

# **THE EXPERIENCES OF SIBLINGS OF PEDIATRIC CANCER PATIENTS: A PRELIMINARY SOUTH AFRICAN PERSPECTIVE**

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## DECLARATION

By submitting this dissertation, I, declare that the work contained therein is my own original work,

And that I have not in its entirety or in part submitted it to obtain any previous qualification. All sources have been properly acknowledged.

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## ABSTRACT

When a child is diagnosed with paediatric cancer, the entire family is affected. Relating to the impact of this new family diagnosis, it is often the siblings of the ill child who carry the greatest hidden burden of stress. Although there is a sound and growing body of international research pertaining to the sibling cancer experience, South African research on this topic is almost non-existent, and there is still much to be learnt. As a result, the present study aimed to gain a better understanding of the cancer experience from the perspective of South African siblings. To this end, semi-structured interviews were conducted with 10 healthy siblings who have a brother or sister who was diagnosed with paediatric cancer. The sibling sample comprised of 4 boys and 6 girls (Aged 8-18) who reside in the Western Cape Province of South Africa. Data collected through the sibling interviews was analysed by means of thematic analyses. Five overall themes evolved from the siblings' narratives. These themes related to the concept of cancer; concerns and worries; emotional experiences; changes; and resources and coping. Within each of these overarching themes, various sub-themes were also noted. In order to gain a holistic understanding of the sibling cancer experience, the five themes were contextualised and discussed in terms of various developmental theories including: Erikson's psychosocial (socio-emotional) developmental theory; Piaget's cognitive developmental theory; and Bronfenbrenner's Bioecological systems theory. Although findings relating to the cancer experience for siblings in the present study did not differ tremendously from those noted in previous research, the results still made a valuable contribution to the existing body of knowledge involving siblings and paediatric cancer. Light was shed on the unique cancer experience for 10 South African siblings, and great insight was gained into their unique emotional worlds. In conclusion the present study's contributions as well as shortcomings were discussed, and intervention guidelines and recommendations for future research were provided.

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# CHAPTER 1

## INTRODUCTION

Chapter 1 comprises of a general introduction to the present study. The motivation and aims for the study are discussed, thereafter an overview of the theoretical framework and key-concepts is provided. The chapter concludes with an outline of the dissertation chapter by chapter.

### 1.1 INTRODUCTION

The diagnosis of paediatric chronic illness seriously effects the entire family (Dauz Williams, 1997; Wilkins & Woodgate, 2005). It is estimated that between 10 and 20 % of children worldwide suffer from some or other form of chronic illness, with the impacts of these illnesses differing considerably relating to various factors (Midence, 1994). The following quote explains the phenomenon of chronic illness aptly. According to Nelson (quoted in Menke 1987), “Any condition, congenital or acquired, that alters physical growth and development and requires extended or sequential services can be legitimately defined as chronic” (p. 134). Each form of chronic illness comprises a different trajectory, this relating to treatment, onset, symptoms, degree of incapacitation and prognosis (Menke, 1987). However, children with chronic illness are not the primary focus of the present study, the population of interest relates to those who feel the secondary impacts of these chronic illnesses, in particular the brothers and sisters of children who have cancer.

Cancer in childhood is one of the most common illnesses of a chronic nature to be diagnosed. The Childhood Cancer Association (CHOC) estimates that worldwide the incidence of childhood cancer is 150 per 1 million, and annually in South Africa 700 children under the age of 15 are diagnosed with some form of paediatric cancer (Childhood Cancer Foundation South Africa CHOC, 2011), and most of these children have siblings.

When a child is diagnosed with a life-threatening illness such as cancer, the whole family becomes involved; families must adjust to the reality of the diagnosis, and at the same time try to balance family functioning. Treatment advances and extended survival means that families often deal with ongoing stress surrounding cancer even after cessation of treatment (Wilkins & Woodgate, 2005). This process of finding balance and adjusting to the cancer diagnosis often alters the pattern of life for the family and healthy siblings (Nolbris, Enskär & Hellström, 2007). Thus, cancer is not only an individual

diagnosis, but one which affects the entire family. Each of the family members has to adopt a new role, a role which evolves around the illness. Relating to the impact of this new family diagnosis, it is often the brothers and sisters of the ill child who carry the greatest hidden burden of stress (Menke, 1987). Siblings are over-looked during the childhood cancer experience, as health care professionals, parents, other family members and friends focus their attention on the ill child (Johnson, 1997; Murray, 1998, 1999a, 2000a, 2001). This inter-related approach to paediatric cancer which involves the whole family is derived from systems theory. This theory notes that what effects one family member also impacts all other members (Murray, 2000a). Some of the stresses noted to have an effect on family functioning include: the ill siblings daily care; the cost of the treatment; trips to the hospital, clinic or doctor; changes in family routines and relationships; differences in feelings and coping behaviours of each family member; the uncertainty surrounding the illness and situation; and the combined demands of coping with all these changes (Menke, 1987).

## **1.2 MOTIVATION FOR THE STUDY**

Many international studies have addressed the topic of chronic illness, and the impacts of this phenomenon on the family, parents as well as siblings. However, most of these studies followed a quantitative approach (Murray, 1998; Pacman et al., 2008), where questionnaires and scales were employed to try and make sense of this complex and emotionally charged topic. It is as a result of this limited approach that a more in-depth and qualitatively based study such as the present is warranted.

It should also be noted that in most of the studies up-to-date parents have been the main focus of research (Sloper, 2000; Van Dongen-Melman, De Groat, Haehlen & Verhulst, 1995). Parents were asked to comment on and assess the adjustment of their healthy children in relation to the presence of an ill brother or sister in the family. It has been shown that these parental comments are often inaccurate when compared to reports by siblings themselves (Houtzager, Grootenhuis, Caron & Last, 2005). This discrepancy thus points to the need for siblings to be the reporters of their own feelings and functioning. The present study is one that is of a self-reporting nature, and as a result of the aforementioned problem it is clear that a first hand account from siblings themselves is needed and justified.

Besides the limited nature of most of the existing studies, it is also important to note that as far as the researcher could ascertain, only one study focusing on the siblings of children with paediatric cancer has been conducted within the South African context (Boshoff, 2009), and as a result there is a contextual aspect lacking in the research to date. Although South Africa is seen as a country which is

on track in terms of development, it is not yet on par with the overseas American and European countries where most of the research to date has been conducted. It is felt that the experiences of South African siblings may differ from those experienced by siblings in first world countries. These differences could be based on the rich cultural diversity of our country and the many cultural strings attached to illness. Another possible influence could relate to the South African medical model, our medical care is good; however, there are definite shortcomings and challenges which could also contribute to different trajectories unfolding around the South African illness experience. This then creating the necessity to gain a deeper South African and home based feeling for the topic at hand.

Besides these above-mentioned motivations, probably the most important motivation for the present study lies in the important value that it may add to the fields of child and developmental psychology and nursing practice. Nurses and health care practitioners are probably the individuals who have the most contact with the family during the difficult time around diagnosis (Mussatto, 2006; Patterson, Holm & Gurney, 2004). Thus, it is necessary for nurses to be aware of the feelings and experiences of siblings so that they can answer questions and provide the appropriate interventions at the correct times (Wilkins & Woodgate, 2005). This timely intervention can aim to ensure that the negative effects which accompany the cancer experience are kept at a minimum.

A further motivation leads from the positive environment which is aimed at and links directly to the ill sibling. If the ill child is in an environment where there is support and where the family is functioning well as a unit, this will have a positive effect on the ill child's general well-being. This leads from the notion that the characteristics of the family and social environment have an important role to play in the process of illness and healing (Midence, 1994). Thus, a further positive outcome of the present study links to the identification of siblings needs to assist in creating a positive family environment where healing and wellness can be promoted.

### **1.3 RESEARCH PROBLEM**

The consequences resulting from paediatric cancer differ in their intensities and results; these results can sometimes take on a negative tone and have maladaptive outcomes for siblings. These adjustment difficulties could lead to depression, anger, anxiety, feelings of guilt, and social isolation (Murray, 2000a). If this is the case, then chronic illness can impact on and affect the daily functioning and emotional health of siblings who are unable to competently deal with the changes that come with diagnosis of cancer in a brother or sister. Therefore, the need to identify and develop modes of intervention for these possible sibling incompetencies is necessary. By doing this the parents, teachers

as well as health care practitioners who are involved in the day-to-day lives of these children can gain a better understanding, and thus a greater awareness of the sibling's emotional world, and the intricacies thereof. Through this understanding and by analysing the results of the present study, the foundation for the development of suitable strategies aimed at future prevention and intervention can be laid down.

Therefore, the purpose of the present study was to promote and broaden a better understanding of the experiences of 10 healthy siblings (aged 8 – 18 years) of children with cancer. These experiences were explored by means of semi-structured interviews.

## **1.4 AIMS OF THE STUDY**

The aims of the present study were:

- To explore the feelings and perceptions of siblings living with a brother or sister who has been diagnosed with paediatric cancer.
- To develop an overall thematic experience relating to living with a sibling with paediatric cancer.
- To develop a South African perspective relating to the topic of paediatric cancer.
- To identify strategies and resources to assist in preventing or reducing maladaptive outcomes in siblings of paediatric cancer patients.

## **1.5 THEORETICAL POINTS OF DEPARTURE**

Shaffer (2002) defined a theory as a set of propositions and concepts that can be used to describe, organise and explain observations. Therefore, theories make use of a specific viewpoint to shape and contextualise otherwise unmanageable data (Loxton, 2005). Leading from this, the present study can be contextualised and understood from the viewpoints of various developmental theories including: Erikson's psychosocial (socio-emotional) developmental theory; Piaget's cognitive developmental theory; and Bronfenbrenner's Bioecological systems theory. Taking these theoretical influences into account, Murray (2000b) stated that the impact that the childhood cancer experience has on siblings depends to a great extent on their developmental level. The socio-emotional and cognitive level at which the sibling is functioning when his or her brother or sister is diagnosed with paediatric cancer determines the psychosocial processes and adjustment that may be adversely affected by the event of a

sibling's cancer. As a result these three developmental theories (psychosocial, cognitive and bioecological) are outlined in terms of their relevance to the sibling childhood cancer experience.

### **1.5.1 Erikson's Psychosocial Developmental Theory**

Erikson (1963) emphasised the cultural and social determinants of personality. He believed that children contribute actively to their development through their efforts to adapt to their every-day environment (Wait, 2005). Erikson postulated that fundamental developmental changes span the entire human life cycle, from infancy to old age, and he consequently divided the life cycle into eight distinct stages of development. Each stage pertains to one of eight critical developmental periods during which certain socio-emotional tasks have to be mastered and a psychosocial crisis has to be resolved. These socio-emotional tasks which children have to work through occur in a circumscribed manner, with each task and crisis resolution being dependant on the resolution and mastering of the crisis and tasks of the preceding developmental stage (Wait, 2005). In the present study, Erikson's fourth and fifth developmental stages are relevant, as school-age (age 8-12) and adolescent (age 13-18) siblings were interviewed.

In terms of the resolution of their developmental crisis, School-aged children are striving to achieve a sense of industry while overcoming a sense of inferiority (Erikson, 1963). The successful resolution of this crisis depends on the child's ability to co-operate and compete with others. Furthermore, school-age children are faced with socio-emotional tasks relating to self-evaluation, team play and concrete operations (Wait, 2005). Linked to the mastery of these tasks, school-age children experience a transition in relationships; their strong relationships with family members evolve to include strong identification with peers. Friendships between school-aged children differ in duration and intensity when compared to those in the earlier years. Children no longer simply play alongside one another, but start to recognise friends and develop the needs and capabilities to cultivate more intimate friendships. The term "best" friend is also often uttered by school-age children. It is this "special" relationship that makes an important contribution to the child's emotional and social development (Wait, 2005). Thus, same-aged peers increasingly influence school-aged children's view of themselves and affect their self-esteem. If there is anything that labels a child as "different", this can influence his or her belonging to the friendship group. This sense of belonging is threatened when children can no longer participate in activities (For example, extra curricular school activities or outings with friends) because day-to-day family life has been altered as a result of additional care taking responsibilities related to the cancer experience. As school-age children become more isolated from their peer group, their sense

of belonging diminishes and intense feelings of loneliness and isolation may become dominant (Havermans & Eiser, 1994; Kramer, 1981; Murray, 2000b).

The physiological, psychological and emotional changes experienced by adolescents play a role in the main socio-emotional tasks of this developmental stage. These tasks include separation from parents, adaptation to a rapidly changing body and acquisition of a sense of identity and autonomy (Erikson, 1963).

For adolescents the peer group continues to grow in importance and becomes the standard against which acceptability is measured. During this time the most intense relationships outside of the home involve best friends of the same gender. Adolescents usually spend more time separate from their parents with their friends. In terms of the cancer experience, adolescents are mostly concerned with how this experience and the additional responsibility placed on them will affect their peer relationships and the time they can spend with friends. Because the childhood cancer experience may also bring about feelings of loss of control over everything in the adolescent siblings life, the role change and greater expectations placed on him or her may become intolerable for a sibling who is in the developmental stage of adolescence (Murray, 2000b). Furthermore, in some cases adolescents may also experience feelings of intense concern and responsibility towards their ill sibling and parents, and these feelings may negatively influence the developmental task of individuation and separation (Houtzager, Grootenhuys, Hoekstra-Weebers, Caron & Last, 2003).

### **1.5.2 Piaget's Cognitive Developmental Theory**

Cognition can be understood as the process of organising and attaching meaning to experience. Cognitive activities include tasks such as the interpretation of statements, synthesising data, solving problems, and the analysis of complex tasks (Loxton, 2005). The Swiss psychologist, Jean Piaget (1972), is acknowledged for his cognitive developmental theory, which has been described as one of the single most comprehensive and compelling theories of intellectual development. Piaget viewed development as “a product of an unfolding genetically driven plan for growth and change” (Loxton, 2005, p. 34). Therefore, Piaget (1972) stresses that as a child's cognitive system develops and matures; his or her knowledge of the world evolves as well (Bensch, 2010). In line with this, Murray (2000b) describes the cognitive developmental level at which the healthy sibling is functioning as the “lens through which understanding must be viewed” (Murray, 2000b, p. 42). Thus, the sibling's level of intelligence and his or her stage of cognitive development will influence the understanding and perception that he or she has of the cancer experience.



According to Piaget, intelligence can be defined as “a basic life process that helps an organism (in this case the healthy sibling) adapt to its environment. By adapting, Piaget means that the organism is able to cope with its immediate situation “(Shaffer, 2002, p. 50). As a result, children are depicted as active explorers who actively construct their cognitive worlds, meaning that children adapt successfully to their environment by making sense of and interpreting the information they come across (Bensch, 2010). This adaptation is done in two ways: assimilation (children interpret new experiences by incorporating them into that which is already known), and accommodation (children modify existing knowledge in order to accommodate new experiences) (Loxton, 2005). The way in which these processes of adaptation take place, are dependent on the child’s level of cognitive development. Piaget (1972) believed that a child’s cognitive development proceeds through an invariant developmental sequence, with each cognitive stage building on the preceding one (Piaget, 1972). Piaget’s third and fourth stages of cognitive development, namely the concrete operational and formal operational stages coincide with the developmental stages of school-age and adolescence, making them applicable stages for the present study.

During the concrete operational stage, great emphasis is placed on the attainment of concrete operational thought. This type of thought is characterised by a collection of concepts affording children the ability to reason (Berger, 2006). Piaget (1972) noted that, at some stage between the ages of 5 and 7, children become less egocentric and start to grasp certain logical principles, enabling them to apply logic in concrete situations – these being situations that deal with visible, tangible, real things - hereby enabling children to become greater thinkers (Bensch, 2010). When children grasp and acquire concrete operations, they start to think and reason more like adults (Wait, 2005). School-age children have a better understanding of causality, are less egocentric and have an advanced perception of time when compared to children in early childhood. Thus, due to their better cognitive understanding and maturity, school-age children may respond well to explanations of the cancer, its causes, treatment and diagnosis. However, despite their greater cognitive capabilities, school-age children may still associate previous misdeeds and bad thoughts with the cause of illness in their brother or sister. As a result siblings may experience feelings of intense guilt and responsibility relating to the cancer diagnosis in their ill brother or sister (Murray, 2000b).

During Piaget’s fourth and final stage of cognitive development (formal operational stage), children learn to explore logical solutions to concrete and abstract concepts. They can also understand and reason by means of analogy, metaphors and hypothetical thinking (Loxton, 2005; Piaget, 1972).

Typical achievements during the formal operational stage include the ability to imagine and reason about hypothetical outcomes (“what if?”), and children also start to show an interest in abstract issues, such as politics, religion, ethics, and other social issues. They are also able to develop an opinion relating to these issues (Meyer, 2005). These cognitive advances enable adolescents to hypothesise about outcomes of events, and they are able to estimate probabilities and limitations realistically. Additionally, adolescents develop an irreversible consciousness relating to their own mortality, which in siblings especially can lead to the development of existential fears. As a consequence of their greater cognitive maturity, adolescent siblings possess the full capability to estimate and understand the present risks and future consequences associated with their ill sibling's cancer. In the same developmental phase where existential fears appear, adolescents may develop increased emotional vulnerability and this could lead to psychosocial adjustment difficulties (Houtzager et al., 2003). The increase in cognitive ability enables adolescent siblings to have greater understanding of their ill sibling's condition, its treatment and prognosis. However, an adolescent's perception of the illness can also be distorted, and adolescents often believe that they are to blame for their brother or sister becoming sick (Murray, 2000b). Thus, to summarise the above, according to Piaget's (1972) cognitive developmental theory, the child's increased ability to understand and interpret his or her social and physical environment may influence the healthy sibling's interpretation and experience of their brother or sister's cancer diagnosis.

Keeping the above in mind, it can be noted that an awareness and understanding of the developmental stage of the sibling provides a perspective for contextualising sibling development, and for understanding sibling reactions to the childhood cancer experience (Murray, 2000b).

### **1.5.3 Bronfenbrenner's Bioecological Systems Theory**

Bronfenbrenner's (2004) bioecological systems theory stresses as its cornerstone the need to understand the development of the self within the context of the everyday environment within which children live and grow. As children grow and develop, they are influencing and being influenced by the context in which they find themselves. This process can be viewed in terms of a dynamic two-way (bi-directional) interaction, where the developing child is influencing and restructuring his or her environment, but at the same time is being influenced by the environment that surrounds him or her (Bensch, 2010; Craig, 1996; Loxton, 2005).

This interactive ecological environment in terms of Bronfenbrenner's (2004) theory views the child's social context as an arrangement of five concentric systems or levels. These levels include: the micro-

system (child's immediate environment); meso-system (interrelationship of various components of the micro-system); exo-system (outside of the immediate environment of the child, but still significant in development); macro-system (society and cultural components) (Craig, 1996); and the chrono-system (system which encompasses the dimension of time in the way that it links the various systems in terms of a child's development) (Moor, 2007). These five systems are interconnected, and change on one level creates a ripple effect causing changes on all levels of the system (Landsberg, Kruger & Nel, 2005; Nelson & Prilleltensky, 2005).

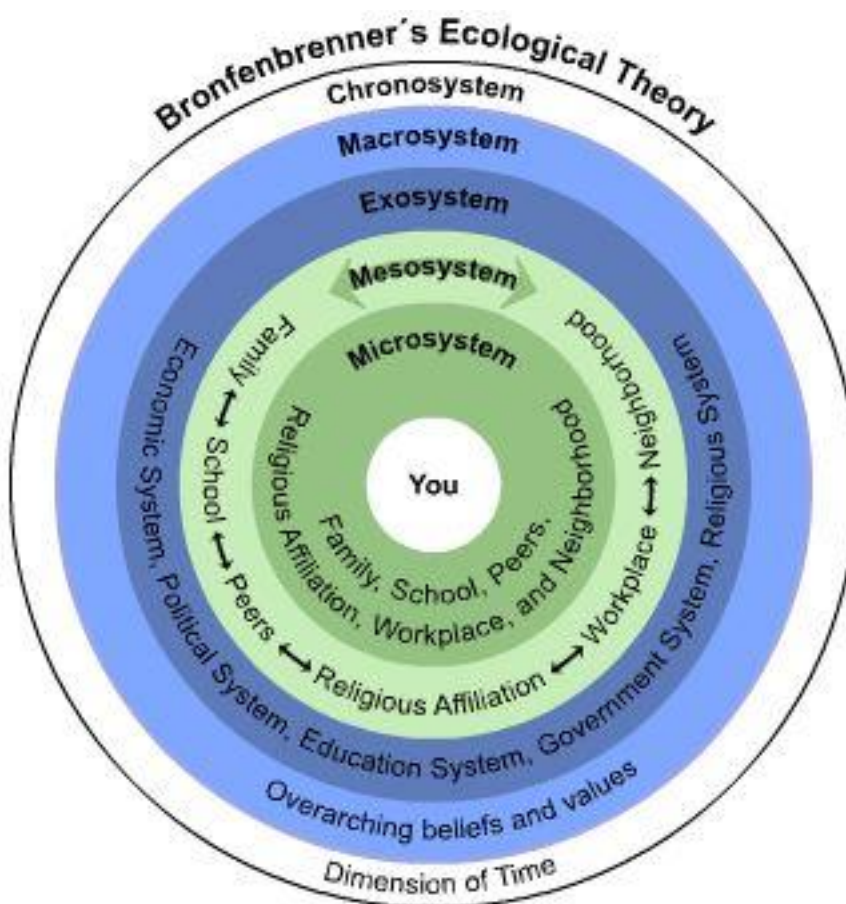
To colour in this explanation, Bronfenbrenner's bioecological system can be conceptualised as a series of five concentric circles with the child's biological and psychological make-up as determined by genetics and history found in the very centre (Loxton, 2005; Meyer, Loxton & Boulter, 1997). The next circle representing the micro-system constitutes the child's immediate physical and social environment, and includes those people with whom the child interacts on a regular and frequent basis (for example, parents, siblings, other family members, classmates and friends). The meso-system goes a step further, and can be viewed as a product of the interrelations amongst the links of two (or more) parts of the micro-system (for example, the links between home, school and friends). The third layer, the exo-system involves the interconnections between the micro-system and other systems which the child rarely has direct contact with, but which nevertheless still influences those which interact with the child and thus still influences the child on a secondary level (for example, the parents place of employment, the hospital and the media). Then the outer most layer of Bronfenbrenner's model, the macro-system, encompasses large-scale societal factors including cultural, political and economic conditions (Craig, 1996; Scileppi, Teed & Torres, 2000). This level incorporates the general beliefs, ideologies and attitudes which members of a certain culture or society promote (Bensch, 2010; Bronfenbrenner, 1979; Meyer et al., 1997). Examples of such promotions include: cultural beliefs with regards to child rearing; the role played by the family and the school regarding education; the impact of war, natural disasters and family or personal crises (for example, cancer); and ethical and moral guidelines held by the specific society which determine the behaviours and beliefs that are deemed acceptable. The macro-systems level plays a critical role in child development since it has the power to influence all the other levels of the system (Loxton, 2005). Then the final and broadest level of Bronfenbrenner's model the chrono-system. This system involves the dimension of time as it relates to a child's development, and this level overarches and has influence on all other levels of the system. Elements of time in the chrono-system can be either external (for example, the timing of a siblings cancer diagnosis) or internal (For example, the course of psychological changes that occur when a child develops and matures). As children grow older they may interpret environmental changes differently and show greater understanding for the outcomes and consequences associated with these

changes (Moore, 2007; Ryan, ND). Thus, children cannot be viewed as single entities floating around on their own, they are inter-linked with others and their everyday well-being is embedded within various levels as depicted through this bioecological systems model (Bensch, 2010).

Bronfenbrenner's bioecological systems model therefore provides a meta-framework within which the experiences of the sibling of a child with cancer can be contextualised and understood. Siblings' experiences could be influenced by or originate from any of the five systems in isolation, or by the interaction between these various systems.

**Figure 1:**

*Diagrammatic representation of the five levels of Bronfenbrenner's Bioecological systems theory.*



Sourced from: <http://faculty.weber.edu/tlday/human.development/ecological.htm>

### **1.5.3.1 Individual Factors**

On an individual level, the sibling's personal individual characteristics including age, psychological maturity, gender and developmental stage are determinants relating to how siblings may perceive the cancer diagnosis in their brother or sister (Barrera, Fleming & Khan, 2004; Gillespie & Scagliola, 2008).

Relating to gender, Barrera et al. (2004) describe healthy female siblings as being more anxious than male siblings. Girls are also said to experience more symptoms of post traumatic stress (PTS) as they often take on more responsibilities and express higher levels of empathy than boys (Lennon & Eisenberg, 1987).

With reference to age, Janes-Hodder and Keene (2002) describe younger siblings as more egocentric. Thus, younger siblings are more likely to feel guilty and view their sibling's illness as being their fault. According to Alderfer, Labay and Kazak (2003), children who were older than 6 when cancer was diagnosed in their brother or sister are more likely to show symptoms of PTS than children who were younger than 6 when the diagnosis was made. Reasons for this higher incidence include: a better memory for the events surrounding the cancer diagnosis and a greater involvement in family discussions on the topic (Alderfer et al., 2003). Labay and Walco (2004) noted that there is a positive correlation between the age of the sibling and his or her level of empathy. In their study they investigated the relation between empathy, concept of the illness, sibling-relationship-variables and psychological adjustment in siblings of paediatric cancer patients. They found that siblings who have a higher level of empathy experience less problems with psychological adjustment. It was further noted that empathy can help siblings integrate differences in the allocation of family resources (for example, time and attention from parents, material belongings, privileges). Siblings who have a greater understanding of the cancer treatment show higher levels of empathy, and thus also better psychological adjustment (Labay & Walco, 2004). Labay and Walco (2004) further state that it is possible that children who are less effective in their understanding of emotional states may find it more difficult to communicate their own emotional feelings. As a result they might resort to more impulsive and aggressive means of emotional expression.

