236); and some degree of independence (Hart, 1992:5&6). Behaviours indicative of control included enthusiasm, independence, self-confidence, assertiveness, acting deliberately and determinedly (Hersch & Scheibe cited in Lefcourt, 1982:176). Keeping the age of the participants in mind, the interviews were conducted after the children had completed all of their AAA sessions, with the aim of gaining insight into their experience of the AAAs in general, and not of any particular aspect of the process. Following each of the AAA sessions, the researcher compiled field notes as a means to reflect on the data and the observations (Bogdan & Biklen, 2003:110-111). In light of the lack of usable data collected from the interviews, the researcher decided to include graphic questionnaires as a complementary form of data collection. This decision was premised on research into the development of alternative communication methods to direct verbal communication, for those children who struggle to express themselves (Rabiee *et al.*, 2005:388; Triangle/NSPCC, 2001).

The researcher made use of the steps proposed by Tesch (1990:142-145) as a framework for data analysis. This included familiarisation and immersion; identifying behavioural themes of participation and control; elaboration and interpretation; and finally checking. External coding and peer examination were conducted extensively by the supervisor and co-supervisor of the study, to ensure the credibility, dependability and confirmability of the findings.

4. SUMMARY OF RESEARCH FINDINGS

The study found that engagement with AAA could enhance the experiences of participation and control of children hospitalised with cancer. This finding is important, given that cancer diagnosis and treatment are typically associated with loss of control and lack of participation. These findings were based on non-participant observations of AAA sessions, graphic questionnaires, and on the researcher's reflections recorded in the field notes.

The participants' approaches to the dog improved over the course of the AAA sessions. They showed greater levels of participation in the final session, as compared to the initial session.

Participants gradually assumed leadership roles in their interactions with the dog and were therefore able to exert greater control over these interactions. The basic human need for affection was met through their grooming of the dog. The sense of responsibility that many of the participants felt towards the dog provided them with a sense of purpose, which according to Owusu-Ansah (2008:63) is essential for the enhancement of control. Another area of improvement was in the children's expression of laughter and joy, which has been shown to assist in the adjustment to cancer (Dowling *et al.*, 2003:271). Cancer and its treatment can have pernicious physical affects, and all of the children participating in the study displayed various physical side effects. As a result, most were initially acutely aware of their bodies during the sessions, displaying discomfort and protecting their bodies. Over the course of the AAA sessions, the participants showed a reduced awareness of their bodies: their body movements were more relaxed and they made fewer efforts to conceal or protect their bodies. The numerous physical benefits of AAA have been thoroughly substantiated in existing literature on AAI, and it is likely that the participants experienced some of these benefits during the sessions. These benefits enabled the children to regain control over their bodies, using them to exert control in their relationships with the dog. These physical benefits may also have allowed children to participate more fully in the sessions, as the physical side effects that had previously represented obstacles to participation were reduced.

The participants' levels of engagement, including their levels of initiative and choice, were also seen to increase over time, with most children requiring less encouragement or coaxing from the volunteer or parent. In the later sessions, most children managed to overcome their initial fears or challenges and began initiating activities on their own and exercising choice. The participants' sense of control was enhanced when exercising choice, since they could participate in the AAAs and interact with the dog according to their own needs and wants. Participants who showed initial dependence, either on a parent or the volunteer, tended to progress towards greater levels of independence, again observed in their self-initiated activities and in those instances where they assumed leadership roles in relation to the dog. Some children exercised their independence by engaging in activities on their own and by physically separating themselves from the volunteer. These findings are in line with previous research that has shown AAAs to increase levels of independence (Kaminski *et al.*, 2002:322). Growing independence signals enhanced control because, rather than the child solely following someone else's lead, he/she had the opportunity to take the lead him-/herself.

