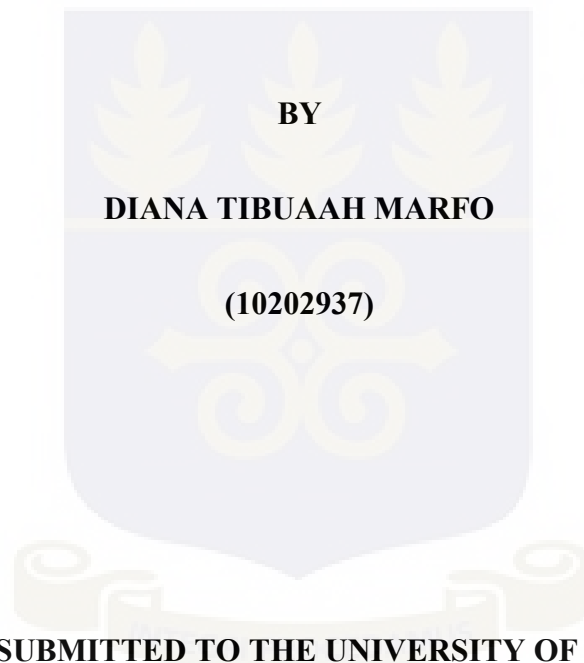


UNIVERSITY OF GHANA
SCHOOL OF NURSING AND MIDWIFERY

**EXPERIENCES OF ADOLESCENTS RECEIVING CANCER TREATMENT AT
KORLE-BU TEACHING HOSPITAL**



**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN
PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF
MPHIL NURSING DEGREE**

OCTOBER, 2018

DECLARATION

I hereby declare that this research work represents my own work and has not been presented to any other institution for award of a degree. The information derived from the literature has been duly acknowledged in the text and list of references provided. The research has been undertaken under the guidance and supervision of Dr. Patience Aniteye of School of Nursing and Midwifery, University of Ghana and Rev. Dr. Thomas A. Ndanu of Korle Bu Teaching Hospital.

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ABSTRACT

Cancer is one of the most challenging and devastating diseases that affects adolescents, as well as adults and children. Unlike children and adults, cancers occurring in adolescents are uncommon in terms of their site, genetic profiles, clinical characteristics, morphology and topography. The treatment regimen of cancer is usually long and may take years to be completed. This may deprive adolescents of school, leisure activities and time to associate with friends and family. Even if these needs are adequately met, the adolescent receiving cancer treatment is confronted with a myriad of psychosocial issues that may affect the quality of life. These include the effects of symptoms and side effects of medications, loss of social function, the importance of peers and other sources of support, the effects of diagnosis and sometimes financial constraints. Most research conducted have focused on the experiences of caregivers and neglected the adolescents who may already be going through a lot of psychosocial challenges associated with this developmental stage. The study therefore explored the physical, psychological, social and spiritual well-being of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital. An exploratory, descriptive qualitative approach was used to describe the experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital using the Quality of Life Model applied to cancer developed by Dow and Ferrell (1999) as an organising framework. Purposive sampling was used to select fourteen adolescents, who have been receiving cancer treatment for six months or more. A semi-structured interview guide was used to collect data from fourteen adolescents receiving cancer treatment at the Korle-bu Teaching Hospital. Each interview was audiotaped and lasted for about 45-90 minutes. Each interview was transcribed verbatim and thematic content analysis used to analyse the data. Five major themes were derived. These were physical well-being, psychological well-being, social well-being and spiritual well-being of adolescents receiving cancer treatment, and health service-related

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factors. The study found out that adolescents receiving cancer treatment experienced symptoms from cancer and side effects of treatment such as gastrointestinal disorders, pain, decrease in functional ability and fatigue. Psychologically, the adolescents were worried, sad and anxious about frequent hospital visits, undergoing treatment, the possibility of cure, mood changes and cognitive/attention deficits. They experienced social isolation, absenteeism from school and church. They however had support from their family, school, friends and health care providers. Caregivers of the adolescents experienced caregiver burden and financial constraints which impacted on the quality of life of the adolescents. Spiritually, the adolescents were hopeful of a future and prayed to God for healing. It was recommended that a multidisciplinary approach be used in the care of adolescents receiving cancer treatment. Also, cancer centres be established in every region and the cost of cancer treatment especially for adolescents be included on the National Health Insurance Scheme to reduce financial burden on caregivers.

