



THE HEALTH RELATED QUALITY OF LIFE IN CHILDREN ADMITTED FOR CANCER MANAGEMENT AND THEIR FAMILIES

S'thembiso Charles Tembe

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University of the Witwatersrand, in fulfilment of the
requirements for the degree of Masters of Science in
Occupational Therapy.

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DECLARATION

I S'thembiso Charles Tembe declare that this Dissertation is my own, unaided work. It is being submitted for the Degree of Masters of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

_____ (Signature of candidate)

_____ day of _____ 20_____ in _____

DEDICATION

It is my genuine gratefulness and warmest regard to dedicate this dissertation to Zoliswa Ngema, for her endless support, motivation, devotion, love and kindness throughout the journey of my work.

ABSTRACT

Children with cancer are treated in specialised hospital facilities, where the temporary environment may cause occupational disruption in the participation of normal occupations and therefore affecting the quality of life in both children and their parents. The parents who accompany the children while they are hospitalised often need to board near the hospital as the specialist unit is far from their homes which results in occupational disruption. Affecting family functioning.

The aim of the study was to describe the health related quality of life (HRQoL) of children aged 8-12 years during their first admission to a specialised oncology unit and that of their parents. A quantitative, descriptive, cross-sectional study was conducted in Steve Biko Academic Hospital of 25 children with cancer and their parents, structured interviews were used with the children to determine their HRQoL in terms of their functioning and occupational disruption using the PedsQL™ Generic Core Scale (4.0) and their HRQoL related to the specifically to their diagnosis and treatment for cancer using the PedsQL™ Cancer Module (3.0). Their parents reported on their child's HRQoL using proxy forms for these same instruments. The parents HRQoL in relation to family function was also determined for the using the PedsQL™ Family Impact Scale (2.0).

Results indicate that most of the children were males with leukaemia, and treated with chemotherapy. The children and parents came from Gauteng and Mpumalanga provinces with low employment rates. Children and parents reported the children's functioning and HRQoL to be at an intermediate level on the Generic Core Scale (4.0) except for physical functioning which parents felt was at a low level. Children scored change in school roles as having the greatest effect on their HRQoL.

Scores on the Cancer Module (3.0) also indicated HRQoL at an intermediate level or at risk for impairment except for treatment anxiety and worry which from the children's perspective fell in a high or normal range for HRQoL. This differed significantly from the parent's perspective as they felt these aspects impacted on their and impaired child's HRQoL along with procedural anxiety. Family function, particularly disruption of activities of daily living was reported by parents as impacting their HRQoL at an intermediate level with a marked decrease in physical functioning. Worry was at an impaired level for HRQoL while family relationships

were at risk for impairment on the Family Impact Scale (2.0). No significant differences were found for HRQoL related to type of cancer or type of intervention provided.

Children and parents were at risk for impairment of HRQoL with parents overestimating the effect of impairment except for treating anxiety and worry which from the children's perspective fell in a high or normal range for HRQoL, which is supported in the literature. The study indicates the need to understand the occupational disruption experienced by children hospitalised for the treatment of cancer and their parents to provide occupational therapy and intervention to facilitate HRQoL.

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NOMENCLATURE

Definition of Terms

Cancer survivorship: *is the period from completion of cancer treatment until death (American Cancer Society, 2019).*

Childhood cancer: *individual who is diagnosed and treated for cancer with ages of zero to fifteen years or they may be younger nineteen years old (World Health Organisation, 2009)*

Consolidation phase therapy: *is the treatment which is given when cancer cells have disappeared following induction therapy, it is used to kill any cancer cell that may be left in the body, and it consist of radiation, stem cell transplant or chemotherapy (American Cancer Society, 2019).*

Excessive daytime sleepiness: *is characterized by persistent sleepiness and often a general lack of energy, even during the day after apparently adequately or prolonged night-time sleep (Crabtree, 2017)*

Induction therapy: *is the first series of therapeutic measures taken to treat a disease (American Cancer Society, 2019).*

Normal occupations: *involves participation in occupations of everyday life which has an influence on well-being and life satisfaction, this encompasses, choosing, execution and pleasing in activities anticipated by an individual and dependent to the importance of what one is doing (Bergström et al., 2017).*

Occupational disruption: *is a temporary or transient state in which the individual is unable to participate in necessary occupations (Sung et al., 2011)*

Occupational deprivation: *is the state of hindrance in performing meaningful occupations due to factors outside of individual's control (Miralles et al., 2016).*

Occupation: *are everyday activities which individual participate in them in families or communities and they bring purpose and meaning to life (Christiansen et al., 2015).*

Occupational performance: *the ability to perceive, recall desire and plan tasks, routines, and roles for the purposes of leisure, responsibility, productivity and self-care, in demand of environments (Christiansen et al., 2015)*

Occupational performance areas: *are the tasks or occupations which the individual participate in them in the following areas; activities of daily living (ADLs), work, leisure, socialisation, community survival and rest (Christiansen et al., 2015)*

Optimism: *refers to general expectancies that good rather bad things will happen in the future, it is important concept for parents of children with cancer as people characterised as dispositional optimists tend to show greater psychosocial adjustment to a number of psychological strains related to chronic illness (Christiansen et al., 2015).*

Abbreviations

ADLs	Activities of Daily Living
ACCO	American Childhood Cancer Organization
AML	Acute Myeloid Leukaemia
IADLs	Instrumental Activities of Daily Living
ALL	Acute Lymphoblastic Leukaemia
ANOVA	Analysis of Variance
APA	Adapted Physical Activity
CANSA	Cancer Association of South Africa
CCS	Childhood Cancer Survivors
CHQ	Child Health Questionnaire
CIT	Cranial Irradiation Therapy
CNS	Central Nervous System
EDS	Excessive Daytime Sleepiness
CRT	Cranial Radiation Therapy
FIM	Family Impact Module
FOP	Fear of Progression
HRQOL	Health Related Quality of Life
IT MTX	Intrathecal Methotrexate
M-ESS	Modified Epworth Scale
MSLT	Multiple Sleep Latency Test
NHRD	National Health Research Database
PACS	Pediatric Activity Card Sorting
PedsQL	Pediatric Quality of Life
PSE	Perceived Self Efficacy
QOL	Quality of Life
QOLCC	Quality of Life for Children with Cancer

SBAH

Steve Biko Academic Hospital

LAYOUT OF THE STUDY

Chapter 1

This chapter provides an introduction and background to the study. The problem statement, purpose and aim of the study, as well as the significance are presented.

Chapter 2

Literature review discusses epidemiology of childhood cancer, cancer treatment in South Africa, effects of treatment sequelae, general functional and health-related quality of life before describing specific health-related quality of life in children with cancer. Parents health related quality of life is discussed, treatment side effects, and different assessment tools used in HRQoL before a summary of the literature.

Chapter 3

The chapter presents the methodology, which was a quantitative correlational descriptive cross-sectional study conducted in SBAH on children admitted for cancer management. All the participants were recruited using convenience sampling. Before data collection, patients whose children met the inclusion criteria were approached, and along with their child invited to participate in the study.

Research procedures that were followed were to obtain permission to use questionnaires from the author, ethical clearance from the University of Witwatersrand and SBAH from ethics committees. Children completed the Paediatric Quality of Life inventories, Cancer Module (3.0) and Generic Core Scales (4.0) in a face-to-face interview. Parents were asked to fill out a demographic questionnaire and the Paediatric Quality of Life, Cancer Module (3.0) parent proxy, Generic Core Scale (4.0) parent proxy, and lastly Family Impact Module (2.0) to determine how the family was coping with child's illness during management. Results were analysed using Statistica software, where different types of data, nominal, ordinal, interval and ratio scales were determined using Analysis of Variance (ANOVA), t-test, correlation coefficient, and Chi-Square.

Chapter 4

Demographics of both parents, children and their families are presented, followed by quality of life, specifically in four functional areas of Generic Core Scales (4.0) comparing HRQoL reported by children and parents using a Mann Whitney test. Family functioning, using Family Impact Scale (2.0), relationships of parents admitted with cancer children is presented. The last section is the description of quality of life from Cancer Module (2.0) and the results of children and parents are compared using a Mann Whitney test. The effect of HRQoL results according to treatment factors were determined using the using Kruskal-Wallis one- way ANOVA, where there were no statistical differences found.

Chapter 5

Chapter 5 is about the explanation of the findings through utilisation of evidence, other or similar studies pertaining to each objectives as stipulated above; firstly, demographics, followed by occupational performance and quality of life in children and their families, looking in Generic Core Scales (4.0), Family Impact Scale (2.0), and Cancer Module (3.0). The limitations of the study are presented.

Chapter 6

The last chapter summarises the main findings of the study and importantly the clinical implications for this population who are at high risk of experiencing occupational disruption and low quality of life with recommendations and further recommendations are stipulated for follow up studies.

CHAPTER 1: INTRODUCTION

1.1 Introduction and background

Occupational therapy practice in paediatric oncology, uses a problem-solving approach in addressing symptoms and dysfunction in physical, emotional, psychosocial and psychological client factors, which also includes planning ahead for the later anticipated functional implications. The child's diagnosis and cancer stage, prognosis, health status and need for family support are assessed using standardized and validated assessments prior to supporting the child with cancer, their family; parents and siblings (Cooper, 2013).

In relation to occupational therapy management of the child with cancer management, early child development must be considered. Children participate in a variety of day to day activities at home, school and communities, where they improve their social and personal developmental components and these provide development abilities which prepares them to face everyday life conditions (Fleer, 2015). Outcomes from serious illness such as cancer, in children is dependent on facilitation of development as well as positive feelings and behaviours or character strengths and participation in meaningful activities, contributing to life satisfaction (Proctor et al., 2011).

Although cancer is considered rare in childhood, the effect of cancer in children is different from that of adults because the lengthy treatment and hospitalisation affects the health-related quality of life (HRQOL), including the disruption in participation in occupations of the whole family, including the parents (Miedema et al., 2008). Factors associated with lower HRQOL in children with cancer are reported to be the presence of fatigue, site and type of cancer and lower socioeconomic status (Meeske et al., 2007). Therefore, research indicates the impact of the treatment and recovery phase after cancer diagnosis in children must be evaluated in terms of physical, psychological and social functioning, and their roles in performing everyday activities as well as an individual's perception of health and well-being for both the child and their parents. The child's health and ability to cope with the condition, treatment and side effects are also included as well as the family function, which might be impacted upon including aspects such as material

well-being, spirituality, and care of the environment (Magal-Vardi et al., 2004; Varni et al., 2002).

In South Africa, most of the population accesses the public healthcare system due to their socioeconomic status, and children with cancer and their parents are referred for specialised services, which are not offered at hospitals at district, provincial and healthcare clinic level (Stefan et al., 2015). Poor services and challenges exist in these clinics or hospitals, as children are often wrongly diagnosed resulting in late referral. Thus, children are transferred to paediatric oncology units in tertiary facilities for care, often at a late stage in their illness. Children with cancer therefore may require extended periods of treatment and hospitalisation in a tertiary facility far from their homes. Lack of finances for transport and the distance between the treating facility and the child's home, prevents everyday travelling for treatment required (Edwards & Greeff, 2017). This results in long periods of hospitalisation for weeks or months for the child who needs to be accompanied by a parent or adult carer who is required to remain with the child during their admission.

Health-related quality of life and autonomy of both the child and parent are affected during the child's hospitalisation, as they are not in their normal environment but a temporary hospital-based environment where they face different treatment regimens. This results in the need to deal with the physical, social and emotional impact of a life threatening illness as well as the disruption of the child's and the family's occupational performance, as they are unable to participate in their normal essential every day activities (Kasven-Gonzalez et al., 2010; Miralles et al., 2016). Engagement in purposeful activities directly affect the quality of life, thus it is important that occupational therapists who facilitate participation in occupations are aware of the effect of disruption and the HRQoL of hospitalised children with cancer and their parents. The therapists understand the social, cultural, and personal relevance in activities of daily living (ADLs), work, school, play, and instrumental activities of daily living (IADLs) and can support participation in meaningful activities to improve function and quality of life for these individuals (American Occupational Therapy Association, 2014; Kasven-Gonzalez et al., 2010). Enhancing an individual's HRQoL should be the ultimate goal of treatment and rehabilitation by

focusing on the individual components making up the construct (Wilson & Cleary, 1995; Pergolotti et al., 2016).

Since children are not always able to provide information, parents may be asked to assist in evaluating their child's HRQOL. It is important that perspectives of both the children and their parents be elicited if possible, however, Levi and Drotar (1999) first reported that parents have different perceptions of HRQOL and performance in occupations to their child. Studies since then have shown parents sometimes underestimate the effect of cancer on the child's HRQOL and activity participation, except for physical functioning and physical limitations (Russell et al., 2006; Chang & Yeh, 2005).

While literature suggests that occupational therapists should understand a child's and their parents' HRQOL and occupational performance (Kasven-Gonzalez et al., 2010; Hogan-Kelley, 2005), there is little research into the disruption in participation in occupations that affect children diagnosed with cancer face during their long admission in hospital (Miralles et al., 2016). Most research of HRQOL in children with cancer has also been conducted in developed countries, where hospital stay is minimised if possible (Varni et al., 2002; Levi & Drotar, 1999). While studies in developing countries have considered HRQOL in children with cancer, these include children who are treated in day care clinics or as outpatients and who do not face long periods of hospitalisation (Stenmarker et al., 2018; Salah et al., 2018).

The effect of the child's illness on their parents who are away from the family for prolonged periods needs to be considered, as Naidoo et al. (2016) indicate in their South African study that mothers accompanying their child with cancer to hospital were concerned about the disruptions at home due to their absence (Naidoo et al., 2016). Thus, it is important to evaluate the HRQOL, which includes the disruption of participation in occupations for children with cancer and their parents.

1.2 Problem Statement

Children are admitted to the hospital for different cycles depending on their treatment protocol. They are referred to the Steve Biko Academic Hospital (SBAH) in Pretoria from Mpumalanga, Limpopo, and North West Provinces. During the admission period, one parent or an adult carer stays on the hospital premises for

the duration of the child's admission to the paediatric oncology ward. Thus, the child's family setting and functioning are disrupted, with one parent or a family member away from the rest of the family with the HRQOL of both the child and parents affected. The child also has less contact with family and their schooling and participation in other activities may be interrupted.

During the child's hospitalisation, other than the illness and concern about the outcomes, the child and their parent or carer face disruption in participation in occupations due to the effect of the cancer on the child's health as well as their temporary environment; a lack of meaningful occupation and inability to engage in the performance of everyday activities will affect their HRQOL (Kasven-Gonzalez, et al., 2010). There is limited literature in terms of children with cancer and parents' experiences during hospitalisation, which appears to have a greater effect on the HRQOL and participation in everyday activities (Miralles, et, al., 2016; Kasven-Gonzalez, et, al., 2010; Naidoo, et, al., 2016; Tolson et al., 2017). There is also a gap in the literature on the association between activity limitations and participation restrictions and other aspects of HRQOL of these children and their parents during this long admission period. This has not been researched during the treatment phase in South Africa in late childhood, between the ages of 8 and 12 years old.

1.3 Purpose of the study

The purpose of this study was to determine the occupational disruption children in early childhood with cancer and their parents face during long admissions in hospital in South Africa, and how this affects their HRQOL, occupational performance and their families' functioning. The profile of the children with cancer admitted to the paediatric oncology ward at SBAH in their first admission period was described and the HRQOL in relation to function in life areas and occupational disruption, as well as HRQOL in coping with cancer were determined. The children's and their parent's perspectives were considered to determine any differences. The effect of the child's admission on the parent's HRQOL and the families' functioning and the disruption in participation in occupations was also determined.

1.4 Research Question

What is the HRQOL and the disruption in participation in occupations for children and their families when the children are admitted to the paediatric oncology ward at Steve Biko Academic Hospital?

1.5 Aim of the study

To determine the HRQOL, the disruption in participation in occupations of children admitted to the paediatric oncology ward at Steve Biko Academic Hospital and for both the children and their families.

1.6 Objectives of the study

- To describe the characteristics of a sample of children with cancer admitted to the paediatric oncology ward at SBAH in their first admission period.
- To determine the HRQoL in relation to function in life areas including; schooling of children during the first admission period for cancer management from the perspective of the children and their parents.
- To determine the family function and HRQOL the disruption in participation in occupations of parents who accompany their children in their first admission period to the paediatric oncology ward at SBAH.
- To determine the HRQOL in relation to coping with the treatment and side effects of children admitted to the paediatric cancer unit at SBAH during their first admission period from the perspective of the children and their parents.
- To determine whether any differences exist in terms of HRQOL and occupational performance with regards to the demographic and medical characteristics of children.

1.7 Significance of the study

Components of poor HRQoL and occupational disruption are appropriate for occupational therapy interventions, which can be offered based on the findings of the research. Occupational therapists can form a part of the supportive care team in children with cancer because their practice emphasises occupational performance and the physical and psychosocial aspects related to this condition. This study will inform issues related to HRQoL and occupational disruption in

children with cancer to recommend improved quality of services from occupational therapy. The assessment used will provide information on parent HRQoL, as well as the occupational needs of parents and family and performance of occupations by a child with cancer to be considered in future occupational therapy programmes.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The literature review focuses on different types of cancer children suffer, its treatment and effects during childhood including access to treatment in South Africa. Health-related quality of life in children and parents and their needs throughout the process of cancer care are described, including the various components of HRQoL incorporating activities of daily living in which disruption may be experienced by parent or carer and child during the period of hospitalisation. The assessment of HRQoL in children with cancer is described and differences in the perception of HRQoL reported by parents and children are considered as well as the effect of demographic and medical factors in children with cancer of HRQoL.

Literature was sourced from PubMed, Google Scholar, Medline Plus, Elsevier, and keywords for searching were, childhood cancer, parents of children with cancer, quality of life in families of children with cancer, outcomes of cancer treatment in children, children cancer treatment, life after cancer treatment in children, parent's quality of life for children with cancer and community perception in children cancer.

2.2 Cancer in Children

According to the World Health Organization (WHO), childhood cancer is diagnosed in individuals who are younger than 15 years and may include some individuals up to 19 years old. Between 70-90% of the causes of childhood cancer are unknown, with family history and genetics identified as the cause in 5-15% of cases and known environmental exposures and exogenous factors accounting for less than 5-10% (World Health Organization, 2009). Jemal et al. confirmed that most cancers largely reflect differences in environmental risk factors, lifestyle and culture rather than genetic differences (Jemal et al., 2010). Risk factors include birth weight, parental age, and birth defects, as well as common genetic variation, exposure to illness and infections, age, gender, and race/ethnicity. Factors which influence survival rate are disease biology, access to therapy, quality of care and comorbidities (Booth et al., 2010; Spector et al., 2015).

Acute Lymphoblastic Leukaemia (ALL) is the most common type of paediatric cancer, accounting for 75% of leukaemia in children, followed by acute myeloid leukaemia (AML). Malignant spinal cord and brain tumours are the third most frequent type of childhood cancers and account for about 21% of cancers; in 26% of children these tumours occur in the cerebellum and brainstem. Lymphomas are the fourth most common cancer in children and adolescents and account for 5% and 4% of childhood cancers as non-Hodgkin lymphoma and Hodgkin lymphoma respectively.

Neuroblastoma, an autonomic nervous system cancer found in children usually younger than 5 years, represents 6% of all childhood cancers. These statistics are similar for Wilms tumour or nephroblastoma, which is cancer of the kidney. Retinoblastoma, a rare cancer affecting the eye, accounts for 3% of childhood cancers, while osteosarcoma, which is an aggressive bone cancer, comprises less than 2% of childhood cancers (Barbel et al., 2015).

The incidence and mortality of childhood cancer is higher in boys than in girls (Ward et al., 2014). Paediatric cancers have an estimated incidence rate of 186.6 per 1 million, while the 5-year survival rate is approximately 83% in the United States of America (Barbel et al., 2015). Research indicates that children from lower socioeconomic status (SES) households have a higher rate of death from cancer and in middle- and lower-income countries the death rate is 70% (Barajas-Nava et al., 2016; Booth et al., 2010), while it is reported at 52% in South Africa (The Cancer Association of South Africa, 2019).

2.2.1 Cancer in children in South Africa

In South Africa, the death rate from cancer is associated with a lack of or late diagnosis. This is due to an overburdened oncology healthcare service and poor cancer awareness at the primary healthcare level, as well as widespread service delivery challenges (The Cancer Association of South Africa, 2019).

The incidence of the five most common cancers in South Africa is similar to that reported in other countries, with Black children having a consistently worse survival rate than other ethnic groups, particularly with nephroblastoma and retinoblastoma. The reasons for these differences include late presentation, poor nutritional status,

genetic factors and associated comorbidities, such as HIV infection and tuberculosis. No differences in survival were found between the genders or between different age groups in this country (Stones et al., 2014).

2.2.2 Cancer Treatment in children

Universal different treatment modalities exist for cancer and they include a combination of chemotherapy, radiation, and surgery depending on the type of cancer and its treatment protocol (Gupta et al., 2015). The individualisation or personalisation of cancer treatment at the time of diagnosis or relapse is based on chromosomal risk features, the pattern of gene expression, clinical condition, demographic location, biological characteristics and response preliminary treatments (Miller et al., 2016; Hinds, 2010).

Curative treatment, radiation and surgery are the most effective methods for cancer in its early stages. Immunotherapy using bone marrow transplants and stem cells are also used (Jemal et al., 2010). Long-term survivors of childhood cancer are increasing because of the improved treatment protocols provided to paediatric malignancies. However, these children continue to present with HRQoL issues due to the late effects of these therapies, which include heart diseases, second neoplasm and endocrine disorders, growth hormone deficiency (Barajas-Nava et al., 2016; Miller et al., 2016; Van Casteren et al., 2009; Blatný et al., 2013; Arboleda and Vazquez, 2017). Survivors of bone tumours and soft-tissue sarcomas have late effects of limb amputations or sparing, which affects functional status thus limiting their ability to perform required tasks in their occupations (Kirchhoff et al., 2011).

Response to cancer treatment differs with each intervention phase. This is dependent on the protocol applied, which is influenced by the stage and type of cancer. During the induction phase, high doses of chemotherapy to eliminate as many cancer cells as possible is used. This is the initial treatment for advanced cancers in order to make radiotherapy more effective in some cancers and before surgery is done if necessary (Zhao et al., 2018). Induction phase treatment, aims to kill all the cancer cells within the affected cells or organ, with the aim of remission after one month (American Cancer Society, 2019).