### **1.5.3.2 Micro-System**

Influences on a micro-system level (immediate environment) include family factors such as family size, birth order and the nature of relationships within the family.

In terms of the experiences of siblings of paediatric cancer patients, the micro-systems level may have the most significant influence, as this is the level where the sibling relationship is directly involved. According to Labay and Walco (2004) there is a significant correlation between psychological adjustment variables and the birth-order of the cancer patient. They note that cancer patients who are later in the birth-order (younger) have siblings who show greater behavioural, scholastic and social problems. The reason postulated for this is that older siblings are more involved when it comes to communication around the cancer; it is also often expected of older siblings to become more self-sufficient as parental attention shifts to the care of the child with cancer.

Labay and Walco (2004) also report a significant correlation between family size and the psychological adjustment of siblings. It is assumed that the increased number of family members increases the complexity of inter-familial relationships, and the possibility of conflict relating to the satisfaction of each family members needs is also increased. In addition, greater family size means that there is increased competition for limited material and emotional resources.

Except for family size and family composition, the nature of relationships within the family can also influence siblings adjustment. Researchers such as Houtzager et al. (2005) and Labay and Walco (2004) note that intimate sibling relationships are not necessarily a prerequisite for successful adjustment during the cancer experience. Children who have a greater attachment to their ill sibling are more likely to show greater maladjustment after the cancer diagnosis. Labay and Walco (2004) claim that intimate relationships make siblings more vulnerable to adjustment difficulties. Children who are more intimately involved with their ill sibling are more likely to be affected by their brother or sisters suffering and pain, as opposed to siblings who are less intimately involved (Labay & Walco, 2004). The separation from, and the decrease in mutual interactions between the siblings (as one sibling is in the hospital), can also lead to higher vulnerability for adjustment difficulties in siblings who are in an intimate relationship with their ill sibling (Boshoff, 2009).

### **1.5.3.3 Meso-System**

Other social factors which could influence siblings during the cancer experience include: the school, peer group and other support networks. According to Barrera, Chung and Flemming (2005) children (siblings) who have a good social support network show fewer symptoms of depression, anxiety and behavioural problems than those whose support network is poor. Except for the family, a child's school and peer-group are viewed as two important social support structures. Landsberg et al. (2005) emphasise the supportive role that a teacher can play in the construction of a positive environment that over time will lead to the sibling keeping his or her self-concept in tact and feeling safe.

#### **1.5.3.4 Exo-System**

On an exo-systems level, siblings are not influenced directly. However, this level could exert an impact on the sibling of a child with cancer, especially in terms of stereotypes and misconceptions surrounding paediatric cancer. These misconceptions and beliefs which are held by others and projected onto the sibling can increase negative experiences and feelings that the sibling may have. The hospital and doctors are also involved on the exo-system level; in many cases siblings do not have direct contact with the specialist who is responsible for their brother or sisters treatment. However, the things which happen at the hospital still influence siblings, and these occurrences are often interpreted by siblings as great sources of uncertainty, fear and worry.

#### **1.5.3.5 Macro-System**

The macro-system incorporates the attitudes, beliefs, values and ideologies held by a specific group or culture (Landsberg et al., 2005). These factors can influence and be influenced by the individual, the family and the social system. Society's beliefs and attitudes towards cancer and the siblings' experience of these cancer-related beliefs is therefore a factor which can influence the cancer experience for siblings on a macro-systems level. Government legislation relating to health care and financial support to families who do not have private medical benefits are also highly significant on a macro-system level. If the family does not have sufficient monetary resources, they often have to rely on others to provide support or run up large bills in order to provide the ill sibling with the treatment he or she requires. This extra financial strain and worry may also exert a secondary impact on the healthy siblings and the family as a whole.

#### **1.5.3.6 Chrono-System**

The chrono-system over-flows to all other levels of the bioecological system and it involves the patterning of environmental events and transitions during the life cycle (Ryan, ND). Timing is very critical on this level. For the healthy sibling of a child with cancer, their age at diagnosis may play a critical role. Cohen, Friedrich, Jaworski and Copeland (1994) noted that the older the sibling at the time of diagnosis, the greater their understanding and knowledge of the cancer. It was also noted that parents shared most of the information relating to cancer closest to the time of diagnosis (Brett & Davies, 1988). Thus, siblings who are younger at the time of their brother or sisters cancer diagnosis may have limited knowledge related to the cancer later on. Therefore, timing and the effects of passing time play an important role on the chrono-systems level.

From the above augmentation it can be noted that Bronfenbrenner's Bioecological systems theory provides a helpful framework within which children's psychological development and its interaction with their everyday experience of cancer can be understood.

## **1.6 DESCRIPTION OF TITLE AND KEY CONCEPTS**

The title of the present study "The experiences of siblings of paediatric cancer patients: A preliminary South African perspective" will be discussed briefly. This title incorporates and synthesises the key concepts central to the present study. The study aimed to gain a deeper understanding of the experiences of the 10 siblings who were interviewed.

### **1.6.1 Experience**

According to the concise bilingual psychological dictionary (Plug, Louw, Gouws & Meyer, 2008), experiences can be defined as any event or feeling of a distinct nature which is associated with much emotion.

### **1.6.2 Sibling**

When using the term sibling in the present study, it refers to two or more children who were not born at the same time, but who share one or both parents (Plug et al., 2008). The sibling relationship could be either biological or legal, in this way not only blood relatives, but half and step siblings were also included. Nolbris et al. (2007) describe the sibling relationship as complex, intense and filled with variety. A sibling relationship is usually the longest relationship that an individual will be part of in their lifetime. Emotional bonds exist between brothers and sisters, and the bond between siblings has been described as fluctuating between warm and sensitive to being negative and filled with rivalry (Patterson, Millar & Visser, 2011). Anything that affects one of the siblings in a family can also have an effect on other family members. The family usually feels best when all members are together, and the relationships which exist between siblings often affect the emotional climate of the whole family (Dunn & McGuire, 1992; Nolbris et al., 2007).

School-age (8-12 years) as well as adolescent (13-18 years) siblings took part in the present study. Gibson and colleagues (Gibson, Aldiss, Horstman, Kumpunen & Richardson, 2010) noted that the needs and preferences of children may shift across different age groups. Children's lives change



drastically in a short number of years as they begin to establish their own autonomy. The understanding that children have of illness and health also changes, and therefore it is hypothesised that as children mature their needs, understandings and perceptions relating to paediatric cancer may also change (Gibson et al., 2010). Thus, the developmental level (socio-emotional and cognitive) at which the sibling is functioning when their brother or sister is diagnosed with paediatric cancer may play a role in the sibling's interpretation and perception of the cancer experience (Murray, 2000b) (See sections 1.5.1, 1.5.2 and 1.5.3).

### **1.6.3 Siblings with Cancer**

Siblings with cancer include the brothers and sisters of the 10 participants who were diagnosed with any form of paediatric cancer at any time in the past. The terms ill and sick siblings were used interchangeably in the present study.

### **1.6.4 Paediatric or Childhood Cancer**

In general, cancer can be understood as a collection of diseases which are characterised by uncontrolled growth and the spread of abnormal cells (Baxandal & Reddy, 1993). Paediatric or childhood cancer is cancer which occurs in childhood (usually diagnosed before age 15). Childhood cancers differ from those diagnosed in adulthood, and generally occur in developing cells, including bone marrow, blood, kidneys and tissues of the nervous system. The most common type of paediatric cancer is leukaemia, followed by brain and other tumours (lymph-retina-bone cancer and tumours found in muscular tissues).

Paediatric cancer requires specialist treatment by a paediatric oncologist, and treatment usually involves chemotherapy, radiotherapy or surgery, and in some patients a combination of these treatments is used. In some cases bone marrow or stem cell transplants are undertaken (CHOC, 2011). The treatment is often described as being more painful than the cancer itself, and these Treatments often involve many side-effects. Radiotherapy affects the nervous system and can cause behaviour problems and problems with concentration and memory (Eiser & Vance, 2002). Children often lose their hair as a result of chemotherapy and they are also said to be more susceptible to infections. Fatigue and tiredness are also common symptoms (Boshoff, 2009; CHOC, 2011). It is assumed that these side-effects also place additional stress on the families of children with cancer.

### 1.6.5 The South African Context

When referring to paediatric cancer and the South African context, there are various factors which should be kept in mind. In South Africa, less than half the children with paediatric cancer are diagnosed early enough and receive treatment in time (CHOC, 2011). International protocol states that children with cancer receive specialised treatment through a multi-disciplinary team of experts. South Africa does have world-class specialists. However, like in other developing countries these specialist services are only available at the major academic hospitals (Kathleen, Garankuwa, Pretoria academic hospital, Red cross children's hospital and Tygerberg in Cape Town, Pelonomi and Universitas in Bloemfontein, Addington and King Edward in Durban and Johannesburg Academic hospital and Baragwanath in Johannesburg) (CHOC, 2011). Thus, South African families of children with cancer often have to travel long distances to reach these facilities. Siblings of cancer patients who live in the "platteland" or rural areas most probably have to remain in the care of one parent or other caregivers while the ill child is taken to the hospital. According to CHOC the travelling involved to receive treatment adds an additional emotional and practical challenge to an already overwhelming situation (Boshoff, 2009; CHOC, 2011).

When describing South African culture, there are various aspects which are prominent. Aspects including multi-culturalism, ethnic diversity and collectivism are some of the important factors comprising South African culture. South Africa has often been referred to as the "rainbow nation"; this is a title which epitomises the country's cultural, linguistic and ethnic diversity. The population of South Africa has been described as one of the most complex and diverse populations in the world. Of the estimated 45 million people who live in South Africa, an estimated 31 million are Black, 5 million White, 3 million Coloured and 1 million Indian (Exploring South Africa, 2010). In addition to the diverse cultures which inhabit South Africa, South African people also speak a variety of languages, and the country boasts with 11 official languages (Explore South Africa, 2010).

Besides South Africa's diversity, the concept of collectivism is another aspect which comprises South African culture. Group cohesion refers to the degree to which individuals are integrated into groups. In terms of degree of cohesion there are two sides to the coin, individualism versus collectivism. On the individualist side, individualistic cultures are characterised by loose ties between individuals, and everyone is expected to look after him or herself and his or her immediate family. On the other side, in collectivist societies, people are integrated into strong, cohesive in-groups (often including extended families with uncles, aunts and grandparents) which protect and support each other with unquestioning loyalty (Hofstede, 2008).

The hospital where data collection for the present study took place is situated in the Western Cape, one of the nine provinces of South Africa. The Western Cape is the fourth largest of the nine provinces, and Afrikaans is spoken by the majority of Western Cape Inhabitants (55.3%). In the 2001 census, the majority (50.2 %) of the people living in the Western Cape described themselves as “coloured”, 31.1 % described themselves as “black African” and 18.4% said they were “white” (Statistics South Africa, 2001).

## **1.7 ORGANISATION OF THE DISSERTATION**

In Chapter 1 an introduction to the present study is provided. The motivation and relevance of the research regarding the South African context is outlined, and the research problem and aims are discussed briefly. Thereafter, the theoretical framework for the research is introduced and key concepts are defined.

In Chapter 2 a review of the relevant literature pertaining to paediatric cancer and siblings is provided.

Chapter 3 gives an overview of the methods used to obtain and analyse the data rendered by the present study.

The results rendered by the present study are reported and discussed in Chapter 4.

The study is concluded in Chapter 5, where results are summarised, conclusions are drawn and limitations and directions for future research are provided.

## **1.8 RÉSUMÉ**

Chapter 1 started with a general introduction to research regarding paediatric cancer and siblings, followed by an explanation of the motivation and significance of the present study. The research problem was then outlined and the theoretical background for the study and key-concepts were explained and defined. The chapter concluded with a chapter-by-chapter outline of the organisation of the dissertation.

Chapter 2 provides a review of the relevant literature pertaining to siblings and paediatric cancer.

## **CHAPTER 2**

### **LITERATURE REVIEW**

In this chapter a general review of the relevant literature is provided. The literature is presented systematically using Bronfenbrenner's (2004) bioecological systems theory as framework. The chapter starts with a brief overview of international literature concerning paediatric cancer and the family, followed by effects of the childhood cancer experience for siblings, with special attention given to emotional, socio-behavioural and physical effects. Research concerning the childhood cancer experience and its relation to needs, changes, quality of life, adjustment, coping and interventions is also discussed. The chapter concludes with an overview of literature relating to paediatric cancer and the South African context.

#### **2.1 INTRODUCTION**

The body of literature relating to paediatric cancer and the family is one which is no longer lacking in substance (Murray, 1998, 1999a). Although this topic has been afforded much attention over the past few decades, and patient and parent experiences of cancer are understood relatively well, very little consideration has been given to the experience of cancer from the perspective of healthy siblings (Murray, 1999a, 2000a, 2001). The first study to touch on this phenomenon was conducted by Cobb (cited in Murray, 2000a) in 1956. Cobb's study aimed to explore the psychological impact of illness and death on the family. The study employed a retrospective design, and unstructured interviews were conducted with parents of children who had died of cancer (Murray, 2000a). Results of this study made it clear that psychological effects of illness on the family do feature in the lives of well parents and other family members.

Subsequent to Cobb's study, interest in this field increased greatly. Studies of both a quantitative and qualitative nature have been undertaken, and studies have been conducted with a variety of different populations. Interest has focused on patients who have cancer themselves (Abrams, Hazen & Penson, 2007; Barrera, Andrews, Burnes & Atenafu, 2008; Bonneau et al., 2011; Enskär & von Essen, 2007; Gibson et al., 2010; Hampel, Rudolph, StachowLas-Lentzsch & Petermann, 2005; Lähteenmäki, Huostil, Hinkka & Salmi, 2002; Last, Stam, Onland-van Nieuwenhuizen & Grootenhuis, 2007; Neville, 1996; Noll et al., 1999; Patenaude & Kupst, 2005; Servitzoglou, Papadatou, Tsiantis & Vasilatou-Kosmidis, 2009; Shankar et al., 2005; Woodgate, Degner & Yanofsky, 2003; Zebrack et al.,

2002; Zebrack & Zeltzer, 2003), parents of children with cancer (Anderzén Carlsson, Kihlgroen, Svantesson & Sorlie, 2007; Barbarin, Hughes & Chesler, 1985; Bennett Murphy, Flowers, McNamara & Young-Saleme, 2008; Boman, Lindahl & Bjork, 2003; Enskär, Carlsson, von Essen, Kreuger & Hamrin, 1997; Goldbeck, 2001; Grootenhuis & Last, 1997; Hinds et al., 1996; Johnson Silver, Westbrook & Stein, 1998; Kästell, Enskär & Bjork, 2011; Morrow, Hoagland & Morse, 1982; Patistea & Babatsikou, 2003; Patterson et al, 2004; Pfeifer, 2003; Sidhu, Passmore & Baker, 2005; Townes, Wold & Holmes, 1974; Van Dongen-Melman, Van Zuuren & Verhulst, 1998; Wills, 1999; Young, Dixon-Woods, Findlay & Heney, 2002), and focus has also been given to the siblings of children who are diagnosed with cancer (Barrera et al., 2004; Houtzager, Grootenhuis & Last, 1999, 2001; Houtzager et al., 2003; Houtzager, Grootenhuis, Hoekstra-Weebers & Last, 2004; Lavigne & Ryan, 1979; Murray, 2000a, 2000b, 2001, 2002; Simms & Hewitt, 2002; Sloper, 2000; Van Dongen-Melman et al., 1995; von Essen & Enskär, 2003; Williams, 1997; Woodgate, 2006). It is as a result of the complex and multi-dimensional nature of chronic illness, that all these different approaches came to stand. However, despite this widespread interest and the variation in research approaches addressing various aspects of cancer, the primary focus of the present study was directed towards the feelings and experiences of South African siblings of children diagnosed with paediatric cancer.

As far as the researcher could ascertain up-to-date only one South African study touching on the topic of South African sibling perceptions of paediatric cancer has been carried out (Boshoff, 2009). International studies focussing specifically on siblings of paediatric cancer patients have shown that the childhood cancer experience is a stressor which may exacerbate subjective feelings of stress in healthy siblings, and in some situations lead to psychosocial difficulties and increased psychopathology (Murray, 1999a). International studies conducted over the past forty years can be divided into three chronological eras. In the late seventies and early eighties researchers became aware of siblings vulnerability and studies were undertaken to document the effects that paediatric cancer has on healthy brothers and sisters (Binger et al., 1969; Cairns, Clark, Smith & Lansky, 1979; Kramer, 1981; Murray, 1998). In subsequent studies conducted during the late eighties and early nineties these effects were further analysed, and a distinction was drawn between short and long-term effects as well as positive and negative outcomes for siblings (Havermans & Eiser, 1994; Sargent et al., 1995). Studies also started to focus on variables which affect siblings' ability to cope with and adjust to their brother or sisters cancer (Barbarin et al., 1995; Breyer, Cunin, Kalish & Patenaude, 1993; Cohen et al., 1994; Dolgin et al., 1997; Madan-Swain, Sexson, Brown & Ragab, 1993). More contemporary studies (late 1990s and early 2000s) covered additional themes such as quality of life, protective factors and intervention strategies (For example, art, support groups and camping programmes) (Barrera et al., 2005; Janes-Hodder & Keene, 2002; Marasca, 2003; Odo, 2005; Pacman et al., 2004; Weil, 2004).

From the above it can be noted that the impact of paediatric cancer on healthy siblings has been the focus of numerous international studies over the past few decades. Yet, researchers such as Murray (1998) and Brody (1998) noted that knowledge pertaining to siblings continues to be limited in amount, scope and conclusiveness.

General effects of cancer on healthy siblings which have been documented at this stage can be divided into emotional (affective), social and academic (Socio-behavioural) and physical (somatic) effects. Landgraaf and Abets (cited in Pacman et al., 2004) referred to the above-mentioned effects as the domains which comprise sibling quality of life. The emotional domain can be understood in terms of internalised reactions of the siblings to feelings of distress that are generated by the illness. Socio-behavioural affects refer to externalising reactions, social competence and school-related problems. While physical effects relate to bodily reactions to the cancer experience. In terms of the effects of the cancer experience reported by healthy siblings, findings show enormous variation from child to child. At one end of the continuum, it seems that siblings may experience personal growth as a result of the cancer experience, with studies reporting positive outcomes such as emotional maturity and greater insight into the needs of others (Sloper, 2000; Wang & Martinson, 1996) and general behavioural improvements (Sahler et al., 1994). These gains withstanding, negative outcomes predominate and the vast majority of parents report withdrawal, mood swings and attention seeking behaviours being displayed by their healthy children (Heffernan & Zanelli, 1997). Parents also reported the presence of psychosomatic symptoms and scholastic and behavioural problems (Heiney, Goon-Johnson, Ettinger & Ettinger, 1990; Zeltzer et al., 1996). At the other end of the continuum, the cancer experience may present serious long-term effects (Alderfer et al., 2003), with some of these effects requiring psychiatric intervention (Ballard, 2004; Patterson et al., 2011).

## **2.2 EMOTIONAL EFFECTS AND THE CANCER EXPERIENCE**

The above explanation suggests that the cancer experience may be emotionally potent for siblings (Wilkins & Woodgate, 2005), and in addition previous research has proposed that healthy siblings are especially vulnerable to a number of emotional difficulties. It has been said that siblings are probably those who are most emotionally overlooked and sad of all family members during the cancer experience (Harding, 1996; Murray, 1999a, 2000a, 2000b; Van Dongen-Melman et al., 1995). During the treatment of their ill brother or sister, striking similarities between emotional distress experienced by the patient and his or her siblings were noted, and in some instances healthy siblings showed even more signs of distress than the patients themselves (Cairns et al., 1979; Van Dongen-Melman et al., 1995).

Throughout the cancer experience, siblings report experiencing feelings of displacement, deprivation, vulnerability, burden (Woodgate, 2006), jealousy (Houtzager et al., 1999; Janes-Hodder & Keene, 2002; Murray, 2000b; Sloper, 2000; Smith, 1998; Woodgate, 2006), guilt for their own health (Sloper, 2000; Smith, 1998; Woodgate, 2006), anger Houtzager et al., 1999; Murray, 2000b; Sloper, 2000; Smith, 1998; Woodgate, 2006), hostility (Smith, 1998), fear, frustration (Houtzager et al., 1999), sadness (Sloper, 2000), loneliness (Houtzager et al., 1999; Sloper, 2000; Woodgate, 2006), confusion (Murray, 2000b), embarrassment – relating to cases where the ill sibling is teased or where there is an abnormality in their appearance – and worry (Menke, 1987).

### **2.2.1 Worry**

Worry is the feeling which siblings reportedly most frequently experience (Menke, 1987). According to the Penguin dictionary of psychology, worry can be understood as the experience of a constant stream of unpleasant and negative thoughts (a troubled state of mind) (Reber, Allen & Reber, 2009). Worries are related to the ill sibling as well as to the self. Siblings worry about the health of their brothers and sisters and worry about death and about getting sick themselves. It is extremely difficult for siblings to see the physical toll that cancer exerts on their ill brother or sister (For example, loss of weight, hair loss, pain and nausea as a result of the treatment and medication). These observations of their siblings suffering increase healthy siblings' worries. There are also instances where worry is directed towards parents, as some siblings reported worrying that their parents would not return from the hospital (Menke, 1987). Janes-Hodder and Keene (2002) also mention that siblings miss their parents and they long for their life before the cancer was there. They further report that siblings worry about their parents' well-being, and this leads to them not talking about their strong emotions (jealousy, anger, worry, fear, etc.), as they don't want to burden their parents with their problems as well (Janes-Hodder and Keene, 2002). Furthermore, siblings are not only worried about their brother or sister and parents; they also worry about what happens at the hospital. Siblings' imaginations are viewed as the fuel for this worry and the terrible conclusions that they draw when they see the situation that their brother or sister is in after a hospital visit, or when they overhear the conversations between their parents and other adults. Several studies also mention that the cancer diagnosis in a brother or sister challenges siblings' perceptions of their own as well as their family's security (Barrera, Chung, Greenberg & Flemming, 2002; Bender 1990; Chesler, Allesewede & Barbarin, 1991; Freeman, O'Dell & Meola, 2000; Havermans & Eiser, 1994; Sargent et al., 1995; Shapiro & Brack, 1994; Sloper, 2000; Wang & Martinson, 1996).

These feelings of insecurity are also related to siblings' worries about their ill brother or sister's health; their parents' health; their own health; the ill child's ability to cope with treatment; reactions of peers and what happens at the hospital. The world is no longer viewed as a safe place. As fears of possible death intensify, siblings' feelings of uncertainty and insecurity increase.

### **2.2.2 Fear**

Closely related to worry is fear. Whereas worry can be understood as a “troubled state of mind”, and worries are related to anticipated future threats, fear is more intense and specific. Fear can be described as a strong emotional reaction to a present danger or threat. Feeling fearful usually involves an internal subjective experience of uneasiness accompanied by sympathetic bodily reactions (for example, increased heart-rate, rapid breathing and profuse sweating) (Reber et al., 2009). Fears experienced by siblings range from the fear that they themselves, or their parents will also get cancer, to a feeling of defencelessness. Sometimes siblings develop fears that are not at all related to the cancer (the fear of being hit by a car, fear of dogs, fear of strangers). McKnight (cited in Odo, 2005) also refers to the fear that siblings have to talk about their feelings; he noted that parents and other role-players are often so focussed on the ill child that the above-mentioned factors go unnoticed. When siblings are neglected, as part of an instinctively human reaction, in the absence of factual information, siblings may fear the worst, they may even fear for their own health.

Parents and health care practitioners may want to try shield siblings from the illness experience, and in good faith they may decide to withhold knowledge of the illness from them. This well-intentioned hiding of truth often drives siblings to fear even worse possibilities, and can lead to the development of additional negative feelings (Spinetta et al., 1999). To help reduce these fears, it is recommended that parents include siblings in discussions of their brother or sisters cancer diagnosis early on. Furthermore, parents should keep siblings up-dated on progress and treatment by using age-appropriate explanations, and parents should give the siblings a choice to how fully and actively they would like to participate in the cancer process with their ill brother or sister (Spinetta et al., 1999).

### **2.2.3 Sadness**

Siblings of children with cancer are assaulted with pain on three fronts, they hurt for their ill brother or sister, they hurt for their grieving parents and they hurt for themselves (Dieter Thren (cited in Boshoff, 2009). As a result, siblings often report feeling sad (Barrera, 2000; Chesler et al., 1991; Iles, 1979; Sloper, 2000; Wilkins & Woodgate, 2005).



Sadness can be defined as an emotional state characterised by feelings of sorrow and unhappiness (Allen, 2007). Sibling sadness is linked to worry that their brother or sister might die; missing their parents and missing the life they used to have. Feelings of sadness were even reported by siblings long after their brother or sister had successfully completed their cancer treatment (Woodgate, cited in Wilkins & Woodgate, 2005). Janes-Hodder and Keene (2002) noted that some children do express their sadness, but others suppress it, and this can lead to depression and other emotional difficulties.

#### **2.2.4 Loneliness**

Loneliness can be defined as a state of unhappiness which results from being without the companionship of others (Collins English dictionary, 2000). The experience of parental absence is a phenomenon which was already noted by Spinetta and Deasy-Spinetta in 1981 (Spinetta & Deasy-Spinetta, cited in Wilkins & Woodgate, 2005) as a factor which affects the healthy sibling. When a triad forms between the parents and their ill child, siblings are left on the periphery and families become divided (Kramer, 1981; Wilkins & Woodgate, 2005). From the time of their brother or sister's cancer diagnosis, siblings often feel abandoned and lonely. As parents spend a lot of time at the hospital and are away from home, siblings are left in the care of others with their immediate family not there. When parents are at home, they often do not have as much time or energy left to be mindful of siblings, this may result from the constant attendance to the attention and time-consuming needs of the child with cancer (Spinetta et al., 1999). Siblings perceived themselves to be less important in the family compared to before their brother or sister got ill. Many siblings also believed that they were alone, and felt that they had no one to talk to about their feelings (Bender, 1990; Chesler et al., 1991; Martinson, Gillis, Colaizzo, Freeman & Bossart, 1990; Murray, 1998). Linked to these feelings of loneliness and loss, siblings also often experienced a loss of energy and companionship when their brother or sister can no longer play with them outside (Murray, 1999a, 2000b).

