# CHILDHOOD CANCER WITHIN A FAMILY AND MEDICAL CONTEXT IN ETHEKWINI: STRENGTHENING PSYCHOSOCIAL AND SPIRITUAL INTERVENTIONS TO ENABLE COPING AND HEALING

A thesis submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy in the Faculty of Health Sciences

By

**Neshika Deepak Munshi**

**Student no. 21425820**

**Durban University of Technology**

**2025**

RBhagwan

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| **Supervisor** | **Co – Supervisor** |
| **Professor Raisuyah Bhagwan** | **Dr Moeti Kgware** |

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**APPROVED FOR FINAL SUBMISSION**

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# DECLARATION OF CANDIDATE

I, Neshika Munshi, hereby declare that except where acknowledged, this thesis is entirely my own work, that all resources used or quoted have been acknowledged and that this study has not previously been submitted for any degree to any other tertiary educational institution.

N.Munshi 22.07.25

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Signature of student Date

# ABSTRACT

Cancer is an ancient disease, with evidence of its existence tracing back to early human history. The earliest documented cases of cancer appear in the Edwin Smith Papyrus, an ancient Egyptian medical text dated around 1600 BCE. Childhood cancer affects not just the physical health of paediatric patients but has profound psychological, social, and spiritual effects, with far-reaching implications for their families as well. This study, titled *"Childhood Cancer within a Family and Medical Context in eThekwini: Strengthening Psychosocial and Spiritual Interventions to Enable Coping and Healing,"* explored the multidimensional effects of this disease on patients and their families and explored the psychosocial and spiritual support systems available within the hospital setting. Conducted at Inkosi Albert Luthuli Hospital in eThekwini, the study aimed to identify interventions that could support both patients and families through the cancer journey.

Guided by a qualitative case study design, the study used non-probability purposive sampling, to recruit parents of paediatric cancer patients. Health and social service professionals who worked closely with these patients and their families, were also recruited to participate in the study. Data was collected through semi-structured interviews and analysed thematically to gather rich insights into the lived experiences of the parents and to explore their experiences, through the lens of health and social service professionals.

Findings revealed that paediatric cancer patients experienced intense emotional distress and anxiety due to the fear of death, the aversion to medical procedures, social isolation, disrupted peer and social relationships, and stigma related to physical changes post-treatment. Families were further impacted because of strain within their marriage, the fear of losing a child, and financial hardship, all of which underscored the multifaceted impact of childhood cancer on paediatric cancer patients and their families.

Despite these challenges, the study found that certain psychosocial interventions within the hospital context helped ease the emotional burden.

Participants emphasized the importance of securing access to therapies such as music and art therapy, yoga, and other spiritually based practices to help them cope. These interventions were seen as essential to promoting strength, comfort, hope and emotional stability for both children and their caregivers.

The study concluded that medical treatment alone does not suffice to address the realm of paediatric cancer patient. Physical care must be integrated with psycho-social and spiritual care to ensure a more holistic healing process. Hope, resilience, and faith were central themes that emerged as powerful enablers of coping and survivorship. The findings advocate for the integration of spiritually grounded, psychosocial, and family-centred care, within standard oncology practice, with the goal of ensuring that the recovery journey is more manageable for paediatric cancer patients and their families.

# DEDICATION

I, Neshika Munshi dedicate this thesis to:

- The young warriors who fight each day to overcome cancer, complete their treatment, and proudly ring the bell in celebration when they achieve remission.
- To their families, whose unwavering love and strength illuminate their path toward healing.
- To the health and social service professionals who dedicate themselves tirelessly each day to caring for children and their families.
- To my family that supported me from the very beginning of my PhD journey.
- To my supervisors for their constant support, dedication and motivation.

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- To my Dad, Deepak Munshi, my future life partner Priyen Lutchmiah, my sisters, Urisha and Isheksha and brothers-in-law's, Keegan and Aveer for their unconditional love, motivation, understanding, support and encouragement throughout my studies.
- To the rest of my family and friends, for their love and support.

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# CHAPTER 1

# BACKGROUND OF THE STUDY

"They ride tricycles in the hallway, not in the park. They know the names of their chemo instead of their classmates. Nurses and doctors are their new family. Their laughter will make the heart melt. Their strength will make a grown person cry. If you've ever seen a kid fight cancer, it will change your life forever"- *Shannon Melton.*

## 1.1 Introduction

Despite huge medical advances being made in the early diagnosis and treatment of cancer, it brings with it a life-altering experience characterized by deep fear, emotional uncertainty, and profound life changes (Martinez-Santos *et al.* 2021: 2971-2994). Childhood cancer is a significant global health challenge, that affects the physical and psycho-social well-being of paediatric patients, as well as the well-being of parents, who have to confront a lethal disease within their midst (Mader *et al.* 2020: 3330-3340; Öhman *et al.* 2021: 2535-2541 and Poix *et al.* 2024: 2361). In South Africa, childhood cancer carries unique complexities due to disparities in healthcare access, socioeconomic challenges, and cultural diversities. Understanding the multifaceted impact of childhood cancer and implementing effective interventions is crucial for improving patient outcomes and family resilience (Edwards *et al.* 2017:8).

This chapter serves as the foundation of this research study, by exploring the psychosocial and spiritual dimensions of coping and healing, at the interface of childhood cancer. It outlines the research problem, aim and objectives, situating the study within the broader framework of paediatric oncology care in

South Africa. By addressing the gaps in current support systems and emphasizing holistic care approaches, the study contributes to the growing body of literature that advocates for integrated medical, psychological, and spiritual support for patients and their families.

Chapter one begins with an overview of childhood cancer in the global and local context. It provides an understanding of childhood cancer and the history of Childhood Cancer Foundation (CHOC), South Africa, a leading non-profit organization in South Africa. The researcher provides an overview of the effects of cancer on the child and family and the salience of psychosocial and spiritual interventions, within the context of paediatric cancer. Prior research which has been conducted in both the global and local contexts related to childhood cancer is reviewed succinctly, capturing the research gap which justified this study. The theoretical framework guiding the study, is also elucidated. It highlights how these frameworks inform the research design and objectives and aims to bridge the gap between clinical practices and the lived experiences of paediatric cancer patients and their families.

By situating the research within the existing body of knowledge, this chapter reviews key developments in paediatric oncology care, particularly in the South African context. It emphasizes the role of healthcare professionals, non-governmental organizations, and community stakeholders in addressing the unmet needs of childhood cancer patients. This review sets the stage for an in-depth analysis of how psychosocial and spiritual interventions can be strengthened, to enhance coping mechanisms and facilitate healing in chapter two.

In conclusion, chapter one provides a robust introduction to the study, presenting a roadmap for the subsequent chapters. It lays the groundwork for a more nuanced understanding of childhood cancer and its broader implications, emphasizing the importance of a holistic, multidisciplinary approach to care. Through this study, the research provides rich insights and

recommendations for improving paediatric oncology care in South Africa, ultimately supporting children and their families on their journey towards healing and recovery. The sub-section that follows, provides a foundational understanding of childhood cancer.

## 1.2 Understanding childhood cancer

Childhood cancer is a heterogeneous group of malignancies (Erdmann *et al.* 2021:15), consisting of diverse diseases, with different patterns of occurrence (Piñeros *et al.* 2021:9), aetiology (Williams *et al.* 2021:1286), treatment and supportive care, survival rates (Botta *et al.* 2022:26) and the risk of acute toxic side (Fidler *et al.* 2016:354). Over the past five decades, substantial advances in diagnostics, pharmacology, treatment combinations and techniques have led to large improvements in survival rates, linked to childhood cancer and have also contributed to declining mortality rates (Pritchard-Jones *et al.* 2013:95). Malysse (2021:2) said that the most common forms of cancer, in the paediatric population includes leukaemia (which accounts for approximately 30% of all cases), lymphomas and tumours of the central nervous system, the prevalence of which varies according to the age of the patient. Research has found that acute lymphoblastic leukaemia is more common amongst children (26%), while Hodgkin's lymphoma is more prevalent amongst adolescents (15%) (Jin *et al.* 2016:2; Ward *et al.* 2014:83).

Almost 400 000 children are diagnosed annually, with South Africa accounting for almost 1500 of this global number. Many children with cancer in low-and-middle-income countries, are either not diagnosed on time or referred too late, for curative care. The World Health Organization, governments, civil society organizations and health care workers have partnered to meet the WHO Global Initiative for Childhood Cancer (GICC) goals, for a 60% overall survival amongst children and adolescents with cancer in low-and middle-income countries, by 2030.

The sub-section that follows, focuses on childhood cancer within the South African context. It highlights the unique challenges and circumstances surrounding childhood cancer in South Africa, such as healthcare disparities, cultural beliefs, and socioeconomic factors that collectively influence diagnosis, treatment, and survivorship.

## 1.3 Childhood cancer within the South African context

Childhood cancer in South Africa has a complex history that has evolved over time. In the early years, childhood cancer in South Africa received limited attention, mainly due to a lack of comprehensive data and specialized treatment facilities. The focus was primarily on infectious diseases and public health challenges. Paediatric and psychosocial oncology, however, is widely established in Europe and America. Similar initiatives are however rare in Africa (Van Heerden and Kruger 2021: 2-3).

The apartheid system in South Africa was instrumental in birthing major disparities in health, education, and socioeconomic status amongst the South African population. As a result, children from lower socio-economic backgrounds endured difficulties in accessing basic healthcare services. A holistic approach to childhood cancer care, not only requires access to psychosocial resources, but consideration of socio-demographic factors such as race, educational level, and socioeconomic status (Ngoma *et al.* 2019:2). However, the establishment of paediatric oncology units during the 1970s and 1980s enabled significant progress to be made in the field of paediatric oncology. These dedicated paediatric oncology units were established in major academic hospitals across the country (Bansal *et al.* 2023:1-19), with institutions such as the Red Cross War Memorial Children's Hospital in Cape Town, the Chris Hani Baragwanath Hospital in Johannesburg, Inkosi Albert Luthuli central hospital in eThekwini and Greys hospital in Pietermaritzburg, playing key roles (Benzing *et al.* 2020:1860-1871).

South Africa is a unique heterogeneous country comprising of a wide array of income groups, cultures, ethnic origins, languages, traditions, and religions. The apartheid legacy created gross disparities in the provision of health services to the local populace (Garton *et al.* 2023:2). According to Torode *et al.* (2023:220) only half to two thirds of the malignancies, amongst Black children are diagnosed and 80% of those who are diagnosed, present with advanced stage of solid tumours, resulting in poorer survival rates. Knowledge of people's perceptions of illness, communication patterns, child-rearing practices and their psychosocial and educational needs and how they handle grief is inadequate. Torode *et al.* (2023:225) argued that it was imperative to ascertain the psychological implications of the diagnosis of cancer in lower socioeconomic families, especially those families from the previously disadvantaged communities of South Africa (Torode *et al.* 2023:225). Once this has been researched, then only can the psycho-social support needs of this population be identified, and provision made to help patients, and their families cope better with the disease and treatment.

Collaboration and support networks in the 1990s, emerged to support paediatric cancer patients and their families in South Africa. Organizations like the South African Children's Cancer Study Group (SACCSG) and Childhood Cancer Foundation (Childhood Cancer Foundation South Africa), were formed to improve research, treatment, and support for children with cancer and their families. The increased awareness and advocacy over the years, has resulted in a growing recognition of childhood cancer, as a significant health issue in South Africa. Various awareness campaigns, fundraising initiatives, and advocacy efforts have coalesced, amongst individuals, organizations, and government bodies to raise awareness regarding childhood cancer and its impact on affected children and their families.

According to Gil *et al.* (2020:2) improving access to care is one of the major challenges that characterizes the history of childhood cancer in South Africa. Ensuring equitable access to quality care for all children, is critical irrespective of their socioeconomic background or geographical location. Efforts have been

made to expand treatment facilities and improve accessibility, particularly in rural and underserved areas. Clinical trials and collaborative research initiatives have been instrumental, in advancing knowledge and treatment outcomes for childhood cancer in South Africa (Atmore 2019:30). Participation in international clinical trials and research partnerships have also contributed to the development of evidence-based treatment protocols and improved survival rates (Akinyemi *et al.* 2019:5).

In recent years, the current landscape has shifted its focus towards strengthening the paediatric oncology infrastructure, improving early diagnosis, enhancing supportive care services, and addressing survivorship issues (Bangura *et al.* 2020:10). Efforts are also being made to integrate childhood cancer services into the broader healthcare system and enhance collaboration amongst healthcare professionals, researchers, and support organizations (Adedokun and Yaya 2020:31). While significant progress has been made, challenges remain in terms of resource allocation, capacity building, and reducing treatment abandonment rates. Continued efforts are required to ensure that all children with cancer in South Africa receive timely and appropriate care, with a focus on improving outcomes and quality of life for affected individuals and their families (Schmidt and Azzi-Lessing 2019:5).

It is important to understand how South African children are affected by this life-threatening disease and what mental health and spiritual resources are available to them to help them cope with pain, discomfort, changes in their bodies and hospitalization. Moreover, it is important to understand how such resources can enable and strengthen children's re-integration into the family, school, and society (Ige *et al.* 2023:200). These systems are also important in helping children deal with the stress of cancer and to develop a multidisciplinary collaborative approach to the treatment of childhood cancer.

In the sub-section that follows, the researcher provides an overview of the Childhood Cancer Foundation, South Africa. Childhood Cancer Foundation, is a leading non-profit organization in South Africa, helping paediatric cancer

patients and their families deal with a diagnosis of cancer and help the child and their family during the treatment and recovery journey.

## 1.4 The history of the Childhood Cancer Foundation South Africa

In 1977 Sister Sadie Cutland and her husband Julian's firstborn child, Hillary was diagnosed with aplastic anaemia at the age of seven. Two years later while leaving the ward one day, Sadie was particularly saddened, because Hillary had been diagnosed for two years, and she had yet to meet another parent of a child with aplastic anaemia (Cotache-Condor 2023:4). Professor MacDougal then sowed the idea of forming a parents' support group in Johannesburg in Sadie's mind. The aim of this support group was to share experiences and provide one-on-one support to each other (Libes *et al.* 2023: 20). The caring and sharing came from firsthand experiences of the different emotional journeys and situations, that both the parent and child find themselves in. It allowed for open communication, within a context of love. This instilled hope amongst many and today, Childhood Cancer Foundation, has become the leading childhood cancer organization in South Africa. It provides comprehensive child and family support to thousands of childhood cancer beneficiaries (Ngwa *et al.* 2022:6). From humble beginnings Childhood Cancer Foundation South Africa, has evolved in contemporary times, by ensuring access to medical fraternities in hospitals across the country. What started off as a need for support, transformed into a helpline to many in need. These needs include psychosocial, emotional support and care and accommodation for patients, in thirteen Childhood Cancer Foundation South Africa homes, the transportation of patients and caregivers through a fleet of twenty-one vehicles and more during their childhood cancer journey and beyond (Hodges *et al.* 2022:470). Childhood Cancer Foundation, South Africa also offers comprehensive child and family support, advocacy and awareness that includes the following forms of support.

### 1.4.1 Emotional support

- Childhood Cancer Foundation's team of psychosocial support staff (social workers and social auxiliary workers), provide full time psychosocial and emotional support in the paediatric oncology units from diagnosis onwards, until the end of treatment, which ensures cure or survivorship or sadly end-of-life and bereavement support.
- Emotional support is also provided by Childhood Cancer Foundation's staff and volunteers through various in-ward and Childhood Cancer Foundation's house-based patient and family support programs.

### 1.4.2 Practical support is provisioned as follows:

- Every newly diagnosed child receives a care-bag with items of practical use.
- Transport assistance is provided to support the patient in attending treatment regularly.
- Nutritional support is offered through the temporary provision of assistance for families in a desperate situation, who cannot provide for their family's basic needs.
- Houses or lodges provide accommodation to out-patients.
- Information to support beneficiaries through the cancer journey is also provided. Financial bereavement support helps and supports parents who have just lost a child.
- Post treatment supports survivors and their families to cope with long-term effects and assists with their reintegration back into society.

### 1.4.3 Advocacy

- Childhood Cancer Foundation South Africa advocates with regards to the cause/s of childhood cancer, to influence decision-

makers (nationally and internationally) and to ensure comprehensive and adequate care for all children and teens with cancer or life-threatening blood disorders.

- Childhood Cancer Foundation, influences policies and the human rights of childhood cancer patients and survivors.

### 1.4.4 Awareness

- Awareness programs significantly increase early detection and diagnosis, so as to work towards improving the survival rate of children with cancer or a life-threatening blood disorder.
- They raise public awareness about childhood cancer, by reaching out to communities.
- They train healthcare workers, traditional healers, and communities on the early warning signs of childhood cancer.

The section that follows explores the multifaceted impact of paediatric cancer, beyond just the medical diagnosis. The researcher delves into the psychological, emotional, financial, and social effects of childhood cancer on both the child and their family.

## 1.5. The effects of paediatric cancer on the child and family

### 1.5.1. Effects of cancer on the child

According to van den Boogaard *et al.* (2023: 627) the effects of cancer on a child, extend beyond the psychological and physical battle against the disease. It disrupts the emotional, social, and developmental dimensions of children's lives. Childhood cancer presents unique challenges, because a child is still developing physiologically and because of the potential long-term consequences of treatment (Petersen *et al.* 2022:3806). The emotional toll of the illness can overwhelm young patients, many of whom may struggle to comprehend the complexities of their condition and the treatment process

(Berkman *et al.* 2022:990). The diagnosis can disrupt a child's normal routine, academic pursuits, and play, affecting their sense of normalcy and stability during crucial life developmental stages (Jeon *et al.* 2022:948). In the sub-sections that follow, the researcher provides a discussion on how childhood cancer affects the various aspects of a child's life.

#### 1.5.1.1 Psychological impact of paediatric cancer

Michel *et al.* (2020:1103-1134) said that paediatric cancer affects a child's psychological health in a profound way. Anxiety is a common response to the diagnosis and treatment process, manifesting itself through heightened fears about mortality, medical procedures, and the unknown trajectory of their illness (Borrescio-Higa and Valdés 2022:559). Many children report experiencing distress at the onset of hospitalization, which stems from both physical discomfort and separation from their familiar routines. As cancer treatments primarily involve invasive and prolonged medical interventions, children are also prone to developing post-traumatic stress symptoms, including flashbacks and hypervigilance (Jacola *et al.* 2021:1696).

In addition to anxiety, depression presents itself as another prevalent psychological outcome among paediatric cancer patients (Lee *et al.* 2023: 790-799). The cumulative stress of living with a life-threatening illness, combined with the side effects of treatments such as fatigue and chronic pain, can lead to a sense of hopelessness (Paul *et al.* 2023:1248-1256). Ochoa-Dominguez *et al.* (2023:5928) said that children may exhibit withdrawal from social interactions and a decline in previously enjoyed activities, further exacerbating depressive symptoms.

Chan *et al.* (2023:4821-4231) asserted that cognitive impairments resulting from cancer treatments, such as chemotherapy and radiation therapy, can significantly alter a child's mental functioning. These impairments, often

referred to as "chemo brain," include changes in memory, attention, and problem-solving (Pancaldi *et al.* 2023:472). As such these cognitive changes, for children can be distressing, as they affect their ability to engage in academic and everyday tasks. Moreover, these effects may persist long after treatment, highlighting the importance of sustained neuropsychological assessments and interventions (Barczyk *et al.* 2023: 263-277).

Efforts to mitigate psychological impacts have increasingly focused on integrating psychosocial care into medical treatment. Techniques such as cognitive-behavioural therapy (CBT), mindfulness training, and play therapy have shown promise in reducing psychological distress (Mavrea *et al.* 2021:262). Support groups for children and their families also provide a shared space to process emotions and develop coping mechanisms (Lange *et al.* 2019:1925-1940).

#### 1.5.1.2 Emotional challenges in paediatric cancer

The emotional toll of cancer on children is profound, affecting their self-esteem, emotional resilience, and overall well-being (Sisk *et al.* 2020:808). Arriaga *et al.* (2020:365) argued that feelings of fear and sadness dominate their emotional being, particularly during hospitalizations and invasive treatments. The visible changes brought about by treatments, such as hair loss and physical debilitation, often leads to a loss of self-identity and emotional insecurity. This emotional vulnerability is compounded by a disrupted sense of normalcy, as children struggle to reconcile their illness with their earlier, healthier selves (McGill *et al.* 2019: 27762). Children often grieve the loss of their routine lives and their inability to engage in age-appropriate activities, such as attending school or playing with peers. Anger from this may be directed towards medical staff, or even family members, thereby reflecting their frustration of enduring a condition that they cannot control. Emotional support through therapeutic outlets such as art therapy and journaling can help children

express and process these feelings in constructive ways (Peterson *et al.* 2020:20859)

Braun *et al.* (2012:398) said hope plays a pivotal role in sustaining emotional strength. Many children derive hope from their families, religious beliefs, or the prospect of recovery. Maintaining a hopeful outlook can act as a buffer against emotional despair. However, when hope is challenged by disease progression or relapse, children may experience intensified feelings of despair (Kelemen *et al.* 2019:31-51). The emotional resilience programs that are designed to reinforce positive coping mechanisms, are essential during such times. Family involvement is critical in managing a child's emotional health. Parents and siblings, as primary caregivers and emotional anchors, can either alleviate or exacerbate a child's emotional struggles (Jensi *et al.* 2022:292). Open communication, combined with professional counselling, fosters an environment where children feel supported and are understood.

#### 1.5.1.3 Social impact of paediatric cancer

Deegan *et al.* (2023: 819-833) opined that paediatric cancer disrupts a child's social interactions and relationships, leading to isolation and altered dynamics. Children undergoing treatment may spend extended periods of time in hospitals, limiting their ability to interact with peers (Pahl *et al.* 2021:15-27). Hernádfői *et al.* (2024:1-11) said that this absence from school and community activities, often results in feelings of loneliness and alienation. Even when children attempt to reintegrate into society, their visible signs of illness can cause others to stigmatize them, causing them to withdraw further.

Peer relationships are particularly fragile during adolescence, making teenagers more vulnerable to stigmatization. Healthy peers may struggle to

relate to a child's experiences, leading to unintentional exclusion. Conversely, some children benefit from strong peer support networks, especially when schools and communities actively promote inclusivity and awareness (Howard *et al.* 2014:85). Programs that educate classmates about paediatric cancer can reduce stigma and foster supportive social environments. Within families, the social impact is twofold. While the cancer journey can strengthen familial bonds through collective coping, it can also strain relationships due to increased caregiving demands. Siblings of cancer patients often feel neglected, resulting in sibling rivalry or resentment (Fox *et al.* 2023:2946).

On a broader scale, community and organizational support play an essential role in alleviating social isolation. Nonprofit organizations and cancer support groups offer opportunities for children to connect with peers facing similar challenges, creating a sense of belonging.

#### 1.5.1.4 Academic challenges of paediatric cancer

The academic trajectory of children with cancer is often severely disrupted by frequent hospital visits, the side effects of treatment, and cognitive impairments (Kirkpatrick 2015:347-365). Martinez-Santos *et al.* (2021:2971-2994) stated that school absenteeism, necessitated by hospital stays and immune system vulnerabilities, leads to missed coursework and a widening academic gap compared to peers. Even when children are physically present in school, fatigue and the syndrome of the "chemo brain" may hinder their ability to concentrate and retain information. The psychological stress associated with falling behind academically, can compound feelings of inadequacy (Yi *et al.* 2016:263-269). For many children, school serves as a primary source of normalcy and routine. The inability to participate fully in this environment often

leads to emotional distress and a diminished sense of self-worth (Larsen *et al.* 2022: e13696).

#### 1.5.1.5 The physiological impact of childhood cancer on the child

Childhood cancer also has a significant physical impact on the child, affected by the disease. When a child is diagnosed with cancer, their young and developing body encounters a severe battle against cancer treatments, such as chemotherapy, radiation therapy and surgery. Research indicates that cancer profoundly impacts the physical being of the child and can include pain, in affected areas or throughout the body, fatigue when undergoing cancer treatments, all of which collectively impacts their ability to carry out daily activities (Davies and O'Connor 2022:1; Hinton *et al.* 2022:652).

Michael *et al.* (2023:518) said that nausea and vomiting can also be induced by certain cancer treatments, such as chemotherapy and radiation. Research has highlighted that chemotherapy often leads to hair loss, which can be emotionally challenging for children in their daily lives (Siegwart *et al.* 2022:1-11). According to Sklar *et al.* (2018:2761) cancer and its associated treatments can weaken the immune system, making children more susceptible to infections and diseases.

### 1.5.2. Impact of cancer on the family

Childhood cancer exerts a profound and far-reaching impact on the entire family system (Moscato *et al.* 2021:16). The diagnosis brings overwhelming shock and distress (Islam *et al.* 2017:45), triggering emotional turmoil for parents and siblings alike (Malysse 2021:18). Families often face the tremendous burden of navigating complex medical decisions, frequent hospital visits, and extended periods of separation during treatments (Christensen *et al.* 2023:3981).

#### 1.5.2.1 Emotional and psychological impact

According to Freedman *et al.* (2023:5549) the diagnosis of childhood cancer triggers intense emotional reactions across the family, ranging from shock and denial to anger and despair. Parents often experience heightened stress and anxiety due to fears about the child's prognosis and the strain of caregiving. Studies have revealed that a significant proportion of parents develop symptoms of depression or post-traumatic stress disorder (PTSD), as they grapple with the realities of their child's illness and treatment demands (Ljungman *et al.* 2023: 592-599).

The siblings of paediatric cancer patients also endure emotional struggles. They may feel neglected as the ill child becomes the focus of family attention, leading to feelings of jealousy, resentment, or guilt (Hoekstra-Weebers *et al.* 2012:903). Younger siblings may struggle to understand the situation, while older siblings often begin to assume more responsibilities at home. Interventions such as family therapy and support groups can help mitigate these psychological stresses by fostering communication and coping strategies (Rosenberg *et al.* 2022:1-10).

#### 1.5.2.2 Financial strain

Alkema *et al.* (2024:1598-1609) said that the economic burden of childhood cancer care is complex and multifaceted. Families face direct medical expenses such as chemotherapy, radiation, and hospitalization, alongside ancillary costs like transportation, accommodation near treatment centres, and dietary needs. Indirect costs, including lost wages from caregiving or job loss, amplify their financial strain (Ilic and Ilic 2023:1-12). According to Johns Hopkins University (2023), over 50% of families with a child undergoing cancer treatment report significant financial distress.

Furthermore, insurance limitations and out-of-pocket expenses often necessitate additional financial planning, loans, or fundraising (Kocarnik *et al.*

2022:420-444). Poix and Elmusharaf (2024:1-6) opined that families from lower socioeconomic backgrounds are disproportionately affected, with reduced access to necessary treatments and higher rates of delayed care. Financial counselling and community-based support programs have been identified as critical resources for alleviating this strain (Alkema *et al.* 2024: 1598-1609).

#### 1.5.2.3 Impact on marital and family relationships

Marital relationships often face significant strain, as couples navigate the emotional toll of their child's illness (Mader *et al.* 2020:3330-33400). Disagreements about treatment options, cultural differences, caregiving responsibilities, and coping mechanisms can lead to conflicts or emotional distancing amongst both parents (Chung *et al.* 2021:194-201). Some studies indicate a higher risk of separation or divorce amongst parents of children with chronic illnesses, although supportive resources can mitigate these risks (Lynn *et al.* 2020: 373-385; Öhman *et al.* 2021:2535-2541; Applebaum and Breitbart 2024:20).

Conversely, Barakat *et al.* (2021:747-755) argued that some families report strengthened relationships as they rally together to support the child. Effective communication, shared decision-making, and external counselling have been shown to enhance marital resilience and family cohesion during this challenging period (Baenziger *et al.* 2020:4467). The role of extended family members, such as grandparents or aunts, can also provide crucial emotional and logistical support during periods of crisis (Ochoa *et al.* 2023:151).

#### 1.5.2.4 Social and lifestyle disruptions

Childhood cancer disrupts the routines and lifestyles of all family members (Zhou *et al.* 2021:1205). Parents may at times need to quit their jobs or reduce their working hours to meet the caregiving demands or take their child to their

follow up or treatment appointments. This results in a loss of financial stability and career progression (Beringer *et al.* 2021:3). Because of the paediatric cancer patient, other siblings may face disruptions in schooling, extracurricular activities, and social interactions, leading to feelings of isolation or alienation from peers (Ferguson and Gray 2023:25).

Moreover, Cheng *et al.* (2018:2) asserted that families often find themselves socially isolated, as friends and relatives struggle to understand their challenges or avoid contact due to discomfort. This isolation can worsen feelings of loneliness and hinder access to emotional support networks (Merriman 2020:35). An existing initiative such as parent-to-parent peer support and community engagement programs have been found to reduce these social strains and improve overall family well-being (Malicka 2019:3).

Despite the resilience shown by many families, childhood cancer, leaves an indelible mark on their lives, necessitating robust support networks, counselling, and resources to help them cope with the challenges they endure throughout this difficult and often protracted journey (Long and Marsland 2011:57). The sub-section that follows, focusses on psychosocial and spiritual interventions in paediatric cancer care. A definition for both types of interventions is provided and the role of the intervention is explained.

## 1.6 Psychosocial and spiritual interventions in paediatric cancer care

### 1.6.1 Definition and scope of psychosocial interventions and spiritual interventions

Thornton *et al.* (2020:408) said that psychosocial interventions encompass a range of strategies aimed at addressing the psychological and social challenges that individuals face in the context of illness. These interventions are designed to improve mental health, emotional well-being, social

functioning, and overall quality of life for patients and their families (Ohan *et al.* 2020:e13237). Kwak *et al.* (2023:12–21) stated that in the context of paediatric cancer care, psychosocial interventions include psychological counselling, therapeutic play, educational support, family therapy, and other supportive measures to address emotional distress, fear, and social isolation associated with a cancer diagnosis. Aubin *et al.* (2019:172-189) opined that these approaches are crucial in mitigating the mental and emotional toll of cancer on children, who often grapple with the fear of medical procedures, uncertainty about their prognosis, and disruptions to their daily routines such as school and play.

Robert *et al.* (2019:e27764) argued that spiritual interventions, focus on the existential and spiritual dimensions of coping with illness and can therefore be therapeutic and empowering for those confronted with cancer during childhood. These interventions aim to provide patients and their families with a sense of purpose, hope, and resilience through practices such as prayer, meditation, and spiritual counselling (Levine *et al.* 2021:e28765). In paediatric cancer, spiritual interventions often address the profound questions about life, suffering, and mortality that arise during the illness journey (Afrasiabifar *et al.* 2021:1-12). These practices can take diverse forms, ranging from engagement with religious leaders and faith communities, to non-religious practices like mindfulness and yoga, which emphasize inner peace and emotional regulation (Kang *et al.* 2022:257–269).

### 1.6.2 Role of psychosocial and spiritual interventions in paediatric cancer care

Psychosocial interventions play an essential role in alleviating the psychological burden of cancer for both paediatric patients and their families (Zhang *et al.* 2021:103291). For children, these interventions provide tools to cope with the emotional distress of their diagnosis and treatment, thereby reducing symptoms of anxiety, depression, and social withdrawal (Orellana-Rios *et al.* 2023:3251–3261). Simpson *et al.* (2020: 371–379) explained that

family-focused psychosocial support, helps caregivers or parents manage stress and improve family dynamics, particularly in navigating the changes imposed by the illness. Simpson *et al.* (2020:371–379) shared an example, saying that educational support programs can help parents understand their child's diagnosis and treatment options, empowering them to make informed decisions. Hsiao *et al.* (2019:278-284) further added that psychosocial interventions such as bereavement counselling offer critical support to families dealing with the loss of a child, facilitating healing and closure.

Chong *et al.* (2023:408-412) argued that spiritual interventions provide huge levels of support by addressing the existential aspects of illness. For paediatric patients, practices such as guided meditation or chanting can promote a sense of calm and focus, helping patients to manage pain and reduce stress (Singh *et al.* 2022:102). Similarly, for families, spiritual interventions can foster resilience by reinforcing their sense of hope and connection to a greater purpose, even in the face of uncertainty (Liu *et al.* 2023:1452-1460). Spiritually based interventions also acknowledge the diverse cultural and religious backgrounds of families, offering tailored support that aligns with their beliefs and values (Levine *et al.* 2021:e28765). By integrating spiritual care and psychosocial interventions into the treatment plan, healthcare providers can offer a holistic approach that honours the emotional and existential needs of both the patient and their family (Chong *et al.* 2023:408-412).

## 1.7 The importance of support for the child and family

Support during the experience of childhood cancer is of paramount importance due to the unique and challenging nature of the disease in young patients (Cialdella-Kam *et al.* 2012:136). Firstly, children undergoing cancer treatment often face physical, emotional, and psychological stress, that can significantly affect their overall well-being (Asadzandi 2018:1026). The support provided by healthcare professionals, family members, and support organizations helps alleviate their distress (Deegan *et al.* 2023:819), manage treatment side effects (Esbenshade *et al.* 2023:3629), and enhance their quality of life

(Cotache-Condor 2023:301). This support network plays a crucial role in ensuring that children can cope better with the rigorous demands of treatment, fostering a sense of resilience and optimism during a trying time (Pletschko *et al.* 2023:1).

Childhood cancer not only affects young patients, but also places an immense emotional and logistical burden on their families (Pritchard-Jones *et al.* 2012:23; Davies and Connor 2022:1; Cannon, Goldsmith, and Roux 2019:104). Parents and caregivers are often required to make critical medical decisions, manage treatment schedules, and provide emotional comfort to their sick child (Christensen *et al.* 2023:3981). Adequate support systems provide parents with information, guidance, and emotional counselling, helping them navigate the complexities of cancer care, while maintaining their own well-being. Siblings of paediatric cancer patients also benefit from support, as they may experience feelings of neglect or anxiety (Park *et al.* 2022:102) due to the attention being placed on the sick child. Offering support to the entire family helps them maintain a stable and nurturing environment, which is essential for the child's recovery (Ananth *et al.* 2022:372).

Childhood cancer support extends beyond the medical realm and encompasses educational, financial, and social aspects (World Health Organization 2021:26). Children with cancer often face interruptions in their education, due to treatment schedules and health limitations (Labib *et al.* 2018:315). Dedicated support in the form of educational programs and resources, ensures that these children can continue their learning, reducing the long-term impact of their illness on their educational progress (Kazak *et al.* 2018:737). Additionally, many families experience financial strain due to medical expenses, travel costs, and potential loss of income. Support networks provide financial assistance, access to resources, and emotional guidance, relieving families of some of these burdens and allowing them to focus on their child's healing journey (Roser *et al.* 2017:1207).

Overall, providing support to children with cancer and their families helps them cope with the holistic challenges they face, improves their quality of life, and contributes to better treatment outcomes and long-term well-being of the child (Gunter and Duke 2018:1). It is essential to adopt a comprehensive approach that addresses not only the medical aspects of cancer but also the emotional, social, and educational needs of the child and their family (World Health Organization 2021:25).

The section that follows, will succinctly elucidate prior research, surrounding childhood cancer and its development globally and in South Africa.

## 1.8 Prior research surrounding childhood cancer

### 1.8.1 Childhood cancer: A global development

The collaboration between researchers, healthcare professionals, advocacy organizations, and families affected by childhood cancer have collectively advanced the progress being made in understanding the disease and discovering better treatments (Moola *et al.* 2023:23). While significant strides have been made, ongoing research is essential to further improve outcomes and enhance the quality of life for children affected by cancer (Murugappan *et al.* 2022:12). The extant research on childhood cancer has contributed to significant advancements being made in understanding the disease (Williams *et al.* 2021:1289), improving treatments, and increasing survival rates (Ige *et al.* 2023:100). Jung (2023:162) revealed that immunotherapies, such as CAR-T cell therapy, have shown promising results in treating certain childhood cancers, by harnessing the body's immune system to target and destroy cancer cells. It was reported that efforts in research have focused on minimizing the long-term side effects of cancer treatments, by improving the quality of life for childhood cancer survivors (Jeon *et al.* 2022:948). Medical advancements in the treatment of cancer, have documented the extensive

research efforts being made, to develop treatments with reduced toxicity to protect the health and well-being of young patients during and after therapy.

Research on the psychological and emotional aspects of childhood cancer have also emerged over the past decades. These have contributed to a deeper understanding of the psychological challenges faced by paediatric cancer patients and their families and the need to develop interventions that can improve their emotional well-being and coping mechanisms (Rao *et al.* 2022:14; Sasi *et al.* 2022:1671; Prasad 2023:5; Brown *et al.* 2023:301; Ball *et al.* 2023:13; Lemmen *et al.* 2023:103).

Given that childhood cancer impacts the child in a multifaceted way, standardized tools like the paediatric quality of life inventory (PedsQL) and distress thermometer for paediatrics, have emerged to assess their emotional well-being (Kazak *et al.* 2020: 315–342; Kearney *et al.* 2021: e28732). In developed countries it has been found that mindfulness programs, have been adapted for paediatric patients to reduce anxiety and improve emotional regulation. Furthermore, interventions now focus on family systems, offering psychological counselling to help family members process their emotions and support one another.

To assist healthy siblings, targeted interventions, such as sibling therapy groups, have also been formed to provide siblings with emotional outlets and coping strategies (Van der Kolk 2015:25). In this vein, Noyes *et al.* (2022:100552) have emphasized that programs like *Bright IDEAS* problem-solving therapy, aim to enhance parents' coping skills and reduce emotional distress. To ease the stress and post treatment effects, Basen-Engquist (2020:369-387) said survivor-to-survivor mentorship programs help individuals share experiences and provide emotional encouragement. To ensure childhood cancer patients receive the correct care, psychosocial care guidelines like the psychosocial standards of care in paediatric oncology (established in 2015 and updated frequently) have gained global traction, promoting integrated emotional and psychological care (Snaman *et al.* 2020:

954-962). Organizations such as the International Society of Paediatric Oncology (SIOP) and childhood cancer international (CCI) have advocated for emotional and psychological care, to be included in treatment protocols, especially in low-resource settings (Racine 2023:45).

The psychological and emotional dimensions of childhood cancer have gained significant attention, leading to a wealth of research and development in assessment tools, interventions, and long-term care strategies. These advancements reflect a paradigm shift not just in treating the disease, but also on its profound impact on the mental and emotional health of patients and their families (McLoone *et al.* 2022:945). The current study positions itself by contributing to the growing global call to recognise the salience of psychosocial and spiritual interventions, in culturally diverse and resource-constrained settings, to advancing holistic healing in paediatric oncology.

### 1.8.2 Childhood cancer within the South African context

South Africa has made significant strides in addressing the psychological and emotional impact of childhood cancer, focusing on integrative approaches to improve the quality of life for paediatric patients and their families (Naidoo *et al.* 2016: 49-54, Jitoo 2004:1-256; Edwards *et al.* 2018:1-8; Edwards *et al.* 2019: 1409-1421). Awareness campaigns, such as those spearheaded by organizations like the Childhood Cancer Foundation South Africa (Childhood Cancer Foundation South Africa), have emphasized the emotional challenges faced by young cancer patients. These campaigns advocate for early psychological interventions to mitigate the trauma associated with diagnosis and treatment (Naidu *et al.* 2023:130-151).

While South Africa still faces resource challenges, progress has been made in establishing follow-up care for childhood cancer survivors (Stones *et al.* 2014:501-504; Geel *et al.* 2021: e29345; Stefan *et al.* 2017:11; Githanga *et al.* 2021: 787-793). These programs focus on monitoring psychological

outcomes and providing mental health resources to help survivors reintegrate into their daily lives (Afungchwi *et al.* 2016:1-12). However, gaps remain, with calls for a formal nationwide long-term follow-up (LTFU) program to ensure consistent care across the country (Lemerle *et al.* 2007:497; Stefan *et al.* 2014:1-14; Parkin and Stefan 2017:11; Van Heerden *et al.* 2023: 203-223).

Additionally, non-governmental organizations have played a critical role in providing emotional support (Jung *et al.* 2023:162). Childhood Cancer Foundation (CHOC, South Africa) for example, offers peer support groups where families can share their experiences and find emotional solidarity. Such programs address the isolation often felt by patients and their families and foster a sense of community and resilience (Howard *et al.* 2018: e252-e266). South Africa has also seen an increased focus on creating child-friendly hospital environments, to reduce treatment-related trauma. Initiatives include play therapy, art therapy, and recreational spaces that allow children to express their emotions creatively (Constantinou 2007:26). These therapeutic methodologies have been instrumental in helping children process their feelings, offering a sense of normalcy during prolonged hospital stays (Boucher *et al.* 2014:302).

Despite these advances, South Africa however faces challenges in ensuring equitable access to physical, psychological and emotional care, particularly in rural areas (Somdyala *et al.* 2010:2420-2429; Johnston *et al.* 2021:101; Liu 2022:106; Hendricks *et al.* 2023:30669). Collaborative efforts between healthcare providers, government agencies, and NGOs are essential to bridge this gap (Petersen *et al.* 2022:3806). Continued investment in training mental health professionals and expanding community-based resources is critical to sustaining progress, in bringing psychological and emotional care to paediatric patients (Christensen *et al.* 2023:3981; Clasen *et al.* 2023:1946).

The problem statement is discussed in the sub-section that follows.

## 1.9. Problem Statement

Childhood cancer affects both paediatric patients and their families, in a myriad of ways. This includes chronic stress for the child, parents and siblings, deprivation of their sense of security, uncertainty, fear, and anxiety all of which disrupts their lives, due to a cancer diagnosis and treatment thereof (Van Schoors *et al.* 2019:2). Parents become increasingly distressed throughout the duration of their child's sickness and are plagued with thoughts on how their child is going to cope with their illness, both physically and mentally. In addition, families must reconstruct a new routine and lifestyle to meet the medical needs and care of their child, coupled with balancing their work lives, financial concerns and caring for their other children, where applicable. As such, they endure a range of emotions inclusive of anger, resentment, and deep emotional distress. In addition, the sick child not only has to cope with painful medical interventions associated with recovery, but also the mental health sequalae, associated with whether they will recover from cancer. Many encounter loss of school life, social life and become sick when undergoing treatment because of the severity of their medication or cancer related interventions (Lewandowska 2021:592-593).

According to Statistics South Africa (2019:5), childhood cancer is increasing rapidly with between 800 and 1000 children in South Africa diagnosed annually. A similar picture is evident in other countries with the American Cancer Society (2022:5) reporting that 10,470 children, under the age of 15 are diagnosed with cancer in the United States annually. Global statistics reflect that childhood cancer has risen exponentially in the past few decades, with 300 000 newly diagnosed cases of childhood cancer being recorded annually (Otoo 2020:1). These statistics reflect the need for both health and social service professionals, to consider what psychosocial and spiritual activities and interventions can contribute to increased coping amongst family members and paediatric patients themselves.

The rationale for the study, is presented in the sub-section, that follows.

## 1.10 Rationale for study

Research has uncovered the value of psychosocial and spiritually based interventions in assisting children and families, to cope with the trauma and distress of a cancer diagnosis and treatment (Lima *et al.* 2013: 1539-1544; Pedersen *et al.* 2019: 1-8; Koumarianou *et al.* 2021:103; Liu *et al.* 2024:15). Such interventions also enable more compassionate relationships to form between health professionals and patients and their families (Pedersan 2020:3-4), where the focus is not only physical care, but extends itself to emotional and spiritual support as well (Steele et al 2015: S585-S618). Such holistic interventions can enhance the quality of their life, reduce anxiety, and enable better coping with the diagnosis, treatment, and recovery from cancer (Boeving 2003:1-15). This allows children and their parents, to keep their inner strength and enables them to adjust to life with a sick child and the treatments that accompany it (Musyoka 2021:3).

Whilst much of the prior research has focussed on finding curative treatments for cancer and the physical effects of cancer amongst children and adults, little empirical work has been devoted to how psychosocial and spiritual support, within the context of paediatric cancer can be empowering and healing. This is particularly true for paediatric patients and their families in South Africa. This research study makes a significant contribution to the evolving body of knowledge surrounding childhood cancer by positioning its focus on addressing the psychosocial and spiritual dimensions of care within a medical context. Childhood cancer research has traditionally focussed on medical and clinical outcomes, such as advancements in diagnosis, treatment protocols, and survival rates. Whilst these are important, there is a growing recognition that holistic care, that embraces the emotional, psychological, social, and spiritual well-being of patients and their families, is equally important as part of a holistic approach to healing and well-being.

Building on existing research, this study will enhance the work undertaken within prior studies internationally, which have documented the physical effects of childhood cancer on paediatric patients. It however contributes new scholarly knowledge related to the mental health sequelae of cancer on paediatric patients and their families. Prior research in the global context has found that children with cancer often experience emotional distress, including anxiety, fear, and depression (Oancea *et al.* 2014:293-303; Huang *et al.* 2017: 309-319; Daniel *et al.* 2019: 903-912). Children encounter disruptions to their daily life, such as challenges in maintaining a normal school life and social relationships (Lupo *et al.* 2020:1081-1094). Furthermore, they experience social isolation and stigma due to the visible effects of treatment like hair loss or physical weakness (Pahl *et al.* 2021:15-27).

Their families are impacted as they begin facing increased financial hardship due to the costs of medical treatment, travelling and disruption to their work, marital strain, and deep emotional distress (Lewandowska 2021:592; Fisher *et al.* 2021:251; Ferraz *et al.* 2024:149). This calls for greater insight into how family life is affected and how psychosocial and spiritual interventions can be integrated into paediatric oncology care, to address these issues within the family milieu holistically. This study therefore positions itself to better understand the plight not only of paediatric cancer patients, but also that of their families and seeks to uncover what other holistic psycho-social and spiritual interventions must be leveraged to better support these patients and their families, as they endeavour to seek medical treatment. Hence this study not only focusses on the patient's journey, but also on the familial ecosystem affected by the child’s illness and what interventions can be used to provide support and healing.

The psychosocial and spiritual aspects of care within oncology settings, is underrepresented in local research, especially in the context of diverse cultural and religious settings, such as KwaZulu-Natal in South Africa. Globally, research related to cancer treatment and care has focussed on therapies like cognitive-behavioural therapy, play therapy, and family counselling

(Koumarianou *et al.* 2021: 103-118; Benedict *et al.* 2022: 159-196; Zhang *et al.* 2021: 103), which may have been poorly explored in their application in resource-constrained environments like South Africa. Similarly, while spiritual care such as prayer, meditation, and faith-based support is acknowledged as valuable (Rossato *et al.* 2021: 4167; Afrasiabifar *et al.* 2021:2), its practical integration within hospital settings and its alignment with patients' cultural and religious identities remains understudied, thus adding to the value of the study.

This research study situates itself at the interface of medical, social, and spiritual care, by addressing key gaps in the literature and research. By conducting a study in the eThekwini region, of KwaZulu-Natal, the study contributes valuable insights into the unique challenges encountered within low-and middle-income families, whose resource limitations and spiritual diversity can also be explored. Moreover, it hopes to unearth the spiritually based interventions, which are appropriate and responsive to the spiritual beliefs of families confronted by cancer. Furthermore, in contrast to traditional research that often separates psychosocial and spiritual care, from medical care within the oncology setting, this study recognizes the interconnectedness and integration of physical and psycho-social interventions, to nurture both coping and healing amongst childhood cancer patients and their families. Whilst many studies have limited their attention to the child as the patient, the current study, has widened its lens to include the family unit, acknowledging the effect their child's illness has on the family system and the relevance of multifaceted holistic interventions to support the child and family.

Hence this study makes a valuable contribution to the scholarly body of knowledge, by advancing research on childhood cancer, and by advocating for the integration of psychosocial and spiritual interventions, into paediatric oncology care. The study supports the need for more transformative spaces in childhood cancer research, by emphasizing that psychosocial and spiritual interventions are equally important to supporting the recovery and healing of paediatric patients and their families grappling with childhood cancer. It calls for a more empathic, compassionate, family-centred, and spiritually sensitive

approach to care within the medical milieu. As a researcher, I have consciously shifted from a descriptive review to a more analytical and critical engagement with the literature, ensuring that each section reinforces the relevance and is interlinked with the objectives of this study. This enhances the coherence between the literature and the research, and better positions the study within both academic and applied discourses. This work therefore not only fills existing gaps but also paves the way for future interdisciplinary research, policy formulation, and practice innovations in holistic paediatric cancer care. The sub-section that follows, elucidates the aim and objectives of the study. This will be followed by a summary of the definitions of key concepts that guide the study. This is followed by a discussion on the theoretical framework that underpins the study.

## 1.11 Aim and objectives of the study

### 1.11.1 Aim

To understand how childhood cancer affects paediatric patients and their families and to explore what psychosocial and spiritual interventions can be levelled to improve their coping and well-being.

### 1.11.2 Objectives

- To understand how childhood cancer affects the physical and psychosocial well-being of paediatric patients.
- To explore how childhood cancer affects the families of paediatric cancer patients.
- To understand what psycho-social and spiritual interventions support patients and their families receive in a medical context.
- To inquire what psychosocial interventions can be levelled within the hospital environment to support paediatric patients and their families.

- To understand what spiritually based activities can support patients and their families through their healing journey.
- To make recommendations with regards to a more holistic approach to support paediatric patients and their families.

## 1.12 Research Questions

- What are the effects of childhood cancer on the physical and psychosocial well-being of paediatric patients?
- How does childhood cancer affects the families of paediatric cancer patients?
- What psycho-social and spiritual support do patients and their families receive in a medical context?
- What psychosocial interventions can be levelled within the hospital environment to support paediatric patients and their families?
- What spiritually based activities can support patients and their families through their healing journey?
- What recommendations can be made with regards to a more holistic approach to support paediatric patients and their families?

## 1.13 Concepts

- **Paediatric cancer**

A term used to describe cancers that occur between birth and 14 years of age. Paediatric cancers are rare and may differ from adult cancers in the way they grow and spread, how they are treated, and how they respond to treatment (Patel *et al.* 2019:48).

- **Childhood Cancer Foundation South Africa**

Childhood Cancer Foundation South Africa (Adams 2009:2).

- **IALCH**

Inkosi Albert Luthuli Central Hospital.

## 1.14 Theoretical Framework: The body-mind-spirit model

A theoretical framework is a structure that guides research by relying on a formal theory constructed by using an established and coherent explanation of certain phenomena and relationships (Osanloo and Grant 2016:13). "The body, mind, and spirit are the intertwined threads, that weave the tapestry of our existence, creating a harmonious symphony of health, knowledge, and inner growth" (Lehrnbecher *et al.* 2023:1774). In the context of this research, the body-mind-spirit model in social work (Lee *et al.* 2009:162-170), was selected by the researcher as the theoretical framework to guide the study, thereby entrenching the importance of this framework within the context of the aim of the study.

The body-mind-spirit model is a holistic framework, that recognizes the interconnectedness of the physical, mental, and spiritual aspects of human beings (Lee *et al.* 2009:162). It suggests that these three components are inseparable and should be considered, when addressing well-being and personal development (Lee *et al.* 2009:162). Lee *et al.* (2009:162) summarized each component of the model as follows:

1. Body: the body aspect of the model refers to the physical form and its functions. It includes the body's physiological processes, sensory experiences, and overall health and vitality. This component emphasizes the importance of physical exercise, nutrition, rest, and self-care practices to maintain a healthy body. As emphasized earlier in the chapter, the paediatric patient is affected by the physiological

challenges of cancer and its treatment, including pain, fatigue, and other side effects. Cancer is a pervasive disease and can impact not just one area of a paediatric cancer patients' body. Instead, the growth and trajectory of the disease is such that it can spread to other organs and cripple the young child's body and health. Moreover cancer related treatments, create huge overall physiological effects such as nausea, hair loss and loss of appetite. Undeniably this affects the young child psychologically.

2. Mind: the mind aspect reflects the thoughts, emotions, beliefs, and cognitive processes. It involves mental activities such as perception, reasoning, memory, and creativity. Nurturing the mind involves practices like education, learning, problem-solving, mindfulness, and the management of emotions to promote mental well-being. Given the adverse toll of the cancer, the young patient is confronted with intense psychological distress such as fear, anxiety, and depression, which are exacerbated by prolonged treatment regimens and social isolation. Not only is the patient affected, but this psychological distress extends itself to the family as well. Some of the mental health sequelae emerging from a diagnosis of cancer and its treatment includes anxiety, fear, depression, and post-traumatic stress disorder, which reflects how the physiological or bodily aspects impact on the mind.

3. Spirit: the spirit aspect is interconnected with the non-physical or transcendental part of an individual. It involves exploring questions of meaning, purpose, values, and connection to something greater than oneself. Spirituality can take various forms, depending on an individual's beliefs and may involve religious or philosophical practices, meditation, reflection, or engaging in activities that foster a sense of connection and transcendence. The spirit of children and their families is affected as they and their families search for meaning, hope, and resilience in the face of a life-threatening diagnosis. Research has found that when confronted with an existential crisis such as cancer, people begin to

either question their faith or purpose in life. Others however turn towards their religious and spiritual practices, for comfort and strength in the midst of their challenges. As such spiritually based interventions such as prayer and scripture reading take on deeper meaning to help them navigate their turmoil and distress.

The body-mind-spirit model therefore reflects that these three dimensions are indivisibly intertwined and reciprocally influence each other (Lee *et al.* 2009:165; Chan *et al.* 2022:261). Hence physical activities can positively impact mental health, and spiritual practices can promote emotional well-being. The model recognizes the importance of including body-mind-spirit interventions, to achieve holistic well-being and personal growth in the face of illness (Boden 2023:1). Research has suggested that the body-mind-spirit model, has emerged as an important framework to guide holistic approaches to health and wellness and has become increasingly popular in alternative and complementary medicine, psychology, and other spiritual and philosophical traditions (Clasen *et al.* 2023:1946). However, the interpretation and emphasis of each component may vary across cultures, belief systems, and individual perspectives.

Given these arguments this framework, has been deemed as appropriate to guide the study. It has enabled the researcher to understand the holistic effects of cancer on children and their families. The body-mind-spirit model also seeks to understand how psychosocial interventions, that underpin the mind component of the model, can help paediatric patients and their families. These interventions, which include counselling, therapy, and educational support, may alleviate mental and emotional distress and foster resilience and well-being in the face of a painful and difficult treatment journey. The medical landscape has previously ignored the spiritual dimension of care. Activities such as prayer and mindfulness underpin the spirit dimension of the model. Spiritual interventions provide families with tools to find hope, meaning, and solace, addressing existential concerns that often arise during serious illness. The integration of physical, mental, and spiritual interventions, reflects the

model’s overall philosophy, ensuring that interventions address the full spectrum of needs experienced by childhood cancer patients and their families.

The body-mind-spirit model then is relevant in terms of addressing the holistic needs of the child with cancer, their family, and the healthcare team (Li *et al.* 2023:251). In the context of childhood cancer, the bodily component reflects the physical aspects of the child undergoing treatment. This includes medical interventions such as chemotherapy, required surgical interventions and radiation therapy. Other holistic interventions can complement medical treatment by providing support services like pain management, physical therapy, and nutrition guidance to ensure the child's physical well-being (Raheim *et al.* 2022:1). With regards to the mind, psychosocial interventions, such as play therapy, art therapy, and counselling, can help children cope with the emotional challenges associated with cancer diagnosis and treatment (Eads 2023:1040). These interventions provide a safe space for expressing emotions, managing anxiety, and developing healthy coping strategies. In addition, educational support and cognitive interventions can also help mitigate the impact of cancer treatment on the child's learning and cognitive abilities (Wong 2022:2).

The spiritual aspect of the body-mind-spirit model, recognizes the need for meaning-making, existential support, and a sense of connection during challenging times. Spiritual interventions can provide comfort, hope, and resilience for the child, their family, and the healthcare team. This may involve engaging in spiritual practices, accessing pastoral care or chaplaincy services, participating in support groups that address spiritual concerns, or finding solace in personal spiritual beliefs and values. Spiritual interventions can help individuals find strength, purpose, and a sense of transcendence, fostering coping and healing throughout the cancer journey (Williamson *et al.* 2022:1087).

The body-mind-spirit model honours the multidimensional nature of the impact of paediatric cancer, through the integration of psychosocial and spiritual interventions within the medical milieu (Moola, Campbell, and Neville 2023:23). It recognizes that by addressing the holistic physical, psychological, and spiritual needs of children, the quality of life can be improved for the child and their support system strengthened (Wong 2022:2). These interventions reinforce emotional support, reduce distress, enhance resilience, and facilitate the process of adjustment and healing for both the child and their family (Hui *et al.* 2022:1). The sub-section that follows, provides an overview of the research methodology that was used to guide the study.