DEDICATION

This work is dedicated to Honourable Abraham Dwuma Odoom (Member of Parliament for Twifo/Ati Morkwa Constituency) and to Oseadeayo Akwasi Kanin IV (Paramount Chief of Twifo/Ati Morkwa Traditional Area) for their assistance and guidance. Also to My Dear Husband (Capt. Mohammed Abubakari) and my two children; Griffith and Chris-Ansel Abubakari for their love, patience and prayers as I was embarking on this project.

ACKNOWLEDGEMENTS

I wish to express my profound gratitude to the Almighty God for seeing me successfully through this programme.

And to my supervisors; Dr. Patience Aniteye and Rev. Dr. Thomas Akuetteh Ndanu for their patience and guidance as I journeyed through putting this piece together.

I am also grateful to all the patients and their caregivers who participated in this study.

My profound gratitude also goes to Mr. George Achempim, Uncle Emma, DDNS Abbey and PNO Joyce Ayisi and all the staff of the Paediatric Oncology unit, Korle- Teaching Hospital for the assistance given.

Also to the Staff of Surgical department, korle-bu Teaching Hospital especially to staffs at the chemotherapy bay.

I am also grateful to all the faculty members of the School of Nursing and Midwifery, University of Ghana for their guidance and input during my course of study.

Again, I am grateful to Mr. Daniel Amiteye of All Nations University and to Mr. Peter Paul Erefaar for their inputs into this study.

And to all my course mates especially Agustina, Joseph, Benjamin, Benson and David for their support and encouragement during my course of study.

My final appreciation goes to all those who contributed in diverse ways to make this dream a reality. I say Kudos to you all.

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LIST OF ABBREVIATIONS

KBTH:	-	Korle-bu Teaching Hospital
KBTH-IRB:	-	Korle-Bu Teaching Hospital- Institutional Review Board
LMIC:	-	Low-Middle Income Countries
NCI:	-	National Cancer Institute
NICU:	-	Neonatal Intensive Care Unit
NMIMR:	-	Noguchi Memorial Institute for Medical Research
NMIMR-IRB:	-	Noguchi Memorial Institute for Medical Research - Institutional Review Board
POU:	-	Paediatric Oncology Unit
QoL:	-	Quality of Life
WHO:	-	World Health Organisation

CHAPTER ONE

INTRODUCTION

This chapter presents the background to the study, problem statement, purpose of the study, objectives, research questions, significance of the study and operational definitions of terms used in the thesis.

1.1 Background to the study

Cancer comprises a wide array of diseases characterised by uncontrolled growth of abnormal cells (American Cancer Society, 2016), most of which are invasive and can spread to both nearby and distant cells (Henrique & de Carlos Back, 2016). Depending on the type and location, individuals with cancer are susceptible to develop other malignant neoplasms, due to metastasis, or develop secondary diseases and loss of certain functional abilities (J. Li, Thompson, Miller, Pollack, & Stewart, 2008). There are various kinds of cancers based on their location, with different types occurring in both males and females. Cancer types based on the location can be categorised as cancers of the lip, oral cavity, pharynx, esophagus, eye, stomach, colon and rectum, liver, gallbladder, pancreas, larynx, lungs, skin, kidney, bladder, brain and central nervous system, thyroid, lymph nodes and blood. Cancers of cervix, uterus, and ovary occur in females whilst cancers of the prostate and testis are found mainly in males (Ferlay et al., 2015). Cancer of the breast however occurs in both sexes but more commonly in females (Siegel, Miller, & Jemal, 2015). The International Classification of Childhood Cancers (2015) provides a classification for cancers based on ICD-0-2 morphology and typography codes. This categorises childhood cancers into twelve (12) main forms as (i) Leukemias, (ii) Lymphomas and other reticuloendothelial neoplasms, (iii) Sympathetic nervous system tumours, (iv) Retinoblastoma, (v) Renal tumours, (vi) Central nervous system and

