

**IMPACT OF CHILDHOOD CANCER ON IMMEDIATE FAMILIES
OF CHILDREN WITH CANCER AT THE UNIVERSITY
TEACHING HOSPITAL, LUSAKA, ZAMBIA.**

By

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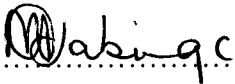
2006

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DECLARATION

I hereby declare that with the exception of the assistance acknowledged, the work presented in this study for the Master of Science in Nursing Degree is the result of my own work. This work has not been presented either wholly or in part for any other Degree and is not being currently submitted for any other Degree.

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CERTIFICATE OF APPROVAL

This Dissertation of Marjorie Kabinga has been as approved as partial fulfillment of the requirements for the award of the Master of Science in Nursing Degree by the University of Zambia.

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ABSTRACT

The study was carried out to assess the impact of childhood cancer on immediate families of children with cancer at the University Teaching Hospital, Lusaka with the aim of making recommendations to assist these families.

Objectives: The objectives of the study were to determine the financial and psychosocial impact of childhood cancer on the families, assess their financial and psychosocial support systems and compare with that of families who have children with other medical illnesses.

Study Design: A case control hospital based study was carried out between June and November 2005. Cases were families of children with cancer admitted to the Pediatric Hematology-oncology ward at UTH while controls were families of children admitted to ward AO8 for medical illnesses.

Setting: The study setting was the University Teaching Hospital, Pediatric Hematology-oncology ward and AO8 (Pediatric Medical Ward), Lusaka, Zambia.

Subjects: A total of 120 subjects were recruited in the study, out of which 60 were cases and 60 were controls. An interview schedule was used to collect data.

Main outcome measures: The main outcome measures were psychosocial impact, financial impact and support systems.

Results: The findings revealed that majority of the cases (53.3%) had a high psychosocial impact OR=4.6 (CI 95%; 2.03, 10.28; $p<0.01$, $df=1$) while 80% of the controls had a low psychosocial impact.

The study showed that families with a child with cancer were more likely to have financial pressures than their counterparts with a child with other medical illnesses ($p<0.01$). The study further showed that there was a statistical significant difference ($p<0.01$) between the cases (88.3%) and controls (3.3%) in terms of expenditure of more than K100, 000 on medication. Majority of controls (41.7%) spent less than K50, 000 on medication. On diagnostic investigation expenses, 61.7% of cases spent more than K100, 000 while 46.7% of controls did not spend any money on investigations. On support systems, most of the cases (66.7%) had inadequate support systems as compared to controls [(50%) ($p=0.064$)].

Conclusion: In order to help these families, some of the recommendations that were made to the concerned parties are:

1. There is need to strengthen counseling sessions to help clients who have children with cancer. More counselors among nurses need to be trained because nurses spend more time with the clients.

2. There is need to raise awareness among community members on support of families who have children with cancer.
3. Support groups should be formed in the community in collaboration with religious and nongovernmental organizations to assist families of children who have cancer.
4. The government should strengthen the social welfare department in assistance of these clients as most of the families come from far places and they have no relatives in Lusaka.
5. There is need for replication of the study using larger samples.

To all the children with cancer in Zambia.

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TABLE OF CONTENT

Item	Page
Declaration.....	i
Certificate of Approval.....	ii
Copyright.....	iii
Abstract.....	iv
Dedication.....	vii
Acknowledgements.....	viii
 CHAPTER 1: INTRODUCTION.....	 1
1.1 Background Information.....	1
1.2 Statement of the problem.....	5
1.3 Impact of cancer on immediate families.....	6
1.3.1 Psychosocial impact on the family.....	6
1.3.2 Financial impact on the families.....	7
1.3.3 Service factors impacting on the families.....	8
1.4 Justification of the study.....	11
1.5 Objectives.....	12
1.5.1 General objectives.....	12
1.5.2 Specific objectives.....	12
1.6 Operational definitions.....	12
1.7 Study variables.....	13

CHAPTER 2: LITERATURE REVIEW.....	15
2.1 Introduction.....	15
2.2 Psychosocial Impact.....	15
2.3 Financial Impact.....	19
2.4 Support systems.....	21
2.5 Conclusion.....	23
 CHAPTER 3: RESEARCH METHODOLOGY.....	 24
3.1 Introduction.....	24
3.2 Research Design.....	24
3.3 Research Setting.....	24
3.4 Study Population.....	25
3.5 Sample size.....	25
3.6 Sample selection.....	25
3.7 Data Collection tool.....	26
3.7.1 Validity.....	27
3.7.2 Reliability.....	27
3.8 Data collection technique.....	28
3.9 Pilot Study.....	28
3.10 Ethical and Cultural Consideration.....	28
3.11 Data processing and analysis.....	29
3.12 Limitations of the study.....	29

CHAPTER 4: DATA ANALYSIS AND PRESENTATION OF FINDINGS.. 31

4.1	Introduction.....	31
4.2	Socio-demographic characteristics.....	31
4.3	Bi-variate analysis of psychosocial impact.....	35
4.4	Bi-variate analysis of financial impact.....	40
4.5	Support systems.....	44

CHAPTER 5: DISCUSSION OF FINDINGS AND IMPLICATIONS

TO NURSING..... 48

5.1	Introduction.....	48
5.2	Socio-demographic characteristics.....	48
5.3	Psychosocial impact.....	50
5.4	Financial impact.....	53
5.5	Support systems.....	55
5.7	Implications to nursing	56
5.8	Conclusion.....	57
5.9	Recommendations.....	58

REFERENCES..... 60

APPENDICES

Appendix I	Informed Consent	64
Appendix II	Interview schedule.....	67

Appendix III	Letter of approval from Assistant Dean Post graduate...	81
Appendix IV	Letter of Approval from Research Ethics Committee.....	82
Appendix V	Letter of permission from executive Director.....	83

LIST OF FIGURES

Figure 1: Problem analysis diagram of probable impact
 of childhood cancer on immediate families
 of children with cancer..... 10

Figure 2: Psychosocial Impact..... 39

Figure 3: Financial Impact..... 43

Figure 4: Support Systems..... 47

LIST OF TABLES

Table 1: Cancer cases in children below the age of 15 years for the years 1999 to 2004..... 2

Table 2: Socio-Demographic Characteristics..... 33

Table 3: Bi-variate analysis of psychosocial impact..... 37

Table 4: Bi-variate analysis of financial impact..... 41

Table 5: Support systems..... 45

LIST OF ABBREVIATIONS

AIDS	-	Acquired Immune Deficiency Syndrome
CBoH	-	Central Board of Health
CSO	-	Central Statistical Office
GLOBOCAN	-	Global Cancer
HIV	-	Human Immunodeficiency Virus
IAEA	-	International Atomic Energy Agency
JCTR	-	Jesuit Center for Theological Reflection
KS	-	Kaposi's Sarcoma
MoF	-	Ministry of Finance and National Planning
OPEC	-	Organization of Petroleum Exporting Countries
UTHB	-	University Teaching Hospital Board
UTH	-	University Teaching Hospital
USA	-	United States of America
WHO	-	World Health Organization
ZDHS	-	Zambia Demographic Health Survey

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND INFORMATION

Cancer may be regarded as a group of diseases characterized by an abnormal growth of cells. Cancer has the ability to invade adjacent tissues and distant organs of the human body, resulting in the eventual death of the affected patient. Terminal cases of cancer can be observed where the cancer has progressed beyond a stage when it can be successfully removed (Park, 2002).

Cancer affects people of all ages. Globally, childhood cancers are becoming one of the commonest childhood conditions. Childhood cancers grow more rapidly than adult cancers because the cancer tissues grow together with the fast growing tissues of the child (Children's Cancer Foundation, 2004). These cancers come in different forms, the major ones being Leukemia, which accounts for nearly one-third of all childhood cancers worldwide, lymphomas, brain tumours, retinoblastomas, neuroblastomas, Wilm's tumour, rhabdomyosarcomas, osteosarcomas, squamous cell carcinomas and Kaposi's Sarcoma (James and Mott, 1988).

Several factors are suspected to influence the occurrence of cancer in children. Incidence of childhood cancer is increased in children with some chromosomal and congenital abnormalities like Down's syndrome. The occurrence of cancer is also higher in children with immune deficiency diseases or those children who have had their immune systems artificially suppressed by drugs. Viruses are also closely linked to the development of certain cancers, for instance, Kaposi's Sarcoma (which occurs in patients with HIV infection), Non-Hodgkin's lymphoma (a late complication of AIDS), Burkitts lymphoma and nasopharyngeal carcinoma. Environmental factors, which may be transmitted to the baby in utero, are also linked to the development of certain cancers, for example, diethylstilbestrol and vaginal cancer (James and Mott, 1988 and Park, 2002).

Cancers in all forms are causing about 12% of all deaths throughout the world and out of an estimated total of 51.3 million deaths during 1996 in the world, more than 7.1 million were attributed to cancer (Park, 2002). This led to the World Health Organization (WHO) to estimate that by the year 2000, the number of cancer deaths may go up to 8 million annually (WHO, 1997). According to Global Cancer report (GLOBOCAN), by the year 2002, the total prevalence of all cancer cases were 24.5 million globally and one third of these were in Sub-Saharan Africa (GLOBOCAN, 2002).

In Zambia, the clinical data available at the National Cancer Registry of Zambia shows that the number of cases of children between the ages 0 and 16 years suffering from cancer is increasing (See Table 1).

Table 1: Cancer cases in children below the age of 15 years for the years 1999 to 2004

Cancer Type	Year					
	1999	2000	2001	2002	2003	2004
Kaposi's Sarcoma	2	5	8	7	15	12
Non-Hodgkin's lymphoma	3	6	2	2	6	12
Burkitt's lymphoma	1	4	5	4	1	15
Hodgkin's lymphoma	-	1	-	-	1	10
Leukemias	-	-	5	9	1	4
Retinoblastoma	-	7	3	3	2	14
Neuroblastoma	-	1	-	-	-	-
Nephroblastoma	-	3	-	1	1	-
Rhabdomyosarcoma	2	2	2	1	5	5
Squamous cell carcinoma	6	3	2	7	5	13
Sarcomas	2	1	3	3	3	6
Adenomas	2	-	2	1	-	1
Others	6	8	9	2	4	20
Total	24	41	41	40	44	112

Source: National Cancer Registry of Zambia (1997-2004)

Table 1 shows the increase in cases from 24 in 1999 to 112 in 2004, the most significant being Kaposi's sarcoma (KS), which had 35% of all cases in 2003. though there was a slight decrease from 15 cases in 2003 to 12 cases in 2004.

The increase could probably be attributed to the HIV and AIDS epidemic. HIV-associated KS in children is becoming common in Zambia. This has enormous implications for families since they have to meet the cost of cancer treatment and Anti retro viral therapy. Another dramatic increase was seen in Burkitts Lymphoma, which increased from 1 in 1999 to 9 in 2004, and Retinoblastoma from 7 in 2000 to 14 in 2004. In a study done by Kumon (2001) at UTH, incidence of overall and individual malignancies was compared between 3 six-year periods; 1980-1985, 1987-1992 and 1995-2000. There was a significant increase in incidence between 1980-1985 and 1995-2000 from 14.7 to 18.1 per 1,000,000 children under 15 per year.

The diagnosis and treatment of cancers affect the economy of the health care system negatively as they require expensive medical technological equipment and expertise in order to arrive at a confirmed diagnosis. Some investigations done on cancer include intravenous pyelogram, which is useful in differentiating neuroblastoma from nephroblastoma and radionuclide scanning used in visualizing the tumours. Computed tomography can determine the nature of the tumour, whilst biopsies can be used for confirming cancer through histological examinations (Berkow, 1997).

Treating childhood cancer is one of modern medicine's greatest success stories. The curative rate for childhood cancer has jumped from 10% in 1970 to today's overall survival rate of almost 70%. This has led to a generation of young adults who are childhood cancer survivors because these children are able to live up to six to ten years after treatment (Keene, 1997). Childhood cancer is treated aggressively often with a combination of chemotherapy, radiation, and surgery at a time when bodies are growing and developing. Treatment can last from one year to several years depending on the diagnosis (Keene, 1997).

While being treated for cancer, patients are assessed to see how they are responding to therapy. In response to treatment the child may have a complete remission for 5 to 10 years; and in this period they are disease free. In other

instances, there is a partial response, where the size of one or more tumours is reduced by more than half (Berkow, 1997).