## 1.15 Overview of research methodology

This study was guided by the qualitative research paradigm. The study aimed to gather rich insights into the experiences of paediatric patients, through the lens of their parents and healthcare professionals in their milieu. The parents recruited were those in receipt of services from Childhood Cancer Foundation South Africa at Inkosi Albert Luthuli Central Hospital. Sample two, was made up of a team of health care professionals located in the paediatric oncology ward based at Inkosi Albert Luthuli Central Hospital and sample 3 consisted of social service professionals from Childhood Cancer Foundation South Africa who rendered their services to children and their families. In-depth semi-structured interviews were used to collect data, and thematic analysis was used to analyse the data.

## 1.16 Structure of Thesis

### Chapter 1 Background of study

Chapter one introduced the background, context and rationale for the study. The research aim, objectives, and research questions guiding the study, are also highlighted. The body-mind-spirit theory, was presented as the theoretical framework, used to guide the study.

**Chapter 2 Literature review**

Chapter two provides a critical review of the literature, capturing salient research around childhood cancer and its impact on children and their families. This chapter also focusses on scholarly theoretical and empirical work, on psychosocial and spiritual interventions, used to promote coping and healing within the context of paediatric cancer.

**Chapter 3 Research methodology**

Chapter three focuses on the study design and research methodology used. Given the exploratory nature of the study, qualitative research was used to gather the experiences of the parents, healthcare professionals and the social workers. The procedure for data collection and analysis is also presented. This is followed by a discussion on the process used to thematically analyse the data and the ethical considerations within the study.

**Chapter 4 Analysis and discussion of findings**

Chapter four presents the data and analysis of the findings made in the study.

**Chapter 5 Conclusion and recommendations**

Chapter five summarizes key critical findings and the recommendations emerging from the study. The limitations are also discussed.

## 1.17. Conclusion

This chapter introduced the research study, by contextualising paediatric cancer in the South African and international context. The background and problem statement of the study was elucidated. The aim and objectives and the research questions were also outlined. Key concepts utilized in the study were also presented. Finally, the theoretical framework and overview of the research methodology were discussed. The following chapter presents an overview of the key aspects of the literature in relation to the objectives.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 Introduction

Literature related to childhood cancer and the empirical research related to paediatric cancer is reviewed in this Chapter. According to Snyder (2019:333), a literature review is a systematic approach to collecting and synthesizing prior research. He added that a rigorous literature review establishes a solid foundation for advancing knowledge, integrating findings and perspectives from other studies and addressing the research questions. It also enables the synthesis of research findings, in a way that gathers evidence of prior studies and uncovers new areas requiring further investigation. research. This enables the building of theoretical frameworks and conceptual models.

In this chapter an in-depth review and discussion of the literature surrounding paediatric cancer and its effects on family life is provided. Definitions of cancer and its characteristics are elucidated, the incidences, types and effects of paediatric cancer and mortality rates documented, and issues related to the survivorship of paediatric cancer discussed. The effects of paediatric cancer on children and their well-being will be discussed. Furthermore, the impact of childhood cancer on families and how different life domains are affected will also be presented. The chapter also focusses on the role of health care and social service professionals. A section is also dedicated to the salience of spirituality along the cancer journey. To conclude this chapter, the researcher has reflected on important psychosocial and spiritual interventions within the context of paediatric cancer.

The literature in this chapter was sourced from the following data bases and through the following search engines, namely Google, Jstor, Elsevier, South African Journal of Oncology, South African medical journal, eCancer Medical Science and Cancer Medicine. To acquire the relevant literature several important key words were used i.e., paediatric cancer, families and paediatric cancer, impact of holistic health, psychosocial interventions, and spiritual interventions. This chapter begins with a definition of cancer to strengthen an understanding of it within the context of this study.

## 2.2 Definition of cancer

According to the National Institute of Health (2015:2) and Endalamaw (2021:21) cancer is “a group of diseases in which abnormal cells divide without control, invade nearby healthy tissues, and spread to other parts of the body through the blood and lymph systems". Research has documented the difference related to cancer amongst children and adults. Erdmann *et al.* (2021:1) indicated that paediatric cancer is a heterogeneous group of malignancies, which constitute the presence of subpopulations of cells with distinct genotypes (genetic makeup of organisms) and phenotypes (observable physical properties of an organism). This includes an array of diseases with divergent patterns of occurrence, aetiology, treatment and supportive care, survival and the risk of acute toxic side and late effects.

The sub-section that follows focuses on the characteristics of cancer and its genes. It also highlights how some children acquire a diagnosis of paediatric cancer.

## 2.3 Characteristics of cancer

With all the diseases present in the world and in South Africa, cancer is considered the most feared of them all, due to its crippling progression on the human body (Jitoo 2004:15). Research has found that the biological mechanisms and markers with which cancer starts and continues are always evolving, as well as its interconnectedness with psychosocial factors (Merriman 2020:7). Although cancer is frequently utilized to refer to various diseases, each type of cancer has different effects on organs and tissues. It is detrimental to the human body, because abnormal white blood cells grow, resulting in tumours that affect vital organs. At times it spreads to other parts of the body causing huge physiological dysfunction, which results in abnormal functioning of the organs (Merriman 2020:14). Children are also at risk of developing certain types of cancer, because of an increase in environmental factors and agents external to the body that enter and attack healthy tissue. These cancerous cells then detach themselves, if the tumour enters the bloodstream or lymphatic system (Jitoo 2004:7), causing it to spread to other parts of the body. Moreover, this may characterize itself as a tumour which can metastasize or as leukaemia which presents as cancer of the blood (Jitoo 2004:8; Merriman 2020:15).

The sub-section that follows, focuses on the types and effects of paediatric cancer. Examples of the types of cancers and the location of specific types of cancer in the human body are discussed.

## 2.4 Types and effects of paediatric cancer

There exists a wide spectrum of common and rare forms of paediatric cancer (Malicka *et al.* 2019:1). According to Islam (2021:2) the usual malignancies in childhood cancer are identified as sarcoma and blastoma. Sarcoma is the malignant development of connective tissue. Examples of sarcoma include rhabdomyosarcoma (tumour of the muscle tissue), osteosarcoma (bone tumour), and fibrosarcoma (tumour of connective tissue). A blastoma occurs from embryonic tissue, which is in immature organs (Kidney tumours), hepatoblastoma (liver tumour), and medulloblastoma (brain tumour). Malicka (2019:2) added that lymphoma, is also a type of cancerous tumour of the lymph tissue and can therefore begin anywhere in the body, because lymph tissue is located throughout many parts of the body. Such examples of lymphoma are Hodgkin's disease (affects nodes near the body surface i.e., neck, groin, and armpits), non-Hodgkin's disease (located in deeper parts of the body e.g., the bowel) and Burkitt's lymphoma, which is an aggressive form of non-Hodgkin's b-cell lymphoma.

William Li *et al.* (2010:47) and Malysse (2021:1) stated that leukaemia is one of the leading types of cancer, that is commonly diagnosed in paediatric cancer. It identifies itself as a group of malignant neoplasms, found in the bone marrow and blood system. It replaces healthy tissue, disrupts organ functioning and vital processes. Acute lymphoblastic leukaemia is identified as the most common type of paediatric cancer occurring between the ages of 2-8 years. The mortality rates of childhood cancer within a local and global context are discussed next.

## 2.5 Mortality rates related to childhood cancer

According to Siegel *et al.* (2020:15) mortality rates are huge indicators of the progress being made in the battle against cancer, rather than incidences or survival rates. According to research early mortality rates have been extremely high in low-income countries, compared to high-income countries (Erdmann *et al.* 2021:5). This is because mortality rates are less affected by biases, for examples alterations in the detection practices (Siegal *et al.* 2020:15). The mortality rate peaked at 215.1 deaths per 100,000 individuals in 1992 and has since dropped to 152.4 deaths per 100,000 individuals in 2017. In South Africa in 2023, an estimated 9,910 children younger than 15 and about 5,280 teenagers between the ages of 15 to 19 were diagnosed with cancer. In children under 15, leukaemia made up 28% of all childhood cancers that were diagnosed. The next most common type of childhood cancer is brain cancer (26%), followed by lymphoma (12%) (Beringer *et al.* 2021:2). According to Merriman (2020:22) the current data reflects that, there were 2,820,034 deaths in the United States in 2017. About 21% of these were due to cancer.

The incidences of paediatric cancer and some statistics on the types of cancer are provided in the sub-section that follows.

## 2.6 Incidences of paediatric cancer

The leading cause of childhood death in the West are malignant diseases (Jitoo 2004:7). Research shows that cancer has superseded HIV/AIDS, respiratory and nutritional issues and is considered the primary factor linked to childhood deaths (Erdmann 2021:1; Huining Zhou 2021:1206-1207). According to Malicka (2019:6) the incidence of various childhood cancers is,

leukaemia 34% (acute lymphoblastic 27%, acute myeloid 7%), brain tumours 22%, embryonal tumours 16% (Wilm's 6%, neuroblastoma 6%, retinoblastoma 3%, hepatoblastoma 1%), lymphomas 11% (Hodgkin's 7%, non-Hodgkin's 4%), sarcomas 11% (soft tissue 6%, bone 5%) and other tumours 6%. Research, however, indicates that leukaemia is the most generic form of childhood cancer globally and in South Africa, which encompasses one third of all diagnosed cases, followed by lymphomas and tumours in the brain and abdomen (Malicka 2019:7). The survivorship of paediatric cancer patients is discussed next.

## 2.7 Survivorship of paediatric cancer patients

Siegal *et al.* (2022:9) stated that paediatric cancer rates vary, depending on the type of cancer and age of diagnosis. The survival rate of paediatric cancer has increased from 30% in the 1960's to 80% in most high-income counties and developing countries. However, not all children have benefitted from this and the outcomes depend on an array of markers, that include the type of malignancy, age of diagnosis, location of cancer, stage of illness and any somatic genetic lesions (Erdmann *et al.* 2019:1). Paediatric cancer survivors are at significant risk of multiple mental and somatic health conditions, that contribute to cancer and the treatment provided. These risks further include poor socio-economic and social circumstances, reduced psychological well-being and overall quality of life (Erdmann *et al.* 2019:2). A discussion on the impact of childhood cancer, on the paediatric cancer patient's well-being is presented next.

## 2.8 The impact of childhood cancer on the well-being of paediatric cancer patients

A cancer diagnosis can feel like a home invasion for a child, the dreaded sound of an alarm system warning of an intruder, the shock of coming face-to-face with a potentially deadly threat, and the realization that one's privacy and home have been infiltrated, and one's safety jeopardised. Following a home invasion, one might upgrade their alarm system or add a deadbolt to the front door (Cahalan *et al.* 2022:1). With childhood cancer, however the alarm bells go off repetitively, with more invaders entering a child's private space, in what feels like a recurring nightmare. Cancer is therefore not cured by upgrading an alarm system, which suggests that treatment options are limited (Cahalan *et al.* 2022:1).

Over the past decades, it has become increasingly evident that survivors of childhood cancer may experience, to varying degrees, a wide range of adverse health outcomes resulting from previous therapeutic exposures, which can affect almost any organ or body system (Erdmann 2021:7). Paediatric cancer patients experience a decline in their psychological, emotional, physical, and social health, which consequently impacts their quality of life. Their interpersonal relationships with parents and siblings decline, leading to a breakdown in family relationships and functioning. In this section the impact of paediatric cancer on the psychological, psychosocial, physical and academic well-being of the child is discussed.

### 2.8.1 Psychological

The psychological aspects, influence a child's emotional well-being. A major concern in the long-term adjustment to cancer, is the range of cognitive and emotional responses it produces (Cheung *et al.* 2019:22). A cancer diagnosis is known to initiate a spiralling progression of psychological and emotional distress. Initially, responses to a confirmed diagnosis, range from denial, shock, fear, anxiety, anger and sadness (Molinaro 2019:6), as well as feelings of worthlessness and helplessness (Jitoo 2004:450).

Research suggests that anxiety and depressive symptoms experienced by paediatric cancer patients and survivors, emerges from a diagnosis of cancer, poor prognosis, changes to psychosocial functioning caused by cancer and treatment protocols which disrupt wellness (Chung *et al.* 2021:194). Cillessen *et al.* (2019:2275) said that, the nature of the illness, its severity and course, and the direct threat to life, influences its psychological outcomes. For the child with cancer, despite a possible 70-90% rate of remission, the fear of death at diagnosis, becomes more pronounced. While the intensity of emotions may lessen with time, emotional adjustment is still challenging (Benedict *et al.* 2022:159).

Cheung *et al.* (2019:104) and William *et al.* (2013:214) stated that in addition to the depressive experiences paediatric cancer patients endure, they also face a psychiatric condition, referred to as "intruded self-esteem." The changes in physical appearance, are common manifestations of the disease, amongst cancer patients and survivors. These include marked physical disfigurement, enduring visible scars and lesions, hair loss, prolonged alopecia, disfigurement of their neck and head and short stature. These pronounced physical changes affect self-esteem and the overall well-being and quality of a patient's life (Cheung *et al.* 2019:105).

In young adults, it has been reported that there are heightened levels of psychological distress, which cause increased use of anti-depressants and higher rates of suicide ideation (Erdmann *et al.* 2021:14). A study conducted by Molinaro (2019:1-10) confirmed that childhood cancer survivors, experience severe psychological distress. Some participants in their study, experienced "survivors' guilt," or frequently thought of why they survived and not their friends at the hospital. Several other cancer patients developed a phobia of needles, because of always being poked or pricked during treatment or check-up visits. This caused them to become needle-phobic, experience greater fears of death, with some reporting that they have "chemo brain" which induces short-term memory loss.

Cancer is therefore a daunting experience, and researchers have uncovered deep emotional effects ranging from disbelief, fear, guilt, hope, loneliness, being overwhelmed, sad and stressed (Ghaempanah 2023:225). Several scholars have described the intense emotional turmoil that these young patients face (Boeriu *et al.* 2023:972; Borjalilu and Sharif 2020:228; Cannon, *et al.* 2019:104, Calonge-Pascual 2023:101; Cash 2022:227). The sick child may grieve the loss of their good health, struggle with changes to their appearance, encounter guilt over the impact of their diagnosis on their family, and experience concerns related to their future. The 5 stages of grief elucidated by psychiatrist Elisabeth Kubler-Ross in 1973, commonly known as DABDA, which stands for "denial," "anger," "bargaining," "depression," and "acceptance" captures the emotions, childhood cancer patients experience as they navigate their cancer journey. The DABDA model describes the emotional responses of paediatric cancer patients, when they are faced with this life-altering disease. These stages do not manifest in a linear or sequential way, but can occur at any time, post a cancer diagnosis. The stages are as follows:

**Emotional Stages**

- **Denial**

According to Kubler-Ross (1973:1-10) a cancer diagnosis triggers emotions/feelings of disbelief, numbness, or shock amongst both children and their families. Childhood cancer patients may want to avoid thinking about it or pretend it is not happening. Denial is therefore a common response to this life-altering experience. Whilst denial dissipates over time, patients begin to experience other emotions.

- **Anger**

Anger is another natural emotional response which although isn't always positive, can open a pathway to express difficult emotions, like anxiety, fear, frustration, and helplessness. Such expression is therapeutic, as opposed to patients withholding these negative emotions. Hence talking about their anger with a trusted family member, friend, health care or social service professional, writing about it in a journal/diary, or engaging in physical activity (e.g., dancing) can create healthy expression of it (Kubler-Ross 1973:1-10).

- **Bargaining**

The bargaining stage provokes feelings that the diagnosis is unfair, and the child may want to do anything to "fix" it to secure their life pre-diagnosis. The child may bargain with a Higher Power, to achieve control over their situation, and may think, "If I get through this, I will never complain about anything again." Bargaining and guilt are experienced collectively, as patients contemplate countless what-if scenarios. This requires that they work through their emotions with a counsellor or with peers in a cancer support group.

- **Depression**

Depression creates enduring feelings of sadness, loss of pleasure in previously enjoyed activities, and low energy. It further results in changes to sleeping and eating patterns, difficulties in concentration and low self-worth. Therapy therefore becomes paramount, as research has shown that people

who receive treatment for depression respond better to their treatments and have a better quality of life (Kubler-Ross 1973:1-10).

- **Acceptance**

Once a child has given themselves the space to grieve, it becomes easier for them to accept the reality of their condition. Acceptance nurtures hope and brings with it a reduction in stress, lowered blood pressure, and improved interpersonal relationships (Kubler-Ross 1973:1-10).

### 2.8.2 Psychosocial problems

Depending on the diagnosis, treatment may include chemotherapy, radiotherapy, stem cell transplants and bone marrow transplants. In most instances, a combination of treatment modalities is needed. During treatment, the child is confronted with threats to their physical integrity, safety and security, loss of their life, increased pain, loss of opportunities to participate in sport, games and other fun activities, and intense illness (Koumarianou *et al.* 2021:103; Bekui *et al.* 2020:1-7; Hendricks *et al.* 2019:1-4; Pan American Health Organization 2023:6). Relapses may also occur whilst they are undergoing treatment or after completion. This may require a re-initiation of treatment, in a more aggressive way, perpetuating a vicious cycle of pain and ill-health. The emotional impact of a relapse is often worse, than the diagnosis, as the life-threatening nature of the disease emerges and is intensified during periods of severe pain, discomfort, and illness (Iniesta *et al.* 2015:2).

Siegwart *et al.* (2021:3) said that the child with cancer experiences greater anxiety, as the disease progresses and with each clinic visit. The medical treatment and procedures including bone marrow aspirations, lumbar punctures and intravenously administered cytostatic, causes acute pain, nausea vomiting and severe physical discomfort, creating huger anxiety and

discomfort (Marusak *et al.* 2018:123). The child's vulnerability to feelings of depression, anxiety and helplessness, is increased during periods of hospitalisation. In-patient treatment poses several problems, as it restricts their freedom of movement, threatens their familial and peer attachment relationships, creating greater social isolation, insecurity, and reduced control over their lives (Adhvaryu *et al.* 2022:2-3; McClean *et al.* 2017:10; Tortora 2019:3; Archie *et al.* 2013:2609).

According to Bowlby's theory, hospitalisation causes greater separation anxiety amongst young patients, when they endure lengthy periods away from their parents (Li 2013:22). Such children present with apathy, withdrawal and regressive behaviour. Several studies have found a higher frequency of emotional and social problems, such as poor self-esteem, poor self-satisfaction, less ambitious ideals, death anxiety, depression, poor social skills, school re-integration problems and school phobia amongst paediatric cancer patients who are separated from their parents for long periods (Afungchwi *et al.* 2022:296; Auletta *et al.* 2020:286; Chrapek 2016:27; Racine 2023:45; Ross and McSherry 2020:97; Malysse 2021:6).

Research has also found that siblings of paediatric cancer patients, are affected emotionally and often experience posttraumatic stress disorder (PTSD) (Weiner 2016:85). Neville *et al.* (2016:55) indicated that these siblings, experience severe self-reported anxiety and depression, bipolar disorder (Abrams 2016:25) and nutritional disorders (Koumarianou 202:3). Furthermore, risk taking behaviours increase amongst healthy and bereaved siblings, as they engage in increased drug and alcohol use, risky sexual practices and suicidal ideation (Fair 2021:6). This emerges from the lack of attention from parents who become more preoccupied with their ill child, and the overwhelming changes in family dynamics.

### 2.8.3 Physical problems

According to Christensen *et al.* (2023:3981) paediatric cancer patients and survivors experience a decline in their physical health and fitness (i.e. cardiopulmonary dysfunction), reduced functional ability (impaired musculoskeletal function) and cancer- related fatigue, which are common tangible and visible effects of cancer. William *et al.* (2013:218) argued that cancer often causes immense fatigue, memory loss, poor concentration, and activity intolerance. A study conducted by Cheung *et al.* (2019:106) found that paediatric cancer patients experienced extreme fatigue and headaches which disrupts their daily functioning. One participant from their study said, “I always feel tired easily, I can’t complete the tasks that my classmates can do during the sports lessons in school, and it makes me feel frustrated.” Another participant said, “headaches really bother me a lot, it will get worse if I engage in physical activity.” Cancer patients and survivors therefore have reduced functional capacity, such as limb weakness and imbalance gaits, which makes them more dependent on others, during their normal day-to-day lives (Cheung *et al.* 2019:106; Abrams 2016:25; Peikert *et al.* 2018:21; Torode *et al.* 2023:220).

### 2.8.4 Academics effects

The harsh side effects of cancer treatment prevent young people from attending school and participating in academic competitions and other sporting activities. Multiple large scale research studies have documented that lower educational drives and achievements have been reported amongst paediatric cancer patients and survivors, in contrast to cancer-free children (Erdmaan 2021:14; Ghaderi *et al.* 2016:87-95; Anomaki *et al.* 2017:284-294; Lancashire *et al.* 2010:254-270). Molinaro (2021:7) added that paediatric cancer patients, develop learning disabilities or previously diagnosed learning disabilities, become more pronounced during or after cancer treatment.

A study conducted by Li *et al.* (2013:214-219) documented the effects of cancer and its treatment on Chinese childhood cancer survivors. The study found that cancer patients and survivors were prone to feeling anxious about their academic progress and reported that this further affected their diagnosis and course of treatment (Li 2013:216). Treatment inevitably affects attention span, causes fatigue, even during remission, as these young patients have to work harder to catch up on their studies (Davies and O'Connor 2022:1; Eads 2023:104; Gunter and Duke 2018:1).

In the sub-section that follows, the effects of childhood cancer on the family and how each domain of their lives is affected, is discussed.

## 2.9 The impact of childhood cancer on families

Childhood cancer permeates every aspect of a parent's life and coalesces into heightened stress, unanswered questions, strain, and dysfunction. An overview of the various domains of parent's lives that are affected is discussed in the sub-sections that follow.

### 2.9.1 General domain

A child's chronic illness influences every part of their physical, mental, socio-economic, and behavioural aspect of life (Lewandowska 2022:2). Because their illness becomes an overarching feature of family life, it also affects the child's closest family, especially their parents and siblings. The caregiver who is a part of the patient's family life cycle and who provides emotional, expressive, instrumental, and tangible support, during a child's chronic, acute disease or disability is most affected (Toledano and Contreras-Valdez 2018:3). Because childhood cancer is a chronic disease that requires continuous care

throughout the treatment and hospitalization journey, it threatens the overall quality of life of the family caregiver, on a personal, social, and professional level and increases their susceptibility to emotional and physical problems (Toledano and Domínguez-Guedea 2019:4; Toledano *et al.* 2020:7765). When families are confronted with their child's cancer diagnosis, they often experience a myriad of emotions and feelings, such as shock, suffering, and changes to their daily family life (Stewart *et al.* 2024:2).

Parents immediately become immersed within the medical milieu, as they begin prioritising the needs of their sick child (Ji *et al.* 2018:7). Furthermore, childhood cancer erodes family life and pushes parents to rethink their personal philosophy of life and death, personal and family goals and their hopes and dreams for the sick child and their whole family (Teng and Zhang 2022:287). As a result of the sudden changes to a family, the psychosomatic balance and functioning of the entire family unit including the siblings becomes disrupted. Psycho-physical fitness deteriorates, somatic ailments increase, and social and professional contacts become more limited (Kaptacz 2018:137).

Lewandowska (2022:144) opined that the diagnosis and process of pre and post paediatric cancer, is unnerving and emotionally stressful for families. It demands a huge level of support from nuclear and extended family and friends, religious and spiritual support, and social networks (Islam *et al.* 2021:2). Moreover, parents may experience a higher level of financial distress due to hospitalization and treatment costs. Direct costs refer to the cost of hospitalization, treatment, medication, diagnosis and travel, accommodation, if parents are travelling from distant rural areas. Indirect costs can be identified as the loss of salary or wages and other family related costs. As a result of both types of costs some families experience greater financial hardship (Malard and Mohty 2020:1146).

### 2.9.2 Psychological domain

According to Lewandowska (2022:2), cancer and the consequent hospitalization of children, is a major catalyst of tension and anxiety for families who are the primary sources of support, for the sick child (Koohkan *et al.* 2019:246). Parents have to cope with multiple stressors linked to the side effects caused by treatment, life-threatening situations, experiencing the death of other patients, financial problems, threats to their professional journey and the overall upheaval they endure (Chrapek 2017:27).

Caring for children with cancer causes anxiety, depression, and greater burdening and burnout of the caregiver, resulting in a deterioration of their physical and mental well-being (Toledano *et al.* 2021:748; Toledano *et al.* 2017:2). Parents are often traumatised after their children are diagnosed with cancer and they struggle to come to terms with this diagnosis. They experience unplanned and significant stressors, which include medical (linked to the diagnosis), intellectual (understanding the medical information), instrumental (hospitalisation and treatment of their ill child and relooking at family life), interpersonal (coping with child's adjustment to diagnosis, spousal/parental relation with family and society), and emotional stressors (connected to the need to answer the questions, why me?; why now?; why my child"?) (Pedersen 2020:56).

Caring for a child with cancer can therefore be an emotionally exhausting task, causing physical, mental, social, and economic well-being to decline, as the cancer progresses (Toledano *et al.* 2020:456; Toledano *et al.* 2020:2). Parents often encounter many healthcare challenges themselves, as they begin caring for their sick children. The assessment of the family's needs is therefore important, as it serves as a predictor of psychosocial risk for parents

(Wilson 2024:67). Parents will always play a decisive role in the care of their child as they have to interact directly with their sick children and deal with the related problems. Hence mental health professionals must provision them with greater support to cope and improve their well-being (Shorofi *et al.* 2016:17; Lewandowska 2022:144).

### 2.9.3 Emotional domain

The entire journey related to paediatric cancer, can cause severe emotional turmoil, for both parents and siblings of the sick child. (Lewandowska 2022:9). Parents experience a sense of loss and sadness following their child's diagnosis. They often grieve for their child and the loss of normality for the rest of their family and their sick child. Moreover, they have to make huge adjustments to their lives and are forced to relinquish their dreams and hopes for their child, which contributes to feelings of hopelessness, shock, denial, disbelief, bitterness, anger and helplessness (Hagedoorn, Krieicberg and Appel 2011:205-211; Erker *et al.* 2018:1-9).

Studies have found that the process of diagnosis and treatment becomes painful and distressing for parents (Stenka 2018:306; Santos 2016:1008; Bruce 2006:223). A study by Bruce (2006:223) found that parents, presented with higher rates of post-traumatic stress disorder (PTSD) and post-traumatic stress symptomatology (PTSS), than their children. This suggests that the experience of being a parent to a child with cancer, can be more traumatic than the actual disease itself. Hence parents of children diagnosed with cancer experience greater mental health sequelae, than parents within the general population (Stenka *et al.* 2018:306; Borjalilu *et al.* 2020:228; Riahi *et al.* 2016:21).

### 2.9.4 Informational domain

Parents need access to relevant information, to cope and function better. Borjalil *et al.* (2020:228) reported that there were four main themes, in terms of parents' health information needs, namely medical, physical health, healthcare, and family lifestyle information. Adams *et al.* (2009:179) argued that the main informational needs of parents of cancer patients include treatment, diagnosis, coping with the disease, self-care and types of cancer, hospital care, and rehabilitation. Inman (2017:9) added that for parents of children with cancer, health information should include the long-term effects of cancer treatment on survivors, concerns related to the physical and psychological consequences, and access to information about behavioural problems, education, sleep disorders, eating, and communication with others. Mitchell *et al.* (2006:805) further suggested that parents of children with cancer across all age groups and stages of the disease should receive proper medical information from doctors and nurses during diagnosis and treatment.

### 2.9.5 Marital stress

The diagnosis of childhood cancer introduces huge stressors that disrupt parental relationships (Fugmann *et al.* 2022:828; Mullis *et al.* 2024:5). Omer *et al.* (2024:66) opined that parents endure changes to their daily routines and family life, including changing caregiver or spousal roles, threats to employment, financial strain, and emotional challenges. These additional stressors, combined with caring for healthy family members and maintaining other relationships, can challenge the marital dyad (Wan Ghazali *et al.* 2023:2). Milville *et al.* (2024:102) argued that because of the physical distance between partners, regular communication between parents is affected as one parent (typically the mother) stays with the child at a treatment facility or hospital. This is often at a distance from their home, while the other parent (frequently the father) manages the household and provides income. This

separation can cause a breakdown in communication related to family care and medical decisions, thereby exacerbating stress and anxiety within the relationship (Wiener *et al.* 2017:2109).

Research suggests that the emotional responses to a child's cancer diagnosis can vary between mothers and fathers, potentially leading to divergent coping styles and increased marital dissatisfaction (Davies *et al.* 2023:26114). Vegrim *et al.* (2022:1130) and Fathollah *Za*deh *et al.* (2021:3697) supported this stance, saying that mothers have been found to experience significantly higher levels of psychological distress than fathers. These differences in the emotions and coping mechanisms can create misunderstandings and conflicts between mothers and fathers, thereby straining the marital relationship.

Huang *et al.* (2023:5160) said the period shortly after diagnosis appears to create the hugest strain in the couple's relationship. Chen *et al.* (2022:733) supported this saying, that many of the changes within families occurs shortly after diagnosis; however, when the child has been ill for one year, parents report fewer changes in their relationships. After two or three years, many couples report positive changes, and after four years or more, most parents experience fewer or no changes. When the child goes into remission, family life is likely to return to normal, and couples report a renewed sense of strength in their relationship (Navabinejad *et al.* 2024:23). However, if the child relapses, the entire crisis process is often reestablished. Moreover, the intense focus on the child's health, may cause the couple to neglect their intimate relationship. This notion is supported within several studies, which found that nearly half of the couples surveyed, had experienced a decline in their sexual intimacy during this period (Chow *et al.* 2022:300; Holm *et al.* 2024:307; Christensen *et al.* 2023:3981). Other studies however reported converse findings, that the experience of managing a child's illness, strengthen marital

bonds over time (Neugebauer *et al.* 2021:1099; Luo *et al.* 2022:1048; Park *et al.* 2022:102; McCarthy *et al.* 2021:293).

Hence contrary to the expectation that childhood cancer leads to higher divorce rates some studies support the view that these couples may experience lower divorce rates, than the general population (Gajda *et al.* 2024:102). A study by Holm et al. (2024:107), at a Swedish paediatric oncology centre found, a person-year divorce rate of 1.19% among parents of children treated for cancer, which was slightly lower than the 2.03% person-year divorce rate amongst married couples, with children in the general population. These findings however do not negate the increased marital stress experienced by these couples, as the same study found higher levels of stress, compared to parents of children with other chronic illnesses. The effects of paediatric cancer on a sick child's siblings, is discussed next.

## 2.10 Effect of paediatric cancer on siblings

Little research exists on how the siblings of children with paediatric cancer are affected. Erker *et al.* (2018:1680-1681) argued that siblings of the ill child are overlooked in the family, whilst the paediatric patient is engaged in cancer procedures and treatment. The life-threatening illness of any brother or sister, however, can drastically alter the other sibling's life (Deavin *et al.* 2018:41). Hoven (2021:1-2) reported that siblings experience a myriad of intense feelings, related to their sibling's cancer diagnosis that range from feelings of loss to fear, helplessness, insecurity, marginalization, anger, and guilt.

Over the last decade research has found that siblings of paediatric cancer patients, are a vulnerable group of young people, who are at an increased risk

of somatic, social, and psychological problems. Prior studies reported that siblings of children with cancer, have limited psychosocial support, cancer related information and involvement in their siblings treatment (Lovegren *et al.* 2016:299; Tasker and Stonebridge 2016:26; Toft *et al.* 2019:356). Family life is hugely disrupted when a child has cancer, and siblings often take on added responsibilities and roles within the family (Foster *et al.* 2012:347). Parents tend to devote greater attention towards their ill child, leaving healthy sibling(s) feeling neglected and invisible to them (Neville *et al.* 2016:188).

A study conducted by Hoven *et al.* (2021:1-19), revealed two important themes related to siblings. The first on family relations, focussed on their feelings of loneliness and neglect within the family and how their relationships were transformed, even with their brother or sister with cancer. The second theme which was on maintaining normality, focused on their quest for normalcy, especially so that the sibling's cancer diagnosis did not overpower school dynamics. These researchers concluded that siblings are faced with dual dilemmas, wherein it becomes hard to control the gravity of the situation whilst coping with the loneliness they experience and their unfulfilled needs. Siblings of the child with cancer therefore require greater psychosocial supportive services, to manage such dilemmas (Hoven *et al.* 2021:1-19).

Siblings also have to watch helplessly, as their sick brother or sister, struggles with the symptoms of the disease and treatment (Nolbris *et al.* 2014:3). They endure multiple transitions throughout the diagnosis of their ill sibling(s) cancer journey. This transition can better be understood within the context of Meleis' (2010:15) middle range theory of transitions, which describes the various transitions siblings move through, and which include developmental, health/illness, situational and organizational transitions. At times siblings can experience developmental and situational transitions interchangeably, hence the transition process is complex and multi-faceted. Components of the

transition include one's awareness, knowledge, recognition of the transition experience, changes in one's identity, roles and level of engagement and behaviours (Melei 2010:20). The following sub-sections focus on what the siblings experience.

### 2.10.1 An array of emotional changes

In line with the transition theory, properties of transition include changes and differences to a person's behaviour, identities, and emotion. D'Urso *et al.* (2017:302) indicated that siblings experience an array of emotions that includes shock, fear, and uncertainty. As treatments progress, siblings have been found to experience anger and jealousy, because their sick brother or sister, receives greater attention from their parents and other family members (Islam 2021:5). Rosenberg *et al.* (2015:5) posited that siblings also endure feelings of uncertainty and anxiety, because at times an exact diagnosis is not available. Hence siblings often feel excluded from their own nuclear family, during the treatment process (Neville *et al.* 2016:190).

Whilst some siblings become more withdrawn during the cancer journey, others experience a sense of depression, anger, fear, and isolation (Yeung *et al.* 2016:463) and a loss of their self-identity (Long 2015:22). A literature review to understand the experiences of siblings of childhood cancer patients, further found that siblings not only experienced grief, but a sense of guilt because their sibling had a terminal illness, and could potentially die (Weiner and Woodley 2018:109-119).

### 2.10.2 Relationship changes

During a child's cancer journey, the quality of relationships and roles with others may also change (Meleis 2010:22). According to Weiner *et al.* (2018:115) siblings of children with cancer, are still expected to continue with their daily lives, regardless of how difficult their circumstances are. Relationships between siblings change, peer relationships are altered, as some detach themselves from peers because of the numerous questions, they are confronted with related to their sick sibling (Rourke and Alderfer 2016:362). Siblings became closer to their father, to preserve a sense of normalcy and emotional support, due to their mother, being at the hospital constantly (D'Urso *et al.* 2017:310).

### 2.10.3 Family and home life changes

There are also many transitions within the familial roles and in the sibling's home life, which interferes with the normalcy of the home (D'Urso *et al.* 2017: 312). Research has also found that siblings have to mature very quickly and assume greater responsibilities and roles at home, to decrease stress for the family. Because of these increased responsibilities, a strained relationship may manifest between siblings and the sick child (Neville *et al.* 2016:56). Those who are ill, feel like a burden to their family and are often unwilling to share their own troubles. Jenholt *et al.* (2014:5) posited that healthy siblings experience grief and feel unworthy of attention. They appear to be forgotten, within their own families, because parental attention is diverted to their sick sibling. Yang *et al.* (2016:465) added that such the attention shifts occur, because parents are mostly at the hospital with the sick child and when the parents are home with the siblings, they are often exhausted or stressed, which affects celebratory holidays and family vacations.

### 2.10.4 School life changes

Siblings experience may also encounter changes related to their school life, particularly behavioural and social changes. Fair (2021:3) reported that they experience hardship in their academic life, soon after they have been told that their brother and sister has cancer. They become distracted and become fearful for the sibling's well-being. In other situations, siblings might want to be absent from school, to help their parents with various responsibilities at home or accompany their sibling to hospital (Weiner *et al.* 2016:116). Hence, they give lesser time to their schoolwork, because of their fear and concern for their sick sibling (Samson *et al.* 2016:370). Those who are bereaved struggle even more with learning after their sibling passes on, as they lose concentration after their loss (Weiner *et al.* 2018:115). The section that follows focuses on the roles of health care professionals in childhood cancer and care.

## 2.11 Health care professionals involved with childhood cancer and care

## 2.11.1 Health care professional

A healthcare professional is a person trained and licensed to provide medical services and care to patients (Zendeh *et al.* 2021:646). According to Kazak and Noll (2015:146) healthcare professionals are doctors, nurses, pharmacists, dentists, physical therapists, occupational therapists and psychologists who work in various settings, such as hospitals, clinics, private practices, nursing homes, and other healthcare facilities (Sisk *et al.* 2018:1).

The primary goal of healthcare professionals is to prevent, diagnose, treat, and manage diseases and injuries while providing compassionate and patient-centred care (Coughtrey 2018:97).

## 2.11.2 Roles of the oncologist and paediatric oncologist

### 2.11.2.1 Oncologist

An oncology doctor, also known as a medical oncologist, is a specialized physician who diagnoses, treats, and manages cancer patients (McClean *et al.* 2014:15; Adams *et al*. 2009:179). They provide comprehensive care to cancer patients and contribute to ongoing research and advancements in the field (Ahomäki *et al.* 2017:284). As experts in the field of oncology, they focus on the treatment of cancer and various aspects of cancer care. They work closely with patients to provide a comprehensive evaluation and diagnosis (Murphy 2022:75), which may involve ordering and interpreting diagnostic tests such as biopsies, imaging scans, and laboratory tests (Pommeret *et al.* 2019:153). Based on the diagnosis, they develop individualized treatment plans, that includes chemotherapy, radiation therapy, immunotherapy, targeted therapy, hormone therapy, or a combination of these interventions (Dijkstra *et al.* 2021:873; Mann *et al.* 2021:697; Klatt *et al.* 2022:2).

Medical oncologists also monitor the progress of patients, adjusting treatment plans as necessary and managing any side effects or complications, as they occur throughout the treatment process (Baselga 2008:1033). Lawrence *et al.* (2016:1223) noted that oncologists collaborate with other healthcare professionals, such as surgeons and radiation oncologists, to provide multidisciplinary care. In addition to direct patient care, they may also

participate in clinical research, contribute to advancements in cancer treatment, and provide counselling and support to patients and their families.

#### 2.11.2.2 Paediatric oncologist

A paediatric oncologist, is a specialized physician, that focuses particularly on the diagnosis, treatment, and management of cancer in children and adolescents (Altenmüller and Schlaug 2017:237; Baker 2018:270). They manage cancers that affect individuals under the age of eighteen (Alogna 2017:47) and can recognize the unique aspects of childhood cancers, which differ from those amongst adults (Baltes and Ralph 2022:94). They work closely with a multidisciplinary team that includes surgeons, radiation oncologists, pathologists, and nurses, to provide comprehensive care to young patients (Belina 2022:10-15).

Their primary responsibilities involve diagnosing various types of cancer in children and adolescents (Beringer 2021:189), which includes physical examinations, ordering and interpreting diagnostic tests (such as blood tests, biopsies, and imaging scans), and assessing medical histories (Calonge-Pascual 2023:101). Based on a diagnosis, paediatric oncologists then design individualized treatment plans tailored to meet the specific needs of each patient. Treatment options may include chemotherapy, radiation therapy, surgery, immunotherapy, stem cell transplantation, or a combination of these approaches (Blaber *et al.* 2015:415).

Chrapek *et al.* (2016:27) argued that paediatric oncologists monitor their patients' progress closely, adjusting the treatment plan as necessary and managing any side effects or complications that occur during treatment. They also provide supportive care to address the emotional needs of the child and their family (Borrescio-Higa and Valdés 2022:599).

In a project commissioned by the National Cancer Institute in 2007, Epstein and Street (2007:1-222), described six core functions of communication in oncology namely, enabling healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient/family self-management. These core functions focus on communication in paediatric oncology, because of the complex relationship between the physician, parent, and child which necessitates dedicated communication. Table 2, that follows illustrates, the core functions, the description of each function and an example related to clinician-patient-parent communication.

**Table:2** Six core functions of clinician-patient/parent communication adapted from Epstein and Street (2007:1-222).

| **Core function of communication in oncology** | **Description** | **Example** |
|---|---|---|
| 1.Fostering healing relationships | Healing relationships provide emotional support, guidance, and understanding. Such relationships are built on trust, rapport, and mutual understanding of each other's roles and responsibilities. Physicians can facilitate a healing relationship by engaging in active listening, | In disclosing a new diagnosis of cancer in a child, the physician listens and speaks in an empathic manner that creates a trusting relationship between the physician and the family. |

| | | |
|---|---|---|
| | partnership building, seeking out goals and values of the patient and family and displaying warmth and empathy in communication. | |
| 2.Exchanging information | Patients and their families seek information about the cause, diagnosis, treatment, prognosis, and lasting effects of cancer and its treatment. Fulfilling information needs, not only helps families to gain important knowledge about a child's illness, but also assists the development of a strong clinician-family relationship and supports decision making, among other outcomes. | Prior to enrolment in a clinical trial, the physician describes the risks and benefits of enrolment, as well as the prognosis of the child. |
| 3. Responding to emotions | Patients with cancer can experience a range of emotions, including fear and sadness. During clinical encounters, the clinician's task is to recognize their emotional state, ask questions, communicate understanding, and respond with empathy or tangible help. | After a CT scan reflects progression of the disease, the child's nurse reflects on the parent's emotional state and provides emotional support as they process the information. |

| | | |
|---|---|---|
| 4.Managing uncertainty | Parents and patients experience huge uncertainty related to prognosis, side effects of treatment, frequency of hospitalization, and long-term effects, amongst others. Family-centered communication helps to communicate clinical uncertainty when it exists, dispel uncertainty when there is an answer, and help patients and families to manage unavoidable uncertainties. | As a child reaches the end of treatment for cancer, the nurse practitioner sets the families expectations, for what is normal versus abnormal after completion of therapy. |
| 5. Making decisions | Effective decision making requires effective communication. Such communication can support decision making in several ways, namely raising the clinician's awareness of the family's needs, values, and fears; clarifying clinical reasoning and treatment options; alerting the physician to the family's preferred role in decision making. | The physician assesses the family's values and fears, then makes a recommendation regarding whether to pursue fertility preservation, for their young daughter who is newly diagnosed with cancer. |

| | | |
|---|---|---|
| 6. Enabling patient self-management | Communication can also help patients to "enhance their ability to solve health-related problems and be responsible for their health. This can encompass recommendation, instruction, and advocacy. | Prior to a family's first discharge from the hospital, the physician discusses dangerous warning signs that merit evaluation in the emergency department. |

## 2.12 The role and benefits of nurses in paediatric cancer

### 2.12.1 Nurse

In a hospital setting, paediatric oncology nurses, fulfil a critical role in the care and support of children and adolescents with cancer (Harper *et al.* 2019: 514). Childhood cancer nurses' responsibilities extend beyond direct patient care (Gao and Yang 2023:41) and involves:

- Patient monitoring and assessment: childhood cancer nurses regularly monitor and assess the health status of young patients, undergoing treatment for cancer. They conduct physical assessments, monitor vital signs, and observe any changes in symptoms or treatment-related side effects. They are vigilant in identifying and addressing any concerns that may arise (Landreth 2023:53).
- Treatment administration and management: childhood cancer nurses are responsible for the safe and accurate administration of cancer treatments, including chemotherapy, immunotherapy, targeted

therapies, and blood products. They ensure adherence to established protocols, assess patients for potential adverse reactions, and manage treatment-related side effects (Gao and Yang 2023:42).

- Central line and catheter care: many children with cancer require central venous access devices, such as central lines or ports, for the administration of treatments and blood draws. Childhood cancer nurses are skilled in the care and maintenance of these devices, including dressing changes, flushing, and ensuring their proper functioning (Simonato *et al.* 2020:79).

- Symptom management: these nurses provide comprehensive symptom management, to alleviate treatment-related symptoms and improve a patients' quality of life. They assess and manage pain, nausea, vomiting, fatigue, mucositis, and other symptoms. They collaborate with the healthcare team to develop individualized plans for symptom control and work closely with patients and families to educate and support their efforts in managing symptoms at home (McCullough *et al.* 2018:86).

- Medication and treatment education: childhood cancer nurses play a crucial role in educating patients and families about prescribed medications, their purpose, potential side effects, and proper administration techniques. They provide detailed instructions, demonstrate techniques, and address any concerns or questions to ensure medication adherence and treatment compliance (Gillespie *et al.* 2020:368).

- Emotional support and psychosocial care: childhood cancer nurses provide emotional support to patients and their families, acknowledging and addressing their emotional needs. They establish trusting relationships, offer empathy, and compassion, and provide a supportive environment. They may involve child life specialists and other psychosocial support to help children cope with their diagnosis and treatment (Andradas *et al.* 2021:157).

- Collaboration and communication: childhood cancer nurses collaborate closely with the multidisciplinary healthcare team to actively communicate and exchange information, ensuring a coordinated approach to care and treatment planning (Yeung *et al.* 2021:3503).
- Patient and family education: childhood cancer nurses educate patients and families about the disease process, treatment options, potential side effects, and long-term implications. They provide information on self-care, dietary guidelines, infection prevention, and other relevant topics to empower families to participate actively in the care of their child (Mammo 2024:35).
- Care coordination and advocacy: childhood cancer nurses, coordinate care and serve as advocates for their patients and families. They assist in arranging diagnostic tests, consultations, and follow-up appointments. They help navigate the healthcare system, address barriers to care, and connect families with support services, financial resources, and community organizations (Chaves *et al.* 2018:225).
- Documentation and record keeping is a further function. Childhood cancer nurses maintain accurate and up-to-date medical records, documenting patient assessments, treatment administration, symptom management, and any interventions or changes in the treatment plan. They ensure proper documentation for continuity of care and effective communication among healthcare providers (Shorofi *et al.* 2016:10).

It can therefore be concluded that childhood cancer nurses play a crucial role in the multidisciplinary care team (Ebelhar *et al.* 2023:300), contributing towards the overall well-being and positive outcomes for children with cancer (Deavin *et al.* 2018:142).

Social work in the context of childhood cancer and care is discussed in the sub-section that follows. The role of a social worker in a medical context is discussed and the key roles they play at outpatient facilities is highlighted.

## 2.13 Social work in the context of childhood cancer and care

### 2.13.1 Social worker

According to Feraco *et al.* (2023:209) a social worker is a professional who works with individuals, families, groups, and communities to improve the well-being and quality of life of individuals.

### 2.13.2 Social workers in childhood cancer in a medical context

According to Beder (2006:176) medical social workers are the “soul of the hospital providing support, understanding, and caring at a person-to-person level.” Berkman and Volland (1997:143–149), argued that social work is premised on the biopsychosocial approach, which considers a person in their entirety, within the context of his or her environment. The biopsychosocial approach considers three interrelated facets of a patient’s functioning, namely the physiological and medical aspects of a patient’s health and well-being; “psycho,” which refers to a patient’s self-worth and emotional and psychological resources, and “social,” which encompasses the social environment that surrounds and influences a patient (Rock 2002:10-15). Hence a holistic assessment enables intervention to be guided by a multidimensional approach, that considers all three facets.

According to the World Health Organization (2024:1) health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Hence interventions levelled at improving the physiological aspects of a person in hospital must be supported, with interventions aimed at improving the psycho-social and spiritual aspects of their being, so that they can heal holistically (Zerden *et al.* 2019:142).

Psychological care is crucial within the hospital context, because it allays a child’s fears and anxieties about their cancer (Lerwick 2016:143). Hence whilst the improvement of the clinical symptoms of a child’s illness is prioritised post admission, attention towards the psychological burden should also be given attention (Koukourikos *et al.* 2015:438). Lilliehorn *et al.* (2021:1-12) asserted that social workers conduct holistic psychosocial assessments to understand the emotional, psychological, and social challenges facing the paediatric cancer patient and their family. These assessments enable them to identify specific needs, such as financial stress, emotional distress, or social isolation (Pockett and Hobbs 2022:133-135). Hence the primary role of a medical social worker, is to improve relationships, between individual patients and their families, and enable patients to regain their health (Parast and Allai 2014:59). By offering individual or family counselling, they provide emotional support to parents, siblings, and the paediatric patient, helping them to process the diagnosis and cope with the fear, anxiety, and grief that accompanies cancer treatment.

Medical social workers can further advocate for children and their families, so as to ensure they have adequate medical, psychological, and social resources and can navigate the healthcare system (Smith *et al.* 2022:437). They are known to assist in coordinating care amongst the multidisciplinary medical team and liaise with insurance providers, community organizations, and government programs, to secure financial assistance, housing near treatment centres, or help in accessing other essential services (Hughes *et al.* 2021:25).

Their role is crucial in bridging gaps in healthcare access and addressing disparities, particularly for low-income or marginalized families (Healy 2022:104).

The high costs associated with childhood cancer treatment, can place a significant financial strain on families (Fitch 2022:1-5). Social workers are positioned to help families explore financial assistance options, within hospital funds, nonprofit organizations like Childhood Cancer Foundation South Africa, government subsidies, or insurance benefits. They also provide practical financial planning advice, thereby helping families manage their budgets during extended periods of caregiving (Deshields *et al.* 2021:407). Linebarger *et al.* (2022:1-9) asserted that in cases where the prognosis is poor, social workers provide critical end-of-life support to help families prepare emotionally and practically for the loss of their child. They guide families through the difficult process of making end-of-life decisions (Boyden *et al.* 2021:12-23), such as palliative care options, and offer bereavement counselling, to support them in their grieving process (Akdeniz *et al*. 2021:1). Social workers also ensure that families have access to support networks, including grief groups and spiritual care (Laube 2021:618).

### 2.13.3 The role of social workers in childhood cancer: outpatient and follow-up care

Chan *et al.* (2023:565) opined that social workers play an invaluable role in providing ongoing support to childhood cancer patients and their families, during outpatient care and follow-up phases. These periods are critical in the cancer care continuum, as they mark a transition from intensive hospital-based treatment to life outside the clinical environment (Hamdy *et al.* 2023:1547). Social workers ensure that the emotional, practical, and social needs of

patients and their families are prioritised, by facilitating continuity of care and promoting long-term well-being (Syvyk *et al.* 2022:323).

Outpatient treatment, which involves regular visits for chemotherapy, radiation, or check-ups, can be stressful for families managing the demands of daily life alongside medical appointments (Jefford *et al.* 2021:1552). Therefore, social workers can provide therapeutic services to address ongoing anxieties, fear of relapse, and emotional fatigue (Gleason *et al.* 2022: e2248696). Jacobs *et al.* (2017:e19) argued that, social workers offer age-appropriate support to help children process their feelings about their frequent hospitalization and medical care. To ensure a smooth transition to normalcy, social workers assist families in adjusting to a "new normal" by addressing concerns about balancing medical treatment with school, work, and social activities (Plage 2021:473). They help patients reintegrate into their new normal routines, whilst navigating the challenges posed by the side effects or physical limitations of treatment (Magasi *et al.* 2022:3112).

During long term follow-up care, social workers monitor the psychosocial well-being of both patients and families (Lam *et al.* 2017:1-5), as the period after treatment often brings a mix of relief and lingering fears of recurrence (Firkins *et al.* 2020:504). Germain (2020:65) argued that psychotherapy, can focus on issues like survivor's guilt, anxiety about long-term health, or difficulty reintegrating into normal life. Anderson *et al.* (2024:33) described the follow-up phase, as an opportunity to prioritise the emotional needs of siblings, who may have been neglected during active treatment. Hence social workers play a huge role in helping them adjust to changes within family dynamics and to build stronger bonds with the recovering patient (Taberna *et al.* 2020:85). Many childhood cancer patients also face long-term effects of treatment (Coughlin 2021:11), such as cognitive impairments, physical disabilities, or secondary health issues (Arch *et al.* 2021:327; Stal *et al.* 2024:635; Brauer *et al.* 2024:5-10; Neuman *et al.* 2025:1-8). Social workers can assist their

families navigate these challenges, by connecting them with rehabilitation services, support groups, and specialized healthcare providers (Ruan *et al.* 2025:1). It has been reported that for older survivors transitioning to adulthood, social workers can provide vocational counselling and help them to access programs that support their educational and career goals while accommodating any limitations caused by their medical history (Figueroa-Gray *et al.* 2024:3073). In outpatient and follow-up care, social workers are therefore important members of the care team, who ensure that childhood cancer patients and their families, continue to receive support beyond the hospital setting.

The subsection that follows focusses on the salience of social support systems in childhood cancer. The different types of social support systems families have, during the child's journey through cancer is discussed. Particular attention is paid to the support received from family, friends and communities, religious communities, specialized non-profit organizations, as well as support received from health and social service professionals.

## 2.14 Social support systems in childhood cancer

According to Fletcher (2011:40) when a child is diagnosed with cancer, the family must quickly adapt to this intense and deeply stressful experience, which presents a multitude of new demands (Hoekstra-Weebers *et al.* 2012:903). Extended family members, communities and friends of children with cancer, can be important sources of support and resilience for parents (Kelada *et al.* 2019:1538). Social support in this context, can be referred to as a social fund from which people may draw to help manage stressors (Thoits 1995:53).

Bouchard *et al.* (2022:409) opined that social support systems are a network of people that includes friends, family, and peers, who can provide emotional and practical support. These networks offer three major functions namely, emotional, informational and logistical support. Thoits (2011:405) explained that emotional support includes showing love, care, concern, sympathy, and compassionate presence or "being there". Informational support encapsulates providing advice or information related to the problem, with which a person is coping. Lastly logistical support involves help with day-to-day activities and can include both instrumental assistance (e.g., providing a ride) or financial assistance (e.g., help paying a bill) (Thoits 2011:405).

### 2.14.1 Support from family

Darlington *et al.* (2019:e28790) stated that in times of adversity, the immediate family plays a crucial role in providing emotional support to the child. Parents become pillars of strength, offering comfort, reassurance, and love during the challenging phase of treatment (Dixon *et al.* 2020:3418-3429). Carlsen *et al.* (2019:1438) added that siblings often contribute to creating a sense of normalcy, engaging in activities that bring joy to their sick sibling and maintaining a semblance of routine.

Moreover, the immediate family, particularly parents become an essential advocate for the young cancer patient, navigating the complex medical system, ensuring that the child receives the best possible care (Ganguly 2021:101). This advocacy involves coordinating medical appointments, communication with primary healthcare professionals, and actively participating in the treatment decisions of their child (Michel *et al.* 2020:1103). As such, the emotional and practical support, provided by immediate family members contributes significantly, to the child's overall well-being (Mulder *et al.* 2021:

e57-e67), by fostering a positive environment that helps in the healing process (Yeh *et al.* 2020:320).

Atout *et al.* (2021:101) opined that extended family members, play a vital role in supporting childhood cancer patients and their families. Grandparents, aunts, uncles, and cousins often step in to offer additional emotional and practical support (Olver *et al.* 2020:3467). They often help with childcare for siblings, provide a shoulder to lean on for parents, and help with daily tasks to alleviate the burdens faced by the family (Peikert *et al.* 2020: e033730). The extended family's involvement, not only strengthens the support network, but also fosters a sense of community and togetherness, reinforcing the understanding that the family is not alone in facing the challenges of childhood cancer (Tan *et al.* 2020:460).

Financial support is another significant aspect where both immediate and extended family members, can contribute (Yabroff *et al.* 2020:292). The financial burden of medical treatments, hospital stays, and ongoing care can be overwhelming, and families may need to turn to relatives to ensure that the child receives the necessary medical attention without added stress about financial constraints (Lu *et al.* 2021:997). Bouchard *et al.* (2023:408) argued that immediate and extended family members provide unwavering support, ranging from emotional encouragement to practical assistance and financial aid. These family units create a strong foundation that helps the affected child, and their loved ones transcend the pain and difficulties accompanying cancer treatment (Zucchetti *et al.* 2023:906).

### 2.14.2 Support from friends and communities

Friends and community members provide an array of emotional, practical, and social support (Deegan *et al.* 2023:819). Melguizo-Garín *et al.* (2023:1757) said that friends act as a much-needed safety net, offering a listening ear, encouragement, and a sense of normalcy, that can help families cope with the distress of a cancer diagnosis. Community-based support groups can create opportunities for families to share experiences and find solace among those who have faced similar challenges, thereby reducing their feelings of isolation (Petersen *et al.* 2022:3806). Gise *et al.* (2022:292) opined that, for young patients, maintaining connections with friends is critical, as these interactions not only bring joy and encouragement, but offset social isolation caused by prolonged hospital stays or treatment-related absences from school.