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miscellaneous intracranial and intraspinal neoplasms, (vii) Malignant bone tumours, (viii) Carcinomas and other malignant epithelial neoplasms, (ix) Soft-tissue sarcomas, (x) Hepatic tumours, (xi) Germ-cell, trophoblastic and other gonadal neoplasms and (xii) Other and unspecified malignant neoplasms (Kramarova & Stiller, 2015).

The actual cause of cancer is unknown. However, about 5% of cancers can be attributed to carcinogens or family history (Raphael et al., 2014). A study conducted by (Howard et al., 2007) indicated a positive association between paternal pre-conception smoking and the occurrence of childhood cancer, especially acute leukemia and lymphoma with the highest risk increasing with pack-years of paternal preconception smoking. Alcoholism is said to account for about 5.8% of deaths from cancer with higher risk in tissues such as the mouth and oesophagus which have closest contact when alcohol is ingested into the body (López-lázaro, 2016). Hashim (2014) also revealed a positive association between exposure to asbestos and lung cancer especially in women due to indoor pollution as well as arsenic contributing to cancers of the bladder, liver, skin, kidney and the lungs. Dockerty, Draper, Vincent, Rowan and Bunch (2011), found an association between age of parents, number of children and social class and certain types of childhood cancers such as Retinoblastoma and Acute Lymphoblastic Leukemia (ALL).

According to WHO (2011), cancer is the leading cause of death worldwide in both adults and children followed by coronary artery diseases. It is estimated that by 2030, the global incidence of cancer is expected to reach 26 million with 17 million deaths per year (Hung, Chen, Horng, & Lin, 2016). Despite the improvement in the treatment of childhood cancers to about 80%, cancer still remains the second leading cause of mortality (following accidents) in children between the ages of 5 to 14 years (Li, Thompson, Miller, Pollack, & Stewart, 2008). Leukemia and lymphomas, the most common malignant diseases affecting children, account for approximately 30% of childhood cancers (Karimi,

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Mehrabani, Yarmohammadi, & Jahromi, 2008). Hung, Chen, Horng and Lin, (2016) however found epithelial tumours as the most frequently diagnosed cancer group in children and young adults with a percentage of (23.7%), followed by Leukemias (18.0%) and lymphomas (13.9%). Primary intracranial tumours account for 25% of all childhood cancers and are associated with the greatest number of cancer deaths. Cancer is the leading cause of death in children and adolescents by disease (Li et al., 2008; Moruno Miralles, Ramón, & Valero, 2016). However, adolescent males have 31% higher death rates from cancer than females (Henrique & de Carlos Back, 2016).

In high-income countries such as the United States of America, cancer accounts for 1 in every 4 deaths in a day with about 1,685,210 new cancer cases expected to have occurred in 2016 (American Cancer Society, 2016).

In 1975, the incidence of cancer in Low- Middle-Income Countries was about half (51%) of all cancer cases worldwide. This rate increased to 55% in 2007 and is projected to reach 61% by 2050 (Thun, Delancey, Jemal, & Ward, 2010). With an increasing population growth throughout the world, it is estimated that more than 20 million new cancer cases are to be expected yearly by 2025 (Ferlay et al., 2015). Out of these, about 70% will reside in Low-Middle Income Countries as a result of improved diagnosis and treatment of infectious diseases, changes in lifestyle and increased life expectancy (Jemal, Bray, Forman, Brien, & Ferlay, 2012).

