

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF PUBLIC HEALTH

PERSPECTIVES AND EXPERIENCES OF
PARENTS/GUARDIANS OF CHILDHOOD CANCER PATIENTS
AT THE UNIVERSITY TEACHING HOSPITAL (UTH) IN LUSAKA

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**A dissertation submitted to the University of Zambia in partial
fulfilment of the award of the degree of Master of Public Health in
Health Promotion.**

Declaration

I **Mulima O. Walubita** do hereby declare that this dissertation is a representation of my own work and that it has never been submitted before for the award of a degree or any other qualification at this university or any other university.

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Dedications

To all parents/guardians nursing a child with cancer and to all childhood cancer patients

This dissertation is dedicated to my husband **Mazuba Muchindu** for the inspiration to aim higher in life and for the career guidance as my mentor, as well as my children **Chabota, Tumelo** and **Wana** who endured my absence and divided attention due to this work. I also dedicate this dissertation to my family and friends for the moral support and encouragement during the course of my studies.

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Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CDH	Cancer Disease Hospital
CT	Computed Tomography
ED	Emergency Department
ERES	Excellence in Research Ethics and Science
HIV	Human Immune Virus
IARC	International Agency for Research on Cancer
IASC	Inter-Agency Standing Committee
ICCCPO	International Confederation of Childhood Cancer Parent Organisation
IEC	Information Education Communication
KCCF	Kayula Childhood Cancer Foundation
KII	Key Informant Interviews
LMICs	Low and Middle Income Countries
MRI	Magnetic Resonance Imaging
PSS	Psycho Social Support
UNICEF	United Nations Children’s Fund
UTH	University Teaching Hospital
SDR	Secondary Data Review
SADC	Southern African Development Community
WHO	World Health Organization
ZACCAF	Zambian Childhood Cancer Foundation

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Abstract

Background: Zambia is experiencing high prevalence of childhood cancer. Cancer is a traumatising disease and affects physical and psychological wellbeing of patients and changes the outlook of life. Therefore, psychosocial support is crucial in helping to uplift the feelings of patients and parents from diagnosis to treatment of childhood cancer. However, Zambia has few organisations that offer psychosocial support services to children with cancer and their families. The study focused on perspectives and experiences of parents/guardians of children with cancer in terms of psychosocial support services offered at the Paediatric Oncology ward at UTH.

Methods: This was an exploratory health facility-based Qualitative study that was conducted at UTH'S Paediatric Oncology Ward. Fifteen (15) in-depth individual interviews with parents/guardians were conducted and seven (7) key informant interviews were also conducted. Data was analysed using thematic analysis.

Results: Parents/guardians exhibited low levels of knowledge on childhood cancer due to low levels of awareness campaigns on childhood cancers. They had financial challenges in meeting the cost of treatment, the cost of transport, cost of living for children back home, providing the needs of the childhood cancer patient and parents' own well-being. They also had difficulty in managing the long period of hospitalisation in relation to their spouses, giving attention to children back home, managing their businesses and maintaining cleanliness in their households during the short breaks from hospitalisation. Parents/guardians could not have sustainable income because they had to stop or put on hold their income generating activities such as farming and retail businesses which led to their income being negatively affected and unable to meet the cost of treatment, transport, providing the needs of the childhood cancer patient as well as their family. Their main psychosocial need was counselling that includes provision of information on childhood cancer in terms of disease management, treatment and side effects of chemotherapy. Therefore, it's important to note that the study found that counselling, shelter and information on childhood cancer management was provided to parents/guardians and some parents/guardians reported that they were happy with; regular checks and provision of medicines, assistance from social welfare that enabled them access services like CT scan and MRI, spiritual and food support from well-wishers, the church and cancer foundations. However, some parents/guardians feel that the psychosocial support services offered at the Paediatric oncology ward were not easily

accessible; mainly because some parents/guardians did not receive some of the psychosocial support services. Even those parents/guardians who received the services still felt that the services were not easily accessible. Parents/guardians turn to God in prayer as a way of coping with the condition of the child which is affected by different factors. They pray as individuals, with peers in the ward and through spiritual support from churches, cancer organisations and medical officials from the oncology ward.

Conclusion

There is need to increase awareness on childhood cancers in Zambia. Increasing human resource to provide specialised childhood cancer treatment and counselling will improve the provision of psychosocial services at the Paediatric oncology ward at UTH. Making cancer treatment available in district/provincial hospitals will help in reducing the financial challenges and challenges caused by long period of hospitalisation, as well as enabling parents/guardians to cope with the burden of nursing a childhood cancer patient.

1 INTRODUCTION

1.1 Background

Cancer has become a big health problem world over. It is the leading cause of death in developed countries and the second leading cause of death in developing countries. A World Health Organization (WHO) report has revealed that the cancer burden is growing at an alarming pace, with the number of annual new cancer cases feared to reach 22 million by 2035 from the current rate of 14 million new cases per year (WHO, 2014). There were 14.1 million new cancer cases, 8.2 million cancer deaths and 32.6 million people living with cancer (within 5 years of diagnosis) in 2012 worldwide. 57% (8 million) of new cancer cases, 65% (5.3 million) of the cancer deaths and 48% (15.6 million) of the 5-year prevalent cancer cases occurred in the less developed regions. The overall age standardized cancer incidence rate is almost 25% higher in men than in women, with rates of 205 and 165 per 100,000, respectively (International Agency for Research on Cancer, 2014).

In developing countries cancer is increasing as a result of among other factors the adoption of cancer-associated lifestyle choices including smoking, physical inactivity, and “westernized” diets in the wake of rising incomes (Jemal et al, 2011). A significant number of these cancer cases involve children. According to WHO, the global incidence rate of childhood cancer i.e. in children less than 15 years of age is approximately at 160,000 per year and the mortality rate is 90,000 deaths per year. In developed countries, it has a mortality of approximately 20% of cases while developing countries have a higher mortality of approximately 80/90% (WHO, 2014). Sub-Saharan Africa has experienced huge challenges in childhood cancer especially in giving the right diagnosis and at the right time and reduced access to appropriate therapeutic facilities and drugs hence the low survival rate (WHO, 2009; Zambian Childhood Cancer Foundation, 2013; Education Scotland, 2013).

Despite this increasing burden, cancer control programs and the provision of early detection and treatment services are limited in most African countries (Jemal et al, 2011). Cancer continues to receive a relatively low public health priority in Africa, largely because of limited resources and other pressing public health problems, including communicable diseases such as acquired immunodeficiency syndrome (AIDS)/human immunodeficiency virus (HIV) infection, malaria, and tuberculosis. It may also be in part because of a general lack of awareness among policy makers, the general public, and international private or

public health agencies concerning the magnitude of the current and future cancer burden and its economic impact. In addition, the incidence of childhood cancer is poorly known in much of the developing world. In Africa, reliable cancer registries cover only 1% of the population as the disease is extensively under-diagnosed. This implies the problem is much bigger than perceived (Jemal et al, 2011).

Zambia has not been spared from the problem of childhood cancer. According to Chintu, Athale and Patil (1995), between the years 1980 and 1992, 698 cases of Paediatric malignancies were diagnosed at the UTH, with a crude annual incidence of 2189 cases/million children. Overall, lymphoma was the commonest reported childhood malignancy (36-95%), followed by retinoblastoma (12 46%) and Kaposi's sarcoma (12 17%) (Athale & Patil, 1995).

Between February 2011 and August 2012 Zambia had about 831 cases with a total number of deaths of about 110. It is sad to note that a big number of these cases are reported and diagnosed when the disease has reached an advanced stage hence making the chances of survival very low (Kayula Childhood Cancer Foundation, 2012). At the same time many cases are not detected at all. Lack of early detection of childhood cancer contributes to late diagnosis, while early detection raises the chances of curing cancer by 70-85% (Kayula Childhood Cancer Foundation, 2012). Zambia loses 81% of children in the age group 0 to 15 years to cancer annually. The country has a mortality rate of 45% and has a record of 45% abandonment cases. This is mainly because some parents are unable to start and complete treatment due to the challenges faced in accessing treatment (Kayula Childhood Cancer Foundation, 2013).

Cancer is a difficult disease to deal with as it affects both the physical and the psychological wellbeing of the patient. It can happen quickly with little or no warning. Childhood cancer is such a debilitating illness with the ability to change the way a child looks at life. For close family members especially parents, having a cancer patient can be equally traumatising seeing a loved one endure such suffering. For both the patient and parents, it is a trying experience from diagnosis to the time of treatment. Several psychosocial effects of cancer and treatment on children and families have been documented. For example in trying to understand the psychosocial needs for children who have a brother or sister with cancer as well as for childhood cancer patients themselves, Patterson (2010) designed an instrument to

measure the psychosocial needs support. It addressed the emotional, social and practical challenges that siblings go through. As D'Agostino (2011) argues, in order to come up with sustainable psychosocial support, the main psychosocial needs that adolescents and young adults are going through need to be considered.

Psychosocial support is therefore crucial in helping uplift the feelings of the patient and the parents as they cope with the condition. Addressing the needs of parents should be looked into by the Paediatric Oncology departments in as much as they address the children's needs. In some hospitals in developed countries, the needs of parents and family are included in the treatment process by making available certain facilities like a living room with an Oncology specialist who is always ready to give advice to parents whose children have cancer (Kayula Childhood Cancer Foundation, 2013; International Confederation of Childhood Cancer Parent Organisation, 2006).

In Zambia the University Teaching Hospital (UTH) is currently the only government-funded institution offering oncology care to both adults and children (Slone et al, 2014). Recently, Cancer diseases Hospital (CDH) was opened at UTH that has enabled patients receive treatment at home. This was because, Zambia recorded a growth in the number of cancer patients to be treated abroad and it was very costly at an average of \$10000 per person. Over 3,000 new cancer cases are being detected in every one million Zambians annually (CDH, 2007). The objective of the CDH was to treat patients locally and to establishing a comprehensive cancer programme in Zambia. This means that the hospital should be able to train cancer specialists such as radiotherapists. However, it is important to note that the CDH did not include a Paediatric oncology ward although an extension to provide a Paediatric ward is now under construction in phase 2 of CDH (CDH, 2014).

Apart from UTH there are other institutions or organisations that offer psychosocial support services to children with cancer and their families to complement other services especially those provided by government. Examples of such organisations are the Zambian Childhood Cancer Foundation (ZACCAF) and the Kayula Childhood Cancer Foundation (KCCF). Realising the challenges families with children with cancer go through especially those from very poor backgrounds, ZACCAF provides psychosocial support to these families in various ways. These include awareness and education of early warning signs; transportation to and from the hospitals particularly for those who live far away from the UTH; food; clothing; organization of prayer and healing groups; interactive play therapy; bereavement support

programs; twinning programs for professionals; and direct medical and treatment support (ZACCAF, 2013).

As for KCCF it was created to support the paediatric oncology ward at UTH. This was due to the lack of deliberate interventions in psychosocial support for parents/guardians taking care of children with cancer at UTH, and the lack of a systematic follow-up mechanism for patients being discharged from the hospital. KCCF has a number of Psychosocial support services that it offers including a parents' house which is a transit home for parents/guardians as they wait for their children undergoing treatment; sensitisation/awareness programmes; parent support group formation; sibling programmes; pastoral care; support for bereaved families; and facilitation of scholarships for doctors in Hemato-oncology (KCCF, 2012).

Given the childhood cancer burden Zambia has, it is clear that a range of services are required including psychosocial support during treatment. As already shown above, Psychosocial support is crucial in the process of treating cancer. It is therefore important to examine the type of services that are available in this country i.e. at UTH. So far very few studies have been carried out on childhood cancer generally in Zambia let alone the parents' perspectives of children with cancer regarding the kind of psychosocial support that they need and receive. It is from this background that this study focuses on the perspectives of parents with childhood cancer patients in terms of psychosocial support services and needs whether met or unmet.