Hence friends and community members are crucial in supporting families overwhelmed by the demands of caregiving (Rasouli *et al.* 2022:93). They may assist with daily tasks such as cooking, childcare for siblings, or running errands, thereby alleviating the stress of parents, allowing them to focus on their child's treatment (Roozbeh *et al.* 2022:776). Financial support includes tangible benefits such as fundraisers who donate, coupled with the presence of caring community members who strengthen a family's hope, reminding them that they are not alone in their struggle (Calderon *et al.* 2021:1955; Nunes *et al.* 2021:497; Liu *et al.* 2021:1981; Hansson *et al.* 2023:917).

### 2.14.3 Support from religious communities

Religious communities provide huge spiritual, emotional, and practical assistance, during the cancer journey (Liu *et al.* 2023:1452; Werk *et al.* 2021:389; Rossato *et al.* 2021: 4167; Chong *et al.* 2023:408; Upenieks *et al.*

2022119). Rossato *et al.* (2021:4168) argued that spiritual and religious communities offer a sense of hope, purpose, and meaning, which is crucial for families grappling with the fear, uncertainty, and grief that accompanies a childhood cancer diagnosis or loss of a loved one. Through prayer, spiritual rituals, and faith-based encouragement, these networks enable a sense of divine connection and reassurance; to help families find strength and resilience in their spiritual beliefs as they navigate the trauma of their child's cancer diagnosis (Asadzandi *et al.* 2021: 271; Nizamis *et al.* 2023:46-61). For many parents, caught up with grave illness their faith acts as an anchor (Akaberian *et al.* 2021:470), enabling their spirituality to buffer feelings of despair and helplessness (Banayat *et al.* 2023:295).

Juškauskienė *et al.* (2023:e79) stated that religious communities act as a nurturing environment, wherein families feel understood and supported. Spiritual leaders often rally around families, offering compassion, encouragement, and a sense of belonging (Saari *et al.* 2022:311). This communal bond alleviates the isolation that many families experience, particularly during extended hospital stays or when their social interactions are limited by the demands of treatment. The collective solidarity and care provided by a religious community therefore serves as a powerful source of comfort, reminding families that they are not alone in their struggle (Asadzandi *et al.* 2023:279).

Moreover, spiritual and religious networks often facilitate connections to broader networks of support, including spiritual counsellors, mental health resources, or community programs tailored to families, confronted by serious illnesses (Rao *et al.* 2022:e1469). This interconnectedness strengthens the family's overall support system, ensuring that their spiritual, emotional, and practical needs are met (Chen *et al.* 2023:120). In essence, support from religious communities, transcends the provision of basic assistance, by

fostering a holistic sense of care and empowerment, that helps childhood cancer patients and their families navigate their journey with faith, hope, and resilience (Ghorbani *et al.* 2021:196).

### 2.14.4 Support from specialized organizations

Piñeros *et al.* (2021:9-15) argued that nonprofit organizations that focus on cancer, such as the Childhood Cancer Foundation (CHOC), play an important role in supporting childhood cancer patients and their families, by addressing critical gaps in care and providing holistic assistance that extends beyond medical treatment. This and many organizations are instrumental in raising awareness about childhood cancer, advocating for improved healthcare access, and funding research to enhance treatment outcomes (Rock *et al.* 2022:230). Ferlay *et al.* (2020:778) argued that by educating the public and policymakers about the unique challenges faced by paediatric patients and their families, nonprofit organizations contribute to shaping supportive environments and mobilizing resources essential for comprehensive care.

For families, nonprofit organizations like Childhood Cancer Foundation, South Africa offer a lifeline of emotional, financial, and practical support (Adedokun *et al.* 2020:3). Badaghi *et al.* (2024:1-5) stated that, they provide counselling, peer support groups, and recreational activities, which helps to alleviate the psychological burden of a cancer diagnosis. Moreover, these organizations foster a sense of community, connecting families with others, who share similar experiences, thereby reducing their social disconnectedness (Balagadde-Kambugu *et al.* 2023:197). Hagger *et al.* (2022:347) revealed that financially, nonprofit organizations provide critical assistance to ill children and their families, such as covering transportation costs to treatment centres, subsidizing medical expenses, or offering accommodation near hospitals, which eases the strain on families already burdened by the high costs of care.

Nonprofit organizations also play a vital advocacy role by amplifying the voices of childhood cancer patients and their families (Ige *et al.* 2023:100). Through these partnerships, organizations like the Childhood Cancer Foundation of South Africa, work to ensure that the unique needs of paediatric oncology are prioritized within public health agendas (Jeon *et al.* 2024:948). Additionally, many nonprofit organizations fund specialized training for healthcare professionals, ensuring that paediatric cancer patients receive the highest standard of care thereby optimising their well-being (Kaptacz *et al.* 2018:197).

### 2.14.5 Support received from health and social service professionals

Kazak and Noll (2015:146-158) stated that health care and social service professionals provide immense support to families facing childhood cancer, as they recognize the profound impact that a cancer diagnosis can have on the entire family unit. Zendeh *et al.* (2021:146) asserted that clear and empathetic communication from these professionals, is crucial in helping families understand the diagnosis, treatment options, and potential outcomes of their child's cancer. By providing children and families with pertinent information, without the use of medical jargon, can enable informed decision-making and promote a sense of trust and collaboration between the medical team and the family (Sisk *et al.* 2018:1-20). Signorelli *et al.* (2018:1-10) argued that the emotional well-being of families is a significant aspect of childhood cancer care. Doctors and nurses, particularly in paediatric oncology, play an essential role in offering emotional support and counselling to families, encountering the anxiety and uncertainty of a cancer diagnosis (Udo *et al.* 2019:1-9).

These professionals can assist families by providing information on the resources available within the hospital or the community, offering guidance on

managing treatment-related side effects, and addressing concerns about the impact of cancer on the child's daily life and routines (Bartlett *et al.* 2022:1-8). By adopting a holistic approach that considers both the medical and non-medical aspects of childhood cancer, these professionals help alleviate some of the burdens that families endure (Jain *et al.* 2019:3411).

Moreover, as Mann *et al.* (2021:679) suggested because these professionals, are involved in the day-to-day lives of children and families at the hospital, they can actively involve families in the treatment decision-making process. Ostadhashemi *et al.* (2019:1871) asserted that engaging parents and caregivers in discussions about treatment plans, potential risks, and expected outcomes, empowers them to actively participate in their child's care. This collaborative approach not only enhances the quality of care, but reinforces a sense of shared responsibility between the healthcare team and the family, strengthening a supportive and trusting relationship that will achieve the best outcome of the ill child's health (Minute *et al.* 2017:1-5).

Furthermore, these professionals have been known to contribute to the long-term well-being of childhood cancer survivors, by addressing survivorship issues (Klatt *et al.* 2022:1-11). This may include providing information on the potential latent effects of treatment, guiding families on transitioning back to normal life after treatment completion, and supporting the child's ongoing health and development (Lawrence *et al.* 2016:1223). Pockett and Hobbs (2022:1-12) noted that through offering holistic support to children and their families that extends beyond the immediate treatment phase, these professionals jointly contribute to the overall resilience and quality of life of childhood cancer survivors and their families (Nukpezah *et al.* 2021:1-10).

The sub-section that follows, focuses on therapeutic interventions.

## 2.15 Therapeutic interventions

According to the United Kingdom's National Institute for Health and Care Excellence (2005:10) the needs of the child and family are idiosyncratic and may change, hence psychometric tests and assessments for paediatric patients, should be ongoing throughout their course of treatment and lifespan, to ensure a balanced psychological plan for them. Zhang *et al.* (2021:3) further proposed a six-domain conceptual framework as a guide for survivors. These domains include the: (a) physical health domain, which includes physical symptoms and functional health and health-related behaviours, (b) psychological domain, which focuses on mental health, cognitive and other psychological outcomes, (c) social (relational) domain, (d) academic domain, (e) general quality of life and (f) cancer related knowledge. In the subsections that follow the psychosocial interventions and spiritual interventions that are relevant to paediatric cancer patients and their families are discussed.

### 2.16 Salience of psychosocial interventions

According to Abdoljabbari *et al.* (2018:2575) psychosocial interventions are treatments that are inclusive of cognitive-behavioural therapies, behaviour modification, counselling and supportive psychotherapy, and psychoanalysis. Although these interventions are used for a variety of diseases and illnesses, research indicates that there is a slight difference in psychosocial interventions for cancer. Pommeret *et al.* (2019:3) stated that psychosocial interventions related to cancer and paediatric cancer includes, counselling, education, coping and psychological support, and more specific forms of psychotherapy in their different formats (group, individual, and family therapy) and orientation (cognitive-behavioural, supportive-expressive, existential, and psychodynamic). Psychosocial interventions are neither non-harmful nor

invasive and can be used by both paediatric patients and their families (Harper *et al.* 2019:515). Several types of psychosocial interventions will now be discussed:

### 2.16.1 Educational support interventions

Educational support interventions are strategies that increase the capacity for care at home and significantly reduce readmissions to emergency services, for cancer patients post-surgery. It facilitates understanding about the causes of various types of cancer, management of symptoms, prognosis, and related problems and helps the cancer patient cope emotionally, thereby decreasing their stress and enabling self-care (Maddocks *et al.* 2016:298-305; Del Fabbro *et al.* 2017:272-277). They also educate the caregiver's family thereby improving the quality of family life after cancer treatment (Abuladze *et al.* 2022:489). The provisioning of adequate information regarding treatment, along with the side effects and self-care strategies, decreases treatment-related complications and psychosocial outcomes as well as understand and manage cancer-related fatigue (Abuladze *et al.* 2022:490).

### 2.16.2 Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy can be described as an approach that seeks to change and replace existing unwanted or distorted thoughts, feelings and behaviours with more positive and acceptable ones, that will alleviate the presenting one (Teater 2016:6). Its implementation involves assessment; intervention and evaluation (Safarabadi-Farahani *et al.* 2016:262). The first stage of assessment exploring with paediatric cancer patients and their families how their thoughts, feelings and behaviours are contributing to the

present problem in terms of frequency, intensity, and duration. The second stage focuses on cognitive restructuring (Metha *et al.* 2016:5); relaxation techniques (Khaleqi-Sohi *et al.* 2022:5); social skills training (Van Schoors *et al.* 2017:6); assertion training and problem-solving skills (Hendricks *et al.* 2019:4); systematic desensitization (Wiener *et al.* 2015:419) and reinforcement, modelling and role-plays (Ke Liu *et al.* 2022:3) to effect behavioral change. The final evaluation stage identifies changes that have occurred in thought processes, feelings and behaviours and the extent to which the presenting problem has reduced after the intervention.

### 2.16.3 Counselling

Counselling refers to the specialized support and guidance provided to children, adolescents, and their families who are facing a cancer diagnosis and undergoing treatment (Maurice-Stam *et al.* 2022: 6839; Huang *et al.* 2022:1-8). It encompasses a broad range of approaches and techniques aimed at understanding and addressing various social and interpersonal challenges by providing support, guidance, and interventions to individuals or groups facing difficulties such as relationship conflicts, trauma or other social and psychological stressors (Levesque *et al.* 2022:103; Clasen *et al.* 2023:1946).

Breitbart *et al.* (2023:399) asserted that in the case of paediatric cancer, counselling serves the following purposes:

**1. Emotional support:** counsellors provide a safe and compassionate space for children and their families to express their fears, worries, and emotions associated with the diagnosis, treatment, and potential long-term effects of cancer. They help normalize these feelings, validate concerns, and offer strategies for coping and emotional well-being.

**2. Information and education:** counsellors play a crucial role in providing age-appropriate information about the cancer diagnosis, treatment options, and

potential side effects. They help clarify medical jargon, answer questions, and address misconceptions, ensuring that families have a comprehensive understanding of the situation.

**3. Coping strategies:** paediatric cancer, brings with it significant lifestyle changes and can be physically and emotionally challenging. Counsellors help children and their families develop effective coping strategies to manage the emotional and practical impact of cancer. This may involve teaching relaxation techniques, problem-solving skills, and providing guidance on how to communicate with healthcare professionals and peers.

**4. Family dynamics and support:** paediatric cancer affects the entire family. Counsellors work with parents, siblings, and extended family members to navigate the complex dynamics that arise during diagnosis, treatment, and survivorship. They provide guidance on maintaining open communication, managing stress, and supporting each other through the challenges.

**5. Transition to survivorship:** paediatric cancer treatment is often a long-term process, and survivors may face physical, emotional, and social challenges, even after treatment ends. Counsellors assist in the transition to survivorship by addressing fears, discussing potential long-term effects, and helping survivors and their families adjust to a new normal.

#### 2.16.3.1 Benefits of counselling

Counselling offers numerous benefits for childhood cancer patients and their families (Boyle *et al.* 2016:1; Cash *et al.* 2022:1; Van Heerden *et al.* 2021:6), as it provides specialized support that focuses on the unique emotional, psychological, and social needs of patients and families (Zhang 2016:1). Several authors, such as Wong (2022:1); Yadav (2019:679); Lee (2020:46); Gao and Yang (2023:1492), have described the benefits of counselling, many of which have already been elucidated in the preceding sub-sections. Over and

above providing emotional support, it can empower children and parents about cancer, treatment options, and potential side effects. It helps individuals understand the medical aspects of their condition, enabling them to actively participate in decision-making regarding their care. It can address concerns related to survivorship, latent effects of treatment, and adjustment to a "new normal" after cancer.

By providing support, guidance, and strategies for managing potential challenges, counselling helps individuals and families adapt and thrive in their post-cancer lives. Moreover, counselling often includes opportunities for children and families to connect with others who are going through similar experiences. Support groups or group counselling sessions provide a platform for sharing experiences, exchanging advice, and building a network of support. Childhood cancer also places significant demands on parents and caregivers. Counselling can provide parents with a space to express their own emotions, concerns, and needs, by offering guidance on self-care strategies, stress management, and where to seek support. Counselling can help parents address their well-being needs, while caring for their child.

### 2.16.4 Therapeutic exercise

Therapeutic exercise which involves repeated, regular activity in different modalities can increase a person's resistance to illness and length of recovery after illness (Filbin *et al.* 2019:367). Lima *et al.* (2018:201) said that, amongst childhood cancer patients, it can reduce treatment-related fatigue, support heart and lung fitness, physical ability, and strength, reduce feelings of anxiety and depression, improve quality of life after surgery and decrease the amount of recovery time needed in the hospital.

### 2.16.5 Group support

Medhi, Varkki, Devapriya, and Muzhumathi (2023:2) stated that group support in the context of childhood cancer, refers to the emotional, informational, and practical assistance provided to children with cancer and their families through organized support groups. These groups create a supportive community where members can share experiences, express emotions, and exchange valuable information. It creates the opportunity for parents and children to support each other and share coping strategies, and empathy (Joaquim *et al.* 2024:133). This collaborative environment establishes a sense of belonging and reduces feelings of isolation within families (Badaghi-Moreno 2024:1).

Scarponi *et al.* (2023:3496) further argued that group support provides a safe space for parents to share their emotional burdens and fears related to their child's cancer diagnosis and treatment and find solace in connecting with peers, who understand the unique challenges they face (Krajc *et al.* 2023: 1685). Srinivasan *et al.* (2015:68) added that it validates their emotions, allowing families to find comfort through the shared normalization of their emotions. Shared experiences create an environment where it is acceptable to express fear (Sasi *et al.* 2022:1671), sadness or frustration, reducing feelings of isolation (Rossetti and Loewy 2021:675) and promoting emotional healing (Esbenshade 2023:3629; Effinger *et al.* 2023:1139; Bouchard *et al.* 2022:408).

For paediatric cancer patients, interacting with peers who share similar experiences can be transformative, by allowing children to build connections outside the hospital setting, fostering friendships that provide understanding and companionship during a challenging time (Bangura *et al.* 2020:1; Afungchwi *et al.* 2022: 296). Moreover parents can share insights about treatment options, coping strategies, and resources, enhancing their ability to cope with the complexities of the medical landscape and through sharing their

knowledge so that they can become better advocates for their children (Gomes *et al.* 2023:1603; Koohkan *et al.* 2019:246; Akinyemi *et al.* 2019:1).

Empowering parents with appropriate information, can help them actively participate in treatment decisions, ensuring that the child receives the best possible care and support. Group support sessions often incorporate coping strategies and resilience-building activities enabling families to learn practical skills to manage stress, uncertainty, and the impact of cancer on daily life. It allows for the joint celebration of milestones, as parents can celebrate small victories during the cancer journey. Recognizing and commemorating these achievements can strengthen a more positive outlook and reinforces the resilience of both children and their families (Torode *et al.* 2023:220).

### 2.16.6 Bibliotherapy

Bibliotherapy is a therapeutic approach that involves reading literature, such as books, poetry, or other written material, as a means of working through emotional issues (Malibiran 2018:2). Janavičienė *et al.* (2023:19) stated that the idea of reading specific texts, is it can provide individuals with insights, comfort, and a better understanding of their own challenges or emotions. Bibliotherapy can take various forms, including self-help books, fiction, non-fiction, or poetry (Huang *et al.* 2023:685). Therapists may recommend books based on the individual's needs and concerns (Roghani *et al.* 2024:138). This process further enables individuals to identify with characters, situations, or themes in the literature, leading to self-reflection and potential emotional healing (Bálint and Magyari 2020:28).

The work of Janavičienė (2023:19-26), "*Bibliotherapy for Cancer Patients and Their Families*", suggests that bibliotherapy is a poignant and supportive tool, offering solace and developing emotional well-being for both children facing

cancer and their families. Janavičienė (2023:19-26) stated that it assists with the following:

**1. Coping with uncertainty:** bibliotherapy becomes a beacon of reassurance, offering literature that addresses the fears, anxieties, and coping mechanisms specific to the paediatric cancer journey. Books tailored to children and their parents provide a platform for shared understanding, helping them navigate the unknown together.

**2. Fostering communication:** bibliotherapy facilitates open communication within families affected by childhood cancer. Specially curated literature can serve as a conversation starter, allowing parents and children to discuss their emotions, fears, and hopes. The shared experience of reading and discussing relevant stories creates a supportive environment, promoting familial bonds and reducing feelings of isolation.

**3. Emotional expression and catharsis:** bibliotherapy offers a means of emotional expression and catharsis, as through literature, children can find characters who share their struggles, providing a sense of solidarity. Likewise, parents can identify with narratives that mirror their own experiences, fostering a safe space for emotional release and understanding.

**4. Empowering patients and families:** bibliotherapy empowers childhood cancer patients by providing resources for coping and resilience. Books designed for young readers often incorporate narratives of bravery, resilience, and hope, instilling a sense of empowerment in children facing cancer. Likewise, literature for parents may offer guidance on navigating the challenges of caregiving and emotional support.

**5. Integration into supportive care:** in the realm of childhood cancer treatment, bibliotherapy seamlessly integrates itself with other supportive strategies. Healthcare professionals can therefore recommend and incorporate literature into therapeutic interventions, offering families, an additional tool to enhance emotional well-being. Support groups and counselling sessions can leverage bibliotherapy to foster a sense of community among families experiencing similar challenges.

The sub-section that follows, focuses on spirituality and spiritual interventions within the context of paediatric cancer. Spirituality is defined, spiritual well-being and spiritual distress is explored and aspects related to a spiritual assessment are discussed. Spirituality in childhood cancer and the types of spiritual interventions used, are then presented.

## 2.17 Spirituality and spiritual interventions

### 2.17.1 Definition of spirituality

Spirituality has been defined as a broad construct, inclusive of religious and non-religious forms of spiritual expression (Puchalski *et al.* 2014:642; Blaber *et al.* 2015:430). Buck (2006:288) described spirituality as "the most human of experiences that looks to transcend self and find meaning and purpose through connection with others, nature, and/or a Supreme Being, which may or may not involve religious structures or traditions". Other scholars have described spirituality as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred (Teater 2016:423; Shorofi *et al.* 2016:10; Toledano-Toledano and Domínguez-Guedea 2019:1). Through the practice of their

spirituality, children seek God and/or a Higher Power by praying for or requesting that they feel better, be out of the hospital, and for family and friends to be cared for (Peikert *et al.* 2018:21; Puchalski *et al.* 2019:1-6).

### 2.17.2 Spiritual assessment

A spiritual assessment which is a detailed process of assessing the spiritual needs and resources of patients helps to understand the patient's needs concerns and resources. The 7×7 model for spiritual assessment which was constructed by a team of chaplains and nursing faculty (Fitchett and Handzo 1998:790-808), utilises a multidimensional view of spirituality, that includes the spiritual beliefs, behaviour, emotions, relationships, and practices of patients. It is reflected in Table 3 below.

**Table 3: The 7x7 Model for Spiritual Assessment (Fitchett and Handzo 1998:790-808)**

| **Holistic assessment** | **Spiritual Assessment** |
|---|---|
| Medical (biological) Dimension | Beliefs and meaning |
| Psychological Dimension | Vocation and obligations |
| Family Systems Dimension | Experience and emotions |
| Psycho-Social Dimension | Courage and growth |
| Ethnic, Racial, Cultural Dimension | Rituals and practice |
| Social Issues Dimension | Community |
| Spiritual Dimension | Authority and g guidance |

According to Ross and McSherry (2020:97) a holistic assessment focuses on the following six dimensions of a person's life as follows:

- **Medical dimension**: what significant medical problems has the person had in the past? what problems do they have now? and what treatment is the person receiving?
- **Psychological dimension**: are there any significant psychological problems? Are they being treated? if so, how?
- **Family systems dimension**: are there any at present, or have there been any in the past, patterns within the person's relationships with other family members which have contributed to or perpetuated present problems?
- **Psycho-social dimension**: what is the history of the person's life, including, place of birth and childhood home, family of origin, education, work history and other important activities and relationships?
- **Ethnic, racial or cultural dimension**: what is the person's racial, ethnic or
  cultural background? and how does it contribute to the person's way of addressing any current concerns?
- **Social issues dimension:** are the present problems of the person created by or compounded by larger social problems?

Ross and McSherry (2020:97) argued that a spiritual assessment focuses on the following seven dimensions of a person's spiritual life:

- **Belief and meaning:** what beliefs does the person have, which gives meaning and purpose to their life? what major symbols reflect or express meaning for this person?; what is the person's story?; do any

current problems have a specific meaning or alter established meaning?; does the person presently or in the past been affiliated with a formal system of belief (e.g., church)?

- **Vocation and obligations**: does the persons' beliefs and sense of meaning in life, create a sense of duty, vocation, calling or moral obligation?; will any current problems cause conflict or compromise in their perception of their ability to fulfil these duties?; are any current problems viewed as a sacrifice or atonement or otherwise essential to this person's sense of duty?

- **Experience and emotion:** what direct contacts with the sacred, divine, or demonic

has the person had?; what emotions or moods are predominantly associated with these contacts and with the person's beliefs, meaning in life and associated sense of vocation?

- **Courage and growth**: can the meaning of new experiences, including any current problems, be fitted into existing beliefs and symbols?; can the person release existing beliefs and symbols in order to allow new ones to emerge?

- **Rituals and practice**: what are the rituals and practices associated with the person's beliefs and meaning in life? will current problems, if any, cause a change in the rituals or practices they feel they require or in their ability to perform or participate in those which are important to them?

- **Community**: is the person part of one or more, formal or informal, communities of

shared belief, meaning in life, ritual, or practice?; what is the style of the person's participation in these communities?

- **Authority and guidance**: where does the person find the authority for their beliefs, meaning in life, for their vocation, their rituals, and practices?; when faced with doubt, confusion, tragedy, or conflict where do they look for guidance? and to what extent does the person look within or without for guidance?

### 2.17.3 Spirituality in childhood cancer

From the moment of diagnosis, through the many treatment modalities, until remission or death, a parent becomes consumed with his or her child's illness, treatment, and the quest to find a cure (Gomes *et al.* 2022:1603). Borrescio-Higa and Valdés 2022:599), described this as a tragic experience for all. Haase (2004:289) argued that spirituality creates hope during the cancer experience. A study conducted amongst parents of children with cancer, supported the importance of spirituality within the context of illness and recovery (Villani *et al.* 2023:203). Whilst most parents find it difficult to have faith, when their child's health state worsens, it still acts as a source of comfort (Kruseova *et al.* 2023:1-8).

Spirituality does not attempt to postpone death; but rather focuses on the psychological and spiritual aspects of care and offers support (Rees *et al.* 2023:150), to relieve their emotional and spiritual distress (Liu *et al.* 2023:101; Hegazy *et al.* 2023:149). It may further guide complex decision making, to enhance the quality of life. Sari *et al.* (2023:301) stated that hope serves as a protective factor, in enhancing resilience and the quality of life amongst paediatric cancer patients, based on the belief that a positive future can emerge for themselves and others.

Consciously or unconsciously, children participate in a spiritual life. Research has indicated that children who nurture their spirituality and have spiritual care have greater positive coping strategies and are more resilient which serves as

a protection factor (Moola *et al.* 2023:3). The practice of spirituality in childhood cancer care not only involves the patient, but also the family of the paediatric patient (Ebelhar *et al.* 2023:300). Plant and Adams's (2023:309) study found that spirituality was a salient coping strategy for caregivers of children with leukaemia. Their study assessed the level of stress of twenty caregivers, and found that spirituality, along with "problem solving" serves to relieve the suffering emerging from a cancer diagnosis. It was found to help caregivers derive strength to deal with the situation and continue their caregiving function. Other studies have documented similar findings supporting the notion that spirituality can help paediatric patients and parents, adapt to stress within the context of a diagnosis of cancer (Filbin and Monje 2019:367; Ward *et al.* 2019:972; Marchak *et al.* 2022:184; van Deuren *et al.* 2022:1110).

Jensen *et al.* (2023:43) stated that there are practical strategies that the health care team can use as part of a spiritually based approach, within the context of paediatric cancer. They are as follows:

1. Support the ill child and their family by using established spiritual coping strategies.
2. Affirm hope through kindness and a purposeful, active presence.
3. Try to create an atmosphere conducive to social and spiritual interactions, that can evolve, over time, into relationships with supportive meaning.
4. Assess children's spiritual needs. When the assessment process itself is done with sensitivity, interest, and receptiveness, a line of communication between the health care practitioner and the child and his or her family opens.
5. School-aged children may be more self-directed in their spiritual practices. Nurses should ask if they use prayer, plan times for spiritual expression, and provide quiet time wherever appropriate.

6. Children should be allowed opportunities for expression of spirituality through art, music, or stories.
7. Establish with the paediatric patient a relationship that allows him/her to express what is meaningful to them.

The following sub-section focuses on spiritual interventions.

## 2.17.4 Spiritual interventions

### 2.17.4.1 Prayer

Prayer is a universal religious practice (Alogna 2017:12), that is embraced by families across different social classes. It can uplift children and their families by connecting them to a Higher Power. Studies have found prayer is crucial for individuals, to seek help from the Gods and Goddesses, and ancestors across different religious and spiritual worldviews, during times of distress and to commune with the Higher Power (Limao *et al.* (2016:1-2). Although it can be done personally it can also be undertaken in the home milieu, with family or communally at religious organizations and in medical and health settings (Lister *et al.* 2020:1-2). It may be spoken out or silently recited or sung aloud (Spilka and Ladd 2012:12).

Carey *et al.* (2023:1467) opined that prayer can help children with cancer cope with the psychological, emotional, and physical challenges of their illness, whilst Afungchwi (2022:296) stated that spiritual practices, including prayer, provide a sense of hope, comfort, and meaning, offering emotional stability during difficult times. Marfo *et al.* (2024:84) said that spirituality is not limited

to religious practices but encompasses a broader search for meaning, purpose, and connection with a Higher Power or the universe. These elements have been shown to enhance the coping mechanisms of paediatric patients battling cancer.

Some studies have revealed that engaging in prayer can reduce stress by promoting relaxation and emotional calmness (Beyranvand *et al.* 2024:74-82; Nagy *et al.* 2024:2349; Miquel *et al.* 2024:43). According to research by Cotton *et al.* (2023:134), children who actively participate in prayer or spiritual activities, exhibit lower levels of anxiety and depression compared to their peers who do not engage in such practices. This is because prayer fosters a sense of surrender, alleviating the burden of uncertainty by placing trust in a Higher Power.

A study by Smith and Johnson (2022:345-360) found that paediatric cancer patients who perceived their illness as part of a divine plan, were more likely to adapt to their treatment with ease and comply with medical regimens so that the recovery trajectory was improved. Research by Benson *et al.* (2023:215-229) found that prayer stimulated the parasympathetic nervous system (a network of nerves that helps the body relax and perform basic functions), leading to a reduction in heart rate and cortisol levels. This reduction in stress, can positively influence the child's body to heal and respond to cancer treatments. Furthermore Gonzalez *et al.* (2022:45-59) argued that prayer serves as powerful coping mechanism for children with cancer, offering them emotional relief, and promoting their physiological well-being. Engaging in prayer also helps parents and sub-units within the family structure cope and manage with any form of adversity that they are experiencing because of their child's cancer, thereby reducing stress (Alogna 2017:13). Prayer also helps individuals to self-reflect which can promote better mental well-being and good health (Banerjee *et al.* 2014:1776-1781; Kvande *et al.* 2015:2). Elliott and

Hayward (2007:110-111) argued that individual prayer provides paediatric cancer patients and their families with a sense of belonging and brings immeasurable well-being, whilst Alogna (2017:13-18) stated that prayer can be beneficial in manging chronic pain because of treatment, which includes adaptive coping and pain tolerance.

Moreover, Farrag *et al.* (2024:31) shared that prayer instils hope, helping parents feel more positive through the life altering experience of cancer within their family. It can also reduce anxiety amongst childhood cancer patients who are undergoing medical treatment and enhance their spiritual well-being (Superdock *et al.* 2024:e837). A study, by Chelladurai *et al.* (2018:849) which examined the role of family prayer and various relational processes, found that families who participated in regular prayer together either at the hospital or in their life space, saw this time and space, as an opportunity for family bonding and interaction, an opportunity for social support, and intergenerational transmission of religion and values.

For parents, prayer strengthened their coping, as Islam *et al.* (2017:27) found that 65% of the parents in their sample, coped with the financial and emotional burden of childhood cancer, through engaging in several types of spiritual activity, including regular prayer. Research has further documented that families that pray together daily, make better decisions regarding the type of treatment their ill child should have and how parents are going to fund the treatment of their children (Chelladurai *et al.* 2018:849). Some parents discussed the inherent power and importance of prayer as an act in and of itself. For those individuals who identified themselves as being spiritual, prayer was believed to be a powerful tool that helped them to cope and enabled their child's ability to heal. Others described the effects of prayer, in terms of its ability to have a direct, impact on their health. It was clear that most parents

were willing to pray to God and believed that this practice could support their child who was ill (Wawrzynski *et al.* 2022:2-4).

### 2.17.4.2 Mindfulness meditation

Meditation involves training the mind to focus and redirect one's thoughts, leading to a state of heightened awareness and inner calm (Hehr *et al.* 2022:299). It includes engaging in a series of mental exercises or techniques to cultivate specific qualities of attention, awareness, and mindfulness (Moreira *et al.* 2022:55). It also includes stillness and silence, and can also be practiced through movement, such as walking meditation or mindful movement practices like yoga or tai chi (Henneghan *et al.* 2022:657).

Mindfulness meditation has emerged as a valuable complementary therapy for children undergoing cancer treatment, offering significant psychological benefits (Majumdar *et al.* 2024:100). Research has found that there are many benefits to meditation, including reduced stress and anxiety (Thakur *et al.* 2023:1158), improved focus and attention (Carr *et al.* 2023:1) enhanced emotional well-being, increased self-awareness, and improved overall mental health (Pommy *et al.* 2023:26). Furthermore, there is a decrease in depression associated with their diagnosis and treatment (Ben-Arye *et al.* 2024:1-22). The diagnosis of cancer and its treatment-related toxicity can cause severe emotional distress for patients and their families. Mindfulness can assist cancer patients, and their families cope with cancer-related pain, fatigue, cachexia, sleep disorders, during radiation therapy and boost their immune response (Metha *et al.* 2019:9-10). Ngamkham *et al.* (2019:161-169) concurred saying that beyond the emotional regulation, mindfulness meditation, alleviates physical symptoms related to cancer and its treatment. Techniques such as deep breathing, guided imagery, and progressive muscle

relaxation have been shown to reduce pain perception, nausea, and fatigue. These practices promote relaxation and a sense of control over one's body, which is particularly beneficial for children facing the uncertainties of cancer treatment (Cillessen *et al.* 2019:2257).

#### 2.17.4.3 Music

Music therapy has been an integral part of childhood cancer care since 1973 (Rossetti *et al.* 2021:675). It has been identified as a complementary approach to conventional medical therapy in cancer care (Landier *et al.* 2010:556). Non-pharmacological interventions for managing symptoms are preferred by children undergoing cancer treatment due to them having minimal side effects. Music therapy is one such low-risk intervention, that has increasingly been supported due to its benefits in addressing symptoms such as anxiety, low mood, and pain (Tuinmann 2017:377).

According to Baker (2016:25) it has the potential to activate emotions, images, memories, and associations, bypassing psychological blocks, that someone maybe experiencing. Hence the imagery evoked by music, can offer an emotionally safe space and respite from the harsh effects of cancer and treatment protocols (Bradt 2015:1261). The aesthetic elements of music can also offer comfort and peace when paediatric patients are distressed (Bradt 2015:1263). Music interventions can therefore provide the opportunity for making independent choices, connections, and enable physical, emotional, and social expressions (O'Callaghan *et al.* 2016:399; Aasgaard 2014:154; Wang 2021:5). Music therapy involves music listening and/or music-making experiences within a therapeutic relationship, between the music therapist and patient (O'Callaghan *et al.* 2016:398). Therapists who use music are professionally trained to clinically assess a child's prior traumas, medical

history, and existing wellness and coping strategies, in order to design and implement a personalized treatment plan to support the child through their cancer journey (Rossetti *et al.* 2021:676).

Studies with children undergoing high-dose chemotherapy with autologous stem cell transplantation have discovered that those who received music therapy, experience significantly fewer disturbances in their mood, have improved pain perception scores, and experience overall positive effects related to their depression and anxiety (Tuinmann 2017:378). Music experiences have been shown to provide strong ties with reward and learning, attention, memory, and emotions which in turn allows the therapist to naturally cater to the child's psychosocial needs (Tuinmann 2017:378; Altenmüller 2015:235).

Research has shown that the activation of dopaminergic neurons through music experiences demonstrates, how music can be used as a coping tool to help relieve feelings of depression and anxiety (Tamplin *et al.* 2016:111; Wang *et al.* 2021:5). There is scientific evidence that endorphins are released through music experiences and are consequently effective in masking pain and positively influencing other related symptoms (González-Martín-Moreno *et al.* 2021:73). Music therapy is therefore an important therapeutic intervention that is deserving of consideration, within a therapeutic plan for children undergoing cancer treatment.

#### 2.17.4.4 Yoga

Yoga is a holistic practice that includes an array of physical, mental, and spiritual practices aimed at promoting overall well-being, self-awareness, and inner harmony (Jindani and Khalsa 2015:394). At its core, it integrates physical

postures (asanas), breathing exercises (pranayama), meditation, and ethical principles into a multifaceted therapeutic system (Silveira and Smart 2020:1389-1340). It extends beyond mere physical movement (Meisser *et al.* 2016:1), by underscoring the importance of integrating breath, mindfulness, and intention (Wolff *et al.* 2017:360).

Stritter *et al.* (2021:1) opined that yoga has gained recognition as a beneficial complementary therapy for children, undergoing cancer treatment, as it addresses the physical and psychological challenges, associated with the disease and its treatment. Yoga can help improve physical flexibility, strength, and balance, which may be compromised due to prolonged hospital stays and the side effects of chemotherapy and radiation (Diorio *et al.* 2015:1-6). A study by Wurz *et al.* (2014:1828-1834) evaluated a 12-week yoga intervention program for paediatric cancer patients and found significant improvements in flexibility and functional mobility amongst this cohort. This suggests that yoga can play a role in physical rehabilitation during and after cancer treatment.

Xavier *et al.* (2020:1-10) further elucidated, the benefits at a psychological level, saying yoga offers strategies for stress reduction and emotional regulation, which are crucial for young patients, who have to cope with the emotional distress of a cancer diagnosis. Techniques such as controlled breathing, meditation, and mindful movement can help reduce their anxiety and promote a sense of calm. Hooke *et al.* (2016:64-73) conducted a study on the effects of a yoga program for children and adolescents, who had completed their cancer treatment and found a significant decrease in anxiety scores, post-intervention which supported the potential of yoga, to improve psychological well-being. Danhauer *et al.* (2017:1357) further reported that yoga has been associated with improvements in sleep quality and reductions in fatigue, which are common issues amongst paediatric cancer patients. Fukuhara *et al.* (2020: 278-283) added that yoga interventions have been found to improve sleep patterns and decrease fatigue levels, thereby contributing to an overall improvement in the quality of life. These findings suggest that yoga can support paediatric oncology care, as it addresses both

the physical and emotional needs of young patients. In the section that follows, the researcher focuses on the benefits of psychosocial and spiritual interventions.

## 2.18 Benefits of psychosocial and spiritual interventions

Psychosocial and spiritual interventions have been found to show great promise in providing therapeutic benefits for paediatric patients and their families. They are therefore discussed jointly in the discussion that follows. Both can be regarded as holistic interventions, that have been found to enable emotional adaption to the disease, coping and to manage the anxiety and depression that paediatric patients and their families experience, during the cancer journey (Hopkinsons 2021:456). These interventions have been found to decrease negative emotions (Li *et al.* 2020:8), improve the emotional burden being experienced and diminish any disruptions to lifestyles, by enhancing the well-being and quality of life (Safarabadi-Farahani 2016:263). Research has suggested that they can improve the physical health of paediatric patients in particular (Chang *et al.* 2021:5), by supporting neuroendocrine functions and immunity, manage their pain and stress and promote coping strategies for the child and their family (Li *et al.* 2020:8). In addition, it promotes moral qualities and beliefs of “gratitude, forgiveness, and humility,” amongst children and families, which can be described as transcendental virtues that facilitate a key role in enhancing mental health and well-being (Kao *et al.* 2020:46). The therapeutic role of these holistic interventions therefore provides a safety net, that not only enhances hope, but promotes physical health (Coyle 2002:594; Mishra *et al.* 2017:1286), self-esteem and emotional growth whilst providing a support system that enhances the overall quality of life and well-being amongst paediatric cancer patients and their families (Koenig 2013:279-281; Sohi *et al.* 2018:2067). This

suggests the importance of integrating psycho-social and spiritual interventions into treatment plans for paediatric cancer patients.

## 2.19 Conclusion

This chapter presented a review of contemporary scholarly literature at the interface of childhood cancer. It focussed on key aspects of literature related to the objectives that guided the study, by exploring the effects of paediatric cancer on children and their families, and the salience and benefits of various psychosocial and spiritual interventions that can be used to enable coping and healing. It also explored the roles of various health and social service professionals, in terms of their care and support of paediatric patients and their families. The chapter that follows, focuses on the research methodology that guided the study.

# CHAPTER 3

# RESEARCH METHODOLOGY

## 3.1. Introduction

Pandey and Pandey (2015:7) described research as “a systematic inquiry to describe, explain, predict, and control the observed phenomenon”. They added that research constitutes an application of significant scientific methods and procedures, that can be used to find solutions to problems using a process that is systematic, formal, and intensive. Patel and Patel (2019:48) further asserted that research methodology reflects the systematic theoretical analysis of the research methods, used within a given field of study. It comprises of the theoretical analysis of a body of methods and principles associated with a branch of knowledge. Research therefore creates opportunities for the researcher to: a) become acquainted with a phenomenon or achieve new awareness; b) accurately portray the characteristics of a particular individual, situation or a group; c) determine the frequency with which something occurs or with which it is associated with something else and d) test a hypothesis of a causal relationship between variables (Patel and Patel 2019: 48-49).

This chapter will detail the research methodology used to guide the study. A discussion on qualitative research, which was the selected research paradigm, will be presented in this chapter. The samples that were selected and the sampling strategy used is also discussed. This chapter also contains an in-depth discussion of the data collection process, and the method used to collect data, namely semi-structured interviews. In addition to the process of data capturing, the analysis is also presented. The ethical considerations in this study, are also explained.

Below the researcher introduces the research paradigm used for guiding the study.

## 3.2. Research paradigm

The qualitative research paradigm was adopted as the guiding research paradigm of this study. According to Anas and Ishaq (2022:90) research is guided by two primary paradigms namely, the qualitative and quantitative research paradigms. Each adopts its own set of standards and methods to conduct research, to accomplish the same goal, although a difference exists with regards to the technique and procedures amongst the two paradigms (Daniel 2019:93). This includes the types of questions asked, the forms of data produced and the foundation of flexibility within the study design (Pandey and Pandey 2015:2). Qualitative research adheres to an inquiry, that focuses on a humanistic or idealistic approach. Conversely quantitative research is an approach, that is predicated on numerical and methods, that can be formulated objectively. Qualitative research produces rich in-depth data, which can answer 'how', 'why', and 'what' questions (Denny and Wecksser 2022:1799; Pyo *et al.* 2023:12).

Qualitative research can therefore be defined as a "systematic scientific method of inquiry, which seeks to build a holistic and a largely narrative description, to inform the researcher's understanding of a social or cultural phenomenon" (Anas and Ishaq 2022:90). Anas and Ishaq (2022:90) further stated that qualitative research is used when the intent is to understand people's experiences, attitudes, behaviours, and interactions. Aspers and Corte (2019:142) asserted that qualitative research is multi-method in focus, involving an interpretive and naturalistic approach as part of its inquiry. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret a phenomenon in terms of the meanings people bring to them.

Qualitative research strives to understand human phenomena by "exploring and interpreting" their meaning from the perspectives of those who went through certain experiences. It is a naturalistic approach that intends to experience the emotions, feelings, experience and behaviours of individuals

and groups of participants in their natural surroundings and tries to interpret the meanings they attribute to them (Cuoco *et al.* 2022:874). According to Denny and Weckesser (2020:1799), qualitative research allows for the exploration of populations, that share similar traits or attributes or experiences of a specific health complication or health phenomena.

Qualitative research involves a study, that embraces an array of empirical methods, such as case studies, personal experience, introspection, life story, interviews, observational, historical, interactional, and visual texts that describe routine and problematic moments and meanings in individual's lives. Qualitative research is therefore used primarily in human and social contexts (family medicine), because it helps to understand individuals and people's beliefs, experiences, attitudes, behaviours, and interactions (Anas and Ishaq 2019:90; Tong and Tan 2022:3).

A naturalistic approach to research has been described as an umbrella, because it embraces a vast range of approaches and methods, that differ according to the area of focus, prior knowledge, and the role of the researcher, through the practice and use of data collection methods, specific to a study. It allows the researcher to explore and describe the findings of the study and explains how and why people behave, the way they do (Yadav 2022:679). Moreover, it provides an understanding of the human and social sciences, as it explores how people think and understand. Additionally, it is holistic in nature, particularly because it focusses on a diverse group and the complexity of the problem (Thunberg *et al.* 2022:757).

The researcher selected this form of inquiry, because it is widely supported in social science studies, which is the focus of the current study. Qualitative research therefore is appropriate in terms of understanding different facets of the human experience, and in understanding family care and healthcare. It also allowed the researcher to understand what paediatric cancer patients and their families experience within the medical setting, which allowed the researcher to explore the holistic effect of paediatric cancer on patients and their families and

to construct a deeper meaning of these experiences. In addition, qualitative research allows the researcher to broaden their knowledge of a particular problem and improve patient and family experiences and outcomes in a medical setting. As a result, qualitative research was salient in guiding the researcher's understanding of the 'social world,' from the perspective of paediatric cancer patients and families experiencing certain social phenomenon.

The collective case study approach is discussed in the subsections that follow. The researcher also introduces the case.

## 3.3 Collective case study approach

### 3.3.1 Collective case study

According to Heale (2018:7) a case study is a type of methodology, typically seen in the social and life sciences. Whilst no singular definition of case study research exists, Heale (2018:7) defined it, as an intensive study of a person, a group of people or a unit, that can be generalized over several units. Twycross (2018:7) similarly wrote that a case study is an intensive, systematic investigation of a single individual, group, community or some other unit, in which the researcher explores data intensively, in relation to several variables. Researchers like Yin (2016:10), further stated that case studies examine complex phenomena in their natural setting, to deepen a researcher's understanding of them. Using a case study approach, then permits researchers to take a complex and broad topic, or phenomenon, and reduce it into manageable research question(s) (Heale and Twycross 2018:8).

Qualitative case study methodology therefore provides tools for researchers to study complex phenomena within their contexts. When the approach is applied correctly, it becomes a valuable method for health science research, to develop theory, evaluate programs, and develop interventions (Baxter *et al.* 2008:543). Yin (2003:46) emphasized that a case study design should be

considered when, (a) the focus of the study is to answer “how” and “why” questions; (b) you cannot manipulate the behaviour of those involved in the study; (c) you want to cover contextual conditions because you believe they are relevant to the phenomenon under study; or (d) the boundaries are not clear between the phenomenon and context. Case study research extends beyond conducting research on a single individual or situation, as this method has the potential to deal with simple though complex situations. It enables the researcher to answer “how” and “why” type questions, while taking into consideration, how a phenomenon is influenced by the context within which it is situated (Baxter *et al.* 2008:556).

The National Institute for Health and Care research (2024:73), stated that a collective case study/studies are those in which multiple cases are studied, either simultaneously or sequentially, to illuminate contextual issues related to a phenomenon. Additionally, in a collective (multiple) case study, the researcher selects multiple cases to illustrate one issue or concern (Creswell and Poth 2018:216). The goal of a multiple case study is to compare cases to identify common patterns, relationships, or similarities. In a multiple case study, whilst the cases may be similar in nature, or they may be diverse, the researcher still searches to discover patterns or relationships across cases (Yin 2018:10). This method is often used when the phenomenon being studied, is rare or difficult to observe.

Collective case studies are a valuable qualitative research method, then that involves the simultaneous study of multiple cases to understand a broader phenomenon. This approach allows researchers to gather comprehensive insights, by comparing different aspects of the same phenomenon. The primary objective of a collective case study is however, to identify patterns and themes that emerge across multiple cases, providing a richer, more nuanced understanding, than what might be possible through a single case study alone. This method is particularly useful in complex social research fields, such as education, health, and organizational studies, where various factors and perspectives need to be considered.

One of the key strengths of collective case studies is their ability, to provide a more holistic view of the research subject. By examining multiple cases, researchers can identify commonalities and differences that can help to illuminate the underlying principles and dynamics at play. This comparative analysis enhances the validity and reliability of the findings, as it reduces the likelihood that the results are idiosyncratic to a single case (Zvobgo 2023:55; Maake-Malatji *et al.* 2023:26).

Another important aspect of collective case studies are their flexibility and adaptability. Researchers can choose cases that are most relevant to their research questions and objectives, ensuring that the selected cases are representative of the broader phenomenon being studied. This selective process helps to ensure that the findings are generalizable within the specific context of the research. Moreover, the iterative nature of data collection and analysis in collective case studies, allows researchers to refine their understanding as new data emerges, making this method particularly suitable for exploratory and descriptive studies (Maake-Malatji *et al.* 2023:27).

Collective case studies however, also present certain challenges. One of the main difficulties is the complexity of managing and analysing data from multiple cases. This requires a systematic approach to data collection, coding, and theme development to ensure that the findings are coherent and meaningful. Additionally, researchers must be mindful of the potential for bias in case selection and data interpretation, as these can influence the outcomes of a study. Despite these challenges, when executed rigorously, collective case studies can provide valuable insights, that can inform theory, practice, and policy in various fields, making them a powerful tool in qualitative research (Yin 2016:89).

### 3.3.2 An introduction to the case

The selected case for this study was the Inkosi Albert Luthuli Central Hospital, which is located within the Province of KwaZulu-Natal, eThekwini. Inkosi Albert Luthuli Central Hospital is a public/private partnership hospital. It is also a tertiary and quaternary hospital, and patients are referred there, by other hospitals via an electronic/telephonic booking system. There are nearby main roads that lead to the hospital, which are the N2 to the West and the M10 to the East of the Hospital. Inkosi Albert Luthuli Central Hospital (IALCH) is uniquely positioned as the ideal case study site, for research on childhood cancer and its impact on families because of its status, as a leading tertiary care facility in KwaZulu-Natal in this field (KwaZulu-Natal Department of Health 2024:1). The hospital offers specialized paediatric oncology services, making it the primary referral centre for complex cancer cases in the region. Its advanced medical infrastructure and multidisciplinary teams provide comprehensive care, that includes not only advanced medical treatments, but also psychosocial and spiritual support services. Therefore, it aligns with the study's focus on exploring the impact of childhood cancer on the children and their families, as well as the psychosocial and spiritual interventions that enable coping and healing for paediatric cancer patients and their families. The hospital's role as a centre of excellence in paediatric oncology is evidenced in the high volume of these cases. This was especially relevant to this study, as the participants selected would include a diverse range of parents emerging from various backgrounds and different health and social service professionals involved in paediatric cancer care. Hence it provided a diverse and robust dataset for the research (KwaZulu-Natal Department of Health 2024:1-2).

Geographically, Inkosi Albert Luthuli Central Hospital (IALCH) is centrally located in eThekwini, serving as a hub for patients from surrounding areas, including hospitals in both urban and rural settings. It draws patients from other regional hospitals that may lack the specialized oncology services available at

Inkosi Albert Luthuli Central Hospital (IALCH), such as Addington Hospital, King Edward VIII Hospital, and RK Khan Hospital and Greys hospital. This centrality ensures that Inkosi Albert Luthuli Central Hospital (IALCH) not only manages a diverse patient population, but also interfaces with a network of other healthcare facilities, thereby providing a comprehensive view of the regional healthcare landscape. Hence the researcher selected Inkosi Albert Luthuli Central Hospital (IALCH) as the study site, as it provided both the hospital's advanced capabilities and its strategic location within a broader healthcare network, offering insights into how different facilities contributed to the overall care and support of childhood cancer patients and their families.

In the subsection that follows, the research design is discussed, with a particular focus on exploratory research and the interpretive paradigm. The use of an interpretive approach within the current study is also explained.

## 3.4 Research design

Every scientific research study undertaken, is underpinned by a guiding methodological framework, which is accompanied by a research design that steers the study. According to Pawar (2020:46), a research design is used to collect the relevant data and to achieve the research objectives. Kumar (2011:5) wrote that "a research design is a procedural plan that is adopted by researchers to answer questions objectively, accurately, economically and with validity." Additionally, a traditional research design is a blueprint or detailed plan of how a research study is to be executed, it highlights the operating variables for measurement, selects a sample, collects data and analyses the results of interest to the study, and tests the hypotheses (Thyer 1990:1). In the most elementary sense, the design constitutes the most logical sequence connecting the empirical data, research questions and the conclusions reached (Yin 2002:10).

According to Singh (2020:3-4) a research design is: (i) a plan that specifies the sources and types of information relevant to the research problem; (ii) a strategy specifying which approach will be used for gathering and analysing the data; and (iii) includes the time and cost budgets, since most studies are done under these two constraints. In brief, Singh (2020:4) emphasized that a research design must, at least, contain (a) a clear statement of the research problem; (b) procedures and techniques to be used for gathering information; (c) the population to be studied; and (d) the methods being used in processing and analysing data. In this study, a case study design, guided by exploratory research designs and interpretivism is discussed.

### 3.4.1 Exploratory research and interpretive paradigm

In research there are several research designs namely descriptive designs, exploratory designs, experimental designs, longitudinal designs, cross-sectional designs, casual designs, action research designs, cohort research designs and case study designs. However, for this study the case study design, guided by exploratory research designs and interpretivism was deemed most appropriate. While the case study design, was the overarching design elements of exploratory research designs and interpretivism further guided the study.

Hunter, McCallum and Howes (2019:7) argued that exploratory research, is designed to illuminate how a phenomenon is manifested and is especially useful in uncovering the full nature of a little-understood phenomenon. Hunter *et al.* (2019:1-2) added that qualitative exploratory research, allows the researcher to explore a topic with limited coverage within the literature and allows the participants of the study, to contribute to the development of new knowledge in that specific area. Exploratory research in qualitative methodology plays a pivotal role in investigating complex and poorly understood phenomena. It is particularly beneficial when limited research exists on a topic, as it allows researchers to delve deeply into the subject

matter to uncover new insights and develop a comprehensive understanding of the phenomenon being studied. One of the primary roles of exploratory research, is to understand the context and complexities of a phenomenon. This type of research is invaluable in identifying the underlying reasons, motivations, and meanings behind certain behaviours or events, making it ideal for studying new or emerging areas of interest (Tracy 2019:25).

Unlike quantitative research, which primarily tests hypotheses, qualitative exploratory research often serves to generate hypotheses that can be tested in subsequent studies. It sets the foundation for future studies, by identifying relevant variables and constructs (Creswell and Poth 2018:10). Additionally, exploratory research is adept at identifying patterns and themes within data. By employing methods such as interviews, focus groups, and observations, researchers can uncover commonalities and differences within their data, which can lead to the development of theories or models, that explain the phenomena underpinning a study (Charmaz 2014:15).

Several authors have argued that exploratory research is a type of research conducted to clarify ambiguous problems or discover potential opportunities. It is characterized by many key features that distinguish them from other research methodologies, which will be highlighted below. The characteristics of exploratory research are as follows:

- **Flexibility**: exploratory research is highly flexible and adaptive. It does not follow a rigid structure, thereby allowing researchers to adjust their methods and focus as new insights and questions arise. This adaptability is crucial when exploring new or poorly understood areas (Stebbins 2001:2).
- **Open-ended inquiry**: this type of research is open-ended, thereby aiming to explore a wide range of possibilities, rather than test a specific hypothesis. Researchers embrace open-ended questions, to gather more detailed and nuanced information from participants (Creswell and Poth 2018:14).

- **Qualitative methods**: exploratory research frequently employs qualitative methods such as interviews, focus groups, and observations. These methods provide rich, descriptive data, that help uncover the meanings and motivations behind behaviours and phenomena as in the current study (Tracy 2019:26).
- **Generative**: exploratory research is often used to generate new ideas, hypotheses, and theories. It helps identify patterns and themes that can inform further research and guide the development of new research questions (Babbie 2020:26).
- **Initial understanding**: the goal of exploratory research is to gain an initial understanding of a phenomenon, context, or problem. It sets the groundwork for more structured research, providing insights that help define the scope and direction of subsequent studies (Marshall and Rossman 2016:45).
- **Small sample sizes**: exploratory research typically utilizes small, non-representative samples. The focus is on depth and detail rather than generalizability, making it ideal for uncovering the subtleties of complex issues (Yin 2016:31).
- **Iterative process**: the research process is often iterative, meaning that data collection and analysis occur simultaneously and inform each other. This approach allows researchers to refine their questions and methods, as the study progresses (Merriam and Tisdell 2015:98).
- **Focus on discovery**: the primary aim is discovery and understanding, rather than providing definitive answers or solutions. Exploratory research seeks to discover new insights and perspectives that can lead to a better comprehension of the research topic (Babbie 2020:26).

One of the significant benefits of exploratory research is the rich, detailed data it provides. Qualitative methods capture the nuances of human experiences and social processes, offering depth and detail, that are crucial for

understanding complex issues (Flick 2018:67). This approach is inherently flexible, allowing researchers to adapt their methods and focus as new insights emerge, which is especially valuable in dynamic or evolving fields (Blandford *et al.* 2016:1-115).

Exploratory research is also participant-centred, emphasizing the perspectives and experiences of those directly affected by the phenomena. This approach is essential for studies that focus on marginalized or under-researched groups, as it provides a pathway for their voices to be heard (Creswell and Poth 2018:11). By exploring uncharted areas, qualitative research can lead to innovative findings and discoveries, contributing to the development of new concepts and theoretical frameworks, that advance their field (Charmaz 2014:17).