Cancer is now an emerging public health concern in Africa, with about 715,000 new cancer cases and 542,000 cancer deaths estimated to have occurred in 2008 and this is expected to double in the next 20 years (Jemal, Bray, Forman, Brien, & Ferlay, 2012; Kingham, Alatisé, Vanderpuye, & Casper, 2013). However, the occurrence and death from cancer in Africa vary greatly across countries and even in the same country, there are variations across ethnic groups and regions (Jemal et al., 2012). It is estimated that about

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148,000 children in low-income countries have cancer (Ferlay et al., 2015).

Most countries in Sub-Saharan Africa struggle to provide the health care needs of people with cancer due to increasing population growth in these countries (Kingham et al., 2013). Moreover, it is difficult for these countries to adopt cancer care models used in the more advanced countries since most countries in the sub-region have less health personnel to patient ratios, face major economic and financial difficulties and are unable to meet the basic needs of their people. These factors may in one way or the other account for the overall case fatality ratio of cancer estimated to be 75% in low-income countries, as opposed to 46% in high-income countries (Jemal et al., 2012). According to Stefan et al., (2013), Cancer is the fourth most common cause of mortality in Ghana. GLOBOCAN (2011) also estimates that 16,000 cancer cases occur annually in Ghana, with cancers of the liver, breast, cervix, prostate, and stomach being the most common types.

Adolescence marks a transitional period between childhood and adulthood. In most societies, especially in Africa, various rites of passage are performed to initiate the child into adulthood. However, the definition of adolescent does not fit into a specific age. Formerly, the term “adolescents” was defined by the National Cancer Institute (NCI) as individuals between 15 and 29 years of age. However, the range was widened to 15 to 39 years of age by the NCI’s Adolescents and Young Adults Oncology Progress Review Group in order to include all the age ranges that may still be experiencing a transition of developmental experiences needed to be recognised as fully grown adults (Docherty, Kayle, Maslow, & Santacroce, 2015). The World Health Organisation and the United Nations define adolescent as an individual between the ages of 10 and 19 years (United Nations & Unicef, 2011; WHO, 2015). In Ghana, the term “adolescent” is often used interchangeably with “teenager” and ranges from 13 to 19 years (Ghana Statistical Service, 2012). It is difficult to set an age range as the stage is influenced by gender,

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culture and each person's unique maturation (Aubin & Perez, 2015).

The period of adolescence is characterised by growth and maturation of physical, physiological, psychological and emotional functioning. In most communities in Africa and the world over, adolescence is a period which involves the assumption of adult roles and economic independence as well as attainment of full potential as an adult. It is a challenging period for the adolescent due to the series of events that take place either physically, biologically or socially. During this period, total control of parents diminishes and is replaced by the adolescent gaining full or partial autonomy. It is a risky period since the adolescent may fall prey to peer pressure, drug abuse and other social vices. It is a period marked by specific health and emotional needs which if not properly managed, can have a tremendous effect later in adult life (Chulani & Gordon, 2014).

There are about 1.2 billion adolescents in the world (Nair et al., 2015). They form the major percentage of most countries in the world, especially, countries such as Ghana that is still in the transition stage of moving from agricultural based economy to a more industrialised one (Magrath & Epelman, 2013). Magrath and Epelman further stated that, adolescents are essential since they constitute the majority of the working class and contribute to improving the economy as well as their unique role in taking care of their family members be it children, adults or the elderly. These roles of adolescents confer on them unique medical, emotional, social, spiritual, and physical needs which must be approached specially in instances of ill health to enable them fully experience this period and develop their full potential (Aubin & Perez, 2015; Kim, White, & Patterson, 2016). Cancer represents one of the most challenging and devastating diseases that affect adolescents and unlike children and adults, cancers occurring in adolescents are uncommon in terms of their site, genetic profiles, clinical characteristics, morphology and topography (Henrique & de Carlos Back, 2016). Adolescents are prone to types of cancers

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in both children and adults (Hung, Chen, Horng, & Lin, 2016; Magrath & Epelman, 2013), hence cancer treatment in adolescents are done using both adult and children treatment protocols (Nasir, Giri, Nunnery, & Martin, 2016).