In countries with sound economic resources and technological advancement, the most effective possible approach for treating a child with cancer is a combination of the three available treatment modalities, which are, surgery, radiation and chemotherapy. In Zambia, currently, radiotherapy is not done and patients have to travel to South Africa or Zimbabwe for treatment by radiotherapy. However, Zambia is one of the countries in Africa that is currently receiving financial support from the Organization of Petroleum Exporting Countries (OPEC) Fund for International Development, with technical support from International Atomic Energy Agency (IAEA) to construct a radiotherapy unit (IAEA, 2003).

For effectiveness, cancer treatment lasts for a considerable length of time and this process has significantly long-term impact on the child including the family's physical and psychological health. For instance, chemotherapy delivered into the spinal column (called intrathecal therapy) has been associated with learning disabilities in children who are under five years of age at the time of treatment. Some children have shown signs of learning disabilities within two to five years of treatment. Parents of children undergoing chemotherapy have also been known to experience strain and tension due to the stress of caring for a sick child (American Cancer Society, 2002).

Due to the length of treatment, families may experience psychosocial and financial problems. Families and patients therefore require a lot of support to assist them in their response and coping to diagnosis and treatment. Currently, the Paediatric Hematology -oncology ward at the University Teaching Hospital (UTH) has been renovated with the help of Dunavant Family Trust in association with other donors. Charitable organizations like Zambia Cancer Foundation -Leukemia Fund sources for funds through donations and other fund raising ventures to assist in the acquisition of chemotherapy drugs and

other medical items to help children with cancer. Paediatric oncology clinics are also held every Monday and children with cancer are seen in these clinics.

1.2 STATEMENT OF THE PROBLEM

Despite all the above measures, childhood cancer still continues to have devastating psychosocial and financial impact on the families.

Children with cancer are usually admitted to the hospital for a long time. They stay several weeks on the ward as they await diagnostic investigations and treatment. This leads to an increase in the in-patient days thereby draining on the hospital resources. The family also has to pay more as they have to cater for the patient and the caregiver's upkeep expenses and they lose more labour time.

Due to poor technological advancement in the country, there are no adequate diagnostic and treatment facilities. Most of the times there are no cancer drugs to treat the patients, and families are required to buy these drugs, which are very expensive for most Zambians due to poverty. At present, access to good cancer treatment in Zambia is a privilege of just a few. Patients needing vital radiotherapy treatment have to travel to South Africa and Zimbabwe. The Zambian Government covers most of the cost but a financial contribution is still needed from the patient, which few can afford (IAEA, 2003). Even for those that can, the waiting period can last from six months to one year because the government decides which case is a priority. All the while the cancer spreads and results in death.

Cancer is one of the leading causes of deaths in children between 1 and 14 years of age, because almost all the children diagnosed with cancer will die (Berkow, 1997). Out of a total of 194 records of cancer cases in children, who presented to UTH between 1994 and 2001, 21.6% were lymphomas, 11.3% were leukemias, 11.3% were retinoblastomas, 26.3% were Kaposi's sarcomas, Sarcomas 5.7%, 8.8 abdominal mass and 7.7 other cancers. Of all these cancers, 76.4 % and 21% underwent chemotherapy and surgery respectively

and out of these, 40.7 died (Kumon, 2001). This probably caused grief and extra financial burdens to the families, as they had to cater for funeral expenses.

When a child develops cancer, the immediate family members are often profoundly affected psychosocially. A diagnosis of childhood cancer is devastating for the child and the immediate family because it causes changes in the family's daily functioning. Families are important because they provide the social support system for the child suffering from cancer, and both the child and the family members are directly confronted with all the experiences that this disease presents. Since families experience common emotional bonds and share certain obligations towards each other, health problems of families are interlocking. A health problem of one family member like cancer in a child, will affect the well being of others. The general level of family functioning and the degree to which the family can work as a unit in dealing with its problems can maximize the potential of each other because of the close association and interaction among members. This in turn will influence the way the family handles its health matters. Families are also economic units, and as such, they make choices and decisions about health care and on how to allocate their family resources like labour, money and time on medical care.

1.3 IMPACT OF CHILDHOOD CANCER ON THE FAMILIES OF CHILDREN WITH CANCER

1.3.1 Psychosocial impact on the family

Most parents experience shock when they are told of the diagnosis of cancer because they are never prepared to hear that their child has a life threatening illness. They report being confused about their child's diagnosis and treatment and later guilt, sadness and depression arise after parents accept that their child really does have cancer. Parents usually have fear and anxiety about the outcome of the child's treatment and recovery since the physician cannot guarantee the outcome of treatment for any particular patient.

Siblings to the child usually feel neglected due to the special attention paid to the child with cancer. They also feel angry and sad as they begin to realize that their brother or sister is very sick and receiving difficult treatment. Younger children will miss the parent who usually provides most day-to-day care when that parent is unable to return home for days or weeks after the diagnosis, and this may affect the play and work of these siblings and also affect their academic performance in school.

Socially the family faces a lot of challenges, and associated costs like “stigma” also affects the families. Stigma may result from cultural beliefs that surround the diagnosis of cancer and also from the association of certain cancers like Kaposi’s Sarcoma to HIV and AIDS and this will further result in social isolation and withdrawal from the community adding more psychological strain on the family.

1.3.2 Financial impact on the families

Financially, the family of a child with cancer is faced with a lot of challenges. Due to the unavailability of radiotherapy in Zambia at the moment, the patients have to go to South Africa or Zimbabwe for radiotherapy and this is too expensive for most families and chemotherapy becomes the only choice of treatment (IAEA, 2003). This becomes very difficult for most Zambians because of poverty. In Zambia, 73% of the population is poor, and majority of the rural households live below poverty level since many of them earn little or no regular income to sustain their livelihood (Mwinga, 2002). According to the Jesuit Center for Theological Reflection (JCTR), the World Bank estimates that over 80% of Zambians live in households that lack adequate means to meet basic daily needs (JCTR, 2000).

Since patients are usually referred to a tertiary care center, the out-of-pocket expenditure on caring for a child undergoing cancer treatment is tremendous, as the family has to meet the cost of drugs, transportation to the treatment center, upkeep and lodging, and other expenses at home. Often the social welfare

programs do not cover these expenses, and for some families, decreased resources might well influence their ability to carry out recommended treatments. The opportunity cost also increases, usually because one of the parents has to spend more time with the child and miss work or other income generating activities. With a sick child in hospital or at home, one or both of the parents may be required to be absent from work or family duties and this leads to loss of labour time. Absence from work might also lead to being laid off from work and thereby loss of income. This will impact negatively on the productivity of the family and will contribute to increase in poor socio-economic status of the family and the nation as a whole.

There could also be changes in family expenditure patterns manifesting in form of increased expenditures on medical care, transport costs and other household expenditures which may lead to reduced family savings, and families may end up selling certain household assets and incur household debts and borrowings and this will lead to poverty in the long run.

Financial concerns for families with a child, who has cancer, may also include insurance benefits, and entitlement programs. In Zambia, very few families are under health insurance schemes and those who manage to be under any form of insurance scheme, conditions like cancer are not covered because they are chronic and are expensive to cover for insurance organizations.

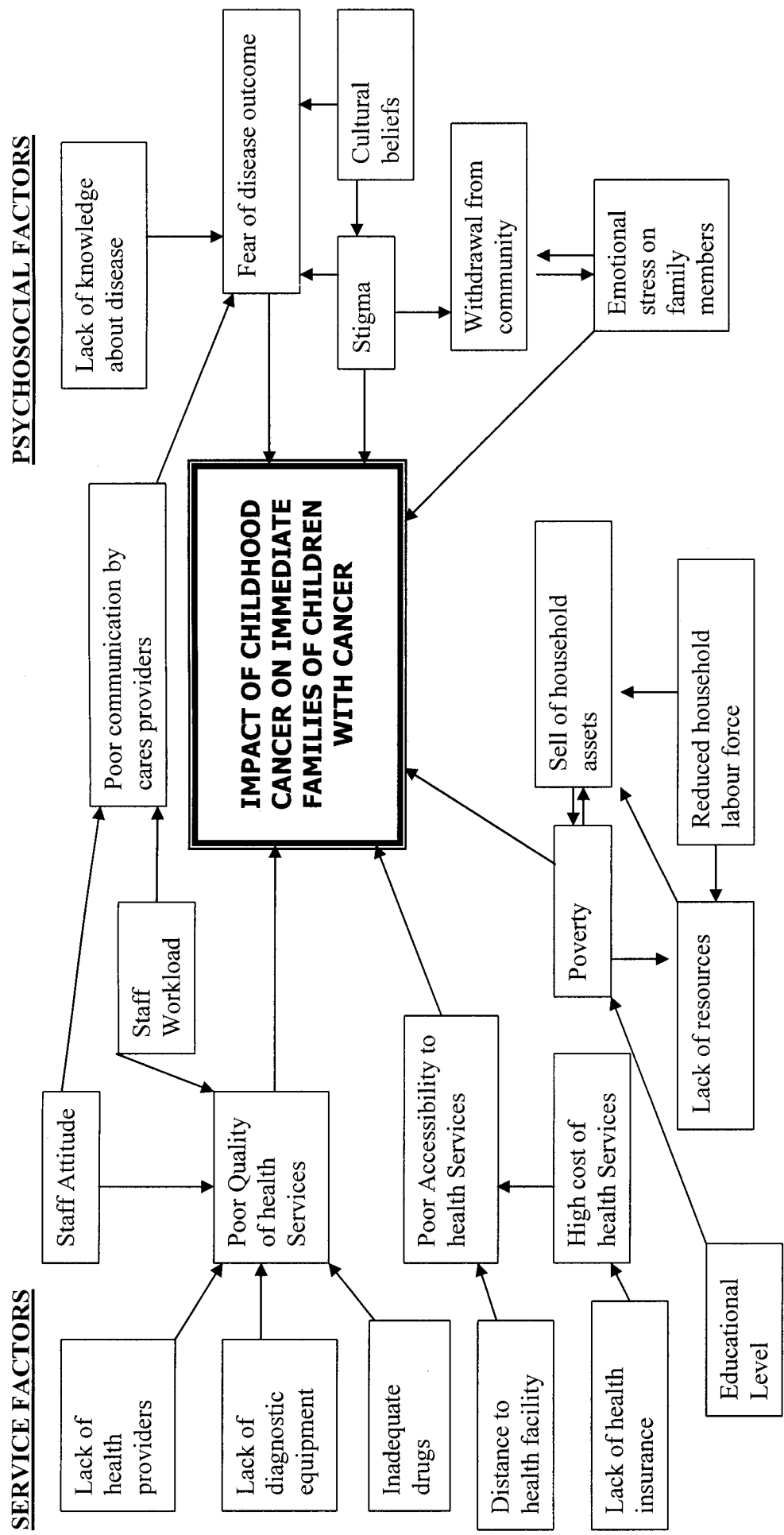
1.3.3 Service factors impacting on the families

Like most developing countries, accessibility to good cancer treatment in Zambia is a privilege of just a few. There are no diagnostic and treatment facilities and most patients are treated palliatively. This has led to most of Zambia's oncologists and radiotherapists to leave the country to seek employment elsewhere thereby causing shortage of specialized human resource and this contributes to poor quality of services being delivered. Lack of trained childhood cancer counselors and oncology nurses also contributes to inadequate information being provided to the families, and this brings about anxiety and

fear of the disease's outcome. The daily frustrations of dealing with a large and complex health care system, unfamiliar surroundings, and numerous care providers are also causes for periodic anger and stress on the family members of children on cancer treatment. Additionally, staff attitude discourages the family members to get enough information regarding treatment protocols, and any support systems available in the community.

The study therefore intends to find out problems, which families with children with cancer face psychosocially and financially and find support systems they use during the child's illness.

FIGURE 1: PROBABLE IMPACT OF CHILDHOOD CANCER ON IMMEDIATE FAMILIES OF CHILDREN WITH CANCER



1.4 JUSTIFICATION

Cancer is becoming an increasingly big problem worldwide. In Zambia, it has been documented that childhood cancer is increasing (Chintu, 1995; Kumon, 2001). Due to the chronic nature of cancer and its long-term treatment, most families are affected psychosocially and financially leading to disrupted family function.

For many years, studies on cancer-related issues have focused only on quantifying the cases of cancer and those on cancer-related stress have focused only on patient adjustment with little attention paid to the family. In Europe, America and Asia, however, studies have been done on psychological impact of childhood cancer on families depicting cultural differences (Martinson et al, 1995).

In Zambia, studies such as “defining the incidence and clinical profile of Kaposi Sarcoma in Zambian children” and “effect of the epidemic on the epidemiology of cancers in children” have concentrated on the epidemiology aspect of childhood cancers. More importantly, none have focused on the actual impact of childhood cancer on the immediate family. One study which was done by Ndashe (1997), focused on knowledge, attitudes and practices of nurses towards death and dying while caring for the terminally ill in Ndola. In this study that included cancer, the focus was on chronically ill patients. The study did not highlight the financial or psychosocial impact of the illness on the family.