In addition to theoretical contributions, the insights gained from exploratory research can inform policy decisions and practical interventions, particularly in fields such as healthcare, education, and social services. Understanding the intricacies of human behaviour and experiences, is vital for creating effective and empathic policies and practices (Tracy 2019:7). Overall, exploratory research within the context of qualitative methodology, is instrumental in understanding new or complex phenomena, providing rich, contextual data that inform.

Given the relevance of the exploratory descriptive design, to gather insights into the experiences of parents and children confronted with the challenges of paediatric cancer, this design was adopted to guide the current study. This enabled the researcher to gather detailed narratives and thread them together to form a comprehensive understanding of how childhood cancer affected both paediatric patients and their families. By using this design, the study was able to uncover the nuances of these experiences, providing a richer, more in-depth perspective that could inform future research and interventions.

### 3.4.2 Interpretive paradigm

Together with the exploratory design, an interpretive paradigm was used to guide this study to achieve a deeper understanding of the participants experiences. An interpretive paradigm was central to understanding the subjective world of human experience (Kivunja and Kuyini 2017:23). Paradigms are salient in the provision of beliefs and prescribes what should be studied about a phenomenon, how it should be studied and how the results needed to be interpreted (Kivunja and Kuyini 2017:24). Given (2008:465) indicated that interpretive research, is a framework and practice within social science research, that is invested in philosophical and methodological ways of understanding social reality. It is widely viewed as a practice (and a set of paradigms) embedded in different theoretical frameworks, ranging from ethnomethodology to critical feminist theory.

An interpretive approach is extremely beneficial to qualitative social science researchers because it focuses on understanding the meaning and experiences of participants in their social contexts. It is rooted in the belief that reality is constructed through social interactions and that understanding these constructions, requires a deeper engagement with the participants' perspectives. Essentially this approach encompasses a set of characteristics, which makes it applicable to use. The characteristics are discussed below.

- **Subjectivity and context**: the interpretive approach emphasizes the importance of understanding the subjective experiences of individuals within their specific social and cultural contexts (Creswell and Poth 2018:20).
- **Meaning making**: this approach focuses on how people create and interpret meaning from their experiences, often through the use of symbols, language, and cultural practices (Denzin and Lincoln 2011:6).

- **Flexible and emergent design**: interpretive research designs are typically flexible, allowing researchers to adapt and respond to new insights, as they unfold during the study (Merriam and Tisdell 2015:45).
- **Researcher reflexivity**: researchers in interpretive studies are considered co-constructors of knowledge, as they actively reflect on how their own backgrounds and biases, may influence the research process and its interpretations (Creswell and Poth 2018:20).
- **Rich, descriptive data**: data collection methods, such as in-depth interviews and participant observation, are used to gather detailed, nuanced descriptions of participants' experiences and perspectives (Denzin and Lincoln 2011:6), as in the current study.
- **Holistic analysis**: analysis in interpretive research is often holistic, considering the complex interplay of various factors that shape participants' experiences and meanings (Merriam and Tisdell 2015:45).
- **Focus on process and change**: interpretive research often examines how meanings and experiences, change over time and across different contexts, highlighting the dynamic and evolving nature of social reality (Creswell and Poth 2018:20).

As an epistemological framework (interpretive research), it has been used widely across the social and human sciences, especially anthropology, sociology, communication, cultural studies, social work, and education, thereby entrenching its value in the current study. Several writers such as Kiaos (2023:216); Means and Mowatt (2023:3); Hughes (2022:31) and *Ugwu et al.* (2021:116) collectively highlighted, that the interpretive paradigm boasts an abundance of advantages for social science research, that includes:

- **Rich contextual understanding**: interpretive frameworks allow researchers to explore the context within which a phenomenon occurs. This helps in understanding the intricate relationships, historical factors,

cultural influences, and other contextual elements that shape a phenomenon.

- **Subjective insights:** these frameworks emphasize understanding the subjective experiences, perspectives, and viewpoints of individuals or groups. This is particularly useful in studying human behaviour, emotions, beliefs, and cultural norms that might not be easily quantifiable.
- **Complexity and nuance:** social phenomena are often multifaceted and complex. Interpretive approaches provide the flexibility to delve into the nuances and complexities of these phenomena, allowing researchers to capture the depth of meaning behind them.
- **Flexibility:** interpretive frameworks are adaptable and open-ended. Researchers are therefore not bound by preconceived categories or rigid structures, which allows them to explore unexpected findings and insights, that might arise during the research process.
- **Emergent design:** interpretive research often follows an emergent research design. This means that the research process evolves as the data collection and analysis progresses. Researchers can modify their approach based on new insights, which can lead to a more comprehensive understanding of the phenomenon.
- **Cultural sensitivity**: when studying cultural contexts, interpretive frameworks are well-suited, for understanding the nuances of cultural practices, beliefs, and values. Given that the researcher interviewed diverse participants, being culturally sensitive, allowed the researcher to connect with the participants.
- **Holistic understanding**: interpretive approaches also encourage researchers to consider a holistic picture of the phenomenon being studied. This means considering the various dimensions, such as the

historical background, social dynamics, individual motivations, and broader societal influences.

- **In-depth interviews:** interpretive research often involves qualitative data collection methods like in-depth interviews, participant observation, and content analysis. Similarly, facilitating interviews with the sample of participants, allowed the researcher to obtain rich and relevant data, that were essential to answering the research questions.
- **Theory development:** interpretive research can also contribute to the development of new theories or the refinement of existing ones. Through immersion in the data and its interpretations, researchers can generate insights that help shape theoretical frameworks.
- **Exploration of change over time:** interpretive research also explores how phenomena change over time, considering historical shifts, evolving narratives, and changing social norms.

### 3.4.3 The use of an interpretive approach within the current study

This paradigm was vital for the study's implementation. The researcher pinpointed the research problem, established objectives, and developed interview questions based on a thorough literature review. Participants who met the inclusion criteria were selected through purposive sampling. To build trust, the researcher met with some participants a month before the interviews and adhered to schedules arranged with the participants. However, participants sometimes requested to reschedule appointments, due to workload, stress, or emotional and mental exhaustion, particularly among parents. The researcher accommodated these requests, which participants appreciated as a sign of the researcher's concern for their well-being. Participants reflected on their individual experiences, considering the physical, psychological, social, and spiritual impacts, and shared these insights with the researcher. The strong rapport developed allowed participants to explore and communicate their experiences, thoughts, and emotions openly and honestly. This paradigm enabled the researcher to understand the full scope of

participants' experiences and worldviews, interpreting them holistically to derive meaning from the data. The researcher achieved this by actively engaging with and analysing the data line by line, and then in paragraphs. This paradigm aims to delve into the participants' minds, looking to understand and interpret their thoughts and the meanings they ascribe to their context.

The interpretive approach is premised on an understanding of individuals and their perceptions of the world around them (Kivunja and Kuyini 2017:24). Similarly, the researcher aimed to understand the experiences of parents and their sick child as they navigated childhood cancer within a medical context. The goal was also to gain insights into the psychosocial and spiritual interventions, that are crucial to supporting their well-being in a healthcare setting. Thus, the researcher chose this paradigm because it aligned with the aim and objectives of the study.

In the discussion below, the researcher highlights the researcher's role and reflexivity.

## 3.5. Researcher's role and reflexivity

There are multiple definitions of reflexivity in research which frequently cause confusion for a researcher. Olmas-Vega *et al.* (2022:2) however, provided a comprehensive definition of reflexivity, saying it is "a set of continuous, collaborative and multifaceted practices through which researchers continuously critique, apprise and evaluate how their subjectivity and context influence the research processes". Reflexivity also includes self-awareness of the personal, interpersonal, methodological, and contextual factors that can alter the study being undertaken. Additionally, it can also be identified as a concept and process. The concept refers to a certain level of consciousness and the process entails introspection on how the role of subjectivity can influence the research process (Haynes 2023:25). Research shows that it is an ongoing journey of reflection by qualitative researchers on their values, recognition, and how understanding their own social background and preconceived assumptions and location can impact their research and

outcomes (Palaganas *et al.* 2017:427). Reflexivity is an important component in qualitative research, as it helps researchers to explain their influence on a study. It allows for confirmability, such that the findings of the research can be explored by fellow researchers and transferability in a way that findings can be transferred to similar or alternate settings (Olmos-Vega *et al.* 2022:3-4).

The researcher comes from a social sciences background, specifically Child and Youth Care, which focuses on children and youth at risk and holistic family well-being. She therefore has a strong understanding of child and family well-being and therapeutic methodologies. The researcher ensured that during the process of the interviews, she refrained from intervening with families or using her knowledge, beliefs and perceptions with participants, but remained empathic and sensitive. The researcher was also aware throughout the interviews that her presence could either positively or negatively influence the response of the participants and the data. To ensure this the researcher engaged in keeping a reflective diary, documenting notes, and other written forms of reflection. Diary entries and journaling helped the researcher make her aware of the perspectives and assumptions during the research process. Journaling consistently allowed the researcher to process the assumptions, decisions, power dynamics and context brought into the study. It also provided a foundation that found gaps in the researcher's knowledge and thinking. To remove the act of being biased, the researcher routinely reminded herself to be alert of any preconceived ideas and notions developed from within, including how it could potentially affect the analysis of the data and the findings.

In the following subsections below, the researcher examines the study setting, study population and study sample as well as the sampling strategy used in the study.

## 3.6. Study setting

The setting for the study was the Inkosi Albert Luthuli Central Hospital (IALCH), which is situated at 800 Vusi Mzimela Road (Bellair Road), Cato Manor in Durban in KwaZulu-Natal. It is the first large-scale new hospital to be built in South Africa since 1994 and the very first hospital in South Africa to adopt a public/private partnership in the delivery of its services. The vision of Inkosi Albert Luthuli Central Hospital (IALCH) is to provide optimal healthcare to all persons in the catchment area and their mission is to provide universally accessible specialized quality health care, through enhanced cutting-edge research and academic training.

## 3.7. Study population

According to Casteel and Birdier (2019:230) the population of interest for a study consists of the individuals, dyads, groups, organizations, or other entities, one seeks to understand and to whom or to which the study results may be generalized or transferred. It is the principal group of which the research is concerned with. In the context of research, a population is defined as individuals in the universe who possess specific characteristics (de Vos *et al.* 2011:223). The population can also be referred to as a complete set of elements that entails common characteristics defined by the sampling criteria. The populations identified for the current study included parents of paediatric cancer patients, allied health care professionals (doctors and nurses) and social service professionals (social workers) from Inkosi Albert Luthuli Central Hospital. There were therefore three samples namely, the parents (sample 1), health care professionals (sample 2) and social service professionals (sample 3). The samples were recruited through the Head of Paediatric oncology. The sampling process is discussed in the sub-section that follows.

## 3.8. Study sample

According to Cash *et al.* (2022:101), a sample is the selection of a subset of a population for inclusion in a study. Sampling is also a technique used to select a small group, with the intent to determine the characteristics of a larger group (Williamson *et al.* 2022:1087). Research indicates that a sample is a smaller set of data, that a researcher chooses or selects from a larger population, using a pre-defined selection method (Muthuli *et al.* 2022:809). The samples for this study were purposively selected. This will be discussed further under the sampling strategy.

Parents (sample 1) were selected so that data could be obtained with regards to their experience in the medical context and how their child and their family had been affected by paediatric cancer. The health care professionals (sample 2) and social service professionals (sample 3) were also purposefully selected, as they were deemed to have first-hand experience in working with paediatric cancer patients and could shed light on their therapeutic and nuclear relationship with them in the hospital setting. Moreover, they could also provide rich insight into how both children and families were affected by cancer and how within the milieu of the hospital and Childhood Cancer Foundation service delivery could be improved. They had firsthand experience of the treatment being provided to their child and how it affected their child and their family. The samples and the initial minimum sample size selected are reflected in Table 3.8.1 below.

**Table 3.8.1: Sample and no. of participants**

| **Sample** | **No. of participants** |
|---|---|
| 1. Parents of children with childhood cancer | n= 15 |
| 2. Health care professionals | n=15 |
| 3. Social workers | n=6 |

## 3.9. Sampling strategy used

According to Islam *et al.* (2016:4) sampling is the process of selecting the objects, participants, or respondents for a research study. The participants can be questioned, surveyed, interviewed, or observed. The importance of acquiring a sampling strategy, in qualitative research is that it guides researchers in accessing and obtaining data from a smaller group, that will provide insights into the behaviour or situation of the broader research population. In research there are two primary strategies for sampling, namely probability and non-probability sampling strategies.

Probability sampling is frequently associated with quantitative studies and is known as “random sampling”. This is a sampling technique which permits every single item from the universe to have an equal chance of presence in the sample (Etikan and Bala 2017:215). There are several types of probability sampling that a quantitative researcher can choose from. These include simple random sampling, systematic random sampling, stratified random sampling, cluster sampling and multistage sampling (Datta 2018:3).

The second type of sampling is non-probability sampling, which is aligned with qualitative studies. Non-probability sampling is often used in qualitative research studies, due to its ability to provide rich and in-depth insights into the research topic. Qualitative research aims to explore and understand the complexities, perspectives, and experiences of individuals or groups in a specific context (Gao and Yang 2023:1492). Non-probability sampling methods are particularly well-suited for qualitative studies, because they allow researchers to purposefully select participants who possess the relevant knowledge, experiences, or characteristics that are essential for addressing the research questions. Baltes and Ralph (2022:94); Tutz (2023:424) indicated that non-probability sampling aligns itself with qualitative research for the following reasons:

- Non-probability sampling methods, such as purposive or purposeful sampling, enables researchers to select participants deliberately, based on specific criteria that aligns with the research objectives. This approach ensures that the participants have relevant experiences or expertise related to the research topic, increasing the likelihood of obtaining rich and meaningful data.
- Diversity and representation: non-probability sampling allows researchers to intentionally select participants from various backgrounds, contexts, or groups of interest, ensuring that a wide range of viewpoints are represented.
- Information-rich cases: non-probability sampling allows researchers to identify and select individuals or cases, that have the potential to provide in-depth information, thereby enhancing the quality and depth of the qualitative data collected.
- Practical considerations: qualitative research frequently involves small sample sizes, as the focus is on depth rather than generalizability.

Etikan and Bala (2017: 217) defined non-probability sampling, as a method in which all population members have an equal chance of participating in the study. Non-probability sampling includes quota sampling, accidental sampling, judgmental sampling or purposive sampling, expert sampling and snowball sampling (Rahman *et al.* 2022:82; Etikan and Bala 2017: 217).

The characteristics of non-probability sampling outlined above, made it the most optimal strategy in the current study. Hence purposive sampling was used to select all three samples. Purposive sampling enables a researcher to rely on his or her own judgment when choosing members of the population to participate in the study (Dudovskiy 2019:1). It is based entirely on the judgment of the researcher, in that a sample is composed of elements that contains the most characteristics, typical attributes or those representatives of the population, that ultimately serves the purpose of the study (Thomas 2022:54).

In the sub-section, that follows, the researcher delves into the sampling process in this study. In this section, literature surrounding the inclusion and exclusion criteria is discussed, including the criterions used for this study.

## 3.10 Sampling process

Grouping individuals can be a complex and unpredictable task. Individuals may or may not want to be scrutinized about their life and lived experiences (Casteel and Bridier 2021:40). Human characteristics are often hidden from superficial examination, presenting a challenge for the researcher in selecting an appropriate group to study. As such, researchers are challenged with the task of identifying the characteristics of groups to be studied and then describing the boundaries. The features that determine one's inclusion or exclusion to the group are relevant to the context (Porzsolt *et al* 2019:92).

In an exploratory study, a small sample is often sufficient (Daniel 2012:237). An estimation of the size of the samples that was required, was made in the planning process, and the principle of saturation was applied. Saturation refers to the point in the data collection process, where information obtained from additional participants "does not add substantially to the codes or themes being developed" (Creswell 2015:77).

Establishing the inclusion and exclusion criteria for study participants is a fundamental practice when designing and carrying out high-quality research. Defining the inclusion and exclusion criteria increases the chances of producing reliable and reproducible results, minimizes the instances of harm to the participants, and guards against exploitation of vulnerable persons (Patino and Ferreira 2018:84). To recruit the participants for the study, such criteria were adopted to find the best suited participants.

The criteria are as follows:

### 3.10.1. Inclusion criteria

According to Patino and Ferreira (2018:84); Hornberger and Rangu (2020:5) inclusion criterion are characteristics, that the prospective subjects must have if they are to be included in the study, or the key features of the target population, that the investigators will use to answer their research question. Typical inclusion criteria include demographic, clinical, and geographic characteristics such as age, gender, race, ethnicity, marital status, educational experience, language, type of occupation, physical activity, medical conditions, and the presence of medical, psychosocial, or emotional conditions. The inclusion criteria for the three samples are detailed below.

### 3.10.2. Exclusion criteria

Exclusion criteria are defined as features of the potential study participants, who meet the inclusion criteria but present with additional characteristics that could interfere with the success of the study or increase their risk for an unfavourable outcome. Common exclusion criteria includes characteristics of eligible individuals that makes them highly likely to be lost to follow-up, miss scheduled appointments to collect data, provide inaccurate data, have co-morbidities, that could bias the results of the study, or increase their risk for adverse events such as side effects (Patino and Ferreira 2018:84; Hornberger and Rangu 2020:5). The exclusion criteria for the three samples are detailed below.

The inclusion and exclusion criterion for all three samples are as follows:

**Inclusion criteria**

**Sample 1: Parents**

- One or both parents whose child is a paediatric cancer patient.

- Those in receipt of services from Childhood Cancer Foundation at the Inkosi Albert Luthuli Central Hospital

**Sample 2: Health care professionals (doctors and nurses)**

- Health care professionals who work closely with the physical/ rehabilitative care of paediatric cancer patients for the past three years.

**Sample 3: Social workers**

- Social workers who are involved in offering therapeutic services to paediatric cancer patients and their families at Inkosi Albert Luthuli Central Hospital.

**Exclusion criteria**

**Sample 1: Parents**

- Parents whose child does not have a diagnosis of cancer.
- Those family members whose child, was not in receipt of services from Childhood Cancer Foundation at Inkosi Albert Luthuli Central Hospital.

**Sample 2: Health care professionals (doctors/nurse's/ occupational therapists)**

- Health care professionals who do not work with the physical/ rehabilitative care of paediatric cancer patients for the past three years.

**Sample 3: Social workers**

- Social workers who have not been involved in offering psycho-social support to paediatric patients and their families at Inkosi Albert Luthuli Central Hospital.

Data was collected until saturation and was reached for sample 1, sample 2 and sample 3. Saturation is the point in qualitative research, where enough

data has been collected to ensure that research questions can be answered and when coding is no longer necessary (Bowen 2008:137; Fusch *et al.* 2015:1407). The study commenced with an initial set of participants per sample. This included ten for sample 1, ten for sample 2 and 6 for sample 3. Saturation was reached after a further ten participants were interviewed. Hence a further five parents and five health care professionals were interviewed.

The following subsection provides a discussion on the data collection process adopted for the study.

### 3.11. Data collection process

Data collection is the process of attaining information on the variables of interest; in a systematic way, that guides researchers to answer research questions and assess the outcomes (Kabir 2016:202). Data collection assists with acquiring quality information, which is translated to rich data analysis, thereby establishing credible data (Kabir 2016:202). Qualitative data is secured using a variety of data collection methods. These include observations, interviews, photographs, maps, focus groups, social networks, diagrams, and genealogies (Marshall and Rossman 2006:98-106). In qualitative research, interviews and focus group discussions, however remain the two primary methods of sourcing data (Gill *et al.* 2008:291).

To proceed with the study, ethical clearance was sought and obtained from the Institutional Research Ethics Committee (IREC) at Durban University of Technology (DUT). The ethical clearance number for the study was IREC 261/22 (Appendix 10). A letter requesting permission (Appendix 6a, 6b, and 6c), was given to the gatekeeper, requesting permission to conduct the study at the research site. Thereafter gatekeeper's permission (Appendix 7, 8 and 9) was secured from the National Health Research Department, Head of Paediatric oncology ward and Inkosi Albert Luthuli Central Hospital- Medical manager. To recruit the participants for the study the following procedure was used:

**Step 1:**

The researcher emailed the Head of Paediatric Oncology, detailing the title, aim and objectives of the study. A meeting was scheduled to discuss the purpose of the study and the inclusion and exclusion criterion. The three samples required for the study were identified and discussed. Thereafter the Head of the paediatric oncology ward began to recruit the participants namely, the health care and social service professionals and parents for the study.

**Step 2:**

The Head of the Department provided the contact details of participants willing to participate in the study to the researcher. The researcher and participants then arranged a meeting to discuss participation. Meetings were arranged for participants based on their convenience and their availability. Interviews were then used to collect data from all three samples. The use of semi-structured interviews and the data collection instrument used, is discussed in the sub-sections that follow.

### 3.11.1 Use of semi-structured interviews

Semi-structured interviews were used to collect data from all three samples. Interviewing is a primary method to obtain data from participants on specific research questions. In qualitative research there are three types of interviews, namely, unstructured, semi-structured and ethnographic interviews (Stuckey 2013:56). Belina (2022:4) and Adams (2015:493) referred to semi-structured interviews, as the process of having a conversation with the participant using an interview schedule. The latter includes a blend of closed and opened questions that are frequently followed up, using prompting why or how questions and that establishes flexibility between the researcher and participant. Schnitzler *et al.* (2023:4) indicated that interviews are a way to understand people's experiences and to discover their own perceptions and opinions before any scientific explanation. Calonge-Pascual *et al.* (2023:101)

further posited that semi-structured interviews, are an attempt to understand the world from the participant's point of view, to uncover the meaning of people's experiences and to discover their lived world, prior to scientific explanations. Researchers then use semi-structured interviews to create a detailed picture of a participant's beliefs about perceptions or accounts of a particular strength (Tusting 2023:413).

Semi-structured interviews were suitable for this study, as they helped to secure rich data and allowed for accurate and direct responses from the participants. They have distinct advantages in qualitative research, as they are a useful way of getting enormous amounts of data quickly and are an effective method of obtaining in-depth data (Tusting 2023:413). The researcher, however, must develop an interview schedule prior to the interviews, which assists in gathering relevant information (DeJonckheere and Vaughn 2019:1-3).

O' Keeffee *et al.* (2016:1911-1912) stated that semi-structured interviews are organized around an interview schedule, which ensures that questions can elicit rich and detailed information from participants who have knowledge and rich experiences related to the study phenomena. Similarly, Newcomer *et al.* (2015:493) posited that, due to the flexibility of semi-structured interviews, it is easier to derive answers from follow up questions that can be obtained through open-ended questions. Hence interviewing provides the researcher with an opportunity to ask probing questions, so that the participant can elaborate further with regards to their responses. Through this the researcher can elicit the individual thoughts of participants and enable them to elaborate on the information and share openly with them (Newcomer *et al.* 2015:494).

## 3.12. Tool used: Interview guide

In the context of qualitative inquiries, the interviewer arrives at the interview with an interview schedule. This is used as a guide to maintain clarity within the context of the multiplicity of information which may be brought to the data collection process, by the interviewee (Hesse-Biber 2017:114). These

questions form what is known as the ‘interview guide’ (Flick 2018: 217), which ensures that the interviewer remains focused and able to cover all salient aspects (Greeff 2011:353).

Within semi-structured interviews, the researcher is required to engage with the participant in a manner that sets them at ease, makes them comfortable and allows for focused engagement (Greeff 2011:353). Hesse-Biber (2017: 115) described the process of creating an interview schedule, as one of identifying a series of “lines of inquiry”, from which questions are distilled. An interview guide explores participant’s perspectives on the research phenomena using guided questions. The advantage of having a predetermined set of guiding questions, protects the interviewer from being thrown off course during the interview by information that arises during the interview session (Nieuwenhuis 2016: 93).

In the process of designing the interview schedules, the researcher was mindful of the three types of questions which were asked. These were identified by Flick (2014:218) as *open questions*; *theory-driven and hypothesis-directed questions*; and *confrontational questions*. In semi-structured interviews, open-ended questions are most frequently used, and structured questions, or closed questions, are rarely used (Flick 2015:140). In developing the interview schedules, the researcher used only *open questions* and did not use other types of closed questions. The researcher made note of distinct areas of enquiry in relation to the objectives, and then formulated these into open questions, to which participants could respond fully. In designing the interview schedule, the researcher brainstormed extensive areas of inquiry and then positioned these in a logical sequence within the interview guide. Questions which would focus on the objectives were then developed, particularly those which were unambiguous and value-free (Greeff 2011:352). Greeff (2011: 352) noted that the interviewer should be mindful of the issue of the sensitivity of the questions, as they could trigger certain memories and emotions. The researcher ensured that this created a logical order, to the questioning process in the guide (Schuster *et al.* 2023:56). Prior to the

interviews, the interview guide was pilot tested with similar participants and amended as per the suggestions received. The changes suggested were integrated into the revised data collection tools. The specific interview guides for each sample, is reflected in Table 3.12.1 as follows:

**Table 3.12.1 Interview guides for in-depth interviews**

| **Samples** | **Data Collection Method** | **Interview guide** |
|---|---|---|
| Sample 1 : Parents | In-depth Interviews | Appendix 3 |
| Sample 2 :Health care professionals | In-depth interviews | Appendix 4 |
| Sample 3 :Social workers | In-depth interviews | Appendix 5 |

The section that follows is the procedure for data collection.

## 3.13. Procedure for data collection

Participants were selected prior to data collection and were reassured of their anonymity in the study and that all the information they provided, would be kept confidential. They were further informed that their participation was voluntary. Once the meeting time with a participant was confirmed, a suitable venue to meet with all participants was scheduled. The researcher made prior arrangements with the Head of the Paediatric Oncology Ward, to secure a comfortable and neutral environment for the interviews. The boardroom of the paediatric oncology ward at the hospital was identified to conduct the interviews with all three samples, who agreed on same. The parents were interviewed first on different days, followed by the health care professionals and lastly the social service professionals. The interviews were digitally recorded. In addition, notes were taken to ensure that valuable information was

captured. A reflective diary was also maintained. Using digital recording proved important as data was captured verbatim. It was important as all pertinent information could be replayed and retrieved.

The process for data collection for all three samples was the same. It was as follows: prior to the scheduled interviews, the participants were handed a consent form (Annexure 2a and 2b) for sample 1 (parents), sample 2 (health care professionals) and sample 3 (social workers) respectively and the letter of information (Annexure 1a, 1b, and 1c). The content of the information letter was explained to the participants and permission was secured to record the interviews using a tape recorder. However, one mother respectfully declined for the interview to be recorded, saying she preferred that the researcher take notes. All interviews were facilitated in person in the boardroom, at the paediatric oncology ward at the hospital. The researcher also made notes in her diary to capture important points mentioned during the interview. The duration of the interview lasted approximately 60 minutes. Refreshments were served after the interviews were completed.

In the section below, the researcher discusses data capturing and data analysis. It also documents how data analysis was applied to the study.

## 3.14. Data capturing and data analysis

### 3.14.1 Data capturing

Data was digitally recorded for all the interviews. The tapes were labelled accordingly and served to identify the participants, and to avoid any potential confusion about the data collected. Moreover, the data collected was stored on an encrypted USB (Universal Serial Bus), which was placed in a safe and secure location which only the researcher had access to. The data was transcribed verbatim, ensuring that the depth of information was maintained.

The researcher listened to the recordings numerous times to ensure that the transcripts were accurate. The hard copies were stored in a locked cupboard.

### 3.14.2 Data analysis

Data analysis is the process of methodically applying statistical and/or logical techniques to describe and illustrate, summarise, and recap, and evaluate data. According to Nowell *et al.* (2017:10) various analytic procedures "provide a way of drawing inductive inferences from data and distinguishing the signal (the phenomenon of interest) from the noise (statistical fluctuations) present in the data". Data analysis is changing the collected raw data into meaningful facts and ideas to be understood either qualitatively or quantitatively. It is studying tabulated material to determine inherent facts or meanings. It involves breaking down existing complex factors into simpler parts and putting the parts together in new arrangements for the purpose of interpretation (Diwadi 2020:64). The analysis and interpretation of data, represents the application of deductive and inductive logic to the research process. This means that the processing implies editing, coding, classification, and tabulation of collected data, so that they are amenable to analysis (Gemma 2018:41).

In qualitative data analysis there are five primary methods to analyze the data (Pervin and Mokhtar 2022:491; Pham 2018:2). These include content analysis, thematic analysis, narrative analysis, grounded theory analysis, and discourse analysis (Alharahsheh and Pius 2020:39; Denny and Weckesser 2022:1799). The researcher was guided by thematic analysis to analyze the data. A description of thematic analysis, its advantages, the rationale for its use and how it was applied as per the steps developed by Bricki and Green (2007:23) is presented below.

#### 3.14.2.1 Thematic analysis

Thematic analysis is a method used to systematically organise and analyse complex data sets. It embraces a search for themes that can capture the narratives available in the account of data sets acquired during the period of data collection. The identification of themes emerges through careful reading and re-reading of the transcribed data (Cassell 2004:15; Rice and Ezzy 1999:10). Research indicates that a rigorous thematic analysis approach, can produce insightful and trustworthy findings (Nowell *et al.* 2017:8-9). Braun and Clarke (2006:77) argued that thematic analysis is theoretically flexible for identifying, describing, and interpreting patterns (themes) within a data set in detail. This form of analysis fits well with any qualitative study, which attempts to explore complex research issues. Nonetheless, it is so flexible that it "can be incorporated into any epistemological approach" (Chamberlain 2015:68).

Data analysis is the process of reducing massive quantities of data, to make sense of the information. It involves the reduction of data, to tell a story. It requires the researcher to be immersed in the data, who has to familiarize themselves with it, in order to understand its depth and meaning. Additionally, the analysis facilitates a procedure to identify patterns and themes within the data and compose a write up of the results.

Thematic analysis can occur in both a deductive (top-down) and inductive (bottom-up) way (Braun and Clarke 2006:79). In inductive analysis, the data is coded without trying to fit the themes into a pre-existing coding frame or the researcher's preconceptions about the research (Braun and Clark 2006:80). Hence, themes emerge from the data itself and are strongly linked to the data, instead of the researcher's theoretical interest in the topic. On the other hand, the deductive approach is explicitly researcher-driven allowing the researcher to analyse the data in relation to their theoretical interest, with regards to the issues being investigated (Braun and Clarke 2006:80). The researcher using

this approach, usually begins the analysis with the themes, that are identified by the researcher through a literature review.

Thematic analysis is a constant-comparative method that involves reading and re-reading the transcripts in a systematic way (Cavendish 2011:115). The most important component in thematic analysis, is that the analysis process should be systematic so that the final product is of good quality. To maintain necessary rigour in the analysis process, a study can adopt the six-phase process, proposed by Braun and Clarke (2006:80). They are discussed in the sub-sections that follow. This analytic procedure is not a linear series of steps, but rather an iterative and reflective process, which constantly involves working back and forward between phases.

#### 3.14.2.2 Advantages of thematic analysis

Thematic analysis is a useful method of examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights (Braun and Clarke 2006:82; Cassell 2004:17). It is also useful for summarizing key features of a large data set, as it forces the researcher to take a well-structured approach to handling data, helping to produce a clear and organized final report (Cassell 2004:17).

Through its theoretical freedom, thematic analysis provides a flexible approach that can be adapted to the needs of many studies, providing a rich and detailed, yet complex account of data (Braun and Clarke 2006:81; Cassell 2004:16). Researchers who are relatively unfamiliar with qualitative methods, find that thematic analysis can be easily understood and can relatively quickly learnt, as it involves few prescriptions and procedures (Braun and Clarke 2006:81). In the sub-sections that follow, the researcher details the steps used in the current study, as described by Bricki and Green (2007:23).

- **Phase One: familiarisation with the data**

The first phase begins with the researchers' interest in becoming familiar with the data, which helps to identify the type (and number) of themes, that might emerge through the data. At the onset all the interviews, the interviews are fully transcribed, to acquire a sense of how the participants responded to the questions raised in this study. All the transcripts are then transcribed for the analysis. Then, a repeated careful reading of each transcript ensues, and the interesting and pertinent information highlighted. This enables the researcher to become fully immersed in the whole dataset and collect initial points of interest (Chamberlain 2015:70). This step allowed the researcher to become familiar with the data and note down meaningful and important extracts that stood out in the transcripts.

- **Phase Two: generating initial codes**

The second phase involves the initial production of codes from the data, which relates to a theorizing process, requiring that the researcher constantly revisits the data. Qualitative coding is a process of reflection and a way of interacting with and thinking about data (Savage 2000:1493). Coding allows the researcher to simplify and identify unique characteristics of the data thereby enabling researchers to move from unstructured data to the development of ideas related to issues within the data (Richards 2002:32).

During coding, researchers identify important sections of text and attach labels to index them, as they relate to a theme or issue in the data (Cassell 2004:20). Boyatzis (1998:56) suggested that a "good code," is one that captures the qualitative richness of the phenomenon. Braun and Clarke (2006:90) recommended that researchers work systematically through the entire data set, giving full and equal attention to each data item, and identify interesting aspects in the data items, that may form the basis of themes across the data

set. In this case the researcher ensured that the codes had explicit boundaries and ensured that they were not interchangeable or redundant (Attride-Stirling 2016:385). She was guided by the suggestion, that too many levels of coding could be counterproductive to the goal of attaining clarity in organizing and interpreting the data (Cassell 2004:78). Hierarchical coding allowed the researcher to analyse texts at varying levels of specificity with broad higher order codes providing an overview and detailed lower order codes, allowing for distinctions to be made within and between cases (Cassell 2004:60). Accounts that departed from the dominant story in the analysis were not ignored when coding data (Braun and Clarke 2006:91).

Creswell (2014:25) suggested a systematic process for coding data in which specific statements are analysed and categorized into themes that represent the phenomenon of interest. Cassell (2004:75) further outlined the process of creating a provisional template to use on the full data set, suggesting that using a template, forces the researcher to justify the inclusion of each code, and to clearly define how it should be used. This was adopted. Code manuals as outlined by Crabtree and Miller (1999:25), often serve as a data management tool for organizing segments of similar or related texts to assist in interpretation, providing a clear trail of evidence for the credibility of the study. The development of thematic these networks enabled the researcher to reflect more deeply into the meaning of the texts, exploring the themes that emerged and identifying the patterns that underlined them (Attride-Stirling 2016:385). Whatever technique is used, it is important to consistently apply it to all the data (Bricki and Green 2007:23). Any changes to the analytic approach need to be documented in audible notations, and any data approached in the old way need to be revisited with the new approach (Sandelowski 1995:52). The researcher perused through the transcript's multiple times and then identified and generated themes in accordance with the research questions and through the surfacing of repetitive data. The data was categorized using a table format. This allowed the researcher to view her themes easily and to eliminate repetitive themes that emerged.

- **Phase Three: searching for themes**

This phase began with a long list of the codes that were identified across the data set. This allowed the discovery of patterns and relationships between and across the entire data set (Chamberlain 2015:4). The codes were then analysed, by considering how different codes could be combined to form an overarching theme (Bricki and Green 2007:23). These codes then served as the building-blocks and combined similar or multiple codes were used to generate potential themes in relation to the research questions (Ansari 2015:10).

This phase was the most challenging and to ease the process a list of the codes were prepared on a separate piece of paper and subsequently organised into theme-piles which reflected, the relationship between codes and themes (Braun and Clarke 2006:42). Because of the explorative nature of the study, it was also important to return to and re-read all the transcripts before clustering the codes according to the themes. Thus, the transcripts were re-read, and different codes were combined into potential themes, collating all the relevant coded data extracts, within the identified themes. When developing the themes, the researcher introduced concepts and issues, previously identified from the literature review. Some of the themes from the literature were truly meaningful and some codes could be subsumed under them. Braun and Clarke (2006:50) suggested that themes in a study should be prevalent in most or all the data items. As the main purpose of creating main themes or categories was to capture the essence of the clustered codes, the main code would include all the related codes. All these initial themes were further refined at the next stage of the analysis.

- **Phase Four: reviewing themes**

At this stage, all the themes (main themes and sub-themes) were intentionally brought together, to refine them in a more systematic way. Bricki and Green (2007:23) suggested that themes must be checked for internal homogeneity

(coherence and consistency) and external heterogeneity (distinctions between themes). This stage consisted of two levels. At level one, all coded extracts relevant to each initial theme were extracted and pasted into a Microsoft Word document, to facilitate cross-referencing of coded extracts with the themes and to carry out the retrieval, comparison and organisation of coded extracts and themes in a meaningful way. The researcher re-read all the collated extracts for each theme, clustered all the themes and sub-themes to check whether they could form a coherent pattern. All the codes and themes along with the collated extracts, were considered to see whether they could form a coherent pattern which adequately captured the contours of the coded data.

- **Phase Five: Defining and naming themes**

This phase began with identifying the essence of what each theme was about (as well as the themes overall), and determining what aspect of the data, each theme captured (Bricki and Green 2007:23). Bricki and Green (2007:23) argued that a theme cannot be too diverse and complex. Hence the researcher returned to the collated data extracts for each theme and organised all the themes into a coherent and consistent account. Careful attention was paid to identify the ‘story’ that each theme told, and how it fitted into the broader overall ‘story’ that she wanted to talk about in relation to the research questions and to ensure that there was not much overlap between the themes. The specifics of each theme were refined carefully. The themes were further refined by reading through all the main themes and subthemes, codes, and extracts.

- **Phase Six: Writing the report**

The final phase of the analysis was to write down the report of the findings. Bricki and Green (2007:23) stated that a report using thematic analysis, should convince the readers of the merit and validity of the analysis. Therefore, great effort was made to provide a concise, coherent, and logical account of the story that the data represented within and across themes, by providing sufficient evidence and particular excerpts which could capture the essence of the points, the researcher was demonstrating.

The researcher discusses the expert validation committee that was used in her study. The process of the committee is outlined, the composition of the panel, the evaluation of the committee and outcome is also highlighted below.

## 3.15 Expert validation committee

In this section the researcher introduces the expert validation committee and rationale for its use. The process followed by the expert validation committee and its composition will be discussed, as well as the evaluation of the findings. To conclude, the researcher will outline the outcome of the committee.

According to Brink *et al.* (2018:15) an expert validation committee is a group of specialists with relevant expertise assembled to assess the validity, quality, or accuracy of a particular study, instrument, or process. The committee members provide their insights and recommendations to ensure that the content, methodology, or tools under review meet the necessary standards of rigor and relevance. This type of validation is especially valuable in qualitative research, where subjective judgments may be required to refine concepts, categories, or coding frameworks.

The purpose of establishing an expert validation committee, within the current research study was to determine the credibility, rigor, and trustworthiness of the data acquired and the analysis and findings made. The committee

comprised of experts from the field of study. They collectively provided a multidisciplinary and personal review to minimize researcher bias, validate the accuracy of themes and subthemes, and ensure that interpretations were made accurately in the data.

### 3.15.1 Process of the expert validation committee

The expert validation committee was initiated by researcher who recruited the panel. In the fourth week of October 2024, the researcher identified seven members, to serve as the panel of experts for the validation committee for her research study. Once this was done, she proceeded to send out separate emails to these experts. In the email the researcher provided a brief invitation to the members, in terms of what was required of them, and the event details. Each email detailed the requirements, in terms of them providing the relevant expertise, offering diverse perspectives, their commitment to the process, maintaining a sense of confidentiality, objectivity, validating the findings made, being familiar with the research methodology and providing recommendations for improvement. It also highlighted the platform where the meeting would take place. Most of the experts responded promptly confirming their participation. Once confirmation of their participation was received, the researcher proposed the 23 and 25 October as dates for the panel to meet. Given there was collective consensus, the researcher began planning her PowerPoint presentations and topics for discussion to the panellists.

The engagement session with the expert committee spanned over two days on the 23rd and 25th of October. Each was scheduled for a maximum of three hours, which was facilitated on Microsoft teams. This was to enable those who were not within geographical proximity to participate. Hence the researcher decided to conduct the review on MS Teams to accommodate all members of the committee. The researcher met with the experts and conducted two formal review sessions using PowerPoint presentations. An outline of both sessions follows:

**Session 1:** 23 October 2024 (17:00-20:00)

The first session consisted of a welcome and overview of the two sessions. The researcher introduced her study, and its aim and objectives. She shared the location of her study, which was the Inkosi Albert Luthuli Central Hospital. She also provided details of the three samples that were recruited for her study. She then proceeded to introduce the themes and subthemes identified from the data acquired. Each expert was given an overview of the coding framework and the thematic structure. The primary goal was to gather initial feedback on the validity and comprehensiveness of the themes and subthemes that had emerged.

**Session 2:** 25 October 2024 (17:00-20:00)

The researcher facilitated the second session by going over the themes and subthemes. She also introduced some of the excerpts related to several subthemes. During the second session, the researcher asked the committee for their feedback in response to the data and whether the research objectives were met. Moreover, she requested their guidance on fine tuning the themes, subthemes and analysis thereof. The interpretations from members of the committee were considered. The committee rigorously discussed the data and the interpretations, concurring with the findings made. Further suggestions regarding interpretations were considered and noted. Finally, the committee members was asked to share any thoughts, feedback or findings that they have made, during the two-day committee expert validation process.

### 3.15.2 Composition of the expert validation committee

The expert validation committee comprised of professionals from various fields relevant to the research, each selected based on their expertise and the value they could add to the validation process. In addition to them parents of children with childhood cancer were also recruited. The committee members and their expertise and experience are detailed in the Table that follows:

**Table 3.15.2: Committee members and their field of work**

| Committee member | Background and expertise |
|---|---|
| 1. Paediatric oncologist | An expert in paediatric oncology, who provided insights into the medical aspects of childhood cancer and who could contribute knowledge related to the physiological effects discussed in the findings. |
| 2. Clinical psychologist | Specialist in paediatric psychological trauma, particularly in the context of serious illness, to assess the accuracy of the themes related to emotional distress. |
| 3. Social worker | Experienced in hospital-based social work, with a focus on family counselling and support services, to evaluate the subthemes related to family dynamics and social interventions. |
| 4. Spiritual care practitioner | A professional in spiritual care with experience in providing support to patients and families in medical settings. This was to ensure that the themes related to spiritual interventions were accurately represented and ethically discussed. |
| 5. Qualitative research methodologist | An expert in qualitative analysis to consider the methodological rigor underpinning the study and ensure that the thematic framework was well-grounded in the data. |
| 6. Childhood cancer affected parent | Selected based on their lived experiences so as to provide unique and valuable insights, that could contribute to the strength and relevance of the research findings related to the experiences of parents and their families. |

| | |
|---|---|
| 7. Childhood cancer affected parents | Parents as experts were important as their experiential knowledge could be acknowledged and to ensure that the study addressed the real-world realities, experiences, and needs that may not have been fully understood by the clinical or academic experts alone. |

### 3.15.3 Evaluation of findings and analysis by the expert validation committee

In the sub-sections that follow, the researcher provides a summary of some the feedback and analysis from the expert validation committee from each session. The researcher highlights how the feedback was adopted into her work.

- **Feedback from Session 1**

During the first review session, the panel members provided extensive feedback on the initial thematic framework. The key points discussed focused on theme 1, subtheme 1.1. The clinical psychologist said that "*The emotional experiences of the children seem clustered together under a general heading. There needs to be a distinction between immediate emotional reactions and those that develop over time as the child adjusts to the illness."* The clinical psychologist noted that the descriptions of emotional despair should be more nuanced, by differentiating between short-term emotional responses (e.g., initial shock and denial) and long-term emotional consequences (e.g., depression and anxiety). The researcher acknowledged these members inputs and presented the data accordingly.

The social worker indicated that "*children's disconnection from their peers isn't just a byproduct of being away from school; it often extends to a broader loss of identity as a 'normal' child, which can exacerbate feelings of isolation."* Essentially, the social worker explained that there was a need to include how

cancer affected the child's interactions with peers and their identity development, as social withdrawal was not just about physical absence from school but also involved emotional distancing from friends. To conclude the first session, feedback from the spiritual care practitioner focused on subtheme 4.2: the role of spiritual leaders in supporting children and their families. The practitioner said that "*Families come with diverse spiritual backgrounds. Some may resonate more with traditional forms of spirituality, such as ancestral rituals, while others may seek guidance from chaplains or clergy."* From this response, the researcher noted that the spiritual care practitioner had highlighted the need to address different cultural perspectives on spiritual leadership. The researcher then considered adding cultural variations in spiritual leadership to subtheme 4.2.

- **Feedback from Session 2**

In the second session, the experts reviewed the changes and confirmed that the revisions effectively had addressed the initial concerns. Additional discussions focused on prospective psychosocial interventions in a medical setting, technological support intervention. One of the parents indicated that "technological *interventions can provide accessible support for families who may not be able to visit the hospital frequently. This is particularly important in the current digital age." This* emphasized the importance of integrating technological support, such as virtual counselling or support groups, especially for families in remote areas, who may not have the means to travel to hospital. The researcher then enhanced this section within the write up of her study. The doctor shared her evaluation of the interconnectedness of psychosocial and spiritual interventions. She said that "*Psychosocial and spiritual dimensions are not separate; they often influence each other. For instance, spiritual beliefs can shape psychological coping strategies, and addressing emotional distress can open individuals up to spiritual experiences.* The response from the doctor revealed the interconnected nature of psychosocial and spiritual support. This interrelationship was also strengthened within the discussion and in the recommendations for holistic care.

### 3.15.4 Outcome of the expert validation process

The expert validation process enhanced the quality of the data analysis and findings of the study undertaken. The discussion points were all considered and rigorously included in the analysis and write up of the findings made. The thematic framework was refined to better reflect the lived experiences of the children with cancer and their families, with a more nuanced interpretation of the psychosocial, spiritual, and familial impacts of childhood cancer. The committee's feedback contributed exponentially to the thematic accuracy, where the themes and subthemes were revised to ensure that they accurately represented the participants' experiences. This holistic approach to extricating the recommendations, also contributed and allowed the researcher to enhance the interconnectedness of the psychosocial and spiritual interventions leading to a more holistic comprehensive set of recommendations.

The researcher discusses the aspect of trustworthiness and its components in the section below.

## 3.16. Trustworthiness

Trustworthiness is one possible way that researchers can persuade themselves and readers that their research findings are worthy of attention (Lincoln and Guba 1985:290). Lincoln and Guba (1985:290) described trustworthiness as an important aspect as it evaluates the worth of the research study and reflects the experiences of participants from their own perspective. Liets *et al.* (2006:444) posited that trustworthiness can be portrayed as an aim, which the research attempts to achieve. Trustworthiness is only achieved when the experiences and opinions of the participants are precisely illustrated. The researcher established trustworthiness by engaging multiple research participants and by generating data using various methods. Participant's views were accurately presented. Lincoln and Guba (1985:291) refined the concept

of trustworthiness by introducing the criteria of credibility, transferability, dependability, and confirmability and suggested that these concepts be considered to obtain trustworthiness. The criteria and how it was applied within the current study, are discussed in the sub-sections that follow:

### 3.16.1 Credibility

Guba and Lincoln (1989:25) stated that the credibility of a study is determined when co-researchers or readers who are confronted with a similar experience, can recognize it. Credibility addresses the "fit" between respondents' views and the researcher's representation of them (Tobin and Begley 2004:15). Lincoln and Guba (1989:20) suggested several techniques to address credibility including activities such as prolonged engagement, persistent observation, data collection triangulation, and researcher triangulation. They also recommended peer debriefing to provide an external check on the research process, which may therefore increase credibility, as well as examining referential adequacy to check preliminary findings and interpretations against the raw data. Credibility can also be operationalized through the process of member checking to test the findings and interpretations with the participants (Lincoln and Guba 1985:20). The researcher applied all the above strategies to ensure that credibility was achieved. She also attempted to provide a detailed description of all aspects of the research process to confirm credibility.

### 3.16.2 Transferability

The concept of *transferability* as it relates to trustworthiness, is associated with whether the research findings would be found in another situation or case (Schurink *et al.* 2011:420). Korstjensa and Moserb (2018:120) added that transferability is the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents. The researcher facilitates transferability, through thick description. Thick description includes an account or explanation of the participants and the

research process, to enable the reader to assess whether the findings are transferable to their own setting. This is the so-called transferability judgement. This implies that the reader, not researcher, makes the transferability judgment because one does not know their specific settings (Korstjensa and Moserb 2018:122). Given (2008:467) said that to increase transferability, qualitative researchers should focus on two key considerations: (a) how closely the participants are linked to the context being studied, and (b) the contextual boundaries of the findings. In the first consideration, the participants need to be relevant members of the community related to the study. The other consideration is with regards to providing a complete understanding of the context being studied and ensuring that the research questions are appropriately answered. It is from here that readers can explore the research document and determine if the findings can be transferred to their setting or environment. To maintain transferability in the research study, the researcher provided a rich account of descriptive data, such as the context in which the research was carried out, the framework adopted, the study setting, sample, sample size, sample strategy, demographic details, inclusion and exclusion criteria, interview procedure and the interview guide.

### 3.16.3. Dependability

In qualitative research, dependability refers to the quality of the research findings, interpretations, and conclusions being consistent, reliable, and reproducible. It is one of the key criteria for establishing the trustworthiness and rigor of qualitative research. To achieve dependability, researchers can ensure that the research process is logical, traceable, and clearly documented (Tobin and Begley 2004:18). When readers can examine the research process, they are better able to judge the dependability of the research (Lincoln and Guba 1985:21). By adhering to practices such as consistency in data collection, detailed documentation, reflexivity and researcher bias, data analysis transparency and the audit trail, researchers can enhance the

dependability of their qualitative research and demonstrate the trustworthiness and credibility of their findings. Dependability ensures that the research process is systematic, reliable, and consistent, allowing for meaningful interpretations and meaningful contributions to the field. Dependability was achieved through an audit trail, which included documenting the research process. This involved clear records of data collection, transcription, coding, and analysis. Secondly, dependability was validated through the channels of the expert validation committee where the research methodology and findings were subjected to peer review. Feedback from the committee of experts was incorporated to validate the consistency of the interpretations.

### 3.16.4 Confirmability

Confirmability is concerned with establishing that the researcher's interpretations and findings are clearly derived from the data, requiring the researcher to demonstrate how conclusions and interpretations have been reached (Tobin and Begley 2004:18). According to Guba and Lincoln (1985:21), confirmability is established when credibility, transferability, and dependability are all achieved. Koch (1994:6) recommended that researchers include markers such as the reasons for theoretical, methodological, and analytical choices throughout the entire study, so that others can understand how and why decisions were made.

The researcher worked to ensure confirmability through being conscious of potential bias in the data analysis process, and through creating a paper trail of documents that provide a view on the process of interpretation of the data followed by the researcher. The researcher noted the complexity in the consideration of quality in qualitative research. This stresses the need not to imitate quantitative quality standards, but to "record a continuous critical

analysis" of the researcher's internal experience, including thoughts and feelings of the entire research process, with an emphasis on the need for mindfulness in respect of the fundamental and unavoidable intrusion of the researcher, in the research context (Schurink *et al*. 2011: 422). This understanding of the need for researcher consciousness throughout the research process was invaluable to the researcher. She attempted, to articulate her cognitive and emotional engagement throughout the process, as well as to follow the dictates of the trustworthiness criteria.

Below, ethical consideration is discussed alongside its principles and related to the current study.

## 3.17 Ethical considerations

According to de Vos *et al.* (2011:114) ethics are a set of moral standards by which a researcher evaluates his/her own conduct. Akaranga *et al.* (2016:2) stated that ethics are a crucial component of research, as it assists researchers in protecting the identity and dignity of the participants and the publication of the information being researched. Ethical considerations are a crucial aspect of qualitative research to ensure that the rights, welfare, and dignity of participants are protected. Qualitative research involves the collection and analysis of non-numerical data, such as interviews, observations, and textual analysis, with the goal of understanding human experiences and subjective perspectives. The current study received full ethical approval (IREC 261/22) from the Institutional Research Ethics Committee (IREC), of the Durban University of Technology (DUT). The following ethical principles were considered for the study and are discussed below. These principles were derived from Strydom (2011:115-124).

### 3.17.1 Voluntary participation

According to Strydom (2011:115) participants must willingly choose to participate in the research without coercion or undue influence. Qualitative researchers need to ensure that participants understand their rights and have the freedom to decline participation or withdraw from the study at any stage. It is important to create an environment, that supports participants' autonomy and protects them from any negative consequences for choosing not to participate. All participants engaging in the research study, did so willingly and were presented with the option to withdraw their participation, if they felt the need to do same. None of the participants were coerced to participate in the study. All participants were well-informed of the study in advance and their permission was sought, through the letter of information form. The researcher informed all participants of this, through an information letter (appendix 1a – sample 1, appendix 1b - sample 2 and appendix 1c – sample 3) prior to the scheduled interviews. The consent form (annexure 2a and 2b) was also signed by each participant prior to the start of data collection.

### 3.17.2 Informed consent

Informed consent is a fundamental ethical principle in research. Researchers must provide participants with clear and detailed information about the study's purpose, procedures, potential risks and benefits, confidentiality measures, and their right to withdraw at any time (Strydom 2011:116). In qualitative research, establishing informed consent is an ongoing process, as researchers may continuously engage with participants and may need to seek their consent for specific activities. Informed consent entails the process of consent, which should be given willingly. The participants should understand what is being asked of them and be equipped to provide all necessary information regarding the study. Moreover, with all the relevant information being provided to participants, they would be better positioned to make a voluntary decision about their participation in the study. For the current research study, participants from all three samples were given a letter of information (appendix

1a, 1b and 1c) and a consent form (appendix 2a and 2b) in advance of the interviews. The letter of information contained detailed information about the study, thereby giving participants the opportunity to ask any questions that they may have about the study and to decide if they want to engage in the study or not.

### 3.17.3 Violation of privacy/anonymity/confidentiality

All participants who agreed to participate in a study, have the basic right to privacy and confidentiality of information and their identity. Maintaining confidentiality and anonymity is essential to protect participants' privacy and to ensure their trust (Paunova 2023:54). Participants were given the right to decide when, where, to whom and to what extent their behaviours, beliefs and attitudes could and would be revealed. It is therefore the sole responsibility of the researcher/s to maintain and protect the privacy, confidentiality, and identity of the participants. All information acquired from the interviews was categorized and labelled with pseudonyms. This ensured protecting the identities of each participant. Confidentiality was maintained by not revealing any of the participants names in the data collection, analysis, and discussion of the findings. The voice recordings were stored on a USB device encrypted with a password. Moreover, the transcripts were stored in a locked cupboard which could only be accessed by the researcher.

### 3.17.4 Beneficence

Researchers should prioritize the well-being and interests of participants. This involves designing studies, that have the potential to generate knowledge that benefits individuals or communities and by ensuring that participants have access to any potential benefits resulting from the research. Researchers should also consider sharing research findings with participants in a meaningful and accessible way. In this context, the researcher incorporated beneficence in the following ways:

- **Participant well-being:** The researcher prioritized the well-being of participants by ensuring that the research process was sensitive to their emotional and physical needs. This included creating a comfortable and safe environment for interviews, providing breaks if needed, and through offering support or resources to cope with any distress that arose during the research.
- **Empowerment and validation:** The researcher empowered participants by acknowledging and validating their experiences. By actively listening, empathizing, and acknowledging the challenges they face, the researcher created a sense of trust and respect. This contributed to participants feeling heard, valued, and empowered to share their perspectives, concerns, and suggestions for improving their child's quality of life and their families.
- **Dissemination of findings:** The researcher will ensure that the research findings will be disseminated in a manner that would benefit the participants. By highlighting the lived experiences and recommendations of the participants, the research findings can inform the development of interventions, policies, or healthcare practices that address their needs and improve their well-being.

## 3.18 Conclusion

This Chapter presented the guiding research methodology for this study, namely qualitative research methodology and a rationale for its use. The use of a case study design was presented. The data collection method, namely semi-structured interviews, was elucidated in relation to the three chosen samples. Thematic analysis was presented as the method used, to analyse the data. Ethical considerations and trustworthiness of the data was also discussed in this Chapter. Chapter 4, which follows, contains the data and an analysis of the findings made.

