

**Family experiences and
viewpoints of palliative and
supportive care for children
with cancer: Can we do better?**

**JHNDUP001
M Phil
Palliative Medicine
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Title

Family experiences and viewpoints of palliative and supportive care for children with cancer: Can we do better?

Declaration

A dissertation presented to the Faculty of Health Sciences, University of Cape Town, in the fulfilment of the requirements for the degree: Master of Philosophy Palliative Medicine.

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(Signature of candidate)

Date: 09/12/2016

Abbreviations

CANSA	-	The Cancer Association of South Africa
CHOC	-	Childhood Cancer Foundation
EOL	-	End-of-life
HCP	-	Health care provider
ICPCN	-	International Childhood Palliative Care Network
NGO	-	Non-governmental organization
PC	-	Palliative Care
PICU	-	Paediatric Intensive Care Unit
PPC	-	Paediatric Palliative Care
QOL	-	Quality of life
SOP	-	Standard operating procedure
UAH	-	Universitas Academic Hospital
WHO	-	World Health Organization

Abstract

Background:

The palliative and supportive care needs of children with cancer and their families are unique and require special attention. Children and their families in Africa facing life-threatening/life-limiting diseases have unique needs and have the right to achieve effective and evidence-based care. Development of appropriate services sensitive to the needs of families and based on observed evidence has become more and more recognized. As an introduction to develop and improve supportive and palliative care services for children with cancer, families were questioned regarding their experiences and suggestions for improvements.

Methods:

Sixteen family members of children with cancer and treated at Universitas Academic Hospital, Bloemfontein, South Africa, were questioned regarding their children's standard oncology and supportive/palliative care. Their responses were studied and repeating themes were identified.

Results:

A number of areas of need were identified: erratic psychosocial support, minimal financial support, poor parental access to basic needs and food provision, preventable errors in procedures and lack of sibling support. Staff were also not always sufficiently equipped to attend to palliative care patients.

Conclusions:

Supportive and palliative care for children with cancer needs to be improved. Family members are a valuable resource and the interviews identified a number of themes, valuable to consider in the expansion of a supportive/palliative care service. The intension of the study was to create the awareness that by making small and affordable changes, the quality of care that children and families receive can be improved.

Introduction:

A journey begins each time a child is diagnosed with cancer, which impacts the whole family.¹ Despite improvements in cure rates for childhood cancer, some will not respond to conventional treatment and will not survive.¹⁻⁶ Stones et al. reported the overall survival rate of children with cancer and treated at the oncology centre in Bloemfontein to be 50.3% between 1987 to 2011.⁷ Many of these children presented late with advanced disease, which negatively affected their survival.^{7,8} The death of a child has a lifelong effect on a family, which puts them at a high risk for suffering.^{9,10} Care for children with cancer should therefore not only consider the child's symptoms but also his/her family's well-being.⁹

The American Academy of Pediatrics and World Health Organization (WHO) encourages a combined model of curative and palliative care for children with cancer and their families, from diagnosis and right through their journey.¹¹⁻¹³ Palliative care (PC) takes into account not only the physical, but also the emotional and spiritual needs and can be defined as a total and active approach to care. PC aims to manage distressing symptoms throughout a child's illness and to provide support throughout the child's disease trajectory, death, grief and respite care to both child and his/her family.^{2,5}

Traditionally, the focus of care for children with cancer has been investigation, diagnosis and treatment to optimize the chances of potential cure.^{8,13} However, an adult study amongst patients with non-small-cell lung cancer, who have a dismal prognosis, showed that early integration of palliative care led to substantial improvements in their quality of life (QOL), psychological well-being and they even survived longer.¹⁴ The aim of PC is to improve the QOL of the patients and their families by managing their physical symptoms and lessening their psychosocial and spiritual suffering.⁸ Children and their family's overall cancer journey can be enriched by merging palliative care early and systematically into their standard oncology care.^{8,15}

Development of appropriate paediatric palliative and supportive care services that are sensitive to the apparent needs of families and based on observed evidence has become more and more recognized.¹⁰ The needs of children with cancer and their

families are unique and require special attention, especially in unit serving a culturally diverse population and a large geographical area. Only a few studies have reviewed the satisfaction and experiences of the family with their child's medical care.^{2,10,12} This study used qualitative methods to learn more about the needs of families of children with cancer during their journey, how well their needs were met and the apparent barriers to palliative care service delivery.

Literature review:

A child's cancer diagnosis has a devastating effect on all facets of family life. They are affected financially and psychosocially.^{1,12,16} Supportive care that controls symptoms related to the disease and intervention is often needed before a child needs palliation.^{12,17} Traditionally the focus of care for children with cancer has been trying to cure the disease.^{8,10} While this approach is crucial, these children and their families are at high risk for suffering.¹⁰ Only when they fail to respond to conventional therapy, the focus of care will change from a curative to a palliative approach.^{5,6,8} However, they also deserve comfort care, care that looks after their physical, psychological, social and spiritual wellbeing. Care that includes their families and allows them to cope, make difficult decisions and maintain family function.¹⁸ They basically deserve effective, compassionate and timely palliative care.¹⁰

Traditionally palliative care has primarily been provided at the end-of-life.^{5,19} Recently, there is a growing interest to address the psychosocial needs of children earlier in their disease journey.^{8,12,15,20} Combining palliative care early into standard oncology care could improve their overall cancer experience.^{8,12,13} The American Academy of Pediatrics and the WHO encourages combining curative and palliative care from diagnosis and right through the disease course.¹² However, parents and health care providers (HCPs) poorly understand the idea of palliative and supportive care.^{1,12}

Wolfe et al. showed that when a child's poor prognosis is recognized early, there is better focus on lessening suffering and integration of palliative care.¹² Their needs can be anticipated well before deterioration and help can be provided with psychological issues and symptoms occurring in the later stages can be addressed.¹² Education about a model of care in which palliative care are combined with cure-directed treatment is needed to ensure that children and their families benefit from both models of care.^{1,12}

The child's physical-, psychological- and spiritual-well-being, as well as that of his/her family should be considered.^{1,9} Psychologists often refer to families as a system rather than a group of individuals and can easily be compared to a set of wind chimes. When one part is moved, the others also move.²¹ A cancer diagnosis affects families financially and psychosocially and changes their family structure permanently.^{1,2,12}

Only a few studies have explored the family's experiences with palliative care and assessed their satisfaction with their child's medical care.^{10,19,22} Popovicu et al. discovered that parents are worried about finances, lack of information about their child's illness, lack of social support/understanding and need guidance how to give information to their children about their disease.¹⁹

Stevenson et al. also noted that there is a scarcity of research on whether current services are addressing the needs of patients and their families.⁹ They also noted that despite providing very useful guidelines how to improve end-of-life and palliative care for children and their families, even the American and Canadian health care systems do not always sufficiently meet the needs of children and their families with life-threatening and limiting diseases.⁹

In their qualitative meta-analysis, Stevenson et al. stressed that the perspectives and wishes of patients and families should be taken into account when creating paediatric end-of-life and palliative care guidelines and services.⁹ They also noted that more research to discover how to best meet the needs, how to implement PPC services and determine if the services/practices meet the patients and families' needs is needed.⁹ In the meta-analysis they grouped the palliative and supportive care needs for children and their families into ten thematic areas, namely:

Health care delivery and accessibility –

Families want PPC services to be available and accessible from the time of diagnosis right through to bereavement. They also felt that there is a need for more HCPs that are competent in palliative and end-of-life care who could address the occurrence of negative events and preventable oversights.^{9,17} Families valued continuous, consistent and coordinated care, because it promotes caring and encourages sharing of expertise and information about the child between HCPs. To them home visits by the HCPs, their child to be able to transition in and out of hospital and having a choice about the place of death are essential aspects of quality palliative/end-of-life care.^{9,17}

Interactions with staff –

Another essential element of quality palliative care is a continuous and ongoing relationships between staff and families. Communication should be honest and

straight-forward and staff need to show sensitivity, empathy, and competency when communicating with families. Families prefer a familiar person to deliver difficult news in a sensitive and caring manner.⁹

Information needs –

Families would like to be part of the decision-making process from the beginning, to be updated regularly and do not appreciate withholding of information. They want to be prepared for what is to be expected with their child's illness and treatments.^{2,9,19,23} They also would like HCPs to provide information, explain benefits and risks, estimate survival and perhaps voice preferences in a culturally competent and decent manner.^{1,15} Families who do not speak the same language as their HCPs face several issues regarding miscommunication and not understanding what is happening to their child.²⁴ Competent translators play an important role to ensure that these families do not receive contradictory or confusing information and rule out communication issues with families in whom English is not their first and/or home language.⁹ HCPs should also be able to effectively communicate and relate to children, which is a rare skill.^{8,9}

Bereavement needs –

Families prefer care to extend from diagnosis throughout the treatment and into the bereavement period. They feel abandoned when the bond, developed during their journey with the treating hospital staff, is broken.^{9,21} They value simple acts such as sending cards, attending memorial services and telephone calls after their child's death from staff involved in their child's care. Coherent with psychosocial needs, they wish to have contact with other families whose children died.⁹

Psychosocial needs –

Children's social status is interconnected with health status and can have psychological consequences.¹⁶ Families of children with cancer face multiple stressors such as financial problems, fear, anger and disruption of their normal family and social roles.⁵ Due to the high levels of emotional stress, both parents and HCPs report the importance of emotional support, such as counselling and play therapy services.^{25,26} Monterosso et al. confirmed previous findings that parents whose children died due to cancer lived in a background of chronic uncertainty and anxiety.^{2,12,27} In order to try

and manage the uncertainties and practicalities of caring for children with a life-threatening illness, parents report that they live from day to day.^{5,12,28} Socially, parents value access to other families and children going through similar experiences.⁹ Many oncology services have incorporated psychology services hoping to support patients and their families through this journey.⁵

Spiritual needs –

Spiritual needs of children and their families vary from a religious nature, such as the need of prayer, to others such as the need for hope and their child to be remembered. As HCPs we need to improve our understanding of how families and children use their spiritual and religious beliefs and practises to cope with their children's sicknesses.^{9,17,29}

Pain and symptom control –

Children with cancer experience several symptoms (not only pain) at diagnosis and during treatments.^{5,7,8} HCPs recognize the need for pain and other symptoms to be reviewed regularly and managed well. However, another crucial measure of good pain and symptom management is the child's need to be soothed and comforted.⁹ Successful symptom control not only decreases the child's symptom distress, but also his/her and the family's emotional distress.^{5,25}

Decision making –

Families want to be treated with respect and be allowed to have a say in treatment decisions.^{3,9} When cure becomes unlikely, families find it difficult to find a balance between their hopes for a cure, for comfort and their child's dignity.^{1,30} This is where HCPs play an important role and should provide adequate information, such as explaining benefits and risks, estimate survival and perhaps even voice their preferences, to assist families.^{1,19} Families are more satisfied with their HCPs if they were involved in shared decision making. They have a better sense of personal control and self-esteem, are more compliant with treatment regimens, better quality of life and even self-reported health status. Experts have shown that shared decision making better informs patients about the risks and benefits of treatment and they feel empowered.²⁰

Siblings' needs –

The needs of siblings are often forgotten. They are often neglected, uninformed and feel confused and worried about their sick sibling.^{2,9,19} Various studies have shown that the influence of cancer diagnosis on siblings is often not recognized. Therefore they do not receive the support they require and families do not know how to support them. Care should therefore be more family oriented and include services and facilities for siblings.⁹

Palliative (PC) and end-of-life (EOL) care –

The focus of PPC is to decrease and prevent suffering and improve the quality of life irrespective of the patient's diagnosis and/or stage of disease.^{7,25} Most families view palliative care negatively as the last phase before the death of a child.¹³ They do not see palliative care as part of a broader and ongoing process of care, but rather an independent process.^{10,28}

Cultural needs –

Information and care should be provided to all families in a culturally sensitive and fair manner.⁹ Muckaden et al. noted that the cultural and spiritual beliefs of Indian families help them cope better with loss than in the West.²⁸ Whereas Popoviciu et al. noted that Romanian families will search for information from other sources, for instance the internet, because they desire to maintain a sense of control and choice regarding their child's care.¹⁹ In the Romanian culture the focus of care is on curative treatment and HCPs make end-of-life decisions with no participation/interaction with the families.¹⁹ Harding et al. reports that in Africa there is an increased need for adequate cancer pain control because patients present late, there is a lack of adequate diagnostic facilities and assessment skills, poor availability of chemotherapy and radiotherapy, and opioids are not widely available.³¹ Harding et al. also noted that the palliative care needs in African countries are different from developed countries and include home and respite care, pain and symptom control, financial, emotional support, as well as help with food, shelter, legal issues and even school fees.³¹ Due to constraints on hospital beds, palliative care in Africa is mostly community-based and relies heavily

on community volunteers. Palliative care coverage is very limited, especially in geographically inaccessible areas, and many seek help first from traditional healers. This necessitates the need for collaboration, quality assistance and supervision. Palliative care models from developed countries should therefore be adapted to African settings.³¹ The World Health Organisation's (WHO) strategy for improving palliative care in resource-poor settings relies more on the integration of palliative care in to the public health care sector than on the development of difficult to sustain parallel services.