#### **2.2.5 Rejection**

Closely linked to feeling lonely and isolated is feeling rejected. The core meaning of rejection relates to a failure to assimilate or accept. Thus, there is an implied system (in this case the parent or family system) that failed to incorporate a person or thing (in this case the healthy sibling) (Reber et al., 2009). Thus, favouritism towards the ill child by parents, other family members and friends reinforce siblings feelings of abandonment and rejection (Bender, 1990; Sloper, 2000; Wilkins & Woodgate, 2005; Yin & Twin, 2004). Siblings often feel unloved and less important than the sick child. Feeling unimportant has been linked to low self-esteem and feelings of hostility (Bender, 1990).

### **2.2.6 Anger**

Anger is an emotional state where a person experiences feelings of great annoyance or antagonism which result from a real or supposed grievance (Collins English dictionary, 2000). Disruptions in family life cause siblings to feel angry (Barrera et al., 2002; Bender, 1990; Chesler et al., 1991; Lehna, 1998; Murray, 1998; Sloper, 2000). Siblings ask questions such as “why does this have to happen to us?” And they resent the inequitable treatment from their parents and the changes in family routine that are necessary to accommodate their siblings rigorous treatment regimen and its potential complications. A dislike of restrictions surrounding social activities is also central to siblings anger. Janes-Hodder and Keene (2002) mentioned that siblings are often left with babysitters, household rules do not hold equal merit for all children, and siblings often have to take on additional responsibilities (chores). These factors further exacerbate siblings feelings of unfairness and anger. Anger outbursts are viewed as behaviours which negatively affect the siblings social functioning.

### **2.2.7 Jealousy**

Jealousy can be understood as an emotional state closely associated with uncertainty. Feelings of jealousy are assumed to result from a lack of sense of security in the affections of a loved one. These jealous feelings are directed towards a third party, this third party being the one who is perceived as stealing the affection of the person who is loved (for example, healthy siblings feel jealous because they perceive their ill brother or sister as stealing all their parents attention and affection) (Reber et al., 2009). Thus, the unequal distribution of parental attention, an unequal application of rules and overindulgence of the sick child are sources of jealousy often reported by siblings (Bender, 1990; Chesler et al., 1991; Freeman et al., 2000; Havermans & Eiser, 1994; Iles, 1979; Martinson et al., 1990; Murray, 1998). Janes-Hodder and Keene (2002) speculate that it is not only the parents who give extra attention to the ill child, but friends, family and other family members also ask siblings about the well-being of their ill brother or sister. Despite the siblings' concern for their brother or sister with cancer, it is seen as a natural reaction for siblings to be jealous of all the attention and gifts that their brother or sister is given. Several researchers found that many siblings understood why their parents and friends acted differently, but their feelings of jealousy were hard to suppress or deny (Chesler et al., 1991; Havermans & Eiser, 1994; Wilkins & Woodgate, 2005).

### **2.2.8 Guilt**

These feelings of jealousy are often followed by feelings of guilt and shame (for example, how can I feel like this about my brother when he is so sick?) (Bender, 1990; Chesler et al., 1991; Janes-Hodder & Keene, 2002; Shapiro & Brack, 1994). Reber et al. (2009) viewed guilt as an emotional state that results from the knowledge that one has violated some moral standard. In a sense guilt can be defined as a form of internal self-punishment (Reber et al., 2009). Researchers have linked guilt in younger children to an ego-centric stage of development. It is said that children often see it as their fault that their brother or sister got ill, because at an earlier stage they may have wished this on him or her (for example, I wish you would die). Some siblings even feel guilty for their own health. In comparison, older siblings reported feeling guilty about wanting to get on with their own lives, yet still wanting to be there for their ill sibling and parents (Bender, 1990). Secondary guilt reactions for healthy siblings mentioned by Murray (1998) included: depression, social isolation, accident proneness and continuous provocative behaviours.

Keeping the above-mentioned emotional difficulties in mind, contemporary researchers agree that siblings not only have to adjust to the diagnosis of cancer in their brother or sister, but they also have to learn to manage and cope with the overwhelming emotions that accompany this diagnosis (Weil, 2004).

## **2.3 COGNITIVE AND SOCIO-BEHAVIOURAL EFFECTS AND THE CANCER EXPERIENCE**

Cairns et al. (1979) stated that emotional effects (as mentioned in the above paragraphs) are only one facet of the cancer experience, and the expression of these negative emotions can lead to greater experiences of stress and fear in siblings. Furthermore, these negative emotions are often internalised leading to a lower self-concept, which may negatively affect the social functioning of siblings (Pacman et al., 2004). These social difficulties can manifest in either disciplinary or behavioural problems (Barrera et al., 2005), poorer scholastic achievement, and even behaviour which could have health risks (for example, unsafe sex, drinking and using drugs) (Boshoff, 2009). Marasca (2003) and Pacman et al. (2004) noted that the cancer experience can lead to siblings becoming socially isolated. This social isolation may result from lack of support from parents or significant others in creating a sense of normality relating to the maintenance of daily routines. Labay and Walco (2004) stated that siblings are less involved and less successful in academic, extra-curricular as well as social activities.

Fife, Norton and Grooms (1987) investigated sibling functioning in the school setting. Academic performance and patterns of school attendance were observed by teachers for siblings and their ill brother or sister during the first year after cancer diagnosis. Observations by the teacher were compared to patterns for the year prior to the diagnosis. Comparisons revealed an increase in absenteeism (19% of siblings, 6 out of 31) and a decline in academic performance for 55% of siblings (17 out of 31). Behaviour problems observed in the school setting were noted in more than half (17 out of 31, 55%) of siblings. Observed behaviour problems related to withdrawal, decrease in self-confidence and anxiety.

In a later Chinese study, Wang and Martinson (1996) explored the behavioural responses of healthy Chinese siblings to the diagnosis of paediatric cancer in a brother or sister. A total of 45 families took part in the study; data was gathered from two sources: both parents and healthy siblings. A total of 30 healthy siblings (ages ranging between 7 and 16 years) took part. Healthy siblings took part in semi-structured interviews (conducted in Chinese) and completed the Piers-Harris Self-Concept Scale (Piers & Harris, 1969). The Interviews focussed on the nature of the healthy siblings daily living environment and the perceptions that siblings have relating to paediatric cancer in the family. Parents also took part in semi-structured interviews and completed various measuring instruments including: a report relating to family demographics and environment; the Child Behaviour Checklist (CBCL) (Achenbach & Edelbrock, 1983); and the Family Environment Scale (FES) (Moos, 1986). Content analyses of the interview data identified three main themes of stress, 1) inadequate knowledge, manifest in fear of contamination and heritability, 2) reduced communication evidenced by lack of cancer information and communication between family members and 3) insufficient support relating to the emotional difficulties resulting from changes in the family and ill sibling. Healthy Chinese siblings showed significantly more behavioural problems and fewer social competencies when compared to a standardised normal Western sample (Wang & Martinson, 1996).

Lavigne and Ryan (1979) investigated the psychological adjustment of healthy siblings of children with chronic medical conditions (including: haematology, cardiology and plastic surgery patients). They noted that siblings behavioural manifestations of stress are linked to their age and gender. Pre-school siblings are more likely to show signs of irritability and withdrawal, whereas school-aged and adolescent children may act out socially to vent their emotional distress. Some researchers investigated the presence of symptoms of PTS in siblings of paediatric cancer patients (Alderfer et al., 2003; Pacman et al., 2004). Findings indicated that levels of PTS were elevated for siblings of paediatric cancer survivors, and it was noted that symptoms of PTS were more pronounced in siblings who were scared that their brother or sister might die (Alderfer et al., 2003). It is speculated that siblings display

symptoms of PTS, because like their parents, in addition to seeing the effects of cancer and its treatment and feeling fearful and helpless, healthy siblings may take on a caring role towards the cancer survivor (Alderfer et al., 2003; Howits & Kazak, 1990). It is further speculated that the levels of PTS in siblings can be higher than the levels in surviving patients, because they (unlike the patient) were separated from their parents – their general source of social support – during the illness experience.

Alderfer et al. (2003) also noted that female siblings are more likely to evince symptoms of PTS, as they often experience additional responsibilities (including caring for their ill sibling). These responsibilities may result in greater exposure to the trauma associated with cancer for girls. Female siblings also show greater levels of empathy and may thus be more vulnerable to the negative effects of the cancer experience (Alderfer et al., 2003; Houtzager et al., 1999; Lennon & Eisenberg, 1987).

## **2.4 PHYSICAL (SOMATIC) EFFECTS AND THE CANCER EXPERIENCE**

Along with emotional and behavioural responses, siblings have also been noted to respond physically to the diagnosis of cancer in their brother or sister (Heffernan & Zanelli, 1997; Walker, 1988). Previous studies reported increased somatic complaints (Smith, 1998). These somatic complaints were often accompanied by the onset of severe enuresis, headaches (Houtzager et al., 2005; Murray, 2000a), stomach pains (Houtzager et al., 2005) and trouble eating and sleeping (Heffernan & Zanelli, 1997; Houtzager et al., 1999; Walker, 1988; Zeltzer et al., 1996). Studies have also indicated that parents under-reported sibling somatic complaints, and that parents were less likely than control parents (parents of families without illness) to seek medical intervention for symptoms reported by healthy siblings (Murray, 1999a; Zeltzer et al., 1996). Furthermore, siblings who showed more interpersonal and intrapersonal difficulties, who experienced elevated feelings of rejection and resentment and who feared the cancer itself reported greater incidences of physical symptoms. Whether these somatic symptoms should be viewed as sublimated emotional reactions, regressive responses (Houtzager et al., 1999) or attention seeking behaviours is not clear in the literature (Walker, 1988, 1990). However, it can be assumed that siblings internalised (emotional) difficulties manifest through physical symptoms, although these symptoms do not result in increased attention from parents.

The healthy siblings' physical complaints may pale in comparison to those of their ill brother or sister (Zeltzer et al., 1996). Thus, parents do not pay much attention to them. The latter somatic symptoms emphasise that the effects of the cancer experience are much broader than generally accepted.

According to Wilkins and Woodgate (2005) the experience of the above-mentioned feelings and symptoms does not strictly imply that siblings are having difficulties. They speculate that these feelings may constitute a normal part of the cancer experience that siblings must encounter. This withstanding, the presence of such a multitude of emotions and symptoms highlights the need for support services that are grounded in research and developed from the sibling's own perspective.

## **2.5 POSITIVE EFFECTS AND THE CANCER EXPERIENCE**

Although early Research predominantly focussed on and identified many negative effects which accompany the cancer experience for healthy siblings, research conducted during the 1980's started to recognise that there were possible positive effects as well. In an early pilot study Iles (1979) examined the experiences of 5 healthy siblings of children with cancer, and open ended questions were used to facilitate the discussion of each participants experience. Positive responses given by the siblings included increased empathy for parents, respect for their ill sibling and improved self-concept (Iles, 1979). Following this, Kramer's (1981) qualitative exploratory study was the first to specifically focus on the possible benefits related to having a sibling with cancer. This study aimed to identify the special needs of healthy siblings, and 11 healthy siblings of children with cancer were interviewed. Positive outcomes identified by the researcher included: increased empathy and sensitivity for the cancer patient and other individuals; enhanced personal maturation; a greater sense of family cohesion; and an increased appreciation for life. In a further quantitative study, Havermans and Eiser (1994) interviewed 21 siblings relating to their experience of having a sibling with cancer. A short general impact scale The Sibling Perception Questionnaire (SPQ) was administered to assess the extent to which siblings felt their lives had been changed by the cancer experience. More than half the siblings who completed the SPQ experienced greater personal maturation or growth, valued life more and reported becoming more sympathetic towards others (Havermans & Eiser, 1994).

Contemporary researchers such as Murray (1998) and Janes-Hodder and Keene (2002) afforded greater attention to the positive aspects surrounding the cancer experience than in the past. Some findings indicated that pre-school siblings show more empathy and consideration when compared to age-matched controls. Older siblings also showed signs of personal growth and reported enhanced maturity, supportiveness, caring and compassion, greater independence and responsibility and an

increase in family cohesion (Barbarin et al., 1995; Chesler et al., 1991; Janes-Hodder & Keene, 2002; Murray, 1998; Sargent et al., 1995). This sense of heightened family cohesion can be attributed to the family pulling together during this time of crisis (Sloper, 2000). While an increase in sensitivity towards others can be linked to greater feelings of compassion and empathy evoked by their ill brother or sister (Midence, 1994; Sloper, 2000; Smith, 1998). According to Janes-Hodder and Keene (2002) siblings felt that the knowledge which they gained relating to their brother or sister's cancer resulted in higher levels of empathy towards others who are sick or disabled; a higher sense of responsibility; a better self-image; greater maturity and they reported adopting better coping strategies. It is also thought that the sibling's involvement in the cancer crisis leads to greater character building.

## **2.6 NEEDS AND THE CANCER EXPERIENCE**

In today's health care profession there is growing awareness that the psychosocial needs of well siblings of paediatric cancer patients are less acceptably met than the needs of other family members during the cancer experience (Murray, 1998, 1999a, 2000a, 2002). Concerned with the identification of what siblings deem helpful, research has identified five needs that siblings consistently report as important to them. These needs are: open and honest communication in the family; adequate information about cancer; involvement in the care of their ill sibling; support to maintain their own interests and activities; and a need for reassurance and relief from guilt (Wilkins & Woodgate, 2005). The impression from research is that these needs are not being met adequately (Wilkins & Woodgate, 2005).

### **2.6.1 Family Communication**

Communication between parents and healthy siblings is viewed as one of the most helpful factors in sibling adjustment during the cancer experience (Murray, 2002; Sloper, 2000; Yin & Twin, 2004). However, a reduction in communication between parents and siblings around the cancer experience is consistently reported in the literature (Barrera et al., 2002; Wang & Martinson, 1996; Yin & Twin, 2004). Several studies mentioned that the communication that does occur between parents and siblings is concentrated on the facts of the illness experience, as opposed to fears and feelings. This is despite the fact that siblings do have a need to share their feelings and discuss problems (Murray, 1998; Wilkins & Woodgate, 2005; Yin & Twin, 2004). Reduced communication has been shown to distort ideas, create anxiety and guilt, and create greater gaps in already strained family relationships (Sloper, 2002).

It has been suggested that not talking about and avoiding the topic of cancer might be beneficial in the short-term until the situation has stabilised. However, long-term avoidance of the topic can lead to ignorance about the illness and increased feelings of isolation and loneliness for siblings (Brett & Davies, 1988).

The importance of family communication relating to coping with the illness and the sibling relationship can be seen many years after the cancer experience has passed. In a study where siblings were asked to write narratives on their past cancer experience, DiGallo (2003) noted that siblings who reported better inter-familial communication were better able to cope with their brother or sister's cancer and had better sibling relations. This was evidenced by their ability to integrate the cancer experience into their lives.

Spinetta et al. (1999) emphasised that communication around the cancer experience should take into account the siblings emotional, social and cognitive capacity. As siblings grow and mature during and after the treatment of cancer in their brother or sister, both their curiosity and capacity to understand grow accordingly. As a result, issues relative to their sibling's illness should continue to be addressed (Spinetta et al., 1999). Keeping this in mind, it has been suggested that sibling age also plays an intermediate role in communication around the cancer experience. It was found that the older the sibling at the time of diagnosis, the greater their understanding and knowledge relating to cancer. It was also noted that parents seem to have a protective attitude towards younger siblings, and older siblings were found to communicate more frequently with their parents (Cohen et al., 1994). It was also noted that parents shared most of the information relating to the cancer experience close to the time of diagnosis (Brett & Davies, 1988). Thus, siblings who are younger and as a result have limited cognitive understanding may lack information relating to their brother or sisters cancer later on.

A further factor involved in parent-sibling communication related to the siblings' communicative and social competencies. Cohen and his colleagues (1994) found that siblings' social competence was positively related to the amount of parent-sibling communication and the siblings' knowledge of their brother or sister's cancer. It was also thought that high levels of social competence may act as a protective factor for sibling adjustment (Houtzager et al., 1999).



### **2.6.2 Information**

A further need closely related to communication relates to siblings wanting accurate information about their brother or sister's cancer and its treatment. They especially want this information from their parents (Barrera, 2000; Freeman et al., 2000; Havermans & Eiser, 1994; Martinson et al., 1990; Murray, 1998, 2002; Sargent et al., 1995; Wang & Martinson, 1996; Yin & Twin, 2004). If parents did share cancer information, many siblings perceived this information to be incomplete, inadequate and misleading (Havermans & Eiser, 1994; Wang & Martinson, 1996; Yin & Twin, 2004). This is despite the fact that access to information can assist siblings in adapting to and mastering change and incorporating this change into their new view of the family.

Furthermore, it has been demonstrated that siblings rely on their own interpretations of the situation when they don't have access to truthful, age-appropriate information (Murray, 1998; Wilkins & Woodgate, 2005; Yin & Twin, 2004). This reliance on inadequate information often yields a distorted picture of what is happening, and of the sibling's role in the family.

### **2.6.3 Involvement in the Care of their Ill Sibling**

It has further been noted that active involvement in their ill brother or sister's treatment process is important for healthy siblings (Barrera, 2000; Sloper, 2000). The benefits of this involvement include: gradually seeing physical changes in their ill sibling; becoming familiar with the hospital environment and its staff; maintaining contact with their ill brother or sister; maintaining a sense of family and having access to and gaining information. The need for siblings to "be present" refers to a need for siblings to be with and be there for their ill brothers and sisters. Being present was important to fostering a sense of connectedness as opposed to feeling abandoned or alone in the world. It was also found that being at the hospital with their ill brother or sister helped siblings cope better with the situation, as siblings become legitimate role-players in the illness and treatment process (Wilkins & Woodgate, 2005). Barrera (2000) clearly illustrated this process of "being present" in his case study of a mother and sibling who acted as co-therapists in the management of procedural pain and anxiety in an ill sibling who had cancer. Prior to the involvement of the healthy sibling in the ill child's treatment regimen, the sibling was described as being irritable, argumentative and outspoken. After receiving instruction on the implementation of cognitive-behavioural techniques, the sibling coached the ill child on how to make bubbles during port access in chemotherapy treatment. It was later reported by the mother that the co-therapist sibling was more talkative, more co-operative and less irritable. Although benefits relating to the involvement of siblings in the care and treatment of their ill brothers and sisters

are evident, siblings report having few opportunities to visit the hospital and get involved (Cramer, 1984; Murray, 1999b). Linked to creating these opportunities for involvement, it is recommended that hospitals implement liberal visitation policies (Lehna, 1998), especially when it comes to siblings visiting their ill brothers and sisters.

#### **2.6.4 Support to maintain their own Interests and Activities**

Being able to have and maintain their own interests is another resource which siblings reported to be helpful in coping with the cancer experience. Researchers have documented that having assistance with important day-to-day tasks (for example, transportation to school and extra curricular activities and attending support groups) helped healthy siblings to maintain some sense of normality, promoted self-esteem and provided a focus and role outside of the family (Murray, 2002; Sloper, 2000).

It was also noted that siblings value certain types of social support more than other types (Ballard, 2004). Emotional support (for example, empathy encouragement and love) and instrumental support (for example, direct help or material support) have been rated by siblings as more helpful than informational or appraisal support (for example, support in examining and interpreting a situation) (Ballard, 2004; Murray, 2001, 2002). Furthermore, it has been shown that parents' perceptions of helpful forms of social support for siblings differ from those forms which siblings themselves deem helpful (Murray, 2001, 2002). Siblings rated help to be able to attend a support group as significantly more important than their parents did (Murray, 2001). Parents may lack the necessary resources, or be unwilling, or unable to allow their child to attend such groups (Ballard, 2004). Other reasons for exclusion from support group attendance could include the belief that their child is too young to learn about cancer; a preference for alternative forms of support (Williams, 1992); or a failure to recognise their well children's need for support (Ballard, 2004). Linking to this, it was noted that sibling participation in a support group resulted in increased understanding of the illness; changed mood (for example, siblings were happier and less fearful); changes in behaviour (for example, siblings were more independent and they showed improvement in their school-work); and the support group provided an opportunity for siblings to discuss their experience with cancer more openly. Thus, healthy siblings need help from parents or significant others to maintain a sense of normality and routine in their day-to-day lives.

### **2.6.5 Reassurance and Relief from Guilt**

The need for reassurance about their ill brother or sister (Evans, Stevens, Cushway & Houghton, 1992); the need for reassurance about their own health (Wang & Martinson, 1996; Zeltzer et al., 1996); the need for reassurance about the health of their parents; and the need for relief from guilt (Adams-Greenly, Shiminski-Maher & McGowan, 1986; Maiden-Swain et al., 1993) were needs emphasised by siblings.

### **2.6.6 Measurement and Identification of Sibling Needs**

As a result of the growing recognition of the unique needs of siblings during the cancer experience, a very recent Australian study by Patterson, Millar and Visser (2011) undertook to develop an instrument “The sibling cancer needs instrument (SCNI)” which was aimed at identifying the unmet psychosocial needs of siblings of children with cancer. The SCNI identifies 10 conceptual domains of need, including: information; peer support (friends); peer support (similar experience); sibling relationship and support; expressing and coping with feelings; access to support; respite and recreation; acknowledgement and attention for self, instrumental support and involvement in the cancer experience.

Results found by Patterson et al. (2011) indicated that siblings' highest endorsements on the SCNI related to the domains of peer support, respite and recreation, attention and acknowledgement for self and involvement in the cancer experience. Thus it seems that siblings need opportunities to socialise with young people who went through a similar experience (for example, other siblings of children with cancer). There is also a need for siblings to take part in recreational activities outside of the home. It also appears important that family relationships and dynamics are addressed, particularly relating to the siblings' role and place in the family system (Patterson et al., 2011).

Furthermore, it should be noted that some siblings endorsed no unmet needs, while others reported over 40 unmet needs. This wide range of results indicated that great variability of need exists in the population of siblings of children with cancer. To an extent this variability may be related to other factors such as time since diagnosis or family dynamics. Even if this is the case, it is important to remember that the sibling relationship existed long before the cancer diagnosis, and each relationship is unique with its own ups and downs. Some children spend their early years with siblings who are friendly, affectionate and supportive, while others may have siblings who are hostile, aggressive or

constantly disparaging. Therefore, the impact that the diagnosis of cancer may have on the sibling relationship is as variable as the relationship is unique (Patterson et al., 2011).

Taken together, the above findings re-emphasise the fact that healthy siblings' needs are often overlooked and unmet as the needs of their ill brother or sister become more pronounced (Wilkins & Woodgate, 2005).

## **2.7 CHANGES AND THE CANCER EXPERIENCE**

A further theme which dominates the literature relates to the tremendous change that siblings perceived in their lives after the diagnosis of paediatric cancer in their brother or sister. Changes related to shifts in family dynamics, relationships and routines. These changes were described in terms of both losses and gains in family life (Wilkins & Woodgate, 2005).

### **2.7.1 Losses**

Research has consistently shown that healthy siblings spend less time with their parents and spend more time with parental substitutes (for example, grandparents, extended family members, babysitters and neighbours), resulting in a loss of parental attention and support (Barrera, 2000; Freeman et al., 2000; Isles, 1979; Kramer, 1984; Martinson et al., 1990; Shapiro & Brack, 1994; Wilkins & Woodgate, 2005). Further changes involving the relationships that healthy siblings have with their parents related to decreased parental tolerance (Kramer, 1984), as well as differential treatment from their ill sibling (Brett & Davies, 1988; Havermans & Eiser, 1994; Wilkins & Woodgate, 2005). Siblings were greatly concerned about the decreased attention they received from their parents. This lack of parental attention was related to physical distance between the parents and the healthy siblings (parents spent a lot of time at the hospital or siblings had to go stay with other family members or caregivers), emotional unavailability of parents and parental focus on the ill sibling to the exclusion of their other children (Bender 1990; Chesler et al., 1991; Sargent et al., 1995; Shapiro & Brack, 1994; Sloper, 2000). Changes concerning the sibling relationship included loss of companionship (Sloper, 2000) and increased sibling rivalry (Kramer, 1984).

A further loss reported by siblings related to the disintegration and change in family dynamics (Barrera, 2002; Chesler et al., 1991; Freeman et al., 2000; Isles, 1979; Kramer, 1984; Sargent et al., 1995; Sloper, 2000; Wilkins & Woodgate, 2005). When the mother is absent (mothers usually stay at the hospital with the ill sibling) the fathers and older siblings take on a mothering role (Woodgate,

cited in Wilkins & Woodgate, 2005). In order to try and help lift the burden on their parents, healthy siblings also take on extra chores and responsibilities (resulting in a loss of free time). A disruption in family life also occurred when daily routines revolve around the ill sibling, and schedules are rearranged around hospitalisations and treatments, and social activities are planned to accommodate the ill sibling, or not done at all (resulting in decreased family cohesion and stability).

Woodgate (cited in Wilkins & Woodgate, 2005) also reported that siblings showed a loss of their sense of self during the cancer experience, and especially during those times when their brother or sister was reported to be very ill. Healthy siblings started to define and view their own world in terms of their ill brother or sisters gains (for example, outcomes of treatment, progress made etc.) (Wilkins & Woodgate, 2005).