1.2 Statement of the Problem

Zambia is experiencing quite a lot of childhood cancer. For example between February 2011 and August 2012 Zambia had about 831 cases with a total number of deaths of about 110. Of those diagnosed with cancer, 81% die due to late diagnosis and treatment. When diagnosed with childhood cancer, many parents go through a difficult time due to the new condition the family is faced with in dealing with cancer. A number of studies have shown that parents' feelings are negatively affected as well as their physical well-being. Many of them experience anxiety, depression and stress (Othman et al, 2011). Despite their need for psychosocial support, there is only one paediatric oncology department in Zambia at the UTH catering for the whole country. As a result the paediatric oncology ward at UTH is over crowded with patients and parents/caregivers (most of who are from far places outside Lusaka). In addition, most of them are from very poor backgrounds and are unable to meet the day to day cost that cancer treatment comes with (Kayula Childhood Cancer Foundation, 2012).

In spite of these challenges, psychosocial support services for parents/guardians of children with cancer are not clearly stipulated. In fact, it has been argued that even in terms of statistics very little data is available on childhood cancer in African countries including Zambia. Notable among the studies on childhood cancer in Zambia include a retrospective study by Chintu, Athale and Patil (1995) looking at the effect of the HIV epidemic on the epidemiology of cancers in children at the UTH between 1980 and 1992; a cohort of children diagnosed with cancer at the UTH investigating treatment outcomes and risk factors for treatment abandonment by Slone and others (2014); and a case control study carried out between June and November 2005 looking at the impact of childhood cancer on immediate families of children with cancer at UTH by Kabinga (2006).

The study conducted by Kabinga (2006), was a quantitative case control hospital based study with 120 participants, 60 cases and 60 controls. The study revealed that majority of the cases (53.3%) had a high psychosocial impact with 95% confidence interval while 80% of the controls had a low psychosocial impact. This showed that families with a child with cancer were more likely to have financial pressures than their counterparts with a child with other illnesses. For instance, 61.7% of cases spent more than K100, 000 on diagnostic investigation expenses while 46.7% of controls did not spend any money on diagnostic investigations. While only 50% of controls had inadequate support system as compared to 66.7% of cases had inadequate support system (Kabinga, 2006).

Therefore, the results of this study and the other studies conducted at UTH showed that there was need to conduct a qualitative research study on the type of psychosocial support services that parents/guardians need and receive at the oncology ward at UTH. This study seeks to contribute to the emerging body of knowledge on childhood cancer in Zambia by focusing on another critical aspect of childhood cancer i.e. psychosocial support services with regard to the perspectives of parents with childhood cancer patients at the University Teaching Hospital (UTH) in Lusaka.

1.3. Justification for the study

This study explored parents'/guardians' perspectives and experiences with childhood cancer psychosocial support services at UTH. This is because few studies, especially qualitative studies have been done on childhood cancer in Zambia despite the increase in cancer cases in Zambia among both adults and children. The study recognises the importance of

Psychosocial support services in aiding parents with children with cancer both in terms of the parents' or guardian's well-being. When the parent/guardian is emotionally defeated, the capacity to care for the child is negatively affected thereby compromising the chances of survival of the child. However, the subject has not been adequately explored in Zambia. Most importantly, the study will contribute to the emerging knowledge on psychosocial services for caregivers of children with cancer, particularly in the context of Zambia. The study will also contribute to policy and practice at the UTH.

Therefore, through the recommendations, the study findings will inform policy makers and guide them in coming up with interventions that will support psychosocial support service delivery at UTH. The study findings will inform policy makers on the specific psychosocial support services that will be appreciated at the oncology ward. The study will also provide valuable information that can be used in designing effective and efficient strategies for health promotion Psychosocial support services for childhood cancer at the paediatric oncology ward at UTH. In addition the study is intended to contribute to the emerging literature on childhood cancer particularly psychosocial support in the context of Zambia.

1.4 Research Question

What are parents'/guardians' main psychosocial needs and experiences regarding childhood cancer psychosocial support at the University Teaching Hospital (UTH) in Lusaka?

General Objective

To find out parents'/guardians' main psychosocial needs and experiences of psychosocial support services for childhood cancer at the University Teaching Hospital (UTH) in Lusaka?

Specific Objectives

1. To assess parents'/guardians' pre awareness levels of childhood cancer
2. To assess the main psychosocial needs of parents/guardians of children with cancer.
3. To describe the experience of parents/guardians of children with childhood cancer regarding the psychosocial support services provided at UTH.
4. To find out the coping strategies that parents/guardians of children with cancer use.

1.5 Conceptual Framework

The conceptual framework used in this study is the psychosocial support (PSS) framework designed by the Inter-Agency Standing Committee for psychosocial support for mentally ill patients. This framework has been adopted from the SADC secretariat in order to help with

understanding the main issues concerning psychosocial support for parents/guardians caring for children with cancer and guide the analysis of the psychosocial support services at UTH.

The framework offers guidance to service providers in the delivery of multi-layered psychosocial support to individuals in stressful conditions. The framework also guides psychosocial responses that help the child, parents/guardians, the family, the peer groups, the community and the broader society. The framework fits in the Zambian setup, particularly the UTH case because of the main issues outlined in the psychosocial support intervention pyramid which clearly shows the different psychosocial needs for children and parents in stressful conditions such as suffering from cancer and nursing a childhood cancer patient. In addition, the framework was created for the SADC member states of which Zambia is a signatory and hence having similar experiences in terms of delivering psychosocial support services to vulnerable populations such as cancer patients and their families. The framework also takes into consideration cultural influences on psychosocial well-being, development, care and support across widely differing cultural and economic contexts.

The framework is linked to my study through its set priorities on psychosocial services and interventions that are similar to my study objectives. These are; knowledge, emotional and spiritual well-being and social well-being. The identified priority areas also help in responding to the needs of parents/guardians in a holistic manner that includes psychosocial care and psychosocial support. Furthermore, the framework shows how parents/guardians depend on other sectors in their day to day lives in order to have a stable well-being. These include; cultural, social, economic and political support, which clearly show that psychosocial support is a cross cutting service. Therefore, the framework can help policy makers in the designing, implementation, monitoring and mainstreaming psychosocial interventions for parents/guardians of childhood cancer patients at UTH.

The SADC secretariat adopted the framework for psychosocial support for orphans and other vulnerable children and youths. The framework has been used by some SADC member states in mainstreaming psychosocial support in various child ministries and noted among the organisations working in SADC member countries are; UNICEF, Save the Children Alliance, World Vision and the National Mandela Children's Foundation. These organisations have mainstreamed psychosocial support services in their psychosocial support policy initiatives and these include; Minimum Package of Services for Orphans and other Vulnerable Children and Youth, 2011; Strategic Framework and Programme of Action (2008–2015);

Comprehensive Care and Support for Orphans, Vulnerable Children and Youth in SADC, 2008; Framework for Advocacy for People Living with HIV and AIDS, 2008; Care and Support to Teaching and Learning, 2008; a framework for integrating comprehensive care and support for Orphans and Vulnerable Children and Youths in the education sector.

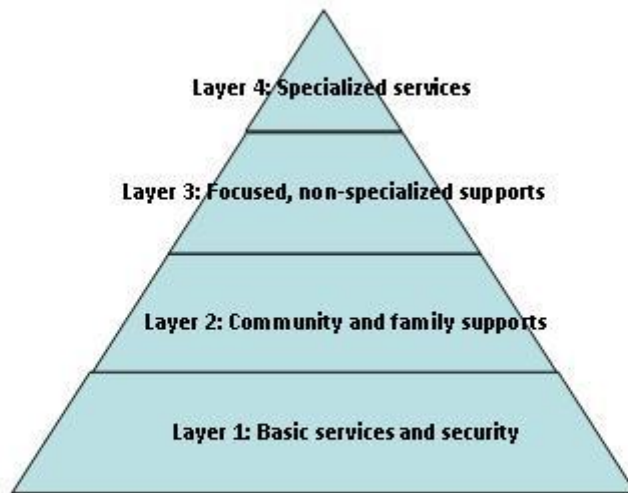
The framework is in form of a pyramid referred to as the psychosocial interventions pyramid. The pyramid has different levels of psychosocial support services that may be required by parents/guardians of children with cancer (SADC, 2011).

Intervention Pyramid for Psychosocial Support

The Inter-agency Standing Committee framework for Psychosocial Support is a framework originally designed for the assistance of mentally ill patients. However it can be adopted for different groups in distressful situations such as childhood cancer patients and their parents/guardians. The Intervention Pyramid is a multi-layered framework with psychosocial support broken into four different layers, namely; basic services and security, community and family support, focused non-specialised support and specialised services. The framework is suited for this study because it enables one to understand psychosocial support from a broad perspective that includes highly specialised support services from qualified personnel and general support at community level (IASC, 2007).

The framework is based on the belief that vulnerable people such as mentally ill people or cancer patients and parents/guardians require different kinds of support that is complementary in addressing the needs of patients. This is illustrated by a pyramid (see Figure 1). It must be noted that all layers of the pyramid are considered important and it is recommended that they should be implemented concurrently.

Figure 1: Intervention Pyramid for Psychosocial Support



Source: Inter-agency standing committee Guidelines on Mental Health and Psychosocial Support in Emergency Settings

- i. **Basic services and security** – Looks at protecting the well-being of patients and care-givers (parents/guardians) through the (re)establishment of security, adequate services that address basic physical needs (food, shelter, water, basic health care etc.). These services should be established in a participatory, safe and socially appropriate ways that protect local people’s dignity, strengthen local social supports and mobilise community networks
- ii. **Community and family supports** - The second layer emphasises the importance of family and community networks in supporting children with cancer and their parents/guardians. These include support groups such as cancer support groups.
- iii. **Focused, non-specialised supports** - The third layer represents support that is more focused through individual, family or group interventions by community health workers (but may not have specialised training).
- iv. **Specialised services** - The top layer of the pyramid represents the additional support provided by specialised or trained psychosocial service providers such as psychologists and oncologists (IASC, 2007).

1.6 Definition of Operational Concepts

Cancer

World Health Organisation defines Cancer as a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. A defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and can then invade adjoining parts of the body and spread to other organs. A process referred to as metastasis. Metastases are the major cause of death from cancer (WHO, 2014). In this study, the focus will be on childhood cancer among Paediatrics 0 – 15 years.

Paediatric

Medicine Net (2014), defines paediatrics as the specialty of medical science concerned with the health of infants, children and adolescents. The Paediatric field is concerned with the growth, development and opportunity of children to have full potential as adults (Medicine Net, 2014). Due to the nature of the disease, the study will focus on the psychosocial support of parents/ guardians of Paediatrics at the oncology ward at UTH.

Childhood

According to United Nations Children's Fund (UNICEF), Childhood is the period between birth and adulthood. However, it means much more than just the early stages of development as it refers to the state and condition of a child's life and the quality of those years. A period in which children should have time to play, go to school, grow strong, should be assured of love and encouragement from their family and the extended community with loving adults. In addition, children should be free in safe environments that are free from violence, abuse and exploitation (UNICEF, 2004). This study will work with the age group 0 to 15 years referred to as Paediatrics and are recorded as paediatrics at the paediatric oncology ward at UTH.

In addition, Southern African Development Community (SADC), defines a 'Child' as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger (SADC, 2011).