PC should be viewed as a total and active approach to care and not as a separate process. It embraces the physical symptoms, as well as emotional and spiritual needs. PC aims to improve the child and family's quality of life and support them by managing distressing symptoms, providing respite care and support through death and bereavement.^{2,5,28} Providing combined care from diagnosis of a life-threatening/life-limiting disease, offer increased likelihood for palliation when needed. (Harding) Not all children with cancer will need access to specialist palliative care; for many a combined approach by their HCP should be adequate to meet their needs.³²

In spite of advances made in providing palliative care for children with cancer, many of their symptoms remain unrecognized and undertreated and service provision remains patchy. Paediatric oncology HCPs are trained to investigate, diagnose, and treat cancer. The primary goal of care is to maximise the chances of cure. This can create a barrier to effective symptom control and they also lack training in palliative care concepts.⁸ It is a rare skill to provide valuable and comprehensive palliative care to children with cancer.^{2,8,19} Further barriers include the need for prognostic certainty, because it discourages the idea that PPC can co-exist with other treatment therapies, language barriers, time constraints of the involved HCPs and families not ready to accept an incurable illness.⁵ The barriers limit the possible positive and sympathetic experience from which both child and family can benefit.⁵

In comparison with adults, the needs of a dying child are different, their families are a lot more involved in their care.² Family members are their main source of support for physical, emotional and spiritual needs. Parents will constantly strive for the best care for their children and have valuable experience regarding their supportive/palliative care needs. Bluebond-Langner et al. reports that parents whilst looking for and

wanting a cure, they expect supportive and symptom care to be given alongside.^{5,33} Parents will constantly do all they can to ensure the best possible care for their children. To them hoping for a cure and comfort care are not mutually exclusive. When HCPs and parents work together and good communication exists between them care is improved.¹⁵

Mostly they have had little or no opportunities to provide feedback regarding the care their child received.¹¹ Robert et al. have shown that bereaved parents specifically felt the need to give feedback to the health care workers who gave so much during their journey. They also wanted to rectify wrongs for future children and families.¹¹ Specific areas of interest were standards of care, emotional care, communication and social support.¹¹ In another study parents indicated the need to receive earlier discussions about EOL options/scenarios rather than near the time of death.²⁵ These parents also stressed the importance of effective communication and close relationships with their health care workers, as this influences the dynamic and personal nature of their journeys.¹¹

While providing paediatric palliative care (PPC) is easing children's suffering, more research in PPC is needed. Adult based palliative care principles cannot easily be applied to children.^{9,12,34} Qualitative research is becoming very common in PPC, because it offers an in-depth exploration of the human experience. Quantitative studies often gives only a partial explanation of difficult processes such as parental grief.⁹ Very few studies have explored the satisfaction and experiences of the family with their child's medical care.^{5,12,19} Children and their families in Africa facing life-threatening/life-limiting diseases have unique needs and have the right to achieve effective and evidence-based care.³⁴

In the South African public sector there is minimal palliative care service provision. Service provision is mainly located in institutions by a few palliative care specialists.³² In a conversation with Dr MA Meiring, MD (May2017), there are only 3 provinces with independently employed hospital based paediatric palliative care consultative teams. Although several children's hospices were established in the pre-HAART era in South Africa with HIV related funding, many of these have since closed down. Although needed especially for dying children with poor social circumstances, these are expensive to run. Community based palliative care is better established for adults in

South Africa but few of these services have the capacity or expertise to care for children.

Many children with incurable cancers and progressive diseases are cared for on an ad hoc basis by less experienced HCPs.¹⁸ Early introduction of palliative care, regardless of whether their treatment is curative or not, could certainly be of benefit to these children. This research study used qualitative methods to learn more about the needs of families of children with cancer at a South African Paediatric Oncology Unit. How well their needs were met and the apparent barriers to palliative care service delivery.¹⁰

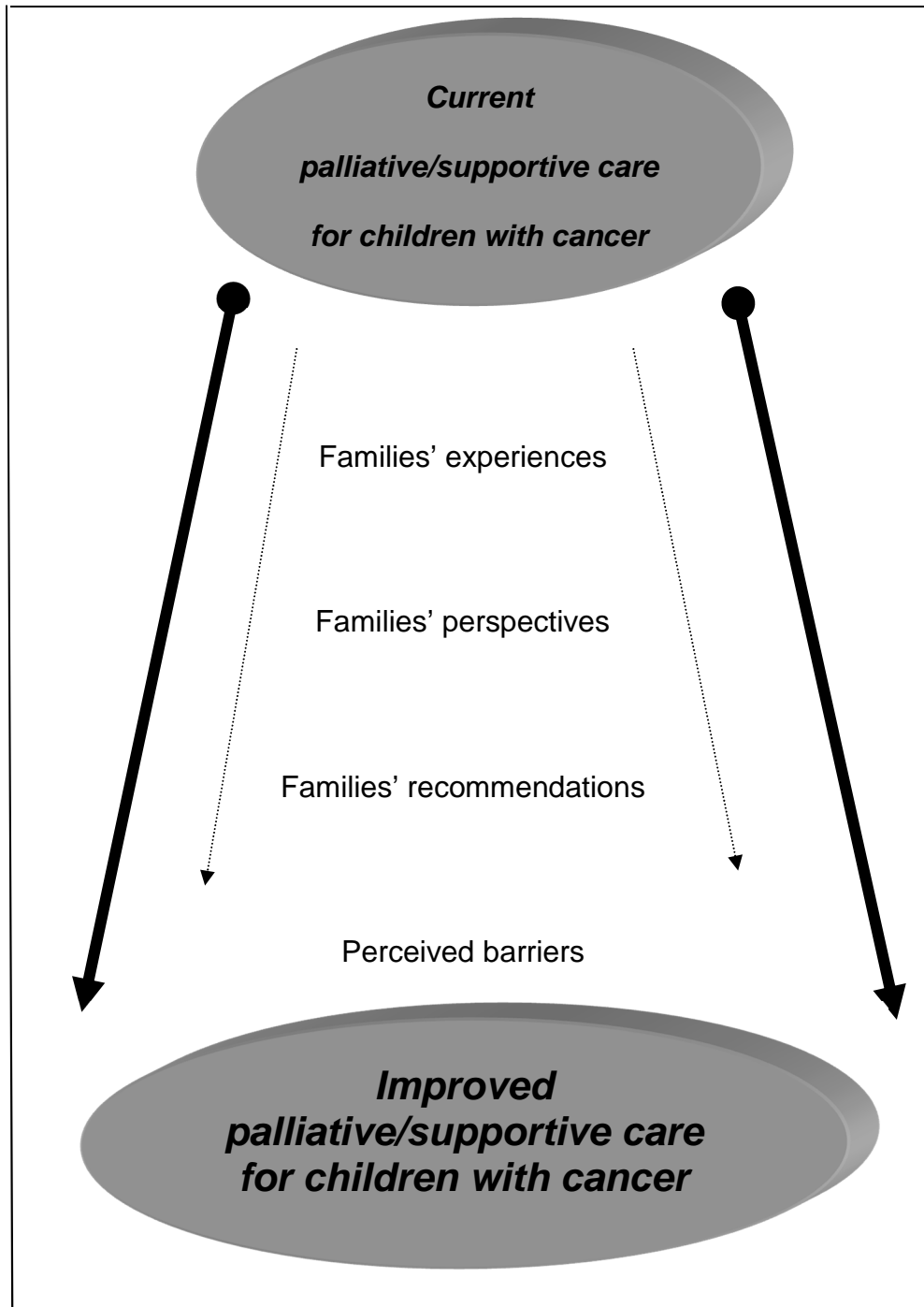
Rationale for the study:

Families of children with cancer will make every effort for the best possible care for their children and are a valuable resource regarding their children's cancer journey. Very few studies have explored the family's satisfaction and experiences with their child's care.^{2,12} The trigger for this assessment was to gain insight from the family's point of view regarding supportive and palliative care for children with cancer.

Aim & objectives:

The aim of the study was to explore the personal accounts of family members of children with cancer regarding palliative and supportive care. The objective was to determine their supportive and palliative care needs, identify areas of need and strategies to improve the care for future children with cancer and their families.

Conceptual Framework:



Participants and methods:

Study design:

This was an exploratory, qualitative study using a grounded theory approach. This approach is a systematic method which involves the development of a theory through careful analysis of the data. After every interview, the interviews were transcribed and reviewed by the researcher, repeated themes were identified and coded. As more data were collected, the codes were re-reviewed and then grouped into concepts and then into categories. These categories formed the basis for the eventual theory.³⁵

Study setting:

The study was performed at the Paediatric Oncology Unit, Universitas Academic Hospital (UAH) in Bloemfontein, South Africa. UAH is a tertiary hospital and is the referral centre for children with cancer from a very large geographical, including the Free State and Northern Cape provinces, parts of the Eastern Cape Province and the neighbouring country, Lesotho.

Study participants and recruitment:

Inclusion criteria were that participants had to be a family member or care-giver, fluent in English or Afrikaans, accompanying a child with cancer to hospital and receiving (currently or previously) treatment at UAH. Due to the large geographic distances, likely emotional distress and difficulty in arranging face-to-face interviews, bereaved family members of children with cancer previously treated at UAH were not included in the study. An observed approach has been adopted for this study due to the diversity in the oncology disease trajectories, population distribution, geography (and location of paediatric referral centres) and disparity of support services.⁹

The study was reviewed and approved by the University of the Free State (UFS) and the university of Cape Town's (UCT) Faculty of Health Sciences Human Research Ethics Committees (ECUFS NR: 90/2015 & HREC ref.: 859/2014) and the Free State Department of Health. The family member/care-giver accompanying the child to hospital/clinic was approached and given a letter describing the project. The

researcher was available to answer any questions. If the parent/care-giver agreed to participate, a time for an interview was scheduled.

Data collection:

For the individual interviews a semi-structured interview guide was developed. The interviews were conducted in the participant's language of choice, either English or Afrikaans and if required Sotho translations were given by the Sotho-speaking social worker. Prior to each interview the participants signed an official ethics committee approved informed consent form. Nine of the interviews were conducted in English and seven in Afrikaans.

The interview began with a demographic questionnaire to capture demographic data for children such as age, gender and disease related data such as diagnosis and treatment. In addition, demographic data about the family member interviewed (age, education and work details) was collected. Participants were then asked to explain the course and treatment of their child's illness, their exchanges with hospital staff, support for them, and their child and for siblings. Participants were encouraged to expand on areas needing improvement, and to discuss any recommendations or concerns that were not addressed in the interview. All of the family members were offered counselling if they experienced emotional distress due to the interview. Only one family member required this support. The interviews were audio-taped and the recordings were transcribed verbatim and checked for accuracy by the interviewer.

A research assistant, not involved with the treatment of the children, conducted the interviews. The interviewer was unknown to the participants in order to avoid critical self-reflection by the researcher regarding expectations, preferences and relationship to the parents and avoid unfair expectations regarding the outcome of the study.