Recognizing this gap in studies done on childhood cancer in Zambia, this study intends to investigate the “impact of childhood cancer on the immediate families of children with cancer”. It is envisaged that the findings from this study will be used by the health care providers in assessing and identifying psychosocial and financial needs of families with children who have cancer thereby referring the family to the available sources for support like church organizations, government departments and non governmental organizations. It

is also hoped that findings and recommendations to be disseminated from this study will be useful in planning for better care by designing training manuals and guidelines, and formulation of deliberate policies in training of the nurses, doctors, counselors, social workers and other health workers who are involved in the care and counseling of children with cancer and their families.

1.5 OBJECTIVES

1.5.1 General Objective

To determine the impact of childhood cancer on the immediate families of children with cancer at the University Teaching Hospital, Lusaka, Zambia.

1.5.2 Specific Objectives

- 1.5.2.1** To determine the psychosocial impact of cancer on the immediate families of children with cancer and compare with families of children with other medical illnesses.
- 1.5.2.2** To determine the financial impact of cancer on the immediate families of children with cancer and compare with families of children with other medical illnesses.
- 1.5.2.3** To assess the financial and psychosocial support systems that families of children with cancer use during their child's illness and compare with families of children with other medical illnesses.
- 1.5.2.4** To identify areas for further research related to impact of childhood cancer on families.
- 1.5.2.5** To make recommendations to policy makers for implementation.

1.6 OPERATIONAL DEFINITIONS

- 1.6.1** A child is a person who is less than 16 years of age.

- 1.6.2** Cancer is any disease in which body cells grow larger, multiply and spread more rapidly and destroy healthy tissue and endanger life.
- 1.6.3** Chemotherapy is treatment of cancer in a child using cancer drugs.
- 1.6.4** Childhood cancer is any form of cancer affecting a child less than 16 years of age.
- 1.6.5** Impact is a strong effect in form of psychosocial and financial pressures of childhood cancer on immediate families of children with cancer.
- 1.6.6** Immediate family is the family where the child with cancer is currently residing whilst undergoing cancer treatment.

1.7 STUDY VARIABLES

The variables under study were psychosocial impact, financial impact, and support systems.

1.7.1 Psychosocial impact is the effect of the child's illness on the minds and thoughts of family members. Families were considered to be more affected psychosocially if they experienced more than two of the following; stress, fear of illness and outcome, guilty feelings, feelings of isolation from friends and relatives, and stigma due to the child's illness.

1.7.2 Financial impact is when a family experiences increased medical and investigation expenses, transport costs, loss of labour time, by both, or, one parent, loss of income, decreased income, increased borrowing, sale of household goods/assets because of taking care of a child who has cancer. A family was considered to have a high financial impact if they experienced more than two of the above.

1.7.3 Support systems are forms of arrangements that provide psychosocial and financial assistance to families with children who have cancer. Families were considered to have adequate support systems if they affirmed to the following; had received any help from relatives and friends in form of financial and material help, encouragement, taking care of the child; if relatives and friends had visited the sick child in hospital; helped look after the other children while parent is in hospital; if family had received any help from a religious organization, or any other group in the community; if the condition of the child was fully explained to family by health care provider and if family had been counseled by a health worker and informed of available support services.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Childhood cancer is one condition that causes a crisis in the family structure and causes severe impact on family function. Due to improvements in treatment, children with cancer are surviving long and currently coping with its detrimental effects.

The literature review focuses on the psychosocial and financial impacts of cancer on immediate families of children with cancer, and support systems that they use. There are few studies and literature is sparse on the impact of childhood cancer on the families in Africa and Zambia. However, majority of the studies have been done in the developed countries. These studies are mostly specific case studies, which provide empirical data for specific locations within specific countries, in Europe, America and Australia. Therefore, their findings cannot be generalized to countries in Africa. Regardless of these limitations, some common characteristics of the impact of childhood cancer on immediate families of children with cancer can be established from these studies.

2.2 PSYCHOSOCIAL IMPACT

Families whose children are diagnosed of having cancer may suffer a lot of psychosocial trauma because most of them feel it is a death sentence passed on to one of their family members. Due to the increased demands of taking care of the sick child and the intensive treatment, parents to the child experience a lot of strain on their relationships with family members, neighbors and their relatives. Parents to the child undergo transitions of shock, fear and anxiety because they do not know what impact the intensive treatment will have on the child's body and self-esteem. Several studies have been done globally to understand the psychosocial effects of cancer on the immediate family of a child who has cancer.

In a study done by Slopper (2000) to examine levels of psychological distress in parents of children with cancer and relationships between distress and measures of illness variables, appraisal, psychosocial resources and coping strategies, questionnaires were completed by 68 mothers and 58 fathers at 6 and 18 months post diagnosis. High levels of distress for 51% of mothers and around 40% of fathers were apparent at both time points, with little change over time. For mothers, their appraisal of the strain of the illness, and their own ability to deal with it, and family cohesion were predictive of distress, both concurrently and prospectively. For fathers, risk factors of employment problems and the number of the child's hospital admissions were significant, along with appraisal and family cohesion.

Family distress is very common in those families whose children are suffering from cancer especially at the beginning when the child has just been diagnosed with cancer. Parents to the children often do not know what to do and only use internal coping strategies. As for fathers their main concern may be their employment since the child is often admitted for extended periods and frequently.

Hae-Ra Han, (2003) conducted a study entitled "Korean mothers' psychosocial adjustment to their children's cancer". She observed perceived level of stress, coping, social support, and time since diagnosis to be significant correlates of maternal psychosocial adjustment. Stress accounted for most of the total variance explained in maternal adjustment. The findings of this study indicate psychological stress on parents having a child with cancer.

A mother is often in a position of caring for the sick child, and because she has to assume several roles like being a wife, a mother and nursing of the sick child, she experiences a lot of stress and this may result in lack of energy to carry on in her daily work. Anxiety and fear about the extent of disease at the time of diagnosis, its spread and ultimate outcome also increases the stress in

parents, and this is compounded by the limited information they have on cancer.

Another study was done by Patterson et al (2003) on the impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. In this study, a qualitative analysis of seven focus groups with 45 parents of children a year or more out of cancer treatment was done and findings were that, the child's cancer diagnosis, treatment, and recovery were perceived as particularly difficult for their family.

In this study important aspects are highlighted and these are the aspects of the period of diagnosis and treatment of the child. These are crucial times in that the family goes through a transition in life in response to the diagnosis and treatment of the child. Ordinary daily life is interrupted, parents require time away from work to be with their child, and the ill child becomes the major focus of family time and attention and other family concerns are put on hold. The way the family will respond to the diagnosis and treatment of the child will influence the way the child will respond to treatment and it will have an impact on quality of life in the child.

In an article entitled 'the psychological effect of childhood cancer on families' Giammona and Malek emphasized the devastating impact on the family the diagnosis of childhood cancer has, because of its life threatening nature requiring major shifts in lifestyle and psychological reality. They mentioned that an awareness of the developmental and cognitive levels of the child at the time of diagnosis, and the psychological and situational status of the family is crucial to providing appropriate interventions and coping skills (Giammona and Malek, 2002).

It is important to also mention that the child and the family need to develop new coping skills, make use of outside support and resources, and receive specific interventions in order to maximize their adjustment. When we understand this as health care providers, and be able to give adequate and

relevant information to these families, it will reduce the psychological impact and assist in the child and family's adjustment to childhood cancer.

As part of a larger study, a descriptive study of the impact of childhood cancer on 50 Chinese families was conducted in the Peoples' Republic of China. In their findings, the parents varied in their degree of openness regarding the child's diagnosis with relatives, friends, and colleagues. Some families had previous experience with a serious illness or death, but all identified cancer as the most frightening disease. Forty-one (41%) percent of the families felt they had not adjusted yet to the diagnosis. Few acknowledged the impact on siblings. Families also described their outlook on life and their fears of death. Seventy-six (76%) percent of the families were paying the total cost of their child's care themselves, and 14% of the total number of families reported major financial problems (Martinson et al, 2000).

Stigma is one issue that is very crucial in families with children who have cancer. It is very difficult for families to discuss cancer with friends and other people, as they would feel ashamed because in many settings, cancer is associated with HIV/AIDS. The more the family fails to discuss the condition openly, the more psychosocially they become affected.

Siblings to a child with cancer are also affected by the diagnosis and treatment of their brother or sister. They experience significant psychosocial distress and are isolated from support systems inside and outside the family, and this affects their well being and academic performance (Samardakiewicz, 2003).

In a study done by Ballard (2004) in England entitled, "Meeting the needs of siblings of children with cancer", she found that siblings were isolated in the care of the child with cancer, however the parents were willing to have their siblings involved in most therapeutic interventions although practicalities would not allow that. This is an important observation because when the siblings of a sick child are involved in the care of the child, it reduces the psychological trauma they feel and become part and parcel of what is taking

place. It also gives them an opportunity to become close to their sick brother or sister.

2.3 FINANCIAL IMPACT.

Cancer treatment can last from one year to several years depending on the diagnosis. The long-term financial impact on the family is huge, often forcing the family into financial ruin. Studies conducted have revealed that there is a huge economic strain on families with a child who has cancer.

A study was conducted by Dockerty et al (2002), to determine the economic effects of childhood cancer on families in New Zealand. The findings revealed that there was a large financial burden on families who have a child with cancer. Expenditure was greater for those whose children spent more time in hospital receiving treatment. Some respondents reported that they needed to borrow money because of the financial effects of the child's illness.

From this study, it is evident that having a child with cancer poses great financial difficulties for families. This is because the medical expenses for this child draws on the family resources and families face problems. In countries where majority of families are poor the financial burden may even be greater and most parents will opt to stop the treatment.

Another study was done by Cohn et al (2003) in Australia on hidden financial costs in treatment for childhood cancer focusing on the impact of out-of-pocket expenses on five domains of family lifestyle: social, assets, credit, utilities, and charity. The majority reflected travel, accommodation, and communication costs, use of work-related entitlements, and changes in paid employment.

In lifestyle terms, the area of greatest impact was found for the social domain, such as canceling vacations and giving up recreational pleasures and social expenditure. Those families living furthest from the major cancer treatment

center experienced the greatest range of out-of-pocket expenses and subsequent lifestyle impact.

The cost of taking care of a child who has cancer in the family also has an impact on the family's labour time as some parents stop work to look after the sick child. In another study done by Clarke et al (2001) entitled Women's Health Care Work with Children with Cancer in Canada; they found that the tasks women performed for their children on a daily basis were enormous. Over 42% of the women in the study stopped work completely, 20% and 7% either reduced the number of hours they worked or changed the nature of work they did respectively, and only 3% did not change anything.

In this study, almost all the respondents had a reduced income as most mothers had to stop work or reduce working hours. This would impact on the family's expenses as they would not have enough money to spend on the child's treatment and the child may default treatment or the family may incur a lot of debts.

In the same study the mothers reported that during the child's treatment, they assumed illness management roles which involved acting as an advocate for their child, ensuring that their child's medical needs were met by the staff and performing the tasks of a 'makeshift nurse' by monitoring all aspects of their child's treatment, which further added tasks to their already heavy workload. This may also be a common phenomenon in Zambia where we already have a shortage with qualified health workers who have left the country. Caregivers usually assume the role of the nurse and this puts pressure on them psychologically and physically.

In Africa a dramatic rise in childhood cancer is stretching already limited resources and equipment. Cancer diseases require specialist treatment at a center where there is expertise in the management and care. In South Africa, as in most developing countries, these specialist units are linked to the major

academic hospitals. Traveling from home to attend these clinics for treatment adds another dimension of practical and emotional difficulty to an already overwhelming situation (Children's Hematology Oncology Clinics Childhood Cancer Foundation South Africa, 2002).

Due to poor economic status in most African families, there are major changes to their lifestyles, and many additional stresses on them. Apart from the emotional upheaval caused by the diagnosis, there are many practical and financial issues that they will need to deal with over a period of probably several years. When a child from a remote area is referred to one of the specialised treatment centres, the family experiences even more of a disruption to their lives. Added to all of the other issues, they have to find the money to bring the child long distances back to the hospital for ongoing treatment. Sometimes this can present major problems, especially to those from a disadvantaged background.

Cancer treatment in Zambia has severe effects on the family's financial well being. As the socio-economic status of most of Zambia's population is very poor, good health care is a privilege of the few and those who have access to it end up buying their own medication, pay for upkeep and cater for food costs.