Consolidation treatment may be multi-stage or singular processes, depending if the child is at intermediate or high risk of relapse. This stage begins when the child goes into remission. Consolidation therapy involves high-dose chemotherapy in an attempt to eliminate any remaining cancer cells. The child intermittently receives cycles of chemotherapy. Those at high risk receive high doses of chemotherapy followed by self-donating blood stem cell infusion or immunotherapy (Hewitt et al., 2003).

During the maintenance phase, additional chemotherapy may be given for up to two years to continue destruction of residual cancer and to effect a cure (American Cancer Society, 2019; Hewitt et al., 2003).

2.3 Disruption of occupations in children with cancer

Disruption in occupations occurs when a person experiences a lengthy exclusion from participation in meaningful and valued occupations due to external factors over which they have little or no control (Tolson et al., 2017; Naidoo et al., 2016). Contextual factors including the need for education and leisure results in occupational disruption more often during admission for cancer treatment in children and adolescents (Miralles et al., 2016). The person's normal pattern of occupational engagement is interfered with due to significant life events, such as the diagnosis of the child with cancer and long admissions in the hospital for treatment. It is an interruption to participation, which is temporary, and although disturbance may be transitory, unmet needs arise when an individual is unable to or is incapable of engaging in daily occupations (Brown and Hollis, 2013).

According to Leadley and Hocking (2017), being unable to meet basic occupational needs leads to a high mortality rate of illness, and is associated with worse health outcomes. This is due to restrictions on the performance when hospitalised with an illness such as cancer, which can have serious health consequences resulting in a loss of the sense of efficacy and difficulty in adapting. This occupational disruption is usually due to hospitalisation for cancer and external factors related to the hospitalisation that the individual is unable to control. Miralles et al. (2016) studied occupational deprivation in eight adolescent's receiving cancer treatment in the hospital as inpatients, using ethnographical methodology and found them to be deprived in occupational needs related to education and leisure. Firstly, educational

needs remain unfulfilled with observable changes in academic performance and secondly leisure needs, as they were unable to participate in leisure pursuits during hospitalisation. Thirdly, the sharing of physical space reduced privacy and this affected the performance of ADLs indicating the need for different ward space for children and adolescents according to developmental stages. Mohammadi et al. (2017) found cancer and its treatment reduces the participation in everyday activities of children significantly. When compared to healthy children, those with cancer have a lower variety of activities including play, ADLs, education and social participation, and had less intensity of participation as well as less enjoyment in the activities. They also participated with fewer others when doing activities except for sleeping, which was when parents were far more involved with their children who had been diagnosed with cancer.

The lack of engagement in meaningful occupations should be considered in relation to both the environment and cancer in children hospitalised for treatment, as the occupational disruption caused may affect both health and quality of life of these children (Miralles et al., 2016; Eiser et al., 2005).

2.4 Health-Related Quality of Life and Childhood Cancer

Health-related quality of life is defined as a broader concept with two components, health and functional statuses, which are related to physical functioning, with a direct influence of social, psychosocial, emotional and role functioning (Varni et al., 2002; Levi and Drotar, 1999). Furthermore Russell et al. (2006) stated HRQoL has a direct influence on participation in daily activities.

Differences exist in the perceived HRQOL for each child with cancer and this should be reviewed from the perspective of the child informant, and more importantly parent or guardian residing with the child who know the normal behaviour of the child (Levi & Drotar, 1999). Health-Related Quality of Life for a child with cancer should also consider the perception on how the child is dealing with the condition and its treatment consequences when in hospital (Varni et al., 2002).

2.4.1 Children with cancer –Health-related Quality of Life

Diminished HRQOL in children in paediatric oncology units has been associated with physical discomfort, emotional stress, withdrawal from social participation and

disruption of daily activities (Mohammadi et al., 2017; Momani et al. 2016). A comparison study by Varni et al. (2002) of normal healthy and children with cancer, revealed the following findings: normal healthy children had better HRQoL with less fatigue than children being treated for cancer, and children who were still receiving treatment or who had completed treatment within one year of the study, had lower overall scores for HRQoL than normal healthy children. This was particularly true for specific factors related to the cancer including worry, treatment anxiety and nausea (Varni et al., 2002). The health-related quality of life in children with ALL for physical, emotional, social, and school functions was found to be 2 standard deviations (SD) below the norm for healthy children with occupational disruption in ADLs and school performance in children with brain tumours (Sung et al., 2011).

2.4.2.1 Components affecting quality of life

Physical functioning

Health-related quality of life is affected by the physical effects of any long term or chronic condition that requires a child to be hospitalised for a prolonged time. This is further exacerbated in a condition where the treatment can result in fatigue and weakness due to reduced daily energy expenditure and lower levels of physical activity often associated with pain, including pain in the joints or organs (Warner, 2008).

Emotional functional

Emotional factors seen in children with cancer are anxiety, fear and depression, and behavioural difficulties with changes in self-esteem and self-image (Sleight and Duker, 2016). This is supported in a position paper on cancer and occupational therapy by Longpré and Newman (2011), which indicates the importance of addressing these factors including post-traumatic stress which has been reported as part of the symptoms in children with cancer. Between 25 and 30% of children, do not cope with stressors, or the consequences of hospitalisation and treatment regimes. Sung (2015), stipulated that during course of treatment, children experience fear, worry and frustration, and failure to maximise on the control of these symptoms leads to long-term psychosocial consequences. Edwards and Greeff (2017), in a study done in South Africa using photovoices (pictures) to

explore and describe challenges experienced by children with cancer and their families, reported that support from a functional family is needed for children to cope well with the emotional consequences of the disease.

Social functioning

According to the study done by Mohammadi et al. (2017), social and economic outcomes are more sensitive to the medical and psychological sequelae of cancer than the cultural context and national differences. The fact that children with cancer may experience social withdrawal because of deformities, which affects their self-image and self-esteem (Mohammadi et al., 2017), is supported in the study by Blatny et al. (2013) who found adolescents, aged 13 to 18 years old, presented with social functioning impairment, caused by severity of late effects, and decreased physical and psychological functioning. These impairments may hinder function in the following areas, family, personal and social functioning and relationships (Patenaude and Kupst, 2005). Socialisation at school for these children may be difficult with their deformities and hair loss affecting reintegration into the classroom (Edwards and Greeff, 2017).

2.4.1.2 Roles and Activities of daily living

Cancer and its treatment causes interruptions in daily routines, affecting how individuals function in their occupational performance areas; human occupations are different and unique with each individual having diverse functional limitations (Longpre & Newman, 2011). This may result in poor adaptive skills and responses in children with cancer (Cantrell & Ruble, 2011). Signs of developmental delay, sleep disorders, eating disorders, dependency on caregivers and disruption in other ways may be seen in children admitted to oncology wards (Moore & Beckwitt, 2006). Difficulties with sleeping and eating are problems parents report for their children following a cancer diagnosis, as found in a study done in Australia with 15 parents of children within the maintenance phase, aged between 2 and 6 years old. Parents reported they needed to use emotional and instrumental eating principles in order to get children to eat meals at home. Sleeping was facilitated by using night-time routines, parent-child co-sleeping and the use of electronics to help manage sleep difficulties, (Williams & Mccarthy, 2015).

Miralles et al. (2016) found adolescents receiving cancer treatment in the hospital as inpatients stressed the need for educational activities and found the lack of a standardised routine and relationships with peers affected their quality of life. Disruption in schooling may be further affected by multiple admissions (Edward & Greeff, 2017).

2.4.2 Parents of a child with cancer –Health-related Quality of Life

2.4.2.1 Components affecting quality of life

Factors that contribute to HRQOL of parents, for both mothers and fathers are both psychosocial and physical. Parents HRQOL is also affected by a disruption in their occupations, financial issues related to parents having to be away from the family and possibly work, with a disruption of roles and responsibilities occurring at home (Naidoo et al., 2016).

Physical functioning

Parents with the characteristics of higher education and income, better sleep quality, and in a younger age group were reported to have better physical QOL in a study by Klassen et al. (2008). The study on 411 parents of children receiving cancer treatment, using the Short Form of Generic Adult QOL questionnaire (SF-36) found this was especially true when the parents' and child's perception of the child's health was better. A lack of exercise, adequate nutrition and quantity of sleep in parents of children hospitalised with cancer resulted in parents gaining more weight and having low levels of physical activity (Klassen et al., 2008).

Emotional functioning and worry

Having a child diagnosed with cancer is a painful life experience for parents. Emotional factors affecting QOL in parents of children with cancer are initially associated with parents' feelings of shock and pain caused by the diagnosis in the child (Maree et al., 2016). Furthermore, parents experience emotional pain seeing their child receive various treatments for the conditions with psychological distress found to be an issue for the parents (Patterson et al., 2004). Emotional changes, which may be seen during hospitalisation of the child, are related to guilt and

anxiety, self-blaming about child's illness (Edwards and Greeff, 2017) as well as the child's possible mortality and the possibility of relapse (Maree et al., 2016).

Poor psychosocial QOL in parents has also been related to a lack of exercise, adequate nutrition and quantity of sleep with parents of children with cancer. The child-related factors independently associated with higher psychosocial parental HRQOL in a study done with 411 parents of children with cancer, by Klassen et al. (2008), were the child's health status, longer survivorship, and lower intensity of treatment.

Cognitive functioning and communication

Components of cognitive functioning, memory, problem solving, decision-making, have received less attention in research on HRQOL of parents with children treated for cancer. The diagnosis in children of cancer has an impact on the mental health of their parents (The Globe and Mail, 2019; Edwards & Greff, 2017). The lack in accessing information and inadequate information given to parents leads to frustration and feeling of powerlessness when communication is poor. A systematic review by Markward et al. (2013) reported that parental hope or expectations are dependent on the accurate and appropriate information reported to them by doctors and health professionals, because they use the information provided to them to accept negative outcomes during the diagnosis and treatment of their children. During communication, parents need to make a decision on what is best for the child, which is influenced by their perception of HRQoL experienced by child, the knowledge and perceptions of the parent and information received from the treating physician (Markward et al., 2013).

The study by Mack et al. (2011) on 194 parents of children treated for cancer and 21 paediatric oncologists in Boston, indicated the importance of discussing the child's future after cancer and the treatment and its effects on the child. Tools used to collect data were the Information Styles Questionnaire, the Information Needs Questionnaire, the Trust in Physicians Scales Support, the Brief Coping from Problems Experienced Scale and the Functional Assessment of Chronic Illness. The ability to process high quality information about the child's prognosis, and adjustment after the illness was found to be dependent on the parent's education, sex and ethnicity in a follow up study by Kaye and Mack (2013).

Fernandez et al. (2009), in a study done with 409 parents and 86 adolescents from the United States and Canada, looked into the mode of communication when presenting results of medical tests relating to cancer treatment to adolescents and their parents. When results were more positive, parents indicated the need for an email, written letter or a phone call and for negative results, they wanted a phone call and personal visit (Fernandez et al., 2009).

2.4.2.2 Activities of daily living

A study by Naidoo et al. (2016) on mothers of admitted cancer children for treatment, found parents to have occupational role disruption at home and shifting in responsibilities, the remaining people at home had to assume the mother's roles and there was a change of household leader. There was also concern and stress about the change of responsibilities at home and balancing family needs (Edwards & Greeff, 2017).

2.4.2.3 Family functioning and family relationships

Family finances are affected by having to provide treatment for a child with cancer and those with low or fixed incomes are particularly vulnerable. Additional expenses are created, with possible job security or loss of work resulting for a parent, meaning they may no longer be able to provide for the family (Edward & Greeff, 2017). Families from low socio-economic situations may postpone consultation at a clinic or hospital due to transport and financial issues resulting in late diagnosis and treatment; this may result in longer more intensive treatment and a further financial burden (Edward & Greeff, 2017) (Njuguna, et, al., 2016).

2.4.3 Health- Related Quality of Life related to cancer treatment side effects in childhood

The treatment of childhood cancer has changed over the years, with the cranial radiation for ALL, and abdominal radiation for Wilms tumour replaced with newer, less toxic therapies although there is still risk of serious health conditions long-term, with surgery, radiation, and some chemotherapies affecting cognitive impairment in up to one-third of childhood cancer survivors. Chemotherapy or platinum-based therapy used to treat tumours in the central nervous system (CNS) and extra cranial and cranial radiation can cause hearing loss and infertility amongst others (Miller et

al., 2016). Children at high risk are those who receive doses of more than 400mg/m² and are below five years old (Brinkman et al., 2015).

The invasive, painful, and prolonged processes of diagnosis, hospitalisation, and treatment of cancer can be stressful.

2.4.3.1 Treatment anxiety and worry

From the transient effects of treatment, children have an increased risk of neoplasm and cardiomyopathies, when they are exposed to pulmonary toxic cancer treatments and individuals may experience pulmonary dysfunction and cardiac abnormalities (Miller et al., 2016). Other side effects are fever, neutropenia, nausea and vomiting, fatigue, loss of weight, muscle wasting, and deterioration of the immune system (Barajas-Nava & Garduno-Espinosa, 2016).

2.4.3.2 Cognitive problems

Neurological client factors affected in children can be verbal learning and competence, memory, information processing speed, visual memory, spatial and psychomotor coordination, attention span and concentration, and executive functions (Blatny et al., 2013). Subgroups with severe educational outcomes include CNS tumours, leukaemia, and neuroblastomas. Cognitive problems result in poor academic achievements, which are caused by learning impairment and neurocognitive sequelae due to neurocranial irradiation and chemotherapy on the central nervous system, especially in patients with ALL and non-Hodgkins Lymphoma (Boman et al., 2010).

2.4.3.3 Perceived physical appearance

Upon treatment completion, children have physical challenges that are side effects from treatment modalities, which result in different impairments disability (Barajas-Nava & Garduno-Espinosa, 2016; Miller et al., 2016; Booth et al., 2010; Hinds, 2010; Boman et al., 2010; Van-Casteren et al., 2009; Chan et al., 2014). Drop out from schooling may result due to the children feeling embarrassed to return to school because of body image change, loss of identity and being rejected by peers (Edward & Greeff, 2017; Brierley et al., 2019).

2.4.3.4 Communication

In a study by Naidoo et al., (2016), conducted on five mothers of children admitted for cancer management in South Africa, found parents of younger children were unable to communicate the information they received to their sick children, as they were informed by professionals using medical jargon and unfamiliar languages. Updating initial information about the condition, prognosis, and treatment is needed by parents of children suffering from cancer who are uncertain about the future of their children. In a study in a South African hospital, it was found there was no consensus on what information was needed at any specific time. However, information should be provided according to the parents' preference, in terms of language and individual needs so that it is understandable (Maree et al., 2016).

2.5 Assessment of health-related quality of life in children with cancer and their families

2.5.1 Assessment tools

Health-related Quality of life is multidimensional, and any assessment must therefore consider the minimum of the physical, mental or emotional health as well as social health, as delineated by the World Health Organization (WHO)(World Health Organization, 2006). A number of different assessment research tools have been used when assessing HRQoL in children with cancer, their parents and siblings, both during the course of treatment, on the completion of treatment and remission stage.

Health-related quality of life in children is most commonly assessed using the Pediatric Quality of Life Inventory (PedsQL™), which consists of a number of sections.

2.5.1.1 PedsQL™ Generic Core Scales (4.0) Child and Parent Proxy

The PedsQL™ 4.0 Generic Core Scales include core physical, mental, and social health dimensions, as well as role (school) functioning. There is a child report for children 5 to 18 years, and parent proxy report for children 2 to 18 years. This generic scale is designed for integration with the PedsQL disease specific modules, which includes a cancer module that also has child self-report and parent proxy-report

scales. The assessment is adequately valid and reliable, having internal consistency $\alpha = 0.88$ for child and 0.93 for parent (Varni, et al., 2002).

The PedsQL™ parent proxy was developed using 13878 cases from the PedsQL™ DatabaseSM. Participants' ages ranged between 2 and 16 years and they were recruited from different locations within California, including primary healthcare, speciality clinics, and hospitals where the children were followed up by their healthcare practitioners. Diagnosis of children ranged from mild acute to chronic illnesses. For each of the PedsQL™ scales and summary scores, across age subgroups, healthy children demonstrated a statistically significant higher HRQOL (with most effect sizes in the medium to large effect size range), than children with a known chronic health condition (Varni et al., 2007). The percentage of missing item responses for the parent proxy-report sample was only 2.1%, supporting the feasibility of these results and the validity of the measure. The majority of the parent proxy-report scales across the age subgroups exceeded the minimum internal consistency reliability standard of 0.70 required for group comparisons (Varni et al., 2007).

2.5.1.2. PedsQL™ Family Impact Module (2.0)

Family functioning is measured using the PedsQL™ Family Impact Module (2.0), to assess the impact of children's illness on family and parents, focusing on the components of physical, cognitive, worry, emotional, social, communication, participation in daily activities and family relationships. The questionnaire was developed using HRQOL and PedsQL™ 4.0 Generic Core Scales (Varni, et al., 2002). The tool was validated on 23 parents of children treated for chronic medical conditions who were living with their parents (Varni et al., 2004).

In terms of reliability, the test-retest reliability correlation values of the PedsQL™ FIM ranged from 0.81 to 0.96 for all subscales, internal consistency reliability demonstrated for PedsQL™ was $\alpha = 0.89$, with Parent Health-Related Quality of Life Summary Score $\alpha = 0.83$, and Family Summary Score $\alpha = 0.73$ (Knez, et al., 2015).

2.5.1.3 PedsQL™ Cancer Module (3.0) Child (8-12 years) Child and Parent Proxy

The PedsQL™ Cancer Module 3.0 is designed to measure the impact of symptoms and treatment of cancer experienced by the child during the course of cancer in relation to the HRQoL. The self-report can be completed by children between 8 and 18 years as an interview if necessary, and a parent proxy form is available for younger children and to support the child's report. Both parents and children are asked the same questions about the symptoms and treatment of cancer.

The parent proxy tool can be used in children 2 to 18 years old, with various cancer illnesses, with parents indicating lower scores for HRQoL for children receiving treatment for cancer on the Pain, Nausea, Procedural Anxiety, Treatment Anxiety, and the Worry subscales (Varni et al., 2002)

The Cancer module was validated on an oncology sample, which included children with ALL, brain tumours, non-Hodgkin's and Hodgkin's lymphoma and Wilms' tumour with no comorbid conditions. The internal consistency of $\alpha = 0.72$ for children and 0.87 was achieved for parent studies (Scapelli et al., 2008; Tanir & Kuguoglu, 2011; Tsuji, et al., 2011).

2.5.2 Difference in perceptions of children with cancer and their parents about their Health-Related Quality of Life

The use of HRQoL interview and self-report measures, which are completed by children with chronic health conditions including cancer and their parents, do indicate differences or imperfect concordance between the self- and proxy-report results (Eiser & Morse, 2001). Cognisance must be taken of this cross-informant variance, agreement between the children and parents is lower for internal problem and thus it is always important to assess the child's perspective if possible. On the PedsQL™ Cancer module, reliability agreement between children/adolescents and their parents was found to range from $r=0.26 - 0.85$ for children/adolescents and their parents, in a study conducted amongst 190 Brazilian families (Scarpelli et al., 2008a).

A study on 27 children with cancer and their parents compared the reported HRQoL of healthy children and their parents using the Child Health Questionnaire-Parent

Form and Child Health Questionnaire. Parents and children with cancer perceive the child's physical functioning differently, particularly pain, which limits functions with parents perceiving the child has a lower HRQoL. It has been suggested that the differences in parent and child reports reflect the inferences that the parents' reports are based on observation and communication with the child. The child, conversely, is reporting their subjective experience and symptoms. The parents and children did agree on the child's HRQoL on half of the items, including performing self-care activities and in the ability to get around (Levi & Drotar, 1999; Momani et al., 2016).

The study by Chang and Yeh (2005) on 141 patients, which included 82 children with cancer and typical children and 59 adolescents and their parents, considered the agreement between child self-report and parent proxy reports within the field of cancer, focusing in quality of life. The assessment used was the Quality of Life for Children with Cancer (QOLCC). There was agreement between the child with cancer and parent reports with correlations ranging from $r = 0.34$ for emotional function to $r = 0.59$ for physical functioning when the child was receiving treatment, compared to typical children and their parents. A significant difference was found however between the children with cancer and their parents with parents reporting lower scores and underestimating HRQoL related to physical functioning. In the typical sample, parents overestimated their child's HRQoL for self-esteem and impact on the family (Chang & Yeh, 2005). Parents were also less satisfied with the participation of their children with cancer in everyday activities than the children themselves (Mohammadi et al., 2017).

2.6 Severity of the effects of treatment in cancer on Health Related Quality of Life

In children, the severity of the effects of their cancer treatment correlates negatively with cognitive functioning, physical, social functioning and body image and their HRQoL (Blatný et al., 2013; Castellino et al., 2014). This is not supported by a study done by Mannix et al.(2009) on the HRQOL and QOL using the PedsQL™, which involved 23 adolescents with cancer from New York. Results found a significant relation between the severity of late effects of cancer treatment and QoL, with lower

severity resulting in high levels of optimism and good physical and psychological functioning. This reflects the findings in previous studies done in adults with cancer.

However, this correlation is not significant in children with cancer (Blatný et al., 2013) as the protective factor of better QoL does not result in positive optimism in children. This is because children are not fully aware of the effects of cancer and cannot anticipate future consequences (Blatný et al., 2013). Younger cancer survivors have been found to have a greater number of unmet needs affecting their quality of life (Burg et al., 2015). Children who are treated using surgery and radiotherapy (proton) were shown to have greater sleeping challenges. A study on 70 children revealed 81.8%, of the participants experienced Excessive Daytime Sleepiness (EDS), when the Multiple Sleep Latency Test (MSLT) and the Modified Epworth Sleepiness Scale (M-ESS) were used to assess sleep latency. Findings of the study showed average low score of six minutes for sleep latency, although the children were not aware of EDS and were not able to report their daytime sleepiness accurately (Crabtree et al., 2019).

The relationship between severity of the effects of treatment in children with cancer and HRQoL are affected also by other factors, such as the diagnosis, tumour localisation, treatment received and age at the time of treatment (Skinner et al., 2007). Patenaude and Kupst (2005) conducted research on psychological distress, coping and adjustment needs for the high risk population of children with cancer by reviewing literature within the paediatric psycho-oncology field. Their findings categorised individuals as having different adjustments and being psychosocially dependent on specific variables. Those with a diagnosis of bone tumour and those who received treatment by chemotherapy had more difficulties with adjustment, while individuals treated for shorter duration period had better adjustment (Patenaude & Kupst, 2005).