Data analysis:

From the onset of data collection and throughout the study a grounded theory approach and immersion in the data were used. The researcher reviewed the responses of the participants and identified the most noticeable themes. As many as possible themes were identified initially and frequencies determined to use as a guide

to identify which themes transpired more (or less) often. The themes were then grouped into categories and the most prevalent themes are described further.

Results:

Table 1 presents the demographic characteristics of the participants. Table 2 presents a breakdown of the children's ages, diagnoses and duration of illness.

A total of 16 family members (mainly mothers and grandmothers) of 16 patients were interviewed about their viewpoints of supportive/palliative care at UAH. Very few fathers accompany their children to hospital, because most of them are breadwinners and are at work and are not always able to accompany the children to hospital. Other reasons for the gender bias could be the distances that patients have to travel, lack of own transport and government provided transport services to and from the tertiary hospital that only allow for one family caregiver to accompany the child to hospital and lack of lodger facilities for fathers/male care-givers.

Nine of the interviews were conducted in English and seven in Afrikaans (only one participant required Sotho-translation during an interview). The average length of the interviews was 50 minutes. Noticeable was that the duration of the interviews with the Sotho speaking parents were shorter, except for the interview with the one Xhosa speaking mother who was well educated and fluent in English. Only 2 of the participants resided in Bloemfontein, of the other participants 6 were from the rest of the Free State, 5 from the Northern Cape, 1 from the Eastern Cape and 2 were from Lesotho.

Participants included family members of children at various stages of their oncology journey. The time interval between the child's initial diagnosis and the interview fluctuated from 2 months to 13 years. Their children's cancer diagnoses included an array of different malignancies (table 2). The treatment they received varied from eleven of whom were currently receiving curative (first or second line chemotherapy) treatment, two receiving purely palliative treatment and three who have already completed treatment and were attending the long-term follow up (LTFU) clinic.

Almost all of the participants described a mixture of positive and negative experiences. All offered suggestions for improvement and voiced thankfulness for the chance to share their experiences. They expressed hope that the information provided would benefit others.

Table 1. Characteristics of the participants

Characteristic	Value*
Sex	
- Female	16 (100)
- Male	0
Relationship to child	
- Mother	14 (87.5)
- Grandmother	2 (12.5)
Age, years	
- Range	25 – 59
- Mean	40
Ethnic identification	
- African	10 (62.5)
- White	4 (25)
- Coloured	2 (12.5)
Education	
- Primary school	1 (6)
- High school	4 (25)
- Grade 12 certificate	8 (50)
- Tertiary education/degree	3 (19)
Employment status	
- Unemployed	11 (69)
- Part time	1 (6)
- Full time	4 (25)
Residence	
- Bloemfontein	2 (12.5)
- Rest of the Free State	6 (37.5)
- Northern Cape	5 (31.25)
- Eastern Cape	1 (6)
- Lesotho	2 (12.5)

* Data given as number (percentage) of participants unless otherwise indicated.

Table 2. Characteristics of the children (diagnoses, duration from diagnosis, ages)

Variable	No. (%) of the 16 children*
Child's current age:	
- 1 – 12 months	0
- > 1 – 5 years	4 (25)
- > 5 – 10 years	7 (44)
- > 10 – 15 years	5 (31)
Child's gender:	
- Male	9 (56)
- Female	7 (44)
Child's diagnosis:	
- Leukaemia	5 (31)
- Neuroblastoma	2 (12.5)
- Nasopharyngeal carcinoma	2 (12.5)
- Brain tumour	1 (6)
- Germ cell tumour	1 (6)
- Kaposi sarcoma	1 (6)
- Nephroblastoma	1 (6)
- Retinoblastoma	1 (6)
- Rhabdomyosarcoma	1 (6)
- Thyroid carcinoma	1 (6)
Time since diagnosis:	
- 0 – 6 months	6 (37.5)
- > 6 – 12 months	2 (12.5)
- > 12 – 24 months	3 (19)
- > 2 – 5 years	0
- > 5 – 10 years	3 (19)
- > 10 years	1 (6)
Treatment received (current &/or previous):	
- Chemotherapy only	8 (50)
- Surgery & Chemotherapy	4 (25)
- Chemotherapy & Radiotherapy	2 (12.5)
- Chemotherapy & Surgery & Radiotherapy	2 (12.5)
Current stage of treatment and intent:	
- First-line curative	9 (56)
- Second-line curative	2 (12.5)
- Post treatment LTFU	3 (19)
- Palliative	2 (12.5)
Number of siblings:	
- 0	4 (25)
- 1 - 2	10 (62.5)
- > 3	2 (12.5)

* Percentages may not total 100 because of rounding

LTFU: long term follow up

Figure 1. Summary of children's primary diagnoses

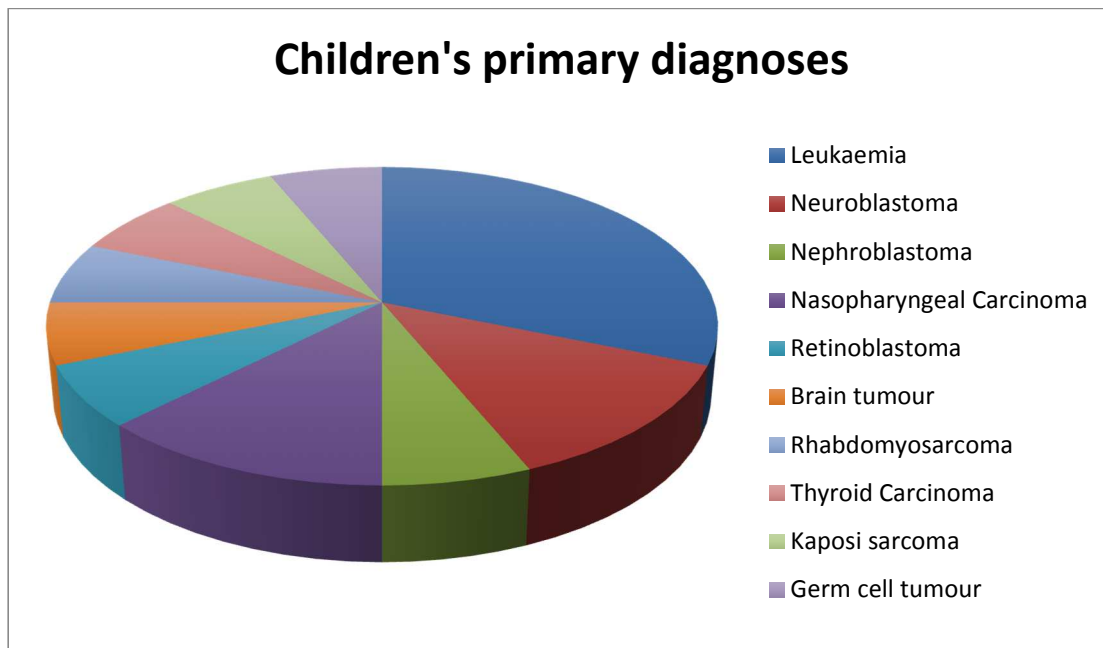


Figure 2. Summary of the children's current treatment stage and intent

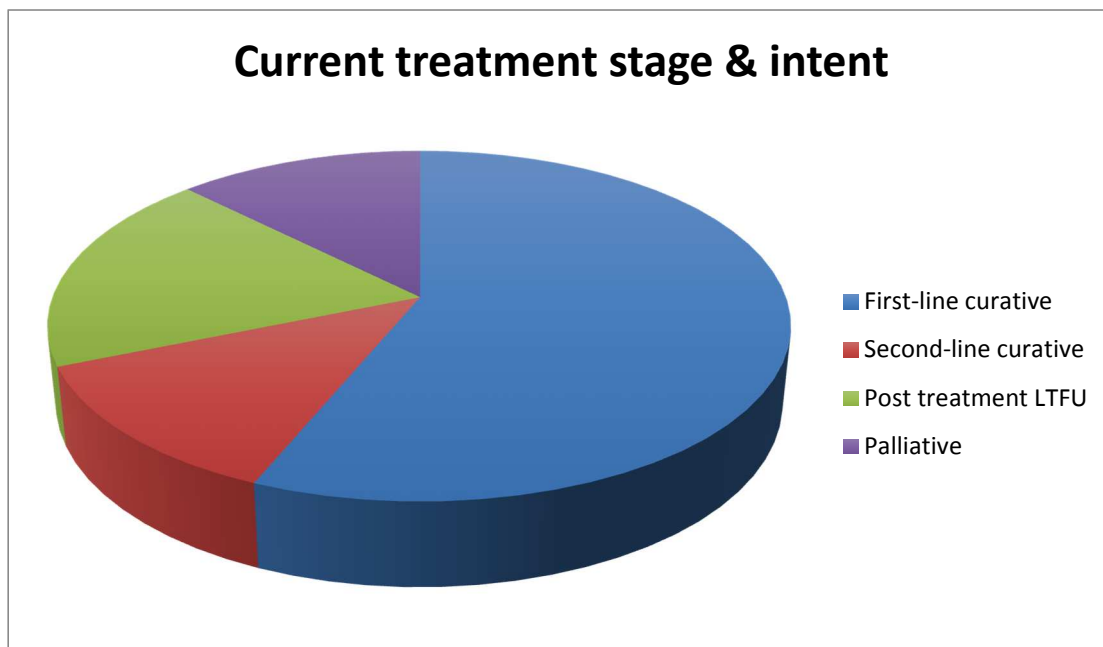
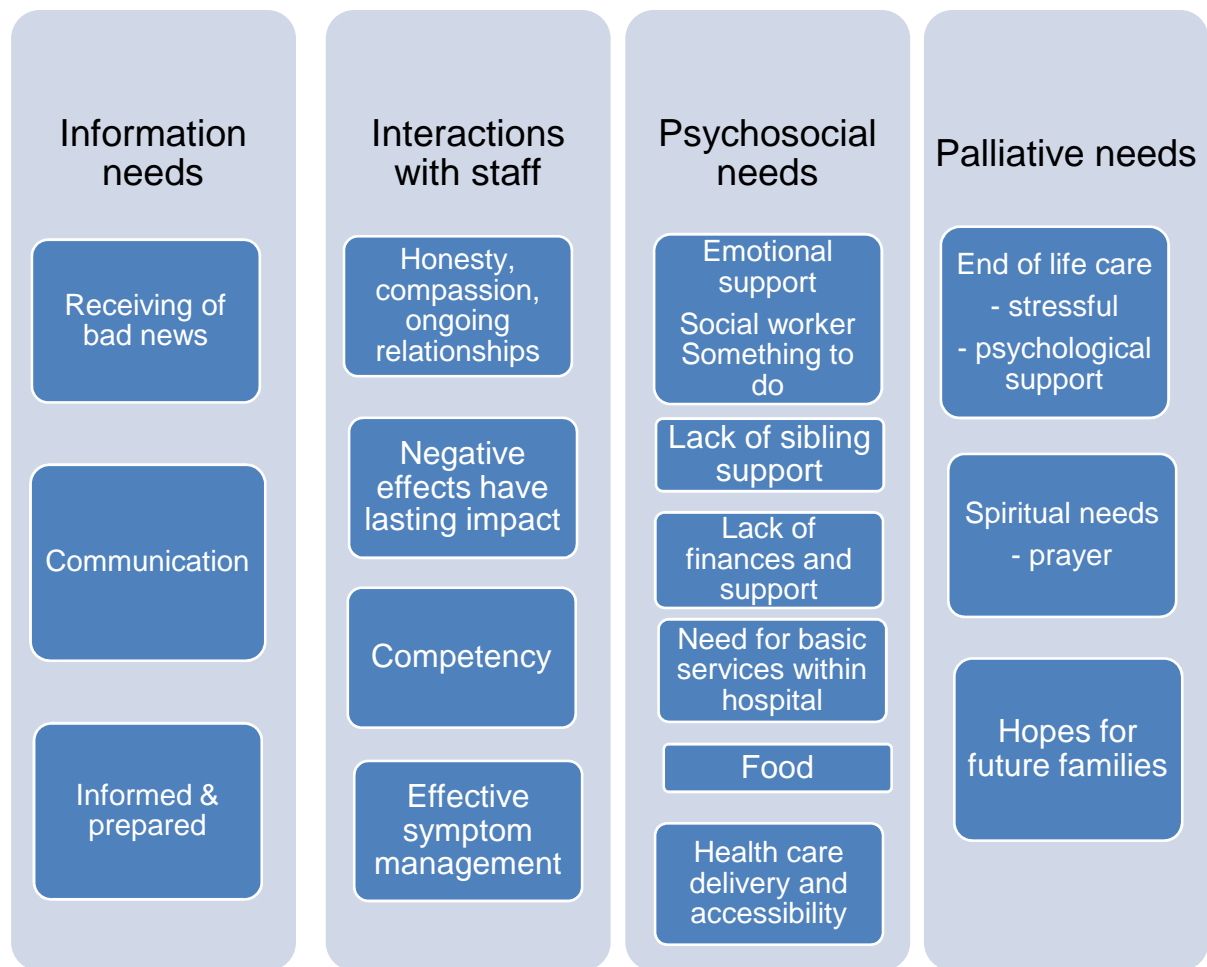


Figure 3. Summary of the most common themes emerging from the study.