### **2.7.2 Gains**

On the other hand, research has also shown that changes in family life surrounding the cancer experience provided an opportunity for siblings to grow. Sargent et al. (1995) noted that if siblings mentioned one positive aspect relating to the cancer experience, they were more likely to experience additional positive effects. Family closeness and cohesion are two positive changes relating to the cancer experience which siblings frequently reported (Chesler et al., 1991; Kramer, 1984; Sargent et al., 1995; Shapiro & Brack, 1984; Sloper, 2000; Wilkins & Woodgate, 2005). Furthermore, personal gains related to taking on additional chores and responsibilities which increased siblings sense of independence and maturity. Siblings also reported heightened feelings of empathy and compassion which increased a desire to help others (Chesler et al., 1991; Freeman et al., 2000; Isles, 1979; Kramer, 1984; Murray, 1998; Sargent et al., 1995; Sloper, 2000; Wilkins & Woodgate, 2005). Lastly, siblings also reported an increased appreciation for life, and many came to appreciate life's fragility (Havermans & Eiser, 1994; Martinson et al., 1994; Sargent et al., 1995; Wilkins & Woodgate, 2005).

From the above it is clear that changes accompanying the cancer experience are viewed in terms of both losses and gains, and although many changes were seemingly negative, the overall experience of cancer was not perceived in a total negative light by all siblings. However, it would be naive to assume that all changes surrounding the cancer experience are navigated easily and smoothly without any consequences present for healthy siblings (Wilkins & Woodgate, 2005).

## 2.8 QUALITY OF LIFE (QOL) AND THE CANCER EXPERIENCE

A few studies have focussed on the quality of life (QOL) of siblings of paediatric cancer patients, with Houtzager and his colleagues conducting the majority of studies relating to this topic (Houtzager et al., 2003; Houtzager et al., 2005; Houtzager, Grootenhuis, Caron & Last, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers & Last, 2004; Pacman et al., 2005). The terms Quality of Life (QOL) and Health-Related Quality of Life (HRQOL) refer to three (physical, psychological and social) domains of health. These three domains are seen as distinct areas which are influenced by a person's experiences, expectations, beliefs and perceptions (Pacman et al., 2005). Factors surrounding HRQOL often relate to everyday issues faced by children including: physical functioning, emotional and social well-being, behavioural problems, self-esteem, school performance and family life (Pacman et al., 2005). Collectively these factors refer to siblings QOL.

Houtzager and his colleagues employed various quantitative methods, using questionnaires and scales to determine the various influences of paediatric cancer on sibling QOL. These assessments were done over a period of two years. Three similar studies were conducted using the same group of 83 siblings from 57 families with ages ranging between 7 and 18, recruited from two paediatric oncology wards in Amsterdam and Groningen in the Netherlands. The first study (Houtzager et al., 2003) focussed on the manifestation of psychosocial problems by siblings. The study measured psychosocial functioning at different temporal points. The findings were compared to determine whether there is a higher risk for psychosocial dysfunction straight after a sibling has been diagnosed with cancer. These comparisons were made by comparing scores on measures administered at two different temporal points. These measures assessed sibling self-reported anxiety, social-emotional problems and QOL. The Dutch version of the children's quality of life questionnaire (DucatQoL) was administered to assess siblings daily functioning and QOL. Results indicated that QOL was lower for siblings one month after diagnosis of cancer in a brother or sister. When the same measure (DucatQoL) was administered six months later the problems seemed very similar and QOL remained relatively impaired (Houtzager et al., 2003).

In the second study conducted with the same group of siblings, the aim was to assess sibling QOL by having healthy siblings complete two standardised questionnaires. The first questionnaire focused on HRQOL and participants were required to complete the Children's Quality of Life Questionnaire (TACQOL). The second measure was aimed at identifying various coping strategies that healthy siblings employed. These strategies were assessed by the use of an adapted version of the Cognitive Coping Strategies Scale for Siblings (CCSS-S).

The CCSS-S assesses four different coping strategies: predictive control, vicarious control, interpretative control and illusory control. These four strategies are identified by means of 20 statements which are rated using a 4 point Likert scale. It was found that in the initial period after diagnosis of illness in a brother or sister, healthy siblings reported a lower QOL and showed more problems relating to sleeping and eating when compared to pre-diagnostic functioning. This previous functioning was assessed by conducting structured interviews with the parents of siblings who participated in the study (Houtzager et al., 2004).

Both these studies seem similar in nature, and the findings are not clearly spelt out. This lack of clarity could relate to the fact that quantitative methods were used to assess an emotionally charged topic such as paediatric cancer. This then further pointing to the need for more qualitative and in-depth studies on this topic.

In a 2005 study Houtzager and his colleagues (Houtzager, Grootenhuis, Caron & Last, 2005) once again investigated the QOL of siblings of paediatric cancer patients measured at one month and two years after diagnosis of cancer in a brother or sister. Houtzager et al.'s (2005) study was directed at comparing the QOL of healthy siblings using both parental proxy and self-report measures of QOL. These responses were compared and similarities and differences were investigated. Two different questionnaires were used to assess correspondence between healthy sibling and parental reports of QOL. A generic Dutch QOL questionnaire (TACQOL) and a standardised questionnaire that is used to assess behavioural and emotional problems in youth. Both these questionnaires contain a parent and child form. Parents reported a more favourable QOL for their healthy children than did the siblings in their self-report questionnaires. Thus, results suggested that healthy siblings experience a greater burden relating to the cancer experience than is perceived by their parents. Physical and emotional complaints tend to go unnoticed by parents. The study's results suggest that sibling self-reports of well-being are necessary to obtain a realistic picture of sibling QOL.

Pacman et al. (2005) administered the paediatric quality of life inventory (PedsQL) to 77 siblings of paediatric cancer patients who registered to attend a summer camp programme in the summer of 2001. The aim was to assess whether participation in a summer camp for siblings leads to improvement in HRQOL. The PedsQL measures physical, emotional, social and school functioning. Qualitative measures including a sibling qualitative interview and the Camp Okizu satisfaction surveys were also completed. Siblings' total scores on the PedsQL decreased significantly pre-to-post-camp, suggesting an improvement in HRQOL. Improvements were especially notable in the emotional and social domains. Siblings' opportunity to communicate and bond with a true peer group, as well as the positive

feedback, reinforcement and recognition from supportive camp counsellors may have contributed to the great improvement in siblings' emotional and social functioning. With regards to overall parent ratings on the PedsQL, there was no significant improvement in siblings' HRQOL following camp. However, non-bereaved parents did report marked improvements in their children's QOL following their return from camp. The overall findings relating to the positive effects of a summer camp on the HRQOL of siblings highlight the beneficial affects of camp as a psychological intervention for siblings. The increased attention on the impact of paediatric chronic illness on siblings' QOL made an important contribution to the progress in understanding the many psychological aspects and social-emotional factors that are affected when children have a chronic illness (Pacman et al., 2005).

## **2.9 ADJUSTMENT AND THE CANCER EXPERIENCE**

The term adjustment has come to be understood as adaptational success. While when defining the term coping, efforts to manage stressful demands regardless of their outcome (successful or not) are included (Grootenhuis & Last, 1997). Studies conducted during the late 1980's and early 1990's started to investigate the adjustment of siblings to the cancer experience and the variables associated with this adjustment (Murray, 1998). Several of these studies identified sibling and family characteristics which directly or indirectly have an effect on sibling adaptation during the cancer experience. On a micro-systems (familial) level, factors including parental depression; annual family income; marital adjustment during the cancer experience; and parent-sibling communication patterns were noted to play a role in sibling adjustment to the cancer diagnosis in a brother or sister (Cohen et al., 1994). Some influential individual factors which relate to siblings themselves include: the sibling's previous functioning; the sibling's perception of the cancer; socio-demographic factors; and sibling coping resources and strategies (for example, social support, communication and denial) (Houtzager et al., 1999). Besides familial and individual characteristics, characteristics of the cancer itself has also been noted to have an impact on sibling adjustment (Houtzager et al., 2003). Cancer characteristics including the specific diagnosis; type of treatments; time elapsed since diagnosis; number of hospitalisations; and side-effects may determine the burden of illness for healthy siblings and other members of the family.

### **2.9.1 Familial Factors**

As mentioned above, sibling adjustment cannot be separated from the adjustment of the family. Factors such as family values, family strengths and the family's adaptability to stressful events may affect the way individual family members interpret the cancer experience (Houtzager et al., 1999).



Parental and family functioning, parental coping strategies and pre-existing or additional problems have been implicated in adjustment to the cancer experience.

According to the family system's approach, adjustment to paediatric cancer is a function of family systems variables. How the family employs new and existing resources to cope with additional physical and emotional demands brought about by stressful events or circumstances plays a role.

These resources may be external (for example, seeking social support or advice from professionals) or internal (for example, promoting family cohesion and communication) (Dolgin et al., 1997).

### **2.9.1.1 Family Functioning and Dynamics**

Variations in sibling adjustment to the cancer experience may partly be related to differing dynamics involved in individual and family functioning, and may thus not necessarily be related to the presence of cancer per se. This may cause second-order effects for sibling adjustment. It has been stated that the quality of family functioning and family relationships has both direct and in-direct effects on sibling adjustment (Houtzager et al., 1999). Family environment can influence the responses of individual family members during periods of transition or stress (Wang & Martinson, 1996). It is emphasised that the influence of the family is especially relevant to children's adjustment, because children are still very dependant on their families. Moos (1986) viewed the degree of family cohesion as one dimension which differentiates the social environments of different families. Moos (1986) views family cohesion in terms of how much help, commitment and support family members provide for each other (Moos, 1986; Wang & Martinson, 1996). Relating to this, several qualitative studies have noted that siblings who report increased family cohesion and closeness have less adjustment difficulties (Chesler et al., 1991; Kramer, 1984; Sargent et al., 1995). This increase in family closeness can either be interpreted as a way of coping with the stressful situation or as an outcome of the cancer experience. Some studies (Cohen et al., 1994; Horwitz & Kazak, 1990) reported that in families who display high levels of cohesion and adaptability siblings show fewer externalising problems and higher social competence. One study provides evidence that heightened family cohesion results in reduced stress responses for healthy siblings (Wang & Martinson, 1996). In an early study, Fife et al. (1987) interviewed 10 families to assess their coping abilities. Half of these families reported poor coping. These 5 families reported experiencing adjustment difficulties and parents showed low levels of marital stability and support. Furthermore, in the families who coped poorly, healthy siblings school performance deteriorated after diagnosis of cancer in their brother or sister, and when compared to the other five families in the functional group, more school-related behavioural problems were reported. However, it should be noted that these results are based on qualitative data collected from a very small sample, and as a result generalisations are made with caution.

Dolgin et al. (1997) examined the cross-cultural familial aspects of Israeli and American siblings adjustment to paediatric cancer. They administered a scale for family functioning; the Family Relations Scale (FRS). The FRS measures family conflict, emotional expressiveness and levels of support between family members. Results suggested that the greater the degree of family support and emotional expression and the lower the degree of conflict, the better healthy siblings adjust (Dolgin et al., 1997).

### **2.9.1.2 Parental Coping and Social Support**

In a study conducted during the early 90's (Horwitz & Kazak, 1990) it was reported that mothers of sick children employ typical coping strategies aimed at minimizing the subjective impact of their child's cancer. Mothers tended to view their ill and healthy children as alike, rather than different. These mothers' views differed from the views of mothers of healthy children and the children themselves, who acknowledged the differences between their children and between themselves and their brother or sister respectively. Viewing healthy and sick children as alike is seen as a risk factor for the development of emotional and behavioural problems in healthy siblings. When parents are not aware of certain behaviours that reflect sibling needs and difficulties, negative attention seeking and emotional re-alignment may occur as a consequence (Houtzager et al., 1999; Horwitz & Kazak, 1990).

Closely linked to parental coping is social support. The level to which parents rely on social support from others has been found to play a role in sibling adjustment to the cancer experience. The social support that families receive and seek is viewed as an important mediating factor in the adjustment of healthy siblings and other family members during the cancer experience. Several studies have noted a positive correlation between the level of satisfaction with social support reported by parents and good sibling adjustment (Cohen et al., 1994; Sahler et al., 1994; Sahler et al., 1997; Sloper & While, 1996). As mentioned above, Dolgin et al. (1997) administered the FRS, and scores obtained on the support subscale were noted to be predominant factors which contribute to the variance in sibling adjustment. The more parents rely on interpersonal support from others, the better siblings are able to adapt to the cancer experience. Sloper and While (1996) found no direct correlation between parents' social support and sibling adjustment. Nevertheless, they argued that good or effective social support may free parents to be more available for the healthy siblings, and thus indirectly contribute positively to good sibling adjustment (Sloper & While, 1996).

### **2.9.1.3 Parental Distress**

It seems safe to say that the more distressed parents are, the less available they will be for their healthy children. Thus, the distress experienced by healthy siblings could be the result of a reaction to a disharmonious or stressed relationship between themselves and their parents, as opposed to a direct reaction to their ill brother or sister's cancer (Houtzager et al., 1999; Lobato, Faust & Spirito, 1988). It has also been noted that maternal depression and marital adjustment problems relate to more behaviour problems and lower social competence in healthy siblings (Cohen et al., 1994).

Sahler et al. (1994) noted the same findings; they found that maternal emotional and physical distress correlated positively with lower levels of sibling adaptation. Also, the lower the mothers' sense of well-being and the less satisfied mothers were with the social support they received, the poorer healthy siblings adjusted to the cancer experience (Houtzager et al., 1999; Sahler et al., 1994; Sahler et al., 1997).

### **2.9.1.4 Pre-Existing Familial Problems and Events in Family Life**

The Clustering of various events, even if these events are not related to the cancer itself may play a role in sibling adjustment during the cancer experience. It has been stated that the diagnosis of cancer rarely precipitates family disintegration, but rather exacerbates pre-existing problems and already unstable relationships (Fife et al., 1987; Houtzager et al., 1999). Non-disease related stressors coupled with unavailable parents and an unavailable sibling may add to the healthy sibling's already high level of stress. Additional problems such as parental relationship or marital difficulties; employment problems; bereavement; change (for example, moving house or changing schools); and health difficulties in other family members (besides the child with cancer) have been noted as additional stressors which could affect family functioning and increase vulnerability to adjustment difficulties (Fife et al., 1987; Houtzager et al., 1999; Schuler et al., 1985; Van Dongin-Melman et al., 1995). However, whether these additional problems are definite risk factors and precisely how they affect family adjustment are not clearly spelt out (Houtzager et al., 1999).

## **2.9.2 Individual Factors**

### **2.9.2.1 Previous Functioning of the Healthy Sibling**

Previous difficulties (including behavioural, scholastic or emotional challenges) experienced by siblings before the diagnosis of cancer in their brother or sister may increase their vulnerability to the development of adjustment problems post diagnosis (Houtzager et al., 1999; Houtzager et al., 2003). Two previous studies have reported a relationship between pre-existing problems and later adjustment

difficulties (Fife et al., 1987; Sahler et al., 1994). Fife and colleagues' (1987) longitudinal study investigated the psychosocial impact of cancer on 33 families who had a child diagnosed with paediatric cancer. It was noted that families who reported experiencing problems prior to the cancer diagnosis also experienced deterioration in family life, and family members had difficulty coping with and adjusting to the illness. Sahler et al.'s (1994) quantitative study on sibling adjustment systematically assessed pre-existing problems and post-cancer diagnostic functioning in 254 siblings. Out of 99 siblings who had pre-existing problems, 40% developed problems which required psychological intervention after diagnosis, while only 2% of siblings without pre-existing problems sought psychological intervention. Thus, sibling functioning pre-diagnosis may be recognised as an important risk factor which could predict post-diagnostic adjustment problems. It is important to note that the results found in the aforementioned studies have not yet been replicated (Houtzager et al., 2003). In a study where interviews were conducted with parents of healthy siblings, diagnosis of cancer in a brother or sister did not play a significant part in the exacerbation of a previous condition, but did enhance the onset of new adjustment difficulties. The contradictory findings in the above-mentioned studies have primarily been attributed to varying measurement techniques (Houtzager et al., 1999).

### **2.9.2.2 Healthy Sibling Perceptions of the Cancer**

Lazarus and Folkman (cited in Houtzager et al., 1999) noted that individual coping responses to stressful situations are specifically determined by the individual's "appraisal" of such situations. Appraisal refers to the cognitive evaluation of the meaning of the paediatric cancer experience in relation to a person's own well-being. Appraisal can be divided into three phases, primary, secondary and reappraisal (Houtzager et al., 1999). Primary appraisal focuses on how stressful an event is for the individual. While secondary appraisal focuses on what he or she can do about the situation. In terms of reappraisal, reference is made to a changed judgement on the basis of additional information gained. Reappraisal follows an earlier appraisal. Appraisal plays an important role in the adjustment process.

Relating to this, Brett and Davies (1988) were the first to investigate siblings' appraisal and reappraisal of the cancer experience. These researchers asked healthy siblings to retrospectively describe their understanding of their brother or sisters health, from the moment of cancer diagnosis to at least 5 years after diagnosis. Siblings' understanding evolved from an initial awareness that something was wrong to the belief in the possibility of cure. The main factors which caused healthy siblings to appraise the cancer experience as threatening included: a lack of open family communication; witnessing of painful procedures; and the presence of restrictive or protective rules for the ill sibling.

The Sibling Perception Questionnaire (SPQ) is an instrument developed by Carpenter and Sahler (cited in Houtzager et al., 1999). The SPQ aims to assess healthy siblings' own perceptions of the cancer experience. Many researchers have used this instrument. The SPQ includes items on 4 factors: interpersonal, intrapersonal, communication and fear of disease. Healthy siblings identified by their parents as having adjustment difficulties report a lack of resources to cope with their feelings; perceive themselves as isolated; and find the illness experience disruptive to family functioning (Houtzager et al., 1999). Keeping in line with these findings, Sloper and While (1996) administered the SPQ and noted that siblings who experience adjustment difficulties had more negative perceptions on the interpersonal scale. Siblings reported a loss of attention from parents and others and expressed feelings of neglect.

A positive correlation between sibling somatisation and scores on the SPQ interpersonal and fear of disease scales was noted by Zeltzer et al. (1996). This finding indicated that siblings who feel neglected by others are more likely to respond with physical symptoms. These reactions may be more pronounced when parents or significant others are not available for siblings to express and discuss their fears and thoughts of the cancer experience.

### **2.9.2.3 Sibling Socio-Demographic Factors**

It has been suggested that several demographic factors including: age, gender, birth order, family size and socio-economic status (SES) can have an influence on the healthy siblings' vulnerability to adjustment problems (Houtzager et al., 1999). However, results pertaining to the influence of demographic factors and illness characteristics on sibling adjustment are contradictory (Houtzager et al., 2003). Several studies found no gender differences relating to psychosocial adjustment of siblings to the illness (Barbarin et al., 1995; Cohen et al., 1994; Houtzager et al., 2003; Madan-Swain et al., 1993; Sloper & While, 1996), while other results did suggest differences relating to age and gender.

When referring to age, it has been noted that siblings of different ages react to the stresses which accompany the cancer experience in different ways. It often seems that pre-school siblings do not seem much affected by their brother or sister's cancer, while school-aged siblings do experience adjustment problems (Horwitz & Kazak, 1990). In contrast to this Schuler et al. (1985) found that younger siblings experienced more difficulties than older siblings. Several researchers have also noted that older siblings report positive perceptions relating to the cancer experience. Older siblings showed positive growth in the form of increased maturation, supportiveness, responsibility and independence (Barbarin et al., 1995; Chesler et al., 1991; Koch-Hattem, 1986; Sargent et al., 1995). Researchers offered several explanations for these findings. It was mentioned that adolescents have greater

cognitive capabilities and are more able to analyse and rationalise their feelings (Kramer, 1984), they have greater access to emotional resources (Koch-Hattem, 1986) and they are more independent and able to seek support outside the family and move away from the everyday stress that is present at home (Sargent et al., 1995).

In line with age variables, it has also been noted that different problems were reported at different developmental levels. Siblings in early-childhood had a lower self-esteem and a negative self-image, while school-aged siblings displayed higher levels of anxiety and depression. These two groups under the age of 13 felt that there was psychological distance between them and their parents. Adolescent siblings perceived their families as conflict-ridden and relatively low on cohesion (Houtzager et al., 1999). Adolescent siblings also experienced more complex feelings such as guilt, burden related to their sense of responsibility towards their ill sibling and feelings of ambivalence towards their brother or sister (Bender, 1990). The above-mentioned results suggest that both younger and adolescent siblings seem to be at risk for the development of adjustment difficulties (Houtzager et al., 2003).

When referring to birth order and family size, the sibling's position in the family has been related to sibling adjustment. Rollins (1990) and Trahd (1986) noted that siblings in two-child families may be at greater risk for adjustment problems than siblings in larger families. On the other hand, it has been noted that the more siblings there are in the family, the better the siblings self-reported adjustment (Madan-Swain et al., 1993). However, Sloper and While (1996) found no correlation between sibling birth order and levels of adjustment.

In terms of SES, high family income, good SES and the possession of a car were noted as protective factors. These factors provide necessary instrumental support to meet the family's needs to overcome mounting medical costs and assist in resolving practical restrictions caused by lack of resources. In addition these socio-economic factors may provide parents with the necessary resources to be able to attend to the needs of their healthy children (Barbarin et al., 1995; Cohen et al., 1994; Sahler et al., 1994; Sloper & While, 1996; van Dongen-Melman et al., 1995; Zeltzer et al., 1996).

### **2.9.3 Cancer Characteristics**

As noted above, besides familial and sibling characteristics, characteristics of the cancer itself can also impact upon sibling adjustment to the paediatric cancer experience (Houtzager et al., 2003). Factors including the specific cancer diagnosis; type of treatments; time elapsed since diagnosis; number of hospitalisations; and side-effects may determine the burden of illness for all members of the family.

An association between sibling coping style and the nature of diagnosis was noted by Madan-Swain et al. (1993). Siblings whose brother or sister had been diagnosed with a solid tumour seemed to make use of more self-orientated introspective coping strategies when compared to other diagnoses. Reasons for this difference were explained by the nature of treatment. Treatment for solid tumour cancers is generally shorter than for other types of cancer. Thus, siblings may have less access to information or support and they may have to rely more heavily on their own cognitive capabilities, as opposed to being able to express their emotions and seek social support from others (Houtzager et al., 2003).

Sloper and While (1996) reported that the duration of hospitalisation (number of nights spent at the hospital) was a predictive factor for adjustment problems in siblings. Illness severity also played a role in sibling adjustment. Barbarin et al. (1995) found that siblings became more independent and self-sufficient the more severe their brother or sisters diagnosis.

In terms of the time elapsed since diagnosis, a Dutch study undertaken by Van Dongen-Melman and his colleagues (van Dongen-Melman et al., 1995) aimed to investigate how siblings of cancer survivors adjust after cessation of treatment for their brother or sister. Results showed that the psychosocial functioning of siblings of childhood cancer survivors is comparable to that of children in normative comparison groups and no major differences relating to psychosocial functioning were found on all measures of emotional difficulties, behavioural problems and competence. The total group of healthy siblings scored the same or even better than the normative controls to whom they were being compared. This leading the researchers to conclude that childhood cancer does not result in a heightened risk of psychological disturbance for siblings as a late effect. Thus, although clinical research demonstrated that siblings have serious problems during the diagnostic and treatment phases of cancer (Isles, 1979; Sahler et al., 1994; Peck, 1979; Walker, 1990) it seems that after treatment is completed siblings adjust well. This absence of long-term effects is in sharp contrast to late effects of cancer experienced by parents and the cancer survivors themselves. Whereas reports noted that during treatment siblings are less adjusted than other family members, after termination it seems that this situation is reversed. It may be hypothesised that after treatment is terminated healthy siblings are able to distance themselves from the cancer experience, whereas with survivors and parents the confrontation with disease, the concerns and anxieties of the disease reoccurring and its long-term medical consequences continue (Houtzager et al., 2003).

From the above-mentioned findings, it can be noted that there are various factors which can impact upon the healthy sibling's adjustment to cancer in their brother or sister. It seems that there may be a relationship between sibling demographic characteristics, pre-diagnostic functioning of the sibling and characteristics of the illness on the one hand, and the persistence and prevalence of psychosocial adjustment problems after the diagnosis of cancer in a brother or sister on the other hand (Houtzager et al., 2003).

## **2.10 COPING STRATEGIES AND THE CANCER EXPERIENCE**

The coping process can be understood as a significant mediating factor in sibling adjustment to the cancer experience. Lazarus and Folkman (cited in Houtzager et al., 1999) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and internal-demands that are appraised as taxing or exceeding a person's resources” (P 141). Linking to this, Houtzager, Grootenhuis and Last (2001) stated that the uncontrollability which persists throughout the cancer experience is one factor which influences the process of coping for children with cancer and their families. Rothbaum et al. (cited in Houtzager et al., 2001) also emphasise uncontrollability in their two-process model of control. A distinction is made between primary and secondary control strategies. Primary control strategies relate to people's attempts to gain control by re-aligning their environment to meet their needs, whereas secondary control strategies relate to attempts to gain control by re-aligning the self with environmental forces. Siblings of paediatric cancer patients cannot influence the disease process, and as a result they tend to make use of secondary control strategies. The many painful experiences which paediatric cancer patients have to undergo often evoke feelings of anxiety and sadness in healthy siblings. In order to cope with these feelings, the following coping strategies are reportedly used: being optimistic about the situation (predictive control); attributing power to the medical caregivers (vicarious control); wishful thinking or hoping for a miracle (illusory control); and searching for information in order to better understand reactions and find meaning in the current situation (interpretative control) (Houtzager et al., 2001).