Lastly, both the verbal and non-verbal aspects of the children's communication reflected the observed changes. Those participants who at first could only talk passively to the dog managed to assertively command the dog in later sessions. This clearly signalled that children were assuming and exerting control. Cancer diagnosis and treatment have been shown to induce feelings of uncontrollability. The unpredictable nature of cancer places even greater importance on the predictability, controllability and reliability of the dog's behaviour (Fredrickson & Howie cited in Fredrickson-McNamara & Butler, 2010:121-130). Specifically, if the dog is compliant with the

children's instructions, it can lead to an increase in control on the part of the child. For those children who were not comfortable with verbal communication, engaging in AAAs provided them with opportunities to express themselves in non-verbal ways and therefore enhanced their participation in sessions, by allowing them to use their preferred medium of communication.

The results of the study strongly indicate that engaging in AAA can enhance the participation and control of children hospitalised with cancer.

5. RECOMMENDATIONS

The researcher's experience conducting research into the participation and control experienced during AAAs by children hospitalised with cancer has provided her with insight into how AAAs can be implemented in practice and how children hospitalised with cancer can be supported, such that their participation and control are enhanced. With hindsight, the researcher acknowledges several challenges to her study, which can be addressed in future research. Several recommendations for future research are provided here so that research in the field of AAA can be expanded.

5.1. Animal-assisted activities in practice

Best practice involves establishing equal importance between the wellbeing of the child *and* the welfare of the animal (Melson & Fine, 2010:240). In order to ensure the wellbeing of the child, the following recommendations for conducting animal-assisted activities can be considered:

- The volunteer should be conscious of providing the child with choices throughout the session. This is easily achieved by asking the child which activity he/she would like to engage in. In this way, the children can begin to exercise control in the animal-assisted activity session and participate according to their own needs and wants.
- The content of conversations can be used to increase participation and control. Participation can be enhanced by allowing children to talk about topics that are relevant and applicable to their lives and by encouraging children to talk about what they want. In cases where participants initiate a discussion about cancer of their own accord, feelings of control can be heightened by the provision of information about their illness. This is in line with previous research, in which children reported the need and desire for information about cancer and expressed that this was an important way for them to feel part of their cancer experience. In these instances, it is recommended that an informed health professional be available for some of the sessions, to provide this information as and when it is needed. However, oftentimes participants did not initiate discussions about cancer, and many of them in fact reported that engaging in the AAA session assisted them in forgetting that they had cancer. They also reported that the sessions helped them think about their bodies and their health as "all right and okay". Here the participants' control may still have been enhanced, as the AAA sessions provided them with an

opportunity to “escape” from cancer. This is consistent with existing research in the field of AAA, which explicates that AAA can function as a form of distraction from illness.

- Based on this, it is recommended that AAT rather than AAA be utilised as AAT is a more goal-directed intervention which can be conducted only by a trained health professional within his/ her scope of practice. As a trained health professional, the individual will have experience and expertise in interacting with children and will therefore be able to utilise the animal in such a way as to encourage self-expression.
- In cases where verbal communication seems to be stagnant, the volunteer could use the activities during the session as a means to deflect the children’s attention away from verbal communication and thus, indirectly, to facilitate it. However, where children are overtly uncomfortable with verbal communication, the volunteer should avoid bombarding the children with direct questions. Rather the volunteer should try establishing a balance between encouraging the non-forthcoming child to engage in the activities and simultaneously respecting his/her nature.
- As such, it is advisable that the volunteer has significant experience conducting animal-assisted activities and significant experience working with children. Previous experience makes it more likely that a volunteer will be well prepared for sessions, bringing all the treats, balls and toys necessary for the activities.
- The age of the dog should also be considered when working with children. In this study, the children seemed to respond better to a younger, more playful dog.

A strict code of conduct should be adhered to by the volunteer, as he/she is responsible for eliciting only desirable behaviour from the dog. The AAA organisation that was partnered with for this study does have its own standards of practice; however, according to Fredrickson and Howie (cited in Fredrickson-McNamara & Butler, 2010:121-130), there are certain general standards of practice that should be adhered to when selecting animals for AAI engagement.