Side effects of treatment manifest later in life, even if they are not present during the treatment phase, but are often observed during survivorship period. Children and parents need to be prepared for the possibility of different adverse events, which are related to sensory loss, impaired growth, development of secondary tumours, being overweight, infertility, as well as cognitive and emotional impairment, which can affect their psychosocial functioning. Cardiovascular complications

including, cardiomyopathy, angina pectoris, and impairment of pulmonary system where they experience tissue hypoplasia, can also occur (Mittal & Kent, 2017).

2.7 Role of occupational therapy in Health Related Quality of Life in children with cancer

The importance of oncology rehabilitation has been ignored, especially during the hospitalisation period (Silver & Gilchrist, 2011), occupational therapy interventions for rehabilitation need to focus on the short- and long-term effects of cancer treatment, which are pain, fatigue, reduced physical strength, reduced joint range of motion, decreased cardiovascular capacity, bone loss, depression, anxiety and lymphoedema (Silver & Gilchrist, 2011).

The functional implications in terms of activity limitations and participation restrictions in daily activities due to cancer treatment need to be considered in relation to occupational performance areas in children, which may affect schooling, socialisation, mobility, play and self-care (Weintraub et al., 2011). A study by Speyer et al. (2010), in France, involved 30 children with age ranges of 5 to 18 years old. Assessment of HRQoL of children and their parents was done using the Child Health Questionnaire (CHQ), which consists of 87 items in 12 dimensions, role/social physical limitation, role/social behaviour, physical functioning, general health, self-esteem, mental health, changes in health, family cohesion, behaviour, role/social emotional, body pain, and family activities. These children were involved in adapted physical activities within a cross-over trial; participants had to be involved in three play sessions within the oncology ward and play was used as a method of learning during different sessions of adapted physical activity (Speyer et al., 2010).

Themes of activities included ball games, soccer, volleyball, and handball, circus art, balancing and juggling. Throwing games included darts, javelin, blowpipe and throwing stones, shooting games using plastic items, rifle, archery and crossbow. Racket sports included badminton, tennis, and squash, self-expression through movement, gymnastics, stretching, dance, relaxation and massage. Fighting activities were karate, fencing, English and French boxing, video games, and Wii fit. The last component was bodybuilding with activities of balancing balls, steppers, exercise bike, and barbells being part of the activity options for the children.

Results indicated a significant improvement in HRQoL scores of both parents and their children when they participated in adapted physical activities during admission periods compared to children who did not participate in the programme, for the physical functioning ($p < 0.0001$), role/social physical ($p = 0.001$), self-esteem ($p < 0.0001$) and mental health ($p < 0.0001$) dimensions. Children reported less body pain ($p = 0.0004$) and better behaviour ($p = 0.01$). The overall scores for the children were higher than of their parents for HRQoL for both groups of children, those who participated in the play activities and those who did not (Speyer et al., 2010).

2.8 Summary

Chances of cancer remission exist during the survivorship period; the survival rate in South Africa is lower when compared to well-developed countries where it is approximately 70%. Causes of cancer differ with each individual and this is influenced by environmental, genetics, and demographic location where the family resides. Relocation to the hospital with the child causes parents to have limited time for themselves, diverse factors occur which influences their QOL. Family finance becomes vulnerable and there is the threat of loss of work because of the temporary environment; they also experience occupational disruption of roles and deprivation of performing their usual occupations. There is limited research done on younger children's experience of occupational disruption while receiving cancer treatment from the oncology unit, only the adolescents' age group has been reported.

Treatment consequences include organ damage, abnormal growth, infertility, neurological disorders, cognitive and physical impairments. Therefore, areas of functioning are social, academic (school), personal in childhood and in adulthood, family and employment, while parents have their own different consequences. Side effects from treatment occur during the survivorship period, when different challenges are experienced by the child, i.e. the severity of the late effects in conjunction with negative cognitive, physical, social functioning and body image. Overall QOL, feeling at peace and having a sense of meaning in life are important to patients rather than being physical comfortable; children in paediatric oncology units' experience negative signs and symptoms of diminished QOL.

During adulthood, survivors have impairment in performing ADLs, social attainment and experience social isolation, which is influenced by work-life and caused by lower educational level. Challenges of service provision from the base hospital and travelling from home occur, and the family of survivors require support from the treatment facility to cope with adjustment skills needed by them. Loss of contact with school increases chances of drop out and late-onset causes risk factors of low life expectancy. Cancer and its treatment lead to poor functional implications affecting QOL, caused by occupational deprivation experienced in the hospital.

CHAPTER 3: METHODOLOGY

3.1 Introduction

A prospective, cross sectional quantitative, descriptive study was conducted in the oncology unit at Steve Biko Academic Hospital, a tertiary hospital, to determine HRQoL and occupational disruption experienced by families and children during hospitalisation for cancer management. Data was collected from children admitted to the paediatric medical oncology ward within one academic hospital, and their parents. During the cross sectional study, assessment was completed at one time and there was no follow up of the participants since the study was descriptive and no variables were manipulated. Identification and recruitment of participants were done simultaneously, but data collection was done at a later stage within a six-month period. Inclusion criteria were used to ensure the selected individuals were representative of the population in determining the HRQoL of both children who were affected by cancer and their parents while the child was hospitalised. All assessments were scored on a Likert scale so all data was numerical, making the study quantitative in nature (Sedgwick, 2014). Strengths of the study participants will be easily accessible and available within the same treatment facility where the study was conducted. Chances of missing potential participants to be recruited was minimal, as research assistance and the research work, was conducted in the ward or facility where the children received cancer treatment. Weaknesses included data collection from one parent who consented to participate in the study, therefore comparison of both parents of the same child was not be done, sample size diagnosis, groups or childhood cancers were limited to ward admission for cancer management during the data collection period.

Description of the population included characteristics of the demographics, both the parents and children's perceptions about experiences of cancer illness side effects, its treatment and functioning of the child. The data on the impact caused by cancer on both children and their families was reported by the children and parents and was not influenced by the researcher. Data collected was objective using, the PedsQL™ Inventory and analysis was done to determine level of agreement, in

HRQoL reported by the children and their parents, as well as to determine the associations of different cancer groups and treatment interventions received by the children and HRQoL (Bhat, 2018).

3.2 Study context

3.2.2 Location

Participants of the study were recruited from the paediatric oncology unit of the Steve Biko Academic Hospital (SBAH), in Pretoria, Gauteng Province. All participants were from the paediatric oncology ward, which has a capacity of 37 patients in the treatment facility (SBAH) and during admission; all the accompanying parents are accommodated in a private facility, sponsored and managed by the Cancer Association of South Africa (CANSA), within the premises of the University of Pretoria, in two different buildings within walkable distance to SBAH. Parents can only be accommodated in shared rooms. On average, time of stay in the ward and accommodation ranges from 2 days to 3 weeks, determined by how the child copes with the cancer treatment and family challenges experienced during cancer management. Children and their parents who were referred from other institutions districts or tertiary hospitals for cancer management were approached to participate in the study.

3.3 Identification and appropriateness of participants in the study

3.3.1 Child

The primary participants were the children admitted to the oncology ward, who had a confirmed diagnosis of cancer made more than a month previously, and who had completed either the induction or consolidation phase of treatment. They had thus experienced the effects and side effects of treatment and could report on the impact upon their HRQoL, but were no longer actively receiving treatment. Selecting children during the admission period who have been ill for at least one month, allowed them to reflect on their performance on specific tasks related to performing roles and responsibilities in school, community and home environments. They would then be able to indicate if there were changes in HRQoL and occupational disruption since the commencement of their illness.

The children from different communities within Gauteng, Mpumalanga and Limpopo Provinces, were referred to SBAH for specialised cancer management from other institutions, districts or tertiary hospitals. The age group of the children was from 8 to 12 years old because they were school-going children who understood verbal instructions, could read, and were able to participate in a face-to-face interview to answer questions related to HRQoL cancer module, which was designed to be answered by children of this age. These children in late childhood, could understand the concept of activities which they participated in, how these were related to their occupational performance areas of play, school, socialisation, and personal management (Taylor, 2017), and were able to provide information on how these specific occupations may have changed since they became ill. The children were residing with their parents or carer at home prior to hospitalisation and thus the parents or carer could provide information about the child's HRQoL on a proxy form, as they knew the child well.

Therefore, the inclusion and exclusion criteria for the children were

Inclusion criteria

- children diagnosed with cancer, referred to SBAH for cancer management
- within the age group of 8-12 years old
- completed the induction or consolidation phase of treatment
- the diagnosis made more than one month previously.

Exclusion criteria

- children who were referred back to their base hospitals for management
- children who were admitted without a parent or carer in the ward
- parent or child not providing informed consent or ascent
- children diagnosed with co-morbid or major developmental disorders or visual impairments.

3.3.2 Parent/Carer

Parents/carers of any age and gender who accompanied a child as described above and who stayed in the hospital lodge during the hospitalisation were invited to participate in the study. This parent or carer was away from the family home for

extended periods and therefore the family setting and functioning could be disrupted. The parent's responsibilities at home would have to be carried by others and the parent would be away from work. During the study, parent's views on how cancer affects family functioning was needed in order to have a holistic assessment of the child within their appropriate context.

The parent or carer had to have received family counselling and discussion about treatment options before they and their child were invited to participate in the study. The study was explained to both the parent and the child and an information sheet was provided after which the parent was asked to provide consent for their own and their child's participation in the study; they and the child were asked to provide signed ascent to participate in the research.

3.3.3 Sample size

A convenience sampling method was used to recruit eligible participants within the medical paediatric oncology ward, due to the study design being cross-sectional participants were assessed once without follow up for intervention within the study time frame. The number of new admissions for diagnosis and treatment of cancer to the ward, during one month, is approximately 20 to 27 children. Planned duration for data collection was six months and was based on an average of 25 new admissions per month; over this period, the population for this study was 150 children. A sample of 45 participants was needed to represent this population, with a confidence interval of 95% and a margin of error of 10% (Creative Research Systems, 2012).

3.4 Instruments used in Data Collection

Parents were required to fill in questionnaires independently under the supervision of a researcher; these included demographics, parents' proxies of PedsQL Family Impact Module (2.0), PedsQL Cancer Module (3.0), and PedsQL Generic Core Scale (4.0). Children were involved in face-to-face interviews independently, where the researcher asked questions relating to PedsQL Cancer Module (3.0) and PedsQL Generic Core Scale (4.0) child proxies. Parents who needed assistance with translation from English were assisted with the student nurse who works in the same ward. Questions on the questionnaire were related to medical complications,

family situations, context, financial difficulties and child's coping with the illness and treatment when in a home.

3.4.1 Demographic Questionnaire (Appendix A)

At the beginning of data collection, parents were requested to fill in the demographic questionnaire. This questionnaire, which was developed by the researcher, included aspects such as age, gender of the parents and children as well as the child's medical history. Although some identifying information was needed to link the data of the parent to that of their child, this was stored separately and was not required for data analysis. All participants were allocated a code, which matched their identifying information, and only coded data was analysed.

3.4.2 Pediatric Quality of Life Inventory (PedsQL)

The measurement tools used to collect data were the PedsQL modules Family Impact, Cancer, Core Generic Scale. Authorisation to use PedsQL inventory forms was received via the MAPI Research Trust, and authorised by Professor J.W. Varni, who was the author of the PedsQL. A user agreement contract was signed between MAPI trust and the researcher (Appendix B).

3.4.2.1 PedsQL Generic Core Scales 4.0 Child and Parent proxies (Appendix C)

PedsQL™ Generic Core Scales 4.0 was used to assess the HRQoL of children. Both parent and child proxies had the same 23 items grouped into four dimensions, which were physical functioning (8), emotional functioning (5), social functioning (5), and role or school functioning (5) (Varni et al., 2002).

Scoring

Item scoring was done using a 5-point Likert scale from zero (never) to four (almost always). Scores were then transformed, as items were reversed scored and linearly transformed from 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, and 4=0. If more than 50% of the items in the scale were missing, the scale scores could not be computed and a mean score, which is the sum of the items over the number of items answered, was calculated. If 50% or more of the items were completed, imputing the mean of the completed items in a scale was done.

A composite score was calculated as:

- Psychosocial Health Summary Score, which is the sum of the items divided by the number of the items answered in the emotional, social, and school functioning scales (Varni et al., 2002).

3.4.2.2. PedsQL™ Family Impact Module (FIM) 2.0, Parent proxy (Appendix D)

The PedsQL™ FIM includes six subscales measuring parents' self-reported functioning: physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (5 items), communication (3 items) and worry (5 items), as well as two subscales measuring parent-reported family functioning, daily activities (3 items) and family relationships (5 items) (Varni et al., 2007). The assessment was translated and validated for use in other developing countries with different languages and cultures, such as Brazil (Scarpelli *et al.*, 2008a).

Scoring

Each item of 36 was answered using a 5- point Likert scale from zero (never) to four (almost always). Scores were then transformed, as items were reversed scored and linearly transformed from 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, and 4=0. If more than 50% of the items in the scale were missing, the scale scores could not be computed and a mean score, which is the sum of the items over the number of items answered, was calculated. If 50% or more of the items were completed, imputing the mean of the completed items in a scale was done.

Total scores calculation, is determined by adding all scores of the 36 items divided by the numbers of items answered, and this was further divided into parents HRQoL and family functioning where different scales within the same modules are used.

- Parent HRQOL was determined using (20 of the 36 items), which was the sum of the items found in physical, emotional, social and cognitive functioning scales.
- Family functioning was determined using (eight of the 36 items) sum scores found in the daily activities and family relationships scales (Varni et al.,2002).

- The remaining eight items, communication (3) and worry (5) were used in the overall QOL.

3.4.2.3 PedsQL™ Cancer Module 3.0 Child (8-12 years) and Parent Proxy (Appendix E)

Both parent and child proxies of PedsQL™ Cancer Module 3.0 consisted of 27 items, which were divided into eight subscales of pain and hurt (2), nausea (5), procedural anxiety (3), treatment anxiety (3), worry (3) and communication (3) (Varni et al., 2002). The assessment was translated and validated for use in other developing countries with different languages and cultures, such as Brazil (Scarpelli *et al.*, 2008b).

Scoring

Responses and item scoring were given in a 5-point Likert scale from zero (never) to four (almost always). Scores were then transformed, as items were reversed scored and linearly transformed from 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, and 4=0. If more than 50% of the items in the scale were missing, the scale scores could not be computed and a mean score, which is the sum of the items over the number of items answered, was calculated. If 50% or more of the items were completed, imputing the mean of the completed items in a scale was done. A total score on all items was calculated (Varni et al., 2002).

3.5 Research procedure

3.5.1 Ethical clearance and permission to conduct research

The School of Therapeutic Sciences in the Health Sciences Faculty at the University of the Witwatersrand reviewed and approved the protocol, and the Human Research Ethics Committee of University of Witwatersrand provided ethical approval for the study (M180766) (Appendix F). The study was registered with the National Health Research Database (NRHD), reference GP_201901_008, which was forwarded to the SBAH for permission to conduct the research. The SBAH research committee, which included representatives from the University of Pretoria, provided additional ethical approval and permission for the conducting of the research (Appendix G).

Principles of ethics were used with all parents and children recruited into the study. Voluntary participation (inclusion, beneficence, non-maleficence, and justice). The guardian and the child were invited to participate in the research and study details were provided to them both verbally and in an information sheet (Appendix I). The information sheet was explained in Setswana and isiSwati, which are the common languages spoken by patients in ward used for the study.

Informed consent and study procedure were explained to the guardian and child in detail. Potential participants were not coerced into participating, and they could withdraw from the study at any time without influencing treatment. Children provided verbal ascent (Appendix H) and parents provided signed consent (Appendix I) for participation in the study.

Referrals to other supportive services within the hospital were provided to Hospivision, clinical psychology and social services when participants and guardian needed additional interventions. Data collection sheets were stored in a locked cabinet, and they accessed only by the researcher and supervisor.

Screening and interviews were done by same therapist, results were discussed with guardians, and proposed times for procedures were maintained during the course of the study for each participant. All individuals were treated in a good and fair manner; the researcher ensured fairness and equity amongst all participants as they were treated fairly and equally. They were provided with refreshments and the procedure of the research was fair and transparent.

Throughout the duration of the study, the researcher had the responsibility to:

- Adhere to methods and procedures as stated in the protocol
- Support and build rapport with participants
- Keep all participants' information and identities private and confidential
- Present results accurately and openly with acknowledge of all resources and assistance used throughout the study.

3.5.2 Recruitment of participants

The researcher collected weekly lists of all the children who were admitted in the paediatric oncology ward and who had completed the first stage of treatment either

the induction or consolidation phase. All admitted children were screened and individuals who qualified for the study were approached to determine if a parent or carer had accompanied them and was staying on the hospital premises. If the parent or carer was available, they were approached and with the child, they were invited to participate in the study. Parents or carers and children who agreed to participate were then recruited into the study according to the ethical requirements of the Ethics Committees who provided ethical clearance for the study (Section 3.7).

3.5.3 Data collection

A small scale pilot study was done on five participants, which included parents and their children. The children were within the same age group. The data were collected from the parents/carers and children as indicated in Table 3.1.

TYPE OF TOOL	TECHNIQUE USED
Demographic Questionnaire – <i>Parent</i>	Document questionnaire – parent report
PedsQL™ 2.0 Family Impact Module – <i>Parent</i>	Survey (manual) - parent report
PedsQL™ 3.0 Cancer Module – parent proxy <i>Parent</i>	Survey (manual)
PedsQL™ 3.0 Cancer Module – <i>Child</i>	Structured face-to-face interview
PedsQL™ 4.0 Generic Core Scales- parent proxy <i>Parent</i>	Survey (manual) - parent report
PedsQL™ 4.0 Generic Core Scales- <i>Child</i>	Structured face-to-face interview

The parent or carer of the child first filled in the demographic questionnaire, they were then asked to complete independently the PedsQL™ Cancer (3.0), Generic Core Scales (4.0) parent proxy forms and lastly PedsQL™ Family Impact module (2.0), with assistance in gaining clarity on questions from the researcher, if necessary. The researcher filled in PedsQL™ Cancer (3.0), Generic Core Scales (4.0) with the child who participated in face-to-face interviews, answering questions asked by the researcher.

All the assessments were done during afternoon, in the CANSA building with parents. The allocated office for counselling was used when the parents (there were no carers) were answering the PedsQL™ Inventory questionnaires.

Four of the parents needed assistance with explanation of some of the descriptions of the questions; this was provided by a research assistant who was a student nurse, trained by the researcher to answer questions about the items of the PedsQL™ Inventory questionnaires. Two of the parents who showed emotional distress, were referred to the treating oncologist in the ward and the social services as well as Hospi-vision for counselling. The time allocated for completion of the PedsQL™ Inventory questionnaires depended on the parent's level of education, and ranged from less than 20 minutes to two hours. The longer duration was the result of small breaks taken during the process and the need for assistance and translation when the participant requested explanations in their home language.

Children were interviewed in the counselling room within the ward; the duration of the interviews was 50 minutes, with a 3-minute break provided on completion of each PedsQL™ inventory form (survey). All parents and children were thanked for their participation in the study and each parent was given feedback with a discussion about the findings after the scoring of all PedsQL™ modules and scales to assist with determining what services they needed after the assessment. All the children's results were shared with the oncology ward's management team, during medical reviews, which were done weekly on Fridays, with agreement from the parents and children. The needs of the children and parents in terms of occupational disruption and HRQoL in their early cancer journey was presented.

3.5 Data Analysis

3.5.1 Organisation of data

Collected data was stored on the researcher's laptop, where the Microsoft Office Excel spreadsheet and the laptop were password protected. Spreadsheets for demographic details of the participants, excluding identifying information, the total scores and sub-scores for PedsQL™ Family Impact Module (2.0) for the parent only were created. The scores for PedsQL™ Cancer Module (3.0) for parent and the child, as well as the total scores and sub-scores for PedsQL™ Generic Core Scales

(4.0) of parent and child, were captured on different spreadsheets. One parent did not answer more than 50% of all questions in three questionnaires therefore the scores were not computed as stipulated from instructions of PedsQL™ inventories. All 25 children filled in or answered all questionnaires accordingly and scores were computed.

3.5.2 Analysis of results

Descriptive and inferential statistical analysis was used. Descriptive analysis included frequencies, median, quantile ranges, percentages and Cohen's d and were determined using Statistica version 13.2. The demographic questionnaire produced the nominal scale of data type, relating to the characteristics of the sample and this was analysed through frequencies, percentages and median scores.

The data from the PedsQL™ Cancer Module (3.0) Generic Core Scales (4.0), using both parent and child proxy, and the PedsQL™ Family Functioning (2.0) parent proxy were analysed using means and standard deviations so scores could be compared to norms for HRQoL (Beverung et al., 2015).

Non-parametric Mann Whitney U tests were used to compare data for children and parent groups, however as the data were ordinal and the sample size small, Statistica v 13.2 was used to analyse the data. Significance was set at *p*-value equal to or less than 0.05 (McCrum-Gardner, 2008). The Chi-squared test was used to determine the effect of cancer type and treatment modality on the HRQoL collected from PedsQL™ Generic Core Scales (4.0) parent and child proxies, as well as the PedsQL™ Cancer Module (3.0) parent and child proxies and the PedsQL™ Family Functioning (2.0) (McCrum-Gardner, 2008; Yockey, 2018). The non-parametric nature of the Chi-squared test was suited to this data as some groups for these variables only had one participant. Quantitative data were presented in graphics and tables for both descriptive and inferential analyses.

3.11 Conclusion

This chapter has explained the methods used in this quantitative study of the occupational disruption and HRQoL in children admitted for cancer management and their parents. Approval for using the research tools, access to participants and hospital records was received before research. Four instruments were used,

Demographic questionnaire, PedsQL™ Family Impact Module (2.0), Cancer (3.0) and Generic Core Scales (4.0).

Convenience sampling was used to select all participants. During the study period, both the child and parent participated; the child was involved in a semi-structured interview. The questionnaires were written in English, and where participants needed rephrasing of the terms to reduce the level of abstraction when asking the questions, this was done by the researcher. While the parent completed surveys independently with the assistance from the student nurse if required. Collected data was organised onto an Excel spreadsheet, and analysis was done using Statistica v 13.2 software where descriptive and inferential statistical procedures functions were performed. The next chapter presents the results.