The coding frame is summarized in figure 3. The most common themes regarding the families' experiences and perspectives on palliative and supportive care for children with cancer are described further.

Information needs –

Almost all of the family members reported that the receiving of bad news of their child's cancer diagnosis was very emotional, difficult and traumatic, but they had to accept it. One respondent said that she did not take the news well, fell into a depression and was angry at everyone for a year. However, they appreciated that the news regarding the diagnosis, treatment and prognosis was delivered in a compassionate, caring and straightforward manner and in a quiet room away from the hassle and bustle of the ward. If they did not understand there was always another physician or nursing staff member available to explain. Even though they were of different cultures, all of the

participants felt well informed and ready for what to expect from their child's illness and possible treatments. Most of the conversations are conducted with the help of a staff member competent in the language of choice of the parent/caregiver and more recently, since her appointment, in the presence of the social worker (also fluent in Sotho). Most found the HCPs explained the information very well and that they are very approachable. A few did mention that if they did not understand there was always someone, fluent in the language of their choice, to ask for an explanation. No one mentioned language or cultural differences as barriers to communication. A few did mention that even though everything was explained well, you do not absorb all of the information at once and that the reality only hits you when you are alone at home.

"The doctors explain good, always there to listen and support." (Interview 03 – Lesotho mother of 9 year old boy ± 2 months on treatment).

"Dokters is goed, verduidelik mooi, ek verstaan alles (Doctors is good, explain well, I understand everything)." (Interview 01 – grandmother of 3 year old boy ± 12 months on treatment).

"Big shock! For the first year I was angry about everything and with everyone around me, so I did not take it well. I fell into a depression. I did not want my daughter, wanted to give her up for adoption. Did not want to share my attention with anyone else except my son." (Interview 15 – mother of 11 year old boy 5 years on palliative treatment).

"If there is something I do not understand, I can ask the one doctor or I go to the nurses and I get answers. When I leave from here I know what they expect of me." (Interview 02- mother of 11 year old boy now ± 5 years post treatment).

"I think you get told all these things, but you do not 'click' everything, it is just too much information." Interview 12 – mother of 3 year 7 month old girl 6 months on treatment).

Interactions with staff -

The family members appreciated medical and nursing staff's honesty, clinical accuracy, compassion, and availability. They value the ongoing relationships that have developed between them and the medical staff. They described the doctors as excellent, very easy to talk to, always there to listen and support. They are always available and they come when something is wrong, even if it is very late. With one or

two exceptions the nursing staff was described as excellent and what matters to the parents/care-givers is how they relate to their children. A few did report that the night staff was not always as helpful as day staff and sometimes tended to be too loud at 3 am in the mornings.

“My grandson is very comfortable with them (nursing staff), they make a fuss about him and that is really what it is about.” (Interview 01 – grandmother of 3 year old boy ± 12 months on treatment).

Negative events –

Another interesting discovery was how a single incident can cause parents intense and lasting emotional suffering. Parents described incidents that included insensitive delivery of bad news, feeling dismissed or patronized, poor and insensitive communication, and apparent disrespect for parents’ judgment about their child’s care. These events unsettled them and convoluted their experience. Only one laid a formal complaint, but the others were too shocked to file a formal complaint as they feared consequences.

“I do not like one of the staff members, very bombastic and cold-hearted towards us. Told me that I have to accept my child is dying and that is that”. (Interview 15 – mother of 11 year old boy ± 5 years on palliative treatment).

Some of the upsetting experiences that left parents feeling angry and victimized were related to avoidable blunders in procedures. Incidents included, children not receiving new tablets if they dropped it on the floor, distasteful nicknames (cheeky and baby for a big 9 year old boy), and unnecessarily shouting at them, staff not trained in resuscitation, staff not familiar with hospital equipment or procedures.

“I asked the lady about transport, she shouts at me. Don’t always shout, maybe she was not feeling well that day, but that was not nice”. (Interview 04 – Lesotho mother of 14 year old boy ± 7 months on treatment).

A few of the participants reported that more health care workers competent in caring for children with cancer are needed to decrease preventable oversights and negative events.

“We need trained staff or staff need to know what they do, I know better how to work the drip (IVAC) than them.” (Interview 08 – mother of 21 month old girl ± 5 months on treatment).

“One day my child was in trouble and the nurse did not know what to do, we called for help but nobody came.” (Interview 08 – mother of 21 month old girl ± 5 months on treatment).

Psychosocial needs –

A very strong need of all the participants were emotional support, such as counselling services for themselves. In order to cope, they live from day to day. They felt the need of someone to talk to, someone that is not going to fall apart when they tell them their child has cancer or is dying. Most of the parents relied on support from family and friends throughout their child's admission or when they cared for their children at home. Almost everybody treasured the social support they were receiving from other parents/families going through similar journeys. They also noted that their children also benefited from access to other children going through similar experiences. One participant emphasized that parents/caregivers should not be scared to ask for help, because having a child with cancer is very stressful and not everyone copes. Parents appreciated the non-governmental organization (NGO) appointed social worker within the ward and that they can talk to her, but some feel that a psychologist is also needed. This need became very apparent in those parents whose children had no more curative options and were receiving purely supportive/palliative care. These participants were very depressed and one reported suicidal tendencies.

“Eight months ago I fell into a depression and wondered why must I wait for my child to die? It was very bad, I considered suicide, but decided that it is the devil trying to get a hold on me, so I decided not to give up, I still have my son, my husband and daughter also. It is important to get someone to talk to, every parent needs it.” (Interview 15 – mother of 11 year old boy ± 5 years on palliative treatment).

“The lady from CHOC we talk to her and the mothers we talk, but it will be better to have something to do, we can do together and then we talk more.” (Interview 03 – Lesotho mother of 9 year old boy ± 2 months on treatment).

Sibling support –

As previously noted, several of the participants mentioned the influence of the child's illness on the siblings and that they, as parents, did not know how to support them. Siblings were cared for by family or friends, while they were in hospital with their sick child. However, the siblings suffered when the mothers were not home. One parent reported how one of a set of twins was left alone at home after school and his schoolwork deteriorated when she was at hospital with the other twin. Jealousy from the healthy sibs towards the sick sibling and damaged parent-child relationships were also reported and related to the long periods away from home and attention given to the sick sibling. Siblings are often forgotten and they did not receive the care they need. The families at home do not know how to support these siblings. More support, counselling and services for siblings are needed.

“My eldest son did not cope very well, the long periods away from home, all of the attention to the sick little brother, our relationship suffered permanent damage.”
(Interview 09 – Lesotho mother of 14 year old boy now \pm 7 years post treatment).

“The brothers’ schoolwork deteriorated a lot and they are alone during the day.”
(Interview 14 – mother of 10 year old girl \pm 12 months on treatment).

Services for parents –

There were recurring reports regarding the poor facilities and services for the parents. The parents wanted and needed to be with their hospitalized children. They came from far (geographically) and during their child's hospitalization need access to a shower, food, seating and maybe a bed for the night. Our parents reported that these basic needs were not met or are poorly met. Seating and sleeping were often on wooden benches or on the floor under their child's bed at night. The shower and washing facilities were not within the hospital, but in a neighbouring building and often without warm water. The children were upset and cried when they leave them and inclement weather made the trip to the ablution block difficult. The hospital did not provide food for them, except under special circumstances (breastfeeding mothers and newly diagnosed children's caregivers). The hospital was not obliged to provide food for the parents, but due to their child's illness they were often unable to work. Thus, they were struggling financially and lacked resources to buy food for themselves or their children.

Sometimes the hospital food for the children was not palatable and they vomited after trying to eat the food. The children also did not like the hospital food and parents were unable to buy them the food they want (i.e. yoghurt). One of the parents whose child has completed treatment, stressed that the hospital or the unit should take better care of the parents that sat next to their children's beds day in and day out. They should be given something to do also, because they got bored just sitting around.

"The bathroom is a big problem, far and not hot water. It is far to walk to buy food and don't have enough money." (Interview 04 – Lesotho mother of 14 year old boy ± 7 months on treatment).

"They take good care of my child, but the food is not good. He vomits when he tries to eat the food. He wants yoghurt, but I do not have the money to buy him and I cannot walk to the shop it is far." (Interview 07 – mother of 7 year old boy ± 5 months on treatment).

"Food is a problem and I don't have the money to buy food for me, I am not working because my child is sick." (Interview 06 – mother of 5 year old girl second line treatment).

Finances –

The parents spoke frequently about difficulties in getting funding for transport, food and providing for their children. Due to the large geographical area that our unit serves, the parents were away from home for long periods of time. Most have left or lost their jobs to look after their sick children. Despite the fact that transport and hospital care were free, they still struggled. They had to pay for taxis to get to the local hospital or clinic to access transport and pay for their own food and their children's needs whilst at the hospital. The parents of our Lesotho patients were even more impoverished than the South African residents. They had to pay for transport to and from UAH and they did not get a child support grant from their government. Despite some already receiving a child support grant, most felt that the disability grant or "sick pension" as they call it, will help more.

“We that come from far have more problems, we don’t get money for children. I am a single parent. We have to pay for transport in Lesotho.” (Interview 03 – Lesotho mother of 9 year old boy ± 2 months on treatment).

“I have asked for leave, but I do not have enough leave and I do not want to lose my job.” (Interview 04 – Lesotho mother of 14 year old boy ± 7 months on treatment).

“Financially it is very difficult, but I do not really want other people to look after him. What if he dies and I am not there?” (Interview 15 – mother of 11 year old boy ± 5 years on palliative treatment).

Symptom management –

Symptom management seemed not to be an issue for our participants. Hopefully this meant that their children’s physical supportive needs were assessed consistently and managed effectively. One or two of the families mentioned that the extended family also needs to be educated regarding the side effects of specifically steroids. The other members in the household regarded the children as being naughty and did not realize the side effects of the medication accounted for their behaviour.

“Mothers, fathers, grandfathers and grandmothers and even great-grandmothers that live with you, need to know, they need to know.” (Interview 01 – grandmother of 3 year old boy ± 12 months on treatment).

Spiritual needs –

Most of the participants’ spiritual needs were religious in nature, such as faith in God and the need for prayer in order to cope. Some also emphasised their efforts to continue hope while coming to terms with their child’s diagnosis/prognosis.

“Despite knowing what is coming (him dying), you cannot live like that, you cannot give up. If you give up, he will also give up”. (Interview 15 – mother of 11 year old boy ± 5 years on palliative treatment).

“Keep your faith in God because for Him anything is possible”. (Interview 13 – mother of 6 year old boy ± 6 months on treatment).

Health care delivery and accessibility –

Participants reported that facilities closer to their homes and community based education programmes regarding childhood cancer diagnosis and care were needed. This could help to avoid misdiagnoses and prevent unnecessary delays in referral. There were also a need to provide and promote better community based support programmes to provide good quality and efficient care for paediatric patients.

“We need a cancer unit in Sasolburg where he (her son) can receive treatment and we can go home after. Better for the child and me and the sister who stay at home with my mother.” (Interview 07 – mother of 7 year old boy ± 5 months on treatment).