Psychosocial

SADC (2011) defines psychosocial as the close connection between psychological aspects of experience (thoughts and emotions) and the wider social experience (relationships, practices, traditions and culture), both of which interact to form the human experience. It also takes into account spiritual (values systems, beliefs) and physical aspects of an individual (SADC, 2011).

Psychosocial support

According to SADC (2011), psychosocial support is a holistic care and support that addresses the social, emotional, spiritual and psychological well-being of a person and influences both the individual and social environment in which people live. However, it's important to note that various countries have tried to clearly separate the meanings of 'psychosocial care' and 'psychosocial support' in terms of 'care' and 'support' (SADC, 2011). For this study, psychosocial support will be used to mean psychosocial care and support.

Parent

According to Universal Naming Convention (UNC), a parent may be a child's biological or adoptive parent, a person who is legally presumed to be a child's parent, or a person who has been determined by a court to be a child's parent (UNC, ND).

Guardian

The UNC defines a guardian as someone appointed by a court to have the care, custody, and control of a child or to arrange an appropriate placement for the child (A child's parent is considered the child's natural guardian). A guardian also has the authority to consent on the child's behalf to medical care and other matters for which a parent's consent ordinarily would be required (UNC, ND).

However, it is important to note that in Zambia, we still have a culture of inheriting children of departed or incapable relatives without going through the legal procedure.

2 LITERATURE REVIEW

This section examines literature on parents'/guardians' main psychosocial needs and experiences regarding childhood cancer psychosocial support. The literature review was grouped in four themes derived from the four objectives of the study. This review starts by looking at pre awareness levels of childhood cancer among parents/guardians of children with cancer followed by parents/guardians psychosocial support needs. It then looks at how parents cope with childhood cancer. Thereafter it examines parents'/guardians' perspectives on psychosocial support services they receive as they nurse children with cancer.

2.1 Parents'/guardians' pre awareness levels of childhood cancer

Low levels of childhood cancer awareness have been observed in different parts of the world. For instance in Romania the low survival rates of children with cancer and late diagnosis that have been observed there (compared to other European countries) has been attributed to low levels of awareness of childhood cancer. This necessitated P.A.V.E.L association to come up with a project entitled 'awareness for early detection of childhood cancer – the Romanian model'. It reached more than 230 people through 5 workshops and a conference with prevention and early detection of childhood cancer messages. Messages disseminated were on signs and symptoms of childhood cancer, possible causes of childhood cancers, types of childhood cancers, treatment of childhood cancers and advice on healthy lifestyle. In turn, all participants were expected to distribute all the IEC materials in all the 4 regions of the country. This was the first such campaign of prevention and awareness addressed to parents, primary medical staff, educators, social workers, and media in Romania (Cridland, 2010).

Elsewhere higher levels of childhood cancer knowledge have been noted. This can be observed in a cross-sectional survey of 742 parents whose children presented to a tertiary care paediatric emergency department with a head injury conducted by Boutis et al (2013) in the USA. The objective was to gain an understanding of parents' awareness of potential cancer risks due to the use of computed tomography (CT) scans in a paediatric emergency clinical setting and to determine the percentage of parents who were aware of the possibility of CT to increase a child's lifetime risk of malignancy in the Emergency Department (ED). The findings showed that almost half of the parents knew that CT scans were not entirely safe and could cause cancer but most of them still underestimated the risk of CT. The parents

understood that ionizing radiation from a CT to the head had a possibility of raising a child's lifetime malignancy risk. However, most of them still underestimated the risk of CT. This study found a higher percentage of parents' knowledge of chances of cancer due to CT scan as compared to a study conducted earlier by (Lee et al, 2004) where they reported 3% in adults who underwent an abdominal CT in the ED. The higher increase in parents' knowledge was attributed to media coverage through conversations with health care providers such as physicians, CT scans technologists, and nurses (Boutis et al, 2013).

A study was conducted by Harrison (2007) in Australia on the sun-protection knowledge of early childhood directors/senior staff, the adequacy of sun-protection behaviours practiced by children and staff members at each nursery school and the proportion of nursery schools with sun-protection policies. The study found that the knowledge levels on sun protection of Directors of nursery schools and other services was just average while pre-school teachers' level of knowledge was below average. Staff members protected themselves by wearing sun-protective clothing, hats and sunglasses but children did not. On the other hand, children used sunscreen more than staff members. In institutions where the directors had adequate knowledge on sun-protection, the attitude on using sun-protection was better. It was even higher in institutions where they had a written policy on sun-protection as compared to those that did not have written sun-protection policies (Harrison, 2007). The study was carried out in Queensland through a survey. A total of 2450 early childhood services (including long day care centres, family day care schemes, state- and privately funded preschools, kindergartens, limited hours care facilities and occasional care facilities) were identified.

Knowledge about cancer among parents is crucial because as Jemal et al (2011) argue, a significant proportion of the worldwide burden of cancer could be prevented through the application of existing cancer control knowledge, and by implementing programs for tobacco control, vaccination (for liver and cervical cancers), and early detection and treatment, as well as public health campaigns promoting physical activity and healthier dietary patterns (Jemal et al, 2011).

Northouse and others also carried out a examining the effect of caregiving on the health and well-being of caregivers, and the efficacy of research-tested interventions on patient and caregiver outcomes study in the US in 2012. The study involved a review of research that described the effects of cancer on caregivers' well-being. Five meta-analyses were analysed to determine the effect of interventions with caregivers on patient and caregiver outcomes. In

addition, various relevant legislation was also reviewed. Northouse et al observe that providing care for patients with cancer is complex and technical, and it requires intellectual and cognitive sophistication and physical stamina. However, family members often assume the caregiving role with little or no preparation and without considering whether they have enough knowledge, resources, or skills. Consequently, caregiving (i.e. providing care to patients with cancer) has a substantial impact on family caregivers' physical and mental well-being and can negatively influence patient and caregiver health outcomes (Northouse, 2012).

2.2 Psychosocial Support needs of parents/guardians of children with cancer

One of the most comprehensive works on psychosocial support needs for parents/guardians of children with cancer has been done by Farkas, A., Patenaude, and Kupst (2005) in the form of a review of qualitative papers from 1998 to May 2001. From this review a range of psychosocial needs parents with children with cancer are identified. One of these is the need for information. As a way of trying to gain control of the situation, it has been found that parents want to learn as much about the illness as possible by talking to health care providers, talking to other parents, and using the Internet. In fact it has been observed that parents want individualized information about the disease, prognosis, and care of their child, particularly during times of crisis and stress. Parents however differ in the level of information they wanted depending on the stage of the child's treatment.

Another important psychosocial support service needed by parents is time and support to enable them deal with the reality of the situation. Farkas, Patenaude, and Kupst (2005) therefore note that it is important that health care providers provide clear and consistent information. Health care providers also need to be aware that parents' ability to comprehend information will fluctuate throughout treatment, and they may need to repeat information, provide written information, and be patient if parents ask questions they have already answered.

Health care providers are also expected to encourage parents to adhere to treatments with scientific evidence for their effectiveness. This is crucial because parents may seek alternative treatments including non-conventional ones. Adherence could also be improved by providing advice about how to emotionally prepare children for treatments.

Providing individualized care is yet another important psychosocial need for parents according to Farkas, Patenaude, and Kupst's findings. This is on account of the differences in

how individuals cope, hence the need for health care providers need to identify each parent's coping styles and their main sources of stress. They go on to advise that it is important to help parents build on their existing resources and adjust their ways of coping so that they can manage this difficult experience especially those families with coping styles that may not match with the rapid response needed for cancer treatment and the unpredictability of the process. Such families may need more assistance in developing alternative coping strategies.

In addition it is recommended that the parents' culture should be considered when providing individualized care. Farkas, Patenaude, and Kupst observe that differences in the experiences of parents from different cultures have been observed hence health care providers need to be sensitive to these differences.

Also important is for staff to ensure that both parents are involved and supported in dealing with the child's cancer. The need to respect the role of the father is given particular emphasis. There seems to be a misconception that fathers do not want to be involved in their child's care, just because they may be away at work most of the time. In this light, services should ensure the hospital environment is welcoming and supportive for men too. Counselling and support programs may also need to be altered to meet the needs of fathers. Services should explain and challenge the gender stereotypes and help fathers and their family establish new patterns of male role behaviour during difficult times. Fathers should have the opportunity to meet with other men in the same situation in order to discuss their roles and coping strategies, especially with regard to coping with anger.

Furthermore, support from families, friends, and other parents is important hence the need to assist parents establishing a support network by for instance running on-going support groups for parents. They should also be encouraged to be spiritual in cases where this is applicable.

Parents also need support to enable them continue to fend for their families financially. Changes should be made in the workplace and in health care policies to provide adequate assistance, leaves of absence, and flexible hours to help ease this burden. Families should be supported with practical assistance, such as child minding for healthy siblings, travel, accommodation, and domestic help.

Equally important is to encourage parents to look after themselves as this will in turn also help them care for their ill child and their family. Nurses therefore need to monitor parents for burn out because of their desire to always be there for their child. Parents should be

encouraged to spend time with their spouse because there is evidence to show that support offered by spouses is crucial in helping parents cope. For those parents who are no longer living together, there may be an additional need for support in reorganizing their family life in the context of other family or personal demands (Farkas, Patenaude and Kupst, 2005).

Grootenhuis and Las in 1995 carried out a review of studies published since 1980 on psychological adjustment and coping of parents of children with cancer were reviewed. All studies were summarized in a review table, with information about the number of participating parents and children, the purpose, measures and major results. It was found that parents' marital relationships were negatively affected because of the emotional pressure due to long periods of hospitalisation. However, an improvement in marital relationships was found to lower the stress levels as well as completion of chemotherapy. 34% of mothers developed a psychiatric disorder. Compared to mothers, fathers worried much about the child's future and health but not about how to cope. Then single parents did not easily cope as compared to married couples. Parents of children with leukaemia were found to have a number of difficulties as compared to parents of children with other childhood cancers. On the other hand, parents of children with leukaemia had a higher acceptability in terms of medical care coping. Some parents experienced depression after 1 year of having a child diagnosed with childhood cancer (Grootenhuis and Las, 1995).

Another study was carried out by Patterson and others (2010) in Australia. Its objectives were to identify the psychosocial needs and unmet needs of young people who have a sibling with cancer and to present the initial findings in the development of a comprehensive needs-based instrument for this population. The study had a qualitative component consisting of a focus group discussion with 4 participants; and telephone interviews with 7 young people who had a sibling with cancer. It also had a quantitative component i.e. a survey of 57 staff who worked with this population. The study found 10 areas of need and an additional 80 items representing the various parts in each area of needs. The 10 areas are ranked as follows; Talk to peers with similar experience, Spend time with friends, To talk without feeling guilty, Spend time with peers with similar experience, Management of feelings/ behaviours, Support from my friends, Spend time with others affected, Do things unrelated to cancer, Coping with added family stress and Information about sibling's health. The top 10 un met needs are Feelings that sibling may die, Coping with added family stress, Talk with sibling about feelings, Open communication with friends, To talk without feeling guilty, Understanding

from friends, Management of feelings/behaviours, Spend time alone with parents, Talk openly without upsetting people and To feel as valued as their sibling (Patterson et al, 2010).

2.3 How parents cope with childhood cancer

How parents with children with cancer cope with their child's ailment is affected by different factors. Also they cope in different ways. From empirical and descriptive studies done by Grootenhuis and Las (1995) regarding emotional reactions and coping behaviour of parents who have children with cancer it was found that, apart from trying to understand the child's medical condition, families residing very far (over 100miles) from the hospital were very sad and more worried about transport. It was also found that in cases where parents were not satisfied with the help they received, they ended up pretending and not bringing out their true emotions. In some instances, they even put the blame on other people. However despite all these emotions and anxiety, some parents remained hopeful of a positive outcome i.e. the healing of their child. It was also found that personal contact with staff enabled families/parents to develop relationships with staff which in turn enhanced the level of satisfaction in terms of treatment offered (Grootenhuis and Las, 1995).