2.4 SUPPORT SYSTEMS

Understanding the complexity of emotions and the special ongoing individual needs of patients and families is very important in childhood cancers. Throughout the illness, support systems should seek to decrease anxiety, encourage development and help patients and their families to discover their own strengths and to enhance their coping mechanisms.

Ritchie conducted a study in Villanova, United States of America in 2001 on 'Sources of emotional support for adolescents with cancer' with the purpose of identifying whom adolescents perceived as providing emotional support and

how helpful these individuals were in helping them cope through the experience of cancer. Participants' responses indicated that the adolescents' mothers and their friends were the two most often cited sources of emotional support. They also described their identified sources of emotional support to be very helpful to them as they lived through the experience of cancer (Ritchie, 2001).

These findings indicate the importance of support systems like families, and these social support systems could extend beyond the family to include friends. Friends and families are very important in providing psychosocial support as they spend a lot of time with the patient and the immediate family of the sick child and they understand what psychosocial stresses the family goes through.

In an article written by Ruffin et al (1997), a retreat for families of children recently diagnosed with cancer was held with the purpose of describing a clinical intervention program designed for children recently diagnosed with cancer and their families. Staff members (nurses, social workers, child life specialists, and physicians) at the Children's Center for Cancer and Blood Disorders of the Richland Memorial Hospital in Columbia, South Carolina, conducted a comprehensive needs assessment of the families of children recently diagnosed with cancer with a purpose of providing education to patients and parents, to reduce isolation within the family and among family systems, and to reduce individual and family stress. The results of the needs assessment indicated that the Family Weekend Retreat met their needs for education, recreation, and mutual support. The families expressed an interest in, and subsequently held, a retreat reunion (Ruffin et al, 1997).

Families with children who have cancer are usually not well informed about the condition of the child, the treatment options available and the possible outcome. It is therefore very important for health care workers to provide information and education to these families. Mutual support is also important because if one family gets to meet another family, which has a similar

psychosocial need, they will be able to share experiences, fears and encouragement. Health care providers are also in a position to provide a network of support among families of children who are struggling through the cancer experience.

2.5 CONCLUSION

From the discussion above, there are several problems that families face when their child has cancer. They face enormous psychosocial and financial challenges and need a lot of support for them to cope with the diagnosis and treatment of cancer.

A lot has been done in other places in identifying these impacts and not much has been done in our setting. It is hoped that this study will identify the impact on the families in our setting and these will be used to make further recommendations to the relevant authorities on how to assist families cope with diagnosis and treatment of cancer in their child in terms of psychosocial and financial support.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

The study assessed the impact of cancer on the immediate families of children with cancer admitted to the University Teaching Hospital and immediate families of children who had other medical illness as a control group.

3.2 RESEARCH DESIGN

This was an unmatched case control study. A case control study is a comparison study that uses two populations, that is, cases and controls (Park, 2002). Data was collected from the parents of children with cancer admitted to UTH Pediatric Hematology -oncology ward, and from parents to children who had other medical illnesses from ward AO8. The reason why this design was chosen was to isolate the impact of cancer other than just the impact of any other illness.

3.3 RESEARCH SETTING

The study was conducted at the University Teaching Hospital (UTH), the largest hospital located in Lusaka Urban in Zambia. Lusaka Urban is one of the four districts in Lusaka province with a population currently estimated at 2 million (Central Statistical Office, 2000).

University Teaching Hospital is a tertiary hospital, the largest referral facility in Zambia with a total admission capacity of 1700. The Pediatric Hematology-oncology unit has a bed capacity of 16 to 18 and admits both oncology patients and hematological patients. The unit runs an out patient clinic on Monday where they see new patients and those that are discharged are followed up. The site was chosen because as a tertiary hospital and treatment center for cancer, most of the patients from all over the country are referred to UTH.

3.4 STUDY POPULATION

The target population consisted of all immediate families of children with cancer who were on cancer treatment at UTH and families of children with other medical illnesses. The study population comprised two groups (cases and control groups). The first group, which is the cases, consisted of families of children with cancer and the control group consisted of families of children who had other medical illnesses. Families were chosen because they provide a psychosocial and financial support system for the patient with cancer.

3.5 SAMPLE SIZE

To calculate the sample size of the two groups, Pococks formula was used as follows: $n = \frac{p_1q_1 + p_2q_2}{(p_1 - p_2)^2} f(\alpha, \beta)$

Where n is the sample size, p₁ is the proportion in the control group, p₂ is the proportion in cases group, q is (100-p) and f (α,β) is 7.85 considering a power of 80% and a two-tailed test at a significance level of 5%. With this formula, a sample of 74 was calculated. However, during the study, adequate subjects could not be recruited. Therefore, a sample size of 60 parents to children with cancer (cases), were recruited in the study and 1 control was selected for each case. The number of controls selected was 60.

3.6 SAMPLE SELECTION

A case is a subject that satisfies the diagnostic criteria and eligibility criteria (Park, 2002). A case control study uses a control group as a comparison group.

3.6.1 Sample I

Sample 1 (cases) consisted of families of children with cancer. Convenient sampling technique was used to select this sample from the Pediatric Hematology -oncology ward. The technique was used because of low numbers

of children with cancer admitted to UTH during the time the study was conducted.

Eligibility criteria

Parents to children who had their cancer diagnosis confirmed by histopathological investigations; had been on treatment for a minimum of three weeks, and admitted to the Pediatric Hematology-oncology ward from May to October 2005 were eligible to be included in the sample.

3.6.2 Sample II

The second sample consisted of the controls and these were families of children who had other medical illnesses. To select this sample, convenient sampling technique was used and sampling was done from the ward AO8.

Eligibility criteria

The control group consisted of families whose children had never had cancer in the family, but with any other medical illness.

3.7 DATA COLLECTION TOOL

A structured interview schedule (Appendix II) was used to collect data from the subjects. The schedule contained three sections and in section one demographic characteristics of the study subjects were measured. Some of the variables measured were age, sex, marital status, level of education, and occupation. These variables are important in order to understand the characteristics of subjects under study. The second section elicited information on the psychosocial impact of cancer on the family. In this section all the questions pertained to psychosocial issues like stress, fear and stigma experienced by the family as a result of having a child with cancer.

In section three, the variable measured was financial impact. In this section questions were designed to elicit information on expenses on medical care, income, household borrowing and work experience. In the last section,

questions were on support systems. Recommendations and suggestions from family members were also covered under this section. This tool was chosen because all the respondents were asked exactly the same questions in the same sequence, thereby reducing interviewer bias and enable objective comparison of the results.

3.7.1 Validity

To ensure the quality of a data collection instrument, it is important to establish its validity and reliability. Validity refers to the degree to which an instrument measures what it is intended to measure (Polit and Hungler, 1995). The instrument consisted of questions on each variable to be measured. In measuring the validity of the instrument, the questions in the questionnaire were checked by experts dealing with children with cancer to see if they brought out the responses on the variables to be measured so that conclusions could be drawn with respect to the sampled population. The instrument was pretested to determine whether they brought out desired information and necessary adjustments were made to some questions for easy understanding by subjects.

3.7.2 Reliability

Reliability is the stability of a measuring instrument over time. It is also a measure of the extent to which random variation may have influenced stability and consistency of results (Dempsey and Dempsey, 2000). Reliability of the instrument was measured by pretesting it. During the pretesting phase, respondents were interviewed in order to identify ambiguity of questions and problems with comprehension and these were clarified. Pre-tested questions yielded similar findings when compared with the main study. In addition, open-ended questions included in the interview schedule provided the opportunity for respondents to add their own ideas in their own words. This helped to generate more critical responses than precoded questions.

3.8 DATA COLLECTION TECHNIQUE

Data collection technique is the process of gathering information needed to address a research problem (Polit and Hungler, 1995). For this study, interviews were conducted using a structured interview schedule to collect data.

Before the interview, the researcher introduced herself to the subjects and verbal permission was sought. The purpose of the study was explained carefully to the respondents and they were assured of confidentiality. When they agreed to participate, they were requested to sign a consent form. This technique is preferred because it increases the response rate. It also enhances rapport between the researcher and the participants.

3.9 PILOT STUDY

Pretest of the interview schedule was done in Ward C12 and Ward AO3. Convenient sampling was done and 6 respondents were sampled as cases and 6 respondents were selected as controls. The purpose of the pilot study was to pre-test the data-collecting instrument, find flaws and make revisions to strengthen the methodology.

3.10 ETHICAL CONSIDERATION

Ethical clearance was obtained from the Research Ethics Committee of the University of Zambia. Permission to conduct the study was sought from UTH Management. The purpose and nature of the study were explained to study subjects and they were requested to sign a consent form after they agreed to take part in the study. Verbal consent was also sought. Those who participated were not remunerated in any way.

Confidentiality and anonymity of respondents' information were assured, seriously maintained and strictly adhered to, throughout the study. Anonymity of respondents was equally maintained throughout the analysis and in the report

writing. Confidentiality and anonymity were maintained by interviewing the subjects individually and in privacy throughout the interviews, ensuring that names of the respondents were not written on the interview schedule, and by keeping the schedules locked safely in a briefcase.

3.11 DATA PROCESSING AND ANALYSIS

Before analysis, data were examined to verify their completeness. Cleaning was done by browsing and frequent checks. Responses to open ended questions were tabulated in their entirety by reading the text to identify persistent phrases and words. Categories were then drawn from data and common themes derived. Data collected was then entered into the computer using EPI-INFO and analysis was done using the same package. The estimated statistics included measures of central tendency in uni-variate analysis. Bi-variate analysis involved use of Chi-square to compute associations between exposure (child with cancer) and outcome variables (psychosocial impact, financial impact and support systems). Only a p value of 0.05 or less was considered statistically significant. P values and odds ratio were reported. Results of logistic analysis were not reported since the estimates were not precise.

3.12 LIMITATIONS OF THE STUDY

1. The study subjects recruited for the study were fewer than expected considering the time frame in which the study was to be completed. Therefore, the findings cannot be generalized to other populations. Convenient sampling used in this study also limited the generalization of findings to other settings.
2. Confounding factors were not taken into consideration therefore further studies need to be done. The research instrument used to measure financial and psychosocial impact also requires further refinement and development to increase its reliability and validity.

3. Literature on impact of childhood cancer on families in Africa and Zambia was inadequate and much of literature was from developed countries.

CHAPTER 4: DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

A total of 120 study subjects were interviewed, out of whom 60 were parents or caretakers to children with cancer (cases), and 60 were parents or caretakers to children who had other medical illnesses (controls). Bi-variate analysis involved use of Chi-square test to compute associations between exposure (child with cancer or other medical illness) and outcome variables (psychosocial impact, financial impact and support systems). P values were calculated using Chi-square tests, and only a p value of 0.05 or less was considered statistically significant. Most of these respondents in the cases (65%) were coming from outside Lusaka and in the control group, 86.7% were from within Lusaka

4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS

Table 3 shows that the age distribution between the cases and controls was similar. Most of the respondents among cases (43.3%) were aged between 36 and 45 years, while the number was higher between 26 and 35 years (61.7%) for the controls. The mean age for cases was 37.2 and median age (Q1, Q2) was 36 (29, 41.5) while mean age of controls was 31 and median (Q1, Q2) was 30 (26, 34.5).

Most of the respondents in both cases (58.3%) and controls (88.3%) were females and the proportions were significantly different ($p < 0.01$). In both groups the number of married respondents were higher with 76.7% in the cases and 61.7% in the controls with no significant difference ($p = 0.143$). Majority of cases (51.7%) had 5 to 10 children while majority of controls (78.3%) had 1 to 4 children.

Majority (50%) of the cases had primary education while among controls most respondents (36.7%) had secondary education. There was no significant

difference ($p=0.235$) in the distribution of occupation between the two groups. Majority (53.3%) of controls and 40% of cases were not employed. Among the 60 respondents in the cases group, 60% received less than K250, 000 per month as opposed to the controls (38.3%).