Palliative (PC) and end-of-life (EOL) care –

For the families whose children received purely palliative/supportive management, described it as very stressful to accept and to manage. They said that it was not easy to see their children deteriorate, but were thankful for every moment/minute that they still had together. They stressed the need for psychosocial support not only for themselves, but also for the child. One of the children was counselled a private psychiatrist and his mother noted that she thought he was better prepared than them (the family) on what is coming, he just did not want to be alone when he dies.

“He told me a while back that he is not afraid to die and that I don’t have to worry.” (Interview 15 – mother of 11 year old boy ± 5 years on palliative treatment).

Hopes for future families -

One of the parents noted that bereavement/end-of-life care was lacking within the unit. She noted that parents whose children died were unsure what to do next (regarding funeral arrangements etc.). They needed guidance regarding issues surrounding the death of their child and the need for funeral cover for their children, because there are no guarantees with this disease. Most hoped for better facilities for them and all the patients/parents in the future: better facilities within the hospital, better financial and psychosocial support.

*“There could be private rooms for the children with cancer, better bath facilities and better care of the mother’s that day in and day out sit here with their children.”
(Interview 09 – mother of 14 year old boy now ± 7 years post treatment).*

Discussion:

The interviews with the parents/care-givers provided valuable information about particular ways in which supportive and palliative care for children with cancer and families can be improved at UAHC. In order to provide good care the families also regarded a good relationship with the caring staff (medical and nursing), together with the technical side of care, as important. As was also mentioned by Contro et al., avoidable mistakes in procedures and/or thoughtless comments troubled parents long after the incident.³⁶

Poor communication increased distress for the parents/care-givers. Families valued receiving ongoing comprehensive information throughout their journey. Crucial to their experience (good or bad) was their relationship with the staff. Even one inconsiderate remark left a distressing and long-term impression on them.²¹ This was the reason for one of the parents seeking support after the interview, worried that now that she has mentioned the incident there would be repercussions.

With the exception of one or two incidents mentioned by the same parent involving staff interactions, different cultural backgrounds or language barriers did not seem to be a barrier to good care within this study. However, of note was the fact that the duration of the interviews with the Sotho speaking parents was shorter. The reason for this could have been that, despite their apparent proficiency in English, the effect of the cultural differences on effective communication could have been underestimated. Cultural differences are often associated with language differences and are a barrier to effective communication.²⁴ Culture affects one's understanding, even perception, of a word or a sentence. Language barriers between the HCP and parent/caregiver are often underestimated and their low health literacy go unrecognized. Underestimating the effect of cultural differences or stereotyping individuals by their culture will interfere with the effectiveness of communication.²⁴

Of note was that the parent who required support from the social worker was a Sotho speaking parent who was worried that she did wrong by mentioning an incident that she found upsetting. As mentioned before, language did not seem to be an issue and parents did not complain that they received contradictory or confusing information. At

any given time within the oncology ward there always are Sotho, English and Afrikaans speaking personnel on duty, able to provide translation for whom it may be needed and HCPs tries to use non-technical language extensively. Most of the communication with patients and parents within the ward also takes place together with either a nursing staff member or the social worker who is competent in speaking the parent's language of choice.

Psychosocial support from the NGO social worker was deemed a very valuable and needed asset within the unit. They felt that psychosocial support was needed from diagnosis throughout the cancer journey and assistance in solving some of the financial issues (applications for grants was helpful). Some also stressed the need for a psychologist to provide continuous psychotherapy to some of the families.

It is well known that a child's cancer diagnosis also affects his/her siblings, however support for siblings remained a problem and was a major component absent in the care of the family of the child with cancer.³⁶ Resolving this issue will not be easy, taking into account the large geographic area our unit serves. However, it probably is worth exploring using social media to address the issue but not all will have access or the financial means to access social media.

On investigating the food issue, specifically the food provided to the children, the dietitian discovered that the ward allocated kitchen worker did not always specify whether an African or Western diet was preferred. This could influence the children's experiences of the food. Gibson et al. reported that parents expressed strong views about wanting a bigger choice of food, food that is well prepared and familiar to the children. Also facilities for them to prepare food if necessary, provided by the hospital, for themselves and if required for their children.³⁶ Parents only received food from the hospital under special circumstances (i.e. breastfeeding and other special cases). This was the reason, combined with financial constraints, why the food issue was a major problem for them.

Comparable patterns of hospital care preferences about the physical surroundings were noted in the literature.³⁷ A bright, colourful and comfortable hospital environment, playrooms, kitchen facilities, separate accommodation and washing facilities for family members while their child is in hospital were preferred. This was also a prevalent need

amongst the parents interviewed in our study. Geographically the unit serves a very large area and would be considered a country unit. Most of our families come from a disadvantaged sector and have poor home/financial circumstances. They struggled financially, but they wanted and needed to be with their children during the long hospital admissions. Hence their need for a comfortable chair to sit/sleep in and appropriately constructed, equipped ablution facilities with warm water etc.³⁷ Most of the participants mentioned they would like to have something to do and contribute to their child's care whilst in hospital (one of the parents was even prepared to wash floors).

The study was intended to be investigative and descriptive. However, because standardized methods were not used, and even though the families' explanations seemed to have significant face value, the trustworthiness and soundness of the interviews cannot be professed.

This study depended on the insights of family members during and after (curative and palliative) treatment has been completed. These personal reflective insights may not always truthfully reflect events that took place. Regardless, it is essential to get and rely on parents' insights when evaluating quality of care for children. Finally, the families were treated within the Paediatric Oncology Unit at UAH. Therefore, these results might not represent the views of all families receiving care from UAH or families receiving care from other health care facilities.

Conclusion:

All of the family members who contributed in the study appreciated the opportunity to “share their stories” and give input into the future care of children with cancer at UAH. However, this enthusiastic gratitude may indicate an unmet need for opportunities to discuss their children’s care and their family’s journey with cancer.³¹

Usually care for children improves when good communication exists between parents and HCPs and if they work together.^{15,18} From this study it was clear that the families regarded their interactions with staff just as significant as the medical aspects of treatment to their overall experience. Thoughtless comments/remarks from staff or mistakes in care (tablets not given etc.) caused added suffering. Siblings did not receive adequate (if any) attention at UAH, despite it being clearly identified as a need in the literature.³⁶ Even though, cultural and language differences were not raised as a barrier to care, what was apparent was the shorter duration of the interviews with the Sotho speaking parents. The effect of the cultural differences on effective communication should not be underestimated. Culture affects one’s understanding, even perception, of a word or a sentence.²⁴

Paediatric palliative care has a lot to offer sick children and their families. In South Africa access to expert palliative care and paediatric oncology specialists remain sporadic and geographically determined.^{31,32} The main model is to provide home-based care to children where possible, with inpatient backup when required and for children without parents or caregivers.³² Support services can therefore provide valuable assistance and supervision with later stage symptoms and psychological issues.^{13,15,31} The children’s needs should be anticipated before they deteriorate (especially with incurable cancers and late presentations with advanced staged disease).

Whatever the outcome, children and families who receive compassionate, holistic care that manages symptoms and addresses their non-physical needs are able to face their illness with dignity and energy.¹⁰ However, further qualitative research is needed to better understand the cultural context of cancer, death and dying for children and their families in African nations.³⁴

Recommendations:

Nurture a better understanding of palliative care tasks and principles:

Literature has shown that integrating palliative care early into standard oncology care will improve the child and their family's overall cancer experience.^{8,12} However, curing the disease has traditionally been the focus of care for children with cancer. While this approach is important, they and their families are at high risk of suffering.¹⁰ In order to cope, make difficult decisions and maintain their family function, families deserve care that makes sure that they are comfortable. Care that includes not only their physical, but also their psychosocial and spiritual wellbeing.¹⁸ They basically deserve effective, compassionate and timely palliative care.¹⁰ The American Academy of Pediatrics and the World Health Organization support a combined model of curative and palliative care for children with cancer and their families, from diagnosis and all the way through the disease course.^{12,13} Both parents and health care providers (HCPs) poorly understand this concept.^{1,12,18}

Nurturing a better understanding of palliative care tasks and principles amongst the paediatric oncology team (doctors, nurses and allied health staff) is a simple method to improve early integration of palliative care into standard care.¹³ Palliative care has actually always been a part of the everyday care of children. Daily HCPs are asked to assist children and families with palliative undertakings.¹⁰ This could be about effective symptom and pain management/prevention, end-of-life care, or tough communication and decision-making issues.¹⁰ Due to its origins, growing out of the hospice movement, palliative care is often viewed to be one and the same with end-of-life care. Cultivating the concept that it is not only about death, but also about dealing with suffering and improving the quality of life by managing pain and other distressing symptoms, and dealing with psychosocial and spiritual issues, will allow early integration thereof into regular care.^{10,18}

Early integration of palliative care and conversations that allow parents to prepare, will improve quality of life and relieve suffering for children and everyone involved.^{10,18} Palliative care principles and tasks can/should be seen as a rational portion of the care of any child with a lethal illness and their family.^{10,18} Limiting it to end-of-life care opportunities to improve the lives of children and their families will be missed.¹⁰ It

should be offered from diagnosis together with curative (disease-directed) treatments and continued all the way through the illness and support the family in grief after the child dies.^{10,18}

Development of specific guidelines/standard operating procedure (SOP) regarding palliative care tasks:

While all HCPs have a basic skill set, in certain circumstances everyone's abilities will be challenged.¹⁰ For children with cancer their paediatric oncologist is essential in recognizing and providing prompt treatment for suffering (physical, emotional, spiritual and social).^{10,38} They should make the decision-making process easier, plan for the future, assess, anticipate and treat the child with cancer's symptoms effectively and provide initial bereavement care.¹⁰

Development of specific guidelines regarding palliative care tasks, such as summarized by Klick et al.¹⁰ (table 3), is a simple method to achieve better coverage. The WHO, Hospice Africa Uganda and Gambia have developed such manuals (The WHO Integrated Management of Adolescent Illness, Hospice Africa Uganda's Blue Book and the Gambian guide for HIV care and Hands on Care manual). These manuals are simple and cost-effective means to increase coverage. They provide palliative care guidelines which can be utilized by any doctor, nurse and volunteer in any setting, especially where specialist palliative care services are not available.³¹

Not all children with cancer will need access to specialist paediatric palliative care; for many a combined approach by their primary HCP/oncologist should be satisfactory to meet their needs. More specialized care is needed for children with more complex symptoms and PC specialists/centres can offer guidance to the primary care team and become a focus for advocacy, resources and education.^{31,32} Within South Africa paediatric palliative care centres and specialists are a very scarce entity. More experts and beacon centres in this new and exciting field are needed.^{31,34} They can provide education regarding basic palliative care principles, advocate for improvements to make the palliative care services within the hospital and community more effective and serve as liaison with the primary care teams. Lastly, they can serve as leaders in this young and exciting field and engage research in order to advance the field of PPC.¹⁰

At UAH the development of a SOP regarding a limitation of care plan was a specific need that arose from the need for specific guidelines for patients with life-limiting diseases and complex needs requiring interventions and possible paediatric intensive care unit (PICU) admission after hours and the need for official documentation thereof. The SOP also includes space for recommendations/actions regarding not only physical symptoms but also for psychological, social and spiritual wellbeing. The document is also a very valuable tool to assist HCPs when developing advanced care plans for children with life-threatening and limiting diseases.

Table 3. Tasks in palliative care¹⁰

Communication/Problem Solving/Decision Making

Objective	Task	Screening Tool
Identifying problems and challenges	Identify decision makers, also family and medical providers	What are you most worried about? What are you most hopeful for?
Exploring hopes Setting goals	Explore challenges, treatment options, child's functional status and disease trajectory	Let us hope for the best but prepare for the worst. What do you think we can do now to make your child's life better?
Advanced care planning	Establish a plan that utilizes resources and accomplishes the attainable goals set by the parents	I think the best manner to accomplish this is to...what do you think?