The volunteer dog should be reliable, with similar responses elicited in similar contexts. This reliability allows for increased safety and consistency, and it can be achieved through rigorous obedience training and behavioural assessment. Most of the children expressed a preference for the dog that came to the first few sessions, and the researcher attributes the preference for and comfort with this particular dog to the dog’s initial consistency. The volunteer should, in general, be able to predict the dog’s behaviour in advance and therefore be able to respond appropriately to what is occurring at any given time between dog and child. Because the focus of this study was on participation and control, it was important that the volunteer allow the child to lead the sessions yet still have confidence in the predictability of the dog’s behaviour. Controllability involves managing or guiding the behaviour of the dog, and the interactions between dog and child. Controllability can be enhanced through volunteer experience as well as through obedience training of the dog.

- Finally, there are definite ethical considerations to consider when working with any animal in an animal-assisted intervention context (Weideman, 2007:122):
 - The dog's basic needs should be met including, but not limited to, food, water, rest and care (Serpell, Coppinger & Fine, 2010:417). This was ensured at the lodge by providing fresh water, shade and snacks to the dogs. AAA sessions ran no longer than 45 minutes so that the dogs did not become exhausted.
 - Zoonotic infections or parasitic disease should be considered when working with dogs. This is especially relevant when AAAs will be conducted either in a hospital environment or with those individuals who are susceptible to infection, such as the children receiving chemotherapy and at risk of neutropenia. Based on this, individuals who want to participate in AAA sessions need to be screened for health vulnerabilities and the environment in which AAA sessions will occur needs to be appropriate such that only those individuals who have expressed a desire and are healthy enough will come into contact with the dog (Weideman, 2007:123). Ward doctors were consulted, and permission obtained, about the health of participants before each and every AAA session commenced.
 - Furthermore, dogs need to follow a comprehensive infection strategy and volunteers, together with the managing AAA organisation, should ensure continuous veterinary check-ups and consultations (NSW Ministry of Health, 2012:9-10). As members of the AAA organisation, volunteers are required by regulation and policy to ensure their dogs are up to date with inoculations and a parasite control programme is in place.

5.2. Supporting children diagnosed with cancer

The following recommendations for supporting children diagnosed with cancer should be considered as a means to enhance participation and control:

- Based on the findings of the research, it is recommended that hospitals establish working relationships with organisations that offer animal-assisted interventions. In the graphic questionnaires, the children reported that they enjoyed the AAA sessions and found them beneficial, and that the interactions with the dogs assisted positively with regards to their self-concept. Moreover, the conclusions drawn from this study suggest that AAAs may offer a form of support, in terms of enhanced participation and control, to those children hospitalised with cancer. It is hoped that this translates to other aspects of children's lives and that they experience the same enhanced participation and control in additional contexts, such as the hospital ward and their home and school environments.

- Hospitals should work towards creating a policy that encourages animal-assisted activities as a supportive intervention.
- In cases where hospital policy does not permit dogs in the wards, hospitals should utilise spaces that are on the hospital premises but not considered part of the ward, such as a garden.
- Children hospitalised with cancer can be further supported through ensuring their participation in the decision-making process. According to Dixon-Woods and Young (cited in Coyne *et al.*, 2011:2), assuring children's participation can prove challenging because of the triadic relationship that exists between the parent, the child and the health professional. Parents and health professionals can, however, be made aware of the importance of children's participation, which would ultimately assist in supporting the child.

5.3. Future research

The following recommendations for future research should be considered:

- Given the limited amount of research into AAAs and children with cancer, particularly in South Africa, it is recommended that future research addresses this gap.
- It is important to understand the qualities of an animal—in this case, a dog—that are most likely to positively influence the health and well-being of individuals from different cultural backgrounds and histories. This is particularly relevant for the South African context, which is composed of a multitude of cultures. Individuals from different cultures may respond differently, and more optimally, to certain animals. For example, many African cultures are premised on animal folklores, which can influence the conceptualisation of certain animals. Without this deeper cultural understanding, we may make generalisations that can result in ineffective AAA implementation. Future research should therefore look to investigate these cultural factors (Beck & Katcher, 2003:85).
- Future studies could explore whether a resident animal would be beneficial to children hospitalised with cancer (Beck & Katcher, 2003:85). The hospital where this study was conducted did not have a resident animal, and this situation is something that could be explored in future research. This could be advantageous in that children would have an opportunity to establish an attachment to the animal and in this way benefit even further from the human-animal bond. This might be particularly applicable to the South African context where many individuals from impoverished situations can not afford to own their own pets. On the other hand, the notion of resident animals is a contentious issue because the welfare of the animal comes into question.
- Future research could explore other aspects of the relationship between AAAs and children hospitalised with cancer, beyond participation and control.
- Future studies on AAAs and on children hospitalised with cancer could also look at alternative non-directive data-collection methods that still obtain the children's perspectives.