Table 2: Socio-demographic characteristics

n=120

Characteristic	Cases		Controls	
	n	%	n	%
Age group (years)				
16-25	4	6.7	14	23.3
26-35	23	38.8	37	61.7
36-45	26	43.3	5	8.3
46-55	5	8.3	4	6.7
56+	2	3.4	0	0
Total	60	100	60	100
Sex				
Females	35	58.3	53	88.3
Males	25	41.7	7	11.7
Total	60	100	60	100
Marital Status				
Married	46	76.7	37	61.7
Single	4	6.7	12	20.0
Divorced	3	5.0	2	3.3
Widowed	7	11.7	9	18.0
Total	60	100	60	100
Number of children				
Nil	3	5.0	2	3.3
1-4	26	43.3	47	78.3
5-10	31	51.7	11	18.3
Total	60	100	60	100

“Table 2, cont”

Characteristic	Cases		Controls	
	n	%	n	%
Educational level				
Tertiary	4	6.7	11	18.3
Secondary	22	36.7	22	36.7
Primary	30	50.0	19	31.7
None	4	6.7	8	13.3
Total	60	100	60	100
Formal	10	16.7	10	16.7
Informal	2	3.3	1	1.7
Self employed	24	40.0	17	28.3
Unemployed	24	40.0	32	53.3
Total	60	100	60	100
Income				
>K750, 000	4	6.7	5	8.3
K500, 000-K750, 000	7	11.7	20	33.3
K250, 000-K500, 000	13	21.7	12	20.0
<K250, 000	36	60.0	23	38.3
Total	60	100	60	100

4.3 BIVARIATE ANALYSIS OF PSYCHOSOCIAL IMPACT

There was no significant difference ($p=0.274$) in response to the child's illness between the cases and controls. Most of respondents among the cases (73.3%) and controls (81.7%) had accepted the diagnosis of their child. When asked on their eating patterns, most of the respondents among the cases (71.7%) reported that they had lost the appetite because of the child's illness, while 53.3% of the controls said they had lost the appetite with a significant difference ($p=0.038$) between the two groups.

Results of the study also showed that there was no significant difference ($p=0.195$) in the sleeping pattern between the controls and cases. Majority of the cases (71.7%) and controls (81.7%) said that they had sleeping problems because of the child's illness.

There were 46 and 37 married respondents among cases and controls respectively, and out of these, 80.4% of cases and 83.8% of controls reported that their marriages were not affected by their child's illness with no significant difference ($p=0.091$) between the two groups.

Out of the 56 respondents among cases and 44 among controls who had more than one child, majority (55.4%) of cases and controls (52.3%) reported that their other children were affected by the illness of the sibling with no statistical significant difference between the two groups ($p=0.759$).

There was no significant difference ($p=0.361$) in terms of self-blame on the cause of their child's illness between cases and controls. Majority of cases (83.3%) and controls (76.7%) reported that they were not the cause of the child's illness. Table 4 also illustrates that majority of the cases (81.7%) and controls (95%) were not ashamed or embarrassed of the child's illness.

The study revealed that there was a significant difference ($p=0.001$) in terms of fear of illness and outcome between the cases and controls. Majority of cases

(76.7%) reported that they had fear of illness and outcome compared to controls (48.3%). With regards to relationship with their relatives, most respondents among cases (51.7%) and controls (45%) said the relationship was the same. Majority of controls (51.7%) reported that the relationship with friends was the same compared to cases (48.3%).

Table 3: Bivariate analysis of psychosocial impact

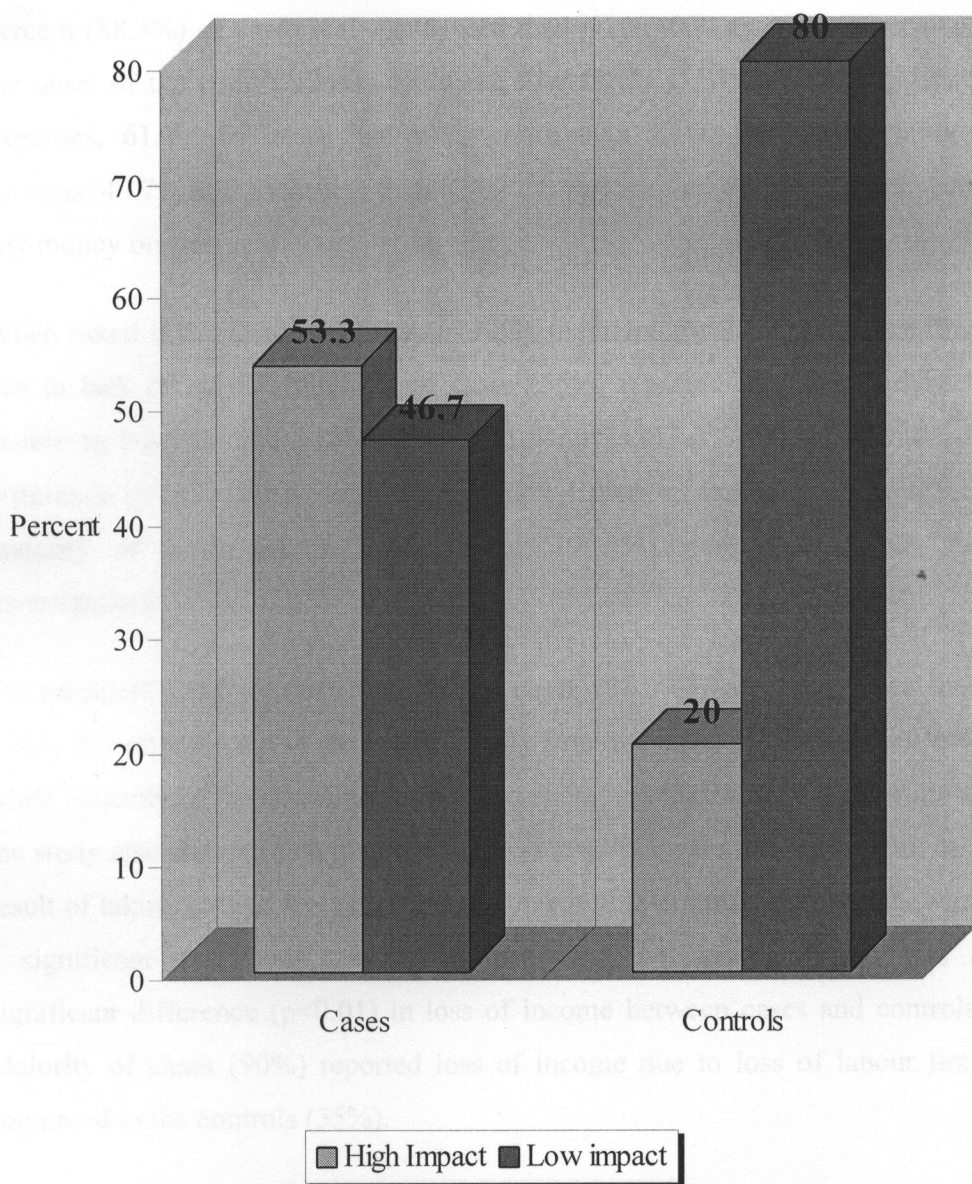
n=120

Characteristic	Cases		Controls	
Response to illness	n	%	n	%
Accepted illness	44	73.3	49	81.7
Failed to accept	16	26.7	11	18.3
Total	60	100	60	100
Eating Pattern				
Good appetite	17	28.3	28	46.7
No appetite	43	71.7	32	53.3
Total	60	100	60	100
Sleeping Pattern				
Sleeping well	17	28.3	11	18.3
Not sleeping well	43	71.7	49	81.7
Total	60	100	60	100
Marriage affected				
Yes	9	19.6	6	16.2
No	37	80.4	31	83.8
Total	46	100	37	100
Effect on other children				
Yes	31	55.4	23	52.3
No	25	44.6	21	47.7
Total	56	100	44	100

“Table 3, cont”

Characteristic	Cases		Controls	
	n	%	n	%
Self-blame on the cause of child's illness				
Yes	10	16.7	14	23.3
No	50	83.3	46	76.7
Total	60	100	60	100
Ashamed and embarrassed				
Yes	11	18.3	3	5.0
No	49	81.7	57	95
Total	60	100	60	100
Fear of illness and outcome				
Yes	46	76.7	29	48.3
No	14	23.3	31	51.7
Total	60	100	60	100
Relationship with relatives				
Same	31	51.7	27	45.0
Closer	8	13.3	21	35.0
Distant	17	28.3	6	10.0
Abandoned	4	6.7	6	10.0
Total	60	100	60	100
Relationship with friends				
Same	29	48.3	31	51.7
Closer	13	21.7	22	36.7
Distant	16	26.7	4	6.7
Abandoned	2	3.3	3	5.0
Total	60	100	60	100

Figure 2: Psychosocial Impact



Majority of cases (53.3%) had high psychosocial impact, while 80% of the controls had a low psychosocial impact. OR=4.6 (CI 95%; 2.03, 10.28; $p<0.01$, $df=1$).

4.4 BIVARIATE ANALYSIS OF FINANCIAL IMPACT

The study showed that there was a statistical significant difference ($p<0.01$) in expenditure on medication between the cases and controls. Eighty-eight percent (88.3%) of cases had spent more than K100, 000 on medication since the onset of the child's illness compared to controls (3.3%). On investigation expenses, 61.7% of cases had spent more than K100, 000 while among controls, 46.7% had spent less than K50, 000 and another 46.7% had not spent any money on them.

When asked if they had been unable to buy medicine for the child at one time due to lack of money, majority of cases (55%) reported that they had been unable to buy medicines as compared to controls (13.3%) with a significant difference ($p<0.01$) between the two groups. However, the study showed that majority of cases (81.7%) and controls (96.7%) were able to pay for investigations.

On transport expenditures, most of the cases (88.3%) had spent more than K100, 000 on transport to the health facility from the onset of the child's illness while majority of the controls (71.7%) had spent less than K50, 000. Results of the study also showed that majority of cases (96.7%) were unable to work as a result of taking care of the sick child as compared to controls (56.7%) showing a significant difference ($p=0.01$) between the two groups. There was a significant difference ($p<0.01$) in loss of income between cases and controls. Majority of cases (90%) reported loss of income due to loss of labour time compared to the controls (35%).

When asked if they had borrowed money to cushion medical expenses, most respondents among cases (68.3%) had borrowed money as opposed to controls (18.3%) and these proportions were significantly different ($p<0.01$). Forty-five percent (45%) of cases had sold household goods and assets to cushion medical expenses as compared to controls (6.7%) with a significant difference ($p<0.01$) between the two groups.

Table 4: Bivariate analysis of Financial Impact

n=120

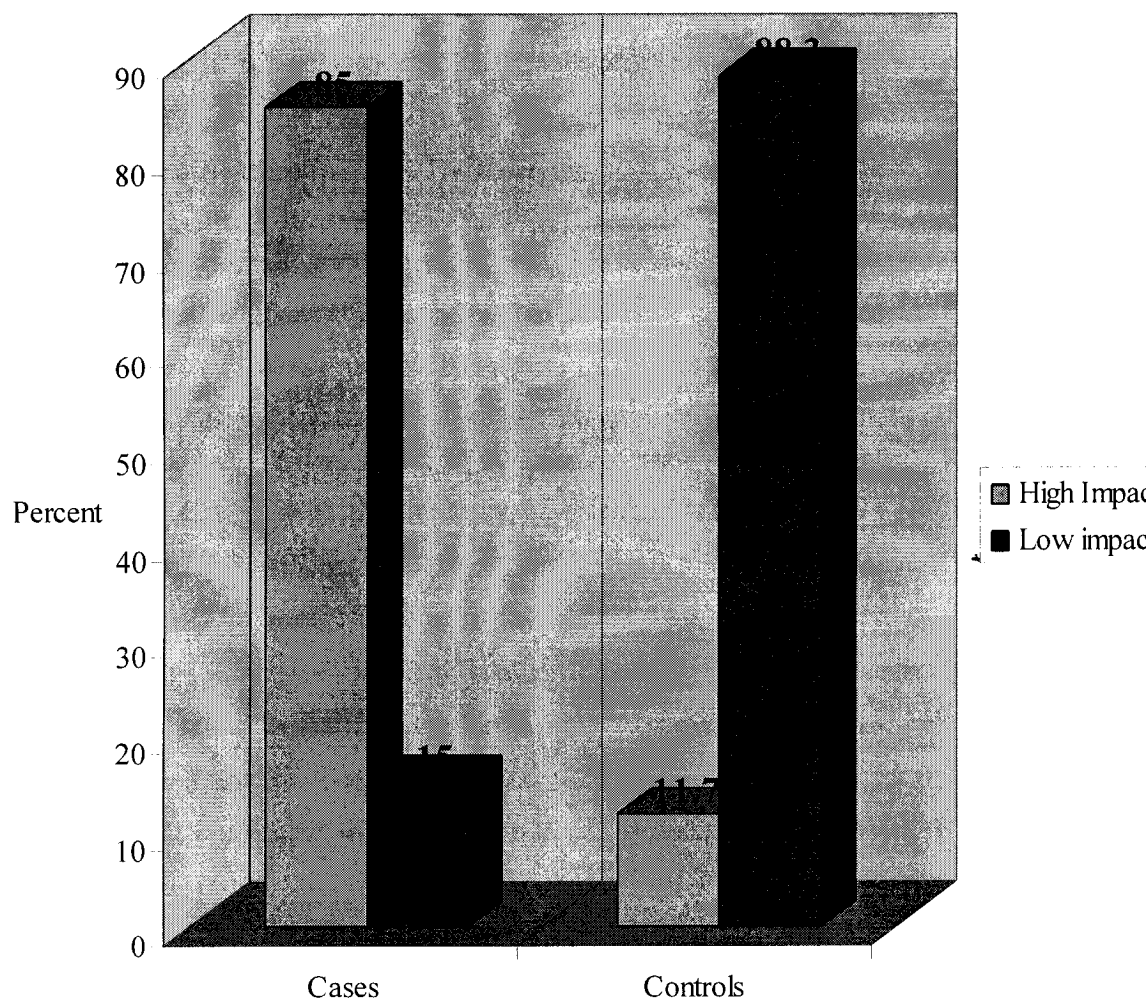
Characteristic	Cases		Controls	
	n	%	n	%
Medication expenses				
>K100, 000	53	88.3	2	3.3
K50, 000-K100, 00	3	5.0	11	18.3
<K50, 000	4	6.7	25	41.7
Nil	0	0	22	36.7
Total	60	100	60	100
Investigation expenses				
>K100, 000	37	61.7	0	0
K50, 000-K100, 00	4	6.7	4	6.7
<K50, 000	17	28.3	28	46.7
Nil	2	3.3	28	46.7
Total	60	100	60	100
Unable to buy medicines				
Yes	33	55	8	13.3
No	27	45	52	86.7
Total	60	100	60	100
Unable to pay for investigations				
Yes	11	18.3	2	3.3
No	49	81.7	58	96.7
Total	60	100	60	100