In a study meant to assess the coping strategies used by parents of children with cancer conducted by Hashemi et al (2007) in Iran, it was found that the most used coping strategy was spiritual support, followed by seeking help, reframing, passive appraisal and social support. The parents in the age group 20 to 29 years old preferred seeking help and reframing more than the parents in the older age groups. This implied that there was a high correlation between age and reframing and seeking help. It also shows that parents in the older age group did not often use coping strategies as much as parents in the younger age group of 20 to 29. There was also a high correlation between level of education and reframing where those with higher level of education used the strategy more than those parents with low levels of education. However, there was no correlation between level of education and other coping strategies. This study also found that fathers used reframing and spiritual support more than mothers who preferred social support, seeking help and passive appraisal coping strategies (Hashemi et al, 2007).

2.4 Psychosocial Support Services for parents/guardians of children with cancer

The role psychosocial support services play in helping to parents with children with cancer is widely acknowledged in literature. Psychosocial care provided to families during a child's

diagnosis of cancer may impact both short-term and long-term adaptation (Clarke, Mitchell and Slopper, 2004; Kazak et al., 2005; Alderfer et al., 2009). Despite this fact, Alderfer et al., found the lack of consistent services matched to the specific needs of families still a troublesome aspect of cancer care and Bauman et al., (1997) makes similar observations. He contends that a child's serious illness or disability can place psychological and social burdens on both child and family. Although children themselves bear the major psychosocial burden of their chronic health condition, studies have documented increased psychological risk among their parents. There is evidence that the psychological and social needs of these children and families are not adequately addressed through conventional systems of care. In particular, it has been documented that access to psychological and support services is limited (Clarke, Mitchell and Slopper, 2004; Kazak et al., 2005; Alderfer et al., 2009 and Bauman et al, 1997).

Some writers have focused on specific aspects of psychosocial support. For example Van Dongen-Melman (2000) particularly looks at aftercare for child surviving cancer, their parents and siblings. Whereas the need for medical follow-up programs is widely recognized, it is observed that psychosocial aftercare is still in its infancy. Van Dongen-Melman goes on to recommend different levels of psychosocial aftercare depending on the level of adjustment, that is, in terms of having no adjustment problems, having mild adjustment problems, and having serious adjustment problems. Specific services suggested include providing medical and psychosocial information. Medical and psychosocial information is considered crucial to reduce uncertainty and aiding patient and parents in reaching an understanding of the long-term medical and psychosocial consequences of childhood cancer (Van Dongen-Melman, 2000).

Others who have written on psychosocial support services for childhood cancer have gone on to argue for the need to have a comprehensive package of services. A review of family-based psychosocial interventions with Paediatric oncology populations by Meyler et al, (2012) is a good example. Findings from the study reveal that a considerable variation among interventions with respect to the intervention techniques used, family members targeted, level of intervention intensity, and methods of evaluation. The review highlights the feasibility of a family-based approach to intervention and the diverse ways in which family members can be incorporated into psychosocial interventions in Paediatric oncology. Overall the majority of interventions reviewed showed positive effects for participants (Meyler et al, 2012).

Progress in terms of coming up with such a comprehensive set of services may however be hampered by the fact that little is known about what types of care are provided, their frequency, or outcomes, even across major Paediatric oncology centres. This clearly comes out in a pilot study of intervention for caregivers of children with cancer by Kazak et al, (2005). Also, it is also observed there are no evidence-based interventions that include multiple members of the family during active cancer treatment (Kazak et al, 2005).

According to Clarke, Mitchell and Slopper (2004) research on the impact of childhood cancer in the UK has demonstrated that psychosocial support is an important part of service provision for patients and their families. It has been observed that parents and children experience a wide range of emotions throughout the illness, including uncertainty which is a key cause of anxiety, and distress. This can persist for both parents and children long after treatment ends. Families also face many changes in their everyday lives, practically, socially and emotionally. Literature shows that in the UK, support is provided and funded by a number of different organisations, both statutory and voluntary. However, services have tended to develop in an ad hoc manner, and historically from a time when patterns of treatment for and survival from childhood cancer were different. Generally there is little information about existing patterns of provision across the UK.

In terms of satisfaction with the psychosocial services provided in different areas, there are variations regarding how parents view them. Clarke, Mitchell and Slopper (2004) identify a number areas such as facilities like playrooms, televisions, videos/DVDs and play stations, hospital visiting hours, the support hospital nurses and/or social workers provide, and involvement in the care and treatment of their child, medical information received from doctors and nurses before and during treatment; support received during hospital to home transitions, support received to catch up with their studies when returning to school.

A lack of standard practices and procedures across centres and considerable variability between centres has also been observed with the main gaps identified being staffing, facilities, social and emotional support, and information. As a result attempts are still being made to develop standards and guidelines for care throughout the National Health Service, for example in the recently published National Service Framework for Children, Young People and Maternity Services, and the National Institute of Clinical Excellence is specifically working on childhood cancer guidelines. However areas for further development

have been highlighted and it is hoped that these results will inform the on-going and future development of psychosocial support guidelines (Clarke et al, 2004).

The importance of psychosocial support is also recognised in other literature. The Leukaemia and Lymphoma Society for instance provides guidelines to families whose child has been diagnosed with childhood cancer on how to cope with anxiety and social matters of the child's illness (Leukaemia and Lymphoma Society, 2012).

2.5 Summary of reviewed literature

A considerable amount of literature exists on parents'/guardians' experiences with childhood cancer especially in relation to psychosocial support needs and services when nursing a child with cancer. Low levels of childhood cancer awareness have been observed in different parts of the world. This has been linked to problems such as late diagnosis and low survival rates of children with cancer. Conversely high levels of awareness have been associated with positive outcomes such as early detection and awareness among parents regarding how to protect their children from known cancers. Concerning the way parents with children with cancer cope with childhood cancer, there are variations depending on factors such as distance to the place of treatment, marital status, marital relationship, and sex. Hence while some parents may cope quite positively, others experience a lot of problems due to nursing childhood cancer.

Coming to psychosocial support, it is evident that it is an important element in the treatment of cancer hence attempts to provide this service to families with children with cancer can be noted in different parts of the world by both state and non-state actors. The challenge however is how to come up with standard practices in providing proper services.

Overall little has been done regarding psychosocial support services to parents with children suffering from cancer in Zambia. Available literature focuses on other aspects of childhood cancer such as the impact of HIV/AIDS on childhood cancer and the abandonment of cancer treatment. This therefore calls for more studies on childhood cancer in order to build the emerging body of knowledge.

3 METHODOLOGY

3.1 Study design

This was a qualitative case study. It was an exploratory health facility-based study. The case study methodology used was an intrinsic approach that allows in-depth, multi-faceted explorations of complex issues in their real-life settings and enables one to generate an understanding as it can be used to explain, describe or explore events in the everyday contexts in which they occur. Therefore, this approach enabled us capture information through describing experiences of parents/guardians by responding to questions such as how, what and why in relation to psychosocial support services. In addition, the methodology brought out insights into what gaps exist in the delivery of psychosocial support services at the oncology ward. It involved parents/guardians of children with cancer undergoing treatment at the paediatric oncology ward at the University Teaching Hospital (UTH) in Lusaka district. The study design was selected because it was appropriate for establishing and bringing forth in-depth insights on perspectives of parents/guardians on psychosocial support needs and experiences at the paediatric oncology ward at UTH. The study design was also chosen because it enables one to learn what is happening within a particular setting and what issues are of concern within that setting.

3.2 Study setting

The study was conducted at the University Teaching Hospital (UTH) in Lusaka district. Lusaka is the provincial capital of Lusaka province and also the capital city of Zambia. It is comprised of urban and rural areas, with the large segment of the district being urban.

The University Teaching Hospital (UTH) is currently the only government-funded institution in Zambia offering oncology care to both adults and children. The UTH is a 2000-bed tertiary care institution in the capital of Lusaka and serves as the country's principal referral hospital. In the UTH's Department of Paediatrics and Child Health, the Haematology-Oncology Unit has a 32 bed-capacity and offers chemotherapy. Radiation therapy became available with the establishment of the Cancer Disease Hospital (CDH) on the grounds of the UTH in 2006. However, there remain inadequate human resources to provide fully adequate services including a typical nurse to patient ratio of 1:15. There is only one subspecialty trained Paediatric haematologist-oncologist in Zambia, and there are limited opportunities for doctors or nurses to obtain further subspecialty training (Slone et al, 2014).

Treatment with chemotherapy, radiation and surgery is offered at the UTH free of charge to citizens of Zambia. Chemotherapy protocols are derived from evidence-based protocols in the literature and are not necessarily adapted for LMIC. However, regardless of the protocol, inconsistent availability of cytotoxic drugs often dictates the regimen delivered to the patients, resulting in a lack of uniformity in treatment of specific cancers. Many patients travel more than 500 km from their homes to receive care at UTH. Once treatment has commenced, patients and caregivers often must remain on the hospital grounds while awaiting the next cycle of chemotherapy due to lack of local housing and inability to return home due to cost of travel (Slone et al, 2014).

3.3 Study Population

The study population comprised of parents/guardians of children with cancer at the paediatric oncology ward at UTH. The inclusion criteria are those whose child have been diagnosed and admitted in the ward. The parents/guardians were purposively selected from the paediatric oncology ward at UTH. The study focused on parents/ guardians of the paediatrics admitted at the paediatric oncology ward at UTH because they are the ones who accompany and take care of their children when they are sick and admitted in hospital. The study population also comprise of counsellors, social workers, nurses, pharmacist (chemotherapy administrator) and oncologist directly involved in the provision of treatment to children and psychosocial support to parents/guardians. In addition the study also included officials from non-governmental organisations providing psychosocial support services namely ZACCAF and KCCF.

3.4 Sampling and Sample size

The sample size was 22 respondents. 7 key informants and 15 parents/guardians. All parents/guardians admitted at the paediatric oncology ward at UTH were eligible for the study. Respondents were purposively recruited through the paediatric cancer register and appointment register from the paediatric oncology ward at UTH. Maximum-variation sampling criteria was used which simply means choosing parents/guardians with different characteristics based on demographic characteristics such as age, marital status and district of residence (Maykut and Morenhouse, 2000). Therefore, respondents coming from different districts (Lusaka and other districts), with varying marital status (Married, Single, Divorced & Widowed) and in different age groups (15-30, 31 and above) were enrolled in the study.

The counsellor, social worker, nurses, pharmacist (chemotherapy administrator) and oncologist directly involved with children with cancer under the paediatric oncology ward at UTH were enrolled on the study as key informants. 5 key informants were interviewed (1 social worker, 1 counsellor, 1 nurse, 1 chemotherapy administrator and 1 oncologist). These key informants were selected to provide information from a technical point of view. They also play a critical role in treating cancer patients. In addition, two key informants from the two cancer foundations operating in Zambia were included, one (1) from each foundation (KCCF and ZACCAF).

Inclusion Criteria

All parents/guardians whose children are admitted at the paediatric oncology ward at UTH were included in the study.

Exclusion Criteria

All parents/guardians whose child did not yet receive diagnosis and may not yet be aware that their child has cancer were excluded from the study.