An early qualitative study conducted by Walker (1988) aimed to identify and describe behavioural and cognitive coping strategies employed by siblings. Open-ended interviews were conducted with 26 siblings of paediatric oncology patients. The interviews were focussed on what the healthy siblings saw as stressors and what thoughts and behaviours siblings used to deal with these stressors. Puppet play, family drawings, cartoon story telling and sentence completion tests were used to facilitate the interview process. Siblings' data revealed three major themes of stressors: loss, fear of death and change. Coping strategies employed by siblings to deal with these stressors included: wishful thinking,



attention seeking behaviours, talking to others and solitary play (Walker, 1988). Three further coping strategies cited in the literature included: seeking of social support and ventilation of feelings; communication about the illness and denial.

When referring to social support, Taylor (cited in Houtzager et al., 1999) noted that parents were the most important source of support for siblings and that siblings often use emotional expression to make sense of and cope with their experiences (Houtzager et al., 1999; Koch-Hattem, 1986). In a study investigating the effects of a social support group for siblings, Heiney et al. (1990) noted three coping strategies used by siblings: avoidance, denial and interaction with peers. Ventilating feelings through anger outbursts, acting out or talking to others seemed to be important strategies used by siblings during the coping process. On the other hand, siblings were also inclined to deny that their brother or sister was ill. This denial acted as a means to avoid thinking about the illness (Houtzager et al., 1999).

Communication is not only an important need identified by siblings, but communication also seems to be another important strategy that siblings employ to help them cope with the cancer experience. Breyer et al. (1993) and Havermans and Eiser (1994) agree with this and viewed sibling coping during the cancer experience and the level of communication between siblings and their parents as positively related (thus, the higher the level of communication between parents and siblings, the better the siblings' adjustment). Sargent et al. (1994) and Sloper and While (1996) further supported this notion as they noted that low levels of communication can lead to distorted ideas and misconceptions for siblings relating to their brother or sister's cancer. These distortions can give rise to confusion, anxiety and feelings of guilt (Houtzager et al., 1999; Kramer, 1984). Three protective factors against these distortions and misconceptions include: open and honest communication between family members; sibling involvement in the illness process and in the care of their brother or sister; and adequate information about the illness and its treatment (These three factors were also identified as important sibling needs during the cancer experience) (Houtzager et al., 1999; Kramer, 1984). Several researchers mentioned that siblings lack these protective factors. Healthy siblings receive inadequate and limited information about their brother or sister's illness (Brett & Davies, 1988; Havermans & eiser, 1994; Heiney et al., 1990; Houtzager et al., 1999; Martinson et al., 1990) and they are not involved in the treatment and care of their ill brother or sister (Fife et al., 1987). Kramer (1981) attributed this lack of communication between parents and siblings to the siblings' increased separation from the family (parents spend more time at the hospital and siblings have to stay with neighbours, baby sitters or extended family members). In addition, fathers and siblings seemed to discuss the cancer experience less frequently and openly than siblings and mothers. This may stem from a lack of involvement of fathers and siblings in the treatment process. It is thought that involvement in the

treatment of their ill sibling and adequate information about cancer are likely to be interdependent protective factors in sibling adjustment during the cancer experience (thus, increase in the one may automatically lead to increase in the other). However, these factors have not yet been studied as such (Houtzager et al., 1999).

Denial is the final factor mentioned by Houtzager et al. (1999) to play a role in sibling coping and the cancer experience. Denial can take on the function of protecting the self or others from painful information and experiences, and is thus an avoidant way of coping with the cancer experience. Several researchers (Brett & Davies, 1988; Chesler et al., 1991; Fife et al., 1987; Heffernan & Zanelli, 1997; Heiney et al., 1990) have noted denial-like processes which family members use to cope. When parents use denial as a coping strategy, this can result in limited cancer information reaching the healthy siblings (Brett & Davies, 1988). This lack of information can result in siblings being ignorant about cancer and may lead to isolation of siblings within the family unit (Houtzager et al., 1999). Parents may choose to limit the information they give healthy siblings about their ill brother or sister as a means to hide their own feelings. On the other hand, siblings also protect their parents from their own negative emotions.

It was noted that even though siblings spend a large amount of time thinking about their brother or sisters cancer, only a quarter of siblings talked to their parents about their thoughts, and a third talked to no one at all (Evans et al., 1992; Houtzager et al., 1999). Siblings keep their thoughts to themselves in order to protect their parents, as they don't want to add to their stress (Bender, 1990; Cairns et al., 1979; Chesler et al., 1991). Van Veldhuizen and Last (Cited in Houtzager et al., 1999) coined this phenomenon "The law of double protection". This strategy is aimed at protecting the self and significant others from confrontation with threatening emotions (Houtzager et al., 1999). These denial-like strategies can have negative consequences. When effective communication is limited, family members are forced to deal with emotional stress on their own. Thus, trying to protect each other from negative emotions can result in isolation and limited communication between the members of the family (Houtzager et al., 1999). Although avoidance behaviours seem to be protective in the acute stress phase shortly after diagnosis, Phipps, Fairclough and Mulhern (1995) warn that in the chronic phase of the illness such avoidance strategies may be harmful.

When age is linked with specific ways of coping, few studies report age-specific coping strategies for siblings. Kingma and Tori (cited in Houtzager et al., 1999) found that older siblings made use of more introspective strategies when dealing with the cancer, whereas younger siblings were primarily focussed on concrete changes which occurred in their lives. It was also noted that older siblings used a

greater variety of coping strategies, and they also used these strategies more effectively. However, older siblings also reported less involvement in family life.

The above findings demonstrate that coping strategies used by healthy siblings may provide health care practitioners with useful information to use when implementing intervention strategies to promote successful coping with the cancer experience.

## **2.11 INTERVENTION STRATEGIES AND THE CANCER EXPERIENCE**

The identification of effects, and the factors that lead to these effects, and the identification of adjustment factors and coping strategies in early studies enabled contemporary research (in the late 1990s and early 2000s) to refine these themes. Except for refining previous themes, contemporary studies have moved to a higher level where intervention strategies were investigated and recommended.

Researchers such as Walker (1992) identified intervention strategies which can be used to facilitate the development of effective coping skills for siblings of children with cancer. Walker (1992) reported that nursing staff can facilitate the development of good coping skills in cancer patients, their siblings and parents. This can be done by using open communication; making siblings feel special; implementing consequent discipline for all children and encouraging regular visits to the hospital or clinic. Murray (1995) introduced two additional skills to this list which are being used with great success by nursing staff. These include: encouraging parents to spend time with their other children and the provision of honest answers to questions asked by siblings (Murray, 1995).

In one of his other studies Murray (2002) investigated what social support interventions 50 school-aged siblings (aged 7 to 12) of children with cancer perceived to be helpful. Siblings were asked to “write about things they wish nurses or parents would do to help children who have a brother or sister with cancer and discuss things that nurses or their parents have done that have been helpful in adjusting to the childhood cancer experience” (Murray, 2002, p. 327). Siblings provided written responses to these questions, and content analysis was used to analyse the data. Siblings responses indicated a need for emotional (a need to be comforted, loved, respected, understood and cared for) and instrumental support (help with transportation to after-school activities, attendance at support groups and camps and any other interventions that can help siblings maintain a sense of normality in

their lives) as being helpful in adjusting to their ill siblings' cancer (Murray, 2002). These findings are consistent with those noted in previous research (Havermans & Eiser, 1994; Kramer, 1981; Murray, 2001; Wang & Martinson, 1996).

In a further interesting study conducted by von Essen and Enskär (2003) the aim was to look at interventions that parents and nurses deemed important for siblings of cancer patients. From this study it became clear that parents were not aware of the fact that their healthy children were facing difficulties. This indicates that interventions in this field are important, not only to the siblings, but to the parents as well. Some of the helpful interventions identified by nurses in this study included: amusement, emotional support, family life, information, normal life, participation, social competence, and time. These different care aspects were derived by means of content analyses performed on interviews conducted with 34 nurses and 97 parents of cancer patients in Sweden. The above-mentioned interventions were described by cross-sectionally comparing the different groups and stating the interventions most frequently noted to be useful. However, previous research involving nurses has also identified barriers to the provision of support to siblings, some barriers which nurses identified included: staff shortages; limited access to healthy siblings; institutional constraints (for example, limited visiting hours); issues of role boundaries (for example, whose job it is to take care of sibling needs, nurses, psychologists, doctors or social workers?); and lack of support and attendance of sibling support groups (Murray, 1999b).

Murray (1995) and Walker (1992) also mention that the siblings' own perceptions relating to helpful intervention strategies and coping skills should be identified, this may increase and promote better adjustment to the cancer experience. This is exactly what Catherine Ballard focussed on a few years later in her study. According to Ballard (2004) there are five needs that siblings have in relation to intervention, firstly there is the need for reassurance with regards to the sick child; second there is a need for information; furthermore, siblings need reassurance relating to their own health and well-being; the fourth need relates to a need for a relief of feelings of guilt and finally siblings express a need for inclusion and social support.

From the above, it can be noted that nurses use a myriad of intervention strategies to help healthy siblings either directly or through their parents (Murray, 1995; Walker, 1988). More recent studies investigated the value of intervention strategies such as camps, chat rooms, group discussions, role-plays and art therapy techniques (Dolgin, Somer, Zaidel & Zaizov, 2007; Houtzager et al., 2001; Pacman et al., 2008; Taddmore, 2004). Various researchers have reported success of camps for brothers or sisters of children with cancer (Barrera et al., 2005; Pacman et al., 2004; Pacman et al.,

2008; Wellisch, Krater, Wiley, Belin & Weinstein, 2006). Wellisch et al. (2006) claim that camps have a positive psychosocial impact on siblings of paediatric cancer patients. In their study Barrera et al. (2005) found that after commencement of a camp, siblings presented a reduction in emotional symptoms of behavioural problems. Pacman et al. (2004) obtained great success with their camp Okizu project; this is a summer camp for siblings of children with cancer which was held in the USA. This camp was designed to address emotional problems, to provide peer-group interactions, and to boost the healthy siblings' self-concept. A decrease in symptoms of PTS and anxiety, as well as an increase in QOL and self-image was noted in campers after commencement of the camp. In a follow-up study with camp Okizu Pacman et al. (2008) delved deeper and investigated the value of art-therapy techniques as a means of intervention for siblings of children with cancer. In this study the investigation was focussed on art as a projective technique and measurement instrument for the psychosocial functioning of healthy siblings. During this investigation it was noted that children's drawings can be powerful tools to aid in the expression of complex and traumatic emotional experiences (Boshoff, 2009; Pacman et al., 2008).

Murray (2001) examined the self-concept of 50 school-age (aged 7 to 12 years) siblings of children with cancer who attended a summer camp. Results obtained on the Personal Attribute Inventory for Children (PAIC) (Parish & Taylor, 1978) suggested that healthy siblings who attended a summer camp scored statistically higher on the PAIC when compared to healthy siblings who did not attend camp. Murray (2001) concluded that social support as provided by the camping experience may contribute positively to coping with the diagnosis of cancer in a brother or sister. Support groups which promote openness and emotional expression may be present as helpful interventions for siblings and aid in the promotion of psychosocial adjustment and improve QOL (Barrera et al., 2002; Barrera et al., 2005; Cohen, 1994; Heiney et al., 1990; Houtzager et al., 1999; Pacman et al., 2005). Pacman et al. (2005) conclude that summer camps are a promising intervention for siblings of paediatric cancer patients.

Meeting up with peers who also have a brother or sister diagnosed with paediatric cancer provides a unique opportunity for siblings to address their needs for recognition, information, communication and reality-testing (Houtzager et al., 2001). Carpenter, Sahler and Davis (1990) reported that a supportive group programme where information relating to cancer was imparted reduced fears experienced by siblings. Houtzager et al. (2001) evaluated the effect of participation in a supportive group on sibling anxiety. Healthy siblings (n = 24) completed a Dutch translation of the child version of the State-Trait Anxiety Inventory (STAIC) (Spielberger et al., 1973) pre-and-post-participation in a support group for healthy siblings. The researchers (Houtzager et al., 2001) noted that siblings experienced less anxiety after participating in the group. Prior to group participation the majority of healthy siblings

reported heightened levels of anxiety when compared to a normative population. According to Taddmore (2004) social support also plays an important role as a preventative measure for families who may lose a child to death. It is claimed that preventative interventions can help ease the grieving process for siblings and parents, help with healthy detachment and ensure the integrity of the family after the death of the child. Important role-players who can provide intervention on a personal level include parents, teachers, doctors, nurses, psychologists, social workers and other health care practitioners (Taddmore, 2004).

Relating to personal intervention, Johnson (1997) aimed to provide an adaptation-based counselling model to use with children whose parent or sibling has been diagnosed with cancer. In her article she discussed various developmental counselling interventions which were found to be useful when dealing with emotional difficulties experienced by well children who had a family member diagnosed with cancer. Effective counselling interventions discussed included: journaling (involving the written expression of feelings, experiences and thoughts); play and activity therapy (involving projective, creative and activity-based expression of feelings); psycho-educational group interventions; facilitation of participation in peer support networks; bibliotherapy (therapeutic reading); relaxation training and guided imagery (involving muscle relaxation and positive visualisations); and advocacy on the part of the counsellor (where advice was given to significant others in the healthy sibling's life). Thus, by making use of developmentally appropriate interventions which seek to facilitate expression, provide information and teach adaptive coping strategies, skilled counsellors can help healthy siblings negotiate the childhood cancer experience in an appropriate and adaptive manner (Johnson, 1997).

On the other hand, some intervention strategies are not necessarily targeted to siblings, but are focussed on the supporters and carers of brothers and sisters of children with cancer. Labay and Walco (2004) suggested that intervention programmes which provide empathy training should be designed. Skills including the ability to discriminate between different emotional messages, the ability to take on a certain role and the experience and expression of emotions should be taught. According to the researchers these interventions can have a lasting positive result for siblings and can lead to greater empathy and pro-social behaviour, less interpersonal aggression and a more positive self-concept (Labay & Walco, 2004). Labay and Walco (2004) further state that methods such as these can be used in various environments where interactions with siblings of children with cancer take place. Thus, support can be given to improve communication between home and school, and the peer group and teachers can be sensitised in terms of the unique needs of siblings. This can ensure the maintenance of sibling participation in age-related activities that are often interrupted when the family has to focus their resources on the care of the child with cancer (Labay & Walco, 2004).

Taking together these findings relating to intervention; it is noted that future research should aim to decrease and eliminate the negative outcomes of cancer and focus on and promote the positive outcomes. This can be done by implementing strategies and creating awareness around chronic illness. Parents, nurses and significant others should keep in mind that children are resilient in nature. They should be cognizant of this and promote and create situations to foster resilience and eliminate malfunction.

## **2.12 THE SOUTH AFRICAN CANCER EXPERIENCE**

As far as the researcher could ascertain, only one study to date has focussed on the experiences of South African siblings of children with cancer (Boshoff, 2009). In her study Boshoff (2009) adopted a case-study approach, and conducted in-depth interviews with 3 South African children (aged 12-16) who had a brother or sister diagnosed with paediatric cancer. Boshoff's (2009) study also made use of art-therapy techniques along with in-depth interviews to gain insight into the conscious and unconscious perceptions that South African siblings have relating to their brother or sisters cancer. Boshoff (2009) stated that her study was not aimed at obtaining a general overview of the effects of cancer, but rather focussed on providing an opportunity for three South African siblings to share their experience of their brother or sisters cancer within a safe and non-threatening environment. Results obtained support concerns which were reported in previous international studies, and thematic analyses brought themes relating to the concept and understanding of cancer, stressors, quality of life, coping strategies and structures of support to the fore. Boshoff (2009) concluded that the way siblings conceive and describe cancer (with relation to causes and prognosis) differs from one child to the next. Furthermore, all three South African siblings in Boshoff's (2009) study reported aspects relating to religion and faith (praying, reading their Bibles) as an integral part of coping with their brother or sisters cancer. The use of faith or religious-based coping strategies has not been highlighted in previous international research. Thus, these strategies may present a unique dimension of coping for South African siblings. When discussing possible South African based interventions, because each siblings experience of and reaction to the cancer in their brother or sister was different, Boshoff (2009) emphasised that a "custom-made" intervention strategy should be used to help each individual sibling. When customising such a sibling intervention programme, role-players (parents, teachers, nurses, doctors, psychologists, social workers and other health care practitioners) must foster sensitivity towards contextual differences (for example, cultural and religious aspects), factors relating to quality of life, unique stressors and verbal and non-verbal means of communication used by siblings.

Further South African studies with related themes were also noted. Landsberg et al.'s (2005) study acknowledged the entire family of children with chronic illness (siblings included) as well as the impacts that these chronic illnesses can have. This study noted that the illness experience exerts enormous strain on the family in terms of finance, emotions and time. Siblings reported sometimes resenting their parents relating to the amount of time and money spent on the ill sibling. Siblings also reported feeling guilt relating to their own health. In line with international studies, Landsberg et al. (2005) viewed the sibling's level of psychosocial, language and cognitive development and age as important factors which play a role relating to the impact of chronic illness on healthy siblings. Thus, it is thought that children are only able to understand the relationship between symptoms and treatment after the age of six. Furthermore, Landsberg et al. (2005) noted that serious chronic illness can lead families to go through a period of grieving and this grief is often mixed up with other feelings including: anger, guilt, denial and blame. High levels of maternal depression as well as marital problems were also viewed as common factors in families with chronically ill children. These families are also at a risk for social isolation as a result of fear, anxiety and embarrassment that can occur in social situations (Landsberg et al., 2005).

In conclusion, Landsberg and his colleagues (2005) emphasised that South African families with a chronically ill child need support from various sources (for example, other family members, friends, health care workers, and other social structures such as the church and school). It is further recommended that siblings may benefit from counselling and support groups where expression of emotions and feelings can occur in a non-threatening environment.

Cutland (cited in CHOC, 2011) emphasised a multi-dimensional approach to support (support on a cultural, educational and psychological level). Health care practitioners should use their skills to make sure that the needs of parents, siblings and patients are met on all levels.

In terms of South African interventions, few were noted. Currently (2011) some South African hospitals (for example, Johannesburg hospital) do foster an awareness relating to the stress that cancer places on the entire family (including siblings) (CHOC, 2011). A group for siblings grieving after the loss of a brother or sister to cancer was started at Johannesburg hospital. Furthermore, the Just footprints foundation, a South African non-profit organisation and the childhood cancer foundation of South Africa (CHOC) aim to provide camping experiences and support for children with life-threatening illnesses and their families (CHOC, 2011; Just Footprints Foundation, 2011). Unfortunately these awareness programmes are still in the developmental stages and further expansion is required.



Most institutions still adopt a patient-focussed approach and programmes are mainly focussed on the patient themselves and his or her parents (Boshoff, 2009). From the above it can be concluded that the South African population is still lacking a relative amount of knowledge relating to the topic of paediatric cancer and its effects on the family and healthy siblings (Boshoff, 2009).

## **2.13 RÉSUMÉ**

In this chapter the relevant literature pertaining to siblings and paediatric cancer was reviewed. The review started with an overview relating to effects of the cancer experience, with special attention given to emotional, socio-behavioural, physical and positive outcomes. Research concerning sibling needs, perceived losses and gains, quality of life, adjustment, coping strategies and useful interventions was reviewed next, and previous international findings relating to these factors were noted. The chapter concluded with a review of literature relating to the South African cancer experience. It should be noted that the bulk of research reviewed was carried out in first-world countries, and as a result generalisations within the South African context are made with caution.

The international research base is used as a point of departure and can assist in directing South African research in terms of trends and the identification of themes.

Chapter 3 provides a description of the methods used to obtain and analyse the data rendered by the present study.

## **CHAPTER 3**

### **METHOD**

In this chapter an overview of the methods used to obtain and analyse the data rendered by the present study is given.

#### **3.1 INTRODUCTION**

The present study was exploratory in nature, based on the fact that there is still a relative lack of knowledge relating to South African siblings and their experience of paediatric cancer. Only one study focussing on this topic has been conducted within the South African context (Boshoff, 2009).

To reiterate and for purposes of clarity, the aim of the present study was to gain a greater understanding of the experiences of South African siblings of children diagnosed with paediatric cancer.

Primarily, the present study sought to explore the feelings and experiences reported by 10 South African siblings who have a brother or sister diagnosed with paediatric cancer. In this way an overall thematic experience relating to living with a sibling diagnosed with paediatric cancer could be developed.

The secondary aim of the present study was to develop a South African perspective relating to the topic of paediatric cancer and its effects on siblings.

#### **3.2 RESEARCH DESIGN**

The present study was qualitative in nature. An interpretive and phenomenological research design was employed, as the outcome was aimed at obtaining a thick-description relating to the feelings and perceptions of siblings who have a brother or sister diagnosed with paediatric cancer (Henning, Van Rensburg & Smit, 2004). In order to gain greater insight relating to the cancer experience from the perspective of siblings, it was important to allow them to tell their stories of experience in their own words (Wilkins & Woodgate, 2005; Woodgate, 2000). It is to this end that qualitative enquiry was best suited. Fundamental to qualitative research is the development of an understanding of an individual's

personal account of a particular phenomenon (Speziale & Carpenter (cited in Wilkins & Woodgate, 2005). Linking to this, the phenomenological approach seeks to portray the meaning attached to experiencing a specific phenomenon for different people. This may be achieved by systematically collecting data which can be analysed to uncover meanings, descriptions and themes relating to various experiences and the contexts in which these experiences occur (De Vos, Strydom, Fouche & Delport, 2008). The phenomenon being explored in the present study relates to the experience of paediatric cancer, more specifically, how this experience is perceived by healthy siblings of patients diagnosed with paediatric cancer.

### **3.3 INCLUSION CRITERIA**

Participants who took part in the present study had to be between the ages of six and eighteen and they could be biologically or legally connected to the cancer patient, in this way not only blood relatives, but half and step siblings could also be included. Furthermore, participants had to be co-residents of the cancer patient, and siblings should have been informed by their parent or guardian regarding their brother or sister's cancer diagnosis. Finally, the chronic illness diagnosed in their sibling should be a recognised form of paediatric cancer.

### **3.4 PARTICIPANTS**

For the purpose of this study a convenience sample was used. Participants were recruited through contact with a paediatric oncologist at the department of haematology and oncology at a hospital in the Western Cape Province of south Africa.

The final sample consisted of 10 participants, with ages ranging between 8 and 18 (mean age of 13.90), including 4 boys and 6 girls. Siblings who took part were from two cultural groups, with 8 coloured and 2 white siblings taking part. Different types of cancer were included in the study, the length and type of treatment varied; however, all the siblings with cancer had received chemotherapy, radiotherapy, surgery or a combination of these treatments. These treatments often resulted in frequent and/or lengthy hospitalisations and with the majority of the cancer patients having one or both of their parents staying with them. In some cases the older siblings also reported staying with their younger brother or sister in the hospital.

Table 1 depicts the demographic characteristics of the total sample.

Table 1  
*Demographic characteristics of the total sample (n = 10).*

NUMBER	SIBLING GENDER	SIBLING AGE AT INTERVIEW	SIBLING – DEVELOPMENTAL STAGE	SIBLING RANK	CULTURE – SIBLING & PATIENT	PATIENT – AGE AT INTERVIEW	PATIENT DIAGNOSIS
1	Male	8	School-age	1 of 2	White	5	Leukaemia
2	Female	18	Adolescence	1 of 2	Coloured	12	Leukaemia
3	Female	11	School-age	2 of 3	Coloured	3	Leukaemia
4	Female	15	Adolescence	1 of 3	Coloured	3	Leukaemia
5	Female	11	School-age	1 of 2	White	3	Leukaemia
6	Female	16	Adolescence	1 of 2	Coloured	10	Lymphoma
7	Female	14	Adolescence	2 of 2	Coloured	19	Lymphoma
8	Male	8	School-age	4 of 5	Coloured	5	Brain Tumour
9	Male	12	School-age	3 of 5	Coloured	5	Brain Tumour
10	Male	15	Adolescence	2 of 5	Coloured	5	Brain Tumour

### 3.5 MEASURING INSTRUMENT

Data in the present study was collected qualitatively by means of a short semi-structured interview. The qualitative interview process enabled healthy siblings to verbalise their recollections and express their feelings and thoughts relating to the cancer experience (Wilkins & Woodgate, 2005). On the other hand, the interviews also enabled the researcher to illicit rich, detailed explanations to be used in the qualitative analyses. The interviews were based on a similar structure to the one employed by Menke (1987) (see addendum A). Interviews were conducted in either English (n = 2) or Afrikaans (n = 8) depending on the participant's home language. Each interview lasted approximately 30 minutes.

#### 3.5.1 Semi-Structured Interview

Interviews were semi-structured, each question in the interview schedule was covered (see addendum A). However, the exact wording and order of questions varied according to the climate of the particular interview. The introductory section of the interview took the form of a motivational talk. The discussion started with general questions (for example, what are some things you like to do? What don't you like doing?; How is it to be a member of your family?). In the section of the interview which focussed on the cancer experience, siblings were asked questions relating to: biographical particulars, changes in family life, relationships and activities (self and parents), relationships with friends and changes in social and school life since their brother or sister got sick (example question, Has anything changed for you since (name of sibling) got ill?); knowledge about the cancer and needs for information (Example question, Tell me what you know about your brother/sisters cancer?); feelings when they first found out their brother or sister was sick; support received and needed; anything that had worried or upset them; ways they used to deal with their feelings and worries; and what has helped

them to cope with the cancer experience (Example question, Who has been the biggest help for you since your brother/sister got sick?).

The first five questions (in the introductory section) were not used for data analyses, but were included to facilitate co-operation and communication between the sibling and the researcher. Siblings were encouraged to talk freely about the above-mentioned topics, and opportunity was also provided for them to address topics and feelings that the interview might not have covered.