“Table 4, cont”

n=120

Characteristic	Cases		Controls	
	n	%	n	%
Transport costs				
< K50, 000	1	1.7	43	71.7
K50, 000-100, 000	4	6.7	9	15
>K100, 000	53	88.3	5	8.3
Nil	2	3.3	3	5
Total	60	100	60	100
Unable to work due to child’s illness				
Yes	58	96.7	34	56.7
No	2	3.3	15	25.0
N/A	0	0	11	18.3
Total	60	100	60	100
Loss of income				
Yes	54	90.0	21	35.0
No	6	10.0	39	65.0
Total	60	100	60	100
Borrowed money to cushion medical expenses				
Yes	41	68.3	11	18.3
No	19	31.7	49	81.7
Total	60	100	60	100
Sale of goods/assets				
Yes	27	45.0	4	6.7
No	33	55.0	56	93.3
Total	60	100	60	100

Figure 3: Financial Impact



Majority of cases (85%) had a high financial impact compared to controls (11.7%).
OR 6.3 (CI 95%; 3.3, 12.3; $p<0.01$, $df=1$).

4.5 SUPPORT SYSTEMS

There was no significant difference ($p=0.843$) in receiving help from relatives among the cases and controls. Most of the cases (68.3%) and controls (70%) had received help from relatives. The results also showed that most of the cases (51.7%) and controls (58.3%) had received help from their friends with no significant difference ($p=0.462$) between the two groups.

There was no significant difference ($p=0.172$) in visitation by relatives whilst in hospital between the two groups. Most of the respondents among cases (61.7%) and controls (73.3%) were visited by relatives. However, only 40% of respondents among cases were visited by friends compared to controls (66.7%).

The study also showed that majority of respondents among cases (80%) and controls (76.7%) had not received any help from religious organizations with no significant difference ($p=0.657$) between the two groups. The study further showed that there was no significant difference ($p=0.093$) in receiving help from any other organization/group in the community between cases and controls. Majority of cases (91.7%) and controls (98.3%) had not received any help from any other organization/group in the community.

There was a significant difference ($p<0.01$) between the cases and controls in relation to satisfaction with illness explanation by health worker. Majority of cases (78.3%) said that they were not satisfied while 58.3% respondents among controls said that they were satisfied with explanation of illness by a health worker.

The results of the study also showed that only 30% of cases had received counseling on how to cope with the child's illness as compared to controls (45%) with no significant difference ($p=0.089$) between the two groups. Of the 30% of cases counseled, only 21.7% were informed of services available to help them cope with the illness and only 1.7% accessed these services

Table 5: Support System

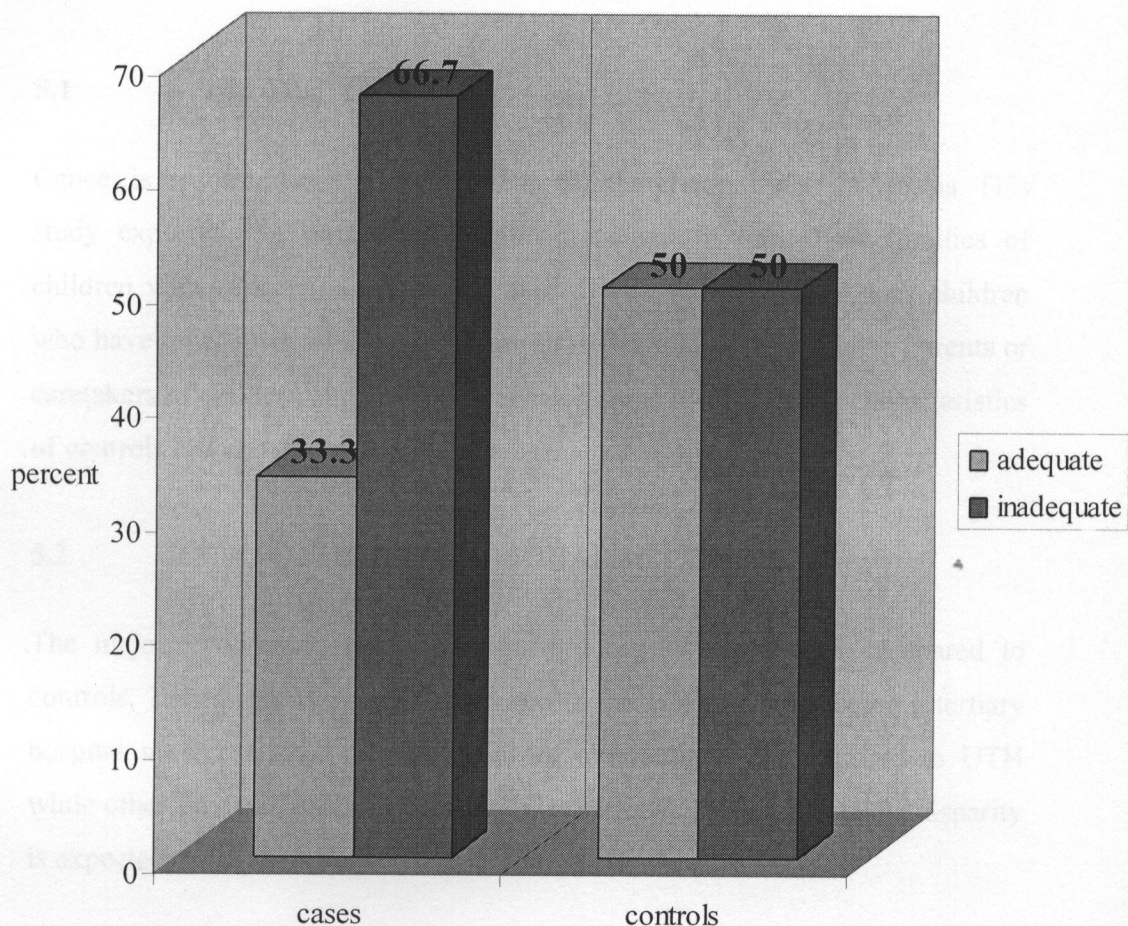
n=120

Characteristic	Cases		Controls	
	n	%	n	%
Received help from relatives				
Yes	41	68.3	42	70.0
No	19	31.7	18	30.0
Total	60	100	60	100
Received Help from friend				
Yes	31	51.7	35	58.3
No	29	48.3	25	41.7
Total	60	100	60	100
Relatives visit sick child in hospital				
Yes	37	61.7	44	73.3
No	23	38.3	16	26.7
Total	60	100	60	100
Friends visit sick child in hospital				
Yes	24	40.0	40	66.7
No	36	60.0	20	33.3
Total	60	100	60	100
Received help from religious organization				
Yes	12	20.0	14	23.3
No	48	80.0	46	76.7
Total	60	100	60	100

“Table 5, cont”

Characteristic	Cases		Controls	
	n	%	n	%
Received help from community group/organization				
Yes	5	8.3	1	1.7
No	55	91.7	59	98.3
Total	60	100	60	100
Satisfied with Illness explanation				
Yes	13	21.7	35	58.3
No	47	78.3	25	41.7
Total	60	100	60	100
Counseled				
Yes	18	30.0	27	45.0
No	42	70.0	33	55.0
Total	60	100	60	100

Figure 4: Support systems



Most of the cases (66.7%) had inadequate support systems compared to 50% of respondents among controls ($p=0.064$).

CHAPTER 5: DISCUSSION OF THE FINDINGS AND THEIR IMPLICATIONS TO NURSING, RECOMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

Cancer is becoming one of the common childhood conditions in Zambia. This study explored the impact of childhood cancer on immediate families of children with cancer (cases) and compared with those families with children who have other medical illnesses (controls). The study subjects were parents or caretakers of children and the study revealed some differences in characteristics of controls and cases in a number of areas.

5.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS

The majority of cases were coming from outside Lusaka as compared to controls. This disparity may be attributed to the fact that UTH being a tertiary hospital most cancer conditions from all over Zambia are referred to UTH while other illnesses could be dealt with in district hospitals, hence the disparity is expected.

The results revealed a similar age distribution between the cases and controls. Most of respondents among the cases (43.3%) were in the age group 36-45, while majority of the controls were aged between 26 and 35 years (61.7%). Most of the respondents were in these age groups, probably due to the fact that it is most reproductive age, as most of these respondents were parents to the children [cases (83.4%) and controls (90%)].

There was a significant difference ($p < 0.01$) between the controls and cases with regards to sex of respondents. Most controls (88.3%) were females compared to cases (58.3%). This probably would be attributed to the fact that women are expected to nurse their sick children while the men go to work. However, there

were more males among cases as compared to controls probably due to the fact that most of the cases were coming from outside Lusaka and as such, the men would rather take the children to the hospital while their wives remain to look after the rest of the family at home. On educational level, half of all the respondents (cases) had attained primary level while among controls, 36.7% had attained secondary level. The assumption is that most Zambians living in the rural areas are illiterate as compared to those in Lusaka. The study also demonstrated that there was no significant difference between the cases and controls with regards to occupation. The high number of cases (40%) was seen in the category of not employed and self-employed. In the control group, majority of the respondents (53.3%) were not employed. This could be attributed to the effects of privatization and structural adjustment programme, which has left most Zambians unemployed or peasant farmers (Mwinga, 2002). After 1991, firm and industry closures and other downsizing operations contributed to rising poverty as many household heads lost their jobs especially in urban areas. In absolute terms, by 1995 there were 55,700 jobs in the employment sector, and by the year 2000, 7,900 jobs had been lost due to firm closures and reduced capacity utilization (MoF, 2000).

Further the study revealed that majority of respondents got below K250, 000 per month. This was probably due to lack of employment as most of them were unemployed, and most Zambians live below K250, 000 per month. As already alluded to, the reduction in formal sector employment has been accompanied by a decline in the real wage index. For instance, the Jesuit Center for Theological Reflection (JCTR) April 2002 monthly survey showed that modal wage for a civil servant in 2002 was US\$ 45 (ZK189, 000) per month. Meanwhile, the cost of a food basket was at US\$200 (ZK840, 000) per month (Zambia Civil Society, 2002). In 2005, this situation may have become worse as poverty levels have kept on rising in the country.

5.3 PSYCHOSOCIAL IMPACT

A strong association was noted between having a child with cancer admitted and psychosocial impact. Families with a child with cancer were more likely to experience psychosocial pressure than those without a child with cancer as noted in the study. The impact was probably higher in respondents who were nursing children with cancer because of the chronic nature of the condition and also because most of them came from other towns in Zambia and had to stay longer in hospital. These results are similar to those found in a study done by Slopper (2000), titled “Predictors of Distress in Parents of Children With Cancer” where they found high levels of distress in mothers and fathers to be apparent, with little change over time.