CHAPTER 4: RESULTS

4.1 Introduction

As stated in Chapter 1, the study determined the HRQoL quality of life experienced by children with cancer who were admitted at Steve Biko Academic Hospital for cancer management while they were in a temporary environment. Family functioning, relationships and parent's HRQoL were also assessed for parents who accompanied the sick child to the hospital. Some children had both parents present during data collection and one parent, either father or mother, was asked to participate in the research. This chapter is organised into five sections, according to the data collection, starting with a description of participant's demographics, medical history, and family demographics. The second section considers the HRQoL related to function in living areas and occupational disruption and the third section, HRQoL related to the impact on family functioning in parents. The last section considers HRQoL related to cancer and the differences in function life areas, family functioning and HRQoL related to the type of cancer and treatment modality is presented.

Twenty-five children and their parents participated in the research, which represented 55.5% of the proposed sample size. Reasons for not achieving a sample of 45 participants was due to the deaths of children in the ward and some children being older than 12 years 11 months.

Although 35 children were eligible to participate in research, only 25 were interviewed. The, exclusion of 10 children was due to two children admitted without parents, three protocols not discussed with the parents, one child with developmental delays, three children were not present at the hospital for booked follow-up on treatment interventions and one child who was medically unstable with physical, cognitive and visual impairment. None of the children and parents who were approached refused to participate in the research. Out of the 25 participants, all the children answered all questions; one parent did not answer more than 50% of questions in all three questionnaires, therefore the score sheets were not computed as stipulated in PedsQL™ inventories scoring.

4.2 Demographics

4.2.1 Personal demographics – Parents

Twenty-five parents were interviewed, 80 % (n=20) were females and 20 % (n= 5) males, with ages ranging from 26 to 48 years old; the mean age was 39 years.

		<i>Number (n)</i>	<i>Percentage (%)</i>
Gender	Females	20	80.00
	Males	5	20.00
Race	Black African	22	85.00
	White	1	4.00
	Indian	1	4.00
	Coloured	1	4.00
Education	No Formal Schooling	1	4.00
	Primary School	2	8.00
	High School	19	76.00
	Technical College Qualifications	3	12.00
Employment	Not working	14	56.00
	Working	6	24.00
	Self-employed	4	16.00
	Studying	1	4.00

Eighty-seven percent of participants in this study (n= 22) were Black African, with 1% (n=1) each being White, Indian and Coloured ethnicity. Seventy-six percent (n= 19) of parents had high school educational level, while 12% (n= 3) had technical college qualifications, 8% (n= 2) had primary schooling and 4% (n=1) had no formal schooling. Within each family, one member was working but this was not necessarily the parents. The parent's work status was divided into four categories, 56% (n= 14) were not working, 24% (n= 6) working part-time or permanently, 16% (n= 4) were self-employed and 4% (n= 1) were studying.

4.2.2 Personal demographics - Children

Children participants (n=25) were 40% (n= 10) females and 60% (n= 15) males. Ages of participants ranged between 8 years 0 months to 12 years and 11 months; distribution of ages was across late childhood spectrum. The highest percentage of children were in the 8 years 0 months to 8 years 11 months' age group (Table 4.2).

		Mean	SD
Age	Years. Months	10.32	1.84
		Number (n)	Percentage (%)
	8.0 - 8.11	8	32.00
	9.0 - 9.11	2	8.00
	10.0 -10.11	4	16.00
	11.0 -11.11	5	20.00
	12.0 -12.11	6	24.00
Gender	Females	10	40.00
	Males	15	60.00
Time out of school	Less than a month	16	64.00
	One month	3	12.00
	Four to 14 months	6	24.00

Out of school duration for all children ranged from 0 to 14 months within all participants, 64% (n= 16) had been out of school for less than a month. These participants had been in contact with the school in the past 30 days prior to data collection. Twelve percent (n= 3) had been out of school for one month and 4% (n= 6) between four and 14 months.

4.2.3 Medical History – Children

Children were diagnosed with different cancers, 56% (n=14) had leukaemia, 12% (n=3) had rhabdomyosarcomas, 8% (n=2) had lymphomas and solid tumours. One child, which is 4%, presented with neuroblastoma, brain cancer, osteosarcoma and haematologic cancer (Table 4.3).

<i>Diagnosis</i>	<i>Number (n)</i>	<i>Percentage (%)</i>
Leukaemia	14	56.00
Neuroblastoma	1	4.00
Brain cancers	1	4.00
Rhabdomyosarcoma	3	12.00
Lymphoma	2	8.00
Osteosarcoma and Ewing’s sarcoma	1	4.00
Haematologic cancer	1	4.00
Solid tumours	2	8.00

4.2.4 Family structure and location of residence

All 25 participants indicated their family structures, the total number of people in the household and parents who were working. The number of people in the household ranged from 3.00 to 8.00. The range for the number of siblings in each household was 1.00 to 5.00 (Table 4.4).

		Mean	Range
Individuals at Home	Number of people in household	5.00	3.00 – 8.00
	Number of siblings	2.00	1.00 – 5.00
		<i>Number (n)</i>	<i>Percentage (%)</i>
Municipality resided in	Tshwane	9	36.00
	Ehlanzeni	8	32.00
	Gert Sibande	2	8.00
	Ekurhuleni	3	12.00
	Nkangala	3	12.00

All parents and children were from two provinces, Gauteng and Mpumalanga, and from six local municipalities. In terms of municipalities, 36% (n= 9) of the parents

were from Tshwane, 32% (n= 8) from Ehlanzeni, 8% (n= 2) from Gert Sibande and 12% (n= 3) resided in Ekurhuleni and Nkangala municipalities.

4.3 Health-Related Quality of life- Function in life areas and roles - Pediatric Quality of Life Generic Core Scales™

The results of the PedsQL™ Generic Core Scales (4.0) were based on 25 children who answered the subsections and 24 parents who answered proxy subsections that applied to the child. The mean score was calculated according to the manual, so missing data did not affect the mean scores obtained. Both parents and children indicated the children to be functioning within the intermediate HRQoL level in the 61 to 80 score range and below the norm of 81 for high or typical HRQoL (Beverung et al., 2015). According to the PedsQL™ Generic Core Scales (4.0), children indicated themselves to be functioning with a total mean of 69.69 (SD 20.23) and parent proxy indicated the children have a total mean of 64.13 (SD 21.48) (Table 4.5).

Table 4.5: PedsQL™ Generic Core Scales (4.0) scores, Parents and Children (n=25)						
	Children		Parents		Difference between child and parent	
	Mean	SD	Mean	SD	p value	Effect size Cohen's d
Physical (n=25)	73.37	24.67	58.20	29.07	0.068	0.61
Emotional (n=25)	67.60	24.87	65.40	26.03	0.825	0.09
Socialisation(n=25)	71.80	25.89	78.12	23.49	0.466	-0.24
Schooling (n=19)	66.84	21.22	62.50	26.91	0.670	0.20
<i>Psychosocial Functioning</i>	63.40	24.01	60.93	26.53	0.793	0.10
<i>Overall Total</i>	69.69	20.23	64.13	21.48	0.347	0.27

Significance $p \leq 0.05^*$
Significance $p \leq 0.01^*$

Cohen's d
0.8 large
0.5 medium
0.2 small

Using the Mann Whitney U test, there was no statistically significant difference between the two groups. Children reported better HRQoL for all subsections than their parents except for socialisation.

4.3.1 Physical function

The physical function had a mean score of 58.20 (SD 41.20) for the parents and 73.37 (SD 26.63) for the children for issues with mobility, washing, chores and energy levels (Figure 4.1).

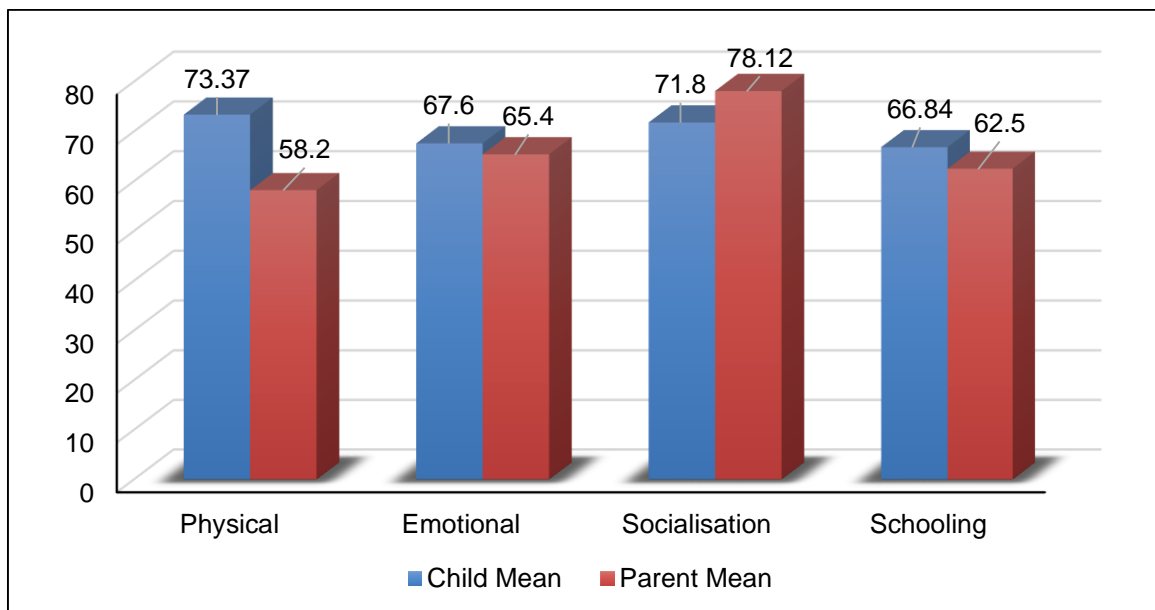


Figure 4.1: Generic Core Scales (4.0) scores of Parents and their Children

No significant difference was found between the scores for the parents and children. Cohen's d for physical function had a medium clinical difference ($d=0.61$). Thus parents placed the children in the low level of HRQoL with a score below 60, while children placed themselves in an intermediate HRQoL level with a score between 61 and 80 (Beverung et al., 2015).

4.3.2 Emotional functioning

Emotional functioning from children had a mean of 67.60 (SD 32.40) and 65.40 (SD 34.60) from parents, with both children and parents indicating a similar decrease in HRQoL for the children at an intermediate level for fear, low mood and sleep

(Beverung et al., 2015) (Figure 4.1). The difference was not statistically significant with an effect size that showed no clinical difference with emotional challenges during their course of cancer within the intermediate HRQoL level.

4.3.3 Social functioning

Parents had a higher score with a mean of 78.12 (SD 21.88) for social function than that of the children, with a mean of 71.8 (SD 28.20) (Figure 4.1). This was the only subsection where children indicated to have lower functioning and more occupational disruption for relationships and play. There was small negative effect size between parents and their children who both rated this subsection at an intermediate HRQoL (Beverung et al., 2015).

4.3.4 Roles -Schooling

With roles related to schooling, 18 parents and 19 children answered questions for this subsection as these children had had school contact within the last 30 days before data collection. Parents indicated a mean of 62.50 (SD 37.50) and children a mean of 66.84 (SD 33.16) (Figure 4.1), indicating children perceived slightly less effect for this subsection on HRQoL. Both rated schooling at an intermediate level of HRQoL and occupational disruption (Beverung et al., 2015) and there was no statistically significant difference between parents and children with a small effect size showing no clinical difference for this subsection which considers performance at school and school time missed.

4.3.4 Psychosocial functioning

The Generic Core Scales (4.0) Psychosocial functioning had a mean score of emotional, social, and school functioning scales 63.40 (SD 24.01) for the children, while the parents mean score was 60.93 (SD 26.53). Although the children's scores were slightly higher, both parents and the children scored their HRQoL at intermediate for this section. The parents mean score was at the low end of the intermediate range at 61. There was no statistically significant difference or clinical difference according to the effect size between children and parent scores.

4.4 Pediatric Quality of Life Family Functioning™ - Family Impact Scale (2.0)

Parent's HRQOL was assessed by the Family Impact Module™ (2.0); the total mean scores were 64.64 (SD 14.30) indicating the 24 parents were functioning within the intermediate level of HRQoL, with scores that fell in the 61 to 80 range (Table 4.6).

Table 4.6: Parents Family Impact Module™ (2.0) scores		
	Parent	
Component	Mean	SD
Physical	52.73	14.75
Emotional	63.54	25.55
Social	64.32	25.56
Cognitive	69.79	26.10
Communication	63.19	26.90
Worry	47.70	25.02
<i>Parent HRQOL</i>	<i>67.29</i>	<i>18.68</i>
Daily Activities	63.88	28.41
Family Relationships	69.58	21.17
<i>Family Functioning</i>	<i>66.72</i>	<i>20.99</i>
Total Score	64.26	14.69

4.4.1 Physical

Physical functioning had a mean of 52.73 (SD 14.75) (Figure 4.2). Parents indicated severe impact and reported feeling tired and suffering headaches resulting in a low HRQoL for this subsection, with a score below the mean of 60 (Beverung et al., 2015).

4.4.2 Emotional

Emotional functioning had a mean of 63.54 (SD 25.55) (Figure 4.2). Parents indicated levels of support from community and families had an impact on their

emotional functioning, which manifested as anxiety, sadness, anger, frustration, and feeling helpless or hopeless. These scores fall within the intermediate level of functioning (Naidoo et al., 2016 & Beverung et al., 2015).

4.4.3 Social

Social functioning had a mean of 64.32 (SD 25.56) (Figure 4.2), indicating an intermediate level of HRQoL. Parents reported they were withdrawn from society and families, and they were limited to participating in their social interactions and finding time for themselves due to the child's illness (Naidoo et al., 2015).

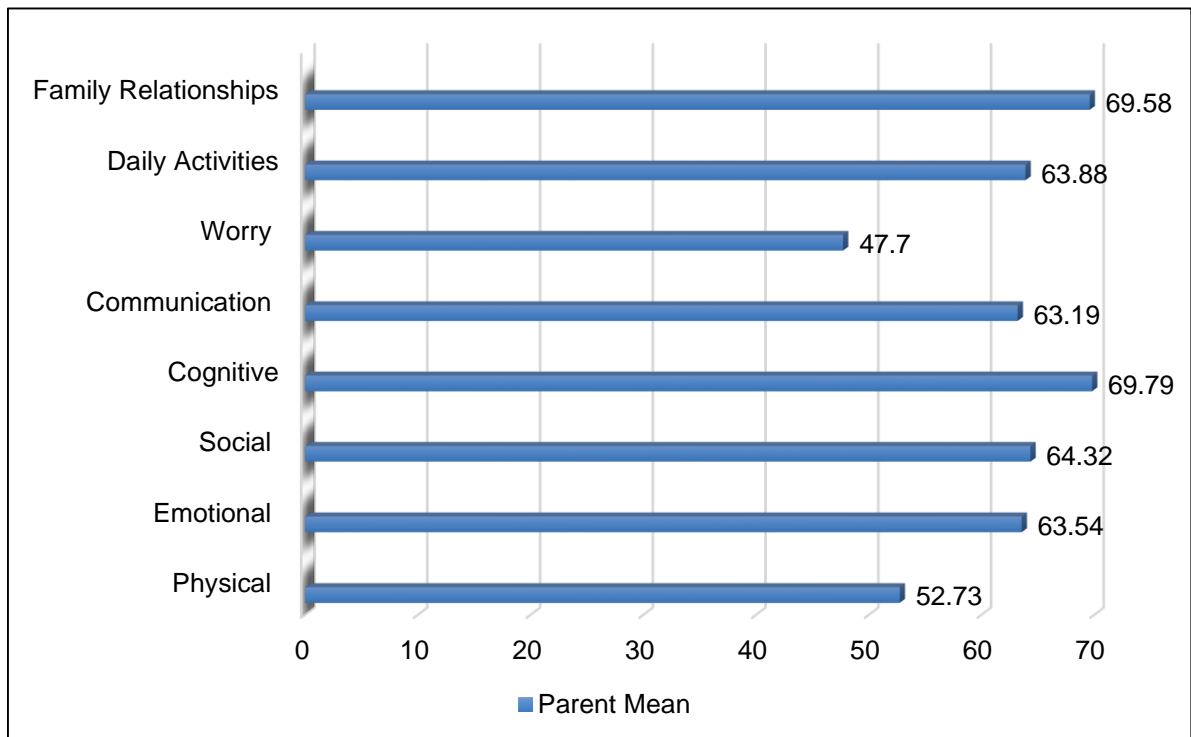


Figure 4.2: Parents Family Impact Module (2.0) Means

4.4.4 Cognitive

Cognitive functioning had a mean of 69.79 (SD 26.10) (Figure 4.2). Parents experienced difficulties with cognitive functioning including attention, remembering things, and thinking quickly, and were functioning within the intermediate level of HRQoL (Beverung et al., 2015).

4.4.5 Communication

Communication functioning was limited for others by not understanding the family's situation, difficulty talking about the child's health condition, and with talking to health care professionals for these parents of children with cancer. They had a mean score of 63.19 (SD 26.90) (Figure 4.2), so the family function was within the intermediate level of quality of life (Beverung et al., 2015).

4.4.6 Worry

Worrying had the lowest mean score, with a mean of 47.70 (SD 25.02) (Figure 4.2), this was below 60 for indicators of high risks with HRQoL (Beverung et al., 2015). These scores were related to worrying about the child's treatments, others' reactions to the child's condition, the effect of the illness on the family, and the child's future.

4.4.7 Daily Activities

Daily activities had a mean of 63.88 (SD 28.41) (Figure 4.2). Parents were still able to finish their house duties but they took more time, they were functioning within an intermediate level of HRQoL (Beverung et al., 2015).

4.4.8 Family Relationships

Family relationships had a mean of 69.58 (SD 21.17) (Figure 4.2). The parents reported they were functioning within the intermediate level of HRQoL (Beverung et al., 2015). There is lack of communication and conflict between all family members, difficulty in making decisions and solving problems as a family.

4.4.9 Parents Health-Related Quality of Life (HRQOL)

Parents' HRQOL was taken from 20 questions, which were physical, emotional, social and cognitive functioning. In total, parents had mean of 64.26 (SD 14.69). With all components of parents' HRQOL, they were functioning within intermediate ranges of HRQoL (Beverung et al., 2015).

4.4.10 Family Functioning

Family functioning was scored from eight questions, which were daily activities and family relationships. The parents had mean of 66.72 (SD 20.99), indicating the parents were functioning within the intermediate level of HRQoL (Beverung et al., 2015).

4.5 Health Related Quality of Life - Pediatric Quality of Life Cancer Module™ (3.0)

The Pediatric Quality of Life Cancer Module assesses how the child is coping with cancer and their experiences with side effects from the treatment. By proxy, the parents had a total mean of 63.92 (SD 17.62), while the children had a total mean of 76.58 (SD14.78) (Table 4.7).

Component	Children		Parents		Difference between child and parent	
	Mean	SD	Mean	SD	p value	Effect size Cohen's d
Pain & Hurt	75.00	25.00	66.14	28.90	0.282	0.35
Nausea	74.60	22.16	62.29	25.66	0.094	0.56
Procedural Anxiety	69.33	31.34	49.30	32.86	0.036*	0.64
Treatment Anxiety	87.00	22.44	71.87	29.97	0.038*	0.67
Worry	82.33	20.45	51.73	31.56	0.008**	1.50
Cognitive problems	74.40	23.99	68.33	24.92	0.340	0.25
Perceived physical appearance	76.00	27.42	71.18	32.59	0.749	0.17
Communication	72.00	22.93	69.44	29.96	0.959	0.11
Overall Total	76.58	14.78	63.92	17.62	0.034**	0.86

Significance $p \leq 0.05^*$
Significance $p \leq 0.01^{**}$

Cohen's d
0.8 large
0.5 medium
0.2 small

Both children and parents indicated the children were functioning within the intermediate level, as overall mean scores were within the 61 to 80 range, (Beverung et al., 2015). Using the Mann Whitney U test, there was a statistically significant difference between parents and children's scores, $p = 0.034$ and a large effect size showing the clinical difference indicating the parents perceived a lower overall total HRQOL for their children.

4.5.1 Pain and hurt

Children had a mean of 75.00 (SD 25.00) when reporting on pain and hurt, while parents had a mean of 66.14 (SD 33.86) (Figure 4.3) with parents indicating a lower HRQoL score. There was no significant difference between the parents and children and the effect size was small indicating clinically, they viewed pain and hurt on a similar level. Their scores were within the intermediate level of functioning, ranging within 61 to 80 ranges of HRQoL (Beverung et al., 2015).

4.5.2 Nausea

When considering nausea, parents had a mean of 62.29 (SD 37.71) and children had a mean of 74.60 (SD 25.40) (Figure 4.3). There was no significant difference between the parents and the children and the effect size was medium indicating clinically, the children viewed nausea as affecting their HRQoL less than the parents. Again the scores fell within the intermediate level of functioning ranging (Beverung et al., 2015).

4.5.3 Procedural anxiety

For procedural anxiety, parents indicated the mean of 49.30 (SD 50.70) with the children having significantly less procedural anxiety than the parents with a mean of 69.33 (SD 30.67) (Figure 4.3). This was confirmed by the statistically significant difference and a medium effect size difference between the two groups, where parents indicated that children had more procedural anxiety. Children scored themselves in the intermediate level of HRQoL, while parents scored them at a low level as the mean score was below 60, indicating more severe effects of procedural anxiety on HRQoL (Beverung et al., 2015).