3.5 Data Collection

In depth Interviews

Face-to-face in-depth interviews were conducted with parents/guardians who were selected to take part in the study using an In-depth interview guide. The interviews were conducted in English, Chinyanja, Chibemba and Silozi depending on the language preferences of the research participants. The four languages were selected in order to facilitate effective communication with respondents from different parts of the country. The In-depth interview guide was translated to at least two languages and this enabled effective communication during interviews. The In-depth interview guides were translated to the languages mentioned above while taking care to make sure the meaning was not lost. Therefore, the interview guides were translated and back translation without losing the meaning. The translation was done with the help of a local language expert, Elliot Ngulube at Centre for Infectious Diseases Research in Zambia (CIDRZ) department of research.

Interviews were recorded using a digital audio recorder. When participants refused to have the interview recorded, detailed handwritten interview notes were taken in an interview notebook. Data collection was done concurrently depending on the appointments made and the availability of research participants. Information collected included parents/guardians'

perspective of psychosocial support services offered, psychosocial support needs, how parents/guardians cope with childhood cancer at UTH and pre-awareness levels of parents/guardians on childhood cancer at Paediatric oncology ward at UTH from key informants.

Data collection and preliminary data analysis was a cyclical process: data collected were informing ensuing interviews and data collection was concluded when no new insight emerged, a stage called data saturation. This means that, even though the total number of participants was reached, no new information came out as I was getting similar/same responses. Therefore, all participants were interviewed as per sample size.

Key Informant Interviews

Key informant interviews (KII) were qualitative in-depth interviews with people who have first-hand knowledge on the subject matter and are part of the group or community of interest. Key informant interviews enabled me collect information from a wide range of professionals (Oncologist, Social Worker, Nurses, Counsellor, pharmacist (Chemotherapy administrator), and two staff from KCCF & ZACCAF who have first-hand knowledge about psychosocial support services at paediatric oncology ward at UTH. These professionals/experts, with their particular knowledge and understanding, provided insight on psychosocial support services and also gave recommendations. The Face to face interview technique using interview tool/guide was used to conduct the KII.

Data management

All recorded interviews were transcribed and translated verbatim is stored on a password protected computer with only access to researcher.

All interview transcripts constitute unit of analysis. Unit of analysis refers to all words and phrases of the interview transcripts. The data was coded into various themes that came out of the interviews. The conversations were coded in full and were read several times in order to make sense of the conversation in the transcripts. The interview conversations were then coded, and the codes were compared for similarities and differences by conducting within- and across-case analysis similar codes were then grouped together to form categories and then themes were developed by interpreting the categories for their underlying meaning (Ayres et al, 2003; Graneheim & Lundman, 2004).

Data Analysis

Recorded in-depth interviews and key informant interviews were listened to repeatedly in order to capture the meaning. The transcripts were shared with supervisors for review. Data was then transcribed and analysed using thematic analysis in word. Key statements, ideas and experiences were noted down and summarized. Similar codes were grouped together and compared the codes for similarities and differences. The data was further categorised in themes. The stages followed in data analysis were as follows;

1. Field notes were read and transcribed in less than 1 hour after the interview.
2. Recorded in-depth interviews and key informant interviews were listened to repeatedly in order to capture the context and meaning of the sentence.
3. Key statements, ideas and experiences were grouped together to form codes.
4. Similar codes were then grouped together.
5. The codes were then compared for similarities and differences.
6. The codes were then grouped into themes.
7. The themes were discussed further under discussion of the findings.

3.6 Ethical considerations

Ethical clearance was sought from the centre of Excellence in Research Ethics and Science (ERES). Permission was also obtained from UTH authorities.

Informed consent

The study was explained in detail to the participants that the objective of the research was to find out parents/guardians' main psychosocial needs and experiences of psychosocial support services for childhood cancer at the oncology ward. It was further explained that the research was going to be conducted through interviews with each participant at a time. The participants were informed that the study was purely an academic prerequisite for Master of Public Health Students.

Participants were not deceived or coerced into taking part in the study as it was clearly explained to them that whether they agree or refuse to take part in the study their treatment was not going to be affected in any way. Therefore, written informed consent was sought from the study participants before they took part in the study.

Respect for persons

In order to ensure participants' confidentiality, no names or personal identifiers were included in the In-depth Interview Guide and KII Guide. Identification of participants was

only done through numerical codes. Those who were unable to write and sign the informed consent, they used the thumb print to accept participation. And those who were not willing to take part did not take part. Those who could not continue with the interview were free to stop the interview, and those who were not comfortable with answering some questions were free and did not answer some questions.

The recorded interviews and transcribed transcripts are stored on a locked computer only accessed by the principal investigator. The interviews were conducted on appointment basis when the parent/guardian was available. The interviews were not conducted in the presence of the child but in private spaces (registry room) within the oncology ward to ensure both confidentiality and openness.

Beneficence

Since childhood cancer affects the emotional and physical wellbeing of both patients and parents hence many parents experience stress, anxiety and depression during the process of nursing a child with cancer. Talking about such a subject is therefore bound to raise quite strong emotions among parents. To address the possible risks of this study such as emotional breakdown (crying) during the interview and not finishing the interview, caution was taken by alerting and involving counsellors from UTH counselling centre, UTH chapel and the Oncology ward for spiritual support, who were informed in advance about the study. Therefore, the counsellor from the oncology ward was available to offer emotional support at the time of the interviews. At the same time, the social worker (counsellor) was also on standby in case the counsellor from the oncology ward was not available.

Parents/guardians were also informed that they were not receiving any direct physical, social and financial benefits from the study. But the information they were giving us will benefit patients and parents who will be admitted in the future. However, the anticipated benefit was the emotional and spiritual support from the counsellor at the oncology ward and UTH chapel who assured me that the doors at the chapel were always open. However, it's important to note that a good number of parents spoken to, were not aware of the chapel or UTH counselling centre. In fact, a good number of parents/guardians appreciated the interview as they were able to share their thoughts and experiences with the PI.

Justice

All eligible research participants were free to participate or decline. Some participants were not comfortable in responding to some questions and did not respond. Some were also not able to complete the interview during the first appointment and were allowed to stop and continue at the time when they were available.

3.7 Plan for dissemination of results

Results were disseminated at the graduate forum and will be shared with the department of Public Health. They will also be disseminated by publication in a peer reviewed journal. The results will be presented in form of a report.

3.8 Plan for disposal of research materials

All data collection tools containing participant responses will be destroyed after seven (7) years as per research standard. The voices from the voice recorder will be deleted from the computer where they are stored, while all written notes in research notebook will be destroyed by burning method.

4. FINDINGS OF THE STUDY

4.1 Background characteristics

A total of twenty two (22) respondents were interviewed, fifteen (15) parents/guardians to children with cancer, and seven (7) key informants. Five (5) out of the seven (7) key informants were members of staff at UTH's oncology ward while the other two (2) were members of staff at the two (2) cancer foundations in Lusaka namely, Kayula Childhood Cancer Foundation (KCCF), and Zambian Childhood Cancer Foundation (ZACCAF). Those from UTH included a Social worker, a Pharmacist (Chemotherapy Administrator), a Registered Nurse (Trained counsellor), an Enrolled Nurse, and an Oncology Doctor. The official from KCCF was also a Social Worker while the one from ZACCAF had health related professional background. It is from the experience that he went through of nursing his son who had a rare blood disorder called haemophilia that he decided to dedicate his energy to helping children with cancer. The officials had varying years of experience ranging from 1 year 6 months to 13 years (Table 1).

Table 1: Duration of service at Paediatric Oncology Ward/ Cancer Foundation

Profession of Key Informant	Duration of Service	
	Paediatric Oncology Ward	Cancer Foundation
Social Worker	2 years	
Social Worker		2 years +
Pharmacist (Chemotherapy Administrator)	3 years	
Registered Nurse (Trained Counselor)	13 years	
Enrolled Nurse	3 years 11 months	
Oncology Doctor	1 year 6 months	
Agricultural Meteorologist		4 years

The age for parents/guardians ranged from 15 years to 58 years. 14 parents/guardians were female and only 1 was male. In terms of marital status, 8 were married, 4 widowed, 1 was single, 1 divorced, and 1 a widower. The parents/guardians came from different parts of the country some as far as Luwingu, Lukulu and Kalabo. There were a good number from Lusaka though. Most of the parents interviewed were biological parents of the childhood cancer patients, but there were 2 who were grandparents, and 1 great grandparent.

Coming to the childhood cancer patients, their age ranged from 2 to 14 years, and they comprised both male and female. Some of them were in school while others were not. Of those not in school, 3 stopped attending school because of cancer while 1 couldn't start attending school because of cancer (Table 3).

Table 2: Age and Sex of Childhood Cancer Patient

Age	Female	Male	Totals
0-1 year	0	0	0
2-5 years	6	3	9
6-10 years	3	2	5
11-14 years	0	1	1
Totals	9	6	15

Six (6) types of cancers were mentioned as the cancers that children were diagnosed with at the oncology ward in this study. 14 out of 15 parents were already aware of diagnosis. Only 1 parent was still awaiting diagnosis. Of the 15 children, 4 children were diagnosed with Cancer of the kidney, 3 with leukaemia, another 3 with Retinol Blastoma, 2 with Lymphoma, 1 with cancer of the liver, another 1 with cancer of the lungs. 14 out of the 15 parents interviewed said their children were receiving treatment. Only 1 parent said her child was not receiving treatment due to low levels of blood and platelets the child had. Out of the 14 parents whose children were receiving treatment, 10 remembered the day and month the child started receiving treatment, 2 only remembered the day, and 2 could not remember when the child started receiving treatment.

4.2. Parents'/Guardians' knowledge of Childhood cancer

Inadequate Knowledge on childhood cancer: Key informants reported that most of the parents/guardians lacked knowledge of childhood cancers before diagnosis. This lack of knowledge contributed to parents/guardians presenting the children late at clinics/hospitals. They suggested that there was need to increase sensitisation on different cancers in order to enhance knowledge levels of cancer among parents/ guardians. One key informant explained this limited knowledge among parents or guardians as follows:

“The knowledge they exhibit is very low. Most people don't know about the different cancers as a result, they bring their children at a very late stage. They usually bring them when it's stage 3 or 4 when the cancer has really advanced and there is very little that the doctors can do”(Key informant 7).

Discussions with most of the parents/guardians confirmed that most of them did not know much about childhood cancer before diagnosis. Most of them had only heard about childhood cancer after diagnosis from the Oncology ward at UTH as one of them put it:

“I wouldn’t lie to you, I never heard about childhood cancer. Even the day I was told, I cried a lot that night and prayed a lot. Other parents encouraged me that it is just a disease, that we were going to be given medicine and that it may even be possible to go home for about 2 weeks and then come back”. (27-year old married female)

Because of limited knowledge on childhood cancer, some of the parents associated childhood cancers with witchcraft and other cultural beliefs. One key informant said:

“Before diagnosis, there is ignorance amongst most of them and they are suspicious and some of them suspect witchcraft” (Key informant 1).

This was worse by the teaching going on in some churches. It was reported that some pastors are teaching the wrong doctrines that misled and discouraged parents/guardians from seeking medical attention in preference for faith healing as one key informant put it:

“In terms of psychosocial needs, some of them don’t want to be counselled, in time when you continue they appreciate after wards but others even if you have counselled them, they stand their ground and want to be evacuated from the wards and they believe that the solution lies in the traditional healers. The other challenge is with the churches that are not teaching the right doctrine where pastors tell parents that their child has been healed even when the child still has cancer” (Key Informant 1).

Factors associated with this limited knowledge include low levels of literacy among some parents/guardians and the general lack of information on childhood cancer. In general, respondents reported that there were no deliberate awareness messages provided to parents/guardians on childhood cancers.

However, most parents/guardians reported that they experienced a change in levels of knowledge after diagnosis as compared to the time before diagnosis as one key informant put it.