# CHAPTER FOUR

# ANALYSIS AND DISCUSSION OF FINDINGS

## 4.1 Introduction

*"Children with cancer are like candles in the wind who accept the possibility that they are in danger of being extinguished by a gust of wind from nowhere and yet, as the flicker and dance to remain alive, their brilliance challenges the darkness and dazzle those of us who watch their light" (Taylor Mathew).*

Chapter three presented an overview of the research methodology and design and the procedures for data collection and analysis. Chapter four contains an analysis of the data, and a discussion of the findings made. Three samples, were recruited for the study, namely, parents of children with paediatric cancer, healthcare professionals and social workers involved in the treatment and care of paediatric cancer patients. The participants were assigned pseudonyms. The acronym "P" was used to refer to the parents, whilst, the interview number, was denoted alongside P, as follows P1. The health care professionals were identified as "Dr1" for Dr and/or "N9" for nurse. The social workers were reflected as "SW," with their respective interview number. The following sub-section and tables that follow, capture the demographic profiles, of all three samples.

## 4.2. Demographic profile of the samples

Table 4.2.1: Sample 1: Parents

| Pseudonym | Gender | Age | Race |
|---|---|---|---|
| 1. Parent (P1) | Female | 27 | Black |
| 2. Parent (P2) | Female | 36 | Black |
| 3. Parent (P3) | Female | 40 | Black |
| 4. Parent (P4) | Female | 30 | Indian |
| 5. Parent (P5) | Female | 41 | Indian |
| 6. Parent (P6) | Female | 25 | Black |
| 7. Parent (P7) | Female | 36 | Coloured |
| 8. Parent (P8) | Female | 42 | Black |
| 9. Parent (P9) | Female | 52 | Black |
| 10. Parent (P10) | Male | 37 | Black |
| 11. Parent (P11) | Male | 39 | Black |
| 12. Parent (P12) | Female | 47 | Coloured |
| 13. Parent (P13) | Female | 30 | Indian |
| 14. Parent (P14) | Female | 29 | Black |
| 15. Parent (P15) | Female | 42 | Black |

Table 4.2.2: Sample 2: Health Care Professionals

| Pseudonym | Gender | Age | Race |
|---|---|---|---|
| 1. Doctor (Dr 1) | Female | 43 | Coloured |
| 2. Doctor (Dr 2) | Female | 30 | Indian |
| 3. Doctor (Dr 3) | Female | 35 | Black |

| | | | |
|---|---|---|---|
| 4. Doctor (Dr 4) | Female | 41 | Indian |
| 5. Doctor (Dr 5) | Female | 40 | Black |
| 6. Doctor (Dr 6) | Female | 47 | White |
| 7. Doctor (Dr 7) | Female | 29 | Black |
| 8. Doctor (Dr 8) | Female | 32 | Black |
| 9. Nurse (N9) | Female | 43 | Black |
| 10. Nurse (N10) | Female | 50 | Black |
| 11. Nurse (N11) | Male | 33 | Black |
| 12. Nurse (N12) | Female | 45 | Black |
| 13. Nurse (N13) | Female | 55 | Black |
| 14. Nurse (N14) | Female | 45 | Black |
| 15. Nurse (15) | Female | 42 | Black |

Table 4.2.3: Sample 3: Social Workers

| **Pseudonym** | **Gender** | **Age** | **Race** |
|---|---|---|---|
| 1. Social Worker (SW 1) | Female | 30 | Black |
| 2. Social Worker (SW 2) | Female | 41 | Black |
| 3. Social Worker (SW 3) | Female | 26 | Black |
| 4. Social Worker (SW 4) | Female | 50 | Black |
| 5. Social Worker (SW 5) | Female | 33 | Black |
| 6. Social Worker (SW 6) | Female | 28 | Black |

## 4.3. Data analysis and findings

The table that follows reflects the main themes and sub-themes, emerging from the study. There were seven main themes and forty-four sub-themes. These are presented in Table 4.3.1 below.

**Table 4.3.1 Themes and sub-themes**

| Theme | Sub-theme |
|---|---|
| 1. Holistic effects of cancer on the child | 1.1 Emotional despair and distress<br>1.2 Fear of death<br>1.3 The impact on school life<br>1.4 Social isolation and withdrawal<br>1.5 Fear of medical procedures<br>1.6 A deep fear of the unknown and reoccurrence of the disease<br>1.7 Physiological effects of both cancer and treatment |
| 2. Impact on the family | 2.1 Mental health distress encountered by parents<br>2.2 Financial difficulties<br>2.3 Disruption of normal family life<br>2.4 Instability within the marital relationship<br>2.5 Pain and anguish experienced by mothers<br>2.6 Disruption of parental academic career<br>2.7 Lack of knowledge regarding child's cancer diagnosis |

| | |
|---|---|
| 3. Psychosocial interventions in a hospital setting | 3.1 Psycho-therapeutic services<br>3.2Cognitive behavioural therapy<br>3.3Relevance of educational support<br>3.4 Social work services<br>3.5 Recreational therapy<br>3.6 End-of-life and bereavement support |
| 4. Spirituality as a source of strength amongst family members | 4.1 Salience of spirituality in a medical context<br>4.2 Prayer<br>4.3The role of spiritual leaders in supporting children and their families<br>4.4 Salience of faith and belief<br>4.5 A sense of spiritual hope<br>4.6 The use of chanting |
| 5.Psychosocial interventions that can support healing | 5.1 An introductory to psychosocial interventions<br>5.2 Technological support intervention<br>5.3 Music therapy<br>5.4 Art therapy<br>5.5 Play therapy and interactive play<br>5.6 Book club/bibliotherapy<br>5.7 Dance therapy<br>5.8 Legacy building |

| | |
|---|---|
| 6. Spiritually based interventions in a medical setting | 6.1 Mindfulness meditation<br>6.2 Yoga<br>6.3 Healing circles<br>6.4 Ancestry healing<br>6.5 The interconnectedness of psychosocial and spiritual interventions |
| 7. Social support systems in childhood cancer | 7.1 Support from family<br>7.2 Support from friends and communities<br>7.3 Support from religious communities<br>7.4 Support from Childhood Cancer Foundation (CHOC)<br>7.5 Support from medical and social service professionals |

#### 4.3.1.1 THEME 1: HOLISTIC EFFECTS OF CANCER ON THE CHILD

The first theme that emerged focussed on the holistic effects of cancer on the child. A total of seven sub-themes were derived from the data namely, (I) emotional despair and distress, (II) the fear of death, (III) the impact on school life, (IV) social isolation and withdrawal, (V) fear of medical procedures, (VI) a deep fear of the unknown and reoccurrence of the disease and (VII) physiological effects of both cancer and treatment. The first sub-theme that emerged, related to the emotional despair and distress experienced by paediatric cancer patients.

Maree *et al.* (2016:19) argued that the cancer journey transforms previously happy, outgoing children into sad, withdrawn individuals. The change in the child is not a temporary phase but often solidifies into a more profound change in their character and outlook on life (Novrianda *et al.* 2022:11). The first sub-theme reflects the emotional despair and distress experienced during the cancer journey.

### 1.1 Emotional despair and distress

The doctors, nurses and social workers in the sample, shared this as follows:

*"Children with cancer often experience significant emotional distress. The stress of the diagnosis, the discomfort of treatments, and the disruption of their normal lives can lead to anxiety, depression, and a sense of isolation. It's crucial to provide emotional support and counselling to help them cope with these intense feelings."* (Dr 1)

*“It is a very big stress for children to go through cancer.” (N9)*

*"Many of the children I work with exhibit signs of significant psychological distress. The impact of prolonged hospital stays, and invasive treatments can't be underestimated. They often feel isolated from their peers and struggle with the sudden and drastic changes in their lives. Therefore, as a team we strive to focus on creating a supportive environment to help them cope and express their feelings."* (SW 1)

*"It's not uncommon for children undergoing cancer treatment to develop symptoms of depression and anxiety. The experience can be incredibly traumatic, affecting their mental health long after the treatment ends. We try to address these issues proactively, providing psychological support as an integral part of their overall care."* (SW 3)

These narratives collectively highlight the profound psychological impact that childhood cancer has, on paediatric patients. Those undergoing treatment experience depression and isolation, feel isolated and struggle with the rapid physiological changes in their lives, which causes deep despair. Hence the participants acknowledged that the trauma of cancer extends beyond the mere physical symptoms, to more enduring emotional effects.

Correale (2022:1) supported this notion saying that “hospitalization is a stressful event for children and their families”. Erker (2018:1620) added that children with cancer can experience decreased emotional health-related quality of life (HRQoL) compared to healthy children. Delemere *et al.* (2020:3-15) therefore called for clinical interventions to support these vulnerable patients. The health care professionals, further argued that cancer treatments should include a component that includes emotional care. The cancer experience therefore is not just a struggle with physical illness, but managing the emotional burden, that often overwhelms these young patients (Fuemmeler 2020:279).

According to Michel *et al. (*2020:1103) depression occurs in 25% of patients with cancer, although it remains frequently undiagnosed. Shorofi *et al. (*2016:10) opined that nurses have an essential role to play in the early detection of depression, because if left untreated, it can cause higher healthcare costs, decreased compliance, and decreased quality of life (QOL).

Patients with cancer often present with psychological symptoms such as depression, feelings of worthlessness or excessive guilt, diminished interest or pleasure in usual activities, and suicidal thoughts, including a preoccupation with death. Studies emerging from Western countries have found that cancer survivors, had higher levels of depression and lower self-esteem than healthy children (Michel *et al.* 2010:1740) Recklitis *et al.* (2006: e3852) shared that with childhood cancer survivors, feelings of depression often diminish their self-esteem and create a higher risk of suicidal tendencies.

Wong *et al.* (2023:435) added that patients commonly experience anticipatory anxiety prior to undergoing tests and procedures or whilst waiting for test results. Preexisting anxiety disorders such as panic disorder, phobias, generalized anxiety disorder, and post-traumatic stress disorder can compound issues for those involved in cancer associated tests and procedures (Akinola *et al.* 2016:128).

A study by Mant *et al.* (2019:1-16) of children diagnosed with cancer during the early stages of treatment in the United Kingdom, provided insights into their initial feelings of shock and fear. They described their chemotherapy as a horrible experience, which suggests that children with cancer, experience more distress due to their treatment, rather than the actual diagnosis. Five of the participants who were receiving chemotherapy shared that it restricted their activities and left them feeling fatigued.

Parents in the sample shared similar sentiments, describing the cancer journey as emotionally debilitating :

*"My son's treatment is currently very aggressive, and he faced many side effects. But what really took a toll was the emotional strain. He became very*

*quiet and started having panic attacks before hospital. It's clear that the psychological impact of cancer is just as challenging as the physical one."* (P3)

*"Sometimes in the ward or in our room at the CHOC house, my child has this blank look on her face, it's like she zoned out from reality, and this only started when she got diagnosed"* (P2)

*"My daughter is sad and depressed but thank God she is alive. I explained to her the diagnosis, treatment and everything that was happening."* (P4)

*"Before my child could be diagnosed and had all these problems, he was a very happy and go lucky child, he should excel in school. Now he is admitted and must be in hospital. It worries him. He worries about school and stresses that he is missing out on his schoolwork. Because of the stress, he stopped being happy, stopped eating. The stress changed him."* (P9)

*"Because of my child's cancer diagnoses, the doctors diagnosed my child with depression and anxiety… he gets depressed, during the cancer treatment, it's horrible"* (P7)

These narratives reflect the personality changes amongst children, whose treatment was aggressive. One parent (P3) shared how her child became withdrawn and started presenting with panic attacks before hospital visits.

Cheng *et al.* (2020:68) supported these findings saying that the diagnosis of a life-threatening illness like cancer, introduces a level of stress that is hugely disorienting and debilitating for children. It disrupts their normal life, routines,

and the intrusiveness of the illness to their young bodies, both through the disease and its treatment, creates a fertile ground for deep psychological distress (Hinds 2020:1). Steineck *et al.* (2022:229) opined that, cancer affects the behavioural and personality of children grappling with their illness and treatment. Parents also shared how their children's academic and school life was disrupted.

Toledano-Toledano *et al. (*2018:2), wrote that a child with cancer or leukaemia faces enormous uncertainty throughout the illness trajectory, from the point of diagnosis to treatment and post treatment. They experience a broad spectrum of emotions, ranging from anxiety, anger, stress, fear, frustration, self-blame, depression, and uncertainty (Li *et al.* 2013:214). The psychological distress amongst patients with cancer, however, differs from patient to patient (Berkman *et al.* 2022:990).

Bernal *et al.* (2022:1-10) affirmed that the changes in the mental status of children are some of the most troubling conditions that patients with cancer face. One of the mothers shared how her child zoned out of her mind, at times in the hospital ward. Similarly, mental changes vary in severity, but the most acute and life threatening is delirium (Benini *et al.*2022: e529). Laronne *et al. (*2021:5) highlighted that delirium occurs in 25%-40% of patients with cancer, at some point during their illness and increases to 85% during the terminal phase of cancer. Snaman *et al*. (2020:954) described delirium as characterized by alterations in patients' level of consciousness that may include changes in perception, memory, attention, thinking, psychomotor behaviour, emotions, and the sleep-wake cycle. Patients may appear depressed or anxious and, therefore, be diagnosed with a behavioural or emotional problem. The misdiagnosis of delirium is therefore common especially if treatment is recommended for what appears to be depression or anxiety, that may worsen a patients' condition.

A study by Cheung *et al.* (2019:104-109) on the quality of life amongst paediatric brain tumour survivors found that a substantial proportion of informants, had expressed experiencing low moods or depression. Some shared that this emerged from the fear of the cancer recurring. Other children struggled to maintain friendships. One survivor said, “because of the limited functional capacity, I can't hang out and play with my friends most of time, I feel like so far apart from them, it makes me down.”

### 1.2 Fear of death

The second sub-theme focussed on the fear of death. Medical professionals described how their cancer patients shared their fear of dying with them. They said :

*“When the doctors including myself are visiting the children during our morning debrief and rounds, there are our little patients who are isolated due to infections always ask “is the treatments making me better or am I going to die. Because I am still small. I don’t want to die because of this.”* (Dr3)

*“Whenever I am doing my rounds in the ward, the children always ask me, Usisi (sister), I am going to die because of my cancer.?”* (N 12)

These narratives capture the deep sense of fear and the existential concerns that these young cancer patients grapple with. The doctor and nurse shared how children would ask whether their illness would lead to death, and often said that they did not want to die. They searched for reassurance that they would recover Doust *et al. (*2020:2857) asserted that fear is a normal response and often encompasses the unknown aspects of cancer and its treatment, including fear of death, disability, pain and suffering, and loss or disruption of

relationships. Lion *et al.* (2019:71) explained that those in the midst of treatment, had to be placed in isolation because of potential infections and the rigorous treatment plans, which exacerbated their feelings of loneliness and helplessness, and amplified their fears. This fear of death also placed a significant emotional burden on their families and caregivers (Blackburn *et al.* 2020:19). Holochwost *et al*. (2020:587) argued for a comprehensive approach that provisions children with psychological support, open communication, and compassionate care, so that they can safely navigate their emotions and fears and build resilience in the face of their illness.

Parents shared similar sentiments regarding their children's fear as follows:

*"My child tells me "If I all of a sudden, have, like, a pain in my, like, the middle of my leg or… I feel like I have a little bump or my throat hurts like, my head instantly goes to cancer, dealing with it has given me kind of like a fear of death. Like I'm, so scared I'm going to die and not be able to do certain things, finish school and become somebody".* (P4)

*"Well, my child was probably the bravest girl that I've ever known before this happened. Now, she's not quite so brave. The cancer it did leave her that way I think. She feels she has a few years to live. When she was smaller, she thought she would live forever, now she's afraid of dying. She doesn't like to hear about anybody dying. And she doesn't like to think about it."* (P13)

These narratives further reflect that their children were anxious that their cancer could recur. A parent shared how her child transitioned from a point of bravery to vulnerability, and now experiences deep fears regarding dying because of her illness. Young patients also frequently questioned their

prognosis, which revealed their uncertainty about their future and their existential distress.

Laronne *et al.* (2021:5) similarly described how children with cancer, fear death constantly. Cuviello *et al.* (2020:1033) explained that this fear is triggered by the sudden and severe nature of the illness, as well as the invasive and painful treatments, they have to endure to heal. Hence as one parent said even when a child experiences minor physical symptoms, they attribute it to their cancer which is a clear sign, that it has fundamentally altered their perception of their own body. Any new pain or discomfort is immediately associated with a potential recurrence of the disease, leading to heightened levels of anxiety (Bergstraesser 2013:31). This fear of death is not just experienced as a thought, but a persistent, underlying dread that affects their day-to-day lives, behaviours, activities, and mental health (Kaye *et al.* 2016:316).

Marcus (2020:369) described this psychological transformation as a shift from carefree lives, to one filled with heightened vulnerability and fear. This shift signifies a loss of innocence and a confrontation with death at such a premature age. The trauma of their illness and the constant threat of death, consequently reshapes their outlook on their life's journey, thereby disrupting their sense of prior safety and security (Snaman *et al.* 2020:954). Sprik *et al.* (2021:1275) concluded that this influences how they engage with the world, leading to chronic anxiety and other mental health sequelae.

### 1.3 The impact on school life

The third sub-theme reflected how children's academic life was disrupted, causing children to miss school for prolonged periods of time. Parents said :

*“My child, he doesn’t go to school since January 2023. The cancer started in 2021, He missed two years of school because of this illness. How is he going to know things, how is he going to pass.?” (P3)*

*“My child has the ability to go to school but because of what the treatment has done to my child, she’s scared. She lost hair, she is disfigured because of the treatment. She believes the children at school will make fun of her.”* (P10)

Not only was academic progress jeopardised, causing children to fall behind academically, but childhood cancer also extended beyond the medical and academic realm, influencing social interactions, as children who had lost their hair were stigmatized and jeered at. Abrams *et al.* (2016:179-180) concurred saying that children with cancer experience physical limitations, that extend to school attendance. Prevatt, Heffer, and Lowe (2000:447) further corroborated these findings saying that childhood cancer patients, were found to miss a total forty days of school per year during their treatment phase. Siegwart *et al.* (2022:1) argued that the visible signs of illness amongst paediatric patients, led to unwanted attention or bullying. This further compounds the stress being experienced, which can negatively impact a child's mental health, thereby exacerbating their anxiety, depression, and other emotional difficulties (Knott *et al.* 2022:9).

Two doctors supported these findings saying :

*“Many of our patients that we see who are admitted and come to the clinic stopped going to school because of the treatment, expense, and the toll the treatment has on their body. Some of them repeat grades and some have completely stopped going to school all together.”* (Dr 8)

"*For adolescents, the first question they ask is about 'missing schooling'. Many of them may be appearing to progress in their grades if they're in higher classes. They ask 'Is there going to be a gap? Are they going to miss a year or more than that? They are worried about that."* (Dr 5)

As evidenced the disruption to normal educational life together with the financial burden of treatment, results in children repeating grades or abandoning schooling altogether.

Abrams *et al.* (2016:1-141) wrote in their book, P*aediatric psychosocial oncology: a textbook for multidisciplinary care,* that "education is often initially disrupted at the time of diagnosis and treatment." Hence, although treatment is meant to stabilize and endeavour to cure the cancer, there are consequences for the rest of the child's life. For children between the ages of five and eighteen, treatment encroaches significantly on their participation at school (Trask and Peterson 2016:176) as evidenced by parents in the sample.

### 1.4 Social isolation and withdrawal

The fourth sub-theme reflected experiences of social isolation and withdrawal. Parents described this as follows:

*"Ever since my child has been hospitalized, he is so alone, none of his friends come and visit him. It's like they have forgotten about him and are no longer friends."* (P1)

*"One of the toughest parts of this journey has been witnessing our daughter's isolation from her peers. Cancer treatment often means missed school days and limited social interactions, this makes her feel disconnected and lonely".* (P6)

Parents shared that after a diagnosis of cancer, hospitalization and treatment many close friends abandon them making them feel even more isolated. Li *et al.* (2013:216) supported these findings, saying that children undergoing cancer treatment often face significant social isolation due to their compromised immune systems and the heightened risk of infections. This isolation is however not voluntary, as they try to protect them from potentially life-threatening complications. These precautionary measures however lead to greater social and emotional distress, including feelings of loneliness and disconnectedness from normal childhood experiences, such as playing with friends.

This was evidenced in the narrative of one of the social workers as follows:

*"I have come across so many children that are socially isolated, not because they choose to but because of their circumstances. Due to their weakened immune system and infection risks, children have to and need to limit their social interactions with outsiders. When I consult with the children and their families during my rounds and counselling sessions, I notice how the sense of isolation impacts them… they tell me, aunty I feel of lonely, I miss playing with my friends."* (SW4)

Borrescio-Higa and Valdés (2022:3) similarly said that separation from friends, likeminded individuals and peers enhances children's feelings of loneliness and exclusion, as children miss out on important social interactions and milestones, that are crucial for their social development. Chrapek (2016:27)

added that the lack of regular contact with their peers can hinder the development of social skills which perpetuates the notion that those afflicted with cancer, are different from other children, which worsens their feelings of isolation. Bouchard *et al.* (2023:408) argued that social interactions are a crucial part of childhood development, and when children are deprived of these experiences, it can lead to emotional distress. Deegan *et al.* (2023:819) added that children in such situations often express feelings of loneliness and a deep yearning for normalcy, as described by one of the social workers in the current study.

### 1.5 Fear of medical procedures

The fifth sub-theme focussed on the fear of medical procedures, which parents narrated as follows :

*"My daughter gets extremely anxious. She's terrified of being poked with needles. Even the sight of a nurse approaching with a syringe sends her into a panic. It's heartbreaking to see her so scared, it's a stressful ordeal for both of us." (P7)*

This child's intense fear of needles, create huge levels of panic, which becomes a stressful ordeal even for them as a parent. McLenon and Rogers (2019:30) opined that this was a common experience in paediatric oncology, where frequent medical procedures were necessary. Thakur *et al.* (2023:115) argued that needle phobia, is well-documented amongst paediatric patients, with studies revealing that up to 50% of children develop significant distress related to needles. Hence a child's panic at the sight of a syringe, underscores the anticipatory anxiety that they experience with each medical encounter. Wikman *et al.* (2018:950) added that anxiety is not only debilitating for the child,

but also emotionally taxing for the parent, as narrated by one of the parents. Nelson *et al.* (2017:1751) supported this saying parents often feel helpless and burdened by their child's suffering, which can lead to increased parental stress and anxiety disorders amongst them.

A doctor and nurse shared their experiences as follows:

*"One of the most common fears among our young patients is the fear of needles. The repeated blood draws, IV insertions, and injections can be incredibly traumatizing. We try our best to use techniques like distraction, numbing creams, and child life specialists to ease this fear, but it's a significant challenge for many children." (Dr 5)*

*"No child likes to be poked and seeing their blood and when I do have to take their blood, they scream and cry which makes it very difficult, but we just have to wait and bribe them with sweets." (N11)*

As evidenced, repeated blood draws, injections and drips were very traumatic for paediatric patients. McLenon and Rodgers (2019:30-31) supported these findings saying that the fear of needles is a profound and pervasive issue, amongst childhood cancer patients. Al-Ansari *et al.* (2024:17) explained that because paediatric patients often undergo several invasive procedures, including blood draws, intravenous insertions, and chemotherapy injections, they can develop a deep sense of dread and anxiety, which reinforces their aversion to medical procedures. The anticipation of these procedures often results in them crying, screaming, putting up resistance physically, and having panic attacks. The mere sight of a medical professional or the approach of a treatment room, creates immense distress and the continued anticipatory

anxiety can disrupt their sleep, appetite, and overall sense of security, making each hospital visit a traumatic event.

McLenon and Rodgers (2019:30-33) argued that healthcare providers and caregivers should therefore be capacitated to manage this intense fear, whilst ensuring that the necessary medical procedures are performed. As one of the nurses mentioned she had to use sweets to distract the child from the imminent blood drawing of their blood. The fear of needles however remains a constant presence along the treatment journey for many young cancer patients (Hendricks *et al.* 2019:2), which can hinder compliance with treatment protocols, prolong procedure times, and contribute to negative feelings regarding medical care, that may influence their willingness to seek medical help in the future. Koumarianou *et al.* (2019:104) argued that medical health support was crucial, not only for the immediate comfort of the child but also for their long-term psychological well-being and overall treatment experience.

### 1.6 A deep fear of the unknown and recurrence of the disease

Parents shared that their children feared their future, as they did not know if they would continue their struggle with their illness and treatment :

*When I am with my child, he always tells me, Mama every day I feel like I am lost, I don't know what is going to happen and I don't like it. I don't know what tomorrow will bring - whether it's another round of chemotherapy, a new side effect to battle, or a glimmer of hope." (P3)*

*"The fear of the unknown makes me so scared. Will I live another day?" (P5)*

*"My child is the eldest from all the children here in the ward and one day she said to me "the fear of the unknown follows me everywhere since my cancer diagnosis Mum. The fact that I do not know what is going to happen next is scary, what the next scan might tell me about my health and progress. I constantly worry about the future." (P12)*

Collectively these responses reflect the children's fear of the unknown, which is real within the context of a disease like cancer The uncertainty about future medical outcomes, such as scan results or whether their treatment would continue, create a constant state of worry, making it difficult for both children and their families to find peace or emotional stability.

Koutná *et al.* (2021:4) similarly argued that the fear of the unknown, was a pervasive and debilitating aspect of childhood cancer, which affected the psychological well-being of young patients. Kang (2023:11) added that children diagnosed with cancer face an unpredictable journey filled with several uncertainties, from the nature and frequency of treatments to the potential side effects and the overall prognosis. Wroot *et al.* (2022:1132) explained that this constant state of unpredictability, generated significant anxiety, as children struggled to cope with the notion that each day could bring rapid changes. This was evidenced in one of the narratives where a participant said, "Mama, every day I feel like I am lost," and "the fear of the unknown makes me so scared." This highlights the emotional turmoil caused by unpredictability of the trajectory of the disease and how it silently creates little certainty regarding their recovery.

Watts and Munir (2024:3) emphasized that the fear of recurrence of cancer, rests heavily on the minds of childhood cancer patients and their families,

casting a perpetual shadow over their lives, even after successful treatment protocols. This pervasive anxiety stemmed from their understanding that cancer, was unpredictable in nature and could resurface at any time, disrupting their sense of normalcy. Children who have undergone the cancer journey of cancer, often fear that the next scan or symptom, could signal a relapse (Kazak and Noll 2015:426). Parents too, grapple with the lingering dread of their child's illness and are often haunted by the uncertainty of this disease. Bouchard *et al.* (2022:428) argued that despite efforts to provide reassurance and follow-up care, this fear of the recurrence of cancer, is still an enduring aspect of childhood cancer.

Social workers and a doctor in the sample supported these views, saying that the fear of their patient's fear was very real. They said:

*During my session with a child, he told me in a very poetic way shall I say, "the unknowns are endless, but I hold onto the small comforts and moments of joy that I get everyday." (SW4)*

*"Many of our young patients and their families experience significant anxiety about the possibility of the cancer returning. This fear is understandable given the life-threatening nature of their initial diagnosis. We try to provide regular follow-up care and reassurance, but the psychological impact of this fear can be profound and long-lasting." (Dr. 1)*

*"The fear of recurrence is a common and persistent concern among childhood cancer survivors. Even after successful treatment, these children often live with the anxiety that the cancer could come back. This fear can affect their ability to fully enjoy life and engage in normal activities, as they're constantly worried about their health and future." (Sw2)*

According to Henneghan *et al.* (2022:657), the haunting uncertainty of their health, requires efforts by healthcare providers to offer reassurance and follow-up care. This was important as Söntgerath *et al. (*2022:743) said that the fear of the unknown, often prevents children from enjoying life fully, engaging in normal activities, and looking forward to the future with confidence. This underscores the need for mental health support within the milieu of their cancer treatment and recovery.

Tutelman and Heathcote (2022:1959) described the fear of cancer recurrence (FCR) as “the fear, worry or concern relating to the possibility that cancer will come back or progress”. A few studies have examined the fear of cancer recurrence (FCR) amongst paediatric samples. Wroot *et al.* (2020:1132-1140), reported that 43% of childhood cancer patients and survivors endorse fear about the possibility of their cancer returning. In a later study, Koutná *et al.* (2021:1-13) found that the fear of cancer recurrence was positively associated with both symptoms of post-traumatic stress and post-traumatic growth amongst children.

Medical vigilance and psychosocial support are therefore crucial to helping children and their families, navigate the emotional challenges of the cancer journey, in a way that will enable them to confront their anxieties and embrace life beyond cancer with courage and resilience.

### 1.7. Physiological effects of both cancer and treatment

The debilitating physiological effects of both cancer and treatment on the child emerged as the final sub-theme, under theme one. The doctors and social workers shared the physical effects of the disease and treatment, saying that

it caused persistent fatigue and weakness, stunted growth and development, compromised children's immune systems and caused pain and discomfort.

*"Cancer and its treatment we recommend often result in extreme fatigue and weakness in children. Chemotherapy, radiation, and other treatments significantly lower their energy levels, thus making it difficult for the children to partake in regular activities in the ward. We see the persistent tiredness in the children during our morning rounds and handover."* (Dr 1)

*"Children with cancer encounter so many nutritional challenges subsequent to the side effects of treatments. Nausea, vomiting, loss of appetite, and difficulty swallowing are some of the challengers they go rough which can lead to weight loss and malnutrition. Therefore, we ensure that children receive the adequate nutrition needed and is essential for their overall health and ability to cope with the rigors of cancer treatment."* (Dr 9)

*"The children in the ward easily catch infections because of how weak their immune system is. We have to isolate them in our rooms and at times, console them, other form of therapy and treatment is paused until they are able to receive treatment. As a result the primary doctors have to re-evaluate their patient plan." (Sw 1)*

*"Cancer and its treatments causes significant pain and discomfort in children. Tumours cause pain by pressing on organs or nerves, and treatments such as surgeries, radiation, and chemotherapy can result in side effects like mouth sores, nerve pain." (Sw 2)*

These narratives reveal the severe physical toll that cancer and its treatments has on paediatric patients, ranging from a loss of appetite, vomiting, compromised immune systems, as well as pain from the tumours or procedures like surgery or radiation. Hill-Kayser *et al.* (2024:558) argued that chemotherapy agents and radiation therapy, causes myelosuppression, a

condition that occurs when bone marrow activity is decreased and produces fewer white blood cells, red blood cells, and platelets. In addition, certain malignancies that metastasize to the bone marrow (e.g., leukaemia, lymphoma, neuroblastoma, sarcomas), cause a decrease in the number of normal blood cell precursors. When the myelosuppressive effect is severe enough, the child consequently becomes predisposed to infection, anaemia, or bleeding, depending on which blood cell line is affected.

Parents shared similar experiences regarding the effects saying:

*"My child is always so tired."* (P5)

*"My child lost weight because of the treatment she is receiving, which was chemo and radiation."* (P1)

*"My little baby gets sick so easily now because her immune system is not that strong compared to before."* (P15)

*"My child cannot keep anything down. He always vomits his food and liquids, especially after chemo."* (P11)

These recurring themes of fatigue, weight loss, weakened immunity, and gastrointestinal distress reflects the harsh physiological effects of both cancer and cancer treatment and the physical decline amongst children with cancer. Li *et al.* (2013:218) supported these findings saying that children who are childhood cancer survivors, are at risk of adverse physical effects of the cancer treatment, resulting from chemotherapy toxicities, radiation or secondary cancers. The side effects may last for years post completion of treatment, severely affecting a child's mental well-being. Abuladze *et al.* (2022:8) further noted the huge physical decline, from the point of diagnosis, through to the duration of their treatment. Bauer *et al.* (2011:34) reported that up to 46 % of

paediatric oncology patients experience malnutrition or weight loss. Oliveira *et al.* (2023:111) explained that weight loss during chemotherapy is linked to the side effects of treatment, which can cause taste changes, a dry mouth, nausea, vomiting, anorexia, mucositis, or other conditions which affects appetite and food intake.

## 4.3.1.2 THEME 2: IMPACT ON THE FAMILY

The second theme that emerged from the data was the impact on the family. This theme coalesced into seven sub-themes, which included (I) mental health distress encountered by parents; (II) financial difficulties; (III) disruption of normal family life; (IV) instability within the marital relationship; (V) the pain and anguish of mothers; (VI) disruption of career and (VII); lack of knowledge regarding child's cancer diagnosis. The first sub-theme focused on mental health distress encountered by parents

### 2.1 Mental health distress encountered by parents

Theme one captured how children transitioned through their journey with cancer. Theme two, explored how parents and the family unit itself was affected. The psychological distress experienced by parents, was evidenced as follows :

*"I became afraid because my other child died of liver cancer. At the time he died, I didn't know anything about cancer. It was just something that came up abruptly, but now, when I was told, I became more afraid that I was going to lose another child to cancer"* (P3)

*“My daughters’ neutrophil count wasn’t rising; it got to a time the doctor prescribed another medication which was very expensive. When my husband checked on that medicine, it has 50% efficacy. They were changing drugs for her frequently, yet her temperature was still rising. I was anxious and shaking. It was a turbulent time” (P5)*

*“I feel traumatized because I had to leave my other children at home. Although my sister brings them regularly to the hospital, it is not easy for me. I take care of my children by myself so leaving them in another person’s care is emotionally traumatizing”* (P7)

*“I feel sad, unhappy, and most often isolated. I am hurt and heartbroken. I don’t go anywhere because I feel pity for myself. My daughter recalls all the experiences since the illness started. Sometimes when she sees pupils in their uniform around the hospital, she would say if not for her sickness she would have been in school. This makes me sorrowful.”* (P9)

These narratives reflect the deep mental health distress experienced by parents, particularly their feelings of fear, anxiety, trauma, and helplessness. As evidenced parents experienced intense emotional turmoil which came from a deep fear, that they would lose their child. One parent had already endured the loss of a child, whilst the other had deep anxiety over her child’s blood count results. Others had to struggle to navigate the complexities of their child's illness amidst their other parental roles, whilst coming to terms with the fact that their child’s normal school life, had been disrupted and their social connectedness to their peers affected.

Research has documented that parents experience a wide range of psychological and emotions, when their child is diagnosed with cancer (Cuviello *et al.* 2022: 1033; Salins *et al.* 2022:175; Kelada *et al.* 2019: 1537–1547). Family members often suffer various forms of distress (Tutelman *et al.* 2020:1964) with regards to the child’s illness, ranging from feelings of anxiety, depression, post-traumatic stress disorder (PTSD), sleep disturbances,

somatic symptoms, fear of disease recurrence and constant worry and fatigue (Koumarianou *et al.* 2020:2). This distress further extends itself to concerns regarding the adjustment of the child's siblings (Toro 2024:26). Nurjanah *et al.* (2022:1-2) opined that parents whose child is confronted with cancer, carry a sense of guilt, worry and sadness which is experienced for a long time. They added that parents of children with paediatric cancer inadvertently spiral out of control psychologically, which influences and affects other family members and the child. Like the participants in the current study, Bouffet *et al.* (2020:1-5) argued that parents feel a sense of guilt and feel responsible for what has happened to their child. They even hope to bear the illness of their children. Carlsson *et al.* (2019:211) therefore argued that parents require emotional support to heal and care for their children.

Cahalan *et al.* (2022:1-11) indicated that parents who are overwhelmed by fear or depression often become incapable of dealing with their child's illness. A recent scoping review conducted by Hrdlickova *et al.* (2021:166), revealed that parents were sometimes so troubled and upset, that it decreased their ability to listen to and understand the information being shared by physicians. Others still have to juggle their other parental duties, as shared by one participant who said that she felt traumatized at the fact that she had to leave her other children at home. Although her sister brought them regularly to the hospital, she still struggled with this separation and the fact that she had to relinquish her other children into her sister's care.

Bartholdson *et al.* (2022:1-11) noted that there is an expectation that parents would be able to juggle a number of roles and responsibilities, which includes them trying to retain a semblance of normality within the home, by continuing their tasks of cleaning, preparing meals and doing the washing for the family as a whole, whilst simultaneously caring for their ill child. This was often done whilst they spent significant amounts of time, staying at the hospital with the child and/or attending clinics with them (Miyagishima *et al.* 2024: e12572).

Wiener *et al*. (2017:2109–2117) said that childhood cancer affects all family members. They added that in families where children had leukaemia, the impact of the disease on parents psychologically was the strongest. Sisk *et al.* (2018:1-20) stated that the diagnosis of cancer is difficult to accept for many parents who often react with shock and emotional distress. They described feeling vulnerable, powerless, angry, confused, anxious and fearful.

As result of this parents often experience burnout symptoms associated with emotional exhaustion because of prolonged stress (Koumarianou *et al.* 2020:3). They feel an acute sense of loss upon learning of their child's diagnosis and report huge feelings of sadness. Liu *et al*. (2022:1-11) argued that parents grieve for their child, even when their prognosis is good. They grieve the loss of normalcy realizing that life will never be the same and they are forced to modify their dreams and aspirations for their child. Even when parents overcome these feelings of helplessness, they are confronted by periodic episodes of fear, panic, and anxiety. In this vein, Jessop and Phelan (2022:1390) argued that after the initial shock of diagnosis, parents often react to their child's illness with denial, disbelief, anxiety, bitterness, anger, and helplessness. Sometimes they blame themselves for illness of their child. Robinson *et al.* (2019:1-12) however argued that chronic parental sorrow should not always be regarded as completely detrimental, as there are times when it helps families to benefit and grow.

A literature review conducted by Nurjanah *et al.* (2022:1-11) concluded that parents who have a child with cancer, experience stress, anxiety about losing a child, uncertainty with regards to child treatment, difficulties in caring for children and family responsibilities. Some scholars have contended that some parents never overcome the initial sadness and grief (Stegemann *et al.* 2019:1-12). Huang *et al.* (2023:685) suggested the need for more enhanced psychosocial, material, and social support for their parents. Maurice-Stam

(2022:6839) added that because of the declining health condition of their children, greater material resources are required by parents of children suffering from cancer. The financial distress confronting parents is presented in the sub-theme that follows.

### 2.2 Financial difficulties

The second sub-theme that emerged under theme two, reflected the financial distress experienced by parents of children with paediatric cancer. This was shared by them as follows:

*"We had to make the difficult decision for one of us to leave our job to care for our child full-time and be at the hospital. As the mother, I decided to leave my job. The loss of one income, coupled with the added medical expenses, hit us hard. We used our savings within a few months and had to rely on family and friends for financial support. It was not just the medical bills; it's the everyday expenses like groceries, paying lights and water and mortgage payments that become overwhelming when you suddenly lose half of your household income." (P2)*

*"Even with health insurance, we were overwhelmed by the out-of-pocket costs. Our plan had a high deductible, and not all treatments were fully covered. We received bills for things we thought were covered, like certain medications and specialist consultations. The constant stream of medical bills, coupled with confusing insurance statements, made it difficult to keep track of what we owed and to whom. We eventually had to take out a second mortgage to manage the debt." (*P5)

*“I run a small tuck shop by home and I’m always here with my child. Since always being here the business is running no income.” (P6)*

*"The financial stress affected our entire family, not just my ill child but we had to cut back on activities and extracurriculars for our other children, which made*

*them feel neglected and added to their emotional burden. We also had to rely on extended family members to help with childcare and household chores, which strained our relationships."* (P7)

*"The financial plans my husband and I made has gone out the window. We had been saving for our children's university funds and our retirement, but we had to dip into those savings to cover immediate expenses. We also accumulated credit card debt to manage day-to-day costs. Now, we are years behind in our financial goals, and the prospect of future financial security feels very unstable."* (P8)

These narratives highlight the financial hardship experienced by parents, from the onset of their child's cancer diagnosis through to their hospitalization, and treatment. One parent had to leave her job to provide full-time care to her child, which significantly affected the loss of household income. This, together with accumulating medical expenses and daily household expenses, and mortgage payments, depleted the family's savings, causing them to rely on family and friends for support. Adu-Assiamah (2022:3) also pointed out that the prolonged hospital stays, and duration of treatment impacted the employment status of parents.

They argued that costs linked to a child's treatment and care was a huge burden that parents struggled with. Most of them used up all their savings, in their quest to seek optimal treatment for their sick child. They however still needed to provide food, clothing, school items and other resources for their other children. Ataguba and Goudge (2012:633) pointed out that, out of pocket, is the only mode of payment that parents can use to meet the expense of chemotherapy, diagnostic tests such as computerized tomography scan and pathology treatment, due to its high costs.

Scholars have argued that that the stressors linked to finances often have a long-term effect on their quality of life (Islam *et al.* 2021:3). The direct costs for a child who has cancer includes hospitalization, treatment, medication, diagnosis, travel, accommodation, and food. The indirect costs that parents encounter include loss of income, unofficial payment, and family costs, which at times leads families into poverty, due to the catastrophic health care expenditure linked to a child's cancer. These financial hardships affect families for years after an initial diagnosis and treatment, due to the late effects of treatment, employment disruptions, and unexpected hospitalizations (Kelada *et al.* 2020:4-5).

One of the doctors in the sample confirmed the financial distress experienced by parents, saying:

*"Over my years at the hospital I have witnessed numerous families struggling to cope with the demands of childhood cancer treatment. Parents are often forced to take extended leave from work or even quit their jobs, leading to significant financial instability. This economic pressure adds to the emotional strain, creating a volatile environment at home where conflicts are more likely to arise."* (Dr 6)

Another parent shared how transport costs began to overwhelm her family. She said,

"L*iving in a rural area meant that my child and I had to initially travel over 200 miles to Albert Luthuli. The cost of transport, staying overnight, and eating food quickly added up. Sometimes we had to stay longer because the clinic line was too long or there was a problem. The financial burden when we had appointments of just getting to and from the hospital was something we haven't thought about."*

Islam *et al.* (2021:3) reinforced this finding saying that parents often had to travel long distances to access specialized paediatric oncology treatments, leading to significant costs for transportation, accommodation, and meals. Travel requirements, also result in loss of income, due to time taken off work, adding to their financial distress. Santos *et al.* (2016:1008) further wrote that the frequent travel visits to the hospital, also disrupts family routines and can create emotional stress, as parents struggle to balance the needs of their sick child with those of their other children and work responsibilities.

Notably, these financial difficulties continue following the death of a child, as parents then have to endure funeral expenses and difficulties in returning to the workforce. Davis *et al.* (2022:2) stated that whilst financial hardships are associated with reduced psychosocial wellbeing amongst parents of children undergoing cancer treatment, this relationship is not as well studied, among cancer-bereaved parents, who may be at even greater risk for negative psychosocial outcomes.

### 2.3 Disruption of normal family life

The third sub-theme that emerged from the data reflected how family life was destabilised. This was narrated by the parents as follows:

*"When our daughter was diagnosed with leukaemia, our world turned upside down. We had to relocate initially to be closer to a specialized hospital, which meant leaving our jobs, friends, and community behind. The financial burden was immense, and my husband and I found ourselves constantly arguing about money when I went back home and how to manage our time. Our other children felt neglected, and the tension at home was noticeable and felt."* (P4)

*"The emotional toll of seeing our son in pain was unbearable. My husband and I had to take turns staying at the hospital, which meant we were rarely home together. This physical and emotional separation strained our relationship. Our other children started acting out, because lack of attention and the stress they sensed from us. It felt like our family was falling apart."* (P6)

*"The long hospital stays meant one of us was always away from home. Our youngest started having trouble in school because we weren't there to help with homework or attend parent-teacher meetings. The disruption in our family routine created a lot of anxiety and frustration for everyone."* (P15)

As evidenced parents endured immense emotional upheaval and their attention towards the child who was sick, caused them to neglect their other children. Their marital relationships also fell apart with the stress, with one parent saying that she barely had time to talk to her husband or emotionally support him. Borrescio-Higa and Valdés (2022:1-2) supported this notion, saying that parental distress impacts the quality of family life, family functioning, and can create marital distress which further influences the well-being of both the sick child and other healthy siblings.

Lewandowska (2022:9) described the diagnosis of childhood cancer as one of the most stressful experiences for a family. Hosoda (2014:18) added that the family system encounters many new stressors, and special challenges and demands, associated with frequent hospitalizations, difficult and painful therapies, uncertainty regarding the course of illness, potential loss of life and loss of hope for the future. Family life as it was before, is therefore often lost. Childhood cancer as evidenced in the narratives, reverses the cycle of family life, forcing parents to redefine their personal philosophy of life and death, their goals, expectations, hopes, and dreams for their child and family.

Koumarianou and Kattamis (2020:1) pointed out that taking care of the sick child created many additional duties and new roles that a parent had to assume. The disease changes the structure of the family and the relationships between its members, making it necessary to reorganize current life and change family roles to cope with these additional roles.

Borrescio-Higa and Valdes (2022:1-14), conducted a study on the psycho-social burden experienced by ninety families of children with blood-related cancer in Chile. Interviews with patients, caregivers, and siblings found that relationships within the household between the patient and their parents, between siblings and parents and within the caregiver's spouse/partner relationship were strained. They also found that the occupational conditions of the primary caregivers were negatively affected. In addition, the paediatric patients reported a range of negative feelings, such as depression, discouragement, and irritability.

Similar findings were made by Siemińska and Greszta (2008:192-201), who found that a child with cancer, had a disrupted family life. One of the parents in their study said that seeing their son in pain was unbearable and that she and her husband had to take turns staying at the hospital, which meant they were rarely at home together. This led to their other children acting out due to the lack of attention and the stress they sense from their parents, which further destabilized the family unit. The physical absence of one parent, due to one parent remaining with the sick child in the hospital, disrupts normal family dynamics and contributes to a feeling that the family was falling apart (Siemińska and Greszta 2008:192-201).

A doctor and the social workers in the study, reaffirmed how the frequent hospitalizations and emergencies related to a sick child had affected families as follows:

*"This focus on unpredictable nature of cancer treatments, with their frequent hospitalizations and emergencies, means that parents have to constantly readjust and adapt to their schedules. This unpredictability can cause immense stress, especially when other children in the family need attention and stability. Parents often report feeling guilty and inadequate, which can exacerbate marital tensions and lead to further instability."* (Dr 8)

*"The families that I am assigned to are dealing with a lot of things and often experience a breakdown in communication. I see this in most families, particularly with parents that where it leads to a sense of isolation and resentment, further destabilizing the family unit."* (SW2)

As evidenced the unpredictable nature of cancer and treatments, disrupted family stability, exacerbated existing stresses and caused immense strain within the marriage and family. Parents had to constantly adjust their schedules, which results in other children being neglected. The additional financial burden and medical responsibilities of the primary caregivers caused them to become overwhelmed, and depleted of energy, leaving them unable to nurture their marital relationship, leading to greater feelings of isolation, conflict and resentment.

Meyler *et al.* (2010:1116) wrote that the lack of communication and emotional support between partners, can lead to feelings of isolation and resentment, destabilizing the family unit further. Hopkinson (2021:451) further concluded that parents often felt guilty and inadequate, which exacerbates marital tensions, leading to further instability. The cumulative effect of these stressors on the marital dyad and family underscores the need for strong mental health support, to help families navigate the complex and challenging journey of childhood cancer. The impact on the marital system is discussed in the fourth subtheme that follows.

### 2.4 Instability within the marital relationship

The fourth sub-theme that emerged under theme two, reflected the tensions within the marital relationship. Most of the participants shared how a diagnosis of childhood cancer had impacted their relationship with their spouse as follows:

*“I had to leave my husband at home because my child wanted me to stay with him. Since then, my relationship has been rocky with my husband.”* (P1)

*“My spouse and I barely had time to talk, let alone support each other emotionally. It felt like we were drifting apart, just trying to survive day by day."* (P15)

*“I felt like I was losing both my son and my wife. My wife and I stopped communicating effectively. She was always at the hospital, and I was always at work. We lived in the same house but were worlds apart. Eventually, we both started to consider separation because the stress and emotional distance seemed insurmountable. The love was still there, but the connection was lost."* (P10)

*“I am currently not with my child’s biological father; we broke up when she got diagnosed. He said he wanted nothing to do with this.”* (P4)

These narratives highlight the strain that childhood cancer bears on the marital relationship, often causing tension, emotional disconnectedness and potential separation. One participant described how he felt that he was losing his wife,

because they had stopped communicating, as she was always at the hospital and the stress of having an ill child had become insurmountable. Gerhardt *et al.* (2016:143) similarly wrote that parents often feel that their marriage is put on hold, as they devoted their time to their sick children while juggling other daily life tasks (e.g., household chores, work, or caring for other children). Consequently communication, shared decision making, and closeness decreases whilst loneliness increases.

Watts and Munir (2024:2) made similar findings saying that parents of children with cancer, experienced increased marital distress and strain, soon after a child's diagnosis. This diagnosis of childhood cancer however not only affect individuals within the family, but also relationships between other family members too (Lavi *et al.* 2019:1244). Borrescio-Higa and Valdes (2022:1-14) noted however that one of the most vulnerable relations that are affected is that of marital relationships. Studies exploring the marital relationship, in families of children with cancer found a decrease in the quality of the marital relationship and particularly in the area of intimacy (Nicholas *et al.* 2009:260-275).

The anxiety, fear, and grief associated with the child's illness often overwhelms parents, leading to a breakdown in their communication as a couple (Plant and Adams 2023:309). Nelson *et al.* (2017:1751) argued that effective communication underpins a relationship, but the stress of a child's illness, can make it difficult for parents to express their feelings and support for each other. The emotional disconnect, shared by participants in the current study, can erode the marital bond, leading to feelings of isolation and helplessness (McLoone *et al.* 2022:1).

Libes *et al.* (2023:2) said that the physical task of caring for a sick child is often naturally relegated to the mother, who becomes increasingly preoccupied with her child. Joaquim *et al.* (2023:133) added that this separation could create resentment, as the non-caregiving parent, may feel neglected, whilst the caregiving parent, can feel overwhelmed and unsupported, thereby exacerbating the emotional strain between the couple (Jeon *et al.* 2024:948). Parents often cope with their child's illness in different ways, which can create conflict and misunderstanding. One parent might seek solace in support groups and therapy, whilst the other might withdraw or immerse themselves in work (Esbenshade *et al.* 2023:3629). Kiaos (2023:1) argued that the inability or unwillingness to cope with this new and painful situation can lead to a breakdown in the relationship.

One of the doctors in the sample similarly reported:

*" I've seen numerous cases where the constant anxiety and fear drive a wedge between parents. They often argue about treatment decisions, financial matters, and parenting styles for their other children. The lack of intimacy and time spent together as a couple exacerbates these issues. In some instances, the relentless strain contributes to separations or divorces. It's a stark reminder of the need for holistic care that includes mental health support for the entire family."* (Dr4)

The constant anxiety and fear associated with a child's cancer diagnosis can lead to arguments about various issues including treatment decisions (Ji *et al.* 2018:6). The lack of connection and increased conflict can cause couples to drift apart from each other, making it difficult for them to support one another emotionally (Atun *et al.* 2020:185).

A social worker added:

*"The reality is that many relationships struggle significantly when a child is diagnosed with cancer. The intense focus on the child's needs often leaves parents with little time or energy for each other. In my experience, I've seen couples where one parent becomes the primary caregiver, and the other feels sidelined or helpless. This can lead to resentment and a sense of isolation. Financial pressures and differing coping mechanisms further strain the relationship. In some cases, these stresses can become too much to bear, resulting in separation or divorce. It's a heartbreaking but not uncommon outcome."* (SW1)

These excerpts exemplify the need for greater psychological support and marital counselling, to help these couples cope. The financial burden associated with childhood cancer treatment, travel expenses for treatments, and the potential loss of income, creates substantial financial stress that impacts the marital relationship. The financial pressures combined with differing coping mechanisms, often leads to resentment and isolation, sometimes resulting in separation or divorce (Deribe *et al.* 2024:1).

Another the social worker highlighted how cultural values also influenced discord between a couple as follows:

*“A lot of marital instability arises from the fact that cultural pressure is being inflicted onto the parents. One parent is on board with the medical treatment versus the other parent who focuses on the traditional sense.”* (SW 4)

Disagreements over treatment approaches can also create tensions, when one parent supports conventional medical treatment approaches, whilst the other leans toward traditional or cultural remedies (Kaptacz 2018:137).

### 2.5 Pain and anguish experienced by mothers

Another significant thread emerging was the deep pain and anguish of mothers in the sample. They shared this as follows:

"*The day my daughter was diagnosed with leukaemia felt like the ground was ripped out from under me. The next few months were a blur of chemotherapy, hospital stays and watching my once energetic child become frail and weak. Every time she cried in pain, I felt helpless, The nights were the long, praying for a miracle and battling my own silent tears. I was breaking.*" (P4)

*"My daughter's diagnosis felt like a nightmare. I felt a constant guilt thinking if I had missed any signs earlier or if there was something. The pain was relentless, a heavy weight on my chest every second of every day."* (P5)

*"The fear of losing him was always present, a dark cloud that overshadowed every moment of our lives. I felt like I was living in a perpetual state of grief, mourning the healthy life he should have had."* (P12)

"*Seeing her hooked up to machines, watching her strength fade was torture for me. The emotional pain and the loneliness… I felt isolated in my grief, watching my child suffer and feeling powerless to stop it. I wouldn't wish on anyone."* (P13)

These narratives portray the deep pain, anguish and emotional turmoil experienced by the mothers. They reflect their fears, isolation, and their profound sense of helplessness, at having to come to terms with their child's illness. Adedokun (2020:2) described the pain of mothers whose children have cancer, as complex and multidimensional. Henneghan *et al.* (2022:657), stated that it feels like a sudden, life-altering shock, that plunges mothers into a world of sterile hospital rooms, grave-faced doctors, and an overwhelming sense of disbelief and helplessness. This was reflected in one of the mother's narratives that watching her child endure painful treatments, such as chemotherapy and surgeries, had torn her apart daily. This pain is compounded by the emotional and social isolation that mothers feel, as friends and family struggle to understand their suffering or drift away, unsure of how to support them (Hughes *et al.* 2022:76).

Nelson *et al.* (2017:1751) said that for most of the time, the hospital becomes a second home, a place where mothers are forced to learn medical jargon and become an advocate for their child's care, while the world continues with life. The constant presence of fear creates an all-consuming agony, that overshadows every aspect of her life (Toledano-Toledano *et al.* 2019:2). Pai *et al.* (2017:207) concluded that these emotions coalesce into a heavy burden, that mothers carry every moment, as they fight to give their sick child, the strength and love needed to endure their harrowing journey.

### 2.6 Disruption of the parental academic career

The sixth sub-theme was the disruption parents experienced to their academic career. One parent said:

*“I completed my LLB degree, and I was supposed to enrol in a prosecution program in February 2023. Due to my child’s diagnosis, I couldn’t attend the program. I am grateful that my child is alive; however, it disrupted my academic and professional career. I had to stop working and forget my career. I had to cancel my research and deregister. I am currently owing the University of Zululand so much of money.”* (P2)

This narrative reflects how the participant who had completed her LLB degree and was provided the opportunity to advance her career by enrolling in a prosecution program, had to abruptly pause her studies because of her child's illness. In this vein Moreira *et al.* (2022:55) contended that childhood cancer significantly disrupts a parent's academic career, as evidenced by the significant personal sacrifice parents make, to prioritize their child's health and well-being. This reflected one participant’s experience as she was unable to continue with her academic pursuits. Pommy *et al.* (2023:2) said that parents are mostly likely to withdraw from educational programs, cancel research projects, and deregister from universities because of their child’s health scares. A child's illness leaves little to no time for academic responsibilities, leading to a complete halt in educational progress and career development (Sasi *et al.* 2022:1671). This interruption can have long-term consequences, delaying or even derailing academic ambitions and professional goals (Stenka and Izdebski 2018:306).

According to Pritchard-Jones *et al.* (2013:96), the financial burden associated with childhood cancer impacts a parent's academic career. In addition to the loss of income as parents have to stop working, they often face other significant medical expenses (Roghani *et al.* 2024:138). This financial strain adds to their stress making it harder for parents to return to their studies or resume their career trajectory, once their child's health stabilizes. Schuster *et al.* (2023:108) added that the dual pressures of caring for a sick child and managing financial

instability, can create acute hardship. Hence the need for supportive measures, such as flexible academic programs, financial aid, and mental health resources, to help them navigate these challenging circumstances that can eventually reintegrate them into their academic and professional lives (Bálint and Magyari 2020:128).

### 2.7 Lack of knowledge regarding a child's cancer diagnosis

The last sub-theme emerging under the second theme, focussed on the lack of knowledge that parents had regarding childhood cancer.