- According to Katcher and Beck (2010:54), a significant amount of research conducted in the field of AAI attempts to contextualise the human-animal bond within the medical model. Quantitative approaches that focus on establishing the precise cause and effect of the human-animal bond may result in the powerful (often qualitative) effect that animals can have on the health and well-being of individuals being overlooked.
- It is suggested that future studies possibly explore the same aspects of AAAs and children hospitalised with cancer, but also investigate whether participation and control are affected by other factors in the children's lives, such as the home environment, the school context and particularly the ward.

6. LIMITATIONS

The following limitations of the study were identified:

- Individuals from different cultures conceptualise and perceive animals in different ways (Melson & Fine, 2010:241), which could have impacted the way each child responded to the dog, especially their initial reactions.
- Gender differences might have influenced the effects of AAA.
 - In general, females have a greater propensity for being nurturing than males. They are also usually more comfortable with smaller animals and might therefore react fearfully towards a dog that is perceived as big and threatening (Melson & Fine, 2010:241).
 - This study only included one female participant, since the population from which participants could be drawn was severely limited, with very few children fulfilling all of the criteria.
 - Including only one female participant implies that results might not be generalisable to other females.
- Although all of the children were competent in their use of English, for most of them English was not their first language. This could have impacted negatively on their ability to express themselves comfortably and effectively.
- The direct nature of the one-on-one interviews proved challenging for both the children and the researcher, and no useable information was gleaned during these interviews. The information derived from the interviews did not pertain specifically to the research question and although it reflected aspects of the participants' experience of AAA, they did not offer much information regarding participation and control. As a result, a large portion of data analysis and results were based on the non-participant observations. One of the ways this shortcoming was addressed was the inclusion of graphic questionnaires, which ensured that the children's viewpoints were still

included. However, future research should consider other data-collection methods in order to increase the amount of data sourced from the children's own perspectives.

- For example, during the one-on-one interviews, AAA itself, as a non-directive technique, could have been considered as a means for enhancing communication. However, this technique would have needed to be conducted by an individual other than the researcher, so as not to confuse boundaries and roles.
 - The inexperience of the researcher in conducting one-on-one unstructured interviews also proved to be a limitation to the study. An assistant interviewer, especially a bilingual interviewer, with more experience could have been brought in to provide support.
 - The researcher experienced difficulty in maintaining her position as non-participant observer during the observation phase of data collection. Oftentimes the volunteer, parents or participants would initiate conversation with the researcher as she was present during the AAA sessions. Sometimes the topic of conversation was very personal in nature and the researcher felt compelled to convey empathy in this regard.
 - Furthermore, the researcher was tasked with organising the logistics of the AAA sessions in terms of liaising with the volunteer, parents and doctors. For example, on some occasions, the researcher had to drive parents and participants to the lodge. Having to assume the role of organiser sometimes resulted in a blurring of roles during observations of AAA sessions.
- The nature of cancer itself is unpredictable. Incapacity, treatment and hospitalisation are therefore constantly changing, according to the responsiveness of the child.
- This had an impact on the selection of participants for the study, as only those children deemed healthy enough to participate could be considered for the sample. Additionally, the children who formed the sample sometimes reacted negatively to treatment and could therefore not participate in the AAA sessions.
 - In light of this, the predictability of the dog sitting when a child instructs it to do so stands out as especially imperative.
- Hospitalisation was also subject to the unpredictability of cancer. While the definition of hospitalisation in this study took into account both inpatient and outpatient statuses, ultimately being hospitalised as an inpatient or outpatient had an effect on the impact of AAAs and participation and control.
- In those cases where children were outpatients, going home could have influenced aspects of participation and control that were not accounted for during data analysis, results and discussions.
 - A child who was exclusively an inpatient and who was hospitalised for the duration of the research process probably would have benefited more from engaging in AAAs, and the

aspects of participation and control would probably have been influenced to a greater extent.