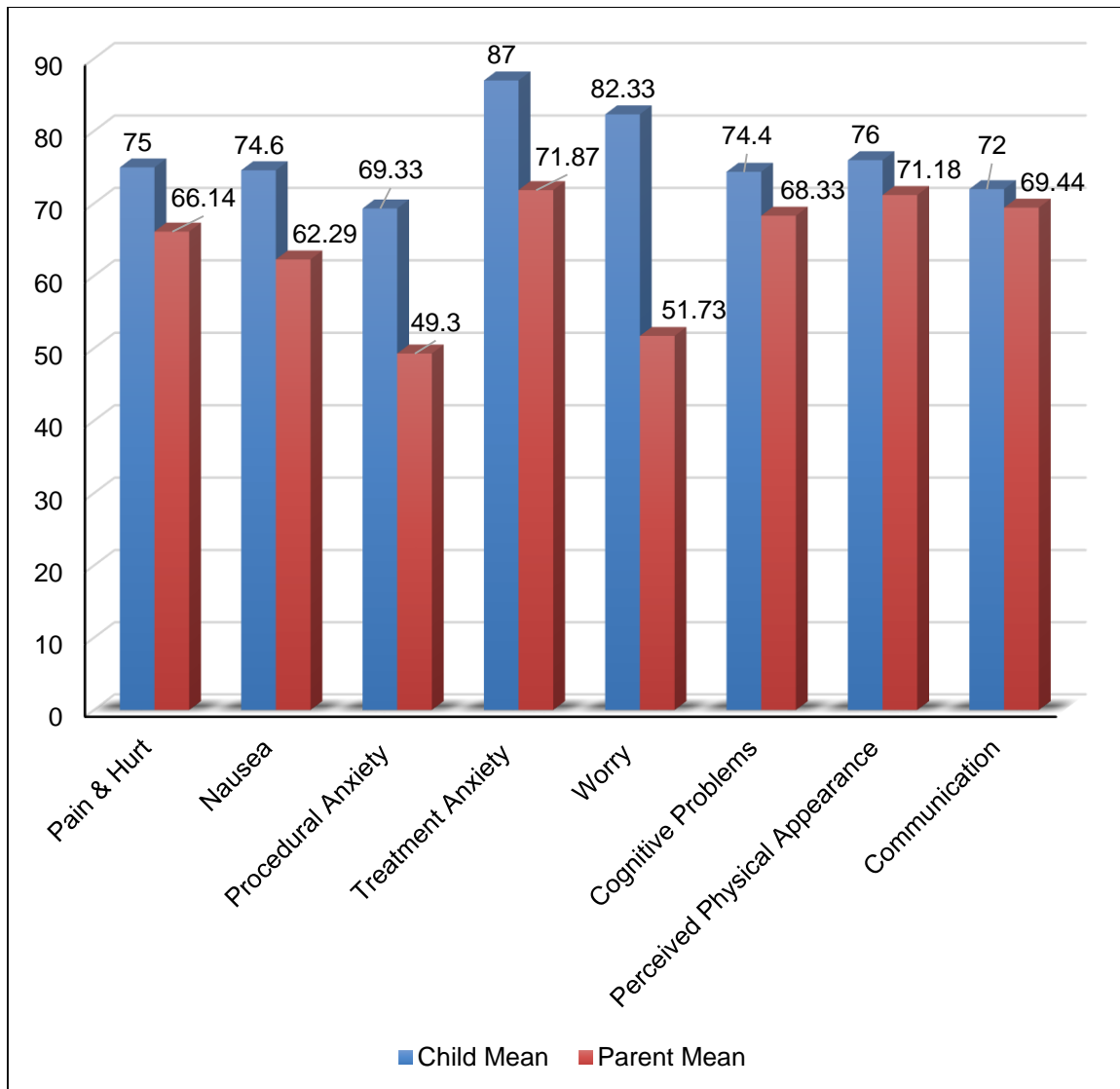


Figure 4.3: Cancer Module (3.0) Mean Scores, Parents and Children

4.5.4 Treatment anxiety

For treatment anxiety, parents had a mean of 71.87 (SD 28.13) while children had a higher mean of 87.00 (SD 13.00) (Figure 4.3). Children indicated to have coped better with treatment, experiencing less anxiety than did the parents. The children placed their HRQoL above 81, which was within the typical range and indicated no problem. The results indicated the parents perceived children to be functioning within the intermediate level of HRQoL (Beverung et al., 2015). There was a statistically significant difference and a medium effect size clinical difference between the two groups.

4.5.5 Worry

Parents worry was not the same as the children, they had a mean of 51.73 (SD 48.27) while children had a mean of 82.33 (SD 17.67) (Figure 4.3). Parents were more worried than their children were about their future and the effects of the treatment. The parents scored the children's HRQoL within a low or severe level, while the children's score was within the higher typical level (Beverung et al., 2015). There was a statistically significant difference and a large effect size indicating a clinical difference between the groups.

4.5.6 Cognitive problems

For cognitive problems the parents indicated a mean of 68.33 (SD 31.67) and the children had a mean of 74.40 (SD 25.60) (Figure 4.3). Parents indicated the children have more challenges with cognitive functioning. The scores of both the parents and children were within the intermediate level of functioning (Beverung et al., 2015). There was no statistically significant difference between the groups, with a small effect size showing no clinical difference.

4.5.7 Perceived physical appearance

Both parents and children had similar scores for perceived physical appearance with the parent's mean at 71.18 (SD 28.82) and the children's mean at 76.00 (SD 24.00) (Figure 4.3). Both children and parents agreed children have an intermediate level of HRQoL for physical changes due to treatment and there was no statistically significant or clinical difference in their scores for this component (Beverung et al., 2015).

4.5.8 Communication

The score parents reported for communication was a mean of 69.44 (SD 30.56) while children had a higher mean of 72.00 (SD 28.00) (Figure 4.3). Children felt they could express themselves and communicate with doctors if they were given the opportunity, parents also indicated children were functioning within the intermediate level of HRQoL (Beverung et al., 2015).

4.6 Quality of Life from Type of Cancer and Treatment Modality

4.6.1 Type of cancer

The Chi-squared test was used to determine differences in the test mean scores according to the different cancer diagnoses of children. There were eight groups with different cancer diagnoses.

4.6.1.1 Pediatric Quality of Life Generic Core Scale™ (4.0)

Using the Chi-squared test, there was no significant difference for diagnosis according to functioning in HRQoL and occupational disruption on the Pediatric Quality Generic Core (4.0). The p-value from parents was 0.369 and children, 0.151 (Table 4.8), with no significant difference according to the cancer diagnoses of the children.

Cancer Group	Child			Parent		
	Mean	SD	p value	Mean	SD	p value
Leukaemia (n=14)	76.15	19.17	0.151	69.49	23.21	0.369
Neuroblastoma (n=1)	59.72	-		59.72	-	
Brain cancer (n=1)	95.65	-		95.65	-	
Rhabdomyosarcoma (n=3)	58.93	3.84		65.75	16.54	
Lymphomas (n=2)	63.04	9.22		53.25	1.53	
Osteosarcoma and Ewing's sarcoma (n=1)	46.73	-		29.34	-	
Hematologic cancer (n=1)	93.47	-		48.91	-	
Solid Tumours (n=2)	38.82	11.87		49.24	8.75	

These results do include some diagnoses with a single individual, and should be viewed in that light, as some of these participants did not report problems with

HRQoL and had scores above 81. Differences in parents and children's means were not always congruent (Figure 4.4).

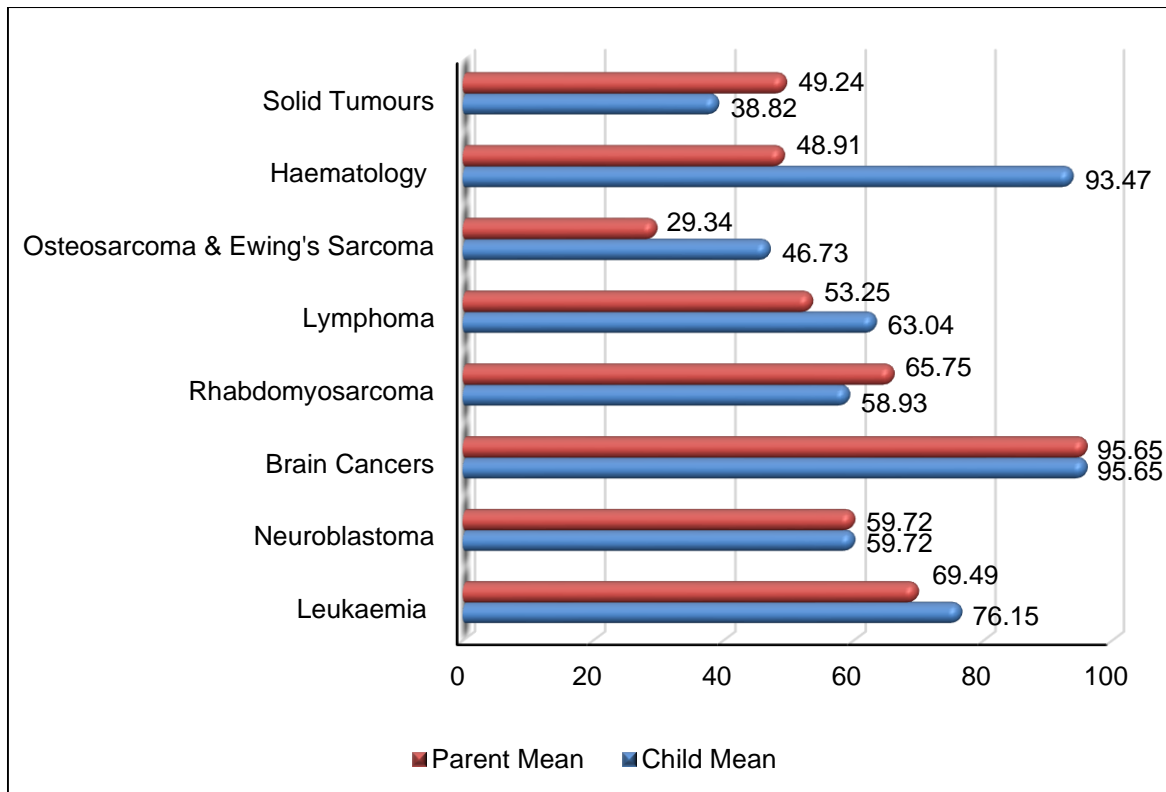


Figure 4.4: Children’s Diagnosis and Generic Core Scales (4.0) means of both parents and children

Within the parents and children’s mean scores, the diagnostic groups within the intermediate range of HRQoL were for children with leukaemia, while groups with low HRQoL were children with neuroblastoma, osteosarcoma, and solid tumours with scores from parents and children below a mean of 61.

For children with lymphoma and haematologic cancer, parents indicated a low HRQoL and the children reported intermediate or high HRQoL. For the one participant with brain cancer, both the child and parent reported a high HRQoL with a score above 81 (Beverung et al., 2015) (Figure 4.4).

4.6.1.2 Pediatric Quality of Life Family Impact Scale™ (2.0)

When using the Chi-squared test in the Family Impact Module (2.0) mean scores, $p = 0.555$ indicating no statically significant difference in family function based on diagnosis (Table 4.9).

Cancer Group	Mean	SD	P value
Leukaemia (n=14)	64.48	15.61	0.555
Neuroblastoma (n=1)	47.22	-	
Brain cancers (n=1)	75.69	-	
Rhabdomyosarcoma (n=3)	56.70	16.29	
Lymphomas (n=2)	59.02	6.87	
Osteosarcoma and Ewing's sarcoma (n=1)	80.55	-	
Haematologic cancer (n=1)	74.30	-	
Solid Tumours (n=2)	73.60	3.92	

Most parents reported intermediate or low HRQoL depending on the type of cancer with which their child was diagnosed. Again, results must be considered with caution due to single individuals with a given diagnosis but the parent of the child with the child during admission. Neuroblastoma had the lowest score, while the parent of the child with osteosarcoma and Ewing's sarcoma was the only one who had a high HRQoL score of 81 (Beverung et al., 2015).

4.6.1.3 Pediatric Quality of Life Cancer Module™ (3.0)

Using a Chi-squared test there was no significant difference in diagnosis on the scores of the children ($p=0.622$) and the parents ($p=0.631$) for HRQoL for the child coping with cancer illness and the treatment side effects related to the different diagnoses (Table 4.10).

Table 4.10: Diagnosis and Pediatric Quality of Life Cancer Module™ (3.0) mean scores, parents and children						
	Child			Parent		
Cancer Group	Mean	SD	p value	Mean	SD	p value
Leukaemia (n=14)	76.63	16.65	0.622	66.02	18.45	0.631
Neuroblastoma (n=1)	81.73	-		72.22	-	
Brain cancers (n=1)	77.77	-		87.96	-	
Rhabdomyosarcoma (n=3)	76.23	11.72		56.78	28.28	
Lymphomas (n=2)	82.86	3.27		54.62	19.17	
Osteosarcoma and Ewing's sarcoma (n=1)	59.25	-		50.92	-	
Haematologic cancer (n=1)	100.00	-		60.18	-	
Solid Tumours (n=2)	81.73	9.82		72.22	12.43	

Within the mean scores of the parents and children for the different diagnostic groups, the children within the intermediate range for HRQoL on both scores were for children with leukaemia, while the child with low HRQoL on both scores had osteosarcoma and Ewing's sarcoma. Parents reported a low HRQoL, below 61, for children with lymphomas and rhabdomyosarcoma although these children reported high and intermediate HRQoL respectively in dealing with their cancer.

Children with scores from parents below a mean of 81 for intermediate HRQoL but who reported higher scores for themselves were those with neuroblastoma, haematologic cancer and solid tumours. The single individuals in some groups meant these scores should be considered with caution (Beverung et al., 2015) (Figure 4.5).

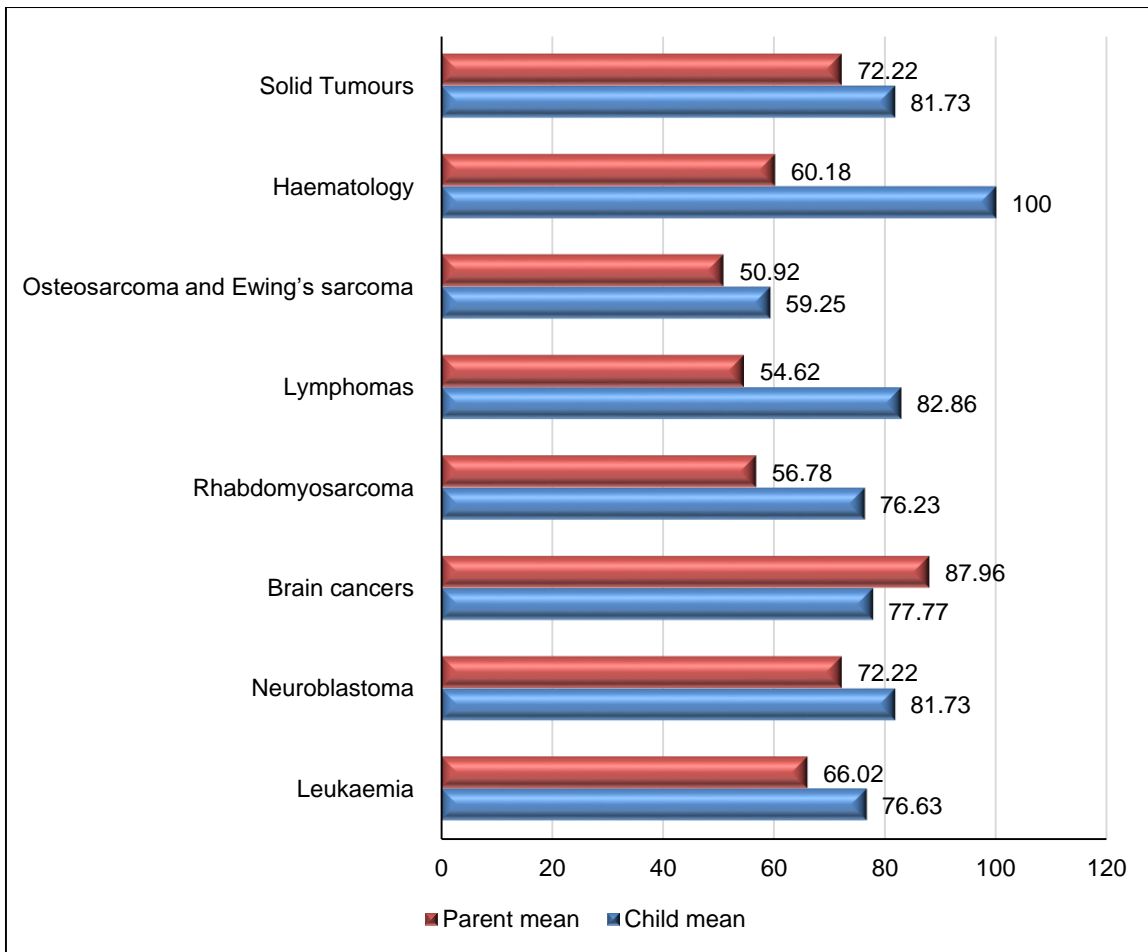


Figure 4.5: Children Diagnosis and Pediatric Quality of Life Cancer Module 3.0 means of both parents and children

4.6.2 Treatment Interventions

All 25 children were treated with either chemotherapy, radiotherapy, received surgery or transplant, or a combination of the above-mentioned treatment interventions; this was dependent on the child's protocol that was followed.

4.6.1.1 Pediatric Quality Generic Core™ (4.0)

When the Kruskal Wallis test was applied, parents had a p-value of 0.956 and children had a p-value of 0.431 when using the Chi-squared test to compare their Generic Core Scales with treatment interventions received by the children (Table 4.11).

Table 4.11: Children and Parents Mean Score of Generic Core Scales by Interventions received						
Treatment Interventions	Child			Parent		
	Mean	SD	p value	Mean	SD	p value
Chemotherapy/radiotherapy/surgery (n=1)	56.52	–	0.431	52.17	–	0.956
Chemotherapy (n=19)	73.24	19.00		64.47	21.42	
Chemotherapy/surgery (n=3)	68.47	24.90		69.56	35.34	
Radiotherapy/surgery (n=1)	30.43	–		55.43	–	

Both parents and children indicated the children treated with a combination of radiotherapy, surgery and chemotherapy, or radiotherapy and surgery functioned at a low HRQoL level.

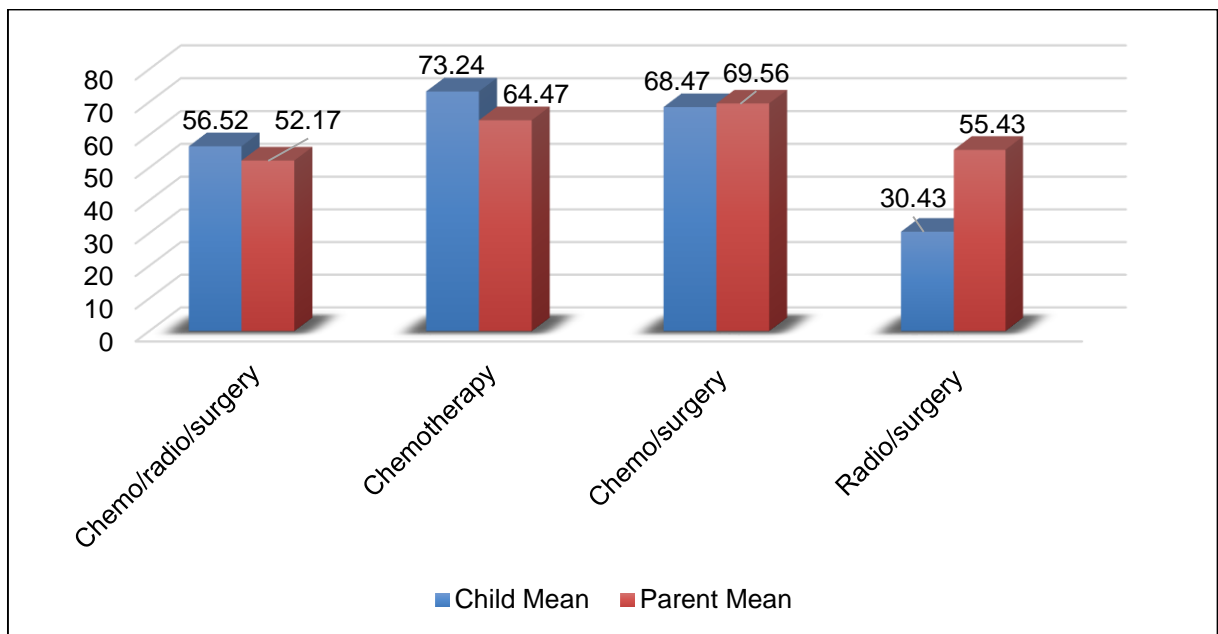


Figure 4.6: Comparison of Children and Parents Generic Core Scale (4.0) Mean from Treatment Interventions received

The child receiving radiotherapy scored their HRQoL as severely affected in comparison to their parent. This was only one child, so the results need to be viewed with caution.

Those treated with chemotherapy or a combination of chemotherapy and surgery were scored at the intermediate HRQoL level on the Generic Core Scales, which assessed life function in socialisation, physical, emotion and school challenges on children (Figure 4.6).

4.6.2.2 Pediatric Quality of Life Family Impact Scale™ (2.0)

The Kruskal Wallis test was used to differentiate between mean scores from Family Impact Modules (2.0) in children's treatment interventions. There was no significant difference in terms of family impact according to the intervention received with a p-value of 0.649 (Table 4.12).

Table 4.12: Treatment Interventions and Family Impact Scale (2.0) Means			
Treatment Interventions	Mean	SD	P value
Chemotherapy/radiotherapy/surgery (n=1)	54.16	-	0.649
Chemotherapy (n=18)	62.96	15.29	
Chemotherapy/surgery (n=3)	72.21	10.50	
Radiotherapy/surgery (n=1)	76.38	-	

All the scores of the parents of the children who received radiotherapy and surgery, chemotherapy and surgery and chemotherapy had mean scores that fell between 61 and 80, indicating they had intermediate HRQoL. Only one child received three interventions, chemotherapy, surgery, and radiotherapy, and their parent had a mean score of below 61 showing great impact on their HRQoL related to family functioning (Beverung et al., 2015). Due to the result reflecting only one individual, this should be interpreted with caution.

4.6.2.3 Pediatric Quality of Life Cancer Module™ (3.0)– Health-related quality of life

When using the Chi-squared test, parents had a p-value of 0.631 and children had a p-value of 0.801 when comparing their Quality of Life Cancer Module scales with treatment interventions received by children. Thus there was no significant difference in HRQoL related to the treatment received (Table 4.13).

Treatment Interventions	Child			Parent		
	Mean	SD	p value	Mean	SD	p value
Chemotherapy/radiotherapy/surgery (n=1)	80.55	–	0.801	48.14	–	0.631
Chemotherapy (n=18)	77.72	15.59		62.85	18.41	
Chemotherapy/surgery (n=3)	75.30	14.96		73.45	19.78	
Radiotherapy/surgery (n=1)	57.40	–		71.29	–	

The one-child who received the three interventions of chemotherapy, radiotherapy and surgery had the highest mean from child proxies of 80.55, which scores at a high HRQoL while the parents of the child had a lower mean of 48.14, indicating low HRQoL. The child who received radiotherapy and surgery however had a mean of 57.40 indicating low HRQoL and their parent scored a mean of 71.29, indicating the child had an intermediate HRQoL. Again, these are the scores of an individual child and parent and this discordance between them must be interpreted with caution.