It is difficult to ascertain the world burden of cancer in the adolescent population especially in low-income countries such as Ghana due to the different age definitions of adolescents, lack of cancer registries and poor population statistics (Erickson, MacPherson, et al., 2013).

The treatment regimen of cancer for adolescents is usually long and may take years to be completed, sometimes requiring that the primary caregiver moves with the adolescent to stay close to the hospital (White, Castle, & Haig, 2013). This may deprive adolescents of school, leisure activities, and time to associate with friends and family. Moruno Miralles, Ramón and Valero (2016), therefore identified the following as needs of adolescents receiving cancer care. These needs are classified as educational, leisure, spacious rooms, communication with medical personnel and absence of separate wards for adolescents. Even if these needs are adequately met, the adolescent receiving cancer treatment is confronted with a myriad of psychosocial issues that may affect the quality of life. These include the effects of symptoms and side effects of medications, loss of social function, the importance of peers and other sources of support, the experience of healthcare, striving for normalcy, the impact of diagnosis and sometimes financial consequences (Taylor, Pearce, Gibson, Fern, & Whelan, 2013). Moruno, Miralles, Ramón and Valero (2016) further stated that the diagnosis and treatment of cancer during adolescence is linked to negative experiences such as fear of alienation, fear of altered body image, fear of dying and various physical concerns that impact negatively on the adolescents' quality of life. It is therefore, important that a unique approach that is holistic in nature such as the Quality Of Life Model be employed in the care and management of

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adolescents receiving cancer treatment. This study thus sets out to explore the experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital using the Quality of life model developed by Dow and Ferrel (1999) as a guide. The model has four main constructs. These are the physical, social, psychological and spiritual domains. These are explained in relation to the well-being of adolescents receiving cancer treatment.

1.2 Problem Statement

Data on autopsy records at the department of Pathology, Korle Bu Teaching Hospital from 1991-2000 indicate that cancers were the ninth commonest cause of both admissions and deaths at the facility accounting for 3.1% and 2.5% of the total admissions and deaths respectively. The leading cancer deaths in females were breast, cervix, haematopoietic organs, liver, stomach and colorectum. On the other hand, the top five causes of cancer deaths in men are liver, prostate, haematopoietic organs, stomach, and pancreas.

In children, the leading causes of cancer deaths are malignancies of the haematopoietic system, followed by brain, kidney, eye, liver and bone tumours (*National Strategy for Cancer Control in Ghana*, 2016). A study conducted by Renner et al., (2018) indicated that the Korle Bu Teaching Hospital Paediatric Cancer Unit treats on average 170 new diagnoses annually. However, a retrospective study from 2012-2014 at the Paediatric Oncology Unit of the Komfo-Anokye Teaching Hospital indicate that there is an observable trend in the progressive increment in the number of cancer cases presenting to the unit over the three years period (Paintsil et al., 2015). Meanwhile, the proportion of adolescents with cancer in the above studies in Ghana is not known since adolescents in Ghanaian health facilities are either managed as adults or children.

Each developmental stage in humans is identified with certain psychosocial tasks

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which need to be accomplished especially during the period of adolescence. A study conducted by Phillips and Davis (2015), indicated that adolescents, despite their unique nature and cancer types are not adequately served by currently available support services. As a result, the adolescent with a life-threatening condition such as cancer is likely to face many more problems with untold ramifications if these problems are not addressed adequately.