“After diagnosis, most of them become quiet knowledgeable and they even educate the new caregivers when they come to the ward on the management of the disease and nutritional needs” (Key informant 5).

4.3. Parents’/Guardian’s main Psychosocial needs

Counselling: Several psychosocial needs were highlighted by the respondents. One of the main psychosocial needs was of counselling during cancer treatment. Almost all parents/guardians and key informants mentioned counselling as the main psychosocial support need for parents /guardians. Counselling is critical given the lack of knowledge among parents/guardians with childhood cancer patients, for example on the side effects of the cure. As exemplified in the quote below

“Parents should also understand the side effects of drugs such as nausea and loss of appetite and how they affect the child. Some side effects are severe while others are mild. Mothers should also be encouraged that the

pain the child is going through will go away in due course and they should just be compliant and follow up on reviews and necessary tests” (Key Informant 2).

Emotional support: This is another psychosocial support need parents/guardians identified. Most of them stated that once their children were diagnosed with cancer, they felt depressed, neglected or isolated and as such needed emotional support. Some parents felt that they needed emotional support from relatives, friends, the church, and the health workers in order to lighten their burden during the cancer treatment process as one parent put it:

“I should have been provided with emotional support so that whatever I am going through, I was going to face it with a strong heart” (23-year old single ‘mother’).

Financial support: Financial support was also mentioned as among the main psychosocial support need for parents/guardians at the oncology ward. Parents/guardians need financial support to among other things, enable them meet the cost of treatment and good nutrition for their children. As confirmed by one key informant,

“For the people coming from the rural setting, their challenges are that some of them their livelihoods are centred on agriculture at a small scale level and during this time, most of them would want to go back home and abandon treatment. Sometimes they would look at a situation where the breadwinner is here and they have a handful of siblings left behind and they need to look after them as well... The other challenge is transport, when they are asked to go back, its costly for them to travel back and then come back and for some, certain petty things need to be bought, but they can’t afford. Others could be things like diapers but they can’t afford them. Others do piece work in the nearby surroundings just to get money” (Key Informant 6).

Shelter: Shelter was also mentioned as an important need because parents/guardians need to be comfortable while taking care of their children. Some parents/guardians were concerned with the inadequate bed spaces whereby some parents/guardians together with the sick child would be sleeping on the floor. One key informant said:

“Bed space is something else, the caregivers have to sleep on the floor, they have no detergents and everybody has to fend for themselves unless otherwise when well-wishers come through to the ward”. (Key Informant 6)

4.4. Psychosocial support services provided to parents/guardians at the Paediatric oncology ward at UTH

Counselling: Counselling, was mentioned as one of the psychosocial support services provided to parents/guardians when they get admitted at the oncology ward at UTH.

“This is the only centre in the whole of Zambia that provides care in the management of children with cancers. So we have a lot of challenges with caregivers because most of them don’t have relatives in Lusaka and they stay here for a very long time like 7 months-1year. So there are a number of services that are provided to attend to the psychosocial needs..., we routinely re-engage the caregivers to provide peer to peer counselling as well” (Key informant 5)

Sometimes the hospital authorities brought a patient who had successfully gone through the counselling process and healing. They use this as an example to motivate the others. An example was even given of a parent/guardian whose child had cancer that could be easily

treated but refused to have the child treated. Several doctors spent time counselling the parents but they refused. They only agreed after the doctors brought a parent whose child had improved greatly after receiving 1 year of treatment.

Shelter: UTH provides shelter by accommodating the childhood cancer patients in the 2 wards at the Paediatric oncology ward. Providing accommodation is important because most of the patients and their parents/guardians come from districts outside Lusaka and do not have capacity to pay accommodation within Lusaka. One key informant said:

Information on Childhood Cancer management: This was also mentioned as one of the services provided to parents/guardians so that they understand what is involved during the treatment process. One key informant said:

“As a pharmacist I provide information on chemotherapy, side effects of drugs and on pain management”. (Key Informant 2)

There were however certain gaps in the services that were being provided identified key among which concerned nutrition.

Limited attention to nutritional aspects of the child: Lack of a nutritionist at the oncology ward was among the major gaps identified. It was found that childhood cancer patients need a special diet that can help them improve their immune system. As one key informant put it:

“We must also look into the nutrition; there are a lot of artificial drinks on the market. I see a lot of people walking tall carrying fizzy drinks and those are toxic. We know that chemo is toxic but why is it that there is no nutritionist at the ward. We have all those challenges when we come to the food and the interaction with the drug” (Key Informant 6).

Patient/health worker ratio: This is another challenge the oncology ward had to contend with. The oncology ward was overwhelmed due to the high number of patients compared to the number of counsellors and doctors hence its inability to provide proper health care to cancer patients.

“The services are definitely inadequate; we have huge challenges in meeting the demands and needs for the caregivers. The patient load is very high; a number of caregivers who need to be at the bedside to look after these patients is enormous and they come from very far off places, there are not many well-wishers to support the needs of these caregivers so we have a huge gap” (Key Informant 5).

Financial constraint: The above challenges are compounded by financial constraints. Due to lack of resources, a number of programmes for delivering psychosocial support services adequately cannot be put in place. One key informant said:

“We have just been burdened with financial constraints. We have a program that we would like to implement. We should be able to test whatever drugs that come because we don't know the effects of these drugs that come in, we must be able to test them we have already drawn a program with Ministry of Health and Mother to Child and it has already been approved” (Key Informant 6).

4.5. Experiences of parents/guardians at the oncology ward at UTH

Provision of treatment and care: Some of the parents were happy with the services that were being provided to them. Those who were happy with the services cited attention from doctors, regular checks and provision of medicines by the doctors and nurses. One parent said:

“I am happy with the doctors. When they come for rounds they take care of our children. They pay attention to them. Even at night, they come to check on the children and when they find a child who is very sick, they give that child medicine. Even nurses check on patients very early in the morning. So on that one I am very grateful” (34-year old married female).

Although some of the parents /guardians were happy with the services, others were not happy. Those who were not satisfied with the services indicated that the services that were being provided were inadequate.

Some parents reported that they were not happy with the attitude of some nurses towards them. Some nurses did not pay adequate attention to the patients as one parent put it:

“Although some nurses are good others are not good. There are those who know how to do the job and those who don’t know. Others pay attention while others don’t pay attention to the patients that is a problem”. (36-year old widow)

Financial Challenges: Most parents/guardians were financially constrained and hence experienced some challenges in meeting the cost of treatment and needs of the childhood cancer patient and those of children back home as exemplified in the quote below:

“I have had financial challenges, all the tests that are done I have to pay, and I have a home to take care of, I am a widow, I have children going to school. The other test was K 800.00 and CT scan I have to pay for all those. If you don’t find the money, cancer gets worse”. (39-year old widow)

Long periods of hospitalisation: Parents/guardians faced challenges because of the long periods they had to stay away from home during the process of treatment at the hospital. They worried a lot about the welfare of children back home and their spouses. In many instances, they were unable to continue with the various income generating activities that they were involved in. In some cases, parents who were in their early twenties had to stop or put school on hold in order to nurse their children as exemplified in the quotes below:

“Since am here, it’s difficult to pay attention to the ones at home. You know very well that as women we are the ones who take care of our homes. But now that am here, my husband back home is also finding it hard to look after the other children. I’m equally worried about them, I don’t know if they have all gone to school and if they have eaten” (44-year old married female).

Managing side effects of chemotherapy: Parents/guardians had challenges in managing the side effects of chemotherapy such as loss of appetite, loss of hair and diarrhoea. They also had challenges in practicing good habits that help in preventing cells from dropping such as limiting the number of visitors at the bedside as explained below:

“Since she started chemo, she has lost appetite; I find it difficult in giving her food” (30-year old married female).

“They say that when the child has cancer, you don’t allow a lot of visitors to visit him in the ward but from outside. So I have to remove him outside every time there are visitors. I was told to do this so that his cells don’t drop and to prevent him from contracting other diseases. This is the problem that I have”. (21-year old married female)

Loneliness: While some parents /guardians were fortunate enough to have supportive spouses or family members during the treatment process, many parents/guardians reported that they felt very lonely. This was common among widows, widower, divorcees, and single parents. They felt that having a spouse to nurse the child with would lighten the burden as one parent put it:

“I have a problem because, when I sit down to think, the mother to my child died, my relatives don’t help me. The relatives to my late wife don’t help me also, not even one of them has ever come to help me on any single day” (35-year old widower).

Poor health/physical strain: Parents/guardians reported experiencing poor health due to the stress of worrying and nursing a child with cancer. This also affected their ability to work hence becoming less productive.

“The problem I have is that I constantly get sick, either my legs or my waist. Such that I can’t do much work, even here at the hospital I keep on complaining. Although I planted some maize in the field before I came, I don’t think I will be able to do much when I get back” (58-year old married ‘great grandmother’).

Rumours and Gossip about childhood cancer: Some parents/guardians had a challenge with the type of advice they received from friends within their communities. In some cases, parents were not happy with friends and community members gossiping about the child’s illness. Some parents were even blamed for infecting their children with cancer by some of their family members as explained below:

“My child’s father’s family talked a lot. They think that I am responsible for the child’s illness; they don’t even pay attention to the child” (23-year old widow).

Bullying: Some parents expressed sadness at the way parents who had stayed longer at the oncology ward treated those who were new at the ward. It was reported that parents/guardians who stayed longer were more privileged to use the cooking space at any time as compared to new parents/guardians. One parent said:

“The only problem I have found here especially at the kitchen is that, those I found here have more authority than me at the kitchen. We fight for cooking space. So for me to cook I have to wait for those I found to cook that’s when I can cook” (36-year old widow).

High death rate of childhood cancer patients: The number of childhood cancer patients passing on at the oncology ward was of concern to parents/guardians. One parent parents said:

“I just pray to God that by God’s grace my child should be healed. Children die a lot here, yesterday one died and today another has died. So the recovery of children really depends on God. Doctors also ask us to pray even if they give us drug”. (35-year old widower)

Frequent change of doctors: Parents/guardians were also concerned with the frequent change of doctors. A number of them preferred to see doctors who had become familiar with their cases. One parent said:

“The problem is that, they change doctors, you will find that the doctor who knows the child’s case is gone, and then there is a new one and it takes time for us to get used to the new doctor. At least they should give us permanent doctors who are specialized in cancer”. (23-year old widow)

Limited shelter: The bed spaces are not adequate to cater for all the patients that are admitted. Most parents/guardians were also not happy with the quality of shelter offered at the oncology ward. This was confirmed by one key informant as exemplified in the quote below:

“And that unit itself is so small, bed space is quiet limited. The treatment of cancers takes very long and parents are asked to go and come back. But when you talk about people coming from far places as far as Ikelengi, Senanga, Petauke, Kalabo etc. those people usually have got nowhere to stay. As you are aware, the cost of treatment is extremely very high”. (Key informant 6)

4.6. Parents’/Guardian’s coping strategies

Given the above challenges parents/guardians they had to employ a number of strategies in order to cope with their situation such as the following:

Praying: This is the most common coping strategy that parents’/guardians use while nursing their children. They pray on their own, they pray with other parents within the wards, with some hospital officials, or with well-wishers who come to visit them. In addition, a number of them congregated at nearby churches where they are able to get spiritual support. One parent said:

“I try not to think hard. I just put God before me so that he cures my child. Time will come when I will go home when am given a break and so I don’t pay attention to myself but to the child. So I just pray to God since the disease has become common among children such that other children are born with cancer” (32-year old married female).