Most of the respondents among cases reported loss of appetite as a result of nursing a child with cancer compared to controls. The reasons attributed to this were that they were very worried about their child’s illness. Usually, when one is nursing a child with a frightening disease and does not know what to expect, they tend to have physiological disturbances as well. These results are consistent with those found by Von Essen et al (2004) in a study titled ‘Swedish mothers and fathers of a child diagnosed with cancer-a look at their quality of life’. In this study, physical, social, and mental well-being were investigated by assessing depression, tension, head, heart-lung, metabolic, musculo-skeletal, and gastrointestinal-urinary symptoms. Von Essen et al found that parents reported more symptoms of depression with disturbed eating patterns.

When asked about their sleeping patterns, there was no significant difference between the cases and controls. However, several reasons were advanced for not sleeping well. Of the respondents (71.7%) among the cases who reported that they had sleeping problems, 93% gave the reasons that they were worried

about their child's condition. Nursing a child with cancer can be so stressful and thereby disturbing sleep. However, out of the 81.7% of controls who had problems with sleeping, 61.2% gave reasons that there was limited space and the environment was not conducive to sleep well.

There was no significant difference ($p=0.641$) when asked if their marriage had been affected in any way as a result of taking care of the sick child. Most of the married respondents in both groups reported that their marriage was not affected. This could probably be attributed to shared responsibility between husbands and wives and an understanding that develops in order for the family to cope with the illness. However, those who said their marriages were affected gave reasons that they were either not at home to take care of their husbands or that the husband blamed them for the illness of the child. This is due to stigma that is attached to HIV and AIDS, most of the respondents who had children with HIV related cancer reported that their marriage had been affected by the child's illness.

Majority of the respondents among the cases reported that the illness of their child had an impact on the other children at home in relation to psychosocial impact. This could be due to the fact the other children were missing their sibling and parent in hospital. Siblings of children who have been diagnosed with cancer are usually sad when they realize that their brother or sister is really very sick and will have to be away for a long time. Younger children miss the parent who usually provides most day-to-day care when he or she is unable to return home for days, weeks or months after the diagnosis. Older children who understand the risk to their sibling's life are depressed by a new awareness that life and health can be fragile, and they also feel sad as they witness their parents' distress. In a study done by Zeltzer et al (1996) they found that siblings were moderately healthy, although they reported significant problems with sleeping and eating due to the stress they also undergo.

The study also revealed that there was a significant difference in the fear of illness and outcome between cases and controls. Most respondents among cases said that they feared the illness and outcome, as compared to controls. This could be due to the fact that most respondents among cases did not understand the illness and possible outcome. It could also be attributed to the fact that majority of the cases were not counseled on how to cope with the illness as compared to the controls that were counseled and illness explained to their satisfaction. Several reasons were given for fear of illness and outcome, and the common reason given by most cases was that the child might die and they could not bear to see their child die so early in life. These results are consistent with results in a study done by Martinson et al (2000) on impact of childhood cancer on 50 Chinese families. In this study, all families identified cancer as the most frightening disease and described their outlook on life and their fears of death. Despite accepting the illness, most respondents still expressed fear of the outcome of the illness.

On self-blame, there was no significant difference between the cases and controls, as majority of respondents in both groups did not perceive themselves to be the cause of the child's illness. This was probably due to the fact that most respondents had accepted the illness of their child in both groups. When asked whether they were ashamed and embarrassed about their child's illness, majority of the cases and controls were not ashamed and embarrassed. It is however, important to note that all the respondents (18.3%) among cases who were ashamed and embarrassed about their child's illness gave the reasons that their child's illness was HIV/AIDS related and people would ridicule them if they knew that their child had cancer. This depicts the stigma that is attached to HIV and AIDS and lack of understanding of cancer among the population.

In terms of feeling isolated, there was no significant difference between cases and controls. The results revealed that majority of respondents among both cases and controls reported no change in their relationship with relatives or friends whilst nursing their sick child. This is probably due to strength of

family ties in the Zambian culture. However, it is important to note that a considerable number of respondents among cases felt distant from relatives (28.3%) and friends (26.7%). This could be due to the fact that most of the cases were coming from far places and it could be costly for relatives and friends to visit them frequently.

5.4 FINANCIAL IMPACT

The financial burden of cancer treatment can be a major source of anxiety for the families of children with cancer. The study showed that families with a child with cancer were more likely to have financial pressures than their counterparts without a child with cancer. Majority of the cases (85%) had high financial impact while 88.3% of controls had a low financial impact. This could be attributed to the fact that cancer being a chronic illness, most respondents among cases had children who had been ill for an average of 6 months as compared to controls who had children sick on average of 2 days. As a result of prolonged stay in the hospital and the chronic nature of the condition, majority of respondents among the cases had excess expenditure on medication, investigations, transport and upkeep while in hospital. This is supported by the findings in a study carried out in the USA (Bodkin et al, 1982) where they found that during the first inpatient week of treatment the sum of income lost plus additional expenditure exceeded 50% of their total income in over 45% of families.

One noteworthy finding is with regard to medication expense. The study demonstrated that majority of the respondents among cases had spent more than K100, 000 for medication from the onset of the child's illness to the time of interview compared to their counterparts. This was probably due to the cost of cancer drugs and more importantly the length of time it takes from the onset of illness to the confirmation of cancer. The family would have been seeking medical care and buying other drugs which may be prescribed thereby spending a lot of money.

From the study, most of the respondents among cases were unable to buy some prescribed medicines for the treatment of their child because of lack of money as compared to their counterparts who had children with other medical illnesses. This probably is due to the fact that most cancer drugs are expensive as compared to other drugs used in treatment of medical illnesses like malaria. It could also be attributed to low income, since most families with children who had cancer, had family incomes of less than K250, 000 per month. Such an income would not enable a family to buy expensive cancer drugs. However, it is interesting to note that most families in both groups were able to pay for investigations despite the fact that most investigations done in diagnosis of cancer are costly. This could probably be attributed to the fact that investigations are only done once to confirm diagnosis, while treatment would go on for months or even years in the case of cancer treatment.

On transport costs to the health facility, majority of the respondents who had children with cancer said that they had spent more than K100, 000 since the onset of their child's illness. From the study, it was revealed that most respondents with children who had cancer were coming from other districts in Zambia and they had to use their own money to bring the child to UTH. The study demonstrated that 96.7% of cases or their spouses were unable to work as a result of taking care of their sick child while only 56% of controls reported loss of labour time. As earlier mentioned, most of the cases had to stay in hospital for a longer period of time as compared to controls who had to stay for a few days, and then return to work. Family labor expended to care for the patient with cancer coupled with loss of income to family members is one of the major components of indirect costs. When this loss is probably combined with the nonmedical costs, the result has a serious strain on the family budget and this leads to increased borrowing. When asked if they had borrowed money to cushion medical expenses, majority of the cases (68.3%) reported that they had borrowed money and 18.3% of controls had borrowed showing a significant difference ($p < 0.01$). The average amount of money borrowed was

K50, 000. The study further demonstrated that 45% of cases had sold household goods or assets to cushion medical expenses. Goods sold were mainly foodstuff like maize, groundnuts, livestock and assets like radio cassettes and bicycles. With high levels of unemployment coupled with loss of labour time and income, sale of foodstuffs poses a great danger to food security for the subjects since some of them mentioned that they are peasant farmers. When they spend a lot of time in hospital nursing their sick child, they will not have adequate time to do their farming and this plunges them further into poverty.

5.5 SUPPORT SYSTEMS

From the study, majority of the cases (66.7%) had inadequate support systems as compared to controls that had half of the respondents with adequate support systems. On further analysis of support systems, most cases had received help from relatives as compared to friends. This could be due to the fact that there are close families and strong extended family ties in Zambia. Families are the strongest support systems that can be useful for a family experiencing psychosocial and financial pressures due to a child's illness. However, much of the help (67.6%) was in encouragement form and this could have contributed to the lower level of psychosocial impact. There was little significance between the cases and controls when asked if they had received help from religious organizations and other organizations in the community. In other countries, however, private, public, or charitable payers pay about 95% of all medical costs for children with cancer (Bloom, et al, 1985). This is not the case in Zambia, as families have to meet almost all the medical costs. The situation in this study could be attributed to the fact that many organizations have put more interest and effort in other chronic illnesses like HIV and AIDS and less concentration on diseases like cancer, especially in children. Intensified efforts could help, in that, when adequate financial and psychosocial support is given to families of children with cancer, more parents could spend less time in

hospitals and spend more time on productive ventures and thereby improve their social-economic status and that of the nation.

Majority of the cases said that they were not counseled and the illness had not been explained to their satisfaction. This could be attributed to the fact that in hospitals, there are no trained counselors who specialize in counseling families in relation to cancer. This causes a problem, because it becomes difficult for the family to identify any services that could be used to help them cope with the illness. Most controls than the cases had their child's illness explained to them. This could lead to the assumption that it led to low psychosocial impact amongst controls.

5.6 IMPLICATIONS TO NURSING

Nurses and other health workers have a leading role in delivery of quality health care in the country. With the increase of cancer in children, the health care system is continuing to experience strain on its services and resources. This is because cancer is a chronic illness and patients have to stay in hospital for weeks or months as they await investigations and treatment.

The study revealed that only 70% of cases were counseled and out of these, 6.7% were informed of available services to help them cope with their child's illness. The study also revealed that the diagnosis had not been explained fully to most of the respondents. This may imply that nurses and other health workers in the health care team do not counsel families and illnesses are not explained to clients satisfactorily. This increases psychological stress on clients as they do not understand the illness and do not know how they can cope with the stresses that come with the illness. Nurses need to be aware of the various coping behaviours that mothers and fathers use while caring for children with cancer. They can only be aware if they are able to make an assessment because assessment of coping strategies is a prerequisite to planning care for parents with children who have cancer.

Another significant finding is that there was high financial impact among families with children who have cancer. Considering the economic status of most respondents and indeed most Zambians, recognition of the hidden costs incurred by patients with cancer as they undergo treatment will enable the nurses to anticipate the financial burden of illness. This will help them make necessary referrals, address quality-of-life issues because of financial distress, and avert critical delays in treatment related to overwhelming healthcare costs. Nurses and all healthcare providers have a responsibility to assess their patients for financial need and assist them in accessing resources. This entails that the nurse should know all the available resources within and outside the healthcare system; in order to assist the clients access these services. Families of children with cancer need more help than is at present available, especially to offset loss of income.

5.7 CONCLUSION

The study was carried out in order to assess the impact of childhood cancer on immediate families of children with cancer with the aim of coming up with recommendations that will assist these families in coping with cancer in their children.

This study has shown significant differences between characteristics of families of children with cancer and those with other medical illnesses in areas of psychosocial impact, financial impact and support systems. Families with children who had cancer had a high financial impact in that, they had more medical expenses, loss of labour time and loss of income due to caring for the sick child as compared to those who had children with other medical illnesses. The cases also had inadequate support systems. The study has also revealed that there was a significant difference in psychosocial impact between the cases and controls because more respondents among cases were likely to experience psychosocial pressures than their counterparts.

One of the most crucial aspects of childhood cancer is support system. Some families indicated that they feel isolated from relatives and friends and this could contribute to the psychosocial strain that these families face. In difficult times like these, families need a strong support system from those that are close to them. The church based organizations have a big challenge in creating awareness among its members on childhood cancer and support that can be given to the families with children who have cancer. The community has also got a challenge as they try to assist these families with children who have cancer. One way they can assist is by forming cancer support groups to assist these families. Cancer being a chronic illness requires coordinated efforts from health care providers, communities and the government. Those groups, which are already in place like the Zambia Cancer Foundation-Leukemia fund, should be strengthened through financial support from the government and other non-governmental organizations.

From the study, it has been revealed that health care workers do very little to assist the families cope with the disease. It becomes very difficult for a family to understand the disease including its effects on family function. Health care providers can assist the family by explaining the disease process to this family, and help them in identifying services that can assist them.

5.8 RECOMMENDATIONS

Based on the study findings, the following recommendations were made:

1. There is need to strengthen counseling sessions to help clients who have children with cancer. More counselors among nurses need to be trained because nurses spend more time with the clients and are able to assess and plan for care.
2. There is need to raise awareness among community members on support of families who have children with cancer.

3. Support groups should be formed in the community in collaboration with religious and non-governmental organizations to assist families of children who have cancer.
4. The government should strengthen the social welfare department in assistance of these clients as most of the families come from far places and they have no relatives in Lusaka.
5. There is need for replication of the study using larger samples.

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Appendix I

INFORMED CONSENT

IMPACT OF CHILDHOOD CANCER ON IMMEDIATE FAMILIES OF CHILDREN WITH CANCER AT THE UNIVERSITY TEACHING HOSPITAL, LUSAKA, ZAMBIA.