Interventions

Objective	Task	Screening Tool
Physical	Assess and treat symptoms using appropriate measures Make plans with clear goals (e.g. improved function) Consider referral to pain or PPC specialist	Are you having any pain, nausea, constipation, agitation etc.? Which symptoms are preventing you from doing the things you enjoy most? If we could fix one symptom, what should we focus on first?
Social	Identify family challenges Identify communication styles/preferences Identify support and coping skills Identify social and financial burdens	Tell me about your family? Who is having a particularly hard time? How are the other kids? Who are the people that make medical decisions? How do you prefer to hear information? Who do you use for support? This can be overwhelming, what do you do to cope?

	Identify use of self-care and potential losses from illness Consider referral to a psychosocial clinician (social worker or psychologist) or PPC specialist	What are the challenges getting through every day? What kinds of things do you enjoy doing? Are you able to do them?
Spiritual	Identify spiritual supports Consider referral to an appropriate spiritual leader	Do you have a faith or spiritual belief that brings you support?
Bereavement	Assess anticipatory grief and bereavement during acute events, stable periods and after death Consider referral to a psychosocial clinician, PPC specialists or to appropriate community programs	How are you doing today? Are you better or worse than last time we talked? How is the rest of the family? Other kids?
Team support	Assess suffering and compassion fatigue among the care team Consider referral to a psychosocial clinician, PPC specialists or to appropriate system-based programs	This kind of work can be overwhelming, how is the team holding up and functioning?

Care Coordination

Objective	Task	Screening Tool
Collaborate with specialists	Identify specially providers including a Paediatric PC team. Facilitate communication between specialists and with family. Help understand illness and coordinate follow up	I would like to contact a team that can help us manage symptoms and better understand our treatment options
Identify resources. Partner with community programs	Determine availability/need/benefit of hospice, home nursing, and community programs	Can I have a social worker help us find some resources that may help some of these needs?
Identify financial resources and payment mechanisms	Discuss availability of services/resources with insurance/case manager	Can I have my nurse coordinator help us find some resources that may help meet some of these needs?
Partner with school programs	Collaborate with school and community in supporting siblings and community children	May I ask a social worker to contact your child's school and help them understand the situation?

“Embedded expert” -

A passionate team member(s) should be encouraged to receive training and certification in palliative care and become the “embedded expert(s)” within the team.³⁸

Through their regular assessments of the children and their families, the primary team

can be alerted regarding their patients' holistic care needs. Thereby promoting early combination of palliative care into regular care. They could also help to promote the voice of paediatric palliative care and improve holistic care for all children with life-threatening illnesses within the UAH. Several online resources is also available and interested parties should be guided towards these, such as the ICPCN's website (www.icpcn.org) and others.³⁹ Also the University of Cape Town offers an excellent Diploma in Palliative care, which will adequately equip the new local expert. These are very valuable resources that provides several modules on paediatric palliative care such as overview to paediatric palliative care, the WHO guidelines on pain management in children, communication with children, management of symptoms other than pain, non-pharmacological pain management, end-of-life care and bereavement care.³⁹

Education -

Education is a valuable method to promote integration of palliative and oncological care.³⁸ Harding et al. also report that when training is done during existing nursing and clinical training, it is most effective. This would avoid feelings of overload from new skills and care frameworks.³¹ Items requiring improvement include training communication skills, learning to cope with issues inherent to the process of death and learning the skill to work together with other HCPs. In this way, quality support could be delivered to patients throughout the disease journey regardless of whether the final outcome of the disease (cure or death).⁴⁰ Within the department of paediatrics and child health at the University of the Free State palliative care has been integrated into the registrars in general paediatrics' education programme to promote their knowledge base and understanding of paediatric palliative care. Within the oncology unit registrars and undergraduate medical students are being taught on a daily basis regarding palliative care tasks and are encouraged to sit in with family meetings and compile complex advanced care and end-of-life care plans.

Interdisciplinary team -

Expanding the knowledge base and involving other professionals with different skill sets will improve management and allow for anticipatory guidance in the care for children with cancer. The needs of a dying children is complex. Suffering is not only

caused by physical symptoms, but also from emotional, spiritual and social distress.¹⁸ Addressing only one aspect of this distress will offer minimal relief for the child and family. Working together with other experts and using each participant's expertise in evaluating and managing the various sources of distress, an interdisciplinary team can provide substantial relief in the child's and family's suffering.^{10,38} Especially when symptoms come to be more severe, coordinating care becomes more complex and communication more life-changing. At a minimum members of such an interdisciplinary team should consist of a doctor, a professional nurse and a social worker (trained in family counselling). Access to a minister/spiritual leader and child play therapist will also benefit the children and their families. Other services, such as psychiatrists, grief counsellors etc. should be referred to when specific children and families need more focussed care.¹²

Advocacy –

Advocacy is the key to promote, expand and establish a successful palliative service. In South Africa less than 5% of children who need PC care receives it and those who do mostly close to the end-of-life.³² Other barriers include the lack of education on PPC, lack of integration of PPC into the primary system, lack of policies on PPC and lack of community and HCP awareness of PPC needs and services.³² Social problems also worsen the needs of these children and not enough children are receiving the social care they need, let alone palliative care. It should be advocated that everyone deserves social and palliative care that meet their cultural, spiritual and economic needs.³⁵

Specific recommendations and outcomes:

The study highlights similarities to findings of other studies (Harding et al.) that the palliative care needs in African countries are different from that in developed countries.^{31,34} Many of these families are starving and exhausted and they need help not only with pain and symptom control, emotional and spiritual support, but also help with food, shelter, finances and even school fees. A comprehensive service that includes all aspects of care and family support from diagnosis to bereavement follow up is needed. For the implementation of a palliative care programme at UAH the following areas of focus emerged from this needs assessment:

Education -

The objective will be to assume responsibility to expand the current lecture series for the paediatric registrars and to develop a palliative care lecture series for both clinical and non-clinical staff to become more aware of and competent in providing palliative and end-of-life care.^{41,42} A publication on this thesis could increase the available literature in this area. Harding et al. reported the value of clinical, nursing and lay education in terminal care in a small number of places (from 1983 at Island Hospice Zimbabwe).³¹ Nurses often expressed frustration that they were unclear about the goals of care and frustrated by the lack of communication between team members. Education can be provided on clinical decision-making, communication skills, advance care planning, boundaries, self-care and bereavement.⁴¹ Also to participate in other educational opportunities within the paediatric department. Starting with the oncology nurses, together with the social worker, wellness groups to offer support with coping with grief and trauma will be held on a regular basis.⁴²

Families and the community should also be educated regarding the early warning signs of childhood cancer. Nurturing a better understanding regarding cancer warning signs and palliative/supportive care will hopefully alert them to recognize and seek help early. Studies found that there is often a delay in presenting to hospital while the children are suffering with treatment-related complications.⁴³ Harding et al. also noted the potential for association between traditional and palliative care. Traditional healers are often the first contact from which help is sought. An educational programme for traditional healers has improved HIV patients' support.³¹ Innovation is crucial in the

African setting and education programmes on paediatric childhood cancer and palliative care will have to be expanded innovatively and include various community groups, leaders and traditional healers.

Visibility -

To increase visibility feedback regarding the outcomes of this study will be given to the rest of the paediatric oncology team (HCPs, nursing and allied health staff), the department of paediatrics and child health, the hospital authorities and possibly community groups (children's cancer support groups and local religious groups). The hope is that this feedback will nurture a better understanding of the scope of palliative and supportive tasks and principles and the struggles the children and their families face on a daily basis. For medical staff handouts will be created bullet points voicing palliative care's philosophy of care. Brochures will also be developed for families to describe the scope of palliative care service and address myths and misconceptions.⁴²

Clinical care

History tells us that team collaboration improves patient care and satisfaction. Staff will be encouraged to identify patients with complex symptom management or those at transition to palliative care. A planning form will be created to assist in identifying key issues that need to be addressed. All clinical staff will be invited to participate and could result in more thoughtful planning and support for the patient and family, goal identification and symptom management. An added benefit could be better communication and empathy between disciplines and improved staff morale.⁴¹ These forms will be based on models from other palliative care programs and accepted standards for palliative care assessments. Before use internal approval will be sought and for easy access added to the electronic medical record system.⁴²

Clinical care will and should include symptom management (pharmacologic and nonpharmacological); psychosocial support for patient, parent and siblings; assisting the family in medical decision making and providing complex care coordination, including transition to home.⁴² Siblings face unique challenges when a sib is diagnosed with cancer. Due to the large geographical area and lack of transport to and from the hospital, addressing the lack of sibling support will be a difficult issue to tackle. HCPs should advise families to involve siblings and offer recommendations on how to

support siblings at home. Families should be allowed to use their own strategies for managing problems. They should be reminded to spend time alone with siblings, to keep in contact with them while in hospital, permit and allow them to continue to live as normally as possible and to be truthful and honest with them at all times. Local community resources that could improve sibling support should be identified. They and NGO's such as CHOC, Cupcakes for kids with cancer or CANSA should also be approached to organize an annual camp for siblings.¹⁶ The logistics involved would be challenging. Getting siblings from home to camp and back home would be a major undertaking. Siblings need a place where they can have fun and bond with other siblings experiencing the same issues. The Choc appointed social worker is already busy investigating the logistics of arranging such a camp.

As HCPs it is important to be aware and have a database of the circles of support within the local community, as to be able to have easy access to them when needed.¹⁶ Establishing relationships with home health care agencies, community volunteer services and even outpatient pharmacies is vital. They can assist assess patients regularly (almost daily) and decrease their need to come into hospital to at least a biweekly review. However, a PC/oncology team member should be available at all time to manage changes and help home agencies troubleshoot problems.⁴² Many African palliative care services depend on community volunteers, however it is not clear what skills can be expected from lay palliative care and how much input from a trained specialist is needed to supervise them.³¹ To achieve and expand sustainable care the community's needs and capacity needs to be understood.

Local support sources, such as individuals, community groups (churches and NGO's) and government agencies are valuable resources to turn to for support for these families. Even if it is in a small way, such as outings or hosting tea parties with demonstrations for the mothers sitting day in and day out with their children in hospital. Letting them feel valued is a great need that was identified by the participants that were interviewed. Giving them someone else to talk to and to feel valued in this very stressful and abnormal reality that they have to live in. Maybe institutions to provide financial support to aid with the food issue and assist the local NGO who already provides transport money for the families to and from hospital. Having a sick child is

very expensive for any family, especially for these families who are far away from home and not able to work or keep their jobs. They need and want to be with their sick children. Families require support to plan ahead, find alternative sources of income and maybe look to organizations and others, such as friends and family, which may be able to assist them.¹⁶

Advocacy -

It is also important that members of the palliative care service create new policies and procedures, describing the scope of the services embraced by palliative care and procedures for palliative care consultation, and policies for management of complex symptomatology such as dyspnoea at end of life etc.⁴²

Psychosocial support and services –

In Africa holistic palliative care, addressing pain, psychological, spiritual, and social care is needed, however psychological needs of patients and families are rarely reported in the published work.³⁴ The findings also served as inspiration for further future research to discover how to best meet the needs of the children and families. Not only to evaluate standards of care, but also determine if the current and implemented practices meet the children and families' care needs and keep finding innovative ways to improve care. Inclusion of bereaved parents and the children themselves in future studies will be considered. Forgotten are the days when children were meant 'to be seen but not heard'. A proposal will be submitted to the local ethics committee evaluate the 'older' children's experiences regarding their disease and care at UAH using the draw, write and tell technique.

Other specific issues that became apparent from the study include financial issues for the families, poor services for parents within the hospital, lack of food and practical guidance after death regarding funeral arrangements/services. Together with the allied health staff and social worker these issues need to be further investigated and brought to the attention of the local authorities, especially the poor services for the parents and lack of food for them. Another important matter is financial support and with the help with the NGO social worker, it need to be investigated whether the families are receiving child support grants from welfare services and if they do whether

it is the appropriate grant. A brochure (updated regularly) should and will be drawn up regarding the practicalities after death such as available funeral arrangements/services, bereavement support services etc. and made available to families when the need arises.