Support from family, friends, officials and well-wishers: Many parents/guardians relied on support from family members and friends during the treatment process as a coping strategy. They felt encouraged through visits, and financial support received from relatives/friends and the social welfare office. They also acknowledged the support from other parents within the wards. Furthermore, they received support from well-wishers/donors who came through to the ward. Below is how the support was explained by one parent:

“How I manage is that my husband is a free person he actually encourages me to take care of the child. He calls whenever he manages and he encourages me even when I tell him that the child is not improving. He says you have come a long way so don’t give up” (58-year old married ‘great grandmother’).

“I only manage because of people who come on Sunday and they bring us bread and drinks. I keep it for the child and give him whenever he asks for it. Otherwise I can’t manage buying food.” (44-year old divorcee ‘grandmother’)

Parents’ own income: Two parents were fortunate enough to be in formal employment hence they were able to cope by using their own income to provide for the child. These parents were also fortunate enough to have been given permission from their work places to nurse their children as one parent put it:

“Right now I manage, when the company gives me money and they bring it here. I do manage to buy for my daughter when she asks for something. I don’t misuse the money because I come from far and I don’t know how long this disease will last. I was given 3months paid leave. The whites also saw the problem that I have, first it was my wife who died then now my child who is sick so they know and I haven’t had a problem with them” (35-year old widower).

Making use of breaks from the hospital: When away from hospital during breaks, parents’/guardians ‘saw this as an opportunity to try and put their homes in order. They also carried their children along with them in order to participate in church or other community activities.

Birth control: Some parents/guardians put child bearing on hold as a coping strategy. They prevent having more children in the interim so that they could nurse the sick child well. One parent said:

“In terms of birth control, you know how men are, you can get pregnant anytime. So I went for an injection for 5yrs so that I don’t get pregnant and have time to look after the child who is not well” (23-year old married female).

Positive thinking: For some parents/guardians, positive thinking was seen as a coping strategy whereby one avoids thinking negatively about the sick child’s condition as one parent put it:

“Sometimes I just make myself happy. I think about nice things, I don’t think about the sickness, I chat with my friends and so on” (36-year old widow).

5 DISCUSSION OF FINDINGS

This study explored perspectives and experiences of parents/guardians of children with cancer in terms of psychosocial support services offered at the paediatric oncology ward at UTH. It particularly sought to assess parents'/guardians' pre awareness levels of childhood cancer; to assess the main psychosocial needs of parents/guardians of children with cancer; describe the views and experiences of parents/guardians of children with childhood cancer regarding the psychosocial support services provided at UTH; and to find out the coping strategies that parents/guardians of children with cancer use.

Below, the findings are discussed around the following themes: Parents/guardians' pre awareness levels of childhood cancer, main psychosocial needs of parents/guardians with children with cancer, the experiences of parents/guardians of children with childhood cancer regarding the psychosocial support services provided at UTH, and the coping strategies that parents/guardians of children with cancer use.

5.1 Parents/guardians' pre awareness levels of childhood cancer

Inadequate knowledge on childhood cancer

This study found that the majority of parents/guardians exhibited low levels of knowledge on childhood cancer. The parents/guardians had not heard about childhood cancer before their children were diagnosed with cancer. They were not knowledgeable about issues such as duration of treatment, care and management of cancer, and side effects of chemotherapy (e.g. loss of hair, vomiting, diarrhoea and poor appetite etc.)

These findings are consistent with the low levels of childhood cancer awareness that have been observed in different parts of the world. In a study conducted in Romania, the low survival rates of children with cancer and late diagnosis that have been observed there (compared to other European countries) have been attributed to low levels of awareness of childhood cancer (Cridland, 2010). A study conducted in Australia found that the knowledge levels on sun protection of Directors of nursery schools and other services was just average while pre-school teachers' level of knowledge was below average. In institutions where the directors had adequate knowledge on sun-protection, the attitude on using sun-protection was better. It was even higher in institutions where they had a written policy on sun-protection as compared to those that did not have written sun-protection policies (Harrison, 2007).

The study also found that due to lack of knowledge on childhood cancer, parents/guardians run to pastors or traditional healers for assistance. In some cases they only sought medical services when the traditional healers have failed. Therefore, such parents/guardians tend to present cases very late in stage 2, 3 or 4 when there is very little that doctors can do. As a result, the chances of survival are very low. Due to high levels of illiteracy coupled with ignorance among family members, some mothers were being blamed for the condition of the child by their families. Therefore, knowledge on childhood cancer among parents/guardians is very important in dealing with childhood cancer. As Jemal et al (2011) argue, a significant proportion of the worldwide burden of cancer could be prevented through the application of existing cancer control knowledge, by implementing programs for vaccination (for liver), early detection and treatment.

5.2 Main psychosocial needs

The psychosocial support needs of parents/guardians nursing children with childhood cancer at the oncology ward were many. These include counselling, support from family and friends, and spiritual support.

Counselling/information on cancer

This study found that parents'/guardians' main psychosocial need was counselling that includes provision of information on cancer in terms of disease management, treatment and side effects of chemotherapy. A study conducted by Farkas, Patenaude, and Kupst (2005), found that parents need information as a way of trying to gain control of the situation. It has been found that parents want to learn as much about the illness as possible by talking to health care providers, talking to other parents, and using the Internet. In fact it has been observed that parents want individualized information about the disease, prognosis, and care of their child, particularly during times of crisis and stress (Farkas, Patenaude, and Kupst (2005). In a study conducted by Van Dongen-Melman, it was found that medical and psychosocial information is considered crucial to reduce uncertainty and aiding patient and parents in reaching an understanding of the long-term medical and psychosocial consequences of childhood cancer (Van Dongen-Melman, 2000). Another study by Grootenhuis and Las found that, personal contact with staff enabled families/parents to develop relationships with staff which in turn enhanced the level of satisfaction in terms of treatment offered (Grootenhuis and Las, 1995).

5.3 Experiences of parents/guardians

Parents/guardians described a number of experiences that they go through at the oncology ward. These are as follows:

Inadequate and not easily accessible services

This study found that most parents/guardians felt that the psychosocial support services offered at the Paediatric oncology ward were not easily accessible as they did not receive some of the psychosocial support services like counselling due to the inadequate human resource to offer counselling and emotional support. There was also inadequate bed space hence some parents slept on the floor with their childhood cancer patients. Other studies found that there is evidence that the psychological and social needs of children with cancer and their families are not adequately addressed through conventional systems of care. In particular, it has been documented that access to psychological and support services is limited in health facilities (Clarke, Mitchell and Slopper, 2004; Kazak et al., 2005; Alderfer et al., 2009 and Bauman et al, 1999). In a study conducted by Alderfer et al (2009) for example, it was found that the lack of consistent services matched to the specific needs of families is still a troublesome aspect of cancer care.

Financial Challenges

The study found that almost all parents/guardians had financial challenges in meeting the cost of treatment (e.g. scan and MRI), the cost of transport, cost of living for children back home, providing food and other needs for the childhood cancer patient as well as the parents'/guardians' own well-being. A study done by Grootenhuis and Las (1995) found similar challenges among families with childhood cancer patients. Apart from trying to understand the child's medical condition, transport costs posed a serious challenge especially for those who lived far (over 100 miles) from the health facility. Slone et al. (2014) confirm these challenges in that they found that many patients had to travel long distances in order to receive care at UTH. (Slone et al, 2014).

Furthermore, this study found that parents/guardians financial challenges were compounded by the fact that they had to stop or put on hold their income generating activities such as farming and retail businesses. This led to their income being negatively affected hence being unable to meet the cost of treatment, transport, providing the needs of the childhood cancer patient and the children back home and their own well-being.

Long period of hospitalisation

This study found that women had a bigger burden to carry when nursing childhood cancer patients. This can be attributed to the gender roles women have to play in Zambia with regard to nursing sick members of the family. In addition, most female parents/guardians had to deal with moody unhappy husbands complaining about their long absence from home and how difficult it was for them to stay without their wives. Some female parents/guardians who were married feared that their husbands may find other women while they were at the hospital. Female parents/guardians also had a problem with giving attention to children back home while at the hospital taking care of the sick child. Furthermore, female parents/guardians had the burden of household tasks increasing while they are away from home and it was a challenge to clean the household during the short breaks they spent at home. This is similar to findings from a study conducted by Grootenhuis and Las, 1995, where it was found that parents' marital relationships were negatively affected because of the emotional pressure caused by long periods of hospitalisation (Grootenhuis and Las, 1995).

5.4 Coping strategies

This study found that how parents with children with cancer cope with their child's ailment is affected by different factors and they cope in different ways. The strategies are discussed in the sub themes below:

Praying

Turning to God in prayer was a common coping strategy among Parents/guardians. They prayed as individuals, with peers in the ward, with medical staff, and with congregants in the nearby churches. Similarly, in a study meant to assess the coping strategies used by parents of children with cancer conducted by Hashemi et al, (2007) in Iran, it was found that the most used coping strategy was spiritual support (Hashemi et al, 2007).

Other coping strategies

Other coping strategies that parents/guardians were using include, carrying the child along for the parent was involved in outdoor activities e.g. for income generation, support/ help from family (financial or presence of family member), making use of breaks from treatment at the hospital to attend to other duties, support from friends within the ward and thinking positively in spite of the child's ailment.

Unable to cope

Despite the above strategies, the study also found that some parents/guardians were not coping well with regard to the following: their spouse if married, giving attention to other children, their own well-being, their work, household chores, meeting expectation from the sick child or needs of the child, participating in religious activities or any community events and in accessing medical services.

6 LIMITATIONS OF THE STUDY

The study only focused on one institution- UTH. Therefore the findings from the study cannot be generalised to other health facilities elsewhere. However, valuable information has been generated concerning perspectives of parents/guardians on psychosocial support needs as they take care of their children with cancer at the UTH oncology ward.

Another limitation is that some parents/guardians could not complete interviews due to the critical condition of their children. It was not possible to follow some of them up due to the demise of their children. Others were lost after being discharged from the hospital during the study period. The study did not include views of the psychologist as planned. At the time of the interview, he was out of the country for further studies.

7 CONCLUSIONS

Due to low levels of knowledge on childhood cancer, parents/guardians tend to present cases late in third or fourth stage when there is very little or nothing that the doctors can do in terms of cure leading to low chances of survival for most of the childhood cancer patients. In addition, parents/guardians do not have adequate counselling and information on cancer. As a result, parents/guardians feel that they do not have control of the situation. They are not fully aware of the prognosis; they don't know how to care for their child in certain conditions and they are not aware of the side effects of chemotherapy such as lose of hair, loss of appetite and vomiting.

A number of experiences parents/guardians of childhood cancer patients at the oncology ward at UTH complained about concerned financial challenges. Financial challenges negatively

affected the process of seeking medical care and provision of nutritious food to the childhood cancer patient, supporting children back home and for the well-being of parents/guardians themselves. It is very important to note that good nutrition is very vital during the process of cancer treatment. If the child lacks good nutrition, then the chances of the childhood cancer patient responding positively to treatment are compromised and hence the survival of the cancer patient being negatively affected.

Since cancer treatment takes long, many parents/guardians especially women complained about the long period of hospitalisation. Due to their gender roles, women carry a heavy burden of nursing the sick and in this case their children. The the long periods of hospitalisation sometimes bring about marital disputes due to suspicion of extra marital affairs. Instead of mothers receiving emotional support from their spouses, they had to deal with nagging/ unhappy/lonely husbands when they are visiting them or communicating via mobile phones. This made the mothers more worried, anxious and depressed.

Lack of adequate and easy access to psychosocial support is likely to negatively affect parents/guardians emotionally as well as add to their already stressful condition of nursing a childhood cancer patient. However, not all hope is lost as parents/guardians find comfort in spiritual support when they pray with peers, with people from nearby churches and cancer organisations that come through to the ward. This helped in uplifting their spirits.