## **3.6 RESEARCH PROCEDURE**

### **3.6.1 Stage 1: Permission**

During the first stage of research, the study's protocol was approved by the ethics committee at the University of Zululand. Thereafter, permission was sought from the hospital's Human Research Ethics committee (HREC) to conduct the research. Once permission was granted by the HREC, prospective families were contacted through a paediatric oncologist at the hospital's department of haematology and oncology. Families on the hospital's database with a sibling between the age of 6 and 18 years old were approached by the ward secretary when they attended follow-up medical appointments at the hospital between August and September 2011. Initial verbal consent was obtained from both parent and sibling, and interested families were later contacted telephonically by the researcher to answer any further questions relating to the study, and if the families were agreeable an appointment for an interview was arranged. During these telephone conversations parents also provided demographic data and information pertaining to the ill sibling's diagnosis and treatment.

### **3.6.2 Stage 2: Data Collection**

In the second stage of the study, data was collected from the participants. The data was mainly of a qualitative nature and no manipulation occurred. Interviews were conducted between 3 and 14 October 2011. Parents as well as siblings were provided with an informed consent form and information leaflet outlining the study (Forms were available in English and Afrikaans) (see addendums, C and D). The researcher took great care to ensure that siblings were able to decide for themselves whether they wanted to participate in the study or not. Consent was again checked before the interviews commenced and the researcher made it clear that siblings could withdraw from the study at anytime without having to give a reason and with no consequences what so ever. Siblings were given the opportunity to be

interviewed alone and information was kept confidential. Participants were asked semi-structured questions relating to their experiences of having a sibling who has paediatric cancer. The interviews were conducted in the children's home languages (either English or Afrikaans). Children were interviewed individually in the play room of the paediatric oncology unit at the hospital. The interview space was child-friendly and a space where participants could feel safe and comfortable. Each interview lasted approximately 30 minutes. With the participant's consent, interviews were recorded digitally.

### **3.6.3 Stage 3: Data Analysis**

Interviews were transcribed verbatim from the digital recordings, and analysed using content analyses to identify themes and categories which reflected each sibling's responses. The transcripts were analysed line for line to identify recurring feelings and experiences. Analyses were based on the transcripts of 10 biological siblings, and this analysis followed a similar approach to that described by Vaughn, Schumm and Sinagub (1996). The analysis was performed in four phases: identifying the overarching ideas, unitising the information, categorising the information and identifying themes.

#### **3.6.3.1 Phase 1 - Identifying Overarching Ideas**

The researcher read the transcribed texts several times in order to obtain an overview and general understanding of the siblings' experiences. Reading was also done to grasp the meaning as a whole and to identify overarching ideas relating to the narratives of the 10 siblings (Nolbris et al., 2006). This process of reading and re-reading has been likened to detective work, where the researcher investigates and identifies reoccurring trends and patterns in the responses of different participants (Vaughn et al., 1996). These overarching ideas were refined as the process of analyses unfolded.

#### **3.6.3.2 Phase 2 - Unitising the Information**

During the process of analyses the researcher tried to be as objective as possible. After reading and re-reading the transcripts line-for-line, the texts were then divided into individual meaning units. In essence, each individual statement of each participant was considered as a unique unit of data (Vaughn et al., 1996).

### **3.3.6.3 Phase 3 - Categorising the Units**

This phase involved grouping the individual identified units into meaningful categories or themes. Information units that were related to the same overarching idea were grouped together. Processing the data in this way enabled the researcher to generate initial headings under which the individual units of data were classified (Vaughn et al., 1996).

### **3.3.6.4 Phase 4 - Identification of Themes**

The final phase in the analyses involved identifying the themes. The overarching ideas (identified in phase 1) were re-examined. The researcher examined whether the overarching ideas were supported or contradicted by the thematic categories and individual units identified in phases 2 and 3. This re-examination enabled the researcher to refine and transform the initial “overarching ideas” into themes (Vaughn et al., 1996). These themes constitute the results of the study which are presented and discussed in Chapter 4.

## **3.7 TRANSLATING THE RELEVANT DATA**

As interviews were conducted in English and Afrikaans, a process of translation was required. The researcher is fully bilingual in English and Afrikaans, therefore the primary data analyses was done using the original English and Afrikaans transcripts. This ensured that no meaning was lost. After relevant quotations were identified they were translated to provide the reader with an English translation of the quotation. Relevant quotations were translated by the researcher; therefore, the translation process could be limited to one level of interpretation. A translator examined and verified the accuracy of the translations to ensure that the translated quotations were grammatically correct and reflected the meaning of the original quotation.

## **3.8 ETHICAL CONSIDERATIONS**

Keeping the aim of the present study in mind, namely to gain a greater understanding of the experiences of siblings of paediatric cancer patients, this research was conducted with the well-being and best interests of the participants kept in highest regard. The present research was non-therapeutic in nature; participants were asked semi-structured questions relating to their experiences of having a brother or sister with paediatric cancer. All participants were briefed on the nature and objectives of the study before its commencement and only consenting children and adolescents took part.

The American Psychiatric Association (1992) stresses that one of the first principles of research involving children, is that the research should not involve any harmful procedures, either of a physical or psychological nature. The participants in the present study were not placed under any physical danger. The topic of paediatric cancer is a sensitive one, and the possibility that siblings may experience feelings of stress or anxiety was kept in mind (Richards & Schwartz, 2002). Thus, great care was taken during the process of data collection to ensure that this study inflicted no psychological harm on the participants. The ethical guidelines put forth by Terre Blanche and Durrheim (1999) namely: informed consent, privacy, confidentiality, competence and ethical reporting were followed during all phases of the research.

The research assistant (an honours student in educational psychology) made an important contribution to the present study. She served as an independent observer and in this way could report objectively on the research process and act as a non-subjective participant during data collection. Furthermore, the researcher, a masters student in psychology, conducted all interviews and was able to facilitate and monitor the process of data collection. This and the aforementioned sensitivity of the research assistant ensured that the participants were closely monitored for any signs of distress or discomfort. The study was supervised by a registered clinical psychologist who was available for consultation during all stages of data collection, which meant that if any signs of psychological distress or discomfort were noted in the participants, they could be referred for counselling. With all these measures in place, there were no complications relating to psychological distress.

### **3.9 RÉSUMÉ**

In this chapter the method regarding data collection and analysis was outlined and discussed. The chapter started with a brief introduction, which reiterated and clarified the primary aims and purpose of the present study. Thereafter the research design was defined. The participants' demographic characteristics were also provided, and an overview of these characteristics was depicted in Table 1. This was followed by a short description of the semi-structured interview process. The three stages of the research were then discussed (stage 1: permission, stage 2: data collection, and stage 3: data analysis). Elements relevant to the process of translation were described and the chapter concluded with the discussion of ethical considerations relevant to the present study.

The results rendered by the present study are reported and discussed in Chapter 4.



# CHAPTER 4

## RESULTS AND DISCUSSION

This chapter presents and discusses the main findings of the study.

### 4.1 INTRODUCTION

In order to explore the paediatric cancer experience from the perspective of South African siblings, 10 siblings with ages ranging between 8 and 18 were interviewed in the present study. After the interviews with the 10 participants were transcribed verbatim, the transcripts were analysed line-for-line to identify recurring themes. Five overall themes evolved from the participants transcripts. These themes related to the concept of cancer; concerns and worries; emotional experiences; changes; and resources and coping. Within each of these overarching themes, various sub-themes were also noted. These themes and sub-themes will be discussed and unpacked in more detail in the following sections. Original excerpts (in English and Afrikaans) from the interviews are included to support the findings that were noted. English transcriptions of the Afrikaans excerpts are also provided for purposes of clarity.

### 4.2 MEET THE PARTICIPANTS

The brief profile provided of each participant serves only to enhance the reader's understanding of their individual contributions. In order to protect the participants' identities, reference is made to code names.

Participant one is an 8 year old Afrikaans White male; K is the eldest of two siblings. His younger brother (age 5) was diagnosed with acute lymphoblastic leukaemia (ALL). K's brother is currently in remission and is receiving out-patient follow-up care. K presented as an intelligent, well-spoken young boy with a well-developed sense of humour. He reported that he enjoys doing his school work (especially multiplication sums) and that he loves dinosaurs.

Participant two's younger sister was also diagnosed with ALL. C is an 18 year old coloured female, her younger sister (age 12) is also currently in remission and receiving follow-up out-patient care. C finished Matric in 2010, and is planning to join the army in 2012. C said that she would really like to work in a helping profession one day.

Participants three and four are sisters; their younger brother (age 3) was diagnosed with leukaemia at the end of 2010. He is currently at home and is also receiving out-patient follow-up care. His eldest sister Q is a 15 year old coloured female currently in grade 9. Q says that she loves playing netball and enjoys spending time with her friends "chatting" and "chilling". Q would like to be a nurse one day, so that she can help children who have cancer like her brother. M is the second born of the three siblings, she is 11 years old and currently in grade 6. M likes to spend her free time reading books and writing stories, and she enjoys learning about new things. M presented as a very shy and quiet young girl. One day when she finishes school M would like to travel and also help children who are sick to feel better.

Participant 5 is an 11 year old Afrikaans speaking White female. R's younger brother (Age 3) was diagnosed with leukaemia. R is in grade 5 and she loves doing art at school and playing computer games on her computer at home. R presented as a very friendly, talkative and kind young girl.

Participant 6 is a very bubbly 16 year old coloured female. S's younger brother (age 10) was diagnosed with lymphoma. S and her younger brother live with her mother, her parents got divorced and her father re-married a few years ago. S enjoys watching movies, socialising and spending time with her friends.

Participant 7 is a 14 year old coloured female. T is the only participant who is younger than her sibling who was diagnosed with cancer. T's sister (age 19) was diagnosed with lymphoma three years ago; she is currently in remission and off treatment. T is very musical, and she enjoys playing the cello, piano and recorder. T presented as a very well-spoken and reserved young woman.

The remaining three participants (Participants 8, 9 and 10) are from a coloured family of five brothers, their youngest brother (age 5) was diagnosed with a brain tumour. He is no longer on treatment, but still has to go for follow-up sessions every three months. O is the youngest of the three brothers who participated; he is eight years old and in grade 2. O says that he enjoys drawing and colouring in and that he likes to go play games at the local games arcade with his friends. O was quite shy during the interview and he didn't say much.

B is 11 years old, he is the third born of the 5 brothers. B is in grade 4, he says that he enjoys learning and doing his school work, he especially likes doing sums. He doesn't like it when the children at school play too rough because he always gets hurt. B presented as a very animated and talkative young boy. F is 15 years old and in grade 9, F also presented as a very quiet and shy young man, he didn't say much and spoke very softly. F says that he enjoys playing cricket and socialising and "braaiing" with his friends.

## 4.3 THEMATIC ANALYSES

### 4.3.1 Theme 1: Concept of CANCER

Most of the participants had some idea about their brother or sister's cancer. When asked to tell the researcher what they knew about their siblings' cancer, some siblings noted:

*"Die chemo laat jou hare uitval, soos my ma gesê het dit laat jou hare krul... en verder weet ek nie so mooi nie."*

*(The chemo makes your hair fall out, like my mom says it makes your hair curl... and more than that I don't know so well)*

[K, older brother, age 8 (+3)]

*"I didn't know anything about leukaemia, the moment the results came from the doctor, and my mother said that my sister had leukaemia, I still didn't know what leukaemia was until I came here (to the hospital) and they said that it was a type of blood cancer, and then I didn't know anything, but now I know about it... I understand now, but not all things, I don't understand completely, it is a bit complicated."*

[C, older sister, age 18 (+6)]

*"I just know that he had Burkett's lymphoma cancer, which is the cancer of the glands, the lymph glands...and that he had different types of chemo, and they first didn't know what was wrong."*

[S, older sister, age 16 (+6)]

*"Oh... ek weet dit (die kanker) vloei in sy bloed in en in sy maag..."*

*(Oh... I know it [the cancer] flows into his blood and into his stomach...)*

[Q, older sister, age 15 (+12)]

*"Hierdie ding (die kanker) dit gaan in sy kop in... en dis al wat ek weet."*

*(This thing (the cancer) it goes into his head... and that's all I know.)*

[F, older brother, age 15 (+10)]

*"Hier agter, hier by die Klein brein... hier by die brein daar is iets verkeerd met die brein..."*

(Here at the back, here where the little brain is... here at the brain, there is something wrong with the brain...)

[B, older brother, age 11 (+6)]

*“Ek weet dis baie seer, en dis ook nie lekker om te sien hoe hulle daai naalde in hom druk nie, en partykeer as ek daar in die wagkamer sit daar, dan hoor ek hoe skree hy, dis nie vir my lekker nie... en ja... O, wat was die vraag nou weer? (Researcher: Wat weet jy van jou boetie se kanker, wat kan jy my daarvan vertel?) Uh... wat ek daarvan weet, nee, ek weet nie.”*

(I know it hurts a lot, and it is also not nice to see how they stick those needles into him and sometimes when I’m sitting in that waiting room there, then I hear him scream, it’s not nice for me... and yes... Oh, what was the question again? [Researcher: What do you know about your little brother’s cancer, what can you tell me about it?] Uh... what do I know about it, no I don’t know. )

[R, older sister, age 11 (+8)]

*“Lymphoma...but I don’t know much.”*

[T, younger sister, age 14 (-5)]

One sibling (M, age 11) said that she knew nothing; she reported that she had asked her mother about her brother’s cancer before, but she couldn’t recall what her mother had said. One of the other siblings (O, age 8) simply stated that his brother was sick, he didn’t know anything else (*“Hulle het gesê X is siek. (Researcher: En het hulle vir jou vertel wat fout is?) Hulle het net gesê hy is siek...”* (They said X is ill. [Researcher: And did they tell you what is wrong?] They just told me he is ill...)) [O, older brother, age 8 (+3)]. From the above it can be noted that siblings’ concept of their brother or sister’s cancer differs, some have greater knowledge than others. However, the general impression was that siblings are lacking cancer information. Siblings identified their parents (mostly mothers), and in some cases nurses and doctors as people whom they could approach and ask for information about their brother or sister’s cancer. Overall siblings reported that they were happy with the information that these sources provided.

#### 4.3.2 Theme 2: Concerns and Worries

Consistent with findings in the international literature, themes relating to concerns and worries were most recurrent (Janes-Hodder & Keene, 2002; Menke, 1987). Siblings’ narratives revealed worries related to their brother or sister’s prognosis and what a follow-up examination might reveal. Siblings were worried about relapse and that their brother or sister may get sick again. Some siblings were also worried about getting sick themselves.

*"I am worried that it happens again, the first time was enough, I won't be able to go through it all again...I will donate (donate bone marrow) because it is my duty.... I will do anything, but seeing her go through that again, I won't be able to cope."*

[C, older sister, age 18 (+6)]

*"Because obviously you don't expect that no one will get cancer, and he got the cancer back...so I am just scared that one day he might get the cancer back or I might get cancer...So that is one thing that worries me."*

[S, older sister, age 16 (+6)]

*"Worry oor my broer en dat hy nie kanker kry nie."*

(Worry about my brother and that he doesn't get cancer.)

[F, older brother, age 15 (+10)]

*"Ek hou nie daarvan dat hy na die hospitaal toe moet gaan nie... (Researcher: Okay, wat hou jy nie van nie?) Netnou se hulle dit (die kanker) kom weer terug..."*

(I don't like that he has to go to the hospital... [Researcher: Okay, what don't you like?] Maybe they'll say it [the cancer] is coming back again...)

[M, older sister, age 11 (+8)]

Other worries and concerns related to what happens at the hospital. Siblings were worried that their brother or sister may experience pain or suffering when they undergo examinations or have to have treatment.

*"Ek is net bekommerd dat hulle (die dokters) hom baie seer maak dalk, dis baie seer."*

(I'm just worried that they [the doctors] hurt him very much, maybe, it is very sore.)

[K, older brother, age 8 (+3)]

*"Worry oor my broertjie, en oor sy treatment, dat hy nie moet ly nie en dat hy nie moet siek raak nie."*

(Worry about my little brother and about his treatment, that he must not suffer and he must not get ill.)

[Q, older sister, age 15 (+12)]

*"Ek is somtyds is ek so bekommerd oor hom... ek worry oor hoe word dit gedoen met hom, die masjiene op sy kop."*

(Sometimes I'm so worried about him... I worry about how it is done with him, the machines on his head.)

[B, older brother, age 11 (+6)]

In addition to worries about pain and suffering, one sibling expressed fear that her sister may not “wake up”, she was worried that her sister may die.

*“...to see what was happening... to witness it for myself, when the doctors injected her, to see when she cried...when she called my name... I couldn’t handle it, I just walked away... and when they inject her to make her sleep... I was worried maybe she doesn’t wake up... I never wanted her to sleep, the moment she fell asleep then I would wake her up because I was scared that she would never wake up.”*

[C, older sister, age 18 (+6)]

One sibling also reported that the after-effects (side-effects) of the treatment concerned her; it was difficult for her to see her brother suffer.

*“When I think back about the times when he would get the chemo and then he would come home and then he would be throwing up and crying and screaming and performing and shouting and that was a really terrible thing... and I know... I love him and it was difficult for me to see him that way... I couldn’t bear to see my brother like that.”*

[S, older sister, age 16 (+6)]

Siblings also expressed protective concerns, their worries related to their brother or sister getting hurt or feeling ill. It seemed as if siblings experienced a constant fear that the cancer may come back, and when their brother or sister showed any signs of illness, the first thing that they thought of was that it was the cancer that had re-appeared.

*“As hy homself seermaak waarvoor ek baie bekommerd... bang is... hy maak homself baie seer, dan kry hy al hierdie blou kolle en ek is baie bang wanneer hy al hierdie blou kolle kry vir wanneer hy weer moet terug hospitaal toe gaan... want daai blou kolle... want die blou kolle... gaan nie weg nie... want hy maak homself baie seer.”*

(When he hurts himself that worries... scares... me, then he gets all these bruises and I am very scared when he gets these bruises or when he has to go back to hospital... because those bruises... because those bruises... don’t go away... because he often hurts himself.)

[R, older sister, age 11 (+8)]

*“The moment she gets hurt, then I tell my mother you have to take her to the hospital, she is a bit rough and bruises easily, and so she fell once and I kept insisting that my mother bring her to the hospital.”*

*“The doctor said that the moment she gets hurt, then just... something... a cancer cell can just get hurt, or something can just go wrong... anything can happen, because she lost a lot of blood that time she got hurt.”* [C, older sister, age 18 (+6)]

*“Ek is bekommerd oor somtyds dan word hy siek, of somtyds dan huil hy sy maag is seer, dan word ek baie bekommerd.”*

(I'm worried about sometimes he gets ill, sometimes he cries that his tummy hurts, then I get very worried.)

[M, older sister, age 11 (+8)]

In some situations when siblings witnessed their brother or sisters suffering or difficulty, not being able to help their brother or sister caused them to experience negative feelings. Siblings reported feeling angry and disappointed.

*“We took her out of X primary school because she was bruising and she was having a hard time, she was in agony, children were rejecting her and they started calling her names and then she told me and I would get so angry. Then when I get so angry I just want to do something...once an older guy, his child said something about my sister. When I went to go fetch her at school and I heard he said something, so I asked him what did you say now? He wouldn't tell me, I got angry and I pushed him... If I get angry I just loose it.”*

[C, older sister, age 18 (+6)]

*“Like at the beginning when we found out that he was sick, it was just very disappointing, because all my life we were busy growing up together and I always tried to protect him from everything and this was the one thing that I couldn't protect him from, the cancer from coming over his life path....I was quite disappointed in life and in myself because I felt like I let him down.”*

[S, older sister, age 16 (+6)]

In two cases siblings also reported that their worries and constant concern about their ill siblings well-being affected their daily functioning, specifically their school work.

*“In that time she was in hospital, I was never at home, everyday I came to the hospital straight from school, I thought I was going to fail that year, because I was here all the time, I didn't study at all and I was very worried, I only cared about her.”*

[C, older sister, age 18 (+6)]

*“Ek is nie meer op die leer nie, want die leer vat my ver weg, ek dink teveel aan my boeta.”*  
(I'm not on the learning anymore, because the learning takes me far away, I think too much about my brother.)

[B, older brother, age 11 (+6)]

All but one of the siblings reported that they could talk to someone about their worries and concerns, with mothers, fathers and grandmothers identified as the main people to confide in during difficult times.

### 4.3.3 Theme 3: Emotional Experiences

Linked to concerns and worries, experiencing intense emotions was another theme which featured frequently in the sibling narratives. Siblings described various situations that related to feeling sad, confused, lonely, angry and fearful.

*“It was bad, I felt very sad and confused, it felt like my life was shattered, why not me or my mother or my father? I mean she was only seven years old, and I couldn’t understand why it had to be her.”*

[C, older sister, age 18 (+6)]

*“When my brother came to live here at the hospital, it felt like the house was emptier... then there was more responsibility... for me it wasn’t actually responsibility, it was just loneliness and missing him.”*

[S, older sister, age 16 (+6)]

*“Upset yes, but angry spiritually, we went to the Pentecostal church, spiritually I was angry, because I wanted to know, why did God have to do this?”*

[C, older sister, age 18 (+6)]

*“First of All I was sad, because I never knew what the chemo was, there are so many different stages as the doctor explained to me, and they said that she had first grade ALL, and we were confused, we didn’t know what to expect, and after a while, she also didn’t know what was wrong, we were in the car on our way to the hospital and we were crying.”*

[C, older sister, age 18 (+6)]

*“I was very angry and I rejected people, and why I was so angry is because eight children died. Before we came here (to the hospital), in the two weeks before eight children had died from cancer. And I didn’t want that to happen to my sister.”*

[C, older sister, age 18 (+6)].

These emotional experiences are common in siblings of children with cancer, and previous researchers have noted that siblings experience intense emotions during the childhood cancer experience (Chesler et al., 1991; Murray, 1999a, 2000a, 2000b; Van Dongen-Melman et al., 1995; Wilkins & Woodgate, 2005).



#### 4.3.4 Theme 4: Changes

Change is another major theme which dominates international literature on the sibling experience of childhood cancer (Wilkins & Woodgate, 2005), and several siblings in the present study experienced the diagnosis of cancer in their brother or sister as precipitating some changes in their lives. Identified changes were framed in both negative and positive terms. Changes that siblings were most cognisant of related to (a) changes in themselves, (b) changes in their ill sibling, (c) changes in the sibling relationship, (d) familial changes, (e) changes in others and (f) changes in daily life.

Some siblings reported noticing changes in themselves, these perceived self changes related to self-realisations and changed interactions with others (both negative and positive changes were noted).

*“For me I realised that life is very short, you know it can be taken away from you very easily... and I think this is the way in which God showed us to love each other.”*

[S, older sister, age 16 (+6)]

*“I am an introvert, I am very quiet, after that (the cancer diagnosis) I started being rude to people, I started rejecting people, going out, started smoking, I never smoked before that, but I started to do bad things, but I don’t do it anymore. I stopped as soon as I knew she was going to be okay.”*

[C, older sister, age 18 (+6)]

Siblings also noticed changes in their ill sibling. Some of these changes related to deterioration in their ill siblings’ physical well-being and health.

*“Hy was so bietjie moanerig en baie slaaperig... en hy het nie eintlik baie geët nie.”*

(He was a bit nagging and very sleepy... and he didn’t really eat much.)

[K, older brother, age 8 (+3)]

*“Uhhhh... ek dink iets wat verander het is... ummmm... wel toe hy nou mos kanker gehad het kon hy nie lekker loop nie, so hy het gesukkel om te loop, toe moes hy nou gekruip het en nou loop hy weer, toe het hy so bietjie verander en dis nou so bietjie snaaks.”*

(Uhm... I think something that’s changed... uhmmmm... well, when he then had cancer he couldn’t walk so good, so he struggled to walk, he had to crawl then and then walk again, and then he changed a bit and that’s now a bit funny.)

[R, older sister, age 11 (+8)]

One sibling also noted various changes in her brother’s personality. S (age 16) reported that when she saw that her brother was being brave and able to cope with his cancer, it made things easier for her.

*“At the beginning it was tough, afterwards like when, when they used to inject him and draw blood, it was very difficult to see him, because he would always scream and cry...or call my mommy he wants my mommy around him, or he would call my daddy and things like that...but afterwards we saw that he was actually very strong, he gave his arm without screaming or crying so afterwards we realised that he is actually becoming better, becoming a strong person from the whole thing... I felt to myself, okay he is getting stronger now, so I told myself: Okay it is not such a big deal we can move forward now. But at the beginning when he used to cry, I felt really bad for him... how is the child going to get through this, it was tough... Before he was sick, he was always such a nice boy, and always so, like he knew he was very conceited about himself... that is what I think... but after he got sick, he just became so quiet. When he started actually realising what was happening to himself and to his body... for me he actually became more intelligent... he knew what was going on and he could explain to the people and tell the people what was happening... and he would also get like a little depressed where he would just say nothing to people, or he would just cry out of the blue... just keep quiet or he would just want to be around my mommy.”*

[S, older sister, age 16 (+6)]

The level of impact the cancer had on the sibling relationship varied across the transcripts. In most cases the school-aged siblings did not regard the cancer experience as creating a significant change in the relationship that they had with their brother or sister. However, one adolescent sibling (C, age 18) experienced heightened closeness with her younger sister, and even likened their relationship to that of a married couple.

*“Before she had cancer, she was irritating and we weren’t that close... and ever since she came here (to the hospital), I started getting that feeling of being very close to her, almost like two married people that doesn’t want to let each other go. Almost like that and I didn’t want to leave her at anytime... but before that it wasn’t like this, we didn’t spend as much time together.”*

[C, older sister, age 18 (+6)]

Siblings also described how their brother or sister’s cancer changed some aspects of familial life. Siblings described positive and negative familial characteristics that they perceived as changing or occurring in response to the diagnosis of cancer in their brother or sister. These included: (a) distance between family members, (b) heightened emotions, (c) spending more time together (heightened family cohesion), (d) greater appreciation for life and (e) being more health conscious.