The largest group of children receiving chemotherapy had a parent and child mean score of 62.85 and 77.72 respectively, which indicated intermediate HRQOL (Beverung et al., 2015). This group and those treated with a combination of chemotherapy and surgery had the intermediate quality of life according to the children’s and parents’ perspectives (Beverung et al., 2015) (Figure 4.8).

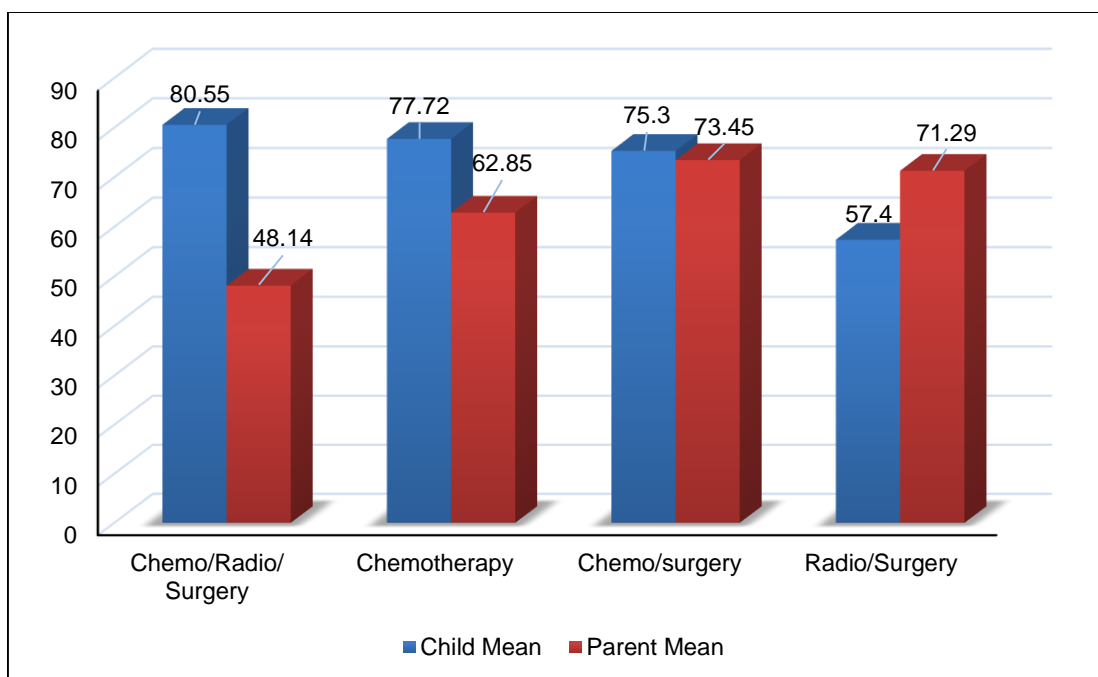


Figure 4.7: Treatment Interventions and Pediatric Quality of Life Cancer Module (3.0) Mean scores

4.7 Summary

The demographics of the parents indicated more females than males accompanied their children to hospital. In the child participants, there were more males than females. The working parents mainly lived in the provinces of Gauteng and Mpumalanga. Children's age was across the late childhood group and parents' ages were within young adulthood group; all children had siblings at home and duration of out of school ranged from zero to 14 months. When considering the cancer diagnosis, the largest group had ALL.

The PedsQL™ Generic Core module indicates that the HRQoL of the children from their perspective and their parent's perspective was at an intermediate level. Both parents and their children indicated similar intermediate HRQoL, and they were in agreement for schooling, emotional and socialisation functioning. They were in disagreement with physical functioning of the child. With overall scores of all four functioning areas, socialisation had the highest and schooling had the lowest mean

score. There was no statistically significant difference in parents and children for Generic Core Scale life functioning.

In the PedsQL™ Family functioning, the module was completed by the parents accompanying children to the hospital. They indicated to be functioning within intermediate QOL, with a total mean of 64.26. Worry was indicated to affect functioning the most with a mean score of 47.70; this was below the mean of 50. None of the other components had a mean above 81 indicating high QOL.

The PedsQL™ Cancer module scores for HRQoL indicated statically significant differences between parents and children for worry and treatment and procedural anxiety as well as the overall score for parents falling within the low HRQoL. Parents perceived children to have lower HRQoL than the children perceived for themselves, with a total overall score for children at 76.58 and 63.92 for parents. Both scores were within intermediate QOL. Components with higher QOL for the children were treatment anxiety, mean of 87.00, worry mean of 82.33, above mean of 81 thus indicating high QOL. Lower QOL was found in the component of procedural anxiety reported by the parents, with a mean of 49.30, which was below the mean of 50, therefore indicating low QOL.

There were no significant differences for diagnosis and intervention for life functioning, family impact or cancer-related QOL or treatment interventions received by children. Groups diagnosed with brain cancer had high QOL, while intermediate QOL was found in leukaemia participants and groups with lower QOL were diagnosed with neuroblastoma, osteosarcoma and solid tumours, with an overall HRQoL below the mean of 50. Parents of the participants treated for brain cancers reported the child had a higher QOL, according to parent's perspectives, which was contrary to the child's view of intermediate QOL. In the other cancer groups, children indicated having better QOL, which was higher than that reported by their parents, although all indicated intermediate QOL, when comparing their overall means.

During comparison of family functioning within diagnosis, groups with lower HRQoL were neuroblastoma, mean of 47.22 and the group with the highest HRQoL was that of osteosarcoma and Ewing sarcoma, mean of 80.55. Treatment interventions had different impacts on the cancer groups. Participants treated with radiotherapy and surgery had lower HRQoL, according to children's perspectives, parents

indicated children to have intermediate HRQoL and in the other three groups, both parents and children agreed children had intermediate HRQoL within Generic Core Scales™ (4.0). All four treatment groups indicated to be functioning within intermediate QOL, their overall HRQOL mean scores were within 50 and below 80. Participants' treatment with a combination of chemotherapy, surgery and radiotherapy had higher HRQoL, according to the children, mean of 80.55, and from parents a mean of 48.14, which indicated low QOL, below mean of 50.

The results presented above indicate the parents psychosocial, family relationships, support from home and their children's challenges when performing normal tasks while the child is in the process of receiving treatment interventions for their cancer. A more detailed summary and discussion is explained in the next chapter.

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter, the findings will be discussed in depth. The demographics of the children and their parents are considered, as well as occupational performance and occupational disruption of children admitted to the paediatric cancer unit at SBAH in their first admission period. This discussion includes the HRQoL of children receiving cancer treatment and their parents, as well as HRQoL specifically aligned with cancer and treatment for cancer. Lastly, the differences in terms of quality of life and occupational performance with regard to the type of cancer or treatment modality are considered and limitations of the study are presented.

5.2 Demographics

Determining the characteristics of children admitted to the paediatric oncology ward at SBAH in their first admission period was the first objective of the study. Twenty-five child participants were interviewed, and the HRQoL questionnaires were completed. The majority of participants were males, aged between 8 years to 12 years and 11 months in the late childhood spectrum. There was a higher percentage of male participants, which is similar to international statistics that report that cancer occurs more commonly in boys than girls. The ratio suggested is six males to five females (American Cancer Society, 2019).

Although older children were included in the study, within the age groups the diagnosis of cancer has been associated with poorer HRQoL in terms of illness-related worry. This group of children did not present with this finding, probably because most of them were slightly younger in the 8 years to 8 years 11 months' age group. At this age the children may not understand the implications of their illness, especially during first admission as this usually occurs six weeks after diagnosis. Older children also have better scores for autonomy and social function but worse scores for positive emotional function, which was noted amongst the children in the current study (Klassen et al., 2008).

According to the statistics from the American Childhood Cancer Organization (ACCO), leukaemia and lymphoma are the most common cancer types children

from sub-Saharan Africa are suffering from within the ages of zero to 14 years old. In the SBAH sample size, 18 of the participants were diagnosed with leukaemia (American Childhood Cancer Organization, 2016).

In total, 25 parents were interviewed. The parents were mostly the children's mothers and their ages ranged from the late 20s to late 40s. The gender distribution of the parents is similar to that reported by other research, with the mother remaining to care for the child in hospital while the father remains at home to help with family responsibilities and to work. This creates different challenges as mothers find the caregiving emotionally intense and fathers feel left out of the care of their child (Young et al., 2002).

The majority of parents had attended high school or obtained a post-secondary qualification, while 12% had primary schooling or no formal schooling. According to Barrera et al., parental education is one of the demographic factors that has an impact on the educational and social development of children with cancer. Although the effect of parental education on the HRQoL for the children and parents was outside the scope of this study, it must be taken into account when offering services to children with cancer. Higher parental education may have a protective effect for these factors, as these parents better understand the illness and can assist the child to adapt and cope with the occupations (Barrera et al., 2017). Provision of emotional or physical caregiving is also influenced by gender and roles of the parent, the father provides emotional support while the mother offers a physical role to the sick child (Jones, 2012). All 25 parents indicated their family structures; this included four to seven people in their households, and within each family there was one parent, carer or family member who was working, although 56% of the parents who participated in the study were not working. The mothers caring for children at home mostly came from Mpumalanga.

The family socio-demographics, which related to limited resources and stressors due to family size, structure and income (Barakat et al., 2010), may have affected access to healthcare resulting in late referral of the children in the current study to SBAH. The disparities which may exist for oncology treatment for patients treated in regional and district clinics, affecting both diagnosis and prognosis, may have also resulted in late referral (The Cancer Association of South Africa, 2019).

Children who are residing in poor families and less-resourced hospital or treatment facilities are not able to receive cancer diagnosis and treatment early, which results in the severity of some children's cancer before they access treatment (Sartorius et al., 2016).

Other external and environmental barriers can affect outcomes and occupational performance and participation in society for these families (Baum et al., 2015) as low family income and overcrowding have been associated with poor overall QOL, even before the factor of an ill child is included (Barrera et al., 2017; Jones, 2012). In the current study, the research instruments used focused on HRQoL and particularly the effects of cancer treatment, but it cannot be discounted that other external factors related to other barriers did not affect the outcomes on these questionnaires. Participants in the current study were from different ethnicities and cultural and religious groups, which may not be accommodated in the healthcare system providing for their children with cancer at a tertiary hospital, such as SBAH. Language differences and cultural barriers may have influenced communication about their child's treatment and the medical and psychosocial support required, further affecting their HRQoL (Jones, 2012).

5.3 Health-Related Quality of Life and Occupational Performance and in children with cancer and their families

Cancer is a predictor of impairment when it occurs at a young age and the time of diagnosis is a significant risk factor for impairment in both emotional and social functioning, which can predict and result in later impairment (Zheng et al., 2018). Therefore, it was important to establish the level of function in relation to the child participants from their perspective and that of their parents so appropriate goals of treatment to mediate the occupational disruption could be set.

5.3.1 Health-Related Quality of life- Function in life areas and roles in children with cancer

The second objective of the study was to describe the HRQoL and occupational performance of children admitted to the paediatric cancer unit at SBAH in their first admission period. The PedsQL Generic Core Scales™ (4.0) were used to assess the participation of the children in this study from the perspective of the children and their parents in four functional areas, which were socialisation, school, physical and emotional.

Children indicated during the interview that they were functioning at an intermediate level in their HRQoL (mean of 69.69). This study confirmed, as did the study by Varni et al. (2007) that children in middle childhood can reliably report on their function. Their parents indicated a similar level of HRQoL with a slightly lower mean of 64.13. These scores are below the cut off described by Varni et al. (2007) and place the children at risk of impaired HRQOL due to disrupted functioning.

The results of the current study are in line with those reported by Varni et al. (2007) for children with cancer, although the overall scores in his study were three to four points higher for the children and parents. However, the study by Varni et al. (2007) covered literature from developed countries where the effects of a low socioeconomic environment and better medical care may have influenced the parents' perception of the children's health. As in the current study, parents in the study by Varni et al. (2007) routinely reported lower scores for function in all components of the children's functioning except socialisation, where parents had a higher score in the current study. As in the study by Varni et al. (2007), the differences were not statistically significant. They also did not report a clinically important difference between the overall scores of the children and parents, which was consistent with the small effect size found in the current study (Varni et al., 2007). These results were consistent with higher parental overprotection and perceived child helplessness related to a lower functioning reported in the parent proxy-report of the child (Momani et al., 2016; Mohammadi et al., 2017). Another reason for the parents lower scores may be related to a finding from Eiser et al. (2005), who reported that mothers who rate their own QOL as low also rated the HRQoL of their child with cancer as lower than the child does, which suggests the mothers' own feelings about their lives colour their perception of their children's

HRQoL. The results of this study must be viewed in this light, as the parents did report factors related to their QoL other than those in relation to the effect of their child's illness.

When considering physical functioning the parents and the children reported they were at risk for impaired HRQoL (Varni et al., 2007). The lower level of physical functioning reported in the current study was supported in a study by Nedović et al. (2013), who found that children who being treated for cancer while hospitalised had lower scores on all eight questions of a physical component in Generic Core Scale. Both parents and children reported lower physical functioning than in the study by Varni et al. (2007), where the scores were between 68 and 71 indicating functioning was within the intermediate level of HRQoL (Beverung et al., 2015). In the current study, parents viewed their child's physical functioning as within low level of HRQoL, while children's mean scores were in the intermediate level of (Beverung et al., 2015).

The scores for the parents were 13 points with a clinical difference as indicated by a moderate effect size between the two scores. Differences in parent-child may reflect, the parents reporting on perceptions based on observation physical function, while the children were reporting on their experience of aches and low energy (Chang & Yeh, 2005; Levi & Drotar, 1999). This section of the PedsQL Generic Core Scales™ (4.0) covers physical function in occupations in mobility, chores and self-care in particular (Varni et al., 2004) and while children indicated there was occupational disruption, parents and children agreed with functioning within intermediate QoL and physical component with a medium clinical difference of ($d=0.61$).

The children reported lower scores for emotional functioning than for their physical functioning, indicating they were more at risk for impaired HRQoL in this component (Varni et al., 2007). The emotional functioning assessed was related to affective processes, anxiety, stress, or depression, which influence perceived self-efficacy (PSE). A low PSE may result in poorly managed symptom clusters, which lead to increased distress, increased depression, anxiety, and decreased functional status, therefore, affecting relationships and daily life. Low PSE also correlates to their lower motivation (White et al., 2017). However, both children and parents reported

HRQoL in the intermediate level of HRQoL (Beverung et al., 2015) for the children's emotional functioning with only a small difference between the mean scores that were lower for the parents with a small effect size showing no clinical difference. It would appear that at this stage in their first admission, the children did not present with low PSE for symptom management but did have problems with sleeping. These scores are supported by Varni et al. (2007) in their study.

Although the effects of gender on HRQoL were outside the scope of this study as the sample of males was too small, according to Klassen et al., female children do have a significantly lower HRQoL at six weeks after diagnosis. Male children had better scores in the emotional and cognitive domains (Klassen et al., 2011).

Although children reported higher scores for socialisation than for emotional functioning, their parents perceived this component mean of 78.12 had less functional deficits than the children themselves who scored a mean of 71.80. This was the only component where children indicated they had lower functioning and more occupational disruption than their parents did, although both parents and children were within the intermediate level of functioning (Beverung et al., 2015). The difference between the parents and children's scores were small with a small effect size, indicating no clinical difference and these scores differ from those reported by Varni et al. (2007) where parents had a lower non-significant score for socialisation. It is possible the current study parents underestimated the difficulty of being away from existing friends and having to make friends and play in a strange environment where children were from different cultures and spoke different languages. Children in middle childhood often participate in activities that require understanding the view of another person and sharing interpersonal relationships with other peers (Barrera et al., 2017; Christiansen et al., 2014). Although most research on social functioning in children with cancer is on long term survivors it is clear that decreased physical and emotional functioning has an impact on social functioning, which includes the ability to maintain friendships with social interactions particularly while hospitalised at SBAH in this small sample of children undergoing intensive treatment, which limited their socialisation. The lack of a structured environment, such as school where it is possible to meet and interact with other children, also affects this component (Gurney et al., 2009). Repeated absence from school has been associated with survivors' poor social integration, especially

patients with leukaemia and central nervous system (CNS) tumours typically missing more school during therapy than patients with other childhood malignancies (Berrera et al., 2005).

Out of school duration for all children ranged from 0 to 14 months for all the children, although most (64%) had been out of school for less than a month and had been in contact with school in the past 30 days. Even the children were in contact with their schools they were limited in the kind of schoolwork they could complete as well as in the amount of time they could spend on these activities due to poor health as reported by Levi and Drotar (1999). Children and parents reported a mean of 66.84 and 62.50 respectively, indicating children perceived occupational disruption in terms of missing school and not being able to keep up with schooling and schoolwork as their greatest occupational disruption except for psychosocial functioning. Both parents and children agreed the child was functioning within the intermediate level of QOL (Beverung et al., 2015) which is similar to the findings of Varni (2002). Parents felt this component had a greater impact on the HRQoL of their children since they probably had a better idea of the long term consequences of prolonged absence from school than the children did. Other aspects, such as attention and memory, were of less concern at this stage although these skills, which have been reportedly impaired in many survivors of leukaemia and brain tumours, may create occupational disruption in academic achievement (Barrera et al., 2005).

When considering psychosocial functioning from Generic Core Scales™ (4.0), the scores emotional, social and schooling are combined for the children, who had a mean score of 63.40, which was their lowest score. This was similar to the low mean scores of the parents (60,93) and the difference between the children and parents was again not statistically significant with little clinical difference according to the effect size. Children and parents agreed the children were functioning within the intermediate level of HRQoL (Beverung et al., 2015) and at risk for impairment in HRQoL (Varni et al., 2007). Speyer et al. (2010) identified different hospitalisation-related stressors, unfamiliar environment and lack of activities associated with occupational deprivation, as resulting in difficulties in the psychological characteristics of HRQoL. This can also be related to behaviour difficulties and problems related to cognition associated with paediatric brain tumours and the side

effects of medication and cancer treatment (Barrera et al., 2017). Arboleda and Vazquez (2017) emphasised that children with cancer need to push through mental and physical exhaustion, fear, and the many side effects of treatment.

It would appear for the children in the current study that their emotional, schooling and psychosocial function was contributing more to their low HRQoL and occupational disruption, whereas the parents perceived it was their physical functioning. Russel et al. (2006) found similar results that agree on most aspects of HRQoL between children and parents, although parents underestimated the children's HRQoL with consistent reports of worse physical functioning. Parents seem to perceive that since their child is sick with cancer, they will have much more difficulty in performing activities that require energy and stamina, which children themselves perceive they can manage (Chang & Yeh, 2005; Eiser & Morse, 2001).

5.3.2 Quality of Life in parents Family Functioning

The third objective of the study was to determine the impact caused by illness on family functioning during cancer management in SBAH. Parents' health-related quality of life (HRQOL) was assessed using the Family Impact Module (FIM)™ 2.0. It has been found that parents HRQOL is connected to medical and non-medical variables of their child with cancer, such as tumour location, children receiving Cranial Irradiation Therapy (CIT) and age of the child at diagnosis (Barrera et al., 2017). The diagnosis and treatment of child's cancer entails challenges, which have a negative impact on parents' physical, emotional and social wellbeing and these, as well as worry, impact on occupational performance due to cognitive and communication disruptions (Varni et al., 2004). The parents of the children in the current study, experienced the greatest occupational disruption, staying in the hospital with their child, giving up or reducing the hours at work, as well as learning how to manage the child's care (Eiser et al., 2005; Naidoo et al., 2016; Fotiadou et al., 2008).

Parents are more susceptible to develop stress symptoms affecting their physical functioning when dealing with a child who has been diagnosed with cancer. The parents in the current study report a low mean of 52.73 with low HRQoL for this subsection, with more fatigue, headaches and not feeling well; this can be associated with sleep disturbance and loss of appetite (Fotiadou et al., 2008;

Naidoo et al., 2016). The scores for physical functioning reported by the parents in the current study were much lower than those reported by Scarpelli et al. (2008a) for children receiving inpatient care but were similar to those of the parents of children who were outpatients. It is reasonable to expect a greater physical demand on parents having to travel to the hospital with a sick child for treatment, but it is not clear why the scores for parents in the current study, where children were admitted to hospital, reflected this lower HRQoL. Although this may be related to somatisation, this needs further investigation.

The occupational disruption of accompanying a child to hospital appears to have had a greater impact on physical functioning, but in combination with other factors in the current study also affected emotional and social functioning. Emotional functioning in parents of children with cancer is affected by anxiety, depression, denial, anger, and low self-esteem (Jones, 2012; Fotiadou et al., 2008; Barakat et al., 2010; Christiansen et al., 2014; Eiser et al., 2005; Klassen et al., 2011; Naidoo et al., 2016). As in these other studies, mothers in particular reported their QOL to be lower than population norms, although both mothers and fathers of newly diagnosed children suffer from acute stress due to the cancer, which was seen as a normative response to life-threatening illness (Jones, 2012). Both mothers and fathers' expressed feelings of uncertainty, helplessness and negative emotional adjustment to the illness (Fotiadou et al., 2008). However, the parents in the current study reported less effect on the emotional functioning than physical functioning at this stage with a score that reflected an intermediate level of HRQoL for emotional functioning, placing them at risk for impairment in HRQoL (Varni et al., 2004). This reflects the elevated levels of depression and anxiety reported by many parents immediately after diagnosis of cancer in their child, which does decrease over time for most of them (Eiser et al., 2005). The higher scores of emotional functioning compared to physical functioning may be due to optimism, which parents may feel as their child is receiving adequate healthcare at this stage. Optimism is important to the process of coping with stress and achieving better health outcomes (Fotiadou et al., 2008) in relation to anxiety, depression, subjective health, and life satisfaction for parents irrespective of the type of cancer, time of diagnosis and prognosis (Fotiadou et al., 2008). The findings for the emotional subsection reported in the current study reflected those reported by Scarpelli et al., (2008a). In their study,

parents of children hospitalised with cancer confirmed they could be at risk for impairment in functioning in this aspect.

The parents reported that social relationships, social support available and caregiver strain influenced social functioning and HRQOL, including their self-perception. Parents in the current study had a mean score of 64.32 and intermediate level of HRQoL. Literature indicates loneliness can be a major problem for parents caring for their child in hospital (Van Schoors et al., 2019) However, a study in South Africa indicated family support with regular telephone calls and visits from relatives, as well as peer support from other parents in the same situation, which was reported as providing good support (Naidoo et al., 2016).