These findings are a reflection of an in-depth, context-specific understanding of the hurdles to delivering psychosocial support services to parents/guardians of childhood cancer patients at the Paediatric oncology ward at UTH. It also creates awareness on childhood cancers in a Zambian specific context that will enlighten the public on childhood cancers as an issue of public health concern.

8 RECOMMENDATIONS

Mainstreaming psychosocial support services into policies: The UTH management should consider mainstreaming and strengthening psychosocial support policies. This will help in informing the public about childhood cancers. It will also help in designing strategies that are context specific to fit the needs of parents/guardians at UTH. Whereby, all the psychosocial support interventions should be able to respond to the needs of the children with their parents/guardians.

Making childhood cancer services available in district hospitals: The government of Zambia through the MOH should consider purchasing equipment such as MRI and CT scans for district/provincial hospitals so that parents/guardians with children with cancer can easily access these services. With the availability of the MRI and CT scans, childhood cancer cases will be detected early. If cancer is detected early and treatment is sought, the chances of survival are higher as compared to when it is not detected in the early stages.

Decentralise cancer treatment to district/provincial level: Making cancer diagnosis and treatment available in district/provincial hospitals will address a number of challenges parents/guardians are facing in accessing treatment at UTH's Paediatric oncology ward. Parents/guardians will be able to access treatment from their district/province of residence. They will reduce on the cost of transport; they may be able to continue with their businesses, they will be able to give attention to other children as they will be home and worry less about the other children. For those who are married this will enable them to be available for their spouses and maintain healthy relations hence reducing on emotional stress.

Increase coverage and frequency of awareness campaigns: Community outreach awareness campaigns will be an ideal way of increasing awareness on childhood cancers. The messages should include; prevention, symptoms and treatment of childhood cancers. These should be conducted at community level in all districts and provinces. Eventually, knowledge on childhood cancer will increase in communities. Stakeholders at grassroots level should be involved during campaigns as they are influential in communities. The media such as print media, radio and television can play a big role in creating awareness in form of commercials and advertisements. The government through the Ministry of Health and UTH should consider creating awareness campaigns frequently.

Produce IEC materials on Childhood cancers: The government with support of companies (social responsibility) should also consider producing IEC materials that should be translated in 7 major languages spoken in Zambia. This will allow those who cannot read English access information on childhood cancers. The IEC materials can be in form of brochures or posters that can be distributed in schools, clinics, hospitals, work places and market places. The messages on IEC materials should be on different types of childhood cancers and their symptoms. This information will help in reducing late presentation of cases and high mortality rate of childhood cancer patients.

Human resource specialised in childhood cancers: The government of Zambia through the UTH should consider training Paediatric oncology doctors who will be specialised in diagnosis and treatment of childhood cancers. Nurses specialised in childhood cancer management and care should be trained as well. More MRI and CT scan operators should be trained as well. More counsellors and psychologists who will be readily available to parents/guardians should be trained too. Chemotherapy administrators should be trained as well. With more human resource trained, the nurse to patient ratio can be reduced, more parents/guardians will receive psychosocial support services as needed and adequate information on childhood cancer management and care as well as side effects of chemotherapy can be provided. This will further reduce the levels of negligence towards care and management of childhood cancer patients.

The UTH management should further consider providing an officer specialised in nutrition. The Officer should be stationed at the oncology ward to offer nutrition advice to parents/guardians of childhood cancer patients. This will enable parents/guardians know what kind of food to provide to their children.

9 REFERENCES

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10 APPENDICES

Appendix 1: In-depth interview guide for parents/ guardians

ID No.....Interviewer.....Date of interview.....

Age of Parent/Guardian..... Sex of Parent/Guardian.....

District of Residence.....

Duration of treatment at Paediatric Oncology Ward.....

Age of Child.....Sex of Child.....

Background information

1. What is your relationship with the child?
2. Does the child go to school? (What grade are they doing or if not in school 'why'?)
3. What type of cancer does your child suffer from?
4. When was the child diagnosed with cancer?
5. Is the child receiving treatment? (If yes, since when?)

Awareness/ Knowledge about cancer

6. When did you first hear about childhood cancer?
7. Where did you hear about childhood cancer?
8. Did you know/hear about it before your child was diagnosed?

Care for children

9. How do you manage taking care of the child on a daily basis?
10. What challenges if any have you experienced since your child was diagnosed with cancer in relation to the following:
 - Relationship with spouse if married
 - Attention to other children,

- Parent's own well-being
- Parent's work
- Looking after your child
- Doing other household tasks
- Relationship with you friends
- Relationship with the community
- Support from family
- Accessing medical services
- General stress or concerns

11. How have you been able to cope with your child's illness in relation to the following:

- Relationship with spouse if married
- Attention to other children,
- Parent's own well-being
- Parent's work
- Household chores
- Expectation from the child or needs of the child
- Religious activities or any community events
- Access to medical services

Support Services

12. What is your comment about support from relatives, friends, the church etc.?

13. What type of psychosocial support services do you receive here at the Paediatric oncology ward?

- Probe for counselling, shelter, spiritual and emotional support
- Probe for the frequency of the services

14. Are the services easily accessible (Probe if they get them any time they need the services).
15. What do you think about the quality/adequacy of psychosocial support services that you receive here at the Paediatric oncology ward?
16. Are you satisfied with the psychosocial support services that you receive here at the Paediatric oncology ward? (If yes, what service are you satisfied with?)
17. If not, what service(s) are you dissatisfied with?
18. What psychosocial support should be provided from diagnosis to treatment of children with cancer?

If there are no questions or concerns, we have now come to the end of our interview. Thank you very much for your time and your participation.

Appendix 2: key informant interview guide

ID No.....Interviewer.....Date of interview.....

Profession of interviewee.....

Duration of service at Paediatric Oncology Ward.....

Duration of service at Cancer Foundation.....

1. What does your work involve in relation to childhood cancer?
2. According to your assessment, what are the levels of knowledge about cancer among parents before diagnosis, and after diagnosis?
3. Do you provide any psychosocial services to parents/ guardians with children with cancer?
 - Probe for services such as counselling, emotional or spiritual support, information about childhood cancer, and
4. Do you have any deliberate awareness messages on childhood cancer for parents after diagnosis?

5. What are the main psychosocial support needs of parents/guardians with children with cancer at the Paediatric oncology ward?
6. What psychosocial support services are provided to parents/guardians with children with cancer at the Paediatric oncology ward?
7. Are the services adequate in relation to the needs of parents with children with cancer?
8. Do the services meet your professional standards (if any) that you are guided by?
9. What challenges, if any, do you face in providing psychosocial services to parents/guardians with children with cancer at the Paediatric oncology ward?
10. What should be done to enhance the psychosocial services?

If there are no questions or concerns, we have now come to the end of our interview. Thank you very much for your time and your participation

Appendix 3: Consent form

Parents/Guardians' Perspectives of Psychosocial Support Services at Paediatric Oncology ward at UTH in Lusaka district, Zambia

What the study is all about

My name is Mulima Walubita. I am a Master of Public Health (MPH) student at the University of Zambia-Ridgeway campus. I am conducting a study on the views of parents/guardians of children with cancer on the Psychosocial Support Services offered at the Paediatric oncology ward at UTH. I will be interviewing caregivers like parents, guardians, as well as health workers at the Paediatric oncology ward at UTH. Due to your involvement or experience of nursing a child with cancer, I am asking for your participation in this study.

I also want you to know that your participation in this study is voluntary. You are free not to answer any questions that you are not comfortable with. You can also withdraw from the study at any time without any consequences for doing so. The information you will provide will be strictly confidential and your identity will be protected and your names will not be used but numerical codes as identifiers.

In case of any emotional issues during the interview, counselling services will be offered to you by a counsellor from the UTH counselling centre. The interview will be conducted in a confidential manner and setting. There will be no direct and immediate material and financial benefits to you. In general, this study will help contribute towards the improvement of the psychosocial support services for children with childhood cancer, parents/guardians who will be admitted at the Paediatric Oncology ward in future.

This study has been approved by the Excellence in Research Ethics and Science (ERES) and permission has also been obtained from UTH, Ministry of health/Ministry of Community Development Mother and child health, Lusaka District Health Office and Paediatric Oncology Ward Management. Should you have any questions or want clarification about the study, do not hesitate to get in touch directly with me. For any questions and concerns you can call me on phone number, 0977-842135 or email me at mulimawalubita@gmail.com.

Purpose of the research

To find out parents'/guardians' main psychosocial needs and experiences of psychosocial support services for childhood cancer at the University Teaching Hospital (UTH) in Lusaka?

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not.

Duration

Kindly be informed that you will only participate in one interview. The in-depth interview will be held once and will take about 30 minutes. The key informant interview will last for 40 minutes.

Risks

Since childhood cancer affects the emotional and physical wellbeing of both patients and parents hence many parents experience stress, anxiety and depression during the process of nursing a child with cancer. Talking about such a subject is therefore bound to raise quite strong emotions among parents. To address the possible risks of this study such as emotional breakdown (crying) during the interview and not finishing the interview, caution will be

taken by alerting and involving counsellors from UTH counselling centre and the UTH chapel for spiritual support, who will be informed in advance about the study.

Benefits

To mitigate the risks, parents/guardians will be informed that they will not receive any direct physical, social and financial benefits from the study. The anticipated benefit is the emotional and spiritual support from UTH counselling centre and UTH chapel. Usually when one is in a distressful condition, receiving emotional and spiritual support will uplift the emotions and give them hope. However, the information they will be giving us will benefit patients and parents who will be admitted in the future.

Reimbursements

All parents/guardians who will take part in the study will be given an amount of K100, 00. The reimbursement is meant to compensate for the amount of time they would have lost in the interview. Will further explain that this is not payment for taking part in the study but compensation for the time they will have spent with me instead of doing their personal errands and caring for the sick child.

Confidentiality

In order to ensure participants' confidentiality, no names or personal identifiers will be included in the In-depth Interview Guide and KII Guide. Identification of an informant will only be done through numerical codes.

Sharing the results

Results will be disseminated at the Graduate forum, to UTH paediatric oncology ward management, department of Public Health and publication in a peer reviewed journal. The results will be presented in form of a report.

Right to refuse or withdraw

The study will be explained to the participants before they take part in the study. Their right to refuse or withdraw from the study will be explained. Those not willing to take part will not take part. Those who will feel like discontinuing/withdrawing the interview middle way will be free to do so, and those who will feel like not answering some questions will be free to do

so. Participants will not be deceived or coerced into taking part in the study. It will clearly be explained to them that whether they agree or refuse to take part in the study their treatment will not in any way be affected. The interviews will not be conducted in the presence of the child but it will be in private spaces within the health facility to ensure both confidentiality and openness.

Who to contact

Should you have any questions or want clarification about the study, do not hesitate to get in touch directly with me. For any questions and concerns you can call me on phone number, 0977-842135 or email me at mulimawalubita@gmail.com. You can also get in touch with Excellence in Research Ethics and Science (ERES) on the following numbers +260 955 155633/+260 955 155634 or email them at eresconverge@yahoo.co.uk. You can also visit them at 33 Joseph Mwilwa Road, Rhodes Park, Lusaka, Zambia.

INFORMED CONSENT FORM

Dear participant,

The material in the consent form has been read out and explained to me. I understand that taking part in the study is voluntary and that my privacy will be respected. All questions I had have been answered to my fulfilment. I choose to take part freely and voluntarily.

Ihas given consent to take part in the study.

Signature or (Thumbprint).....

Date.....