- Focusing on the aspects of participation and control in relation to AAAs and children hospitalised with cancer had definite value; however, this specificity could have resulted in other important and unexpected aspects being overlooked.
- Another possible limitation is the inability to generalise enhanced participation and control reported during the AAA sessions to other aspects of the children's lives, particularly the hospital ward. This limitation could have been addressed if the researcher had observed the participants in the hospital ward and investigated other aspects of their lives, such as home and school.
- The hospital's policies proved limiting in terms of the areas in which AAAs could be conducted since dogs were not permitted in the wards.
- Internal hospital politics sometimes created confusion in terms of which children could be considered for the study, with some doctors approving certain children for AAAs while others disagreed. On certain occasions, doctors disagreed about whether a child who was already participating in the study was well enough to participate in the AAA session for that day.
- Future research should ensure that a non-disclosure agreement is signed by volunteers providing AAA as a means to maintain anonymity and confidentiality of participants.

7. GENERAL CONCLUSION

The findings from the study revealed increased participation and control experienced during AAAs by children hospitalised with cancer. Although these findings cannot be generalised to instances other than those AAA sessions in which the children engaged, the powerful effect of the human-animal bond on which AAA is premised is compelling enough to suggest that the AAA sessions have merit in and of themselves.

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SECTION E: ADDENDA

Addendum I: Observation Schedule

The Setting

- Physical environment, layout, context

Participants

- Describe who is in the setting
- Number of people and their roles

Activities and Interactions

- What is going on?
- Is there a definable sequence of activities?
- What activities does AAA consist of?
- Interaction of: child and dog; child and volunteer; volunteer and dog; child and activity; child and others
- Who listens? Who speaks? Content of conversations

Frequency and Duration

- When does the activity begin?
- Length of activity?
- Is it a typical activity?
- Exceptions?

Subtle Factors

- Body language, non-verbal behaviour, facial expressions, physical space
- Silences
- Norms and rules that structure the activities

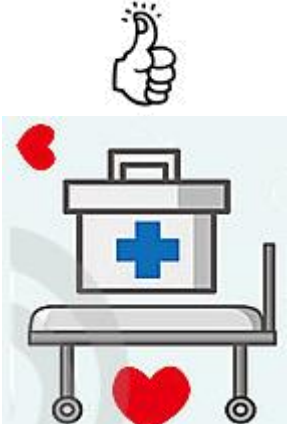


Addendum II: Intervention Interview Schedule

Intervention Interview Schedule


Now that the dog has visited you how was it for you?

Addendum III: Graphic questionnaire



Shante and Flossie coming to the hospital...

<p>Made it easier for me to come to the hospital</p> 	<p>Made it harder for me to come to the hospital</p> 	<p>It did not change how it was for me coming to the hospital</p> 
--	--	---



My visits with Shante and Flossie made me think about myself...

<p>As happy, strong and believing in myself</p> 	<p>As sad, not strong and like I can't do things</p> 	<p>As no differently than before they came to visit me</p> 
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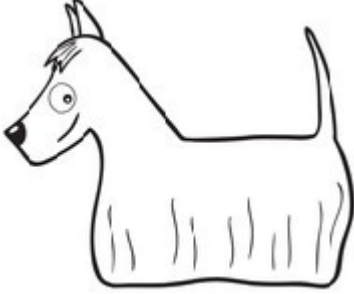

During the visits with Shante and Flossie...

<p>I thought about my cancer</p> 	<p>I forgot about my cancer</p> 
--	--



My visits with Shante and Flossie made me think about my body and health...