The mere mention of cancer brings a feeling of fear, anxiety, and grief among the individual diagnosed with cancer, their family, and the general public (Tippy, 2016). In African and the Ghanaian society, children are expected to grow, take care of their parents in their old age, bury them when they die and sometimes contribute financially to support the family (United Nations & Unicef, 2011). It therefore becomes a great burden and stress on a family to note that an adolescent is diagnosed with a life-threatening condition such as cancer. This creates a myriad of life-altering events for them as well as their families (Li, Thompson, Miller, Pollack, & Stewart, 2008). Meanwhile, in most cases, there are no special units in place to better deal with the psychological issues of young cancer patients in Low-Middle Income Countries (LMIC) coupled with limited studies on issues affecting adolescents (Magrath & Epelman, 2013).

Medical advancements in paediatric oncology have improved over the past decade with a corresponding increase in the survival rates of young children, however adolescent cancers have not seen the same improvement (Phillips & Davis, 2015). Cancer survival depends on the specific cancer type, which means that the survival rate can be lower in adolescents than in younger or older cancer patients, for instance non-Hodgkin's lymphoma or acute lymphoblastic leukemia (Richter et al., 2015). Hence, much attention needs to be paid to adolescents with cancer in order to realise advancements in their care.

Most research conducted have focused on the experiences of parents, family

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members and significant others and neglected the adolescent who may already be going through a lot of physical, emotional and biological stressors associated with this transitional period. Some organisations have initiated actions to ensure the holistic care and treatment of adolescents with cancer with the main focus of soliciting their own experiences and needs in providing such care (Kim et al., 2016). However, there are only a few psychosocial interventions designed specifically for adolescents with cancer (Phillips & Davis, 2015) and in Ghana, some of these interventions are not available.

Furthermore, the impact of cancer on adolescents has not been fully explored in the country which may be due to lack of awareness among policy makers, stakeholders and the general public about the impact of adolescent cancer burden on the economy (Jemal et al., 2012). Based on the discussions, it is therefore, imperative to delve into the experiences of adolescents receiving cancer treatment in order to enhance the care offered them, increase their life expectancy and contribute to the improvement of the economy.

1.3 Purpose of the study

The purpose of this study was to explore and describe the well-being of adolescents undergoing cancer treatment at the Korle-bu Teaching Hospital.

1.4 Specific objectives

1. To describe the physical well-being of adolescents receiving cancer treatment.
2. To explore the social well-being of adolescents receiving cancer treatment.
3. To explore the psychological well-being of adolescents during the period of undergoing cancer treatment.
4. To describe the spiritual well-being of adolescents on cancer treatment.

1.5 Research Questions

1. What are the physical experiences of adolescents receiving cancer treatment?
2. What social issues do adolescents face during this period on cancer treatment?
3. What are the psychological issues adolescents encounter during the period of receiving cancer treatment?
4. What issues of spirituality do adolescents experience whilst receiving cancer treatment?

1.6 Significance of the study

This study was to bring into light the physical, social, psychological and spiritual experiences adolescents go through in the course of receiving cancer treatment. These experiences if identified would serve as a guide to care that is tailored to the special needs of the adolescent with cancer. The study findings would highlight the need for the health care management team to bring on board various health care professionals such as clinical psychologists, social workers, occupational therapists among others in the management of adolescents with cancer. This study will also inform the government, other policy makers and Non-Governmental Organisations to incorporate the needs of the adolescent with cancer into policy formulations.

Moreover, the study findings will also add to the existing body of knowledge on the experiences of adolescents receiving cancer treatment in Ghana. Finally, this study will serve as a basis for further studies.

1.7 Operational definitions

Cancer: Uncontrolled growth of abnormal cells in any part of the body.

Adolescent: An individual between the ages of 13 years and 19 years.

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Cancer treatment: Any form of intervention aimed at getting rid of cancer or reducing its symptoms.

Experience: An instance of encountering something or a situation

Psychological well-being: A state of joy and ability to gain a sense of control in relation to fears, anxiety, emotions and death as one experiences cancer treatment and its side effects.