One of the doctors said:

"*One of the biggest challenges we face on a daily basis is the gap in knowledge that parents have about childhood cancer. They often come with fears and misconceptions, influenced by their community or media portrayals of cancer. Educating parents is a critical part of our job. We provide detailed information sessions, written materials, and support groups to ensure they have a thorough understanding of their child's condition and the necessary treatments*." (Dr 7)

"*Many parents that we see come to us with very limited knowledge about childhood cancers. This lack of understanding can significantly hinder the treatment process. They often don't know the signs and symptoms, the importance of early detection, or the various treatment options available. We spend a considerable amount of time educating them, breaking down complex information into understandable terms to them."* (Dr3)

A social worker similarly shared:

"*As a social worker, there were many families who have no idea about their child's cancer diagnosis. They are unfamiliar with the medical jargon and the treatment protocols, which creates a lot of fear and confusion. Many parents rely on information from unreliable sources or cultural beliefs that might not be medically accurate. This lack of knowledge can lead to poor decision-making or resistance to recommended treatments*." (Sw 3)

Unfamiliarity with medical jargon and treatment protocols creates further fear amongst parents. This requires that they be capacitated with knowledge and understanding regarding the disease, as suggested by one of the doctors in the sample. This can help resolve the information gap, so that misconceptions around cancer and its prognosis are not perpetuated. Chaudhuri *et al.* (2022:1-19) argued that such misconceptions can hinder treatment, as parents may resist recommended treatments or have unrealistic expectations about outcomes. Some, may fear that chemotherapy could do more harm than good or believe, that alternative remedies could be more effective. Hence breaking down complex information, as suggested by a doctor in the sample, was crucial to educating parents about the realities of cancer and the importance of early and aggressive treatment. This can capacitate parents to become better equipped to support their child's treatment and make decisions in the best interest of their child's health.

Medical social workers therefore play an important role in demystifying a diagnosis and in ensuring proper decision-making and acceptance of sound medical advice, so as not to complicate the child's treatment (Žukauskas *et al.* 2018:190). Social workers can provide comprehensive education and support, helping parents understand the disease, treatment options, and long-term prognosis. This support is revered as an essential component for parents' emotional and mental preparedness, enabling them to cope with the stresses and demands of their child's illness more effectively (Lin *et al.* 2020:701).

The dilemmas confronting parents were shared as follows:

*"When my daughter was diagnosed with leukaemia, I realized how little I knew about the disease. The medical terms were overwhelming, and I felt completely lost in understanding what was happening to her body. The doctors explained things, but it was hard to understand the severity of her condition. I didn't know the difference between the various treatments or their side effects, which made the decision-making process very hard and stressful. It felt like I was always playing catch-up, googling her cancer and types of treatment, trying to understand her diagnosis and what each new piece of information means for her*" (P5)

"*When my son was diagnosed with neuroblastoma, I didn't even know what that meant. We had never heard of this type of cancer before and had no idea how serious it was. The doctors explained it, but it took a long time for us to fully understand the implications.."* (P10)

Both parent's narratives reveal the confusion and uncertainty of understanding what leukaemia and a neuroblastoma was. One parent turned to the internet to strengthen her understanding of her child's condition, as she felt overwhelmed by the unfamiliar medical terminology and the complexity of the information presented by healthcare professionals.

This created confusion regarding the severity and implications of the type of cancer her child had. Aung *et al.* (2012:175) highlighted the importance of understanding the specific type of cancer, so that the various treatment options available, their potential side effects, and the long-term implications for their child's health could be understood. Žukauskas *et al.* (2018:190) argued that a lack of information, created helplessness and fear.

Another parent said:

*"When my daughter was diagnosed with leukaemia, I realized how little I knew about the disease. The medical terms were overwhelming…the doctors explained things, but it was hard to understand the severity of her condition. I didn't know the difference between the various treatments or their side effects, which made the decision-making process very hard and stressful. It felt like I was always playing catch-up, googling her cancer and types of treatment, trying to understand her diagnosis and what each new piece of information means for her*" (P5).

Lin *et al.* (2020:701) opined that proper information was important to improve treatment adherence and contribute to better symptom management. A review by Kaye *et al. (*2018:55) in the United States of America (USA), revealed that clear empathic communication between paediatric oncologists, children and their parents enables better therapeutic alliance and aligns medical management to the expectations of the child and the family. Solid relationships between patients and professional care providers within the context of paediatric oncology, is therefore crucial with hospital staff being willing to listen to the views of the patients and their families and adapt their services (Neighbour 2015:59).

## 4.3.1.3 THEME 3: PSYCHOSOCIAL INTERVENTIONS IN A HOSPITAL SETTING

The third theme that emerged from the data, focused on psychosocial interventions that were available at the hospital for paediatric patients and their families. A total of six sub-themes emerged under this theme, namely (I) nature of psycho-therapeutic services; (II) cognitive behavioural therapy; (III) relevance of educational support; (IV) social work services; (V) recreational therapy and (VI) end-of-life and bereavement support. The first sub-theme focussed on :

### 3.1 Nature of Psycho-therapeutic services

Psycho-therapeutic services include counselling and family therapy within the hospital milieu. Two doctors shared their views as follows:

*"From a medical perspective, I have witnessed significant improvements in my patients who receive individual counselling. It helps them manage the emotional aspects of their diagnosis and treatment, which in turn can improve their overall well-being and compliance with medical protocols. Patients who are mentally and emotionally supported tend to have better outcomes because they are more resilient and engaged in their care."* (Dr.5)

"*One of the most important psychosocial interventions we have here is individual counselling which plays an essential role in the holistic treatment of paediatric cancer patients. It addresses the psychological stress that can impede recovery and impact the effectiveness of treatment*." (Dr 8)

This was supported by a social worker from the sample who said:

"*As a social worker, I see firsthand how individual counselling supports the emotional and mental health of paediatric cancer patients. Many of these children face intense fear, anxiety, and sadness, and having a dedicated space to talk about these feelings is incredibly beneficial. Counselling helps them develop resilience and provides them with tools to cope with their illness, which is essential for their overall well-being and helps ease the burden on their families as well."* (SW 3)

These professionals emphasized the importance of counselling and psycho-social support to help both paediatric cancer patients and their families. Bocioaga (2022:20) opined that individual counselling for paediatric cancer patients, was a crucial component of comprehensive cancer care. The primary focus of counselling cancer patients is the management of a chronic illness, and the emotional, psychological, and social needs of each child diagnosed with cancer (Salem *et al.* 2017:367). This is because the experience of cancer can be extremely traumatic for young patients and can affect their health and overall well-being.

According to Jain *et al*. (2019:3411) individualized counselling provides a safe and supportive environment, where children can express their fears, anxieties, and other emotions related to their illness and treatment. It is tailored to meet the precise developmental and emotional needs of each child, ensuring that the care they receive is effective and beneficial (Salem *et al.* 2017:367). Koumarianou *et al.* (2020:104) indicated that there are several benefits to individualized therapy**.** It offers a space for children to share their feelings about their cancer diagnosis and treatment. The therapeutic setting allows children to explore their emotions, which might include fear, sadness, anger, and

confusion, in a safe and non-judgmental environment. For many paediatric cancer patients, the hospital environment and the medical procedures that they undergo can be frightening, overwhelming and difficult to process (Morgan *et al.* 2022:529). Therapeutic techniques, such as play therapy for younger children or cognitive-behavioural strategies for older ones, can help patients build resilience and find ways to cope with their experiences (Nakata *et al.* 2018:422).

Parents in the sample also supported the need for psycho-therapy saying:

*"Individual counselling has been an important intervention for my son. The therapist helps him express his fears and emotions in a safe space, which he couldn't do with us. It was a relief to see him open up and start to process what he was going through. The sessions also taught him coping strategies, which made a huge difference in his ability to handle the stress and pain of treatment*." (P5)

*"My daughter was really struggling with being alone and fear that came with her cancer diagnosis. Getting counselled provided her with a supportive environment where she could talk about her feelings without worrying about burdening us or making us feel bad. Because of the sessions she has had with the therapist, you can see her self-esteem blossom."* (P10)

They described the transformative effects of therapy, saying it helped their children navigate their fears and anxieties. Moreover it equipped them with effective coping strategies, reducing the trauma of their illness. Moreira *et al.* (2022:55) opined that therapy can help reduce symptoms of anxiety and depression, improve a child's mood, and enhance their quality of life. Morgan *et al.* (2022:529) therefore recommended the need for mental health support for children during their cancer journey. Means and Mowatt (2022:2) stated

that counselling helps children understand the importance of their treatment and prepares them for the physical and emotional challenges ahead. This reduces resistance and fear related to treatment procedures and improves compliance leading to better health outcomes, as patients were more likely to follow through with their prescribed medical protocols and maintain regular follow-up appointments (Davies and O'Connor 2022:1-11).

Family counselling also emerged as important as follows:

*"I have observed that families who participate in family counselling tend to have a more balanced and supportive home environment compared to those families that refuse family counselling. The therapy sessions help address the emotional needs of all family members, not just the patient. This holistic approach can lead to better adherence to treatment plans and a more positive overall experience for the child and their family*." (Dr1)

*"Family counselling provides a safe space for families to address the complex emotions that come with a child's cancer diagnosis. It helps family members articulate their fears, anxieties, and hopes, fostering a supportive environment. The therapy sessions serve as a platform to also educate families about the impact of the illness on their family dynamics and teach them practical strategies for managing stress and maintaining emotional well-being."* (SW3)

Both the doctors and nurses supported the need for family therapy to help parents and their children cope with the complex emotions, related to the cancer diagnosis and to ensure that parents adhere to the child's treatment. Davies and O'Connor (2022:1-11) wrote that therapists have a diverse range of techniques to facilitate open and honest communication that can help family members process each other's experiences and emotions. Family therapy therefore reduces individual stress levels and promotes emotional resilience within the family (Cannon *et al.* 2019:104). Tuinmann *et al.* (2017:377) argued

that because of such therapy, families can develop a stronger support network, and this collective strength can maintain the emotional and psychological well-being of both child and the family. Moreover, support systems will further amplify the family's ability to cope and manage with the challenges of paediatric cancer, ensuring that they do not face their journey alone but rather through guided interventions (Lam *et al.* 2013:21).

These enhanced benefits for families were described by families as follows:

*"Family counselling was transformative for us. It gave us the tools to communicate better and support each other through our son's illness. We learned to express our fears and frustrations in a healthy way and became a stronger, more cohesive unit. The therapist helped us navigate the emotional turmoil and find ways to maintain a sense of normalcy and hope."* (P13)

*"Before family counselling, we were all dealing with our daughter's cancer in our own way, and it felt like we were drifting apart. The sessions helped us understand each other's perspectives and brought us closer as a family, especially for my wife and I. We learned strategies to support our daughter as a team and manage the stress and anxiety together. It made a huge difference in how we coped as a family."* (P11)

Filbin (2019:367) supported this, saying that family therapy creates a structured environment where families can address the challenges, of their child's cancer together. Similar to the narratives of parents, Flores-Toro *et al.* (2023:401), argued that family therapy aims to improve communication, resolve conflicts, and strengthen familial bonds, ensuring that the family unit can provide mutual support throughout the child's illness and treatment. This collaborative approach recognizes that the well-being of the child is intricately linked to the overall health and functioning of the family (Ernst *et al.* 2023:65). From the responses of participants, it was evident that therapy helped each family member to express and manage their emotions effectively.

In conclusion family therapy ensures that children and their family, received the necessary psychological support, crucial to navigating the cancer journey with resilience and hope (Afungchwi *et al*.2022:3; Brown *et al.* 2023:301).

### 3.2 Cognitive behavioural therapy (CBT)

The second sub-theme, cognitive behavioural therapy, emerged as a distinct approach that was being used at the hospitals. Kazak *et al*. (2015:146-158) described it as a structured, goal-oriented form of psychotherapy that can change negative thought patterns and behaviours, to improve emotional regulation and develop personal coping strategies amongst young cancer patients and their families. It provides a framework for understanding and managing emotions, building resilience, and promoting healthier thought processes, essential for coping with the diagnosis and treatment of a life-threatening illness.

Parents described the value of this approach saying:

*"Cognitive behavioural therapy has been instrumental for our family. When our daughter was diagnosed, the emotional turmoil was overwhelming. The techniques we learned through CBT sessions helped us all manage our anxiety and communicate more effectively. It provided us with practical tools to cope with the day-to-day challenges of her treatment."* (P2)

*"The structured approach of CBT was particularly helpful for our child. It gave her a sense of control over her fears and anxieties. By breaking down her worries into manageable parts and addressing them step by step, she felt more*

*confident and less overwhelmed. Seeing her use these skills has been incredibly reassuring for us as parents."* (P4)

As evidenced, cognitive behavioural therapy, appeared to be a tool in helping both the paediatric cancer patient and their family to reduce their fears and cope with their fears and anxieties. Melesse *et al.* (2022:1) described the severe effects of cancer on the child, saying 20–30% of them, experience cancer-related post-traumatic stress disorder (PTSD) and other symptoms of trauma. Moreover, cancer treatments, cause anxiety, mood disturbance, low self-esteem, deficits in motor and physical functioning, sleeping and behaviour problems, academic difficulties, and problems with socialisation for cancer survivors.

According to Phipps *et al.* (2012: 625) cognitive behavioural therapy, has helped children beyond symptom management. Salley *et al.* (2024:413-422) opined that it equips both patients and their families with practical skills to navigate the complexities of cancer care, enhancing their ability to communicate and cope with stressors. As described by one of the parents, it can empower children by breaking down their fears and anxieties into manageable parts. Compas *et al.* (2017:455) suggested that a structured approach which is a key component of cognitive behavioural therapy be adopted. The social workers in the sample supported this saying:

*"CBT is a cornerstone of our psychosocial intervention program. It empowers children to understand and manage their thoughts and feelings, which is crucial when they are facing a life-threatening illness. The cognitive restructuring techniques are particularly effective in helping them challenge irrational fears and develop healthier thought patterns."* (SW1)

*"We integrate CBT into our holistic care approach because it addresses both the psychological and behavioural aspects of cancer treatment for the children. It's not just about reducing anxiety or depression; it's about equipping children with coping skills that they can use throughout their lives. This approach also involves parents, helping to create a supportive environment for the child."* (SW 6)

The doctors and nurses further attested to its benefits, supporting the parents by saying :

*Cognitive behavioural therapy has proven to be highly effective in our paediatric oncology unit. By focusing on changing negative thought patterns and behaviours, CBT helps our young patients manage the psychological stress of their diagnosis and treatment. We've seen significant improvements in their ability to cope with procedures and adhere to treatment regimens."* (Dr 8)

*"The integration of cognitive behavioural therapy into our treatment protocols has had a noticeable impact on patient outcomes over the years. Children who participate in cognitive behavioural therapy sessions tend to show better emotional resilience and a more positive outlook. This not only enhances their quality of life during treatment but also supports their long-term psychological health."* (N9)

As evidenced cognitive behavioral therapy, helped to alleviate immediate anxiety and develop a sense of mastery that was crucial for children's emotional well-being during and after treatment (Salem *et al.* 2020:1-12). Social workers also supported its integration into paediatric oncology, saying it helps children cope with any irrational fears they have and develop healthier thought patterns. Kazak *et al.* (2015:147) added that it helps children develop

critical cognitive skills, enabling them to confront and reframe irrational thoughts, thereby promoting healthier emotional responses and build resilience.

A study conducted by Zeltzer *et al.* (2009:2396-2404) on the psychological status of childhood cancer survivors, found that the integration of CBT into treatment protocols, has demonstrated significant improvements in patient outcomes. One doctor in their sample similarly said, "children who participate in cognitive behavioural therapy sessions tend to show better emotional resilience and a more positive outlook". Another highlighted that cognitive behavioural therapy "helps our young patients manage the psychological stress of their diagnosis and treatment". Hence cognitive behavioural therapy not only enhances quality of life during treatment, but also supports long-term psychological health, contributing to better adherence to treatment regimens and improved overall outcomes.

**3.3 Relevance of educational support**

The third sub-theme focused on the importance of educational support. One of the medical doctors said:

*"One of the key aspects of our care program is providing comprehensive educational support to the families of our paediatric cancer patients. We understand that the diagnosis and treatment process can be overwhelming, so we make sure to offer detailed informational assistance."* (Dr 7).

Similarly, a social worker expressed that:

"*I see firsthand the difference that educational support can make for families dealing with a child's cancer diagnosis. We provide them with a comprehensive education program that includes written materials, videos, and workshops. We also offer personalized sessions where they can ask questions and discuss their concerns in detail."* (SW 6)

These narratives reflect that personalized educational resources for children and their families, were crucial. Çömez and Karayurt (2020:2) supported this saying, that educational assistance and support was an important psychosocial modality in the battle against childhood cancer, as it empowered families and children with the knowledge and understanding regarding their cancer journey. It can enable families to make informed decisions, alleviate their fears, and enhance their coping strategies. Families are also equipped to access critical resources and support networks, helping them to navigate the complexities of treatment, leading to improved outcomes and quality of life for young patients.

Armington *et al.* (2016:107) described the variety of teaching tools, including teaching dolls (Medkin and port-acath dolls), books (*chemo*, *craziness and comfort*: *my book about childhood cancer* and *healing images for children*: *teaching relaxation and guided imagery to children facing cancer and other serious illnesses*), visuals, and interactive activities, that are tailored to the diagnosis of the patient. Kolator *et al.* (2018:711) added that such educational interventions, were closely linked to improved quality of life after cancer treatment. Sobh (2019:30) argued that by providing sufficient information about treatment, its side effects and self-care strategies, treatment-related complications and psychosocial outcomes in children and adult cancer patients can be decreased.

Parents in the current sample supported the benefits outlined in the literature saying:

*"When my son was diagnosed with leukaemia, the hospital provided us with a wealth of information about the disease, treatment options, and what to expect. We received brochures, booklets, and access to online resources that were incredibly helpful. The nurses and doctors took the time to explain medical terms in layman's language, which made it easier for us to understand what was happening."* (P8)

"*The educational support we received was very help. The hospital staff provided us with detailed explanations of the disease and the various treatment options at our disposal. They gave us access to educational resources and connected us with other families who had been through similar experiences. This support made us feel more in control and better equipped to handle the challenges of our daughter's illness."* (P11)

Armington *et al.* (2016:107) opined that by providing children with information about their illness and medical care at the beginning of their cancer treatment, parents can be helped to frame the purpose of subsequent procedures, increase understanding, address misconceptions, and open the door for continued communication. Parents of children with cancer have information needs that reflect their supportive care needs (Tan *et al.* 2022:143). Information however should be culturally sensitive, accurate, honest, and developmentally appropriate and provided in a child and family-focused, nonthreatening manner (Sobo and Kurtin 2007:25). Based on past studies, the educational and informational needs of parents of children with cancer are extensive, ranging from disease-related information, treatment-related information with regards to their child, practical information on resources, and

coping strategies (Koohkan *et al.* 2019:246; Tan *et al.* 2022:143). The provision of psychoeducation and information is therefore one of the strongly recommended international standards of care for childhood cancer (Wiener *et al.* 2015:94). Such diagnosis-related and treatment-related information, however, may need to be individualized to the caregivers' health literacy, culture, and psychological readiness.

Educational support may also help siblings grasp the situation, gain perspective, and feel grounded. It has been identified as one of the most important support mechanisms in dealing with their brother or sister's cancer (Wawrzynski *et al.* 2022:3). This system may include knowledge of how to cope with stress and self-care (Tan *et al.* 2022:143), knowledge on how to navigate the health system to reduce anxiety and stress (Garton *et al.* 2023:1), resulting in better emotional health for caregivers (Feraco *et al.* 2023:109)

### 3.4. Social work services

The need for social work and its related services to be integrated into the overall care plan, emerged as the fourth sub-theme. The social work profession has had a long history of working with families (Goldring and Solomon 2019:453), revolving around identifying the strengths of the family. Social workers in a paediatric setting provide a safe, empathic and supportive environment for children and their families (Safarabadi-Farahani *et al.* 2016: e262–e270).

These were the perspectives of professionals in the sample regarding social work services. They said:

*"At Albert Luthuli Hospital, the social work team is an important aspect of our holistic approach to patient care. They bring a holistic perspective that addresses the psychosocial aspects of patient health, which is crucial for recovery*." (Dr1)

*"Social workers play a very important role in our team. They provide psychosocial support to children and their families which links perfectly to the medical interventions. Social workers have the ability to identify any stressors from children and parents that could possibly impact treatment and outcomes."* (Dr3)

*"Social workers are important professionals in the care of our young cancer patients. Their ability provide emotional support and counselling to patients and their families, helps decrease the stress and anxiety in their child's cancer journey"* (N10)

One of the social workers supported this saying:

*"Our role working at a hospital includes coordinating with medical staff such as doctors, oncologists, paediatricians and nurses to address the psychosocial needs of the patient, we arrange for financial assistance from organizations like CHOC and connect families with community resources to help them in their journey. We also facilitate support groups to parents and recreational activities for the children that offer emotional support and a sense of normalcy for the children."* (SW6)

These participants highlighted the huge role that social workers play as part of a holistic approach to cancer treatment and care. Support for the role of oncology social workers has increased significantly, as the main providers of

psychosocial services for cancer patients and their families in the literature (Knott *et al.* 2022:49-59). Middleton (2022:1) said paediatric oncology social work is a nuanced profession, requiring detailed knowledge and social work practice skills in a variety of areas, including oncology, hospice and palliative care, and paediatrics. Social workers work for their clients as advocates for comprehensive care (Ostadhashemi *et al.* 2019:1871). This was evidenced in the excerpt that follows:

*"Our role working at a hospital includes coordinating with medical staff such as doctors, oncologists, paediatricians and nurses to address the psychosocial needs of the patient, we arrange for financial assistance from organizations like CHOC, and connect families with community resources to help them in their journey."* (SW1)

Lilliehorn *et al.* (2021:1) supported this saying that oncology social work, is core to the psychosocial care of cancer patients and the most salient characteristic of paediatric oncology is the family-centred team approach. Beginning with the workup and diagnosis until the end of treatment and beyond, the interdisciplinary team provides expertise and helps children, and their families receive the best medical care and psychoeducation, whilst learning to understand, accept, and cope with a life-threatening illness (Goldring and Solomon 2019:453).

Middleton (2022:11) further mentioned that health care systems are multifaceted, with long-held systems of power and hierarchy that use complex language, that can exclude those without knowledge, understanding of, or access to their hallowed walls. Social workers play a significant role in assisting with the medical information, emotional support and care for children and their families (Nicholas *et al.* 2019:596).

Some of the specific roles that social workers played, were shared as follows:

"*As a parent, the social work services at Albert Luthuli Hospital have been a saviour to our family. When our daughter was diagnosed with cancer, we felt overwhelmed and lost. The social worker that assisted us was by our side, from explaining the medical procedures, to providing us with constant emotional support to by husband and other children, this eased our anxiety"* (P1)

*"They helped find financial assistance programs, which tremendously helped. They constantly checked in especially during our counselling sessions as a family"* (P2).

*"The social worker helped me a lot with accommodation from CHOC, they encouraged me when I get any results from the doctor. The social worker always tells me to take it easy."* (P3)

*"They connected us with other families in the oncology ward which created a support network for us who are going through the same experience."* (P5)

As evidenced social workers played a multifaceted role, ranging from linking parents with CHOC, to demystifying medical procedures and creating support networks.

The literature further reflects the huge level of psychosocial support provisioned by social workers, to families who require constant emotional support and advice on their cancer journey (Rezaei *et al.* 2018:425). Services within the hospital are often provided within a complex, fragmented medical system replete with its own terminology, hierarchy, power dynamics, and expectations (Nicholas *et al.* 2019:596). Paediatric oncology social work uses a specialized approach to care for children and their family members by demystifying these strange and complex systems and processes (Middleton 2022:10). It involves assessments, counselling, referrals, and discharge planning to support the patient and family, dealing with a life-threatening disease.

Other studies such as by by Verulava *et al.* (2019:315-319), further supported the role of social workers in paediatric oncology, as they uncovered that social workers could support cancer patients and families. This finding resonates with the current data. They identified and reported on the strength and psychological stability provided by social workers which empowered families. Beaune *et al.* (2014:170), added that practical assistance for patients and families in the health care system, can further help the family identify and overcome barriers such as a lack of access to resources, medication, or transport and contribute to a care plan that is both realistic and feasible Medical social workers are therefore known to play a vital role, in ensuring that the patient and their family needs are met and preferences reflected in medical care and treatment planning (Mulkerin 2019:17-30).

### 3.5 Recreational Therapy

Recreational therapy emerged as the fifth sub-theme in the data under theme three. Doctors supported the importance of recreational therapy saying:

*"We believe that recreational activities are a vital part of the holistic care we provide. We have a dedicated playroom where children can engage in various activities like puzzles, video games, and group games. Those children who are isolated because of infections play on their own until fully recovered. These activities help in improving their mood and provide a therapeutic escape from their medical routines."* (Dr 4)

**"***We integrate educational activities into our recreational programs to ensure that children continue to learn and develop during their hospital stay. We have tutors who assist with schoolwork and educational games that make learning fun and engaging, helping children stay on track academically despite their treatment schedules."* (Dr3)

A social worker added to this saying:

*"These activities that are conducted during recreational time stimulates the children's minds but also help them maintain a sense of routine and normalcy, which is crucial for their overall well-being."* (Sw5)

Collectively these participants believed that recreational activities could improve the mood of children and offer a therapeutic escape from their medical routines, coping and recovery. These activities can stimulate children's minds, help them maintain a routine, and provide a sense of normalcy. As one of the doctors said it can sustain a child's learning and development, which was crucial if they were hospitalized. According to Tortora (2019:1-17) recreational activities at hospitals are a crucial psychosocial intervention that contributes significantly to the emotional and psychological well-being of patients. Sari *et*

*al.* (2023:2) opined that for those undergoing long-term treatments like chemotherapy, recreational activities provide a necessary distraction, from the stress and pain associated with their medical conditions, as evidenced in the data.

For Gil (2020:5) recreational activities facilitate social interaction and community building within the hospital setting and amongst oung patients. Group games and shared activities allow children to connect with peers who are experiencing similar health challenges, thereby reducing feelings of isolation and loneliness (Clasen *et al.* 2023:19). Tortora (2019:1-17) added said that these interactions promote a sense of belonging and support, which is vital for emotional resilience. As one of the doctors in the current sample said, children who are isolated due to infections, require individualized recreational options, to ensure that they too can benefit from these interventions. Kaye *et al.* (2018:55) stated that such inclusive strategies help maintain social connections and support networks, which are essential components of effective psychosocial care.

The sub-theme that follows focuses on end-of-life bereavement.

### 3.6 End-of-life and bereavement support

A doctor and nurse reflected on palliative care saying:

*"Palliative care is about improving the quality of life for patients facing serious illness. We focus on symptom management, pain relief, and addressing emotional and spiritual needs to ensure patients live as comfortably and fully as possible."* (N15)

*"Our approach to palliative care involves personalized care plans that respect patients' preferences and values all across dimensions. We strive for open communication to ensure patients understand their treatment options and have a voice in their healthcare decisions."* (Dr 2)

Social work practitioners supported this saying:

*"In palliative care, we work closely with patients and families to provide holistic support."* (SW 3)

*"We offer counselling sessions and support groups tailored to families for their emotional needs, helping them cope and manage with grief and find ways to memorialize their loved one's life."* (SW2)

As evidenced the end-of-life care and bereavement support at a hospital, enables a holistic and compassionate approach, to focused end-of-life care and bereavement so that families can through their loss, adjust and find ways to memorialize their loved ones life. Children's palliative care provides active, holistic care for children and young people with life-limiting illnesses. It is provided from the point of a child's diagnosis, throughout the child's life, death, and bereavement (Laronne *et al.* 2021:1-5). As shared by the participants, it encompasses all elements of quality of life; physical, emotional, social, and spiritual. It focuses on enhancing a child's quality of life and provides support to the family. The scope of palliative care provision, is not limited to symptom management, but also includes respite services, end of life care, and bereavement support (Cahalan *et al.* 2022:1-11). Benini *et al.* (2022:529) and Kattner *et al*. (2019:673) added that palliative paediatric care (PPC), differs from palliative care in the adult patient, as it considers the particular characteristics of the paediatric patient at a physical, developmental, psychosocial, ethical, and spiritual level. Palliative care is the science and art of lessening physical, psychosocial, emotional and existential suffering particularly in paediatric oncology where levels of suffering are significant. Cahalan *et al.* (2022:1-11) stated that paediatric palliative care focuses on the

enhancement of quality of life for the child and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. Furthermore, it also incorporates respite care, bereavement support and personalizing the care approach (Bergstraesser 2013:31).

The World Health Organization (WHO) released a seminal report, titled *cancer pain relief and palliative care in children*, in which it recommends that palliative care (PC) for children with cancer begin at diagnosis, irrespective of prognosis (World Health Organization WHO 1988:26). Benini *et al.* (2022:529) said that palliative paediatric cancer begins at a diagnosis of incurability or supposed incurability, and continues regardless of whether the patient receives any oncological treatment. As such, palliative paediatric cancer is considered a general approach continuing over the entire disease trajectory, which includes, but is not limited to, end-of-life (EoL) care (Salins *et al.* 2022:175). Benini *et al.* (2022:529) supported the sentiments emerging from the data in the current study saying, that the implementation of palliative paediatric cancer in paediatric oncology improves the quality of life (QoL) of the child and family, helps reduce symptom burden, diminishes costs of care and access to intensive care units at EoL and has become accepted practice globally. Patients in palliative paediatric care and their families should therefore be integrated into specific care programs according to the available resources (Marcus *et al.* 2020:339; Jankovic *et al.* 2019:2) and should be part of the hospital program.

Although children were not interviewed due to ethical issues, scholars have argued that children with cancer and their parents have reported enhanced quality of life through palliative care involvement (Groh *et al.* 2013:848). This makes it an increasingly important area of consideration, that should be

incorporated alongside active disease-directed therapies (Baker *et al.* 2015:46714; WHO 2020:5).

## 4.3.1.4 THEME 4: SPIRITUALITY AS A SOURCE OF STRENGTH AMONGST FAMILY MEMBERS

The fourth theme that emerged from the data, related to spirituality as a source of strength amongst family members. Six sub-themes emerged, under theme four namely (I) salience of spirituality in a medical context; (II) prayer; (III) the role of spiritual leaders in supporting children and their families; (IV) salience of faith and belief; (V) a sense of spiritual hope and (VI) the use of chanting. Gao *et al.* (2012:1-12) wrote that religion and spirituality have co-existed in Western and Eastern civilizations for millennia, making it an important pathway for individuals to cope during hardship. This is particularly important after the death of a loved one or when faced with a debilitating, illness such as cancer. The salience of spirituality in a medical context emerged as the first subtheme and is discussed next.

### 4.1 Salience of spirituality in a medical context

Spirituality emerged as a salient factor within the context of childhood cancer in a medical setting. Paediatric cancer is a huge challenge for a patient and their family. Spirituality and faith, appear to be one of ways to find meaning in their journey and deal with their anxiety, distress, hopelessness, pain and sadness (Balboni *et al.* 2022: 184-197 and Ghaempanah *et al.* 2023:225–244). Parents described their personal spirituality as:

*“Spirituality has been a source of strength for our family throughout our child's cancer treatment. We found that spiritually based interventions, like prayer and guidance from our spiritual leaders, provided us with comfort and hope during the most challenging times. These practices helped us feel connected to something greater than ourselves, giving us the resilience to support our child."* (P1)

*As a parent, spirituality means finding hope and strength when faced with the uncertainty of my child's cancer diagnosis. It's about connecting with our faith community and finding comfort in prayer and our spiritual practices. For our family particularly, spirituality provides a sense of peace and a reminder that we are not alone in this journey. It helps us focus on the present moment and trust that we will find the resilience to face whatever challenges come our way."* (P4)

*As a parent I see the transformative power of spirituality in my child and all the children in the ward, even those who are isolated because of infections they have picked up. Spiritual care services and interventions provides my family and I a space explore our beliefs, find solace, and build resilience in the face of cancer."* (P7)

These narratives emphasize the huge role spirituality plays, in deepening parents’ relationship with their faith community and enabling them to find comfort in prayer and in their spiritual practices. Another parent shared the huge transformative power of spirituality to heal children, even those who are in isolation. The relation between spirituality and health has become a subject of growing interest amongst researchers (Lima *et al.* 2013: 1539–1544), with spirituality serving as a source of comfort and hope for many children and

families. According to Puchalski *et al.* (2014:642) spirituality is a dynamic and intrinsic aspect of humanity, through which persons seek ultimate meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. A study conducted by Schneider *et al.* (2006:3-24) similarly found that the spiritual beliefs of parents offered a great deal of comfort to them, as they dealt with their child's illness. Some parents discussed the power and importance of prayer as an act in and of itself. Zelcer *et al.* (2010:225-230) supported these findings saying that faith was believed to have been a tremendous source of support, for most of these parents throughout the childhood cancer journey. In addition, spirituality had helped them in decision making. Even the health and social service professionals in the sample, emphasised the importance of spirituality in the lives of their patients and families, saying :

*"In the context of childhood cancer, spirituality encompasses the beliefs and practices that help families find meaning and purpose amid a challenging experience. It's not just about religion; it's about whatever helps individuals feel connected to something larger than themselves. As a social worker, I see spirituality as a crucial element in helping children and families cope with cancer. Whether through prayer, meditation, or other spiritual practices, spirituality offers a source of comfort, hope, and emotional support that complements medical care."* (SW 4)

*"Incorporating spirituality into cancer care provides holistic benefits that address the emotional and psychological needs of paediatric patients. Spiritual interventions, such prayer, faith and hope and chanting can reduce anxiety and improve quality of life, helping children and families find meaning and hope during difficult times."* (Dr 1)

*"Spirituality plays a significant role in the healing process for many families. Offering spiritual support through chaplain services or quiet reflection spaces in the hospital allows families to tap into their spiritual resources, which can be a crucial part of their emotional resilience and recovery journey."* (N15)

*"For many families, spiritual interventions offer a sense of community and support that is essential during cancer treatment. Programs that include any form of spiritual interventions help families feel less isolated and more empowered to face the challenges ahead."* (SW 6)

These narratives highlight the support for spiritual practices such as prayer and meditation in strengthening families and in connecting them with spiritual resources and networks where they can be less isolated.

Puchalski *et al.* (2018:2) supported these findings saying that spirituality had positive health outcomes for patients with cancer across the trajectory of disease. An article titled *spirituality, religion, and paediatrics: intersecting worlds of healing,* also highlighted that religion and spirituality, had played huge roles in shaping the way families live their lives and suggests that it has broader implications for children's health (Barnes *et al.* 2000:899). Hence spiritual care should be structured according to patients and their needs. As one of the nurses suggested, quiet spaces for spiritual reflection should be created in the hospitals. Memaryan *et al.* (2020: 82–95) argued that to provide holistic care to patients with breast cancer, care providers or professionals are required to provide spiritual remedies or interventions. Toledo *et al.* (2021:3017) argued that "spirituality is an important component in dealing with diseases and life stressors and serves as a shield against these adverse events."

A study by Faria and Cardoso (2010:13-20), found that spirituality was an effective coping strategy for caregivers of children with leukaemia. The study assessed the level of stress of 20 caregivers and found that spirituality served as a source of relief and provided caregivers with strength to deal with their situation and continue with their caregiving function. It is therefore essential for health care professionals to acknowledge the importance of spirituality and faith for this specific patient population and recognize the importance of spirituality and spiritually based interventions, as a crucial component of healing for cancer patients and their families (Balboni *et al.* 2022: 184-197; Ghaempanah *et al.* 2023: 225–244).

The subthemes that follow are linked to the spiritual interventions used by families.

### 4.2 Prayer

Most of the participants described prayer as an important spiritual intervention that can help both the child and family members to cope. Grossoehme *et al.* (2011:432) wrote that individuals cope religiously or spiritually, and religious coping through prayer was important. Spiritual practices such as prayer have been used by individuals for every type of illness and across all age groups, cultures and religions (Dehghani *et al.* 2012:178). Conk *et al.* (2010:175) described prayer as human communication with the Divine that is considered the natural language of religious experiences. The doctors, nurses and social workers in the current sample said:

*"Prayer does help with anxiety, depression and stress. It gives parents the ability to understand better about what is happening and praying helps with acceptance"* (Dr3)

*"We have realized that prayer is an important aspect in holistic care, I have seen firsthand how incorporating prayer into the care plan has provide comfort and hope to both patients and their families. It helps to alleviate anxiety and can foster a sense of peace and resilience. Our social workers frequently conduct prayer sessions and/or connect families with spiritual support resources, making sure that this aspect of care is respectfully integrated into the patient's treatment journey."* (Dr6)

*"Prayer plays a significant role for many families we support at the Hospital. As social workers, we see the significant impact that spiritual practices, such as prayer, can have on the emotional well-being of our patients and their families. We always try to accommodate the diverse spiritual needs of our patients by offering to facilitate prayer sessions"* (SW 6)

*"Working with different families and children.. you can see that prayer provides a sense of comfort, community, and strength to them, which is crucial during their cancer journey."* (N10)

Prayer therefore helped parents cope with anxiety, depression, and stress, offering them comfort, hope, and acceptance. It fostered a sense of peacefulness and a sense of community to parents. Hence integrating prayer into care plans creates a holistic approach, that taps on spiritual support resources and a commitment to accommodating the diverse spiritual practices of patients and families, to help them cope and heal.

It is therefore evident that most cancer patients use religious and spiritual resources in their response to their disease. Sisk *et al.* (2018:1-20) argued that prayer helps patients cope with distressing symptoms, anxiety-provoking medical procedures, and to manage cancer pain. For this study, prayer is

defined as an activity and expression of the human spirit reflecting connectedness with God.

Cahalan *et al.* (2022:1-11) stated that prayer is frequently utilized as a coping mechanism in hospitals. Phelan (2022:1390) added that prayers included a range of advantages, such as assistance and reassurance, to young patients and their families, especially while facing serious illnesses like childhood cancer. Meireles *et al.* (2015:1-13) believed that nursing staff can listen to those who wish to discuss their spiritual beliefs; by engaging in prayer; and by mobilizing spiritual resources, when needed. Similarly, Stegemann *et al.* (2019:1-15) believed that, incorporating prayer into holistic care in hospitals reflects that professionals consider the various needs of their patients and recognize the positive impact of prayer on the emotional well-being of families. A holistic approach to healing therefore goes beyond physical treatments and addresses the psychosocial and spiritual aspects of health (Robinson *et al.* 2019:1-10).

Parents further supported the importance of prayer, saying:

*"Prayer ... makes me happy; I feel a source of comfort when I am alone."* (P2)

*"I pray to help us all to be strong. Give us guidance ...Please continue to guide her and all those helping her so she can fully recover. Please help us make the right care decisions. There are tough choices to make, but I pray she'll continue to improve" (P4)*

*"We have telephonic prayer sessions, where my spiritual community prays with me and for my child." (P5)*

Some parents shared their prayer aloud and said:

*“I always ask God in my prayer to Lord, please, please help it is so hard to see her in such pain. I pray you can help her see the hope she needs to recover. Give all those working with her the skill and compassion ...I pray for continued strength for all of us.* (P9)

*“Please help us find the best treatment and help it to be successful ...Please give this beautiful, sweet young lady a good, long, happy life. I will do all I can - please help me to make the best choices even when they’re hard”* (P11)

These narratives reflect that prayer brought comfort, strength, and guidance to parents navigating the complexities of their child's illness. It connected them to a higher power and acted as a pathway to coping with uncertainty and fear during a challenging time. Research on the coping strategies of caregivers of seriously ill children suggests that prayer is invaluable in managing the distress associated with serious childhood illness (Cotton *et al.* 2009:313). Similar to the narratives in the current study, Gross Oehme *et al.* (2010:3), reported that prayer helped parents whose children had cystic fibrosis, sickle cell disease or autism spectrum disorders.

### 4.3 The role of spiritual leaders in supporting children and their families

The third sub-theme focused on the role of spiritual leaders in supporting children and their families. Spiritual leaders will be identified as priests, pastors and chaplains. Parents described their role as follows :

*"The pastor who comes on Sunday's helps me a lot. He prayed over my child and also gives me advice on how to deal with my child's cancer and motivates me."* (P4)

*"The chaplain encourages me; he prays with me and for my family over the phone. He says I must be strong; my son will be fine."* (P6)

Spiritual leaders therefore provided advice on how to deal with their predicament, prayed with them and offered them strength and comfort.

Cipriano-Stefens *et al.* (2020:2341) similarly wrote in their study, *titled "Let go, let God: a qualitative study exploring cancer patients' spirituality and its place in the medical setting",* that the chaplain who is provided by the hospital offers comfort and advice, talks to and prays with patients and reassures them that everything would be okay. Participants in the study shared the same sentiments saying "*they [chaplains] offer comfort and let us [patients] know that everything is going to be alright.*

Doctors also supported the presence of spiritual leaders saying they offered support as follows:

*"We do allow priests and spiritual leaders to come in the ward as it helps relieve stress of parents, it helps patients which are terminally ill."* (Dr 1)

"*Having priests come over to the Pead's ward and praying for all children and families does make it easier for them each day, going through the treatment, information and interventions."* (Dr4).

Lion *et al.* (2019:2) similarly supported interdisciplinary spiritual care, saying it improves collaboration between physicians, nurses, social workers, therapists, and acknowledges the spiritual care specialists. Sprik *et al*. (2021:1275) further advocated for hospital chaplaincy services in the provision of religious/spiritual care for patients. Hence spiritual leaders can play a unique role within the interdisciplinary team in supporting patients and families facing paediatric cancer. In providing whole-person care, they bear witness to the deeply human experience of both children with cancer and their families.

**4.4 Salience of faith and belief**

Many parents described the importance of faith through their journey with cancer. This emerged as the fourth sub-theme as follows:

"Faith and belief in God give's my child, me and my family the strength to go through the treatment procedures." (P2)

*"It has a tremendous impact!" It's just healing. My faith keeps me strong, emotionally and mentally."* (P9)

"*It has helped my child and I each time we have doctors consult, or when he's going for chemo treatment. Although I dreaded hearing my child's diagnosis,*

*some time has passed and I feel a sense of safety and peace, I am in good hands of God who is helping my child every day."* (P3)

*"Having faith means, you have the attitude and ability to fight through each day, each treatment and any form of bad news, it helps me to help my child every day."* (P7)

*"Because of my faith, I am always looking to God for answers and for help. Because of my belief that God is guiding these doctors to help my child."* (P6)

Faith provided parents with strength, peace, and hope that they could endure their daily challenges with cancer treatments, bad news and to remain hopeful regardless of their circumstances. Reyes (2023:65) similarly described faith as the root of a person's strength to endure the cancer process. Meireles *et al.* (2015:1-18) added that religious faith is where individuals draw their source of strength. Findings from other studies reflected that most cancer patients and survivors (70%) reported that their religious faith created a positive impact in their life (American Cancer Society 2020:19). Other researchers agreed that religious faith played a significant role in facilitating coping and reducing parental stress (Vitorino *et al.* 2018: 1900–7; Mazhari *et al.* 2021:2878). In this vein Nkoana *et al.* (2022:1390–1400); Visser *et al.* (2020:1) argued that many patients and their families draw on their faith and use their religious/spiritual meaning making processes, to cope with their condition. Hence as participants said, that despite their child's cancer experience, they were resilient because of their faith. Nkoana *et al.* (2022:1390–1400) reported that participants in their study, relied on their faith to cope with the daunting physical and psychological challenges, brought about by their child's cancer diagnosis, including the treatment side effects.

As such Mant *et al*. (2019:3-18a) and Watts and Munir (2024:1-10) believed that faith was a vital component of the health care plan and treatment protocol of the family, to cope and heal throughout the cancer journey. It can provide direction enabling families to cope with the unpredictability and anxiety of cancer treatments (Kwarteng *et al.* 2024:1-15). It is therefore important that patients and families engage in spiritual activities, receive aid from religious communities, and use their faith to reduce loneliness and hopelessness (Kordi-Tamandani and Hakimifar 2023:1-18).

### 4.5 A sense of spiritual hope

Similar to faith, a sense of hope emerged as important for children and their families.

One of the doctors said:

*"I have witnessed the positive effect that hope can have on a child's healing process. Families who hold a positive attitude are more likely to actively participate in treatment plans and show support for their child's care, resulting in improved results."* (Dr 3)

A nurse and social worker added that:

*"From what I have seen, families that hold onto hope, even in small amounts, demonstrate impressive resilience. Over my years as a nurse, I realized that hope is not always about having faith in a remedy, but about discovering ways to appreciate the current moment and treasure every second. It is an essential part of the process of emotional recovery."* (N15)

*“Hope serves as a strong tool for families to deal with challenges. It motivates them to find fresh knowledge, engage with support communities, and play an active role in their child's treatment. Taking this proactive approach frequently leads to a more favourable hospital experience and increased emotional strength.”* (SW 2)

Sprik *et al.* (2021:1275) similarly reported that healthcare providers have acknowledged the importance of hope in the process of healing. As a nurse shared, families who display resilience hold onto even small amounts of hope, not in the anticipation of a cure, but rather discovering methods to value the present and treasure each moment. Snaman *et al.* (2020:454) and Stefan (2019:1-5) argued that this mindset was crucial for emotional healing, enabling families to concentrate on the good things and sustain their emotional health amid the unknowns of the illness.
Even as one doctor observed, families that had hope were more likely to participate actively in treatment plans, which could improve outcomes for their child. Hope not only enabled emotional coping but also could enhance the overall effectiveness of the treatment process (Laronne *et al.* 2021:15; Cuviello *et al.* 2020:1033).

Parents further shared that:

*“Hope is the driving force that motivates us to keep moving forward each day. Despite facing difficult days, the possibility of a brighter future keeps us resilient for our child. It's like a beacon during the hardest moments.”* (P4).

*“When my daughter was diagnosed, I was shattered. However, maintaining a sense of spiritual hope, whether it be from a potential new therapy or just the belief in her eventual recovery, supported me in facing each day. Hope empowered my family and I have to battle alongside her.”* (P6)

These narratives of parents revealed that hope empowered them to endure, fight, and maintain a positive outlook, revealing its vital role in their ability to cope with their child's cancer journey each day. Servitzoglou *et al.* (2009:415) added that in times of stress, spirituality may be a source of comfort and hope. Kamper *et al.* (2010:301) described hope as a protective factor for enhancing resilience and quality of life in paediatric cancer. Haase (2009:289) proposed that hope was important to helping patients develop resilience throughout their cancer experience. A parent highlighted the importance of hope, saying that she felt devastated when her daughter was diagnosed but found comfort in holding onto hope. Cialdella-Kam *et al.* (2012: S136–S143) said hope, for a possible new treatment or faith in her daughter's recovery, provided strength to her family. Hope allowed families to approach each day with fresh energy and to actively stand by their daughter as she fought cancer. This reflects how hope can change hopelessness into an active and involved way of dealing with the illness.

### 4.6 The use of chanting

The last sub-theme under the theme of spirituality was chanting. Parents from different religious backgrounds shared their sacred verses as follows:

*"Om Tryambakam Yajamahe Sugandhim Pushtivardhanam Urvarukamiva Bandhanan Mrityor Mukshiya Maamritat (A powerful chant for healing and protection, often invoked to seek divine intervention for health and longevity*)" (P4)

*"Abaphansi abangcwele, nimanazileth' amandl' okwethusa. Ningasekho esiswini sethu. (Holy ancestors, you bring forth the power of awe. You are not forgotten in our hearts)"* (P9)

*"The Lord is my shepherd; I shall not want. He maketh me to lie down in green pastures: he leadeth me beside the still waters. He restoreth my soul: he leadeth me in the paths of righteousness for his name's sake. Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me." (A psalm of trust and reassurance in God's guidance and protection)"* (P7)

Each parent drew on their unique chants and sacred verses, which reflected their faith in the divine or their ancestors for protection. Chanting is a rhythmically repeated exclamation or song, related to a spiritual or religious tradition (for example in the form of mantras). Perry *et al.* (2021:1) stated that chanting involves rhythmic, repetitive singing or speaking of sounds and phrases vocally or mentally. Pundir *et al.* (2023:2) further indicated that chanting has been used in almost every tradition throughout history, as an act of worship, a form of healing (emotionally), for ceremony, and to transcend mundane states of awareness as well as for spiritual growth.

A parent shared the benefits they received from chanting as follows:

*"Chanting every morning has become a ritual for my child and I and my family at home. It brings a sense of peace and hope. When my child is in pain, I feel that these chants are my connection to the divine, asking for strength and healing."* (P2)

Several authors have supported this. A study conducted by Maungtoug *et al.* (2021:35–49), titled "*adding ritualized chanting to the palliative care of cancer patients at the end of life*, found that chanting had enabled their participants to feel calm and experience less pain and for certain participants to accept their impending death with ease. Participants also said that they felt more joyful, even when they were alone without the caregivers beside them.

Under this sub-theme a doctor, nurse and social worker in the sample shared:

*"I have observed that parents who engage in spiritual practices like chanting often exhibit remarkable resilience. It helps them stay grounded and hopeful,*

*which positively impacts their child's emotional well-being and recovery."* (Dr 1)

"*I've seen parents who perform ancestral chants or prayers feel a deep sense of connection and support from their lineage. This spiritual practice seems to empower them, making them more resilient and able to cope with the stress of their child's illness."* (N15)

*"Encouraging families to incorporate their spiritual practices, such as chanting, into their daily routine can be very beneficial. It provides a sense of control and peace, helping them to navigate the emotional and psychological challenges of their child's cancer treatment."* (SW 5)

Collectively these professionals supported the role of spiritual practices, in coping with the child's cancer treatment. A study by Rafii *et al.* (2020:19), found that most of their participants had said that parents and families drew strength and healing from chanting and prayer. Khait and Lazenby (2021:1-22) argued that chanting led to decreased anxiety and depression, and increased positive mood, focused attention and relaxation.

## 4.3.1.5 THEME 5: PSYCHO-SOCIAL INTERVENTIONS THAT CAN SUPPORT HEALING

The fifth theme introduces psychosocial interventions that were used or suggested for use in a medical setting. A total of eight sub-themes emerged from the data, which included (I)understanding psychosocial interventions; (II) technological support intervention, (III) music therapy; (IV) art therapy; (V) play therapy and interactive play; (VI) book club/bibliotherapy, (VII) dance therapy, and (VIII) legacy building. The first sub-theme is understanding the nature of psychosocial interventions.

### 5.1 Understanding psycho-social interventions

The first sub-theme focussed on how healthcare professionals and social workers perceived the nature of psychosocial interventions. Doctors and nurses shared that:

*"From a medical standpoint, psychosocial intervention is a critical component of comprehensive cancer care. It encompasses a range of services designed to support the mental and emotional well-being of patients and their families. This includes psychological counselling, educational resources, by addressing these aspects, we aim to improve the overall treatment experience, enhance adherence to medical protocols, and support the child's developmental and emotional health throughout their cancer journey."* (Dr 1)

*"One of the key benefits of psychosocial interventions is improved adherence to treatment protocols. When children and families are emotionally supported and informed, they are more likely to follow through with the treatment plan. This can lead to better health outcomes and a smoother treatment process."* (N10)

One of the social workers from the sample said:

*"Psychosocial intervention in the context of childhood cancer involves a comprehensive approach to care that addresses the psychological, social, and emotional needs of the child and their family. It's about providing therapeutic support to help them cope with the diagnosis, treatment, and the changes it brings to their daily lives. This includes individual and family counselling, facilitating support groups, and connecting families with community resources.*

*Our goal is to help them build resilience, reduce stress, and improve their overall quality of life during and after treatment."* (SW2)

Collectively the perspectives of these professionals revealed that psychosocial interventions are essential for fostering resilience, reducing stress, and improving the overall quality of life for paediatric cancer patients and their families, thus ultimately making the treatment process more manageable and effective. There was a general consensus that, psychosocial interventions have become an integral part of comprehensive care for children with cancer, by addressing the multifaceted challenges faced by these young patients and their families. Koumarianou *et al.* (2020:1-16) concurred saying that these interventions encompass a wide range of strategies aimed at improving emotional, psychological, and social well-being, which are critical for coping with the stress and trauma associated with cancer diagnosis and treatment. Routine psychosocial assessment beginning at diagnosis and continuing throughout the child's treatment trajectory and beyond, has been identified as a standard of psychosocial care for children with cancer and their families (Kazak *et al.* 2015:s426). Routine and ongoing psychosocial assessments allows for early identification of risk factors (e.g., pre-existing mental health conditions) amongst parents, the child with cancer, and their siblings.

Gerhardt *et al.* (2015:s750) described the psychosocial assessment tool (PAT) as an instrument that is completed by the primary caregiver(s) of paediatric oncology patients. Development of the PAT was based in part on the Paediatric Psychosocial Preventive Health Model (PPPHM), which was developed to provide a conceptual model for categorizing a family's level of psychosocial risk following a child's cancer diagnosis. Following this model, the PAT can assist clinicians with assessing psychosocial risk levels within a family system, following a child's paediatric cancer diagnosis.

According to Sardi-Brown *et al.* (2017:33) the long-term benefits of psychosocial interventions, extend beyond the treatment period. Survivors of childhood cancer who have received such support are better equipped to manage the psychological and social challenges that may arise later in life. They often exhibit improved emotional adjustment and reduced symptoms of post-traumatic stress, contributing to a higher quality of life in the long run. In addition to supporting patients and their immediate families, psychosocial interventions also benefit siblings, who are often affected by the cancer diagnosis. Siblings can experience significant emotional distress and may feel neglected, as the family shifts focus to the sick child. Interventions that include siblings helps address their needs, improve their understanding of the illness, and provide them with coping strategies, thereby enhancing the overall family dynamic (Gise *et al.* 2022:292). Research underscores the importance of integrating psychosocial care into paediatric oncology practices. Moscato *et al.* (2021:1-12) said that the holistic approach not only supports the emotional and psychological health of patients and families, but also contributes to better medical outcomes.

Parents described the benefits of psychosocial interventions saying:

"*The psychosocial interventions have been a tremendous support for our family. The counselling sessions helped us process our emotions and fears. It was reassuring to know that we weren't alone in this journey, and there were professionals who understood what we were going through and could provide the emotional support we desperately needed."* (P1)

*"As a parent of a child with cancer, psychosocial intervention has been integral for us. It's not just about treating the disease but about addressing the emotional and social challenges we face daily. Having this coping mechanism*

*for us, it means having access to counselling to cope with the stress and fear, support groups to connect with other families going through similar experiences, and resources to help us navigate the practical aspects of treatment. It's about feeling supported and understood in a situation that can often feel overwhelming and isolating for any parent or person for that matter."* (P12)

*"For my child, the educational intervention and recreational therapy is a highlight. They not only helped her express her feelings but also built her resilience. She learned coping strategies that she could use during difficult moments especially during chemo, which made a significant difference in how she handled treatments and hospital stays."* (P13)

These responses highlight the profound impact psychosocial interventions have on both the emotional and practical aspects of coping with childhood cancer for families. These interventions have a tangible effect on the child's ability to manage treatment, highlighting their importance in supporting both families and young patients, through the cancer journey. Participants affirmed that these interventions are an essential part of childhood cancer care. They described it as a comprehensive approach that focuses on the entirety of the child and family's well-being. In the same vein, Inamani *et al.* (2020:809) argued that psychosocial interventions are a broad range of strategies designed to address the psychological and social needs of individuals. These interventions aim to improve mental health, enhance coping mechanisms, and create links to social support networks. The primary goals of psychosocial interventions are to reduce psychological distress, improve emotional and social functioning, and enhance overall quality of life (American Psychological Association 2020:3).

Koumarianou *et al.* (2020:1-16) posited that one of the primary benefits of psychosocial interventions, is the reduction of emotional distress amongst

patients and their families. Studies have shown that mothers, who are often primary caregivers, experience significant reductions in distress and improvements in problem-solving skills through these interventions. This not only enhances their ability to support their children but also improves their own mental health (Hrdlickova *et al.* 2021:166). Another significant advantage of psychosocial interventions are improvements in treatment adherence and overall medical outcomes. When patients and their families receive adequate emotional and psychological support, they are more likely to follow through with treatment protocols. This adherence can lead to better health outcomes and a smoother treatment process, as emotional distress and misunderstandings about the disease and treatment are minimized (Koumarianou *et al.* 2020:1). Regardless of its type, scale, or target group, every intervention is focussed on the ability of parents to maintain their psychological well-being during their child's treatment (Moscato *et al.* 2021:1-12).