The following excerpts describe some of these changes.

*“Toe X siek gewees het was dinge baie anderste gewees dit was ongemaklik gewees...almal was nie saam nie en almal was nie gelukkig nie... niemand was saam as n gesin nie ons was almal uitmekaar uit... en almal was, hoe kan ek sê... vresend, hartseer, huilerig... vir my was dit die ergste, want hy was amper soos my eie kind vir my, ek is sy groot suster en ons was baie saam.”*

(When X was being ill things were very different, it was uncomfortable... everyone was not together and everyone was not happy... nobody was together as a family we were all apart from each other... and everyone was, how can I say... fearing, sad, weepy... for me it was the worst, because he was almost like my own child to me, I am his big sister and we were together lots.)

[Q, older sister, age 15 (+12)]

*“Before my brother got sick, my dad didn’t worry much with us...he never came to visit, he would always drop things off at the house he wasn’t bothered. Now he comes to visit us, he comes to fetch us...he always comes to fetch my brother. It is like very different, because we realised that we should all love each other we should all appreciate each other... I am happy about my dad... It makes me feel quite good as a person... Because now I know that my dad is still there for us and I realised that my brother is actually fine, and it makes me feel happy and like a better person man, then I used to be.”*

[S, older sister, age 16 (+6)]

*“Obviously we (the family) like watch our health more now... we still eat more or less the same, but we worry more about our health now we are more aware... I think it was sort of good to have that experience you know... I think we needed a bit of a wake up call.”*

[T, younger sister, age 14 (-5)]

From the above it can be noted that siblings perceived certain aspects of their family life changed in response to the cancer. Patterns that existed previously were disrupted and new ones constructed.

In addition to familial changes, some siblings also reported that other people (including: relatives, friends or acquaintances) treated them differently since the onset of their brother or sister’s cancer. Siblings generally felt positive about the change in the way that others treated them; they felt happy that others took the time to ask how their brother or sister was doing.

*“When people see me they don’t ask me how I am doing, they first ask me how my sister is doing then they ask me how I am doing? (Researcher: and how is that for you? How does that make you feel?) I don’t feel sad or anything... I know that I would also ask the same thing if someone else who I knew sister or brother had cancer... but if she didn’t have cancer and they ask me how is she doing, then I might be a bit angry.”* [C, older sister, age 18 (+6)]

*“Hulle (ander mense) is meer vriendelik met my, en dan praat hulle saam met my (Researcher: Okay...so hul vra jou meer hoe dit gaan... en hoe is dit vir jou?) Lekker... ek hou daarvan as mense vir my vra hoe dit met my gaan en met my broer, dan sal ek sê nee hy is alright en dit gaan goed by hom.”*

(They [other people] are friendlier to me and then they talk to me [Researcher: Okay... so they ask you more often how things are... and how is that for you?] Nice... I like it when people ask me how I am and how my brother is, then I'll say: no, he's alright and everything is well with him.)

[M, older sister, age 11 (+8)]

However, one sibling experienced the way other people treated her as “weird”, she did not enjoy the experience and said that it made her feel funny.

*“Hul (kinders by die skool) het na my toe gekom en gesê jammer, jammer, soos veral tot kinders wat ek nie eers ken nie. Al my maatjies wat ek gehad het hulle weet daarvan... maar dan was soos ander kinders dan kom staan almal so om my en sê eks so jammer, ek is so jammer en ALS... dit was net weird... Almal wat my nie ken nie, hulle kom vat aan jou en sê eks so jammer... en nou, ken niemand my nie... maatjies, mense wat ek nie eers ken nie... um... kinders wat ek ken, maar hulle hou nie eers eintlik van my nie. hulle voel baie jammer vir my, hulle gee vir my al hierdie goeters, al hierdie koekies en hierdie kos en dis net vir my baie snaaks, want hulle doen dit nie gewoonlik nie.”*

(They [children at school] came to me and said sorry, sorry, like even children I don't even know. All my friends I had they know about it... but then there were like other children then they come and stand all around me and say I'm so sorry, I'm so sorry and ALL that... it was just weird. Everyone that doesn't even know me come and touch me and say I'm so sorry... and now, nobody knows me... friends, people I don't even know... uhm... children I know, but they don't even like me, they feel very sorry for me, they give me all these things, all these biscuits and this food and it's just very strange for me, because they don't usually do it.)

[R, older sister, age 11 (+8)]

Sibling narratives also revealed themes relating to changes in daily life. Siblings spent more time at the hospital and experienced greater care-taking responsibilities. Once again, these changes were viewed in both positive and negative terms.

*“I stayed out of school also, if she had to go for blood tests, I stayed with her. (Researcher: And how was that for you? That experience?) It was bad, I felt very sad and confused, it felt like my life was shattered...”*

[C, older sister, age 18 (+6)]

*“I was only at home on weekends, otherwise I would be here, then I would go home, clean the house, buy the food and then cook for them (the family) as well... a lot of it my mother did as well, but at that time even if I did a lot it didn't feel like a lot.”*

[C, older sister, age 18 (+6)]

*“It was difficult, he (the ill brother) kept on waking me up, if I had to get the bottle for him or he wee'd in the bed or something, then I had to clean him also... (Researcher: And how was that for you?) I was just very irritated because I want to sleep... then every time it is a different story... so then I must always get up you know, so I wasn't sleeping...”*

[S, older sister, age 16 (+6)]

The above-mentioned changes suggest that when a child or adolescent is diagnosed with and treated for cancer the situation for the healthy siblings and the family as a whole is affected (Nolbris et al., 2006).

#### **4.3.5 Theme 5: RESOURCES AND COPING**

Siblings identified a number of resources and strategies which they felt helped them to deal with the cancer experience. A distinction can be made between resources and coping strategies. Resources can be understood as something which siblings have that they can use, and coping strategies relate to things that siblings do to help them feel better (Patterson et al., 2004). Despite this distinction, resources and coping strategies are often intertwined, and the availability of a resource is often related to the coping strategy that is adopted. Some resources which siblings identified related to supportive relationships and the availability of others, while coping strategies which were adopted included talking to others, avoidance or normalisation and focussing on their own interests and activities.

Relationships which allowed them to voice their concerns and where they could find comfort and support were noted to be helpful by 9 out of the 10 siblings. These relationships could be with parents, other relatives or friends.

*“Net om my ma te sê het my laat beter voel. Sy het mooi met my gepraat, en my getroos.”*

(Just to tell my mom made me feel better. She spoke nicely to me and comforted me.)

[R, older sister, age 11 (+8)]

*“Gewoonlik vertel ek dit (bekommernisse) vir my ouma, my ouma weet alles, maar gewoonlik kan ek dit ook vir my een matjie X vertel... en sy hou iets vir haarself... So ek vertel net goed vir haar...”*

(Usually I tell my gran about it [the worries], my gran knows everything, but usually I can also tell my one friend X... and she keeps something to herself... So I only tell her about things...)  
[R, older sister, age 11 (+8)]

*"My grandmother... she passed away... but at that time she was the biggest help... she was here... every time I came here she was here...we were here together... everyday all the time... she was very helpful... And I can speak to her about anything, if my sister goes for blood tests and I am worried and crying then she comforts me.*

[C, older sister, age 18 (+6)]

*"They (friends) were always there for me. They would even phone me in the middle of the night to ask if I am ok... because I couldn't sleep."*

[C, older sister, age 18 (+6)]

*"I would speak to my mom, because she would always talk to the nurses and she was always knowing what was going on... And there is a lady at church also she works at the hospital, and she also like brought some information home for us to read..."*

[S, older sister, age 16 (+6)]

*"My family... that is what actually helped me the most, because the time we found out...the night of the 14th when we found out then the next morning we still couldn't believe it, like we knew what was happening but we couldn't actually believe this whole... It was quite difficult. They (family) are always at home there... Sometimes we don't even want them there... and they are there... Luckily my friends and cousins and so were all around me... they were always there... they talk to me."*

[S, older sister, age 16 (+6)]

*"My ma en my pa praat altyd saam met ons..."*

(My mom and dad always talk to us...)

[B, older brother, age 11 (+6)]

As noted by Sloper (2000) the availability of supportive relationships was important in enabling siblings to adopt the coping strategy of talking about what they are going through. This strategy was adopted by the majority of siblings in the present study. However, on the other hand, some siblings also reported that normalising and keeping their thoughts and feelings to themselves helped them; in this way they were not confronted with having to explain and discuss difficult emotions.

*"I didn't want them (friends) to comfort me, because the moment they started to comfort me, I started to cry."*

[C, older sister, age 18 (+6)]

*"People like... they would just ask me, you know, how's your brother? And I would say no he is fine, but I think it is the way I reacted, I acted with them man... like if my friends at school*

*asked... I would say, no he is ok, he will be fine and then go do something else... So I wouldn't like act if I am sad or something, I would just like be my normal self and if people ask, how is X, no he is ok, he is full of his normal nonsense."*

[S, older sister, age 16 (+6)]

*"Ummmm... ek het op my eie gecope."*

(Uhmhhh... I coped on my own.)

[Q, older sister, age 15 (+12)]

Contrary to international research findings, information was not a significant resource that siblings identified. In one case a sibling said that she would rather not have information as it upsets her to much:

*"Ek wil nie regtig weet nie, want wat met my gebeur partykeer as ek dinge weet, dan kry ek baie nagmerries, en sleep walk ek en alles... want as ek alles weet dan kry ek nagmerries, dan kry ek nagmerries van die naalde wat hulle in jou steek."*

(I don't really want to know, because what happens to me sometimes when I know things, then I get lots of nightmares, then I get nightmares about the needles they stick into you.)

[R, older sister, age 11 (+8)]

Furthermore, focussing on their own interests and activities were coping strategies which helped some siblings; these activities distracted them and took their minds off their brother or sister's cancer for a little while. Activities which were reported to be helpful in this regard included watching TV, talking to others about everyday things (not about the cancer), reading a nice book, playing games or taking a nap. Linking to this, two of the siblings reported using distraction as a means to help them cope with thoughts and worries about their siblings situation.

*"Um, dis of ek kyk TV, wat ek nou soos lekker storie kan kyk of ek bou puzzle of ek speel op die rekenaar of ek slaap."*

(Uhm, it is either I watch TV, where I now can watch like a nice story or I build a puzzle or I play on the computer or I sleep.)

[R, older sister, age 11 (+8)]

*"Somtyds dan praat ek saam met my niggie, dan sê sy vir my dan praat ons sommer daaroor allerhande goed van haar. (Researcher: Okay, dan praat julle sommer oor ander goedjies... so dit help vir jou?) Ja."*

(Sometimes then I talk to my [female] cousin, then she tells me then we just talk about it or about all other kinds of things of hers.) [Researcher: Okay, then you just talk about other things.. so does that help you?] Yes.) [M, older sister, age 11 (+8)]

*“(Researcher: Okay... so jy is bang hy kry dalk weer kanker of hy raak weer siek...en as dit gebeur, as jy so bang voel, wat doen jy dan?) Somtyds dan praat ek met my ma, somtyds dan lees ek ‘n boek.”* (

*[(Researcher: Okay, so are you scared he might get cancer again or get ill again... and when it happens, when you feel so scared, what do you do then?)] Sometimes I talk to my mom, sometimes then I read a book.)*

*[M, older sister, age 11 (+8)]*

When confronted with fears and concerns about the future, some siblings chose to adopt a positive outlook. If thoughts about the cancer reoccurring or their brother or sister not surviving occurred, they were constricted, and siblings chose to replace negative thoughts with positive ones.

*“In the night or in the afternoons when I lie with her (the sister with cancer) and then we are watching TV, and then we see someone in bed, somebody is sick or so I tell them (the family) we are not going to worry, don’t be scared it is not coming back again, she is cured.”*

*[C, older sister, age 18 (+6)]*

None of the siblings had attended support groups, when asked if they would like to talk to other children who have a brother or sister with cancer, siblings had mixed reactions. More than half of the siblings (n=6) felt that if possible it would be helpful to share their experiences with others.

*“I would like to share my sister’s story, because if she was cured, if her cancer was cured, then they can cure your brother or sisters cancer as well.”*

*[C, older sister, age 18 (+6)]*

*“Ek sal daarvan hou, want ek het al daar deur gegaan ek weet wat om te maak.”*

*(I would like that, because I’ve already been through it and I know what to do.)*

*[Q, older sister, age 15 (+12)]*

*“I would like to know how they (other siblings) felt because everyone doesn’t feel the same and what helped them.”*

*[S, older sister, age 16 (+6)]*

However, on the other hand, other siblings were reluctant and said they would decline such an opportunity. One sibling reported that she didn’t really want other people to know about what was going on in her family’s life.

*“...nie eintlik nie, want ja ek wil nie heeltemal van ander mense se goeters weet nie en ja...ek wil ook nie regtig hê ander mense moet van my gesin se goeters weet nie...”*

*(...not really, yes because I don’t want to know all about other people’s stuff yes and... I don’t really want other people to know about my family’s stuff.) [R, older sister, age 11 (+8)]*



It was clear that some of the siblings felt strongly about making a difference and helping others through sharing that which they had learnt and discovered during this difficult period of their lives. Linking to wanting to share their stories and experiences, the desire to help heal others who were sick was also expressed by some of the siblings when sharing their childhood cancer stories.

*“Ek wil graag met kanker werk eendag. (Researcher: En kom dit van jou boetie af? Het hy jou geïnspireer?) Ja. (Researcher: En wat dink jy wat sal jy wil doen?) Verpleging.”*

(I would like to work with cancer one day. [Researcher: And does it come from your little brother? Did he inspire you?] Yes. [Researcher: And what do you think you would like to do?] Nursing.)

[Q, older sister, age 15 (+12)]

*“Ek wil eendag ‘n goeie... ek wil werk...ek wil travel... ek wil kinders gesond maak...”*

(One day I want to be a good... I want to work... I want to travel... I want to cure children.)

[M, older sister, age 11 (+8)]

## 4.4 DISCUSSION OF RESULTS

The results of the interviews conducted with 10 South African siblings indicated that the childhood cancer experience is appraised in various ways. These various appraisals highlighted five themes which embody some of the experiences and emotions highlighted in previous international research studies. The reported experiences can be linked to various levels of the siblings' lives.

When referring to the concept of cancer, this involves the participants' understanding of cancer (including: symptoms, causes and prognosis that the illness involves) as well as the sources that were used to gain this understanding (Boshoff, 2009). In terms of the concept of cancer for siblings in the present study, most siblings had some idea about their brother or sister's cancer. However, some siblings had greater cancer knowledge and a better understanding than others. Significant in this regard is the sibling's level of cognitive development, as cognition plays a role in understanding. As noted by Loxton (2005), cognition can be understood as the process of organising and attaching meaning to experience. It was noted that the two eldest participants C (age 18) and S (age 16) seemed to possess the greatest knowledge about their siblings' cancer (they knew about the specific cancer diagnosis and had a better understanding of the symptoms that were involved). This finding is in line with that noted by Cohen et al. (1994), they found that the older the sibling at the time of diagnosis, the greater their understanding and knowledge of their brother or sister's cancer. Both C and S were around age 15 when their siblings were diagnosed with cancer, S's brother was diagnosed earlier this year (2011) and C's sister had been diagnosed four years ago (2007). In terms of the other adolescent participants, it

was noted that their concept of cancer was not as comprehensive. Time of diagnosis could have played a role in this regard, as it has been noted that parents tend to share most of the cancer information closest to the time of diagnosis (Brett & Davies, 1988). Thus, siblings who are younger at the time of diagnosis may have limited knowledge pertaining to their siblings' cancer later on. This hypothesis could hold merit in terms of participants T and F. Both T (age 14) and F (age 15) were in an earlier stage of development (school-age) when their siblings were diagnosed with cancer. Thus, the temporal factor may explain their limited cancer knowledge. In terms of the other school-age siblings, their understanding and concept of cancer was mainly focussed on the physical characteristics of the illness (for example, cancer side-effects, location of the tumour and the pain that the cancer caused). These explanations could be linked to the cognitive-developmental stage of school-age children. According to Piaget's (1972) cognitive developmental theory, children between the ages of 7 and 11 are in the third stage of cognitive development (concrete operational stage). School-age children have the capability to apply logic in concrete situations – these being situations that focus on visible, tangible, real things. This then explaining the school-aged siblings focus on concrete (physical) aspects of their siblings' cancer (for example, physical symptoms and pain) This finding is in line with those noted by Kingma and Tori (cited in Houtzager et al., 1999), they noted when focussing on intervention strategies older siblings were more introspective, while younger siblings focussed on concrete aspects of the cancer experience. Therefore, the siblings' cancer understanding is influenced on both an individual and chrono-systems level, where the siblings' age and the course of development influences their understanding and interpretation of the world around them.

Keeping in line with previous research findings (Menke, 1978, Wilkins & Woodgate, 2005), siblings in the present study experienced worries as a constant presence, these worries were linked to a pervasive threat that suddenly things might change. Siblings worried about their brother or sister's health, their prognosis, what happens at the hospital and siblings also worried about their own health. The common thread in all these worries related to an element of uncontrollability and unpredictability. Most of the adolescent siblings reported worries which were future orientated. Adolescent siblings' worries related to the possibility of relapse or death, what a follow-up examination might reveal and the possibility of getting sick themselves. This finding ties in with the adolescent's stage of cognitive development that of formal operational thought (Piaget, 1972). One of the cognitive achievements during this stage includes the ability to imagine and reason about hypothetical situations (What if?) situations) (Loxton, 2005; Piaget, 1972). School-aged siblings expressed concerns relating to physical symptoms (bruises and stomach aches) and their relation to their brother or sister's health, and they were also worried about what happens at the hospital. These findings relating to worries are in line with those noted in previous international research (Janes-Hodder & Keene, 2002). Overall, siblings'

concerns can be contextualised on an exo-systems level. This level includes situations over which the sibling does not have direct control, but which nevertheless still influence the siblings' cancer experience. As mentioned previously, doctors have an influence on the exo-system level (see section 1.5.3.4). Often siblings do not have direct contact with the specialist who is responsible for their brother or sister's care, and siblings cannot control the disease process (Houtzager et al., 2001). It is this element of uncontrollability that may influence siblings' worries and increase their fears.

Emotional expression can be defined as the way in which an individual outwardly displays feelings (King Emmons, cited in Polce-Lynch, Myers, Kilmartin, Forssmann-Falck & Kliewe, 1998). Included in this outward expression is verbalisation of emotions. Siblings in the present study described various situations that related to feeling sad, confused, lonely, angry and fearful. In line with Boshoff (2009) it was noted that when the emotional expressions of the siblings in the present study are compared to those in international literature, a certain degree of correlation can be noted. All the emotions expressed by the siblings in the present study have also been noted in previous research (Binger et al., 1969; Boshoff, 2009; Cairns et al., 1979; Kramer, 1981; Marasca, 2003; Pacman et al., 2004; Wilkins & Woodgate, 2005). This may point to a certain degree of universality in the sibling cancer experience.

Interestingly, adolescent siblings voiced their emotions more prominently than school-aged siblings, and female siblings reported greater emotionality than males. Therefore, age and gender seem to play a role in emotional expression. This finding is in line with that noted in previous research. Kramer (1984) noted that adolescents have greater cognitive abilities and are better able to analyse and rationalise their feelings. When looking at gender differences and emotional expression, the composition of the sample may possibly explain the higher reporting of emotional experiences by adolescent girls, only one of the adolescent siblings was male. However one other possible explanation for the gender differences in emotional expression could relate to different modes of socialisation and gender-role expectations experienced by boys and girls. Where keeping in line with male character, boys are expected to be tough and brave, thus expression of emotions might conflict with their internalised view of masculinity. Girls on the other hand are socialised to be feminine and gentle, and the expression of emotions is encouraged and more acceptable in their daily socialisation. Linking to this, research which investigated the correlations between emotional expression and age and gender noted that boys restrict emotional expression from early through late adolescence, while girls increase emotional expression during this developmental stage (this is the developmental stage applicable in the present study) (Polse-Lynch et al., 1998).

Furthermore, events surrounding the childhood cancer experience were appraised as resulting in a number of changes in the sibling's life. These changes occurred on various levels, with change occurring on a personal, relational, familial and community level. Changes which were noted related to self-realisations (life is short), changes in relating with others (shut other people out and became rebellious), physical changes in the ill sibling (being more sleepy, difficulty eating, not being able to walk), changes in their ill sibling's personality (more grown-up, stronger, more intelligent), changes in the sibling relationship (a heightened sense of closeness and spending more time together), changes in family life (greater emotionality, heightened sense of family cohesion, more health conscious) and change on an interpersonal level (others were more concerned and treated siblings differently). Reflecting on these changes, siblings perceived change in terms of both losses and gains. This links up with the description of change put forth by Wilkins and Woodgate (2005).

Some of the siblings showed an ability to reflect on and find meaning within the cancer experience. This was particularly evident when looking at one sibling's narrative. S (age 16) described how her brother's cancer had highlighted life's fragility and she reported that this realisation resulted in heightened cohesion and greater "love" amongst the members of her family. The ability to analyse and find meaning within change can act as an important coping strategy. In one case, one of the siblings noted that her sister's cancer diagnosis caused some changes in her behaviour: *"I am an introvert, I am very quiet, after that (the cancer diagnosis) I started being rude to people, I started rejecting people, going out, started smoking, I never smoked before that, but I started to do bad things, but I don't do it anymore. I stopped as soon as I knew she was going to be ok."* [C, older sister, age 18 (+6)]. This finding is in line with findings noted by Lavigne and Ryan (1979). They found that siblings' behavioural manifestations of stress are linked to their age and gender. Pre-school siblings are more likely to show signs of irritability and withdrawal, whereas school-age and adolescent children may act out socially to vent their emotional distress.

In contrast to international studies where it was noted that increased attention to the ill sibling (for example, people asked about the ill sibling before asking about the healthy siblings well-being) resulted in siblings feeling unloved and less important than the ill child (Bender, 1990; Chesler et al., 1991; Martinson et al., 1990; Murray, 1998; Wilkins & Woodgate, 2005), most of the siblings in the present study viewed this greater concern in a positive light. Siblings reported that they "liked" it when others asked them how their brother or sister was doing, this concern made them feel happy and special. Although one sibling (C, age 18) noted that if people first asked her how her sister was doing and her sister wasn't sick, this would make her angry.

When referring to changes in daily life, in line with findings by Nolbris et al. (2006), siblings felt it was important to be loyal and supportive to their ill brother or sister. However, this caused some disruptions in daily life. Siblings experienced conflicts of loyalties where they had to be at school, but at the same time needed to be at the hospital to support their sibling, or where one sibling needed to sleep, but she also felt a sense of responsibility to wards her brother where she had to take care of his needs.

A few Coping strategies and resources were also identified by siblings. Last and Grootenhuis (1998) noted that resilience (“the ability to bounce back”) is an important factor which helps children who have a sibling with cancer pull through. The resources and coping strategies mentioned by the siblings in the present study are in line with this notion, as it was noted that employing coping strategies such as avoidance, social support and open communication play an important role in the process of sibling adjustment during the childhood cancer experience. During the interviews siblings mentioned persons who were good sources of support for them. Although developmental theorists describe the adolescent’s peer group as the most influential during this stage (Erikson, 1963; Wait, 2005). Adolescent siblings in the present study referred to parents, grandparents and extended family members as their primary sources of social support. This finding is in line with that noted by Boshoff (2009), where she also noted that siblings reported that various people offered them helpful social support during and after their siblings cancer diagnosis. Interestingly, the participants in Boshoff’s (2009) study identified their teachers as playing an important role during the cancer experience. This was not the case in the present study; three of the siblings even noted that their teachers didn’t know about their brother or sisters cancer. One sibling even noted that he didn’t tell his teacher because she wouldn’t be able to do anything anyway. One possibility for the identification of greater educational resources in Boshoff’s (2009) study could relate to the fact that the study was conducted from an educational psychology viewpoint (as the research formed part of a masters degree in educational psychology).

Overall South African siblings seemed to experience less negative emotions and reported fewer adjustment difficulties when compared to international studies on the sibling cancer experience. A possible explanation for this difference could relate to the sample itself, all but two of the participants in the present study came from coloured communities in the Western Cape province of South Africa. This sample composition resulted from the location of the hospital where the data was gathered (the hospital is situated in a predominantly coloured area). The area surrounding the hospital is known for its high levels of crime and poverty (Department of Health, 2007). Thus, the coloured children in the present study are more likely to come from households with a low socio-economic status (SES) and

live in areas where the rates of violence and crime are high. It may therefore be hypothesised that as a result of their constant exposure to situations and events that pose a threat to their own well-being and safety these children may have developed a greater resilience and possess a greater repertoire of coping strategies which they can employ in stressful situations.

Furthermore, in a recent sociology paper by Muyeba and Seekings (2011) a low-income Cape Town coloured community was described as follows: “there is more community and more interaction in poorer neighbourhoods where walls are lower, gardens smaller, and people walk on rather than drive on the streets” (Muyeba & Seekings, 2011, p. 657). Thus, the greater sense of community and interaction and support from others (collectivism) may have acted as a protective factor in the present study. In line with this notion, Sloper (2000) noted that the existence of a positive support system in the healthy sibling’s family and wider community network is an important protective factor in fostering children’s resilience in relation to stressful life events. However, attitudes relating to community and community support were not assessed in the present study; therefore the aforementioned hypotheses are merely speculative.

## 4.5 RÉSUMÉ

This chapter commenced with a short descriptive profile of each of the participants, these descriptions were provided in order to outline a brief background from within which each participant’s contribution could be understood. Thereafter the five overall themes namely: the concept cancer; worries and concerns; emotional experiences; changes; and resources and coping were presented. Sub-themes within each of these five categories were also outlined. The chapter concluded with a discussion of each of the themes. Relevant literature and theoretical viewpoints were incorporated to contextualise the findings.