<p>As all right and okay</p> 	<p>As not alright and not okay</p> 	<p>As not differently than before they came to visit me</p>
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Shante and Flossie coming to visit me was...

<p>Helpful</p> 	<p>Not helpful</p> 	<p>So so I don't know Kind of</p>
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When Shante and Flossie came to visit me I...

<p>Had pain, nausea and sickness</p> 	<p>Had no pain, nausea and sickness</p> 
--	---


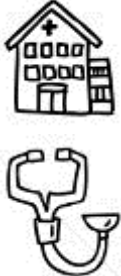
When Shante and Flossie came to visit me I felt...

<p>Stressed, anxious and depressed</p> 	<p>Calm ,relaxed and happy</p> 	<p>So so I don't know</p>
--	--	-------------------------------

When Shante and Flossie came to visit me...

<p>I enjoyed it</p> 	<p>I did not enjoy it</p> 	<p>So so I don't know Kind of</p>
--	--	---

When Shante and Flossie came to visit me...

<p>I forgot that I was at hospital</p> 	<p>I did not forget that I was at hospital</p> 	<p>Kind of</p>
--	--	----------------

I liked _____ the most

Brushing the dog	Walking the dog	Petting/ touching the dog	Throwing the ball for the dog	Swinging the dog in the swing	Telling the dog to sit/ lie down/ stay	Giving treats to the dog	Nothing
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Addendum IV: Child assent form

PARTICIPANT INFORMATION LEAFLET

TITLE OF THE RESEARCH PROJECT: Participation and control experienced during animal-assisted activities by children hospitalised with cancer

REFERENCE NUMBER: NWU-00082-12-A1

PRINCIPAL INVESTIGATOR: Monique Simon

ADDRESS: 1 Rue Mer, Marais Road, Sea Point, Cape Town, 8005

CONTACT NUMBER: 072 3702732

Dear Child,

My name is Monique and I am a student at North-West University. I would like to invite you to be a part of my research study.

What is a research study?

Research studies help us learn new things. We can explore new ideas. First, we ask a question. Then we try to find the answer.

This leaflet talks about my research and the choice that you have to take part in it. I want you to ask me any questions that you have. You can ask questions at any time.

What is my research study about?

My study is about dogs and you. I am interested in your experience of the dog that comes to visit you at the hospital. I would like you to tell me about how you find the visit.

Important things to know...

- You get to decide if you want to take part.
- You can say 'No' or you can say 'Yes'.
- No one will be upset if you say 'No'.
- If you say 'Yes', you can always say 'No' later.
- You can say 'No' at any time.

What would happen if I join this research study?

If you decide to join this research then I will ask you some questions before the dog comes to visit you then you will say your answers out loud. The dog will then come and you will do some fun activities together like playing. After the dog has left, I will ask you some questions again.

Who will know what I have said?

If you tell me something and do not want me to tell anybody else, even your parents, then we will keep it a secret. I will also not use your real name in the research study so no one will know that it was you who took part in the study. It is important to remember that we do not need to talk about anything that you are not comfortable with, and you are allowed to say ‘no’ to being part of the study even after we have started.

Could bad things happen if I join this research?

I do not imagine that something bad will happen to you. The dog that will come to visit you is trained and well behaved. The dog will be a friendly dog who has also visited lots of other people.

Could the research help me?

This research will not help you. I do hope to learn something from this research though. And someday I hope it will help other kids who are hospitalized with cancer like you.

Is there anything else?

If you do not want to take part then you do not have to. If you want to be in the research after we talk, please write your name below. I will write my name too. This shows we talked about the research and that you want to take part.

Name of Participant.....

Signature of Parent/ Guardian.....

Printed Name of Researcher

Signature of Researcher.....

Signed at (place) On (date) 2013.