Bouchard *et al.* (2022:408-508) advocated that support groups and community-building activities, are also essential components of psychosocial interventions. These groups provide a platform for patients and families to share their experiences, gain insights, and receive emotional support from others who understand their situation. The sense of community and mutual support that develops in these groups can significantly alleviate feelings of isolation and helplessness, which are common amongst families dealing with childhood cancer. Furthermore, educational resources and workshops form another critical aspect of psychosocial support. By providing families with information about the disease, treatment options, and coping strategies, they can be empowered to make informed decisions and manage their challenges more effectively. This empowerment leads to increased confidence and a greater sense of control, which are vital for psychological well-being (Li *et al.* 2021:102).

In conclusion, psychosocial interventions are indispensable in the care of children with cancer. They provide critical support that addresses the emotional, psychological, and social challenges faced by patients and their families, leading to improved mental health, better treatment adherence, and enhanced overall well-being. As the understanding of these benefits grows, the integration of psychosocial care into standard oncology practices continues to advance, offering hope and improved quality of life to countless families (Li *et al.* 2021:102). There is support for psychosocial interventions in a medical setting. The following subthemes introduce the types of psychosocial interventions, that were supported as essential within the medical context. .

### 5.2 Technological support intervention

The second sub-theme that emerged focussed on technological support interventions for children and parents in the paediatric haematology ward and at the CHOC residence based at the hospital. One doctor described this saying:

*"Telehealth or technological interventions services in the healthcare context is the use of digital tools, devices, and applications to support, enhance, or deliver medical and psychosocial care. It includes a wide range of technologies such as telemedicine platforms, mobile health apps, wearable health monitors, virtual reality systems, and digital educational tools. Because of budget restrictions we had to downsize the types of interventions we use. However, technological interventions will allow us to provide continuous psychological support to our young patients and their families, even when they are not physically present in the hospital, for example they are at the CHOC house. It*

*will be beneficial for follow-up consultations and emergency psychological interventions." (Dr1)*

In discussing its benefits other doctors said:

*"The use of interactive tablets will help engage children in educational games and activities that not only entertain them but also provide therapeutic benefits. These tools will help maintain a sense of normalcy and routine, which is crucial for their mental well-being." (N13)*

A social worker further supported its benefits saying:

*"With our patients being so young and advanced, we would promote the use of mobile apps which are specifically designed for mental health support and has proven invaluable. These apps will offer mindfulness exercises, relaxation techniques, and coping strategies, which children and their families can access at any time. This constant availability of support will make a significant difference in managing stress and anxiety." (SW 2)*

Researchers have also noted that technological advancements, have advanced and brought essential transformations in the diagnosis, treatment, and follow-up processes of diseases, especially in health systems (Koyu and Torüner 2023:1-8). Novrianda *et al.* (2022:11) shared that such interventions consist of electronic health (e-health) applications and mobile health (m-health) applications. E-health applications include web-based applications, digital applications, and virtual reality, while m-health applications include mobile and wireless applications such as messaging, mobile applications, wearable technologies, and social media. Cheng *et al.* (2020:68) and Wong *et al.*

(2021:435) argued that technology-based health interventions for children and adolescents provide information, feedback, and assessment; facilitate child-health professional communication; offer supportive networking and real-time health problem detection. Hinds (2020:27) added that one innovative approach for adolescent survivors are technological interventions, because of their importance in supportive care. Ramsey *et al. (*2020:17) opined that as a digital generation, adolescents have grown up with technology as part of their everyday lives and use technology as a common practical tool to meet their enjoyment, educational, and other needs. Technology-based interventions in paediatric oncology is therefore increasing essential (Baggott *et al.* 2020:133)

Koyu and Torüner (2023:1-8) added that technology-based interventions in paediatric oncology is also related to physical care such as monitoring health status and symptom management. It can be used for strengthening self-care, and providing psychosocial support (Arpaci *et al.* 2023:14). Researchers have suggested that technologies can be used to provide health promotion and psychosocial support for adolescent survivors including online chats, writing assignments, video conferencing, video games, websites, social media platforms, and mobile apps (Kopp *et al.* 2023:13; Sansom-Daly *et al.* 2021:1).

Parents also supported the need for this saying

*“I feel having these gadgets on hand such as a cell phone, tablet or laptop/iPad will make a very big difference to the children, it will keep them distracted from the cancer.” (P3)*

*"The use of having a cell phone or tablet will definitely help my child. It will distract him during painful procedures and reduce his anxiety significantly, especially when he sees the doctors and nurses coming around." (P4)*

*" I feel that the online support groups and forums will provide my child and I with a sense of community and understanding. It will definitely be comforting and empowering." (P6)*

These narratives reveal that technological support can reduce anxiety and help manage pain during procedures, as well as during routine hospital visits. Linder *et al*. (2021:301) supported these tools saying it helps maintain normalcy and routine for children, which is essential for their mental well-being. Several researchers have reported that technology-based interventions for psychosocial and emotional health were significantly effective when used with childhood and adolescent and young adult, (AYA), survivors of cancer (Zhang *et al.* 2020:6; Ozturk *et al.* 2022:1-16). Technology-based interventions are therefore appropriate approaches because of their compatibility with the visual, auditory, and kinaesthetic thought processes of children and adolescents, and their interactive nature that supports their self-efficacy and creativity.

### 5.3 Music Therapy

The third sub-theme that emerged under theme five was music therapy. Music therapy has become a standard supportive care service, in many paediatric hospitals across the United States (American Music Therapy Association 2020:24; Knott *et al.* 2022:50).

Two doctors, advocated for the introduction of music therapy in hospitals saying:

"*Music therapy has shown remarkable benefits in reducing stress and anxiety among our young cancer patients. It would establish a calming environment,*

*making medical procedures and hospital stays less daunting for children."* (Dr 1)

*"Integrating music therapy into our treatment plans would allow us to address the emotional and psychological needs of our patients. It will provide a non-verbal outlet for expressing fears and emotions, which is crucial for children who may struggle to articulate their feelings."* (Dr3)

A nurse and social workers supported this, saying that music therapy can strengthen family relationships and help children to process the difficult experience of childhood cancer. They shared as follows:

*“It creates a shared experience that strengthens family bonds and provides emotional support during a challenging time."* (N15)

*"Music therapy offers a unique way for children to process their experiences and emotions. It can be particularly effective for those who are non-verbal or have difficulty expressing themselves through traditional therapy methods."* (SW2)

*"The impact of music therapy extends beyond the individual child. It helps create a supportive community within the hospital, where children and families can connect with others going through similar experiences, fostering a sense of belonging and understanding."* (SW 5)

Scholars such as Giordano *et al.* (2020:1-5) argued that paediatric patients treated for oncological and haematological pathologies undergo various

diagnostic procedures, such as bone marrow aspiration (BMA), lumbar puncture (LP) and bone marrow biopsy (BMB). These procedures evoke fear, anxiety and pain before, during and after the procedure (Ortiz *et al.* 2019:498). Hedstorm *et al.* (2003:120) described this type of pain as one of the worst experiences for children with cancer. Their anxiety impacts the sympathetic nervous system, the endocrine system and the immune system, causing tachycardia, hypertension, increased myocardial consumption of O2, arrhythmias, increased peripheral resistance, crying with mucus secretions, hypercoagulability, immunodeficiency and catabolic response (Giordano *et al.* 2020:1-5).

As a non-pharmacological health care intervention, music-based activities are cost-effective and, for children, enables a lesser need for medication (e.g., sedatives and analgesics) (Johnson *et al.* 2021:71). As one of the participants shared, music therapy reduces anxiety and stress (Giordano *et al.* 2020:1-5 and Knoerl *et al.* 2022: e358), depression (Wong *et al.* 2021:7), fear, and distress and modifies moods (Rodgers-Melnick *et al.* 2022:71-97).

Parents echoed the benefits of music therapy that were elucidated in the literature, by saying :

*“The familiar melodies and rhythms provides comfort and distraction, helping to alleviate pain and discomfort during treatments."* (P4)

Another said:

*"Incorporating music therapy in the paediatric oncology ward will definitely transform the atmosphere. It’s going to bring a sense of normalcy and joy,*

*allowing children to momentarily escape from the clinical setting and just be kids."* (P12)

One parent shared how music therapy, could provide both comfort and distraction for young patients undergoing treatments, consequently allowing children to momentarily escape the clinical environment. Knott *et al.* (2022:49) similarly affirmed that there was a growing body of evidence, reflecting the beneficial effects of music interventions for children in paediatric health care. Giordano *et al.* (2020:1-5) opined that music therapy in paediatric health care, acts as a distraction (from the hospital environment) (Vernisie 2015:26), the management of distress and pain (Holochwost *et al.* 2020:587), emotional regulation (Archambault *et al.* 2019:381), and overall wellbeing (Cheung *et al.* 2021:3145;).

Researchers have further reported that music aids in managing symptoms, supports development, improves coping (Stegemann *et al.* 2019:2-12) and provides family support (Facchini and Ruini 2021:101). As evidenced in the narratives of the professionals, music therapy assists in supporting positive experiences and reduces negative emotions, and uncomfortable procedures. It also supports coping and social integration and social skills (Rodgers-Melnick *et al.* 2022:71-97), and promotes feelings of normalcy and calmness. Roberts *et al.* (2021:1-8) therefore concluded that oncology units that incorporate best evidence-based practices to support zen and solace for their patients should include music therapy.

### 5.4 Art therapy

The fourth sub-theme that emerged focussed on art-therapy. Hart (2010:140) stated that art therapy, has been used widely as an adjuvant therapy for a

variety of conditions including cancer. It has been demonstrated as a helpful tool in coping with stressful and traumatic situations, increasing self-esteem, and reducing stress and anxiety (AATA 2013:3-4).

Doctors described its benefits by saying:

*"Art therapy will provide a creative outlet for children undergoing cancer treatment, allowing them to express their emotions in a non-verbal way. This is especially important for young patients who might struggle to articulate their feelings. Engaging in art can reduce anxiety, improve mood, and offer a sense of control during a time when much of their life feels out of their hands."* (Dr 3)

*"The therapeutic benefits of art therapy in paediatric oncology are multifaceted. It not only serves as a distraction from pain and medical procedures but also helps in building resilience and coping skills. Art therapy sessions can be a safe space for children to process their experiences and connect with others going through similar journeys, fostering a sense of community and support."* (Dr 5)

In a similar stance social workers stated that:

*"Art therapy plays a crucial role in the holistic care of childhood cancer patients. It addresses the emotional and psychological needs of children, which are often overshadowed by the focus on medical treatment. Through creative expression, children can work through trauma, fear, and sadness, ultimately aiding their overall well-being and quality of life."* (SW 3)

*"Integrating art therapy into the treatment plan for childhood cancer patients can significantly enhance their hospital experience. It offers a positive, engaging activity that can improve a child's outlook and provide a sense of normalcy. Moreover, art therapy can be tailored to each child's interests and abilities, making it an accessible and effective intervention for promoting emotional healing and resilience."* (SW 6)

As evidenced in these narratives, art therapy serves as a distraction and acts as a non-verbal outlet for emotional expression, reduces anxiety, improves mood, and offers a sense of control. It also builds resilience and coping skills, providing a safe space for processing affected emotions. Furthermore, it enhances the hospital experience by providing a sense of normalcy and is adaptable to individual interests and abilities, making it accessible and effective.

Malchiodi (2013:5) argued that art therapy in the health care setting includes, but is not limited to, “psychosocial care, rehabilitation, health benefits, and reauthoring the dominant narrative of illness”. Art therapy however appears to be an underutilized tool (Bitonte and De Santo 2014:18-19), despite its potential to produce significant health benefits for the paediatric population.

A literature review conducted by Aguilar (2017:173-178), titled *the efficacy of art therapy in paediatric oncology patients: an integrative literature review,* found that art therapy helped children to express their emotions, develop better coping skills, and improve their symptomology and behaviour towards their illness. Cohen-Yatziv and Rege (2019:100) concurred saying that art therapy can provide children with coping mechanisms and enables distraction techniques. Distraction from the stress and pain that patients previously experienced, allows nurses to perform a more focused and accurate assessment on a calmer child, ultimately leading to a higher quality plan of care which may help in improving the patient’s quality of life (QoL) during chemotherapy (Abuladze *et al.* 2022:493). Hendricks *et al.* (2019:6) concluded that children can take their completed artworks to the ward. These creative and tangible extensions of themselves can be a reminder of their energy, creativity and independence. Depending on what was produced, it could also be a reminder of life which is beyond the hospital setting and their illness.

### 5.5 Play therapy and interactive play

Play therapy emerged as the fifth sub-theme in the data.

The doctors in the sample, advocated for the interweaving of play therapy into the hospital environment saying :

*"Play therapy has proven to be an invaluable tool in helping young patients cope with the emotional and psychological challenges of cancer treatment. By engaging in play, children can express their fears and anxieties in a safe and controlled environment."* (Dr1)

*"It also helps them to regain a sense of normalcy and control, which is often lost during their illness."* (Dr 4)

*"This therapeutic approach not only helps to reduce stress but also promotes emotional resilience, which is crucial for their overall well-being during such a difficult time."* (N15)

Its benefits were reported by nurses and a social worker as follows:

*"Play therapy offers a creative and engaging way for children with cancer to process their experiences and emotions."* (N15)

*"One of the most significant benefits of play therapy for childhood cancer patients pertains its ability to provide a sense of normalcy and joy amidst the turmoil of treatment. Through structured play sessions, children can explore their feelings, develop coping strategies, and connect with others who are going through similar experiences. This intervention is not only therapeutic but also empowering, helping children to build resilience and hope for the future."* (SW 6)

These participants believed that play therapy can enable emotional expression, reduce stress, promote resilience, normalcy, and create supportive environments, all of which contributes to better psychological outcomes for these young patients. Landreth *et al.* (2023:7-26) opined that hospitalization and surgery can be an emotionally threatening and psychologically traumatizing experience, for children. Play therapy can reduce behavioural issues by giving the child a place of freedom, control, and autonomy during hospitalization, thereby supporting children emotionally in

their time of chaos, fear, and pain (Lerwick *et al.* 2013:129). Vargas *et al.* (2016:92-95) added that play therapy is valuable for those whose capacity for verbal expression and learning of coping skills may be limited. Philips (2010:13-25) noted that some of the best evidence for play therapy comes from work with children with health conditions, including those who are facing needle sticks and medical procedures.

There are studies which have demonstrated the efficacy of play therapy to reduce anxiety and improve outcomes within the hospital setting (Lerwick *et al.* 2013:129). Given that play therapy has been utilized to ease children's fears and help them adjust to stressful and challenging situations in medical contexts, it should be considered, as part of a holistic approach to care (Vargas *et al.* 2016:92-95). Providing puzzles, pictures, or other fun activities, can help children ease into a therapeutic atmosphere and can be easily combined with other modalities (e.g., relaxation training, cognitive coping strategies) to facilitate a child's coping.

One of the parents also voiced her support for play therapy saying:

*"As a parent I have done my own research on how to help my child and I found that integrating play therapy into the treatment plan will help my child by addressing his psychological needs. It provides a non-verbal outlet for expression, which is particularly important because some children do not have the verbal skills to describe their feelings."* (P12)

Landreth (2023:53) supported this saying that art therapy helps children regain a sense of normalcy and control, which is often lost during their illness. Dewi (2024:142) added that it offers a supportive and understanding environment, ensuring that children feel heard and understood, which is essential for their emotional healing. Cochran *et al.* (2023:26) concluded that the benefits of play therapy extend beyond emotional expression to include the development of coping strategies and resilience. Zakaria *et al.* (2024:84) supported this notion, saying that this intervention is not only therapeutic, but also empowering, thereby allowing children to build resilience and hope for the future. The

transformative impact of play therapy on a child's outlook and ability to cope with treatment, demonstrates its critical role in supporting the holistic care of childhood cancer patients (Journey *et al.* 2024:419; Baker *et al.* 2023:3901).

### 5.6 Book club/bibliotherapy

Bibliotherapy refers to reading specific books or e-books (electronic books) which are related to certain challenges in someone's life (Oluwaseye 2017:2). A person can be assigned or offered reading material that is relevant to their own personal challenges, ranging from self-help books to memoirs, written by individuals with similar backgrounds (Jones *et al.* 2021:2). Book club or bibliotherapy emerged as the sixth theme, with doctors, nurses and social workers, describing it as a valuable methodology as follows:

*"Reading stories that reflect their own experiences will definitely help them with a sense of normalcy and hope, making the hospital environment less intimidating."* (N10)

*"Bibliotherapy is an invaluable tool in my opinion and previous experience. It allows me to connect with young patients on a deeper level, helping them to articulate their feelings and cope with their diagnosis. The stories serve as a bridge for difficult conversations and can significantly ease the emotional burden on both the children and their families."* (SW1)

*"Incorporating bibliotherapy into the treatment plan for paediatric cancer patients proves to be highly effective. It facilitates emotional expression and processing, which are crucial for psychological resilience. The shared experience of reading and discussing stories can also strengthen the bond between the child and their caregivers."* (Dr 3)

These narratives affirm that the reading of stories helps create a sense of normalcy and acts as a bridge for difficult conversations. Moreover, the shared experience of reading and discussing stories can strengthen the bond between the child and their caregivers. The choice of books and content which children,

decide to read, often manifests as an instrumental tool that can help with the process of “reflection, interpretation and dialogue.” This instrumental tool creates opportunities for the reader to explore other thoughts, feelings and behaviours, that could arise from their circumstances, experience a sense of belonging, eventually allowing them to develop new meanings (Lucas and Saores 2013:138) and start the process of healing (Shechtman 2009:21), for paediatric patients.

As evidenced in the data, bibliotherapy can deepen connections with patients and enable their emotional expression. Scholars have added that it reduces stress, anxiety, depression, fear (Jones *et al.* 2021:3), enable problem solving and strengthen coping skills, enhances empathy (Jones *et al.* 2021:3), develop emotion and self-exploration (Lucas and Soares 2013:140) and boosts self-esteem (Akinola 2014:1281-1285).

Even parents shared the benefits of bibliotherapy saying that:

*"When my child was diagnosed with cancer, we felt lost and overwhelmed. Reading about cancer in the form of story books provided a much-needed outlet for my child's emotions. The books we read together helped us understand and navigate the journey, making the experience a little less daunting and more manageable."* (P4)

As evidenced bibliotherapy can demystify the cancer experience, empowering both patients and their families, to face the cancer journey with greater resilience.

### 5.7 Dance therapy

Dance or movement therapy (DMT) or dance movement psychotherapy (DMP), is a body- and movement-based psychotherapeutic field, that utilizes the creative expressive elements of dance to enable patients to express feelings and gain a deeper understanding of experiences that may be difficult to speak about (Tortora 2019:2). It emerged as the seventh sub-theme in the data. Parents supported its use saying:

*"When my daughter was at home, she would always dance to our kind music, and it would always make her happy."* (P2)

*"If the doctors had to implement dance therapy it would provide a break from the constant medical procedures and give children a chance to have fun. It's an excellent way to support the emotional health of the children and help the parents relieve some stress."* (P6)

As shared by the parents, the general innate pleasure gained through creative dance, can be especially therapeutic for paediatric oncology patients, who have the sense that their body and their disease are out of their control (Rosário *et al.* 2024:100). Nearly all treatments for traumatic stress include mastery and control over traumatic events (Van der Kolk *et al.* 2015:8). These treatments offer solutions for their feelings of helplessness by helping the patient reimagine their body's potential for health and comfort.

Goodwill (2018:1778) further added that the body, mind, and the emotionally integrative approach of DMT, coupled with the primary use of nonverbal and dance and movement-based expressive methods, of assessment and intervention make DMT in paediatric oncology, a strong psychotherapeutic method of support for the patient and the whole family system. Navigating medical illness during this important time of self-formation, exploration and discovery can affect the child in profound ways, but is often difficult to understand and express in words (Tortora 2019:1-27) making it a valuable therapeutic approach.

Doctors and a social worker in the sample, also recognised its therapeutic value, saying:

*"Dance therapy offers a unique blend of physical activity and emotional expression. For our young patients, it can potentially be a way to release stress, improve mood, and enhance overall well-being. While traditional therapies address the medical aspects of cancer, dance therapy can provide an emotional and psychological outlet that is just as crucial for recovery."* (Dr 1)

*"Dance therapy has the potential to significantly reduce anxiety and depression in paediatric cancer patients. However, my only concern is what happens to the children who are isolated because of infections or who are "hooked up" to machines… won't they be sad. I have read that the rhythmic movements and creative expression involved in dance can help children process their emotions and improve their mental health, which is often compromised during long-term hospital stays."* (Dr 4)

*"Dance therapy can be a powerful tool for social interaction and emotional expression. It helps children communicate what they might not be able to put into words, fostering a sense of community and support among patients. This can be especially beneficial in reducing feelings of isolation and loneliness during treatment."* (SW 2)

Doctors believed that the rhythmic movements of dance enabled social interaction, emotional expression, released stress and improved mood. It however was not possible for this methodology to be used by children in isolation because of infections or by those who are "hooked up" to machines.

Lopes-Júnior *et al.* (2025:15) argued that DMT enables patients to express their nonverbal felt-experiences through emotionally rich dance and movement-based activities developed around themes of creative self-expression. "By using creative expression, a child or adolescent with cancer

can express feelings about the course of the disease and tumultuous treatment through dance/movement, music, and art. This outlet allows the patient to creatively and kinaesthetically process the assaults of cancer and its treatment and thus establish a stronger sense of self and improved quality of life" (Raybin *et al.* 2024:12). With the current understanding of the integral relationship between the body-mind-emotions, and the embodied nature of paediatric medical DMT, it is uniquely positioned to be a strong member of the integrative oncology team (Tortora 2019:1-27).

### 5.8 Legacy building

Boles (2014:43) described legacies as "universal human experiences personal and relational summations of our unique histories, current activities, and hopes for the future". Boles and Jones (2021:530) added that children cultivate their legacies incidentally as they live their lives despite their diagnoses and develop personal characteristics that define who they are. Incidental legacy building therefore is a process that happens naturally, without intervention or encouragement (Akard 2019:49). Legacy building emerged as a further important subtheme under theme five.

The doctors and social workers described legacy building saying:

*"Legacy building is a powerful tool in palliative care. I have known it to allow children to leave behind something tangible, which can be a source of comfort and pride. This process not only helps the child but also supports the family's emotional well-being by creating cherished memories and honouring the child's life."* (Dr 4)

*"Engaging in legacy-building activities helps children feel a sense of control and accomplishment during a time when much of their life feels out of their control. This intervention can significantly boost their emotional resilience."* (Dr 5)

The social workers believed through writing letters, making handprints, or recording video messages, such activities can help preserve the child's legacy and provide a sense of continuity and love for the family. They described its benefits as follows:

*"I think facilitating legacy-building activities will definitely allow children with cancer to express their hopes, dreams, and experiences in a creative and impactful way. For families, these activities can be a source of solace and a way to celebrate their child's life, offering comfort during and after the cancer journey."* (SW 4)

*"Legacy building can be transformative for families facing paediatric cancer. It helps children and their parents find meaning and connection during difficult times. Whether it's through writing letters, making handprints, or recording video messages, these activities help preserve the child's legacy and provide a sense of continuity and love for the family*." (SW 5)

As evidenced the participants believed that legacy-building interventions, are a powerful transformative tool in supporting children and their families through the paediatric cancer journey. Boles and Jones (2021:529) opined that legacy-building interventions can be especially meaningful for paediatric cancer care patients who can share their hopes, dreams, and fears, in the context of a life-threatening illness. Interventions surrounding one's legacy can promote connection between patients, their families, and their care team

members during times of uncertainty. Gordon *et al.* (2020:317) added that despite the establishment of robust psychosocial teams, at many paediatric cancer care centres, providers may not know the extent of the pain and suffering children with cancer encounter.

Cahalan *et al.* (2022:1-11) opined that although cancer care providers may be unfamiliar with legacy-building interventions, the processes by which building a legacy for cancer patients can occur, and the benefits for patients' overall well-being when engaging in these activities, during their cancer journeys, has been successful. Akard (2015:658) argued that legacy building in the context of paediatric cancer care can be an intentional intervention individually tailored to a patient, to maximize agency in the face of life-limiting illness. Cuviello *et al.* (2020:1033) suggested that interdisciplinary team members can help facilitate legacy building projects with children with cancer, by providing opportunities for them to express themselves creatively and find meaning in their healthcare experiences and journeys with their illnesses. Children living with cancer often experience existential suffering associated with concerns about death and dying Even for children with curable disease, the life limiting aspect of cancer can lead to thoughts about mortality and the reality of death, which in turn can lead to children organically reflecting on their lives and their legacies. Gordon *et al.* (2020:317) asserted that legacy building offers an opportunity for children to create meaningful and thoughtful memories with family members, that will assure the child, that they will be remembered after their death, which is especially important for children with terminal illness.

Facilitating legacy building in this way, can therefore improve the quality of life of children with life-threatening conditions and can increase communication between the child, their family members, and interdisciplinary team members (Cuviello *et al.* 2020:1033) making it deserving of greater attention, as part of paediatric patient care. Daniels *et al.* (2024:e31066) further said that having

open and honest discussions about death and how a child wants to be remembered can lead to decreased emotional suffering and psychological distress amongst children suffering from chronic illness. These discussions can also promote healthy grieving processes for parents and the siblings of dying children and the process of legacy building, allows family members to have tangible memories they have created with their child prior to death (Keller *et al.* 2024:948). Legacy-building interventions have therefore been found to decrease pain and respiratory distress amongst certain children, as well as increase overall coping for patients and their family members (Foster *et al.* 2012:573) further entrenching its value with children with paediatric cancer patients.

Parents supported its use saying:

"*If the doctors or hospital could help my family and I with remembering our child during this time, like a box of something, her drawings or toys would be nice, sometimes even her records. We have pictures of our child but having other things would nice so I can cherish it"* (P2)

*"Although my child is 12 years old, she still has difficulty expressing herself and how she feels about all this, by her speaking, venting out, writing or even drawing with help her release all those feelings. As a parent, I want to cherish her growth and remember these moments. So having something like a pretty box or a container to store all of this, I will appreciate this."* (P 7)

These narratives highlight the emotional significance of tangible keepsakes in helping families cope with their child's cancer journey. They illustrate how

legacy-building through tangible mementos can provide families with emotional solace and a way to honour their child's journey. As mentioned by the parents, legacy building can therefore be used as a meaning-making activity to encourage family bonding and communication. Cahalan *et al.* (2022:1-11) posited that parents of children who have participated in legacy-building activities, have positive experiences, as it can benefit emotional expression and increase communication, about a child's cancer experience of cancer. Gray *et al.* (2024:4) further stated that parents recognize that intentional exercises in legacy building allow for further exploration of their child's feelings and worries, allowing parents the opportunity to address these concerns with their child.

Legacy building is therefore a relevant impactful psychosocial intervention for paediatric cancer patients and their families, as it creates lasting keepsakes that offer comfort, continuity, and a way to celebrate their child's life for their family. This intervention enhances emotional resilience and provides meaningful support during challenging times. Overall, legacy building fosters connection, healing, and hope amidst the cancer journey (Boles and Jones 2021:530), giving it a deserving space in the holistic care of paediatric cancer patients.

### 4.3.1.6 THEME 6 SPIRITUALLY BASED INTERVENTIONS IN A MEDICAL SETTING

Theme six reflected the use of spiritually based interventions in a medical setting. Five sub-themes emerged which included (I) mindfulness meditation; (II) yoga; (III) healing circles; (IV) ancestry healing and (V) the interconnectedness of psychosocial and spiritual interventions. Although

parents already have pre-existing spiritual interventions that they use to copy with their child's cancer and day-to-day adversities, the following spiritual interventions have been found and suggested to further enhance their coping and healing.

### 6.1 Mindfulness meditation

Several participants described the value of introducing mindfulness meditation into the medical context saying:

*"Mindfulness meditation and yoga will definitely be beneficial to the parents because it will allow them to release their stress and tension."* (Dr 4)

*"Mindfulness meditation does help with reducing anxiety levels. It provides individuals with a sense of peace and helps connect on a deeper, more spiritual level, making the treatment journey a bit more bearable."* (SW 3)

*"It can help them cope with the emotional turmoil of their diagnosis and treatment. By fostering a sense of spirituality and inner calm, mindfulness can improve their quality of life and provide much-needed emotional support."* (SW 6)

Children receiving chemotherapy are often severely affected by the symptoms and treatment experience throughout their cancer journey (Johnston *et al.* 2018:1750). Zucchetti *et al.* (2019:361) argued that the management of these symptoms evolves continuously and complementary and alternative medicine, can help manage symptoms associated with cancer therapy. Mind and body practices have in fact been introduced within healthcare practice, to assist with issues such as depression, anxiety, chronic pain and cancer (Creswell 2017:491). Mindfulness meditation focusses on fatigue, emotions and trauma

sensitive considerations (Murphy *et al.* 2022:43) all of which affects cancer patients. Children with cancer experience fatigue, loss of strength, dizziness, drowsiness and exhaustion. Abedini *et al.* (2021:141) argued that because mindfulness meditation, pays careful consideration to the emotions of an individual, it may benefit paediatric cancer patients, presenting with anxiety. Children with cancer have significant social-emotional challenges, which not only result from the illness itself, but from anxieties associated with diagnosis and prognosis, side effects of treatments, and hospital stays resulting in separation from family and social support structures.

A parent in the sample also supported its use saying,

*"I have read that mindfulness meditation can be source of comfort for families, whose loved ones are going through cancer. It supposed to help them handle the stress and fear that comes with cancer treatment."* (P 2)

Mindfulness practices have the potential to help children, become aware of their emotions as they arise in the present moment and become familiar with identifying, understanding, using, and managing them (Murphy 2019:5). Herscu *et al.* (2023:5) further advocated that this was a potentially beneficial intervention in the realm of childhood cancer care. As indicated it offers tailored support for older children who can grasp its concepts, and adaptable methods for younger children to engage meaningfully.

**6.2 Yoga**

The second sub-theme that emerged under this theme, was yoga.

Although one parent was unaware of the benefits, she was willing to consider it. Other parents however have been using it and supported its use for therapeutic purposes as follows:

*“I have not heard of yoga before nor do I know what it does, but if it is going to help my family and my child then I am willing to give it a try.” (P1)*

*"I would not be opposed if the medical staff recommended yoga into my child’s care plan. We often use Yoga in our family and has been a lifeline for our family. It gives my family a sense of peace and control during health scares, it helps maintain a healthy and disciplined lifestyle. The breathing exercises help manage my pain and anxiety, and the meditative aspect allowed us to bond and find strength in spirituality." (P4)*

*"My eldest daughter finds a spiritual connection through yoga. It wasn't just about physical exercise; it was about finding inner calm and resilience. The spiritual practice of yoga gives her a sense of purpose and hope, which is crucial to her as she battels to come to terms with her sibling’s diagnosis." (P7)*

De Padova *et al.* (2020:43) stated that this psychological distress, can adversely affect bio-behavioural responses, harm immune health and function, and contribute to immunological ageing. In addition to children and adolescents undergoing treatment for cancer, they are also exposed to a wide variety of stressors. Paediatric oncology patients suffer from side effects such as fatigue, pain, fear, anxiety (Fukuhara *et al.* 2020:179), sleep disorders, restlessness, depression, nausea and vomiting, and hair loss (Ameringer *et al.* 2020:80). Yoga, a scientific practice that originated in India has gained prominence for its potential benefits in managing treatment-related symptoms and improving health outcomes in cancer patients (Sharma *et al.* 2021:86). It includes physical postures (asanas), breathing exercises (pranayama), meditation, and ethical principles, creating a harmonious balance between the body, mind, and soul (Raghavendra *et al.* 2017:227). Cramer *et al.*(2020:60) added that yoga is recognised for enhancing bodily systems, improving posture, regulating sleep, and reducing stress and anxiety, among other benefits.

Studies by Gonzalez *et al.* (2021:1196-208) and Hsueh *et al.* (2021:264-76) have demonstrated substantial reductions in anxiety, depression, and stress (Sharma *et al.* 2021:86), highlighting yoga's effectiveness in managing psychological symptoms linked to cancer which support the views of parents in the sample. Other studies by O'Neill *et al.* (2020:1-10) and Pan *et al.* (2017:79-95) consistently observed enhancements in overall wellbeing, indicating a positive impact on QOL.

The doctor and social worker further stated:

*"Yoga has been a treatment modality for many years in alternate medicine, some people do yoga as part of their daily exercise. I personally believe that as an intervention it is and will be an invaluable practice in paediatric oncology. Because it helps children and their families find their inner strength and peace, which can improve their overall well-being. The practice encourages a mind-body connection that is essential for holistic healing and recovery."* (Dr 1)

*"As a paediatric oncologist, I've seen the positive impact of yoga on our young patients before I could be employed here. The spiritual aspects of yoga, help children cope with the emotional stress of their illness. It fosters a holistic healing environment that supports both the mind and the body."* (Dr 4)

*"Yoga offers a unique and personal and spiritual place of solace for young cancer patients. It provides a safe space for them to express their emotions, reduce stress, and find hope. The meditative and breathing techniques promote emotional resilience and help families navigate the challenges of treatment and recovery."* (Sw 4)

These arguments for the inclusion of yoga, was supported within a synthesis of findings from an umbrella review conducted by Giridharan *et al.* (2024:1-13) which indicated that yoga is an effective supplementary therapy for cancer patients, that significantly enhances the QOL in reducing psychosocial symptoms such as anxiety, depression, and stress. Yoga has influenced the outcomes for various health conditions, including neurological diseases, heart and lung diseases, and chronic pain (Li *et al.* 2021:102; Anshu *et al.*

2023:101), thus making it deserving of consideration within the realm of cancer treatment (Casuso-Holgado *et al.* 2022:103).

### 6.3 Healing circles

The third sub-theme focussed on healing circles as a therapeutic methodology.

Monshat (2023:16-24) argued that we long to belong and unquestioningly belong; to be seen in how we feel and what we need; and to feel safe from being judged as good or bad. He argued that being a member of a group which offers a communal caring presence can reconnect humankind to each other. Talking circles have been compared to network therapy, which mobilizes members of the family and the extended family into maximizing their resources and coping mechanisms. Hodge (1996:1592) added that healing circles have been used successfully in other contexts, including Native American communities, to successfully increase the rate of screening for cervical cancer. Montano (2022:1-13) opined that these circles increase knowledge, emotional support, social and informational support, and decrease negative mood and stress.

A nurse and social worker reflected on these circles saying:

*“If all the parents are encouraged to come together and communicate, reflect, pray, chant or even read holy scripture, it can have a very positive impact on their entire well-being. The spiritual support these circles will provide will help families feel more grounded and hopeful, enhancing their overall ability to manage the emotional toll of the disease."* (N15)

*"Healing circles provide a unique spiritual intervention that can deeply benefit families of children with cancer. They offer a space for spiritual reflection and communal support, which can be vital for emotional and spiritual resilience during such a difficult time." (SW4)*

These narratives reflect the value of spiritual support, so that parents can come together to support each other and pray and chant. According to Umbreit (2003:2) talking circles, peace-making circles, or healing circles, are deeply rooted in the traditional practices of indigenous people. In North America, they are widely used among the First Nations people of Canada and among the many tribes of Native Americans in the US. The circle starts with a prayer, usually by the person convening the circle, or by an elder, when an elder is involved. Mehl-Madrona (2014:4-9) explained that healing circles are often called hocokah in the Lakota language, which means a sacred circle and is also the word for altar. One of the participants (SW4) also described it as a space for spiritual reflection and communal support. The healing circle process then can serve as a unique instructional approach that can foster respect, model good listening skills, settle disputes, resolve conflicts, and build self-esteem (Mehl-Madrona 2014:4-9). Ludvigsen (2024:26) concluded that this ancient practice of a healing circle, preserved in spiritual, self-development and peer support traditions, can help parents reconnect with our collective identity whilst offering emotional support through their difficult circumstances.

### 6.4 Ancestry healing

Ancestry healing emerged as the last subtheme, with a doctor and social worker saying:

*"Integrating ancestry healing in paediatric oncology can offer families a holistic approach to coping with cancer. It provides emotional relief by connecting them to their cultural and familial roots, fostering a sense of spiritual support."* (Dr 5)

*"Ancestry healing offers a unique approach to support families dealing with childhood cancer. By reconnecting with their ancestral lineage, families find spiritual strength and emotional grounding, aiding in their overall coping and healing process."* (SW 6)

Another doctor shared although ancestry healing was not offered in their hospital, it allows families to connect with their ancestors' providing comfort and a sense of continuity. He added however,

*“We are not opposed by the idea, it allows individuals, but particularly in this case families, to connect with their ancestors' resilience, providing comfort and a sense of continuity. It is crucial in helping them cope with their child’s illness by offering spiritual support and strength from our lineage." (Dr 1)*

It is evident that ancestry healing, holds significant potential as a spiritual intervention for families coping with childhood cancer. Ancestry healing as a spiritual practice connects individuals with their ancestral roots to address generational traumas and draw strength from familial histories, is increasingly recognized for its potential benefits in the context of childhood cancer (Edwards 2011:335–348). This practice involves rituals, reflections, and honouring ancestors, so as to offer families emotional and spiritual support during their challenging journey. According to traditional Zulu culture, there is a continuous relationship between the living and the ‘living-dead’ (abaphansi). Marfo *et al.* (2024:84) continued to say that some illnesses are believed to be related to ancestral displeasure (abaphansi basifulathele). This may have been because certain rituals were forgotten, or customs neglected (ukulahla amasiko) which requires that appropriate ceremonies (umsebenzi) are needed to re-establish balanced relationships with the ancestors.

Robinson *et al.* (2019:1-12) argued that integrating ancestry healing into paediatric oncology can strengthen a holistic approach to treatment. Saidi and Heidari (2024:226) supported this notion, saying that it complements medical interventions by addressing the emotional and spiritual needs of families,

fostering resilience and hope. This reflects the views of one of the doctors that by “integrating ancestry healing, emotional relief by connecting families to their cultural and familial roots, can be provided and by enabling a sense of spiritual support.

Parents were also in favour of this saying:

*“It allows us to connect with our ancestors' resilience, providing comfort and a sense of continuity. It is essential in our culture in helping us cope with our child’s illness by offering spiritual support and strength from our lineage." (P3)*

*"The rituals involved in ancestry healing will keep us grounded. I have been told that it will transform our fears into a deeper understanding and acceptance of our child's illness..." (P8)*

*"When my elderly aunts and uncles came to visit us in the hospital, they told me that by honouring our ancestors and seeking their guidance through ancestry healing, I will find emotional relief and a sense of purpose mostly give me the power I need to navigate the emotional challenges of my child’s cancer." (P9)*

Parents reported finding comfort and strength in connecting with their ancestors' resilience, which provided emotional relief and a sense of continuity. This practice also helped in addressing generational traumas, thereby creating a positive and hopeful environment, by transforming fears into deeper understanding and acceptance of the illness. For many families, especially those from cultures with strong ancestral traditions, ancestry healing, provides deeper comfort. Ancestry healing rituals, such as honouring ancestors and seeking their guidance, can therefore transform fears into acceptance and provide a sense of purpose (Metcalf *et al.* 2024:15). As one parent shared, “by honouring our ancestors, I found emotional relief, and the power needed to navigate the emotional challenges of my child’s cancer.”

While not universally offered in clinical settings, its benefits are clear, making it a complementary practice, that can significantly support the well-being of affected families (Weaver *et al.* 2016:212–223).

### 6.5 The interconnectedness of psychosocial and spiritual interventions

The last sub-theme that emerged under theme six, reflected the interconnectedness of psychosocial and spiritual interventions. Although it is placed at the end it highlights the relevance of interweaving psycho-social an d spiritual methodologies, in a synchronous way with medical interventions.

The doctors and nurses in the sample expressed that:

*"Incorporating spiritual care into psychosocial interventions allows us to address the full spectrum of a child's needs. This holistic approach not only helps manage stress and anxiety but also enhances overall well-being and healing."* (Dr 1)

*Spiritual practices offer hope and meaning, while psychosocial support provides practical coping skills, creating a balanced care approach."* (Dr 6)

*“When working with children and their families, you must have both interventions. One cannot work without the other.”* (N16)

The social workers had similar sentiments saying that spirituality was an important factor alongside medical and psycho-social support:

*"Spirituality is an integral part of psychosocial care, providing families with a sense of purpose and connection. Together, these interventions help children and families find strength and resilience during the cancer journey."* (Sw 2)

*"By integrating spiritual care into our psychosocial support programs, we offer a more comprehensive approach that address the whole child. Which in turns supports the overall quality of life in the child and families."* (Sw 5)

These narratives reflect the indivisibility of the biopsychosocial and spiritual components of a human being. It entrenches the notion that spirituality and spiritual care should support both the physical and mental health care being offered to children and their families. The American Psychological Association (2020:3), supported this notion confirming the interconnectedness between psychosocial and spiritual interventions in childhood cancer care, saying that it is important to address the complex needs of young patients and their families. These interventions can range from counselling, support groups, and cognitive-behavioural therapy, aiming to enhance mental health outcomes and improve the overall quality of life (Anshasi *et al.* 2024:207).

Spiritual care extends itself to prayer, meditation, or guidance from spiritual leaders, as evidenced in the narratives from the different participants, thereby offering comfort and a sense of connection to something greater than oneself (Beyranvand *et al.* 2024:74). As such, healthcare providers are encouraged to incorporate holistic interventions, that include spirituality within treatment plans, tailoring their approaches to meet the unique needs of each patient and family (Safarabadi-Farahani *et al.* 2016:e262).

Parents themselves reported on the benefits of spirituality saying:

*"For our family, combining psychosocial support with spiritual care has been invaluable. The counselling sessions helped us process our emotions, while our spiritual practices gave us hope and peace. Together, they provided a very beneficial support system during our child's treatment."* (P1)

*"Spiritual practices like prayer, along with psychosocial interventions such as therapy, have helped our family cope with the emotional challenges of cancer. They work together to strengthen our resilience and maintain a positive outlook."* (P13)

These narratives support earlier findings regarding the value of spiritual practices such as prayer, in creating a synergistic effect that combines psychosocial support with spiritual care. Collectively, these findings underscore the integration of emotional, psychological, and spiritual care in offering a more comprehensive support structure for families, enhancing their ability to navigate the emotional complexities of cancer (Dose *et al.* 2018:201). A summary of a review conducted by Koumarianou *et al.* (2020:1-16) titled, *A review of psychosocial interventions targeting families of children with cancer,* explored various psychosocial interventions aimed at supporting families of children diagnosed with cancer. It also illustrated the importance of interweaving psychosocial and spiritually based interventions in childhood cancer care.

## 4.3.1.7 THEME 7: SOCIAL SUPPORT SYSTEMS IN CHILDHOOD CANCER

The seventh theme focussed on the social support systems available to childhood cancer patients and their families. These systems are identified within, the five sub-themes which emerged namely, (I) support from family, (II) support from friends and communities, (III) support from religious communities, (IV) support from CHOC (Childhood cancer foundation of South Africa), and (V) support from medical and social service professionals.

### 7.1 Support from family

Parents described the importance of support from family as follows :

*"My partner provides support, by calling me and checking up on the child, sees to the child's needs and my needs as well. He buys us food and toiletries. Most importantly, he encourages us to be strong."* (P3)

*"My mum would help and cook for my husband and other children. At times she would come to the hospital and bring food. Because my daughter at one time preferred eating chicken sweet corn soup. So, she would be cooking a lot of that and bring it here. Ever since I stayed back with my child at the hospital, my mum also said she will stay a couple of days at my home, get things organized and help my husband out with the kids. I will never forget how helpful my mum has been."* (P 4)

*"My family supports me so much. They look after the other children, bathe them, monitor any school issues and help them academically." (P6)*

*“Majority of my family lives overseas, so they cannot come and visit because of the distance. But they constantly provide me with emotional support. My in-laws especially are very supportive. If my mum or sister isn’t available and if I am having a bad day, I call on my in-laws and just vent.”* (P12)

These narratives reflect the importance of support that parents had, which enabled them to cope and manage the care of their ill child. Bouchard *et al.* (2022:408-418) asserted that when a child is diagnosed with cancer, the family must adapt to this new, intense and often stressful experience. Fletcher *et al.* (2011:40) opined that parents often feel guilty and responsible for what happened to their child and need help and support from all to heal and care for their children (Nurjanah *et al.* 2022:1-12). van Bindsbergen *et al.* (2021:4875 - 4884) added that everyday routines change, family relationships are challenged, and social activities are often disrupted by the distress that accompanies the disease and its treatment. Social support may consist of personal friends, extended family members, or community groups. As evidenced in the narratives, these groups provide important help for patients and families. Suzuki *et al.* (2003:160) said that despite the new demands, social support is one factor that plays a significant role in shaping adaptation to paediatric cancer caregiving.

Social support can serve many functions that are often categorized into emotional, informational, and logistical support. Salem *et al.* (2017:1-9) described emotional support as including showing love, care, concern, sympathy, and compassionate presence or “being there”. Logistical support includes help with day-to-day activities, such as instrumental assistance (e.g., providing a ride) or financial assistance (e.g., help paying a bill) (Thoits 2011:154). Collectively this social support and social capital, highlights the importance of both access to resources, as well as the nature and helpfulness of resources offered by several types of network ties.

Researchers have agreed that social support is one factor, that can play an important role in shaping adaptation to paediatric cancer caregiving (Adu-Assiamah 2022:1-15). Participants shared several forms of support from their families, which ranged from emotional reassurance, practical help with childcare, and provision of necessities like food and toiletries, to managing household duties, thus alleviating the burden on the parents. Two of the parents described this as follows:

*"My partner provides support, by calling me and checking up on the child, sees to the child's needs and my needs as well. He buys us food and toiletries. Most importantly, he encourages us to be strong."* (P3).

*"My family supports me so much. They look after the other children, bathe them, monitor any school issues and help them academically" (P6).*

Bouchard *et al.* (2022:408-418) made similar findings in their study, as they found that "family members were the most common source of emotional support and logistical support, and health care providers were the most common source of informational support. Emotional support from family and health care providers was perceived as most helpful." A study conducted by Kelada *et al.* (2019: 1537–1547), identified grandparents and aunts and uncles, to be important sources of emotional and instrumental support, after their child was diagnosed. This was consistent with findings from other studies with parents (Williams *et al.* 2014:39-60) and grandparents, of children with cancer, which found that grandparents may provide comfort and sympathy to parents and offer care to the 'healthy' siblings (Moules *et al.* 2012:119). In addition Kelada *et al.* (2019:1537) reported that female family members such as mothers, sisters, mothers-in-law and sisters-in-law are particularly supportive.

A doctor and social worker in the current sample shared as follows :

*“Support from families is a crucial element in helping children and families cope with the cancer diagnosis and treatment. It is an integral part of our treatment we recommend for the children. When parents receive that support from their families in any form, they are more inclined to respond to and understand the treatment we recommend for their child, simply by having that support from their families” (Dr 5)*

*“Many families here look for and some have that support of their extended family members. I cannot explain how important support from families are because it’s what gives parents the encouragement and motivation every day to stick by their child every day through treatments, poking, nausea and good days” (SW3).*

These participants further supported the notion, that support from family, is a crucial element in coping with the daily treatments and bouts of nausea their children endure. Salem *et al.* (2017:367) similarly described familial support as essential in optimizing treatment success for the child facing cancer treatment. Zendeh *et al.* (2021:646–654) indicated that from meeting daily responsibilities to offering unwavering emotional encouragement, family support not only eases the burden on caregivers, but also strengthens their resilience and commitment to their child's care (Rao *et al.* 2021:1-6). Hence, creating and facilitating family support systems is crucial to strengthening outcomes and ensuring holistic care for children facing cancer diagnoses (Abdoljabbari *et al.* 2018: 2575-2580).

### 7.2 Support from friends and communities

The second sub-theme focussed on the support received from friends and communities. Parents described this as follows:

*"Our friends have been incredible throughout the cancer journey. They set up a schedule to bring us home-cooked meals, which majority of the time goes to my home for my husband and children, ensuring we always had something to eat without any extra concern. The overwhelming and deeply touching generosity and kindness of the community have been greatly appreciated." (P3)*

*"The community group in the area has shown immense support. They volunteered to look after our other kids, picking them up from school and assisting with homework. This enabled us to concentrate fully on our child's care without having to be concerned about the welfare of our other children." (P5)*

*"Our close group of friends discussed amongst themselves when they are going to come see us in the hospital. They provide our child with so many gifts and snacks to maintain a sense of normalcy. Having someone to talk to other then parents and hospital staff to confide in has also provided a sense of comfort for me, reducing the feeling of loneliness during the journey." (P6)*

*"The support we received from our community back home has been a source of great encouragement, love and hope. They regularly host prayer gatherings and offer us encouraging messages." (P14)*

These participants revealed that friends and community members played a meaningful role in providing support to their child and the family. They shared how every act of kindness from cooking meals, to wanting to take care of the "healthy children", to creating visit schedules, eased their emotional distress and provided the practical help required to ease their burden. Nurjanah *et al.* (2022:5) said that these acts of kindness provide solace and security in a chaotic period. The regular provision of meals reflects how it can alleviate other

daily duties, parents have thereby enabling them to concentrate better on taking care of their child's health (Sprik *et al.* 2021:1275). Wawrzynski *et al.* (2022:1-15) opined that a community group's readiness to take care of the other children by fetching them from school and assisting with homework, demonstrates an important level of support. Nash *et al.* (2018:6) therefore concluded that the community played a crucial role in upholding a sense of normality and stability within the family, by looking out for the well-being of siblings, thereby ensuring the emotional health of everyone in the family.

Rezaei *et al. (*2018:425) further acknowledged that, having a group of friends to communicate with and share personal things with, provided parents with the opportunity to share their feelings and lessen their loneliness and isolation.

### 7.3 Support from religious communities

Faith based organizations were identified as important spiritual systems in the data. They include “faith-based civil society organizations, community-based organizations, larger national and international non-governmental organizations, and congregations such as places of worship, religious leaders, faith-based healthcare facilities” (Olivier *et al.* 2015:1765). The third sub-theme focussed on the support parents received from religious communities.

Parents shared this as follows:

*Our temple community has shown us incredible love and support. They have special services and prayer sessions for our child, as well as give us meals and groceries. This goes beyond spiritual support; they are a family, who are trying to help us manage the emotional and practical realities of this journey."* (P4)

*"We have been given countless forms of support through our faith-based organizations. The congregation takes care of my family at home, and they have organized volunteers to help with our other kids. It has been completely invaluable to be able to relieve our everyday stresses to give us time to focus on our kid. We are deeply grateful for the community and the support."* (P5)

*"Our faith-based organization has been our rock during my son's cancer journey. Our religious community prays for us during church prayer meetings once a week, and this brings me an incredible amount of peace. Everyone has shown such kindness, from the pastor all the way down to the congregation, who have held fundraisers for our medical expenses. Being able to count on their unwavering faith and kindness is huge for us."* (P7)

These narratives highlight the significance of faith-based community support, as they provide spiritual solace and offered a network of emotional, practical, and financial support. Kwarteng *et al*. (2024:1-15) opined that they provide survivors with spiritual and emotional support, educational assistance, as well as financial resources. Parents shared that the support received from faith based organizations moved beyond the emotional and spiritual to the practical help of acquiring hot meals and groceries for the families.

A doctor and social worker reflected the sample's views that:

*"Faith based organizations or religious communities play a very pivotal role for families and children at the hospital. Spiritual leaders and a few congregation members come to the ward frequently and offer prayers and make sure children and parents find comfort and spiritual guidance. When this occurs, we provide them with privacy. The support is comforting to children and families*

*because these organizations are aware of their role and impact they have"* (Dr 1)

*"The support from the religious community has been incredible. They set up a prayer chain, where people sign up to pray for or with children throughout the day - continuously. This continuous prayer has offered an amazing amount of peace without being particularly noteworthy. In addition to this, they have also been their families and children emotionally. That is to say, they have provided a listening ear and some words of encouragement when we needed it most."* (SW 6)

These narratives reflect the ongoing support, provided by spiritual networks from setting up prayer chains, to offering a compassionate presence, and providing continuous emotional reinforcement.

### 7.4 Support from Childhood Cancer Foundation (CHOC)

The fourth sub-theme that emerged in the data coalesced around CHOC. Childhood Cancer Foundation, is the organization started and run by parents who have had a child diagnosed with cancer or a life-threatening blood disorder (Bindsbergen *et al.* 2021:4875). Naidoo *et al.* (2016:4) highlighted that CHOC offers a range of informational support services that includes, educational materials, workshops and seminars, support groups, one-on-one counselling, online resources, advocacy and awareness, hospital support, survivorship programs, resource centres, and financial guidance.

Parents described the type of support they received from the Childhood Cancer Foundation as follows:

*"They provide me emotional support…we have prayer sessions and on Thursday we have cooking classes to keep us busy, rather than sleeping in the wards."* (P7)

*The fact that we live together here at CHOC as mothers, and we share our experiences even though our children's sicknesses are different." (P1)*

*I am happy here. They help me find accommodation here, to stay over and be closer to my child because I live far away from here. It saves me to much travelling money."* (P4)

*"They provide my child and I with everything we could possibly need, from food and accommodation, comfort and support at the CHOC house."* (P 5)

*"As a parent, I am scared of what is going to happen to my child, what are the procedures etc. But at CHOC, they provide me with information about my child's cancer, what it is, what to expect and I am glad that they give me all the information I need to understand this new journey."* (P7)

CHOC therefore played an essential role in the lives of paediatric cancer patients and their parents. The mothers residing at the CHOC residence, found the peer support from other mothers staying there hugely beneficial, as they found comfort in their shared experiences and through the realisation that they and their children were not alone, on their cancer journey. van Belzen *et al.* (2023:618) shared that by residing in one house, mothers were able to collectively confront the reality that they were not the only ones with a child

with cancer. This enabled them to form a new community, that allowed for mutual emotional expression and sharing and participation in the psychosocial programmes offered (Wilford *et al.* 2020:1-14).

Naidoo *et al*. (2016:49) said the primary goal of CHOC, is to provide a wide range of support for both the children and their families, throughout the long period of treatment. Mothers staying at the CHOC house were reassured that their sick child's basic needs of food, shelter, security and play activities were being met. Because CHOC is situated on the hospital premises, travel costs in relation to accessing treatment from the hospital, lessened their financial burden (Sweet-Cordero *et al.* 2019:1170). Moreover mothers who lived in places, at a geographic distance from the hospital, were able to remain with their child during their hospitalisation.

Moreover, children receiving out-patient treatment, but who lived away from the hospital were offered the opportunity to stay at one of our CHOC accommodation facilities, free of charge (CHOC 2021-2022:6). CHOC also provided transport, to ensure that children were brought back on schedule, for the whole of the course of treatment, and that the treatment programme was not abandoned because of financial constraints (Miller *et al.* 2020:423).

According to the doctors, social workers and nurses from the sample:

*"CHOC plays a very significant part in the hospitalization of our paediatric patients, they offer a range of services that include accommodation on the premises, financial assistance, contributes to psychosocial interventions and so much more."* (Dr 3)

*"CHOC is very good and an important part in our treatment plan for the children and assistance to the families. They aid basic and essential needs to the families that maybe struggling financially."* (Dr 5)

*"We work hand in hand with professionals at CHOC, there is a system that is followed in order for parents to receive CHOC services."* (Sw 1)

*"The organization provides a lot of gifts for the children, the volunteers come here either on a Tuesday or Thursdays and they bring backpacks for the kids, teddy bears, beanies and soaps for the children."* (N13)

"*The volunteers at CHOC decorate the ward and hospital setting, they try to make it appealing for the children and families, because the hospital clinic and ward can be very scary place, so youth and sometimes older individuals decorate the place with colourful aesthetics, pictures, drawings and decorations. I remember every special holiday like easter, and Christmas, the children's ward and clinic is always decorated with ornaments, strings of lights and presents*." (N14)

These narratives captured the salient role that CHOC has played, with regards to supporting the treatment journey for the child and most importantly to reduce the external burden of parents, by providing essential resources at their disposal. Hendricks *et al*. (2019:3) shared that a social worker meets all new families to assess their needs, coordinate various psychosocial and spiritual interventions, refer patients to group support meetings and coordinate a patients' domiciliary placements.