Social well-being: The ability of the individual to enjoy the company of or relate to family, friends or significant others or to partake in leisure and social activities as one experiences cancer treatment and its side effects.

Physical well-being: The ability to gain control over signs and symptoms and to achieve a level of independence.

Spiritual well-being: A sense of inner peace with oneself and relation with one's object of worship as one experiences cancer treatment and its side effects.

Quality of life (QoL): The effect of a condition on the ability of an individual to live a fulfilling and satisfying life.

CHAPTER TWO

LITERATURE REVIEW

This section focusses on The Quality of Life model as applied to cancer and how the constructs in the framework serve as a guide to the development of objectives. The model was used to explain concepts that are specific to adolescents in order to gain an insight into the peculiarities of adolescents receiving cancer treatment. The section will also highlight related literature based on the constructs of the theoretical model.

The literature was obtained from electronic data bases such as “SCIENCEDIRECT”, “PUBMED”, “GOGGLE”, “GOGGLE SCHOLAR”, “CINAHL” and “TAYLOR AND FRANCIS” using search terms such as adolescent, cancer, experiences, spiritual, physical, psychological, social and quality of life either as single words or in combination.

2.1 Theoretical framework of the study (the quality of life model applied to cancer)

Quality of life (QoL) is defined as a personal sense of well-being encompassing a multidimensional perspective that generally includes physical, psychological, social and spiritual dimensions or domains (Almutairi, Mansour, & Vinluan, 2016). The concept, in a more liberal sense includes at least three basic constructs; namely physical, social and psychological well-being (Franciosi, Saps, & Pohl, 2015). Quality of life is viewed by authors in two different ways; as an objective state arising from influence of the society or as a subjective state based on the individual’s needs (Davis, Waters, Shelly, & Gold, 2008; Haraldstad, Christophersen, Eide, & Karin, 2011). Gupta and Kumar (2017), therefore integrate these two ideas by saying that QoL is a complex, ever - changing concept that a patient uses to evaluate him or herself in relation to the society. The WHO also defines QoL “as individual’s perception of their position in life in the context of the

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culture and value systems in which they live and in relation to their goals, expectations, standards and concern” (WHO, 1999 p.3). Hence, QoL is a subjective experience which may be influenced by side effects of treatment and complications and the overall health status of the person (Monastyrska et al., 2016; WHO, 1999). QoL therefore, according to the WHO is not synonymous with phrases such as satisfaction of life, health status, physical, emotional, psychological or spiritual well-being but it is a combination of these concepts, the individual’s perception and other aspects of life (WHO, 1999).

Mellion et al., (2014), buttress the above definition by saying that QoL results from the cumulative effect of an illness, its various modes of treatment and the health institution’s policy on the patient’s capability to function effectively and to obtain self-satisfaction in terms of social, physical and psychological functioning.

As part of normal development in adolescence, there are physical and psychological changes that occur and which affect their lives, sometimes negatively. It is therefore not far from reach to draw the conclusion that adolescents score lower on QoL when distressing events such as cancer symptoms and its treatment occur in their lives (Riel et al., 2014).

QoL measures are essential aspects of cancer care as they enable clinicians to ascertain the impact of cancer and its treatment on the patient hence, they enable clinicians provide care that is tailored to the peculiar needs of their patients (Bottomley et al., 2016).

The Quality of Life model applied to cancer was developed by Ferrell, Hassey Dow and Grant (1995) and modified in 1999. This theoretical framework comprises of four main dimensions which are physical, psychological, social and spiritual which are explained in terms of the well-being and symptoms experienced by adolescents with cancer. The dimensions are presented in the ensuing sections.

2.1.1 Physical well-being and symptoms

Physical well-being is the ability of the individual to have total control over clinical manifestations of a disease and side effects of treatment. In this domain, the physical well-being and symptoms comprise of functional ability, dyspnea /breathlessness, strength/fatigue, sleep and rest, nausea, appetite, constipation /diarrhea and pain.