Addendum V: Parent informed consent form

TITLE OF THE RESEARCH PROJECT: Participation and control experiences during animal-assisted activities by children hospitalised with cancer

REFERENCE NUMBER: NWU-00082-12-A1

PRINCIPAL INVESTIGATOR: Monique Simon

ADDRESS: 1 Rue Mer, Marais Road, Sea Point, Cape Town, 8005

CONTACT NUMBER: 072 370 2732

Dear Parent

Your child is being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how your child could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline the participation of your child in this study. If you say no, this will not affect you or your child negatively in any way whatsoever. Your child is also free to withdraw from the study at any point, even if you do agree to the consent of your child taking part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of this research is to explore and describe the experiences of participation and control during animal-assisted activities by children hospitalised with cancer.

Animal-assisted activities are casual encounters involving activities with animals, usually dogs. These causal meetings are generally flexible and unstructured, and the child may be in charge of the nature of these encounters. Activities can include any number of things such as brushing the dog or having

the child share his/her feelings with the dog. Animal-assisted activities are managed by a specially trained volunteer with a dog who is also specially and strictly trained. The dog will also have been bathed before visiting the child, be up to date with his/her vaccinations and be in strictest health.

Child hospitalised with cancer can sometimes feel out of control and a lack of power over their own lives. Some children may also feel sad, lonely and anxious in addition to also experiencing pain and discomfort as a result of their cancer treatment. Research that has been done before has found that many children who are involved in animal-assisted activities feel more control and power over their lives.

Why have you been invited to participate?

Your child has been invited to participate in this research and as the child's parent/guardian you are being asked to give your consent for your child to take part in this study. Your child will also be asked if he/she would like to be involved. Again, this is entirely voluntary and either you or your child may decline. It is believed that your child might be able to share his/her experiences during animal-assisted especially around the topics of participation and control.

What will your responsibilities be?

Your responsibilities will not include anything more than what you are currently responsible for. If you do decide that your child may take part in this research he/she will be take part in animal-assisted activities at the CHOC house over a period of approximately one month. In the final week your child will be interviewed by the researcher. The researcher will ask your child questions about his/her experiences during animal-assisted activities. An audio recording will be made of the interview.

Will you/your child benefit from taking part in this research?

Although there are no direct benefits for your child by taking part in this study, research that has been done before indicates that your child may feel happier, less lonely, less anxious, a decrease in pain as well as experiencing feelings of greater control over his/her life. Your child may also feel like he/she is participating more in decisions concerning health and treatment which could positively affect the child. It is thought that as the parent/guardian of the child who is taking part in the research you might see these potential positive effects.

Are there in risks involved in your taking part in this research?

The risks are very minimal. Every precaution is taken when doing animal-assisted activities. The dog handler is specially trained; the dog has gone through strict behavioural training and has been assessed to be child and people friendly. The dog is also required to be in excellent health and up to date with all vaccinations.

Who will have access to your/ your child’s information?

The identity of you/ your child will remain strictly confidential. Personal detailed will not be shared with anyone besides other researchers who are directly involved in this project. All recordings, interview transcripts and any other materials associated with this study will be securely stored under lock and key on university or hospital premises. Anonymity will be ensured by the use of pseudonyms so that no one will be able to identify your child/ you.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you/ your child, if you do take part. If however unexpected transportation costs are necessary, you will be provided for this.

- You can contact Professor Stefan at 021- 938 9584 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I give consent for my child to take part in a research study entitled Participation and control experiences during animal-assisted activities by children hospitalised with cancer .

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I/ my child have not been pressurised to take part.
- I/ my child may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I/my child may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I/my child do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2005.

Signature of participant

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2005.

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.

- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

Signature of interpreter

Signature of witness

Addendum VI: AAA organisation permission letter



4 October 2013

Ms Monique Simon

Dear Monique

Re: PERMISSION DO TO RESEARCH

On behalf of the Pets as Therapy (PAT) EXCO, it is our pleasure to grant you permission to conduct your research "*Participation and control experienced during animal-assisted activities by children hospitalised with cancer*" in cooperation with Pets as Therapy.

Please remember that our members are volunteers and that they are giving their time for this project. They do have to work according to PAT rules and the rules of the facility, in this case the hospital. We do need a copy of your final research proposal, consent forms and ethical clearance for our records purposes.