Wilford *et al.* (2020:1-14) shared that most children's oncology units in South Africa, strive to create a child friendly environment, with colourful interior

decorations of the wards and rooms and through provisioning toys, books, TV sets, video machines, games and other items to make the child's stay comfortable. Moreover, all newly diagnosed paediatric patients receive a CHOC care-bag with items of practical use and information to support them through their journey (CHOC 2022:6-8).

### 7.5 Support from medical and social service professionals

The last sub-theme emerging under theme seven, related to the support parents received from medical and social service professionals, during their child's cancer journey and hospitalization. Parents described the support they received as follows:

*"When the team comes in the morning during their rounds, the head of the ward doctor always asks for a summary from one of the other team members of what is happening to my child, like the treatment and progress. While this is happening, I am present by my child's bed side. When the doctors are done. The head of the ward (Dr1) always explains to me what is happening in terms I understand. She gives me advice; she encourages me and always tells me how amazing my child is doing." (P5)*

*"The nurses and social workers are God sent. They know how to take care of my child and the mothers here; they talk to us and always comfort us when we get bad news." (P7)*

*"During the clinic appointments, the primary doctor for my child clarifies what is happening, giving test results in the language I understand." (P13)*

These narratives reflect the tremendous, support and comfort healthcare professionals provide to parents. They shared how attentive they are to their varying emotional states offering hope, and reassurance during stressful times. The feedback from doctors who patiently demystify test results, by breaking down medical jargon, helps them to understand their child's situation and alleviate their anxiety. Both Tan *et al.* (2022:143–152) and Pletschko *et al.* (2023:2) argued that this type of holistic care was important in addressing both the medical and emotional needs of the child and family. As one parent shared healthcare personnel detect when they are feeling stressed and respond with comfort and reassurance. According to Larsen *et al.* (2022:1-10) giving parents that individualised care and support was important, as it helps them to manage the emotional toll of their child's cancer and treatment.

A study conducted by Bouchard *et al.* (2022:8) revealed that the attention provided by doctors and nurses, was crucial especially during medical emergencies. Dijkstra *et al.* (2020: e873-e879) similarly reported that meaningful communication between the medical staff and parents, enabled them to keep abreast of their child's treatment plans, development and progress. This also helps build trust as parents become more involved in their child's treatment plan (Signorelli *et al.* 2018:1-10). Klatt *et al.* (2022:1-18) concurred saying that the communication skills and relational abilities of medical staff are core competencies, in patient-centred care, that are linked to improved patient health outcomes and better patient adherence to treatment. However, as Bartlett *et al.* (2022:1-8) argued clinicians must have empathy and the requisite skills for them to engage in patient-centred communication.

Nurses played a huge role providing not just medical care, but also emotional support to children and families (Udo *et al.* 2019:1-8; Zendeh *et al.* 2021:647). One participant referred to them as a gift from God, because of their devotion

to the care of sick children. In fact some institutions assign patients and their families, a primary nurse who serves as a constant presence throughout the duration of their treatment (Cantrell *et al.* 2011:178).

The doctors and nurses reflected on their roles saying:

*"As doctors we show a lot of empathy to the parents especially." (Dr1)*

*"As nurses we are trained in our role as paediatric oncology/haematology nurses on how to manage and support parents during this uncertain period. As much as possible we aim to provide a sense of normalcy for the parents and child in whatever way we can. For example, we will have conversations with them while we are checking up on the child or filling in our reports, just to create a sense of normalcy for the parents and child as if they were home". (N13)*

These narratives highlight the importance of empathy and compassionate care amidst the distress endured by families of paediatric cancer patients. Derbie *et al.* (2023:1-13) reported that members of the psychosocial oncology team are crucial in providing social support to paediatric patients with cancer and their parents. Information that is communicated in an honest, sensitive, and empathic way can help parents find peace of mind and feel comforted (Bouchard *et al.* 2022:8).

## 4.4 Conclusion

This chapter captured the deep complexities and experiences confronting paediatric cancer patients and families within the milieu of the medical context. It highlighted the immense distress and anxiety encountered by parents and their children, who grappled with understanding this new disease, the fear of

death, a total upheaval to their family life and financial hardship as they navigated a new, painful and difficult journey. The support within the hospital context proved essential in enabling them to stay emotionally grounded and the various psycho-social and spiritual interventions, were invaluable, in helping them cope with different facets of hospitalisation, treatment and at times end of life support. Finally salient spiritual interventions also emerged that can be integrated within a holistic plan to support these fragile and vulnerable patients and their families. The chapter that follows present the key findings and recommendations.

# CHAPTER 5

# CONCLUSIONS AND RECOMMENDATIONS

## 5.1. Introduction

This study focused on childhood cancer within a family and medical context, in the eThekwini area, of KwaZulu-Natal, South Africa. This Chapter synthesizes the major findings made in this study, within the context of the six objectives that guided the study. It presents the key conclusions reached and recommendations for future research. The limitations of the study are also discussed. The data presented in Chapter 4 was sourced from parents of paediatric cancer patients (sample 1); health care professionals (doctors and nurses) (sample 2) and social workers (sample 3). Data was gathered using thirty-six in-depth interviews with participants from all three samples. The major findings of the study are presented in the sub-section that follows.

## 5.2. Major findings

A succinct summary of the key findings made, are presented within the context of the objectives that guided this study. These key critical findings are presented below.

#### 5.2.2.1 The impact of childhood cancer on paediatric patients

The first objective of the study was to understand how childhood cancer affected the paediatric patient at a physical, psychological and social level. The findings revealed that children experienced an array of effects, which starts at the onset of their diagnosis until post treatment. This notion was supported by Ehrhardt *et al.* (2023:679), who opined that children encounter an insurmountable number of adversities, when diagnosed with any form of

cancer, which gradually erodes their overall well-being. The study found that children experienced immense physiological challenges, which included fatigue, pain, nausea, and physical deterioration due to both the cancer and the side effects of treatment. The study also found that children experienced debilitating levels of emotional distress, which emerged from their fear of death, social isolation, and disruption to their school life. Collectively these issues coalesced into other psychosocial issues, such as diminished self-esteem, heightened levels of depression and withdrawal from peer interactions (Wright *et al.* 2024:1095). The study further documented that paediatric cancer patients, had to grapple with intense fear, brought on by unknown and painful medical procedures, uncertainty regarding their ability to survive and, thwarted plans for their future. It can be concluded that childhood cancer disrupts the normal developmental trajectory of paediatric patients, leaving them at a loss in terms of how this insidious disease may further cripple their physical and emotional well-being (Mora *et al.* 2023:107).

#### 5.2.2.2. The impact of childhood cancer on family life

The second objective of the study was to explore how childhood cancer affected the families of paediatric cancer patients. The study found that childhood cancer infiltrated and disturbed normal family relationships, thereby affecting all members of a nuclear family. Nizamis *et al.* (2024:229) asserted that childhood cancer, creates a myriad psychological, social, and family problems, as well as practical and financial issues, which every parent has to cope with, together with their ill child. The study found that parents, as well as single parents encountered huge psychological, financial, and social challenges, including marital instability, financial strain, and disruption to their overall family life, as they moved through the cancer journey with their sick child. One significant finding was that mothers in particular experienced heightened emotional anguish (Seyoum *et al.* 2024:2024), while both parents

reported experiencing feelings of helplessness and a lack of knowledge about their child's diagnosis. Their feelings of helplessness, emerged as a common thread in the data as parents were at a loss to find effective treatments for their sick child and wished that their child's cancer could be removed. They constantly endured heightened anxiety regarding the trajectory of the disease and their child's ability to withstand the onslaught of its physical effects. This together with the high demands of caregiving, led to huger levels of emotional stress after the child's diagnosis and placed greater strain on their marital relationship (Gajda *et al.* 2024:102).

As a result, parents had to make difficult decisions that included, interruption of their own studies, leaving their full-time job to accompany and stay with their child at hospital and leave their healthy children in the care of extended family's members. Cho *et al.* (2024:70) similarly reported that when parents receive a diagnosis of their child's cancer, they are confronted with balancing the demands of their children's illness and caregiving responsibilities, resulting in them making huge personal sacrifices, to ensure their family's well-being. The current study found that siblings felt neglected and invisible within their family space, as their parents intensified efforts to be around their sick child and prioritise his or her recovery. The lack of attention towards their other healthy children left them feeling sad, as in most instances they were entrusted to the care of other family members. This amplified family disconnect and tensions within the nuclear family. The siblings of children with cancer were also found to be affected by their brother or sister's illness. During their treatment, siblings experienced a greater disruption to their daily personal and academic life, changes in family relations and feelings of deep concern and loneliness as their parents grappled with the recovery of their sick sibling (Joosten *et al.* 2023:1401).

#### 5.2.2.3. Interventions in a medical context

The third objective of the study focussed on understanding what psychosocial and spiritual support, patients and their families received in a medical context. The study uncovered that there were efforts for paediatric cancer patients and their families, to receive psychosocial and spiritual interventions, to support them through the cancer journey. Pedersen *et al.* (2019:1-8) similarly argued that comprehensive, coordinated psychosocial, supportive and spiritual care is an essential component of holistic care that should be provisioned to childhood cancer patients and their families in a medical milieu. Some of the psychosocial interventions provisioned to patients and their families, included both individual and group counselling. Paediatric patients had access to individual counselling sessions with social workers and doctors, to help them cope with the emotional complexities of the disease. The study found that family counselling sessions were useful, in helping the family transition through the challenges of the effects of cancer on the patient and its treatment, but importantly its impact on the nuclear family. Other psychosocial interventions included cognitive behavioural therapy, educational support related to understanding the disease, its progression and demystifying its treatment protocols. This also included difficult end-of-life and bereavement support required when necessary. In addition to these interventions, paediatric patients and their families, were also encouraged to use spiritually based interventions, to draw their strength, comfort and coping from. The spiritual interventions, that were most commonly used were prayer, tapping into help from spiritual leaders, to support patients and their families, upholding their faith to stay strong and hopeful, as well as chanting to stay balanced and connected to their Higher Power or God.

#### 5.2.2.4. Psychosocial interventions that can support coping and healing in a medical context

The fourth objective related to the realm of psychosocial interventions, that can be integrated within the hospital environment, to better support medical and therapeutic services, being provided to paediatric patients and their families. Several interventions emerged within the current study, which had the potential, to enhance the well-being of paediatric cancer patients and their families. These holistic and creative methodologies included, music therapy, art therapy and play therapy, which were identified as interventions that were salient to helping the sick child and family members, transcend the harsh and debilitating physical effects of cancer and treatment protocols, as well as manage the emotional stress emerging from the onslaught of the disease. Steele *et al.* (2015:S585-S618) supported the need for psychosocial interventions to be interweaved within the hospital milieu saying they play a crucial role in supporting paediatric patients and their families during the recovery process. Structured activities like play therapy were found to alleviate psychological distress and create enhanced opportunities to bond with other patients and children and facilitate emotional expression. Collectively the interventions emerging from the data, reflect huge promise in terms of resolving emotional difficulties, social isolation whilst promoting the developmental needs of children caught up in their struggle with cancer.

#### 5.2.2.5. Spiritually based activities that support patients and their families through the cancer journey

The fifth objective was to understand what spiritually based activities can be harnessed to support patients and their families as they navigate the child's physical recovery. Whilst certain families were already using spiritual interventions, such as prayer and tapping into spiritual guidance from their spiritual leaders, they also recommended other beneficial interventions, such

as mindfulness meditation, yoga, healing circles and ancestry healing. Although some parents shared that they had little knowledge, regarding mindfulness meditation and yoga, a few expressed willingness to use these interventions to achieve a sense of calm and balance, through the stressful experience that accompanies treatment, management of the disease and changes to the treatment process. Murthy (2024:1-5) supported the introduction of these spiritually based activities, within the paediatric oncology milieu, saying they provided comfort, solace, and a sense of meaning to patients and their families as they endeavoured to transcend the difficulties linked to recovery from cancer. The nature of spiritual interventions, however was found to be deeply personal, and hence a more individualised approach to interweaving it within the medical care plan, was crucial to ensuring it was meaningful and effective based on each child and parents beliefs and values.

#### 5.2.2.6. A holistic approach to support paediatric patients and their families

The last objective of the study, which was to make recommendations, with regards to a more holistic approach to support paediatric patients and their families. The study found that supporting paediatric patients and their family required a multifaceted and holistic approach that not only addressed the physiological or medical needs of the child, but also their emotional, social, and developmental well-being.

The interconnectedness of the physical with the psychosocial and spiritual is premised on the notion, that the well-being of individuals, particularly in relation to challenging contexts such as paediatric cancer care (Kang *et al.* 2022: 257–269) is dependent on a holistic approach to assessment and care. Singh *et al.* (2022:102) argued that by synchronizing physical with psychosocial and spiritual interventions, recognizes that the human experience of illness, is not solely physical but also pervades the mind, emotions, relationships, and a person's sense of purpose or meaning. This interconnectedness reflects the

synergistic aspects of the holistic paradigm, that underpins the study. More importantly it enables a multidimensional approach to addressing the needs of patients and their families.

This holistic approach which combines both psychosocial and spiritual interventions within the medical milieu, can therefore significantly enhance the coping and recovery of paediatric cancer patients, whilst strengthening the coping abilities of their families. Kang *et al.* (2022:257-269) therefore argued that combining psychological counselling with mindfulness meditation can address both the cognitive and emotional aspects of distress, whilst creating a more balanced therapeutic approach.

To meet the final objective of providing recommendations for a more holistic approach to care, a summary of interventions emerging from the data and literature is presented in Table 5. The insights of several scholars were used to map out the recommended interventions (Levine *et al.* 2021:e28765; Kang *et al.* 2022:257–269; Singh *et al.* 2022:102; Marshall *et al.* 2024:452-460; Pozniak *et al.* 2024:2670-2683).

Table 5 elucidates relevant psychosocial and spiritual interventions, that may support paediatric patients and their families, transcend the complexities of the cancer journey. Each intervention is briefly described, outlining its nature and scope, followed by a description of how it supports holistic care. These interventions emphasize how they may contribute to emotional relief, improved coping, reduced isolation, and spiritual support and healing, making them deserve of consideration, within the milieu of paediatric oncology care.

Table 5 Psychosocial and spiritual interventions

| **Psychosocial Intervention** | **Description of intervention** | **Contribution to paediatric patients and families** |
|---|---|---|
| Parent support groups | Peer-to-peer discussions amongst parents of paediatric patients, facilitated by a therapist. | This may provide emotional support, shared coping strategies, and reducing the feelings of isolation amongst parents. |
| Sibling support programs | Counselling sessions designed for siblings of paediatric patients to help them cope and support groups, that can help siblings share the emotional distress linked to their sibling who is ill with the disease. | Can address the emotional turmoil and distress experienced by siblings, by creating therapeutic group support, deepening their understanding of the disease, and reducing feelings of neglect or jealousy. |
| Virtual support platforms | Online forums, virtual counselling, or telehealth services for remote families. | Virtual support platforms enable continuous emotional support to be provided to paediatric patients and their families. This is especially for those in rural or remote areas but who still require therapeutic services. |

| | | |
|---|---|---|
| Narrative therapy | Narrative therapy encourages patients and families to tell their stories and reframe their experiences positively. | Narrative therapy enhances emotional resilience and helps families find meaning in re-storying and transforming the negative elements of their journey into positive ones. |
| Respite care | Respite care services are essential to providing caregivers with a break from their responsibilities. | It reduces caregiver burnout and allows families to recharge. Allowing extended families or hired help, to provide parents a break. |
| Parental coaching | Parental coaching focusses on empowering parents with knowledge and skills to support their child emotionally and practically throughout their treatment. | This empowers parents to cope with their emotional distress and cope effectively with their challenges. It strengthens the parent-child relationship. |
| Expressive writing | Journaling or therapeutic writing activities for patients and families. | Journaling provides an outlet for paediatric cancer patients, parents and siblings to process their emotions and reflect on their difficulties and personal |

| | | |
|---|---|---|
| | | growth that emerges during the cancer journey. |
| Interactive digital apps | Apps offering relaxation exercises, guided breathing, or educational games for children undergoing treatment. | Apps can be created that combine relaxation exercises, guided breathing, or educational games thereby creating therapeutic effects and helping paediatric cancer patients to cope with treatment in a more engaging way. |
| **Spiritual interventions** | | |
| Labyrinth walking | Guided or independent meditative walks through a labyrinth. | Where possible access labyrinths to promote mindfulness, spiritual reflection, and a sense of peace during stressful times for paediatric cancer patients, their parents and siblings. |
| Sacred music therapy | Use of hymns, chants, or spiritually uplifting music. | Provides spiritual comfort and enhances emotional well-being for the sick child and their family through familiar |

| | | |
|---|---|---|
| | | and meaningful spiritual or religious music. |
| Gratitude practices | Encouraging families to reflect on positive moments or blessings during their journey. | Gratitude practices can strengthen emotional resilience amongst paediatric patients and their parents and foster a more positive outlook amidst the challenges they are experiencing. |
| Art therapy | Mandala-making, religious iconography, or other art forms with spiritual significance. | Engaging in spiritually based art therapy, can nurture stronger bonds between paediatric patients and their family members whilst also providing a therapeutic outlet for emotional expression and healing. |
| Pilgrimage or sacred rituals | Arranging visits to spiritual sites or performing meaningful cultural or religious rituals. | This can enable prayer, promote feelings of well-being, and provide a sense of comfort and ground families in their spiritual beliefs, as they navigate the complexities of a child's ill health and recovery or end of life experience. |

| | | |
|---|---|---|
| Ethno-spiritual support | Integrating culturally specific spiritual practices or connecting with cultural healers. | Honors and respects diverse spiritual and cultural backgrounds, enables culturally specific traditions and rituals to be included to support the child's recovery. This can enable deeper connectedness with one's cultural beliefs, building strength and resilience to cope. |
| Visualization and imagery | Guided visualization exercises can facilitate positive healing scenarios or enable connection with spiritual symbols. | This can reduce stress and anxiety and create a sense of peace and calm, during distressing moments that include treatment. |
| Wilderness therapy | Nature therapy, garden walks, or eco-spiritual practices. | This can also reduce stress and anxiety by connecting paediatric cancer patients and their families with nature. |

There are several other holistic psychosocial and spiritual interventions that can used to help paediatric cancer patients and their families cope and heal. These psychosocial interventions can include programs and services aimed at addressing the emotional, social, and practical challenges faced by patients and families. They highlight various approaches to improving emotional well-

being, reducing stress, and fostering family cohesion. Furthermore, spiritual interventions can focus on nurturing the spiritual and existential needs of paediatric cancer patients and their families. Examples include using spiritual music, spiritual bibliotherapy or the reading of spiritual books or attending religious or spiritual services, all of which can connect individuals with a sense of peace, hope, and spiritual resilience during challenging times. They can empower paediatric patients and their families with strength to cope, build resilience and hope, which can enable their holistic well-being. The interweaving of physical approaches with psychological and spiritual approaches, ensures that all their emotional and spiritual resources are harnessed, in way that makes the therapeutic and support system more robust and inclusive of holistic approaches.

The interventions emerging from the study and the literature reviewed can easily be integrated into hospital settings, community programs, or family-centred care plans. The interventions elucidated within Table 5 creates a beginning pathway to interweaving holistic psycho-social and spiritual interventions, into the medical context and advance their relevance within the treatment and recovery process.

## 5.3 Major conclusions

The study documented the profound impact, childhood cancer has on paediatric patients and their families, by bringing to light the challenges paediatric patients endure and the emotional struggles of their parents and siblings as they navigate a new and difficult journey together. A diagnosis of cancer was found to coalesce into excessive levels of emotional distress, that disrupted normal family dynamics and interactions, stymied social connectedness, which led to a tsunami of mental health problems, for both the paediatric patient, their parents and siblings. These mental health issues cannot be overlooked if cancer related treatment approaches are to be effective.

Patients and parents were found to grapple with fear of death, a disruption to the child's education, which further diminished their self-esteem and led to withdrawal from peers. Physically, patients were found to endure severe fatigue, pain, nausea, and the debilitating side effects of the harsh effects of cancer related treatment. Moreover, the huge uncertainty surrounding their future and the invasive nature of medical procedures were found to worsen their feelings of anxiety and despair. It can therefore be concluded that childhood cancer, collectively not only threatens physical health, by disrupting the normal trajectory of growth, but also affects the psychological well-being of young patients, creating deep emotional effects for the young patient.

It can further be concluded that childhood cancer extends beyond the patient, into the realm of the family unit. Parents, particularly mothers, experienced heightened emotional anguish and feelings of helplessness. Financial hardship was found to be common with many parents being forced to sacrifice their jobs, or educational opportunities to care for their sick child which added to the emotional strain being experienced. Moreover, the study uncovered the deep suffering of siblings, who endured feeling neglected, lonely and had to cope with disruptions to their academic and personal lives. They too were not immune to the huge fear, that their sick sibling would not survive. These dynamics were found to inevitably affect the marital relationships of paediatric patients, creating tension within the nuclear family, as parents strived to balance caregiving responsibilities with the needs of other family members.

Amidst this landscape of immense emotional pain and distress, the study uncovered a wealth of psychosocial and spiritual interventions, that supported both children and families in coping with the burden of paediatric cancer. It can be concluded that the psychosocial support received within the medical context, which included individual and family counselling, cognitive behavioural therapy, educational support, and recreational therapy, had helped to ease the challenges faced by patients and their parents. It can therefore be concluded

that such interventions are crucial to helping families navigate the emotional and psychological challenges associated with childhood cancer. Moreover, the study documented the value of spiritual interventions, such as prayer, guidance from spiritual leaders, and religious chanting in creating comfort, providing families with solace and a sense of hope.

Moreover, the participants recommended the integration of other psychosocial interventions such as music therapy, art therapy, and play therapy, in alleviating the psychological distress being experienced by patients and their families. Although the findings made, were specific to a single hospital in eThekwini, they provided rich insights into reconstructing the realm of paediatric cancer, which moves the focus from a medical one, to one which respects and integrates the psycho-social and spiritual aspects of humankind, so that a holistic approach may underpin the recovery process. This understanding can be used to inform the consideration and development of holistic strategies within the context of paediatric cancer care in South Africa. Hence, the study advocates for a holistic approach to paediatric cancer by not just prioritizing the physical health needs of paediatric patients, but also recognizing the psychological, social and spiritual needs of their parents and siblings. This will nurture a more family-centred approach, which is predicated on open communication, collaborative decision-making, and the active involvement of caregivers in the treatment process. Providing clear information that can be understood about the child's condition and treatment options, will ultimately empower families to respond decisively whilst alleviating their feelings of uncertainty. Finally, it can be concluded that a multidisciplinary approach, involving healthcare providers, social workers, educators, and community-based spiritual leaders can nurture the well-being of paediatric cancer patients and their families, by strengthening a more compassionate and effective approach to care.

## 5.4 Major recommendations for further research

Based on the findings of the study, several following recommendations for further research can be made. These are as follows:

### 5.4.1 Understanding family dynamics and coping mechanisms

The following recommendations with regards to understanding family dynamics and coping mechanisms can be made:

- It may be beneficial to further explore the experiences of siblings, by investigating how their psychosocial and emotional needs are affected and supported within the family system. The study found that thus far they have been neglected but an inquiry, which includes their experiences would be valuable.

### 5.4.2 Expanding psychosocial and spiritual support in medical contexts

The following recommendations can be made to expand the need for psychosocial and spiritual support in medical contexts:

- To explore the “how”, of integrating psychosocial and spiritual support services, at various healthcare institutions using best practices from an international context.
- To undertake studies that include the views of medical staff, social workers, and chaplains to understand the systemic barriers to delivering holistic care and develop ideas for of the implementation of such interventions.
- To explore how digital platforms, such as teletherapy or mobile apps, can enhance access to psychosocial and spiritual support services, particularly for families in medical contexts in underserved areas.

### 5.4.3 Salience of psychosocial interventions in a medical context

The following recommendations can be with regards to psychosocial interventions in a medical context.

- It is important to conduct research that will assess the impact and efficacy of specific psychosocial interventions, such as play therapy, music therapy, and cognitive-behavioural therapy, in relation to how it supports the emotional well-being of paediatric cancer patients.
- It is also important to explore how psychosocial interventions can be more effectively adopted within standard paediatric oncology care, and to assess their feasibility and scalability in resource-constrained settings.

### 5.4.4 Longitudinal research studies to investigate how the physical and psychosocial effects of childhood cancer can progress across different stages of the illness

- Further studies can investigate how the physical and psychosocial effects of childhood cancer progress across different stages of the illness**,** from the onset of diagnosis to remission or end-of-life care is important.

### 5.4.5 Develop Training Modules for Healthcare Professionals

- Educators and health sector leaders should design interdisciplinary training modules that equip doctors, nurses, social workers, and child and youth care workers with skills to recognize and respond to the psychosocial and spiritual needs of paediatric cancer patients and their families. This will enhance holistic care delivery and promote institutional capacity-building.

## 5.5 Interweaving the body-mind-spirit model as a holistic approach to practice

In order to implement the suggested framework, each discrete part of the theoretical framework elucidated in Chapter one, is recognised and the interventions embedded within it considered. The body-mind-spirit model adopted as the guiding theoretical framework of the study, acknowledges the inseparability of the mind-body-spirit and the intricate interplay between the physical, psychological, and spiritual dimensions of health as being crucial to the well-being of any individual.


Diagram of the body-mind-spirit model (Lee *et al.* 2009:1-417)

When applied to paediatric oncology, this model, exemplifies the need for a comprehensive care approach, that addresses not only the medical and physical challenges of the child but also the psychological resilience and spiritual grounding of the child and their family. Hence the patient and family are supported as whole beings, rather than as fragmented discrete entities.

- **The body: supporting physical well-being**

Cancer and its associated treatment protocols quickly erode a child's physical health, with side effects such as fatigue, pain, nausea, and weakened immunity

interventions, related to pain and symptom management. This requires not just medication but complementary therapies such as acupuncture and massage therapy can be beneficial in pain and symptom management. Hence, introducing gentle massage sessions for children can reduce both their pain and anxiety. Other interventions related to nutrition and exercise programs, can provide tailored dietary plans, to boost immunity and support energy levels. Light physical activity can also help to improve strength and reduce fatigue. This can be done through offering nutrition workshops for families to help them prepare nutritious meals that address a child's unique dietary needs. Yoga and physiotherapy can support physical recovery and mobility during and after treatment, allowing children to regain their strength and engage in activities they enjoy.

- **The mind: enhancing psychological resilience**

As found within the current study, paediatric cancer affects the mental health of the child and their family, causing heightened stress, anxiety, depression, and feelings of isolation. Counselling and therapy (individual and family), can help paediatric cancer patients and their families process their diagnosis, manage their fears, and strengthen their emotional resilience. Family therapy programs within the medical milieu, can help the whole family, transcend their emotional distress, improve communication between the parents and children, and strengthen their bonds. Child-focused therapy programs using art or play may enable young patients to express their emotions. This was supported by participants, from the current study who shared that art therapy can be a creative outlet for children undergoing cancer treatment, allowing them to express their emotions in a non-verbal way. Cognitive behavioural therapy (CBT) can teach children and families to reframe negative thoughts and focus on constructive coping strategies. Mindfulness techniques can reduce stress and nurture greater levels of calm during hospital stays. A parent from the study were supportive in using mindfulness meditation to help handle their stress. Addressing the educational disruptions caused by the illness, such as missed school, through tutoring or academic liaisons. This intervention

reduces feelings of social isolation and boosts the child's self-esteem. Lastly, incorporating recreational activities such as music therapy, or interactive play will help to improve mental well-being. For instance, conducting weekly music therapy sessions where children create or listen to songs will help them process emotions and experience joy.

- **The spirit: nurturing spiritual and existential well-being**

Spiritually based interventions like prayer and faith-based support were found to help support families, to practice their faith or spiritual beliefs. Hence access to chaplains, prayer rooms, or spiritual leaders are crucial to recovery. Mindfulness and meditation practices can help children and families, become more peaceful. Offering yoga and meditation classes for both children and their parents, either in a medical context or in housing facilities can reduce anxiety during treatment procedures. Group healing circles can help families share their experiences and draw strength from one another, as they offer a space for spiritual reflection and communal support, which is crucial to developing emotional and spiritual resilience. Honouring cultural traditions by valuing ancestral practices, also reinforce the value of spiritually based rituals in order to facilitate healing.

## 5.6 Recommendations for practice: the interconnectedness between the body-mind-spirit

The following recommendations can therefore be made with regards to practice, by honouring the interconnectedness of the body-mind-spirit model, in enabling coping and healing for paediatric cancer patients and their families.

- **Holistic well-being**

The current study acknowledged the indivisibility between the medical and psychosocial and spiritual realms of care. It further recognized that the paediatric patient does not exist in a silo, but interacts with the family unit, peers and religious and community networks, all of whom support the recovery process. By advancing interventions that focus on the emotional, social, and psychological aspects of care and considering the role of these support networks, much of the anxiety, depression, and social isolation experienced by both patients and family members can be reduced. Hence individual therapy programs, family counselling, and group support, are salient in building mental health and social connectedness. Spiritually based activities are equally salient, as they address existential concerns, help to find meaning in illness, overcome fears of mortality, and nurture hope. Through prayer, meditation, or engaging with spiritual leaders, these interventions can enhance the efficacy of medical procedures by providing comfort, strength and courage.

Therapeutic counselling was found to open avenues for exploring existential questions, offering spiritual insight, whilst coping with emotional distress and anxiety. Psychosocial and spiritual interventions were therefore found to work synergistically, building the emotional resilience of families empowering them with the strength to confront adversities linked to their child's illness.

Developing more robust social support networks, are also critical to creating greater belonging and support. Moreover, family counselling and support groups can help spouses and families improve their communication, resolve conflicts, and find strength in shared experiences. Introducing faith-based activities and spiritual groups can provide increased emotional and spiritual support, thereby supporting medical therapeutic goals. Consideration of these strategies can collectively coalesce into a comprehensive network of care, that can strengthen medical practice, ensuring that patients and families do not feel isolated and can draw their strength from their relationships and shared beliefs. This synergistic approach will create a more unified framework for holistic care

that will ensure that patients and families will receive support that is multifaceted and deeply impactful, by addressing all their needs and not just the treatment of the child's cancer.

## 5.5 Limitations of the study

There were several limitations to the current study. Firstly, it focused on a single hospital in eThekwini. Hence other regional variations in healthcare delivery and cultural practices across South Africa may have been overlooked. Further since the focus was a single hospital in eThekwini, the generalizability of the findings may be limited. Qualitative inquiries however gather rich insights which nonetheless help in understanding the plight of paediatric patients in other contexts. Healthcare systems in the country are highly diverse, with significant disparities between urban and rural areas in terms of resource availability, infrastructure, and access to specialized services. These differences could influence the types of psychosocial and spiritual interventions that can be available to childhood cancer patients and their families and also affect whether they may be integrated easily within resource limited environments. The rich cultural diversity that colours the South African terrain, suggests that the beliefs, values, and practices surrounding illness, coping, and healing varies widely across different communities. By focussing on one hospital, the potential to understand these cultural influences may have limited the findings related to how culture supports the journey to health and recovery.

## 5.6 Conclusion

Whilst cancer has been the leading cause of disease amongst children, medical advancements have seen the number of survivors increase. As patients traverse through the difficult journey of treatment, they may experience medical, physical and psychological problems, which affect their

transition back into the life, they had prior to diagnosis. As found in the current study, the family is not insulated from the wrath of the disease, with parents experiencing turmoil, anxiety, depression and at times grief. Siblings were found to also feel neglected, guilty and overwhelmed. Mental health issues such as anxiety can impede treatment and heighten susceptibility to infections, creating a protracted recovery period. The study found however that through a holistic approach, which uses psycho-social and spiritual interventions a more nurturing journey can unfold for patients and families, which can result in decreased levels of stress and an easier journey to recovery. A framework elucidating several psycho-social and spiritual interventions, that can support medical care, serves as the roadmap that health care institutions can build on to create a more holistic approach to paediatric cancer care.

***"Someday, God willing, we are going to beat all the odds and make childhood cancer a thing of the past" (Thomas 2020:1).***

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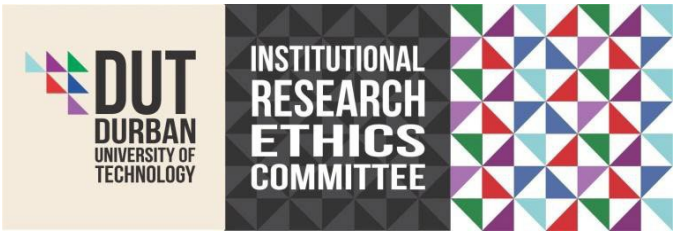
# APPENDIX 1 A (SAMPLE 1): LETTER OF INFORMATION




**LETTER OF INFORMATION**

**Title of the Research Study :** Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.

**Principal Investigator/s/researcher:** Neshika Munshi (Masters in Health Sciences).

**Co-Investigator/s/supervisor/s:** Professor. Raisuyah Bhagwan (Ph.D) Community and development disciplines; Dr M. Kgware, Doctor of Management Sciences.

**Brief Introduction and Purpose of the Study:**

**Greeting** Good day, I trust you are well.
**Introduce yourself to the participant** I am a Ph.D. student at Durban University of Technology currently pursuing research for my Ph.D qualification in Health Sciences.

**Invitation to the potential participant** I would like to invite you to participate in the research study.

**What is Research** Research is a systematic search or enquiry for generalized new knowledge.

Your participation in the study will be of value to add to the current research. Your participation in the study is voluntary, you are not forced to participate, should you feel the need to withdraw from the study at any point in the study, and you may do so. You are able to ask as many questions as you like. A consent form will be provided to indicate your participation in the study; however you are not obligated to continue with the interview if you are not comfortable.

**Outline of the Procedures**:

The aim of the study is to understand how childhood cancer affects paediatric patients and their families and to explore what psychosocial and spiritual interventions can be levelled to improve their coping and adaptation. Interviews will be conducted to collect the required information. The interviews that you participate in will depend on your availability during your child's consultation dates. Each interview will be between 50-60 minutes. Questions will also be asked to assist you in sharing the desired information. You qualify for the study as a parent who has a child who is diagnosed with paediatric cancer. The interviews will be facilitated in the hospital board room for the parents. If necessary, a follow up session will be conducted. The sessions will be recorded on a tape recorder to gather all information that is being shared. These recordings will be handled with great confidentiality. The only requirement and responsibility of you is to be present, on time for the interview and to share as much information as possible on the questions and topic that will be discussed.

**Risks or Discomforts to the Participant:** There will be no risk or discomfort to the participant.

**Explain to the participant the reasons he/she may be withdraw from the Study:** You are given the right to withdraw from the study at any time should you wish to do so, if you are not comfortable to proceed any further.

**Benefits:** None to the participants. The information, experiences and knowledge rendered will contribute significantly to the research study. The researcher will be able to publish scholarly articles with the information the participants have shared.

**Remuneration:** There will be no remuneration for you in this study.

**Costs of the Study**: You will not be required to endure any cost associated to the study

**Confidentiality:** All information discussed/disclosed in the interviews will be noted as anonymous. Your identities will not be revealed for the purposes of confidentiality. The taped recordings will be stored in a safety volt. No person will have access to the recordings other than the researcher. The results of the study including personal details will be anonymously processed into a study report.

**Results:** The results of the study will be converted into a research report, and accredited publications.

**Research-related Injury:** Given that this is an interview there are no expected injuries.

**Storage of all electronic and hard copies including tape recordings** Data transcripts and recordings will be stored in a locked volt that only the researcher and supervisor has access to. After 5 years the transcripts will be shredded and electronic recording will be deleted permanently and the device (USB) will be destroyed.

**Persons to contact in the Event of Any Problems or Queries:** Please contact the researcher on (0614991206), my supervisor Prof. Bhagwan (031 373 2197), my co-supervisor Dr Moeti Kgware (031 373 2249) or the DUT-Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the: Research and Postgraduate Support on researchdirector@dut.ac.za

# APPENDIX 1 B (SAMPLE 2): LETTER OF INFORMATION

**LETTER OF INFORMATION**

**Title of the Research Study :** Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.

**Principal Investigator/s/researcher:** Neshika Munshi (Masters in Health Sciences).

**Co-Investigator/s/supervisor/s:** Professor. Raisuyah Bhagwan (Ph.D) Community and development disciplines; Dr M. Kgware, Doctor of Management Sciences.

**Brief Introduction and Purpose of the Study:**

**Greeting** Good day, I trust you are well.
**Introduce yourself to the participant** I am a Ph.D. student at Durban University of Technology currently pursuing research for my Ph.D qualification in Health Sciences.

**Invitation to the potential participant** I would like to invite you to participate in the research study.

**What is Research** Research is a systematic search or enquiry for generalized new knowledge.

Your participation in the study will be of value to add to the current research. Your participation in the study is voluntary, you are not forced to participate, should you feel the need to withdraw from the study at any point in the study, and you may do so. You are able to ask as many questions as you like. A consent form will be provided to indicate your participation in the study; however you are not obligated to continue with the interview if you are not comfortable.

**Outline of the Procedures**:

The aim of the study is to understand how childhood cancer affects paediatric patients and their families and to explore what psychosocial and spiritual interventions can be levelled to improve their coping and adaptation. Interviews will be conducted to collect the required information. Each interview will be between 50-60 minutes. You are required to share your experiences and thoughts on this research topic. Questions will also be asked to assist you in sharing the desired information and to guide you in answering the questions. As a Health care professional who engages with paediatric patients and their families at the hospital are invited to participate in the interview to share your thoughts on what psycho-social activities and support can be included as part of a holistic plan to support paediatric cancer patients and their families. The interviews will be facilitated at your own offices or in the hospital board room. If necessary, a follow up session will be conducted. The sessions will be recorded on a tape recorder to gather all information that is being shared, these recordings will be handled with great confidentiality. The only requirement and responsibility of you is to be present on time for the interview and to share as much information as possible on the questions and topic that will be discussed.

**Risks or Discomforts to the Participant:** There will be no risk or discomfort to the participant.

**Explain to the participant the reasons he/she may be withdraw from the Study:** You are given the right to withdraw from the study at any time should you wish to do so, if you are not comfortable to proceed any further.

**Benefits:** None to the participants. The information, experiences and knowledge rendered will contribute significantly to the research study. The researcher will be able to publish scholarly articles with the information the participants have shared.

**Remuneration:** There will be no remuneration for you in this study.

**Costs of the Study**: You will not be required to endure any cost associated to the study

**Confidentiality:** All information discussed/disclosed in the interviews will be noted as anonymous. Your identities will not be revealed for the purposes of confidentiality. The taped recordings will be stored in a safety volt. No person will have access to the recordings other than the researcher. The results of the study including personal details will be anonymously processed into a study report.

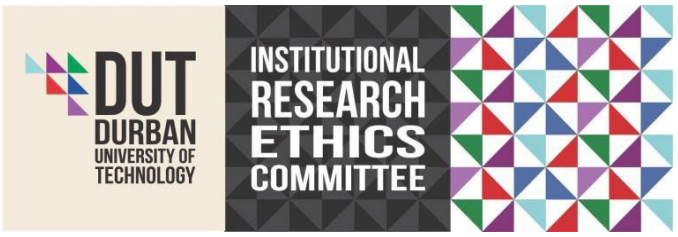
**Results:** The results of the study will be converted into a research report, and accredited publications.

**Research-related Injury:** Given that this is an interview there are no expected injuries.

**Storage of all electronic and hard copies including tape recordings** Data transcripts and recordings will be stored in a locked volt that only the researcher and supervisor has access to. After 5 years the transcripts will be shredded and electronic recording will be deleted permanently and the device (USB) will be destroyed.

**Persons to contact in the Event of Any Problems or Queries:** Please contact the researcher on (0614991206), my supervisor Prof. Bhagwan (031 373 2197), my co-supervisor Dr Moeti Kgware (031 373 2249) or the DUT-Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the: Research and Postgraduate Support on researchdirector@dut.ac.za

# APPENDIX 1 C (SAMPLE 3): LETTER OF INFORMATION




**LETTER OF INFORMATION**

**Title of the Research Study :** Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.

**Principal Investigator/s/researcher:** Neshika Munshi (Masters in Health Sciences).

**Co-Investigator/s/supervisor/s:** Professor. Raisuyah Bhagwan (Ph.D) Community and development disciplines; Dr M. Kgware, Doctor of Management Sciences.

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Your participation in the study will be of value to add to the current research. Your participation in the study is voluntary, you are not forced to participate, should you feel the need to withdraw from the study at any point in the study, and you may do so. You are able to ask as many questions as you like. A consent form will be provided to indicate your participation in the study; however you are not obligated to continue with the interview if you are not comfortable.

**Outline of the Procedures**:

The aim of the study is to understand how childhood cancer affects paediatric patients and their families and to explore what psychosocial and spiritual interventions can be levelled to improve their coping and adaptation. Interviews will be conducted to collect the required information. Each interview will be between 50-60 minutes. You are required to share your experiences and thoughts on the research topic. As a Social worker you qualify as a participant for the study whom engages with paediatric patients and their families. The interviews will be facilitated at your offices. If necessary, a follow up session will be conducted. The sessions will be recorded on a tape recorder to gather all information that is being shared; these recordings will be handled with great confidentiality. The only requirement and responsibility of you is to be present and on time for the interview and to share as much information as possible on the questions and topic that will be discussed.

**Risks or Discomforts to the Participant:** There will be no risk or discomfort to the participant.

**Explain to the participant the reasons he/she may be withdraw from the Study:** You are given the right to withdraw from the study at any time should you wish to do so, if you are not comfortable to proceed any further.

**Benefits:** None to the participants. The information, experiences and knowledge rendered will contribute significantly to the research study. The researcher will be able to publish scholarly articles with the information the participants have shared.

**Remuneration:** There will be no remuneration for you in this study.

**Costs of the Study**: You will not be required to endure any cost associated to the study

**Confidentiality:** All information discussed/disclosed in the interviews will be noted as anonymous. Your identities will not be revealed for the purposes of confidentiality. The taped recordings will be stored in a safety volt. No person will have access to the recordings other than the researcher. The results of the study including personal details will be anonymously processed into a study report.

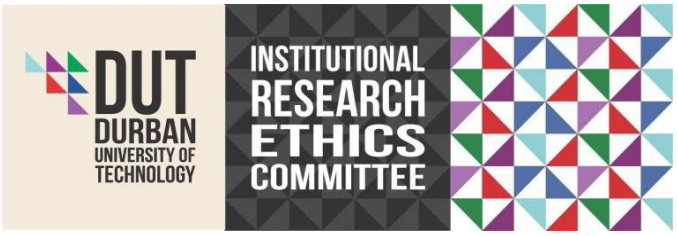
**Results:** The results of the study will be converted into a research report, and accredited publications.

**Research-related Injury:** Given that this is an interview there are no expected injuries.

**Storage of all electronic and hard copies including tape recordings** Data transcripts and recordings will be stored in a locked volt that only the researcher and supervisor has access to. After 5 years the transcripts will be shredded and electronic recording will be deleted permanently and the device (USB) will be destroyed.

**Persons to contact in the Event of Any Problems or Queries:** Please contact the researcher on (0614991206), my supervisor Prof. Bhagwan (031 373 2197), my co-supervisor Dr Moeti Kgware (031 373 2249) or the DUT-Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the: Research and Postgraduate Support on researchdirector@dut.ac.za

# APPENDIX 2A: CONSENT FORM




**Names of Researcher/s:**

**CONSENT**

Full Title of the Study: Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.

Names of Researcher/s: Neshika Munshi

**Statement of Agreement to Participate in the Research Study:**

□ I hereby confirm that I have been informed by the researcher, _____ (Neshika Munshi ), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: IREC 261/22

□ I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.

□ I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

□ In view of the requirements of research, I agree that the data collected during this study can be processed in computerized system by the researcher.

□ I may, at any stage, without prejudice, withdraw my consent and participation in the study.

□ I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared

to participate in the study.

 I understand that significant new findings developed during the course of this research which may

relate to my participation will be made available to me.

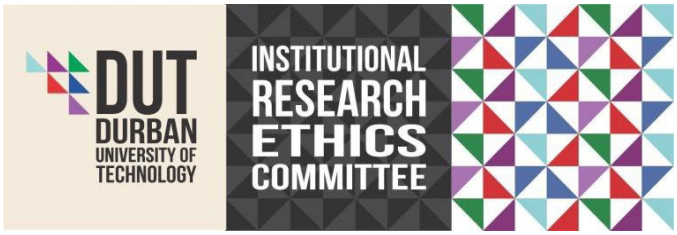
| | | | |
|---|---|---|---|
| **Full Name of Participant** | **Date** | **Time** | **Signature / Right Thumbprint** |

I, (Neshika Munshi ) herewith confirm that the above participant has been fully

informed about the nature, conduct and risks of the above study.

| | | |
|---|---|---|
| **Full Name of Researcher** | **Date** | **Signature** |
| **Full Name of Witness (If applicable)** | **Date** | **Signature** |
| **Full Name of Legal Guardian (If applicable)** | **Date** | **Signature** |

# APPENDIX 2B : CONSENT FORM




**Incwadiy**

**emvume**

**Isihloko esigcwele socwaningo:** Umdlavuza wezingane ngaphakathi komndeni kanye nomongo wezokwelapha eThekwini: ukuqinisa ukungenelela kwengqondo nangokomoya ukuze sikwazi ukubhekana nokuphulukisa

**Amagama Womcwaningi / s:** Neshika Munshi

**Isitatimende Sesivumelwano Sokubamba iqhaza Esifundweni Sokucwaninga:**

- Ngiyaqinisekisa ukuthi ngaziswe ngumcwaningi, ( Neshika Munshi), ngemvelo, ukuziphatha, izinzuzo kanye nobungozi balolu cwaningo - Inombolo Yokucwaninga Yokuziphatha Okucacile: IREC 261/22
- Ngithole futhi, ngifunde futhi ngaqonda imininingwane ebhaliwe engenhla ( Incwadi Eyingxenye Yolwazi ) maqondana nocwaningo.
- Ngiyazi ukuthi imiphumela yocwaningo, kufaka phakathi imininingwane yomuntu maqondana nobulili bami, ubudala, usuku lokuzalwa, ukuqalwa nokuxilongwa kuzocutshungulwa ngokungaziwa embikweni wokufunda.

- Ngokubheka izidingo zocwaningo, ngiyavuma ukuthi imininingwane eqoqwe phakathi nalolu cwaningo ingacutshungulwa ohlelweni lwekhompyutha ngumcwaningi.
- Ngingahle, nganoma yisiphi isikhathi, ngaphandle kokubandlulula, ngihoxise imvume yami kanye nokuzibandakanya esifundweni.
- Ngibe nethuba elanele lokubuza imibuzo futhi (yenkululeko yami yokuzikhethela) ngizimemezele ukuthi ngizimisele ukubamba iqhaza ocwaningweni.
- Ngiyaqonda ukuthi okutholakele okusha okusha okwenziwe phakathi nalolu cwaningo olungahlobene nokubamba iqhaza kwami kuzotholakala kimi.

| | | | |
|---|---|---|---|
| **Igama eligcwele lomhlanganyeli** | **Usuku Date** | **Isikhathi** | **Isihinesha /** |

**Right Thumbprint**

I Neshika Munshi herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study

| | | |
|---|---|---|
| **Full Name of Researcher** | **Date** | **Signature** |
| **Full Name of Witness (If applicable)** | **Date** | **Signature** |
| **Full Name of Legal Guardian (If applicable)** | **Date** | **Signature** |

# APPENDIX 3: INTERVIEW GUIDE: PARENTS

1) Can you share with me a little more about your child's diagnosis and treatment.
2) Can you describe how the diagnosis and treatment has affected : a. you as parents, the child, c. siblings d. the entire family system ?
3) What has been the major stressors that you and your family have had to endure since your child has taken ill a. financial, b. emotional, c. social
4) Can you describe what level of support you have received from the : a. hospital, b. CHOCS, c. faith based organizations ?

5) Please describe the nature of the help you have received from:

- Family (external)
- Health care staff
- Social workers
- Spiritual support systems

6) What type of further support would you require from:

- Family (external)
- Health care staff
- Social workers
- Spiritual support systems

7). Briefly describe how spiritual and psychological services can be introduced into the overall program at the hospital.

# APPENDIX 4: INTERVIEW GUIDE: HEALTH CARE PROFESSIONALS

1) Can you describe your experience of working with childhood cancer patients and their families?
2) What are the major sources of stressors paediatric cancer patients and their families face?
3) Can you share your thoughts on the importance of both psychological support services to patients and families ?
4) Can you share your thoughts on the importance of spiritual support services to patients and families ?
5) What are some of the ways both psychological and spiritual activities can be included in the CHOCS program?

# APPENDIX 5: INTERVIEW GUIDE: SOCIAL WORKERS

1) Can you describe your experience of working with childhood cancer patients and their families?
2) What are the major sources of stressors paediatric cancer patients and their families face?
3) How can the level of psychological support be improved in relation to these families and children ?
4) What is the nature of therapeutic services being offered to these families and children ?
5) What other therapeutic support services can be introduced to assist these families?
6) What are your views on the importance of spiritually based activities in a social work context?
7) Can you share what spiritual interventions can be used to enable the healing and recovery of these patients and assist families to cope better : a. prayer, b. spiritual music, c. spiritual bibliotherapy d. meditation f. art and music therapy?

# APPENDIX 6A (DEPARTMENT OF HEALTH- KWAZULU-NATAL): LETTER REQUESTING PERMISSION FROM GATEKEEPERS

28 November 2022

**Request for Permission to Conduct Research**

Dear Dr. Lutge

My name is Neshika Munshi, a PhD: Health Sciences student at the Durban University of Technology. The research I wish to conduct for my Doctoral thesis involves “Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.”

I am required to conduct interviews with a few health care professionals, namely doctors and nurses, occupational therapists and social workers from Inkosi Albert Luthuli Central Hospital. I also need to interview family members linked to CHOCS at the hospital. I am hereby seeking your consent from the Department of Health to conduct the study at Albert Luthuli Hospital. I would be grateful if the interviews can be done on the hospital premises and that a private, comfortable room be availed.

My proposal is attached so that you have an idea of what the study is about. I also will provide a letter of information and informed consent during data collection.

If you require any further information, please do not hesitate to contact me my cell number: 0614991206 or email neshikam@gmail.com. Thank you for your time and consideration in this matter.

Yours sincerely,

Neshika Munshi
Durban University of Technology

# APPENDIX 6 B (HEAD OF PAEDIATRIC ONCOLOGY/HAEMATOLOGY): LETTER REQUESTING PERMISSION FROM GATEKEEPERS

5 August 2022

800 Bellair Road
Cato Manor
Durban

**Request for Permission to Conduct Research**

Dear Dr. Berverly Neethling

My name is Neshika Munshi, a PhD: Health Sciences student at the Durban University of Technology. The research I wish to conduct for my Doctoral thesis involves “Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.”

I would be required to conduct interviews with parents, in receipt of services from CHOCS foundation. I am hereby seeking your consent to conduct interviews with families whose children are paediatric cancer patients and are linked to CHOCS. As such I will need your help to recruit these parents and to forward their names and contact details to me. Once this is done, and I can collect data, please assist with providing a comfortable venue wherein these interviews can be done.

My proposal will be attached so that you have an idea of what the study is about. I also will provide a letter of information and informed consent upon data collection.

If you require any further information, please do not hesitate to contact me my cell number: 0614991206 or email neshikam@gmail.com. Thank you for your time and consideration in this matter.

Yours sincerely,

Neshika Munshi
Durban University of Technology

# APPENDIX 6 C (HOSPITAL MEDICAL MANAGER): LETTER REQUESTING PERMISSION FROM GATEKEEPERS

5 August 2022

800 Vusi Mzimela Road
Umkumbaan
Durban
4091

**Request for Permission to Conduct Research**

Dear Dr. A. Harrichandparsd

My name is Neshika Munshi, a PhD: Health Sciences student at the Durban University of Technology. The research I wish to conduct for my Doctoral thesis involves “Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.”

I am required to conduct interviews with a few health care professionals, namely doctors and nurses, and occupational therapists from the hospital and social workers. I also need to interview family members linked to CHOCS at the hospital. I am hereby seeking your consent from Albert Luthuli Hospital to conduct this study and then to get your assistance with recruiting the aforementioned participants from the hospital. I would be grateful if the interviews can be done on the hospital premises and that a private, comfortable room be availed.

My proposal is attached so that you have an idea of what the study is about. I also will provide a letter of information and informed consent during data collection.

If you require any further information, please do not hesitate to contact me my cell number: 0614991206 or email neshikam@gmail.com. Thank you for your time and consideration in this matter.

Yours sincerely,

Neshika Munshi
Durban University of Technology

# APPENDIX 7 (DEPARTMENT OF HEALTH-KwaZulu-Natal): GATEKEEPER'S PERMISSION

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2809/ 3189/ 3123 Fax: 033 394 3782
Email:
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

NHRD Ref: KZ_202211_034

**Dear Ms N D Munshi**
(DUT)

**Approval of research**

1. The research proposal titled '**Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.**' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central hospital.

2. You are requested to take note of the following:
   a. ***Kindly liaise with the facility manager BEFORE your research begins.***
      *This is to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   b. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Dr. G Khumalo on 033-395 3189.

Yours Sincerely

**Dr E Lutge**
Chairperson, Provincial Health Research Committee
Date: 01/05/2025

Fighting Disease, Fighting Poverty, Giving Hope

# APPENDIX 8 (HEAD OF PAEDIATRIC ONCOLOGY/HAEMATOLOGY): GATEKEEPER'S PERMISSION

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 800 Vusi Mzimela Road, Mayville, 4058
Postal Address: Private Bag X03, Mayville, 4058
Tel: 031 2604349 Fax: 031 2604388 Email: NeethlingB@ukzn.ac.za
www.kznhealth.gov.za

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL: MOTHER & CHILD DOMAIN

22/02/2023

Medical Manager
Inkosi Albert Luthuli Hospital

To whom it may concern

I am granting Neshika Munshi permission to interview parents who have children with cancer as well as the medical staff who manage children with cancer from our Pediatric Oncology unit at IALCH.

She is conducting a study:
**"Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing"** for her PhD studies.

This study will be conducted in two public healthcare facilities in KwaZulu-Natal; namely, Inkosi Albert Luthuli Central Hospital and Greys Hospital and she have obtained an ethics provisional approval of this study from the DUT Institutional Research Ethics Committee. The study will be conducted in the oncology hematology pediatric department.

This research study will involve data collection from Pediatric cancer patients in the form of a survey questionnaire and in-depth interviews with parents and medical staff.

Yours Sincerely

Dr B. Neethling
Pediatric Hematologist
Head of Department Pediatric Hematology / Oncology
Inkosi Albert Luthuli Central Hospital
Kwazulu Natal

# APPENDIX 9 (HOSPITAL MEDICAL MANAGER): GATEKEEPER'S PERMISSION

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
OFFICE OF THE MEDICAL MANAGER
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville,4091
Tel: 031 240 1059 Fax: 031 240 1005 Email: Ursula.john@ialch.co.za

Reference: IRFC 261/22
Enquiries: Medical Management

23 February 2023

Ms N D Munshi
41 St. Pauls Avenue
Reservoir Hills
Durban
4091

Dear Ms Munshi

**RE: PERMISSION TO CONDUCT RESEARCH AT IALCH**

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully

**Dr A Harrichandparsad**
**Acting Medical Manager**

# APPENDIX 10 (DURBAN UNIVERSITY OF TECHNOLOGY): INSTITUTIONAL APPROVAL LETTER


**Institutional Research Ethics Committee**
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lenthall@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

8 March 2023

Ms N D Munshi
41 St. Pauls Avenue
Reservoir Hills
Durban
4091

Dear Ms Munshi

**Childhood cancer within a family and medical context in eThekwini: strengthening psychosocial and spiritual interventions to enable coping and healing**
**Ethical Clearance number IREC 261/22**

The Institutional Research Ethics Committee acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the DUT-IREC according to the DUT-IREC Standard Operating Procedures (SOP's).

Please note that any deviations from the approved proposal require the approval of the DUT-IREC as outlined in the DUT-IREC SOP's.

**It is compulsory for a student or researcher to apply for recertification on an annual basis. The failure to do so will result in withdrawal of ethics clearance. It is the responsibility of the researcher and the supervisor to apply for recertification.**

**Please note that you are required to submit a Notification of Completion of Study form together with an abstract to the DUT-IREC office on completion of your study.**

Yours Sincerely

Prof J K Adam
Chairperson: DUT-IREC