Lastly, in the USA many of the larger paediatric centres now include at least one palliative oncologist on their teams.³⁸ A palliative oncologist is someone who is dually trained in both palliative care and oncology and can do clinical work in both fields. The palliative oncologist not only educates other oncologists about palliative care, but also expands the knowledge base through research in palliative oncology and creates greater awareness.³⁸

The intention of the study was not to fix everything. However, rather to create awareness that by making small and affordable changes the quality of care the children and families receive can be improved.

“You treat a disease you win, you lose.

**You treat a person, I guarantee you,
you’ll win, no matter what the outcome.”**

- Patch Adams (1998)



Used with permission

Acknowledgements:

This research project was made possible with the help and support of the following persons:

The family members who shared their experiences in the hope of improving services for other families.

My supervisors: Prof DK Stones and Dr MA Meiring. Thank you for reading my work, giving valuable advice and the informal meetings.

Mrs. Y. Goosen, the research assistant at the Department of Paediatrics, UFS. Thank you for her support and inputs throughout my research journey (Developing the protocol and guidance regarding submissions to DOH and UFS ethics committee).

Mrs. E. Matthee (Physiotherapist and research assistant) for all her work, conducting the interviews, reading my work, valuable advice and support.

Mrs. M. Ntonxa, CHOC social worker, who provided support throughout the study to me and the participants.

Dr A. van der Byl for her support, being a good friend and reading my work.

Dr A. van der Vyver for reading my work and informal discussions.

Mrs. Naomi Fray, thank you for liaising with my supervisor and the UCT HREC and for just being on the other side of the phone and/or emails.

Thank you to all the children with cancer and their families, it is a privilege to be able to be a part of their journeys. Especially when they are going through their worst nightmare and help them navigate that. Paediatric oncology is a unique speciality because we get to see the children and their families in a very profound way. We get to build a relationship with the children and their families.

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Appendices:

1. Free State Department of Health Approval letter
2. UCT Ethics Committee Approval letter
3. UFS Ethics Committee Approval letter
4. Participant Consent form
5. Participant Information document
6. Demographic Questionnaire
7. Interview Guide
8. Distress Protocol



health

Department of
Health
FREE STATE PROVINCE

07 September 2015

Dr JP Du Plessis
Dept. of Paediatrics and Child Health
UFS
Bloemfontein

Dear Dr Du Plessis

Subject: Palliative and supportive care needs of children with cancer from the family's viewpoint: Can we do Better?

- Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of Universitas Hospital nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and no names will be used.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of the Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of the Free State and to Free State Department of Health.
- Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to khusemj@fshealth.gov.za or sebelats@fshealth.gov.za before you commence with the study
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- ~~Future research~~ will only be granted permission if correct procedures are followed see <http://nhrd.hst.org.za>

Trust you find the above in order.

Kind Regards

Signature removed

Dr D Motau
HEAD: HEALTH

Date: 8/9/2015

Head : Health
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Form FHS006: Protocol Amendment

HREC office use only (FWA00001637; IRB00001938)		
<input checked="" type="checkbox"/> Approved	<input checked="" type="checkbox"/> Type of review: Expedited	<input type="checkbox"/> Full committee
This serves as notification that all changes and documentation described below are approved.		
Signature: Chairperson of the HREC	Signature removed	Date: 27/9/2016
<p>Note: All major amendments must include a local PI Synopsis justifying the changes for the amendment. Please note that incomplete amendment submissions will not be reviewed.</p>		
<p>Comments from the HREC to the Principal Investigator:</p> 		
<p>Note: The approval of this protocol amendment does not grant annual approval. Please complete the FHS016 / FHS017 form for annual approval at least one month before study expiration.</p>		

Principal Investigator to complete the following:

1. Protocol Information

Date (when submitting this form)	19.09.2016	
HREC REF Number	859/2014	
Protocol title	Palliative and supportive care needs of children with cancer from the family's viewpoint: can we do better	
Protocol number (if applicable)		
Principal Investigator	J du Plessis	
Department / Office Internal Mail Address	Palliative Medicine; Public Health and Family Medicine; Falmouth Building	
1.1 Is this a major or a minor amendment? (see FHS006/16) Major (tick box) Minor (tick box)	<input type="checkbox"/> Major	<input checked="" type="checkbox"/> Minor
1.2 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
1.3 If the amendment is a major amendment and receives US Federal Funding, does the amendment require full committee approval?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

RESEARCH ETHICS COMMITTEE
 2016-04-25
 HEALTH SCIENCES FACULTY
 UNIVERSITY OF CAPE TOWN



Other. Please specify:

4.1. In your opinion, will there be any increase in risk, discomfort or inconvenience to participants?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If yes, please provide a detailed justification/explanation:		

4.2. What follow-up action do you propose for participants who are already enrolled in the study?

<input type="checkbox"/>	Inform current participants as soon as possible
<input type="checkbox"/>	Re-consent current participants with revised consent/assent forms (append)
<input checked="" type="checkbox"/>	No action required
<input type="checkbox"/>	Other. Please describe:

5. Detailed description of the change(s)

Please attach, for each amendment, a summary of all changes which clearly indicates:

- i. Old wording (e.g. strikethrough text, CHANGED FROM and CHANGED TO)
- ii. New wording (e.g. italicized, bold, tracked)
- iii. Detailed rationale/ justification/ explanation for each change

6. Signature

My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.

Signature of PI	Signature removed	Date	19-04-2016
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UNIVERSITY OF CAPE TOWN
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Human Research Ethics Committee



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31 July 2015

HREC REF: 859/2014

Dr M Meiring
Palliative Medicine
Public Health & Family Medicine
Falmouth Building

Dear Dr Meiring

PROJECT TITLE: PERSPECTIVES AND LIVED EXPERIENCES OF BEREAVED PARENTS / CAREGIVERS OF CHILDREN TREATED IN A PAEDIATRIC ONCOLOGY UNIT IN BLOEMFONTEIN. CAN WE DO BETTER? (MPhil- J du Plessis)

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30th July 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the following student: Dr JP du Plessis is also involved in this project.

Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

Signature removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Hrec/ref:859/2014



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
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30 June 2015

HREC REF: 859/2014

Dr M Meiring
Palliative Medicine
Public Health & Family Medicine
Falmouth Building

Dear Dr Meiring

PROJECT TITLE: PERSPECTIVES AND LIVED EXPERIENCES OF BEREAVED PARENTS / CAREGIVERS OF CHILDREN TREATED IN A PAEDIATRIC ONCOLOGY UNIT IN BLOEMFONTEIN. CAN WE DO BETTER? (MPhil- J du Plessis).

Thank you for your response letter to the Faculty of Health Sciences Human Research Ethics Committee dated 15th June 2015.

Before formal approval can be granted, please address/respond to the following issues:

- Please describe the background and training of the research assistant who will be conducting the interview.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

Signature removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE



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Human Research Ethics Committee



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11 December 2014

HREC REF: 859/2014

Dr M Meiring
Palliative Medicine
School of Public Health & Family Medicine
FHS

Dear Dr Meiring

PROJECT TITLE: PERSPECTIVES AND LIVED EXPERIENCES OF BEREAVED PARENTS / CAREGIVERS OF CHILDREN TREATED IN A PAEDIATRIC ONCOLOGY UNIT IN BLOEMFONTEIN. CAN WE DO BETTER? (MPhil- J du Plessis)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

Before formal approval, please address the following;-

- 1) The student should also sign the application to conduct research.
- 2) The statement "participating bereaved parents could have emotional reactions" does not recognise the fact that all bereaved parents are likely to have strong emotional reactions when recounting the story of their child's illness and death. The distress protocol indicates that the participant's mental health provider or CHOC social worker is contacted to follow up distress resulting from the research. Have these care professionals been requested to provide support following the recruitment &/or interview?
- 3) The HREC is concerned that an interview of such sensitivity will be conducted telephonically. Please provide detail of how the participant's distress can be contained through this method of data collection. We would strongly recommend that these Interviews are conducted face to face.
- 4) Please describe detail of how the research assistant conducting the interview will be recruited and trained.
- 5) Please describe sampling more clearly; sampling information currently described under selection criteria should be described in a separate section.
- 6) Please justify exclusion of participants not fluent in English or Afrikaans. It is recommended that recruitment of the research assistant could include language requirements.
- 7) The participant is required to email or fax consent to the researcher, this also limits participation to those with access to this technology.
- 8) Parents will be offered follow-up counselling if they experience emotional distress. This counselling should be arranged prior to the research starting. Please describe how this will be arranged.
- 9) The researcher proposes grounded theory approach. Please describe how grounded theory will be applied to data collection through a telephonic process.
- 10) Informed consent :-
 - o Please provide information prior to consent form;
 - o please simplify the language of the information document;
 - o Is there a direct benefit to the participants, please state clearly;

Hrec/ref:859/2014



IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

16 March 2016

DR JP DU PLESSIS
DEPT OF PAEDIATRICS AND CHILD HEALTH
FACULTY OF HEALTH SCIENCES
UFS

Dear Dr Du Plessis

ECUFS NR 90/2015

DR JP DU PLESSIS

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

PROJECT TITLE: PALLIATIVE AND SUPPORTIVE CARE NEEDS OF CHILDREN WITH CANCER FROM THE FAMILY'S VIEWPOINT: CAN WE DO BETTER?

1. You are hereby kindly informed that, at the meeting held on 15 March 2016, the Health Sciences Research Ethics Committee (HSREC) approved the above project after all conditions were met.
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval and annually for long term studies.
5. A final report should be submitted at the completion of the study.
6. Kindly use the **ECUFS NR** as reference in correspondence to the HSREC Secretariat.
7. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully

Signature removed

DR SM LE GRANGE

CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

26 February 2016

DR JP DU PLESSIS
DEPT OF PAEDIATRICS AND CHILD HEALTH
FACULTY OF HEALTH SCIENCES
UFS

Dear Dr Du Plessis

ECUFS NR 90/2015

DR JP DU PLESSIS

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

PROJECT TITLE: PALLIATIVE AND SUPPORTIVE CARE NEEDS OF CHILDREN WITH CANCER FROM THE FAMILY'S VIEWPOINT: CAN WE DO BETTER?

1. You are hereby kindly informed that the Health Sciences Research Ethics Committee (HSREC) approved the above project after all conditions were met when the signed permission letter from the Free State Department of Health was submitted. This decision will be ratified at the next meeting to be held on 15 March 2016.
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval and annually for long term studies.
5. A final report should be submitted at the completion of the study.
6. Kindly use the ECUFS NR as reference in correspondence to the HSREC Secretariat.
7. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully

Signature removed

DR SM LE GRANGE

CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

26 February 2016

DR JP DU PLESSIS
DEPT OF PAEDIATRICS AND CHILD HEALTH
FACULTY OF HEALTH SCIENCES
UFS

Dear Dr Du Plessis

ECUFS NR 90/2015

DR JP DU PLESSIS

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

PROJECT TITLE: PALLIATIVE AND SUPPORTIVE CARE NEEDS OF CHILDREN WITH CANCER FROM THE FAMILY'S VIEWPOINT: CAN WE DO BETTER?

1. You are hereby kindly informed that, at the meeting held on 23 February 2016, the Health Sciences Research Ethics Committee (HSREC) approved the following:
 - *Minor amendment to the protocol*
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
5. Kindly use the ECUFS NR as reference in correspondence to the HSREC Secretariat.
6. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully

Signature removed

DR SM LE GRANGE

CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

04 June 2015

DR JP DU PLESSIS
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH
UFS
BLOEMFONTEIN

Dear Dr JP Du Plessis

ECUFS NR 90/2015 **DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH**
PROJECT TITLE: PALLIATIVE AND SUPPORTIVE CARE NEEDS OF CHILDREN WITH CANCER FROM THE FAMILY'S
VIEWPOINT: CAN WE DO BETTER?

1. You are hereby kindly informed that the Ethics Committee reviewed the above research project and it was presented at the meeting on 02 June 2015. Research may not be conducted before the following condition(s) has/have been met and the Ethics Committee grants final approval for the project:

- *The signed permission letter from the Free State Provincial Health Research Committee has to be submitted before the study may be conducted*

*Upon receipt of the above feedback/document(s), the Ethics Committee will issue a final approval letter. Only thereafter may the study be conducted.