On behalf of PAT, we wish this initiative much success and look forward to regular progress reports as well as a copy of your final thesis.

Yours sincerely

Dr. Marieanna C le Roux
Chair: Pets as Therapy

Addendum VII: Ethical clearance



Private Bag X8001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Ethics Committee

Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za
2013/06/19

This is to certify that the next project was approved by the
NWU Ethics Committee:

Project title: *"Developing Sustainable Support to Enhance Quality Of Life and Wellbeing for Children, Youth and Families In South Africa: A Trans-Disciplinary Approach"*

NWU Ethics approval no: NWU-00082-12-A1

Project leader: Dr. Herman Grobler


We hereby confirm that the next student's research project is running under the above mentioned, approved Research Ethics project.

Student: Monique Simon)

Title: "Participation and control experienced during animal-assisted activities by children hospitalised with cancer"

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely



Me. Marietjie Halgryn
NWU Ethics Secretariate



UNIVERSITEIT-SELLENBOSCH-UNIVERSITY
Jou kennisvennoot • your knowledge partner

**Approved with Stipulations
Response to Modifications- (New Application)**

08-Nov-2013
Simon, Monique M

Ethics Reference #: S13/08/145

Title: Participation and control experiences during animal-assisted activities by children hospitalized with Cancer.

Dear Ms Monique Simon,

The **Response to Modifications - (New Application)** received on , was reviewed by members of Health Research Ethics Committee 2 via Expedited review procedures on 16-Oct-2013.

Please note the following information about your approved research protocol:

Protocol Approval Period: 08-Nov-2013 -08-Nov-2014

The Stipulations of your ethics approval are as follows:

1. On p.27 kindly update the section "What is my research study about?" to indicate that the participant is being offered AAA and that someone will ask them about their experiences of the AAA, if they decide to try it.

Please remember to use your protocol number (S13/08/145) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rdi and should be submitted to the Committee before the year has expired.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rdi

If you have any questions or need further assistance, please contact the HREC office at 0219389207.

Included Documents:

LETTER

ETHICS AMENDMENTS

DEC LETTERS

APPLIC FORM

IC FORM

Addendum VIII: Author guidelines of the journal – *Supportive Care in Cancer*

13/5/2014

Supportive Care In Cancer



www.springer.com

Medicine - Oncology & Hematology | Supportive Care In Cancer



Supportive Care in Cancer

Editor-in-Chief: Fred Ashbury
Editor-in-Chief Emeritus: Hans-Jörg Senn
ISSN: 0941-4355 (print version)
ISSN: 1433-7338 (electronic version)
Journal no. 520

Instructions for Authors

Instructions for Authors

• Original Articles – bodytext is limited to 3500 words. There may be 45 references and no more than six figures/tables.

Review Articles – generally solicited by the editors but unsolicited proposals containing an abstract and outline can be sent to the editors for consideration. The word limit for Review Articles is up to 4,000 words for body text (excludes figures, charts, references, abstract).

Letter to the Editor – SCC occasionally accepts letters to the editor pertaining to articles published in the Journal. These should not exceed 1000 words bodytext and will be passed to the authors of the article to which the comment applies to solicit a response. There may be up to 10 references.

Commentary – articles should be on innovative areas or opportunities for further research. The bodytext is limited to 1,000 words. There may be up to 10 references, and one figure or chart.

REVIEW PROCEDURE

All manuscripts undergo strict peer review. Manuscripts are initially considered by the Editor-in-Chief. Any manuscript that does not meet the general certain criteria of the journal, e.g.

- relevance to the aims of the journal with the topic being of overall general interest
- sufficiently original and contributing to the advancement of the field,
- clearly written with appropriate study methods, well-supported data and conclusions which are supported by the data

will be returned to the author without review.

All other submitted manuscripts are assigned to an Associate Editor who will manage the external peer review process and editorial decision. The Journal encourages authors to recommend individuals who could be considered as reviewers, providing the editorial office with full names and contact details. Authors are also given the opportunity to request the