INTRODUCTION

I, Marjorie Kabinga; a student of Master of Science in Nursing from the University of Zambia is kindly requesting for your participation in the research study mentioned above because it important to assess the impact of childhood cancer on the families of children with cancer. Before you decide whether or not to take part in this study, I would like to explain to you the purpose of this study, any risks to you and what is expected of you. If you agree to take part, you will be asked to sign this consent or make thumb print in front of someone. Your participation in this study is entirely voluntary; you are under no obligation to participate. You should be aware that the Research Ethics Committee of the University of Zambia has approved this study, which is there to protect you.

PURPOSE OF THE STUDY

The study will assist to obtain more information on the impact that childhood cancer has on the immediate families of those children who have cancer and the support systems that they use to cope.

PROCEDURE

After you sign the consent form and have had a chance to ask questions, you will be asked questions concerning how your child's illness has affected you psychosocially, financially and I will also ask you to give advice to health authorities on how families who have children with cancer can be assisted psychosocially and financially.

RISKS AND DISCOMFORTS

No risks or discomfort is involved apart from the use of your time in answering the questions that you will be asked by the interviewer. Answering the questions will take approximately 30 minutes.

BENEFITS

By taking part in this study, you will be able to provide us the information that would help relevant authorities and policy makers to come up with strategies and policies on training health care providers and counselors in caring for children who have cancer, and also try to improve the support systems for families with children who have cancer. No monetary favours will be given in exchange for information sought but counseling and information will be given to you on support systems available for you.

CONFIDENTIALITY

Your research records and any information you will give will be confidential to the extent permitted by law. You will be identified by code and personal information will not be released without your written permission, except when required by law. The Ministry of Health, University Teaching Hospital and the University of Zambia Research Ethics Committee of the School of Medicine may review your records, but again this will be done with confidentiality.

CONSENT TO PARTICIPATE IN THE STUDY

I.....have been fully informed of the purpose of the study, the benefits, discomforts, risks and confidentiality, and I agree to participate willingly.

Sign/Thumb print:_____

Date _____

Witness (Name): _____

Sign_____

PLEASE NOTE

1. Your participation in this study is entirely voluntary.
2. You are free to refuse or withdraw from participation without affecting the care of your child.

Persons to contact if there are problems or questions

1. Marjorie Kabinga, University of Zambia, Post Basic Nursing Department, P.O. Box 50110, Lusaka. Cell: 097 889430.
2. Mrs. P. Ndele, University of Zambia, Post Basic Nursing Department, P.O. Box 50110, Lusaka.
3. The Chairman, Research Ethics Committee, University of Zambia, P.O. Box 50110, Lusaka.

Appendix II

**UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE**

INTERVIEW SCHEDULE

**TITLE: IMPACT OF CHILDHOOD CANCER ON IMMEDIATE
FAMILIES OF CHILDREN WITH CANCER AT THE
UNIVERSITY TEACHING HOSPITAL, LUSAKA, ZAMBIA.**

RESPONDENT’S NUMBER.....

INSTRUCTIONS TO THE INTERVIEWER

- 1) Do not write the name of the respondent on the questionnaire.
- 2) Tick in the box next to the chosen answer, for questions with alternatives.
- 3) Write in the space provided for open-ended questions.
- 4) Do not omit any questions.
- 5) Write all answers accurately.

SECTION A: DEMOGRAPHIC DATA

1. How old were you on your last birthday? _____

2. Sex

1). Male

--

2). Female

3. What is your marital status?

1). Single

--

2). Married

3). Divorced

4). Widowed

5). Others (Specify) _____

4. What is your relationship to the patient?

1). Father

--

2). Mother

3). Sister

4). Brother

5). Others (specify) _____

5. How many children do you have?_____

6. What is your religious denomination?

1). Roman Catholic

--

2). Seventh day Adventist

3). Jehovah's Witness

4). Pentecostal

5). Others (Specify) _____

7. What is your highest level of education?

1). Primary

2). Secondary

3). Tertiary

4). None

--

8. What is your occupation?

1). Formal employment

2). Self employed

3). Not employed

4). Informal

5). Others (Specify) _____

--

9. What is your family monthly income?

1). Less than K250, 000

2). Between K250, 000 and K500, 000

3). Between K500, 000 and K750, 000

4). Above K750, 000

--

10. Which district are you coming from?

11. For how long have you been living there?

SECTION B: PSYCHOSOCIAL IMPACT

Stress on the family

12. What illness is your child suffering from?

13. For how long has your child been ill?

14. What was your response when you were told that your child has this condition?

1). Accepted the illness

--

2). Failed to accept the illness

3). Other (specify)_____

15. How has been your appetite since your child fell ill?

5). Good appetite

--

6). No appetite

Give reasons for your answer to question 14 above

16. Have you been sleeping well since your child fell ill?

1). Yes

--

2). No

Give reasons to your answer to question 15 above.

17. If you are married, has your marriage been affected in any way as a result of nursing the patient?

1). Yes

--

2). No

If the answer is yes explain? _____

18. Has the illness of your child had any effect on your other children?

1). Yes

--

2). No

If the answer to question 17 is yes in what way?

Fear of disease and outcome

19. Have you got any fears about your child's illness and outcome?

1). Yes

--

2). No

Give reasons for your answer

Guilty feelings

20. Do you sometimes feel responsible for your child’s illness?

1). Yes

--

2). No

Give reasons for your answer

Stigma

21. Do you ever feel ashamed and embarrassed about people knowing your child’s illness?

1). Yes

--

2). No

Give reasons for your answer

22. Are you able to discuss your child’s illness freely with other people?

1). Yes

--

2). No

Give reasons for your answer

Isolation

23. How has your child's illness affected your relationship with your relatives?

- 1). Feel closer to my relatives
- 2). Feel distant from my relatives
- 3). Feel abandoned
- 4). Relationship is the same
- 5). Others (specify) _____

--

24. How has your child's illness affected your relationship with your friends?

- 1). Feel closer to my friends
- 2). Feel distant from my friends
- 3). Feel abandoned
- 4). Relationship is the same
- 5). Others (specify) _____

--

SECTION C: FINANCIAL IMPACT

Medical expenses

25. How much have you spent on medication from the onset of the child's illness to date?
 - 1). Less than K50, 000
 - 2). Between K50, 000 and K100, 000
 - 3). More than K100, 000
 - 4). Nil
26. How much have you spent on investigations from the onset of the child's illness to date?
 - 1). Less than K50, 000
 - 2). Between K50, 000 and K100, 000
 - 3). More than K100, 000
 - 4). Nil
27. Are there any medications that the doctor prescribed and you were unable to buy due to lack of money?
 - 1). Yes
 - 2). No
28. Are there any investigations that the doctor advised and were not done due to lack of money?
 - 1). Yes
 - 2). No

[illegible]

Transport costs

29. How much have you spent on transport from home to the health care facility from the onset of the child's illness to date?

- 1). Less than K50, 000
- 2). Between K50, 000 and K100, 000
- 3). More than K100, 000
- 4). Nil

--

Income loss

30. Have you or your spouse ever been unable to work because of taking care of your child?

- 1). Yes
- 2). No

--

31. If the answer to question 31 is yes, has there been loss of income?

- 1). Yes
- 2). No

--

32. How has your child's illness affected the family's financial income?

- 1). Not affected
- 2). Decrease in income
- 3). Increase in income
- 4). Others (specify) _____

--

33. Have you ever-borrowed money to cushion medical expenses?

1). Yes

2). No

If yes, how much? _____

--

34. Have you ever sold any household goods/assets to cushion medical expenses?

1). Yes

2). No

If yes, what household goods/assets did you sell and how did this affect the family? _____

--

SECTION C: SUPPORT SYSTEMS

35. Have you ever received any help from relatives during your child's illness?

1). Yes

2). No

--

36. If so, what kind of help?

1). Encouragement

2). Financial and material support

3). Taking care of the child

4). Others (specify) _____

--

37. Have you ever received any help from friends during your child's illness?

1). Yes

☐

2). No

☐

38. If so, what kind of help?

1). Encouragement

☐

2). Financial and material support

☐

3). Taking care of the child

☐

4). Others (specify) _____

39. Do your relatives visit the sick child in the hospital?

1). Yes

☐

2). No

☐

40. Do your friends visit the sick child in the hospital?

1). Yes

☐

2). No

☐

41. If you have other children at home, who helps take care of them when you have to stay in hospital?

42. Have you ever received any help from any religious organization during your child's illness?

1). Yes

☐

2). No

☐

43. If so, what kind of help?

1). Encouragement

2). Financial and material help

3). Taking care of the child

4). Others (specify) _____

--

44. Have you ever received any help from any other group in your community during your child's illness?

1). Yes

2). No

--

45. If the answer is yes, which organization?

1). Government Social welfare department

2). Insurance Company

3). Non-Governmental organization (specify)

4). Others (specify) _____

--

46. What kind of help did you receive?

1). Psychological support

2). Financial and material help

3). Others (specify) _____

--

47. Has the illness of your child been explained to your satisfaction?

1). Yes

2). No

--

48. If the answer is no, which of the following has not been explained to your satisfaction?

1). Illness

2). Cause

3). Treatment

4). Possible outcome

5). Others (specify) _____

--

49. Have you ever been counseled to help you cope with your child's illness and treatment?

1). Yes

2). No

--

50. If yes who counseled you?

1). Doctor

2). Nurse

3). Trained psychosocial counselor

4). Others (Specify) _____

--

51. Were you told of services available to assist you cope?

1). Yes

2). No

--

If yes, which services?

52. Have you ever accessed these services?

1). Yes

2). No

--

If answer is yes describe these services

53. Give suggestions on how families with a child who has this illness can be assisted in your community

THANK YOU FOR YOUR PARTICIPATION

Appendix III



**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE**

Telephone: 252640
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Telex: UNZALU ZA 44370
Fax: + 260-1-250783
Email: kbowa@yahoo.com

Dean's Office
P.O. Box 50100
Lusaka, Zambia
Your Ref:

9th August, 2005

Ms. Marjorie Kabinga
Department of Post Basic Nursing
School of Medicine

Dear Ms. Kabinga,

Re: MASTER OF SCIENCE IN NURSING RESEARCH PROPOSAL

Your research proposal for the Master of Science in Nursing entitled: **"Impact of Childhood Cancer on Immediate Families of Children with Cancer at the University Teaching Hospital"** was presented at the Graduate Studies Committee of the School held on 9th June, 2005.

I am pleased to inform you that your proposal was approved by the Committee. You can proceed to Part II of the programme and your Supervisor is Mrs. P. Ndele and your Co-supervisor is Dr. T. J. M'soka.

I wish you every success in your studies.

Yours sincerely,

Prof. K. S. Baboo

ACTING ASSISTANT DEAN, POSTGRADUATE

c.c Director, Graduate Studies
 Dean, School of Medicine
 Head, Department of Post Basic Nursing
 Mrs. P. Ndele
 Dr. T. M'soka



THE UNIVERSITY OF ZAMBIA

RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
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Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

13 June, 2005
Ref.: 008-04-05

Ms Marjorie Kabinga, BSc N, RN
Department of Post Basic Nursing
School of Medicine
University of Zambia
P.O. Box 50110
LUSAKA

Dear Ms Kabinga,

RE: **SUBMITTED RESEARCH PROPOSAL**

The following research proposal was presented to the Research Ethics Committee meeting held on 4 May, 2005 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal has now been approved. Congratulations!

Title of proposal: **"Impact of childhood cancer on the immediate families with cancer at the University Teaching Hospital, Lusaka, Zambia"**

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study (Progress Report Forms can be obtained from the Secretariat).
- Written permission should be sought from the various institutions before data collection.

Yours sincerely,

Prof. J. T. Karashani, MB, ChB, PhD
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Date of approval: 13 June, 2005

Date of expiry: 12 June, 2006



THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF POST BASIC NURSING

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P.O. Box 50110
Lusaka, Zambia

17th June 2005

The Executive Director
University Teaching Hospital
LUSAKA



Permission granted but have to obtain consent from family before question is given
J.M.O.

Re: **REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY AT THE UTH PEADIATRIC ONCOLOGY-HEAMATOLOGY WARD AND WARD AO 8**

The above mentioned is a Master of Science in Nursing student at the University of Zambia, Department of Post Basic Nursing, School of Medicine. As partial fulfilment of the Masters Program, She is required to conduct a research in the area of her specialty, **Medical-Surgical Nursing**.

The purpose of writing this letter is to request for permission to conduct a study entitled **Impact of Childhood Cancer on immediate families of children with cancer at the University Teaching Hospital (UTH)**.

The Department will be very grateful if your Organization can give the necessary assistance the student may require.

Thanking you for your continued support and co-operation.

Yours faithfully