2. All relevant documents e.g. signed permission letters from the authorities/institutions; amendments to the protocol, questionnaires etc. have to be submitted to the Ethics Committee before the study may be conducted.
3. Kindly use the ECUFS NR as reference in correspondence to the Ethics Committee Secretariat.
4. Thus, this letter only serves as **conditional** approval.
5. The Ethics Committee functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite).

Yours faithfully

Signature removed

DR SM LE GRANGE
CHAIR: ETHICS COMMITTEE

cc: Prof DK Stones



Research Division
Internal Post Box G40
☎ (051) 4017795
Fax (051) 4444359

E-mail address: EthicsFHS@ufs.ac.za

Ms J du Plessis/hv

2014-09-18

REC Reference nr 230408-011
IRB nr 00006240

DR JP DU PLESSIS
DEPARTEMENT OF PAEDIATRICS AND CHILD HEALTH
FACULTY OF HEALTH SCIENCES
UFS

Dear Dr du Plessis

ECUFS NR 164/2014

DR JP DU PLESSIS

DEPT OF PAEDIATRICS AND CHILD HEALTH

PROJECT TITLE: PERSPECTIVES AND LIVED EXPERIENCES OF BEREAVED PARENTS/CAREGIVERS OF CHILDREN TREATED IN A PAEDIATRIC ONCOLOGY UNIT IN BLOEMFONTEIN. CAN WE DO BETTER?

1. You are hereby kindly informed that the Ethics Committee reviewed the above research project and it was presented at the meeting on 16 September 2014. Research may not be conducted before the following condition(s) has/have been met and the Ethics Committee grants final approval for the project:

- **Kindly indicated under the inclusion criteria that the language will be English and Afrikaans speaking participants only, and amend the exclusion criteria accordingly**
- **The phrase "language of choice" should be removed and replaced by English and Afrikaans throughout the whole protocol, as Ms Goosen will do the interviews in these two languages**
- **The following approval letters have to be submitted to the Ethics Committee:**
 - **Signed approval letter from the CEO Universitas Academic Hospital**
 - **Signed approval letter from the Head of the Department**

[Upon receipt of the above documents, an approval letter will be issued by the Ethics Committee. Only thereafter may the study be conducted].

2. Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research. Clinical Trial Guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004; Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition (2006); the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines.
3. Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
4. The Committee must be informed of any serious adverse event and/or termination of the study.
5. All relevant documents e.g. signed permission letters from the authorities, institutions, changes to the protocol, questionnaires etc. have to be submitted to the Ethics Committee before the study may be conducted (if applicable).



6. A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
7. Kindly refer to the ETOVS/ECUFS reference number in correspondence to the Ethics Committee secretariat.
8. Thus, this letter only serves as conditional approval.

Yours faithfully

Signature removed

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PROF WH KRUGER
CHAIR: ETHICS COMMITTEE

Palliative and supportive care needs of children with cancer from the family’s viewpoint: Can we do better?

CONSENT TO PARTICIPATE IN RESEARCH

You have been asked to participate in a research study and informed about the study by

You may contact the researcher (Dr J du Plessis) if you have questions about the research and/or if you are experiencing distress as a result of the research.

Ethics approval for the study has been granted by the University of Cape Town (HREC ref.: 859/2014), the University of the Free State (ECUFS NR: 90/2015) and the Free State Department of Health.

You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 and/or the Faculty of Health Sciences, UCT if you have questions about your rights as a research subject/participant.

Participation in this research is voluntary.

There will be no remuneration for participating, also no costs to you for participating.

Results from this study might be published.

If you agree to participate, a signed copy of this document as well as the participant information sheet, which is a written summary of the research, will be given to you.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means, I voluntarily agree to participate and that I understand that I can withdraw at any stage.

Signature of Participant

Date

Signature of Witness
(Where applicable)

Date

Please return a signed copy of this document to Dr J du Plessis as discussed initially.
Contact details of Dr J du Plessis: 0823768914 (cell); 051 444 3230 (fax) or duplesjp@ufs.ac.za (email).

Palliative and supportive care needs of children with cancer from the family's viewpoint: Can we do better?

INFORMATION DOCUMENT

In this study the researcher would like to determine the experiences and needs of care of children diagnosed with cancer from the family's perspective. Each child's cancer story is unique and they and their families have different needs during this journey with cancer. Exploring the needs and expectations of care from the families might help to influence the care future families will receive.

Very few studies have looked at the family's experiences, views and needs of the care they and their children received other than the chemotherapy. However, families going through the cancer journey with their child, have a lived experience regarding the needs of similar children and their families. They can offer valuable opinions about the care they would like their children to receive during this journey. They might also have good insight about end-of-life care for children dying from cancer and their families.

Request to participate:

For these reasons, you are invited to participate in this research study.

What is involved in the study?

Once consent you have given your consent to participate an interview will be scheduled and conducted at a convenient time to you. The time duration of the interviews will vary, but it might take up to an hour.

During the interview you will be invited to reflect on and discuss your experience of your child's journey with cancer. The interviews will be done by a research assistant, because the doctor-patient relationship could influence your true perspectives and experiences.

Risks:

Due to the sensitive nature of these interviews, with your consent, the Choc oncology social worker has been asked to assist with counselling if you experience emotional distress prior, during or after the interview. It might/will be difficult to tell the story of your child's illness.

Benefits:

One of the benefits of participating may be to give feedback to the treating team about the care your child is receiving and how this care could be improved. Talking about your child's cancer journey could also serve as a debriefing.

This information can also be used to educate medical and nursing staff about combined compassionate and cancer directed care. This could allow future children diagnosed with cancer and their families to benefit from both philosophies of care.

Confidentiality:

Efforts will be made to keep personal information confidential and no information which can identify yourself or your child will be made available.

Contact details of researcher (for any further information about the study or reporting of study related disadvantages/issues):

Dr JP du Plessis

- 082 376 8914

Contact details of the Secretary and Chairman of the Ethics committee of the Faculty of Health Sciences, University of the Free State (for reporting of complaints or problems):

- (051) 405 2812

Experiences and perspectives of families

For office

Subject

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1. Demographic of family member/caregiver (Interviewee)

1.1 Age of interviewee _____ years

1.2 Gender

1	Male
2	Female

1.3 Race

1	Black
2	Caucasion
3	Coloured
4	Asian
5	Other

1.4 Relation to child

1	Parent
2	Grandparent
3	Sibling
4	Other family member
5	Caregiver, not family

If sibling, position of sibling in family: _____

If sibling, is the sick child:

1	Younger
2	Older

If sibling, role of sibling:

1	Care giver
2	Escourt to hospital

1.5 Level of education

1	Currently in school
2	Grade 12 certificate
3	Tertiary education
4	No education

1.6 Employment status

1	Not applicable (sibling)
2	Full time
3	Part time
4	Unemployed

1.7 Number of siblings in family: _____

2. Demographic data of child

For office u

Subject n

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2.1 Age: _____ months

2.2 Gender:

1	Male
2	Female

2.3 Diagnosis:

1	Leukemia
2	Braintumours
3	Neuroblastoma
4	Nephroblastoma
5	Retinoblastoma
6	Rhabdominosarcoma
7	Lymphoma
8	Hepatoblastoma
9	Germ cell tumours
10	Bone tumours
11	Other

2.4 Treatment

1	Chemotherapy
2	Surgery
3	Irradiation
4	Chemo + surgery
5	Chemo + radiation
6	Surgery + radiation
7	Chemo + surgery + radiation

2.5 Current stage of treatment:

1	First-line
2	Treatment for second malignancy
3	Post treatment LTFU
4	Relapse - chemotherapy
5	Relapse - surgery
6	Relapse - surgery + chemo
7	Relapse - surgery + chemo + radiation
8	Palliative

2.6 Time since initial diagnosis: _____ months

Palliative and supportive care needs of children with cancer from the family's viewpoint: Can we do better?

INTERVIEW GUIDE¹²

The interview guide has been adapted from Monterosso et al. published in Palliative Medicine 2008 and only used as a guideline to guide the research assistant when she conducted the interviews.¹²

The participating family members were thanked for agreeing to participate in the research and reminded that they can withdraw at any point during the interview.

The following unrestricted and semi-structured stimuli was used to cover the following points:

- At the beginning of each discussion a less tough question was asked to ease the family member into the discussion: Tell me what _____ was like as a child... and how their journey with cancer started?
- They were asked to elaborate about the time the time when doctors told them about the cancer diagnosis and for the family members whose children are receiving palliative management to elaborate about their feelings and experiences when the treatment was are not helping and _____'s illness got worse?
- They were also asked to describe the care they and their children received?
- They were asked what their needs were and were they met?
- They were asked when they realized that their children were getting sick.
- Who was involved in caring for _____ (your child) and your family?
- What did they hope each of these individuals/services could deliver?
- Did they feel they had enough interaction from hospital staff and were they helpful? If not, what would have been helpful?
- For the family members whose children were receiving palliative care the following questions were added:
 1. Where was/is _____ (your child) being looked after?
 2. Was this in line with your and _____ (your child)'s wishes?

3. What was/is most important to _____ (your child) and your family during the last few months of _____ (your child)'s life?
- To everyone was asked, what aspects of care were most helpful to _____ (your child) and your family? What aspects were unhelpful?
 - Or they were asked what aspects of care can be improved and what was barriers to good care? What aspects of care that they needed that was difficult to get?
 - What could be different for families faced with this circumstances in future?
 - They were also asked what their perspective of palliative care: what is it?

During the interview they were probed to get a better understanding of the topic. Probes that were used included: "tell me more ...", "... can you explain..." etc. The interviewer tried to avoid using the probe "why", not to give the family member the impression that their answers were not correct.

Palliative and supportive care needs of children with cancer from the family’s viewpoint: Can we do better?

SCREENING INTERVIEW AND DISTRESS PROTOCOL³⁶

All of the screening was done by the research assistant (Mrs. Matthee), and the screening interview was done as noted below:

The research assistant introduced herself and thanked each participant for their willingness to participate and asked if they have any questions about the study. If yes, their questions were answered and if no, the rest of the screening interview proceeded as below.

Because the topic of perspectives and experiences of family members of children with cancer be sensitive and might bring strong feelings, individuals experiencing a high levels of emotional suffering not to contribute at this time.

The participants were asked if they were experiencing emotional or other distress to decide if there is any reason they not participate.

The screening interview was adapted from the screening interview drawn up by Drauker et al.³⁶ and conducted as noted in the table below and the actions that was taken.

Screening question			Follow up questions If yes, ask questions	Caller’s response	Acute emotional distress or safety concern? (Y or N)
	No	Yes			

<p>Are you experiencing a high level of stress or any emotional distress?</p>		<ol style="list-style-type: none"> 1. Tell me what you are experiencing? 2. Is it getting in the way of you doing things you need to do (work, family obligations)? 3. Is it getting in the way of you taking care of yourself? 4. Have you been in the hospital recently for this problem? 		
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Palliative and supportive care needs of children with cancer from the family's viewpoint: Can we do better?

SCREENING INTERVIEW AND DISTRESS PROTOCOL⁴⁴

Actions for screener:

1. If answer to screening question is NO, the confidentiality declaration was read to them and an interview scheduled.

CONFIDENTIALITY STATEMENT:

All the answers that you give will be kept private. This means anything you tell us will not be given out to anyone, unless you say it's okay.

2. If a participant's responses reflected acute distress the following actions was taken:

- a. No interview was scheduled.
- b. The participant was encouraged to either contact his/her mental HCP or the CHOC Oncology social worker for follow up.
- c. With their permission either Dr Du Plessis and/or Mrs. Maria Mtonxa (CHOC oncology social worker) contacted them next day.
- d. Dr J du Plessis were informed of the results of the screening.

3. If during an interview a participant's experienced acute distress the following actions were taken:

- a. The interview was stopped.
- b. The participant was encouraged to either contact his/her mental HCP or the CHOC Oncology social worker for follow up.
- c. With their permission either Dr Du Plessis and/or Mrs. Maria Mtonxa (CHOC oncology social worker) contacted them next day.
- d. Dr J du Plessis were informed of the results of the screening.