Chapter 5 concludes the study and outlines the main findings, limitations, aspects which added value, and recommendations which resulted from the present research.

# CHAPTER 5

## CONCLUSION

The motivation for the present study stemmed from the need to gain greater insight into the cancer experience from the viewpoint of South African siblings who have a brother or sister diagnosed with paediatric cancer. This was done by addressing the following aims:

- Exploring the feelings and perceptions of siblings living with a brother or sister diagnosed with paediatric cancer.
- Developing an overall thematic experience relating to living with a sibling diagnosed with paediatric cancer.
- Developing a South African perspective relating to the topic of siblings and paediatric cancer.
- Identifying strategies and resources to assist in preventing or reducing maladaptive outcomes in siblings of paediatric cancer patients.

On these grounds, this chapter summarises the main findings of the present study. The studies limitations are discussed and recommendations for future research are made. The contributions made by the present research are highlighted and the chapter concludes by outlining guidelines which can be used when interacting with siblings of children with cancer (These guidelines are presented in terms of a bioecological model).

### 5.1 MAIN FINDINGS

The exploration of the South African sibling experience of childhood cancer has highlighted the effects of this phenomenon in 10 children's lives. Thematic analyses of the sibling narratives presented five broad themes relating to the concept of cancer; worries and concerns; emotional experiences; changes; and coping and resources. Similar themes have been noted in previous research which focussed on the sibling experience of paediatric cancer.

When referring to the theme concept of cancer, it was noted that most of the participants had some idea about their brother or sisters cancer, although the extent of sibling knowledge differed. Some siblings had more cancer knowledge than others. The most significant factor relating to the sibling's concept of cancer was noted in terms of the healthy sibling's age and level of cognitive development.

Older siblings seemed to have a greater understanding and perception of their ill sibling's cancer. Linking to this, healthy siblings identified their parents (mostly mothers), extended family members (grandmothers) and in some cases nurses and doctors as people whom they could approach and ask for cancer information. However, the general impression was that healthy siblings are lacking cancer information.

In terms of the second theme, worries and concerns, in line with international literature on the sibling cancer experience, aspects relating to this theme were most recurrent (Janes-Hodder & Keene, 2002; Menke, 1987; Wilkins & Woodgate, 2005). Healthy siblings identified worries relating to their ill brother or sister's health and prognosis, what happens at the hospital and healthy siblings also worried about their own health. Adolescent siblings worries were future orientated, while the worries expressed by school-age siblings related to concrete physical symptoms. Overall, siblings perceived worries as a constant presence in their lives.

The third theme related to emotions that healthy siblings felt in relation to their ill brother or sisters cancer. Healthy siblings described various situations that related to feeling sad, confused, lonely, angry and fearful. Feeling intense emotions such as the afore-mentioned has been noted as a common experience for siblings of children with cancer (Chesler et al., 1991; Murray, 1999a, 2000a, 2000b; Van Dongen-Melman et al., 1995; Wilkins & Woodgate, 2005). Interestingly, adolescent siblings voiced their emotions more prominently than school-aged siblings, and female siblings reported greater emotionality than males. Thus, sibling age and gender may play a role in emotional expression.

Change was the fourth theme that emerged from the sibling narratives. The experience of change is a theme which is prominent in international literature relating to the sibling cancer experience. Healthy siblings in the present study experienced the diagnosis of cancer in their brother or sister as precipitating some changes in their lives. Identified changes related to siblings themselves, their ill brother or sister, the sibling relationship, the family, other people and daily life. Changes were framed in both negative and positive terms.

The fifth and probably most important theme which presented from the 10 siblings narratives related to resources and coping strategies. This theme highlighted important resources that siblings used and things that siblings did which helped them cope during the cancer experience. Some resources which healthy siblings identified included supportive relationships with others. While coping strategies which healthy siblings adopted included talking to others about their feelings, worries and problems, avoidance or normalisation of feelings surrounding the cancer experience and focussing on their own



interests and activities to take their minds off their ill sibling's cancer. These resources and coping strategies mentioned by healthy siblings are in line with the notion put forth by Last and Grootenhuys (1998). These researchers noted that strategies which foster resilience (the ability to bounce back) are important to assist healthy siblings adjust successfully during the cancer experience.

The identification and exploration of the above-mentioned five themes provided the researcher with an opportunity to glimpse into the cancer experience from the perspective of 10 healthy South African siblings living with a brother or sister diagnosed with paediatric cancer.

## **5.2 LIMITATIONS AND RECOMMENDATIONS**

No study is without its limitations; as such the limitations of the present study are discussed below. In line with these limitations, recommendations for future research are also provided.

The present studies small sample size was its primary limitation. The inclusion of only 10 siblings limits the generalisability of the findings to all siblings of children with cancer. The original sample consisted of 16 participants. However, 1 participant did not arrive for her interview, 4 participants who had initially agreed to take part withdrew from the study, and the last participant's ( $n = 1$ ) responses were not included as she was very reluctant to talk and the researcher decided to discontinue the interview process. One reason for this small sample size can be related to the nature of the research. The ethical factor relating to client-patient confidentiality added an additional dimension to the recruitment process. The researcher could not contact families directly; contact had to be made through the hospital to ensure that patient records were kept private.

A further limitation relates to the composition of the sample. The majority of the siblings who took part in the present study were coloured ( $n=8$ ) and only two were white, and all participants lived in the Western Cape province of South Africa. It is suggested that future studies include a larger sample from different regions in South Africa. In this way a more diverse picture relating to the sibling cancer experience within the South African context can be gained.

The present study was cross-sectional in nature, and due to time constraints interviews were only conducted at one temporal point. A longitudinal design is necessary. This will enable future researchers to evaluate how the sibling cancer experience differs and develops over time. Multiple interview opportunities may produce rich and detailed findings and help build trust between the

researcher and participants. Linking to this, controlling for time since diagnosis may be an important factor to keep in mind, as in the present study siblings were in different phases of the cancer experience.

A one-time semi-structured interview was the main source of data collection in the present study. Although the interview provided a good first-hand account of the sibling cancer experience, it is recommended that future researchers consider additional sources of data collection. Collecting data from a variety of sources (for example, parents and teachers) adds breadth to qualitative data (Wilkins & Woodgate, 2005). Furthermore, the interviews conducted in the present study were semi-structured and they addressed specific topics surrounding the cancer experience. A more in-depth unstructured interview may have provided siblings with greater opportunity to express their feelings in a more open-ended manner. Focus group discussions may have been helpful in this regard. Some subjects may not have been able to put their feelings into words, thus other methods such as projection, observation or play might be used in conjunction with the interview schedule, in this way the researcher may be able to obtain more comprehensive data.

Finally, qualitative interpretations may be affected by the perceptions, biases and assumptions of the researcher, despite the rigorous efforts taken to avoid this in the methodology. However, the potential benefit of these interpretations outweigh the inherent risks associated with qualitative methodology to support and illustrate the findings of the present study (Pacman et al., 2005).

### **5.3 CONCLUDING REMARKS**

Although the present study incurred some limitations, aspects that added value most certainly existed. Firstly, the present study is one of the first of its kind (exploring the experience of paediatric cancer from the perspective of South African siblings) to be conducted within the South African context. This in itself made a valuable contribution to the existing body of knowledge involving siblings and paediatric cancer.

Although the use of a semi-structured interview was described as somewhat limiting, this method of data collection added great value as well. One of the strengths of the present study when compared with previous research on this topic is that the 10 siblings were given an opportunity to tell their own stories first-hand, instead of parents or staff being interviewed about the siblings situation. This data is an invaluable source in itself. In line with Boshoff (2009) it can be noted that the results of the present study underline and emphasise the unique nature of the cancer experience for each sibling.

Although findings relating to the cancer experience for siblings in the present study did not differ tremendously from those noted by Boshoff (2009) or from previous international research, Light was still shed on the unique cancer experience for 10 South African siblings, and great insight was gained into their emotional worlds.

In addition to Boshoff's (2009) South African research, the present study extended the age range of participants (participants in Boshoff's (2009) study were between the ages of 12 and 16 years) and included school-age siblings as well. This additional age dimension added important value to the data. It was noted that school-age children (age 8-12) interpret the cancer experience in a different way when compared to adolescent siblings (age 13-18). School-age sibling's concept of cancer was focussed on physical symptoms and pain, whereas adolescents seemed to possess more information relating to their brother or sisters specific diagnosis. Furthermore, school-age siblings were not as emotionally expressive as adolescent siblings and they reported less emotional experiences. This was also noted in terms of gender, where male siblings were less expressive than female siblings.

To conclude, the investigation of the significance of the cancer experience for South African siblings of children with cancer is in its infancy. The present study is one of the studies conducted in the beginning stages of this process. The qualitative phenomenological research approach used in the present study is an important research method which can assist in promoting the understanding of the lived experiences of siblings who have a brother or sister with cancer (Murray, 1998). This approach to studying the effects of childhood cancer on siblings could play an instrumental role in the formulation of supportive care and intervention strategies for this special population. Health care practitioners, especially nurses who have contact with families of children with cancer on a regular basis have a unique opportunity to provide special support to siblings. Nurses can confirm or dispute sibling thoughts and worries and provide them with support and accurate cancer information. The findings rendered by the present study can help in this process, and findings can also provide those who are in the siblings support network and who interact with them daily (parents, extended family members, friends, teachers and caregivers etc.) with important insights relating to the healthy siblings situation. If the results of this study can lead to siblings recognising mutual characteristics and finding that they are not alone in their experience a great deal can be achieved (Nolbris et al., 2006).

In line with the above, in her 2009 study Boshoff outlined various guidelines that could be helpful to those who want to help and support siblings of children with cancer. These guidelines as well as additional strategies derived from the present South African sibling cancer experience and the broader literature are outlined in terms of their implementation within a bioecological model. It may be

beneficial for future research studies to investigate the feasibility and outcomes of these suggested interventions.

### **Micro-systems level (guidelines for parents and other family members)**

- Immediately involve siblings in the cancer experience, share the diagnosis and relevant cancer information with them. In this way misconception and confusion can be avoided.
- Acknowledge siblings and let them know that you as a parent are available for them to talk and to ask questions.
- When providing cancer information, take the siblings age and developmental level into account.
- Keep siblings up-dated on their brother or sister's progress and the process of treatment.
- Give siblings a choice relating to the extent that they would like to be involved in their ill siblings care
- Support siblings in maintaining a sense of normality, by allowing and assisting them to participate in normal daily activities (for example, extra curricular activities and social events).

### **Meso-systems level (Guidelines for teachers, friends, class-mates, and other people with whom siblings interact on a regular basis)**

#### **Teachers:**

- Enquire about and show interest in what is happening in the lives of the learners in your class.
- Ask the learner how he/she is doing, and enquire about their sick brother or sisters well-being as well.
- Support the learner through this difficult time, but don't exclude them or treat them different to before.
- Offer extra academic assistance and adapt test/exam schedules if the sibling is going through a crisis time.

#### **Friends:**

- Ask your friend how he/she is doing, and enquire about their sick brother or sisters well-being as well.
- Go visit and spend time with your friend at home or at the hospital

- Support your friend and offer an ear to listen, and keep that which you and your friend talk about private.
- Phone or SMS your friend to hear how they are doing.
- Support your friend through this difficult time, but don't exclude them or treat them different to before.

### **Exo-systems level (guidelines for doctors, nurses and other hospital personnel)**

- Introduce siblings to other children who are going through the same experience
- Provide siblings with information relating to their brother or sisters cancer and its prognosis.
- The information that is provided should be easy to understand and age-appropriate.
- Allow the sibling to spend as much time as they need with their ill brother or sister (for example, be lenient with visiting hours and make siblings comfortable if they would like to stay over at the hospital).

### **Macro-systems level (Guidelines for broader societal/governmental implementation)**

- Government should provide support to organisations such as CHOC and the just footprints foundation to extend cancer support services to siblings.
- Government can also provide funding for further research aimed at exploring intervention and support programmes for healthy siblings.
- Government can also provide financial support to families of children with cancer who cannot provide the required finances for the ill child's care. This can help alleviate the families financial strain and relieve some of the stress for parents.

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## **ADDENDUM A: OUTLINE OF QUESTIONS FOR THE SEMI-STRUCTURED INTERVIEW**

1. What is your name?
2. What is your surname?
3. When is your birthday? /How old are you?
4. What are some things you like to do?
5. What are some things you don't like to do?
6. How many brothers/sisters do you have?
7. What are their names?
8. How old are your brothers/sisters?
9. Which of your brothers/sisters is sick?
10. What is it like being a member of your family? /what is it like to live in your house?
11. What are your responsibilities in your family/can you tell me some of the things you have to do in your house?
12. What grade are you in? What are the things that you like most about going to school?
13. How many friends do you have?
14. What do you like doing with your friends?
15. Do your friends come and play over at your house? /What do you like to play?
16. Tell me what you know about your brother/sisters cancer?
17. Who told you about your brother's/sister's cancer?
18. If you have questions about (name of sick child) or about the cancer or treatment, who do you go and ask?
19. What are some of the things you like doing with your brother/sister?
20. How do you and (name of child with illness) get along?
21. Has anything changed for you since (name of child with illness) got ill? If so, what?
22. a) What kinds of things? b) How have they changed? c) How does that make you feel?
23. What is it like for you when (name of ill child) has to go back to the hospital?
24. What do you find most difficult about having a brother/sister who has cancer?
25. Since your brother/sister got cancer, has anything changed in the ways that other people treat you?
26. a) Friends? b) Teachers? c) Neighbours? d) Relatives?
27. What kinds of things do you worry about?
28. Can you tell anyone about these worries?
29. If so who do you tell?
30. What kinds of things do you dream about?
31. Who has been the biggest help for you since your brother/sister became sick?
32. If you had the opportunity to talk to other children who also have a brother/sister with cancer, would you like this? If so, why?
33. If you had three wishes what would they be?

## PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS

**Title of the Research Project:** The experiences of siblings of paediatric cancer Patients: A South African perspective

**Reference Number:** N11/03/099

**Principal investigator:** Ms Lisa Visagie

**Address:** (address removed)

**Contact Number:** (number removed)

**E-mail:** (e-mail removed)

Dear Parent/Guardian

Your child is being invited to take part in a research project, which is currently being undertaken at the Tygerberg hospital. Please take some time to read the information presented here, which will explain the details of this project. If you have any questions or concerns with regards to the project, please feel free to contact the researcher. It is of great importance that you are satisfied and understand what the research entails, and how your child may be involved. Your child's participation is completely voluntary and you may decline to consent. No adverse consequences will result for your child if he/she does not take part. You may also withdraw your child from the study at anytime, even if you initially gave consent for his/her participation.

This project was approved by the Human Research Ethics committee at the University of Stellenbosch, and will be executed in accordance with the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for good Clinical Practice and the Medical Research Council's (MRC) ethical guidelines for research.

### **What is this Research project all about?**

The main aim of this research is to gain greater understanding into the feelings and experiences of siblings living with a brother/sister diagnosed with paediatric cancer. When a child is diagnosed with cancer; this is not only an individual diagnosis, but one which affects the whole family. Relating to this new family diagnosis, it is often the brothers/sisters of the ill child who carry the greatest hidden burden of stress. Qualitative research on this topic is limited, and only one study of this nature (to the researcher's knowledge) has been conducted within the South African context. The advantage of this study is that greater insight into the unique emotional world of siblings of paediatric cancer patients can be gained.

Should you give your consent, your child will be asked to take part in a short child-friendly interview (duration of approximately 30 minutes). Interviews will be conducted at a time and place which is convenient for you as well as your child.

### **Why has your child been invited to participate?**

The target group of this study includes children between the ages of 6 and 18 who have a brother/sister diagnosed with paediatric cancer. As your child falls within this group, he/she has been invited to take part in the study. The qualitative data provided by your child will assist in gaining a greater understanding as to the experiences of siblings living with a brother/sister who has/had a form of paediatric cancer.

### **What is your responsibility?**

As the parent/guardian of a child who has a brother/sister diagnosed with paediatric cancer it is your responsibility to sign and return the attached informed consent form if you would let your child participate in the study. Please, if you do not feel comfortable do not feel obliged to let your child take part in the research. No adverse consequences will result for your child if he/she does not take part.

### **Will your child benefit from participation in this research?**

There are no direct personal benefits for your child if he/she takes part in this research. However, your child's participation will make a helpful contribution to the understanding of the experiences of brothers/sisters of paediatric cancer patients.

### **Does Participation in this research present any risks for my child?**

Due to the fact that the research is non-therapeutic in nature, it is expected that no physical discomfort which could impact upon your child's well-being will occur. In a similar study undertaken in the Stellenbosch area by Boshoff (2009), no emotional discomfort was reported by any of the children who took part. If any unexpected signs of emotional discomfort come to the fore, your child can be referred through Prof C.D. Stefan (Tel. 021 938 9404) to the unit for community psychological Services: Unit for Psychology at the University of Stellenbosch.

### **Who will have access to your child's interview data?**

All information gathered from the children will be treated as confidential at all times, and all children will remain anonymous. When reporting the results, reference will only be made to the children in terms of aspects such as: age, gender and culture. No information used in the study will be related back to your child in his or her own personal capacity. Only me (the primary researcher) and my study leader will have access to the data.

### **Will you or your child be remunerated for participation in the study, and are there any costs involved?**

Neither you nor your child will be remunerated for participation in this study. It will cost you nothing to allow your child to participate.

### **Is there anything else that you should know or do?**

If you have any questions or concerns with regards to the above, please feel free to contact me or Prof (name removed) (study leader) on (number removed) or (e-mail address removed)

You can also contact the Human Research ethics Committee on (number removed) if you have any further concerns or complaints that were not adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

## DECLARATION BY PARENT/LEGAL GUARDIAN

By signing below, I (name of parent/legal guardian) ..... agree to allow my child (name of child) ..... who is ..... years old, to take part in a research study entitled: The experiences of siblings of paediatric cancer patients: A South African perspective.

I declare that:

- I have read or had read to me this information and consent form and that it is written in a language with which I am fluent and comfortable.
- If my child is older than 7 years, he/she must agree to take part in the study and his/her ASSENT must be recorded on this form.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that participation in this study is voluntary and I have not been pressurized to let my child take part.
- I understand that all information gathered from the study will remain confidential and anonymous.
- I may choose to withdraw my child from the study at any time and my child will not be penalized or prejudiced in any way.
- I understand that no potential risks exist for my child if my child participates in this study.
- I understand that the interview will be administered in my child's medium of instruction at school.
- I understand that the information gathered in the study will be published; however, any of the presented information will not be linked to my child in any way.

Signed at (place) ..... On (date) ..... 2011.

\_\_\_\_\_  
Signature of parent/legal guardian

\_\_\_\_\_  
Signature of witness

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## PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

**(School age – 6 to 12 years)**



**TITLE OF THE RESEARCH STUDY:** The experiences of brothers and sisters of children who have cancer

**RESEARCHERS NAME:** Lisa Visagie

**ADDRESS:** (address removed)

**CONTACT NUMBER:** (number removed)

**E-MAIL:** (e-mail removed)

### **What is research?**

Research is something we do to find out how things and people work. We use research projects and studies to help us find out more about different problems. Research also helps us find better ways to help people.

### **What is this research study all about?**

This research study wants to find out how it is to have a brother or sister who has cancer. The researcher wants to find out more about the things that children have to deal with when their brother or sister is sick. What you tell the researcher can help her, help you, and other children who have brothers or sisters with cancer to deal with feelings and problems in a healthy way.

### **Why have I been asked to take part in this research study?**

This research study wants to hear the stories of children who have a brother or sister with cancer. You have been asked to take part because you are one of the children whose brother or sister has cancer. The researcher wants to hear about your feelings and thoughts in your own words. Children who are 6 to 18 years old are taking part in the research.



### **Who is doing the research?**

Lisa Visagie is doing the research. Lisa is a masters student and she is studying psychology at the University of Zululand. Lisa is doing this research study for her school work. She wants to find out more about how it is to have a brother or sister who has cancer.

### **What will happen to me in this study?**

You will be asked to answer some questions about yourself, and about how it is to have a brother or sister with cancer. The questions are about your own feelings and thoughts, and there are no right or wrong answers. It will take about 30 minutes to ask all the questions. You can leave out any questions that you do not want to answer.

### **Can anything bad happen to me?**

Nothing bad will happen to you, but, if you feel that you don't want to take part in the research anymore, you can stop and nothing will happen to you. You won't get in trouble and nobody will be cross with you. If you don't feel good after the questions, the researcher will make sure that you talk to someone who can help you feel better. If you don't like a part of the study you can tell the researcher or your parents and stop taking part straight away.

### **Can anything good happen to me?**

There are no good things that will happen to you straight away. But, if you take part in the study you can help the researcher understand more about how it is to have a brother or sister with cancer. What you tell the researcher can help other children who have the same problems in the future.

### **Will anyone know I am in the study?**

The only people who will know you are in the study are the researcher, your parents and you. When doing this research, everything you say will be kept confidential. This means that all the things you tell the researcher will be kept secret, and the researcher won't tell other people what you said. If the researcher has to use the stories that you told her, she will change your name so that no one knows what you said.



### **Who can I talk to about the study?**

If you have any questions or problems about the study, you can talk to:

- The researcher, her name is Lisa Visagie, you can phone her on 082 456 4622 or send her an e-mail at [visagie.lisa@gmail.com](mailto:visagie.lisa@gmail.com).

OR

- Prof. Christina Stefan, she is a doctor who works at Tygerberg hospital, you can phone her on 021 938 9404 or send her an e-mail at [cs@sun.ac.za](mailto:cs@sun.ac.za).

### **What if I do not want to do this?**

If you do not want to take part in the study you don't have to. Even if your parents already said yes, you can still say no. No one can force you to take part in the study, it is your choice. If you say yes to take part in the study, but change your mind later nothing will happen to you. You are free to pull out of the study at anytime.

### **Do you understand this research study and do you want to take part in it?**

☐ YES☐ NO

**Has the researcher answered all your questions?**

☐ YES☐ NO

**Do you understand that you can pull out of the study at any time?**

☐ YES☐ NO

\_\_\_\_\_  
Signature of Child

\_\_\_\_\_  
Date

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## PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

**(Adolescents – 13 to 18 years)**



**TITLE OF THE RESEARCH STUDY:** The experiences of brothers and sisters of children with cancer

**RESEARCHERS NAME:** Lisa Visagie

**ADDRESS:** (address removed)

**CONTACT NUMBER:** (number removed)

**E-MAIL:** (e-mail removed)

### **What is research?**

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about different problems. Research also helps us discover and explore different ways to help people.

### **What is this research study all about?**

This research study will look at the experiences of children who have a brother or sister with cancer. The researcher wants to try and understand the things that children have to deal with when their brother or sister becomes ill. By doing this, the researcher wants to try and help you and other children who have brothers or sisters with cancer to deal with your feelings and problems in a healthy way.

### **Why have I been invited to take part in this research study?**

This research will focus on the experiences of children who have a brother or sister with cancer. You have been invited to take part because you are one of these children whose brother or sister has cancer. The researcher would like to try and understand your feelings and experiences from your own point of view. Children between the ages of 6 and 18 will take part in this research.

### **Who is doing the research?**

The research is being done by Lisa Visagie. She is a master's student in psychology, studying at the University of Zululand. Lisa is doing this research to complete her master's degree, and because she wants to find out more, and try to understand the experiences that brothers and sisters of children with cancer go through.

### **What will happen to me in this study?**

You will be asked to take part in a short interview. You will be asked to answer a few questions about yourself and about how it is to have a brother or sister with cancer. The questions are about your own feelings and thoughts, and there are no right or wrong answers. The interview should take about 30 minutes to finish. You are free to leave out any questions that you feel uncomfortable or unhappy with.

### **Can anything bad happen to me?**

Nothing bad will happen to you. But, if you feel that you don't want to take part in the research anymore, you can withdraw from the study without any consequences. You won't get in trouble and nobody will be cross with you. If you don't feel good after the interview, the researcher will make sure that you talk to someone who can help you deal with these feelings. If you are uncomfortable with any part of the study you can tell the researcher or your parents and withdraw from the study immediately.

### **Can anything good happen to me?**

There are no good things that will happen to you straight away. Although if you take part in the study you can help the researcher understand more about having a brother or sister with cancer. This information will help the researcher to help children with the same problems in the future.

### **Will anyone know I am in the study?**

The only people who will know you are in the study are the researcher, your parents and you. When doing this research, all your information will be kept confidential. This means that all the information you share with the researcher will be kept private, and the researcher won't discuss what you said with other people. If the researcher has to use the information that you gave her, she will change your name so that no one knows what you said.



### **Who can I talk to about the study?**

If you have any questions or problems linked to the study, you can talk to:

- The researcher, her name is Lisa Visagie, you can phone her on 082 456 4622 or send her an e-mail at [visagie.lisa@gmail.com](mailto:visagie.lisa@gmail.com).

OR

- Prof. Christina Stefan, she is a doctor at Tygerberg hospital, you can phone her on 021 938 9404 or send her an e-mail at [cs@sun.ac.za](mailto:cs@sun.ac.za).

### **What if I do not want to do this?**

If you do not want to take part in the study you don't have to. Even if your parents already said yes, you can still refuse. No one can force you to take part in the study, it is completely up to you. If you agree to take part in the study, but change your mind later nothing will happen to you. You are free to pull out of the study at anytime.

**Do you understand this research study and are you willing to take part in it?**

☐ YES☐ NO

**Has the researcher answered all your questions?**

☐ YES☐ NO

**Do you understand that you can pull out of the study at any time?**

☐ YES☐ NO

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Signature of Child

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Date