Social functioning is often reported with communication, which had a mean score of 63.19 for parents in the current study and had a level for HRQoL similar to social functioning. The means scores for social and communication were lower by 10 points than those reported by parents in a similar situation in Brazil (Scarpelli et al., 2008a). And it would appear that support from the community, as well as communicating the child's illness to others had a greater effect on HRQoL in South African parents. Naidoo et al. (2016) found the communities lack of knowledge regarding the diagnosis of cancer resulted in little support from them. The lack of knowledge of cancer has been reported to be common in the South African context with false information in stigma around cancer. They also found judgement from the community means that mothers do not disclose their child's diagnosis to the community (Mosavel et al., 2010) and receive no assistance from them. Mothers also reported problems with communication with health professions and reported feeling uninformed about their child's diagnosis and treatment process (Naidoo et al., 2016).

Cognitive function was the component of HRQoL that had the highest mean score for parents in the current study. It was similar to that reported by Scarpelli et al., (2008a) for children hospitalised for cancer in Brazil. The lower scores seem to be related to being distracted and forgetful due to worry about their child. For both the current study and the study in Brazil, parents reported low levels of HRQoL associated with worry, which was at a low level for HRQoL. This was related to concern about their child's future, the effect of the treatment and whether it would

be successful, as well as the effect on the family and how the child would reintegrate into the community. This includes the fear of a future relapse or uncertainties about the child's future development.

Worry was also related to family functioning, which was reported from combined scores for questions on daily activities and family relationships in PedsQL™ FIM (2.0); parents had mean of 66.72 and this was within the intermediate level of QOL (Beverung et al., 2015). Daily activities, as for the study in Brazil, had a lower score than family relationships (Scarpelli et al., 2008a). Family's activities therefore had a greater impact on HRQoL as the daily function of being parents was disrupted, especially household chores and care for the children. Mothers of children experienced guilt about their change of role for both the sick child and their "healthy" children, who they cannot care for at home. Employment and financial issues were also adversely affected (Fotiadou et al., 2008; Naidoo et al., 2016). Cancer-related occupational disruption includes issues related to autonomy, interpersonal relationships, and cognitive maturation of family members (Kazak, 2004).

The coping strategies of the family need to change as the family, including the child with cancer, enter into the uncertainty of treatment, prognosis and outcome of the cancer (Jones, 2012). The stress experienced by parents due to this occupational disruption adds to the stress experienced in relation to the child's condition can be associated with poor family functioning. The parents in the current study reported concerns about family relationships, as their HRQoL for family relationships was at an intermediate level. The ability to retain family and social relationships and family adjustment through risk and resistance factors were affected (Fotiadou et al., 2008) with levels of conflict and disorganisation, inadequate communication, and emotional dysregulation within the family unit indicated by some parents.

However, other parents reported little disruption and it is possible that the family may have become closer (Zheng et al., 2018). When family dynamics as well as role identify within the family and the family's sense of meaning and spirituality facilitate HRQoL, family functioning promotes positive outcomes for children who are stressed, and this is a resource for children and adolescents with cancer. Thus, it is important for parents HRQoL to be assessed and addressed from the time of the child's initial diagnosis (Barakat et al., 2010) since lower HRQoL related to the

symptoms of anxiety, depression, psychological distress recorded for the parents may also impact on the HRQoL of their children.

Resistance factors, which assist the parents to cope, include intrapersonal aspects such as dispositional optimism as well as social support and relationships. In the current study, these factors were reported to impact family functioning but the risk factors, which may further affect family function, were not assessed by the PedsQL™ FIM. These are the parents' socioeconomic status indicators and parental level of education. The majority of parents in the current study come from impoverished communities, with fewer people working within each family household and although most parents did have secondary school education it is possible that their financial situation impacted their QOL prior to their child's diagnosis. The effect of existing environmental factors must therefore also be considered when assessing and interpreting the HRQoL reported by these parents (Klassen et al., 2011; Jones, 2012; Naidoo et al., 2016).

5.3.3 Health-Related Quality of Life of children related to symptoms and treatment of cancer

The fourth objective was to determine the quality of life for children admitted to the paediatric cancer unit at SBAH during their first admission period related to the cancer and its treatment using the Quality of Life in Children, PedsQL™ Cancer Module (3.0).

When reporting on the child's HRQoL, in relation to the cancer, and their experience of the treatment, parents had a mean score of 63.92 while children had a mean score of 76.58. This indicates both parents and children place their HRQoL at an intermediate level (Beverung et al., 2015) below the norm of 82.30 for healthy children, where the scores range from 78 – 88. The parents mean score was well below that of 73.10 for children with chronic conditions, while the children scored their HRQoL as higher (Kuhlthau et al., 2012).

Parents reported lower HRQOL than their children, which is consistent with a study by Eiser et al., (2005) but differs from other studies where parents scored the children's HRQoL as better for some components (Scarpelli et al., 2008b; Varni et al., 2002). Both children and parents in the current study reported the child was

compromised by pain, nausea from illness leading to an intermediate HRQoL (Beverung et al., 2015) and occupational disruption for everyday activities. The mean scores in the current study were similar to those for pain and hurt reported by Varni et al., (2002) in the study validating the PedsQL™ Cancer Module (3.0) for children with cancer on treatment. In their study, as well as the study by Scarpelli et al. (2008b), the parents' scores for nausea were higher than those of the children, with no clinically meaningful difference as reported in the current study with a medium effect size. It is not clear why the parents in the current study perceived nausea as affecting the children's HRQoL more than other studies since the scores of the children in all studies, including the current, were similar (Scarpelli et al., 2008b; Varni et al., 2002).

For procedural anxiety, treatment anxiety and worry, parents indicated a significantly lower score on the parents' proxy than the children themselves. The children in the current study and the study by Scarpelli et al. (2008b) had a mean score for treatment anxiety that showed no deficits in HRQoL. Thus, the children were comfortable with the hospital and doctors in relation to being treated for their condition. The parents' score for procedural anxiety in the current study reflected those reported by Scarpelli et al. (2008b), confirming parents perceive the fear of the procedures affect the children's HRQoL significantly more than the children do themselves; this is possibly due to the children not understanding the implications of their blood tests. The children's scores in the current study for worry was also higher than those reported by Scarpelli et al. (2008b), confirming children may not fully understand the consequence of their illness in terms of prognosis and extended treatment periods with continuing side effects after hospitalisation. The scores in the study by Varni (2002) for both the children and parents fell into the intermediate level of HRQoL for procedural anxiety, treatment anxiety and worry, but their study included adolescents who may have a better understanding of the implications of the condition. The adolescents and adults suffering from cancer displayed a normal reaction to life-threatening illness, which is Fear of Progression (FOP), that the "illness will progress with all biopsychosocial consequences or it will reoccur" (Dinkel et al., 2014, p 1).

None of the other studies indicated a significant difference between the scores of the parents and the children (Scarpelli et al., 2008b; Varni et al., 2002). The much

lower scores of the parents for treatment anxiety and worry in the current study may be related to the parents' perception of these components, which resulted in a low HRQoL for the children, in terms of their own low scores for worry on the PedsQL™ FIM (2.0). This indicated they could be judging what the children were experiencing from their own feelings and concern about the outcomes of the treatment.

For cognitive functioning, the SBAH parents indicated the mean score of 68.33 and children a mean score of 74.40 indicating some occupational disruption due to this component with HRQoL at an intermediate level (Beverung et al., 2015). This is similar to the scores reported by Varni (2002) for children on treatment for cancer and Scarpelli et al., (2008b). The scores appeared to be related to the side effects of treatment and pain causing distraction rather the long term cognitive impairments found in long term survivors of childhood cancers from prophylactic Cranial Radiation Therapy (CRT) and Intrathecal Methotrexate (IT MTX) (Barrera et al., 2005).

Communication had mean score of 69.44 from parents and children had mean score of 72.00, placing HRQoL at an intermediate level (Beverung et al., 2015). Generally, the children reported they could express themselves to medical staff members and their parents about their illnesses current needs and how they were coping with treatment side effects however, they were unable to explain their illness to other people. Again these scores were similar to those reported by Varni (2002) for children on treatment for cancer and Scarpelli et al. (2008b) and may reflect good support for the children in terms of care in the hospital where they felt able to talk to adults around them. Perceived physical appearance, was also reported by both parents and children at an intermediate level of HRQoL (Beverung et al., 2015) as they had similar scores, with the parents' mean score at 71.18 and children's at 76.00. This was consistent with reports in other studies (Scarpelli et al., 2008b; Varni et al., 2002) as at this stage children did not have a major change in their bodies and they believed and maintained they were still the same individuals, their body image had not changed as reported for most children initially.

It would appear during the hospitalisation phase of treatment that the children with cancer were at risk for impairment in HRQoL and needed support for pain and hurt, treatment anxiety, communication and perceived physical appearance. Parents

needed to discuss their fears for the children, especially in terms of procedural anxiety and worry so their over estimation of these aspects of HRQoL did not result in over protection of the child, in hospital and at home.

5.4 Differences in Quality of Life in terms of diagnosis and treatment modality

The fifth objective of the study was to determine whether any differences existed in terms of quality of life and occupational performance with regard to the characteristics of children, such as type of cancer or treatment modality.

The cancer diagnosis of children

Children's diagnoses comprised of different cancers, 56% had leukaemias, 12% had rhabdomyosarcomas, 8% had lymphomas and solid tumours and 4% neuroblastoma, brain cancers, osteosarcomas and haematologic cancer, with one child for each. There was no significant difference in HRQoL for different types of cancer.

The parents and the children with brain and haematologic cancer agreed the children's HRQoL was at a high level, with a mean above 81 (Beverung et al., 2015). Since there was only one child with this diagnosis, these results cannot be considered as a trend. A study by Klassen et al. (2011) indicated that younger children with brain tumours have poor QoL, specifically from procedural anxiety domain as they may have radiation and surgery. These procedures were still to be faced by the participant in the current study. Children with low level of HRQoL (Beverung et al., 2015) from a generic core scale were those with neuroblastoma, rhabdomyosarcoma, osteosarcoma and solid tumours.

Children with leukaemia and lymphoma indicated an intermediate level of HRQoL (Beverung et al., 2015) in line with other studies, which found HRQoL in these two types of cancer was moderately affected with impairments. For children with leukaemia, this included minor change in capacity to achieve physical roles as well as lower hopes of future life satisfaction and greater psychological distress with symptoms of depression, somatisation, fatigue and sleeplessness. Children with Hodgkin's lymphoma have more impaired physical health when compared to those with leukaemia, including fatigue, sleep disruption, daytime sleeplessness. Children

with non-Hodgkin's lymphoma reported lower vitality in the assessment of their HRQOL scores (Zeltzer et al., 2009) and the need for higher cancer care (Barakat et al., 2010).

Treatment interventions received by children

Children were treated with either chemotherapy, radiotherapy, surgery or a combination of the treatment interventions; this was dependent on the protocol being followed for each child. One child had a combination of chemotherapy, surgery and irradiation, three children underwent chemotherapy and surgery, radiotherapy and surgery in one child and chemotherapy for 18 children. There was no significant difference between the children's HRQoL according to the treatment received.

The children who received radiotherapy with other treatments reported the lowest HRQoL on the generic scale and the cancer module. Literature reports that irradiation leads to psychological distress specifically somatisation, particularly in children suffering from solid tumours, neuroblastoma, and osteosarcoma. Additional to somatisation they experience fatigue and impaired physical health in general, poor physical functioning, low fulfilment of roles and more activity limitation (Zeltzer et al., 2009). For the child who received radiation and surgery, the parent was the only one who rated the child's HRQoL above the scores the child reported and thus appeared to underestimate the effect the treatment was having on the child. For this reason, the family functioning for this parent was not reported at low level of HRQoL, as the parent appeared not to have understood the severity of the child's condition. The children receiving chemotherapy had the highest HRQoL when compared to children receiving other treatments. The children's mean scores were always higher than the parents were for all three PedsQL™ modules. All the means scores indicated these children were at an intermediate HRQoL (Beverung et al., 2015) and needed support in terms of their treatment, functioning and family function.

Complications related to treatment, such as surgery, have been related to an impairment in HRQoL as seen in the current study, where children who had surgery reported lower HRQoL. Improvements in treatment and the satisfactory management of pain and nausea in the early management of treatment are reported to have a positive effect on HRQoL in the initial treatment stages accounting for the

intermediate level of HRQoL reported by the children and parents for those not undergoing radiation and surgery (Vlachioti et al., 2016).

5.5 Limitations of the study

The methodology applied to the study was limited by the use of single time to collect data using questionnaires filled by parents and an interview with the child with cancer. This was a stressful time for the parents and children although every attempt was made to include them at a time suited to their treatment regime and the parent's availability. Some parents found the questionnaires difficult to fill in due to language issues and assistance with the procedure added to the time required to complete all three sections of the PedsQL™.

Data collection was done over two months and children who were not admitted in the hospital during this period were not included in the study, even though they were on the cancer register of SBAH. This limited the sample of children available for inclusion in the study and the initial anticipated sample size was not reached. This may have resulted in a type II error decreasing the power of the study. The environmental effects of the parents and children's lives were not included by assessing the HRQoL of healthy children from the same communities. Thus, the effect of other four factors on the parents and children's HRQoL could not be delaminated.

CHAPTER 6: CONCLUSION

6.1 Introduction

The children managed at SBAH for cancer, are severely ill as they are often diagnosed late and are referred when all other alternatives have been exhausted in the referring institutions. When these children are transferred to this tertiary institution for management, they need to be accompanied by a parent throughout the management and hospitalisation period. During this period away from home to access treatment, which may last weeks or months, there is occupational disruption due to the change in environment, activities of daily living and functioning, which may affect occupational performance and engagement in meaningful participation related to personal management, work, play, and the community or family. This, in conjunction with the diagnosis of cancer and the accompanying distress and effects of treatment, will affect the HRQoL of the child with cancer and their parents. The current study assessed both perspectives of children and their parents in relation to the child's role at school, socialisation, emotion and physical functioning, as well as family functioning and the effect of cancer, its treatment and side effects on HRQoL.

6.2 Main Findings

The main findings of the study indicated that children aged 8-12 years admitted for management of cancer to a tertiary hospital in Tshwane and the parents accompanying them experience occupation dysfunction that results in a HRQoL at an intermediate level with risk of impairment in a number of components. The children in the current study indicated the loss of their school roles and decreased social functioning impacted mostly on their HRQoL, while their parents perceived the children's physical functioning had the most impact.

The change in activities of daily living and occupational disruption, which occurred for the families of the children admitted to a specialist oncology unit, had a greater effect than disruption of family relationships on the HRQoL for parents who accompanied the children while they were hospitalised. Physical functioning and worry in particular impacted the parents HRQoL. Parents were mostly from households with a low socioeconomic status, and it is unknown what effect this and other environmental issues had on the QoL. Parents poor HRQoL was

characterised by disruption of activities of daily living, a lack of understanding of cancer and less support from the community.

Scores on the Cancer Module (3.0) indicated children scored their own HRQoL at an intermediate or high level. This differed significantly from the parent's perspective as they felt treatment anxiety and worry impaired the child's HRQoL along with procedural anxiety. The parents appeared to overestimate the effect of cancer treatment on the children's HRQoL

There were no significant differences for diagnosis and types of intervention and HRQOL, although there were some differences between the scores for the children and parents with one parent underestimating the effect of the treatment on the child's HRQoL. These results, due to the small sample numbers in the group, must however be viewed with caution.

6.2.1 Relationship of the current study to other research

As with other studies the most common diagnosis for the children in the current study was leukaemia, and chemotherapy was the most common treatment (American Cancer Society, 2019) . Similarities to other studies were found in that parents overestimated the effect physical function and procedural anxiety had on the child, HRQoL (Chang & Yeh, 2005; Scarpelli et al., 2008b). This has been attributed to parents basing their report of HRQoL on observation of the child and procedures they undergo and not actual experience of these as reported by the children.

Worry is the component that most impacts on the parents HRQoL in relation to their child with cancer, as confirmed by other authors (Scarpelli et al., 2008a). This could be expected due to the uncertainty of the outcome of the child's prognosis and future impairments, as well as the disruption to the family occupations and relationships when dealing with a life-threatening condition and long hospitalisation of the child far away from home.

6.2.2 Explanation of unanticipated findings

The current study differed in terms of the factors that parents reported as having an impact on the HRQoL. Parents indicated a low score for physical functioning not reported in other studies (Varni et al., 2004; Scarpelli, et al., 2008a), which may be due to somatisation. The parents previous physical functioning was not considered and this may have been affected due to their low socioeconomic status prior to their child's illness.

Children scored higher than parents' proxies on the PedsQL™ Cancer Module, indicating parents overestimated the effect of the cancer and its treatment on their child's HRQoL. In other studies, this was not the case (Scarpelli et al., 2008b) and it is possible that a lack of understanding of the implications of the illness by the younger children in this study resulted in the difference in the scores, particularly for treatment anxiety and worry.

6.3 Implication for the practice in Occupational Therapy

The results of this study indicate the importance of occupational disruption on HRQoL in children hospitalised for cancer management and their parents who accompany them. Although a number of factors including dealing with the initial diagnosis of cancer and other environmental issues may also play a role, the intermediate level of HRQoL of the children and parents indicated intervention is required. It is clear that occupational therapists need to deal with the engagement and participation in meaningful occupations for these children and their parents to facilitate their HRQoL.

Intervention, as suggested by Speyer et al.(2010) should be considered to adapt activities while hospitalised as well as preparation for return to previous occupations on discharge. Intervention should include socialisation and school roles for children in particular, while addressing physical functioning and worry for the parents. It is clear that a multidisciplinary approach to HRQoL is required with inter-professional referral for individual issues.

6.4 Recommendations for further research

Further research should consider comparing the HRQoL of the participants to that of healthy children and their parents in similar communities to those from which the sample of children with cancer is drawn. This would provide a better understanding of pre-existing factors related to HRQoL and those that occur due to the hospitalisation of the child for cancer management far from home.

Research into the various components of HRQoL and the differences found for the South African sample, including differences in parents and children's scores need to be investigated.

The effectiveness of occupational therapy programmes to address occupational disruption and HRQoL for children hospitalised for cancer management, and the parents accompanying them, need to be established.

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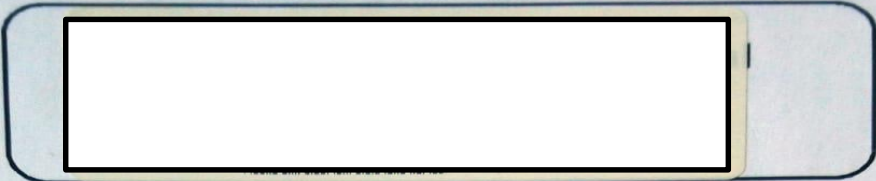
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APPENDIX A – Demographic Questionnaire

Screening tool (To be kept separate)

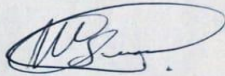
Researcher: S'thembisio Tembe

Study: The occupational disruption and quality of life in children admitted for cancer management.



Meet criteria	<input checked="" type="checkbox"/> Y / <input type="checkbox"/> N
Onset of illness	<input type="checkbox"/> Y / <input checked="" type="checkbox"/> N 2017
Protocol discussed with parent	<input checked="" type="checkbox"/> Y / <input type="checkbox"/> N
Received 1 st treatment	<input checked="" type="checkbox"/> Y / <input type="checkbox"/> N
Qualify for participation	<input checked="" type="checkbox"/> Y / <input type="checkbox"/> N

Date of screening: 08/01/2019

Screened By: B.J. Seubelweke 

Code: 2A#B

PARENT		CHILD	
Name		Name	
Surname		Surname	
Town	Pembisa	Town	Pembisa
	Ekurhuleni : JHB (eP)		Ekurhuleni : JHB (eP)

CODE:

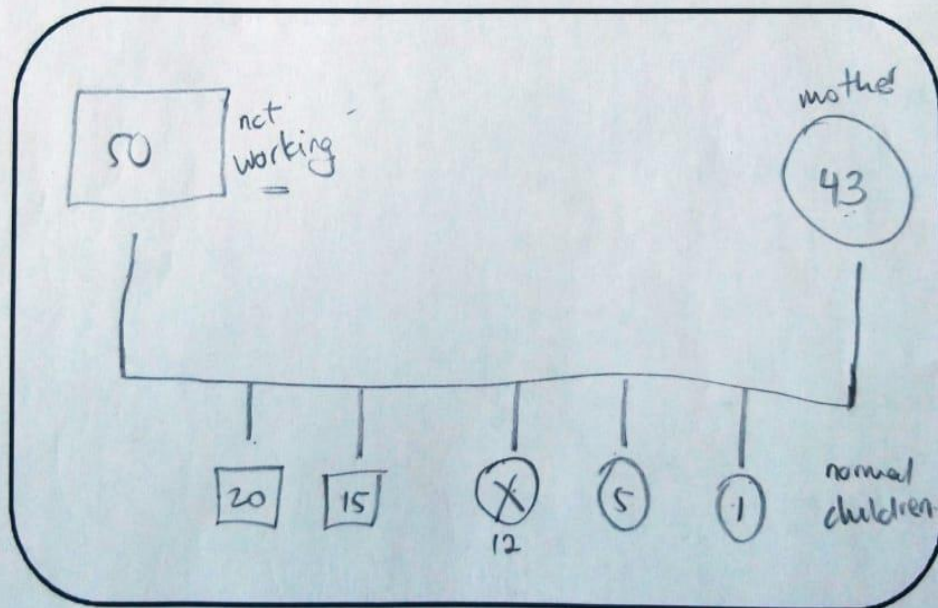
2A & B

Date: 08/01/2019

Ward: 1.1

PARENT				CHILD			
Age	43	Gender	M/F	Age	12	Gender	M/F
Educational level	Grade 11			6			
Work / occupation	Admin Clerk			Number of siblings	4		
MEDICAL HISTORY							
Date of onset of illness				August 2017			
Admission date in SBAH				05/01/2019			
Diagnosis				Acute Leukemia			
Stage of cancer				stage 4			
Planned Treatment Interventions	1) Chemotherapy 2) 3)						
Initiation date of Treatment							

FAMILY ORGANOGRAM REPRESENTATION



User agreement to use PedsQL

APPENDIX B – Mapi Trust Research



User agreement Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

MRT Contact:

Mapi Research Trust
PROVIDE
Address: 27 rue de la Villette, 69003 LYON, France
Telephone: +33 4 72 13 65 75
Fax: +334 72 13 66 82

RECITALS

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. CONDITIONS SPECIFIC TO THE USER

Section 1.01 Identification of the User

User Name : [complete the name of the individual or of the company] Sthembisio Charles Tembe
Legal form : [Individual or company's legal form]
Address : [personal address or address of registered office] Occupational Therapy, Steve Biko Academic Hospital, corner of Malan Street and Steve Biko Road, Gezins
Country : SOUTH AFRICA
Name of the contact in charge of the Agreement: Email, Post (mail)
Telephone number: 012 354 1665 Fax number: (427)12 354 3810
Email address: sthe.tembe.st@gmail.com

If different:

Legal form : [Individual or company's legal form]
Address : [personal address or address of registered office]
Country :
Billing address:
VAT number (if applicable):
Addressee:
PO number or internal reference (if applicable):

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S.C.

Section 1.02 Identification of the Questionnaire

Title of the Questionnaire: PedsQL™ (Pediatric Quality of Life Inventory™)
 Author: James W. Varni
 Owner: James W. Varni
 Copyright notice: Copyright © 1998 JW Varni, Ph.D. All rights reserved.
 References: See Appendix 2

Article 2. RIGHTS TO USE

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.
 [Tick the box and complete the corresponding fields]

individual clinical practice (please go directly to section 2.02)

Planned term of use:
 Number of patients expected:

clinical project or study

Title: Occupational disruption caused by child illness

Study/protocol reference:

Disease or condition: Pediatric oncology: cancer

Type of research:

clinical trial : Phase II / Phase III

epidemiologic/observational

other:

Questionnaire used as primary end point:

yes

no

Number of patients expected: 445 patients.

Number of submissions to the Questionnaire for each patient: one submission by each participant.

Term of clinical follow-up for each patient: No follow-up; cross-sectional study.

Planned term for project:

start (month/year): February 2018
 end (month/year): November 2018

Mode of Administration:

paper

electronic

If electronic administration, please indicate mode of data collection:

Hand held device - specify device:

Interactive Voice Response (IVR) - specify:

Web - specify website:

Digital Pen - specify device:

Tablet - specify device:

other - specify:

no

Use of IT Company (e-vendor):

yes - names of IT Company and contact:

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(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing MRT of the same beforehand by the signature of a Translation Agreement indicating the terms of it and to providing a copy of the translation thus obtained as soon as possible to MRT.

(iii) In the context of commercial studies or any project funded by the pharmaceutical industry, the User undertakes to have the Questionnaire translated in this language by Mapi Language Services. Mapi Language Services is the only organization authorized by the Owner to perform linguistic validation/translation work on the Questionnaire.

The User acknowledges and accepts that it is not entitled to amend, modify, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without MRT's prior specific written consent.

(b) Specific conditions for the Owner

The Owner has intended to transfer a part of the copyright on the Questionnaire and/or the Documentation to MRT in order to enable MRT to make it available to the User for the purpose of the Study, subject to the User respecting the following conditions:

User shall not modify, abridge, condense, translate, adapt, recast or transform the Questionnaire in any manner or form, including but not limited to any minor or significant change in wordings or organisation in the Questionnaire, without the prior written agreement of the Owner. If permission is granted, any improvements, modifications, or enhancements to the Questionnaire which may be conceived or developed, including translations and modules, shall become the property of the Owner.

The User therefore undertakes to respect these special terms.

(c) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.

In the case of use of an electronic version of the Questionnaire in academic studies, the User undertakes to respect the following special obligations:

- In case of use of an IT Company (e-vendor), User shall check with Mapi Research Trust that IT Company has signed the necessary License Agreement with Mapi Research Trust before developing the electronic version of the Questionnaire
- Not modify the questionnaire (items and response scales, including the response scale numbers from 0-4)
- Cite the reference publications
- Insert the Owner's copyright notice on all pages/screens on which the Questionnaire will be presented and insert the Trademark information: PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved.
- Mention the following information: "PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France - Internet: <https://eprovide.mapi-trust.org> and www.pedsq.org/index.html"
- Submit the screenshots of all the Pages where the Questionnaire appears to Dr James W. Varni before release for approval and to check that the above-mentioned requirements have been respected.

In the case of use of an electronic version of the Questionnaire in commercial studies / projects, the User undertakes to respect the following special obligations:

User shall:

- In case of use of an IT Company (e-vendor), User shall check with Mapi Research Trust that IT Company has signed the necessary License Agreement with Mapi Research Trust before developing the electronic version of the Questionnaire
- Not modify the questionnaire (items and response scales, including the response scale numbers from 0-4)
- Cite the reference publications
- Insert the Owner's copyright notice on all pages/screens on which the Questionnaire will be presented and insert the Trademark information: PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved.
- Mention the following information: "PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France- Internet: <https://eprovide.mapi-trust.org> and www.pedsq.org/index.html "

- For the first migration of the Questionnaire (generally the original version) into a specific electronic device
 - o Review of screenshots:

After implementation of the Questionnaire into the device, the user/IT Company will generate screen captures (screenshots) of the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user/IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

Dr James W. Varni will review all approved screenshots for a final validation.

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o Usability testing:

Usability testing is a methodology which aims to examine whether respondents are able to use a device and associated software as intended. Major issues of concern in usability testing typically include device complexity, navigation and response selection for example.

The objective of this investigation is to ensure that the electronic version of the questionnaire as included in the device meets usability criteria, focusing on functional aspects and respondents' understanding of instructions. Usability testing consists in interviews with patients where patients will complete the electronic version of the Questionnaire on the device and comment on their understanding of the instructions, ease of use and handiness of the device. A Usability testing report presenting results will be produced. If any changes are recommended, these will be implemented by the user/IT Company. If issues raised by respondents are rated as major, the user/IT Company may need to perform additional developments and another round of interviews may be needed.

Dr James W. Varni will review the changes suggested, if any, following the interviews.

The review of screenshots is mandatory. The usability testing is highly recommended by Mapi, however should the User and/or IT Company decide not to perform this step, Mapi Research Trust shall not be held responsible for any consequence and expense associated with this decision which shall remain the User and/or IT Company's sole liability.

The review of screenshots and usability testing, when and if performed, shall be performed exclusively by Mapi and shall be sponsored by the User.

The performance of the review of screenshots and usability testing will result in a certification of the electronic device original version of the Questionnaires by Mapi for future licenses.

For the migration of other language versions of the Questionnaire on an existing certified specific electronic device

o Update version

After the electronic device original version of the Questionnaire is fully ready, the Questionnaire's language versions developed for paper administration will be updated to reflect the changes in wording of instructions implemented in the electronic device original version of the questionnaire.

Native speakers of the languages will reflect the changes made to the electronic device original version of the Questionnaire and will provide English equivalents of all changes made for Mapi's quality control.

o Review of screenshots:

After implementation of the Questionnaire into the device, the user/IT Company will generate screen captures (screenshots) of the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user/IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

The update of version and review of screenshots are mandatory. These steps shall be performed exclusively by Mapi and shall be sponsored by the User.

The performance of the update of version and review of screenshots will result in a certification of the electronic device language version of the Questionnaires by Mapi for future licenses.

• Use in a publication:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the Owner (PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved)
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France. Internet: <https://aprovide.mapi-trust.org> and www.pedsq.org
- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

• Use for dissemination or marketing:

In the case of use in a dissemination/marketing context:

- On a website with unrestricted access:

The publication of a copy of the PedsQL™ on a website with unrestricted access is not permitted.

- On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a version of the Questionnaire that may be amended, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.

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S.C.

Article 3. TERM

MRT transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. BENEFICIARIES

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. TERRITORIES AND LANGUAGES


MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Language:	For use in the following country	Language:	For use in the following country	Language:	For use in the following country
English	South Africa				

Article 6. PRICE AND PAYMENT TERMS

The User undertakes in relation to MRT to pay the price owed in return for the availability of the Questionnaire, according to the prices set out in Appendix 3, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

Agreed and acknowledged by:

User's Name: Sthembiso Tembe
 User's Signature: 

User's Title: Mr. S. Tembe
 Date: 30/10/2017

S.C.

APPENDIX C- PedsQL (4.0)

ID# _____

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past **ONE** month by circling:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID# _____
Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

APPENDIX – D: FIM (2.0)

ID number _____

Date: _____

PedsQL™

Family Impact Module

Version 2.0 - English (UK)

PARENT REPORT

INSTRUCTIONS

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

COGNITIVE FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4

COMMUNICATION (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel that others do not understand my family's situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

*In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...*

WORRY (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

INSTRUCTIONS

Below is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month**.

*In the past **ONE month**, as a result of your child's health, how much of a problem has **your family** had with...*

DAILY ACTIVITIES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

FAMILY RELATIONSHIPS (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

APPENDIX – E: Cancer Module (3.0)

ID# _____

Date: _____

PedsQL™

Cancer Module

Version 3.0 - English (United Kingdom)

CHILD REPORT (ages 8-12)

DIRECTIONS

Children with cancer sometimes have special problems. Please tell us **how much of a problem** each one has been for you over the **PAST MONTH** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

Over the **PAST MONTH**, how much of a **problem** has this been for you...

PAIN AND HURT (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I ache or hurt in my joints and/or muscles	0	1	2	3	4
2. I hurt a lot	0	1	2	3	4

NAUSEA (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I become sick to my stomach when I have medical treatments	0	1	2	3	4
2. Food does not taste very good to me	0	1	2	3	4
3. I become sick to my stomach when I think about medical treatments	0	1	2	3	4
4. I feel too sick to my stomach to eat	0	1	2	3	4
5. Some foods and smells make me feel sick to my stomach	0	1	2	3	4

ANXIETY ABOUT THE PROCEDURES (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. Needles (i.e. injections, blood tests, intravenous drips) hurt me	0	1	2	3	4
2. I get scared when I have to have blood tests	0	1	2	3	4
3. I get scared about having needles (i.e. injections, blood tests, intravenous drips)	0	1	2	3	4

TREATMENT ANXIETY (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I get scared when I am waiting to see the doctor	0	1	2	3	4
2. I get scared when I have to go to the doctor	0	1	2	3	4
3. I get scared when I have to go to the hospital	0	1	2	3	4

WORRY (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I worry about side effects from medical treatments	0	1	2	3	4
2. I worry about whether or not my medical treatments are working	0	1	2	3	4
3. I worry that my cancer will come back or relapse	0	1	2	3	4

COGNITIVE PROBLEMS (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
2. I have trouble solving maths problems	0	1	2	3	4
3. I have trouble writing school papers or reports	0	1	2	3	4
4. It is hard for me to pay attention to things	0	1	2	3	4
5. It is hard for me to remember what I read	0	1	2	3	4

Over the **PAST MONTH**, how much of a **problem** has this been for you...

PERCEIVED PHYSICAL APPEARANCE (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel I am not good-looking	0	1	2	3	4
2. I don't like other people to see my scars	0	1	2	3	4
3. I am embarrassed when others see my body	0	1	2	3	4

COMMUNICATION (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4

ID# _____

Date: _____

PedsQL™

Cancer Module

Version 3.0 English (United Kingdom)

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

Children with cancer sometimes have special problems. On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PAIN AND HURT (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Aches in joints and/or muscles	0	1	2	3	4
2. Having a lot of pain	0	1	2	3	4

NAUSEA (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Becoming nauseated during medical treatments	0	1	2	3	4
2. Food not tasting very good to him/her	0	1	2	3	4
3. Becoming nauseated while thinking about medical treatments	0	1	2	3	4
4. Feeling too nauseous to eat	0	1	2	3	4
5. Some foods and smells making him/her nauseous	0	1	2	3	4

ANXIETY ABOUT THE PROCEDURES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Needles (i.e. injections, blood tests, intravenous drips) causing him/her pain	0	1	2	3	4
2. Getting anxious about having blood taken	0	1	2	3	4
3. Getting anxious about having needles (i.e. injections, blood tests, intravenous drips)	0	1	2	3	4

TREATMENT ANXIETY (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Getting anxious when waiting to see the doctor	0	1	2	3	4
2. Getting anxious about going to the doctor	0	1	2	3	4
3. Getting anxious about going to the hospital	0	1	2	3	4

WORRY (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Worrying about side effects from medical treatments	0	1	2	3	4
2. Worrying about whether or not his/her medical treatments are working	0	1	2	3	4
3. Worrying that the cancer will reoccur or relapse	0	1	2	3	4

COGNITIVE PROBLEMS (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Difficulty working out what to do when something bothers him/her	0	1	2	3	4
2. Trouble solving maths problems	0	1	2	3	4
3. Trouble writing school work or homework	0	1	2	3	4
4. Difficulty paying attention to things	0	1	2	3	4
5. Difficulty remembering what he/she reads	0	1	2	3	4

In the past **ONE month**, how much of a **problem** has your child had with ...

PERCEIVED PHYSICAL APPEARANCE (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling that he/she is not good looking	0	1	2	3	4
2. Not liking other people to see his/her scars	0	1	2	3	4
3. Being embarrassed about others seeing his/her body	0	1	2	3	4

COMMUNICATION (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
2. Difficulty asking the doctors or nurses questions	0	1	2	3	4
3. Difficulty explaining his/her illness to other people	0	1	2	3	4

APPENDIX – F: Wits Ethical Clearance



R14/40 Sthembliso Tembe

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180766

NAME: Sthembliso Tembe
(Principal Investigator)
DEPARTMENT: Occupational Therapy
Steve Biko Academic Hospital


PROJECT TITLE: The occupational disruption and quality of life in children admitted for cancer management

DATE CONSIDERED: 27/07/2018

DECISION: Approved Unconditionally

CONDITIONS:

SUPERVISOR: Lyndsay Koch

APPROVED BY: 
Doctor CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 11/12/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I agree to submit a yearly progress report. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in July and will therefore be due in the month of July each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).


Principal Investigator Signature

14/12/2018
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

PERMISSION LETTER TO CONDUCT RESEARCH AT STEVE BIKO ACADEMIC HOSPITAL

Permission to do Research, access Records / Files / Data base at the Steve Biko Academic Hospital

To: Chief Executive Officer/Information Officer From: The Investigator

Steve Biko Academic Hospital

Steve Biko Academic Hospital

Re: Permission to do research at Steve Biko Academic Hospital

Mr. Sthembiso Tembe is a researcher working at the Paediatric Oncology Unit, Department of Occupational Therapy at Steve Biko Academic Hospital. I am requesting permission to conduct a study on the hospital grounds that involves access to patient records.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

The title of the study is: The occupational disruption and quality of life in children admitted for cancer management.

The researchers request access to the following information:

Access to the clinical files, record book and the data base.

I intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

I intend to protect the personal identity of the patients by assigning each patient a random code number.

I undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Witwatersrand.

Yours sincerely

Signature of the Principle Investigator

Permission to do the research study at this hospital and to access the information as requested is hereby approved.

Chief Executive Officer [Redacted] Hospital Steve Biko Academic Hospital

Dr [Redacted]
Signature of the CEO





PARTICIPANT ASSENT SHEET FOR MINORS*

Project Title: *The Occupational disruption and quality of life in children admitted for cancer management*

1. I have been given a Participant Information Sheet for Minors, which explains what this study is about;
2. The study was explained to me and I understand what will happen if I take part;
3. I was given time to ask any questions I wanted to and was happy with the answers I was given;
4. I understand that I will not benefit from the study, should I agree to take part. I also understand that I will not be paid to take part in the study; taking part will not cost me anything either;
5. I have been given a range of contact details, repeated below, should I require further information at a later stage, or have any cause for concern over anything which is done to me during the study; and
6. I understand that even if I agree to take part in the study, I can change my mind later and stop being a part of the study
7. My parent(s) or guardian(s) know that I have been invited to take part in the study. They agree that I may do so, but the decision to take part is also mine.

Contact details:

S'thembiso Tembe, Principal Investigator, telephone no. 081 767 2092, or by e-mail at s.the.tembe.st@gmail.com ,

Lyndsay Koch, Supervisor, on telephone no. 011 717 3701, or by e-mail at Lyndsay.koch@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant:
Date: 10/01/2019
Place: Steve Biko
Signature or mark: DASH

Name of Parent or Guardian:
Date: 08-01-19
Place: Steve Biko Academic
Signature or mark:

All consenting Participants should be given a copy of this Form to keep, for their records, after signature



STUDY INFORMATION DOCUMENT (Children)

Study title: The occupational disruption and quality of life in families of children admitted for cancer management.

Hello,

Introduction:

I, S'thembiso Tembe, a student at Wits University, doing school work on difficulties of children and their families who are admitted for cancer treatment at Steve Biko Academic Hospital.

In this study I want to learn how your life changes when you are admitted to Steve Biko Academic Hospital.

I want to understand how cancer treatment disturbs things which you do at home, school and with friends as well with your family, this will help to plan on what other things we can help your family at Steve Biko Hospital.

Invitation to Participate: I am asking you to take share information in my school work, also asking you to read your ward file about surgeries or procedures and scans which were done on you.

Wants in the study:

- This study has two parts, one for your parent (mom / dad / granny/ brother / sister and with you.
- If you agree to participate, I will make a time with you just before you go home to ask r some questions about your life in the hospital.
- We will have a discussion asking you few questions about problems and then we will play game of pictures.
- In the game of pictures, they will be a child doing something, I will ask you if you can do or not of what is done by the child
- You will only have to answer questions once.
- The questions and game will take about 45 minutes.

Risks of being involved in the study: There are no physical risks involved in participating in this research study but you feel uncomfortable in your mind when answering some questionnaires will If you become upset I will organize counselling for you with Social worker or psychologist.

Paybacks of being in the schoolwork: There are no paybacks for you joining in this research study.

Sharing is free and not forced: It is important you understand that you can choose to participate or not in this school work. You will still get all the help you need from the ward including me. You can ask to stop sharing information or playing without reasons and they will be no problems with it.

Privacy: All personal information from you will be available to me and my teacher. I will not use your name, file number or where you stay to any of your papers where I write answers and no other person in the hospital and ward will see your information.

Contact details of researcher/s: If you would like to ask me any questions, please contact me on the following email address or telephone number.
Email: sthe.tembe.st@gmail.com
Tel no: 081 767 2092 / 021 354 1665

Outputs: I will show you the results after I am finished with my school work.

Contact details of HREC administrator and chair

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (“Committee”). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

S'thembisio Tembe

Date: 04 September 2018



PARTICIPANT CONSENT SHEET

Project Title: *The Occupational disruption and quality of life in children admitted for cancer management*

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

S'thembisio Tembe, Principal Investigator, telephone no. 081 767 2092, or by e-mail at sthe.tembe,st@gmail.com,

Lyndsay Koch, Supervisor, on telephone no. 011 717 3701, or by e-mail at Lyndsay.koch@wits.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

The text in the Consent Sheets below is intended to be neither exhaustive, nor applicable in every circumstance. Researchers are free to customize them according to the particulars of their study

Name of Participant: [redacted]
Date: 08-01-2019
Place: Steve Bithwa academic
Signature or mark: [redacted]

Witnessed by:
Name of Witness: [redacted]
Signature: [redacted]
Date: 10/01/2019



STUDY INFORMATION DOCUMENT (Parent/ Carer/ Guardian)

Study title: The occupational disruption and quality of life in families of children admitted for cancer management.

Good day,

Introduction:

I, S'thembisio Tembe, a Masters' student at the University of the Witwatersrand, am doing research on the occupational disruption of children and their families who are admitted for cancer treatment at Steve Biko Academic Hospital. Research is a process used in seeking new knowledge. In this study I want to learn how your life, and your child's life changes, when your child is admitted to Steve Biko Academic Hospital. I want to understand how cancer treatment for your child affects your quality of life and the quality of life of the members of your family so that the cancer unit at Steve Biko can plan appropriate services for families like yours.

Invitation to Participate: I am asking you to take part in a research study, also asking you for your permission to include your child in this research study and permission to access your child cancer file to get information on what types of surgeries or procedures and scans which were done on the child.

What is involved in the study. This could include but would not necessarily be limited to such features as:

- This study has two parts, one for you as a parent and one for your child.
- If you agree to participate, I will make an appointment with you just before discharge to ask you and your child to answer some questions about your life since being at Steve Biko Academic Hospital.
- As a parent, I will ask you to fill in 3 questionnaires. These questionnaires ask about your child's problems as well as what has happened in your family since your child has been at Steve Biko Academic Hospital. These questionnaires will be printed and I will be available to help you fill in the questionnaires if you need help.
- I will ask your child to take part in an interview where I will ask your child a few questions about their problems and then we will use pictures of children doing different things to ask your child about what he/she can do and what he/she can't do.

- You and your child will only have to answer questions once.
- The questionnaires will take about 45 minutes of your time. The interview and the picture sorting activity with your child will also take about 45 minutes of your time.

Risks of being involved in the study: There are no physical risks involved in participating in this research study. The questionnaires will ask you about your quality of life, the quality of life of your child and about some of your child's problems. If at any point you become upset while filling out the questionnaire, or if your child is upset, I will organize counselling for you with your cancer unit counsellor that you met on admission.

Benefits of being in the study: There are no direct benefits for you or your child from participating in this research study. You will be helping me understand what kind of support and help families with children admitted to the cancer unit need. This will help the staff at the cancer unit plan relevant services in the future for families with children admitted for cancer treatment.

Participation is voluntary: It is very important that you understand that you can choose to participate in this research study or you can choose not to participate. If you choose not to participate in this research study, you and your child will still get all the treatment you need and you will still have access to the cancer unit counsellors. You may also decide to withdraw from the research study at any time and if you decide to withdraw, I will destroy any information you have already given me. You also do not have to give me a reason for why you want to withdraw.

Confidentiality: All personal information from you and your child will be treated in the strictest confidence and will only be available to me and my supervisor. I will not use your names, hospital numbers or any other identifying information on your questionnaires and only I will be able to link your questionnaire to your personal information. I will at all times try to keep your participation confidential and none of the doctors, nurses or any other staff in the cancer unit will know whether you are participating or not.

All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Contact details of researcher/s: If you would like to ask me any questions, please contact me on the following email address or telephone number.

Email: sthe.tembe.st@gmail.com

Tel no: 081 767 2092 / 012 354 1665

Outputs: If you would like to see the results of the study, I will show you the results after I am finished with my data analysis. The results of this study will be published in a scientific journal, but will not include any personal or identifying information.

Contact details of HREC administrator and chair

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (“Committee”). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

S'thembisio Tembe

Date: 04 September 2018

APPENDIX –J: Turn-in Report

**Turn-In Report (The Health Related Quality of life in Children
Admitted for Cancer Management and Their Families)**

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ORIGINALITY REPORT

0 %	0 %	2 %	0 %
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

MATCH ALL SOURCES (ONLY SELECTED SOURCE PRINTED)

2%
★ dc.uthsc.edu
Internet Source