Physical changes related to cancer and cancer treatment include stretch marks, alopecia, functionality of the affected limb, loss of limb/ amputation, loss of mobility (Riel et al; 2014), pain, fatigue, appearance changes, nausea/eating problems, sleep-wake disturbances, mood disturbances, and symptom clusters (Erickson, MacPherson, et al., 2013).

2.1.2 Psychological well-being and symptoms

The psychological well-being is the attainment of peace of mind and control in times of life threatening situations, emotional disarray and uncertainty about future health status and its consequences. The domain comprises of anxiety, depression, enjoyment /leisure, pain distress, happiness, fear and cognition/attention. Most psychological symptoms reported are fear, depression, uncertainty and low self-esteem (W. Li, Lopez, Chung, Yan, & Chiu, 2013).

2.1.3 Spiritual well-being and symptoms

Spiritual well-being is the ability to derive hope, meaning, purpose and transcendence from cancer and its associated side effects. Adolescents with cancer, irrespective of the treatment modalities and prognosis, see death as inevitable hence they become more spiritually oriented which may impact either positively or negatively on their quality of life. These spiritual needs include maintaining strong relationships with

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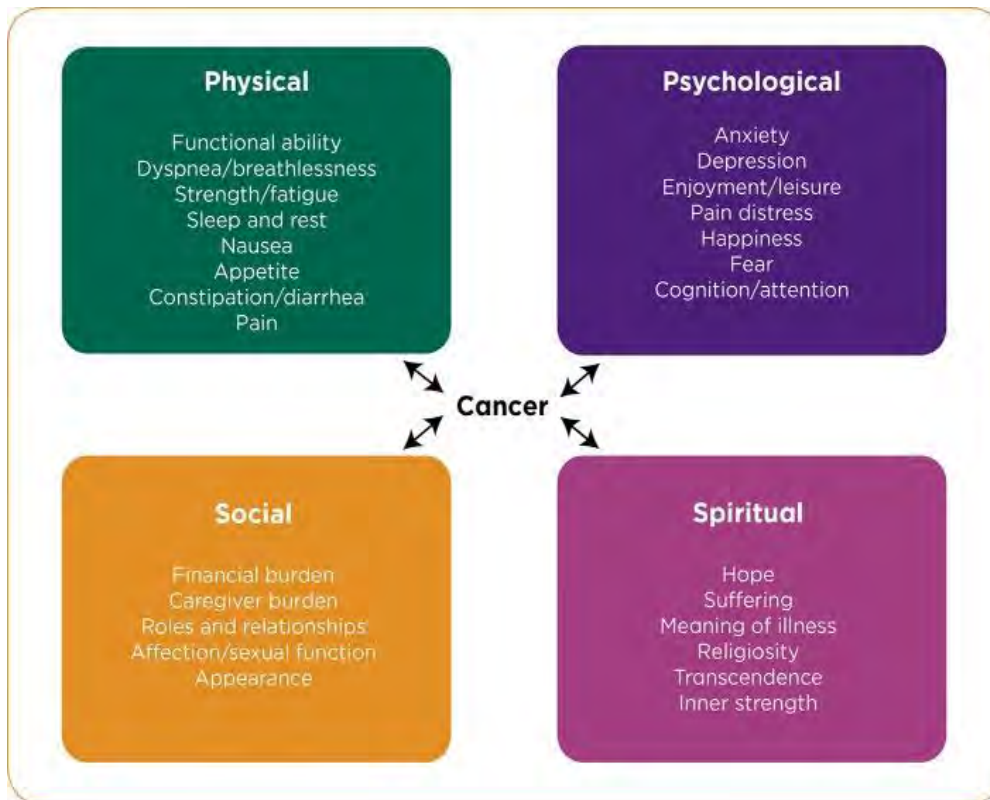
humans and the divine forces or their objects of worship which gives them a sense of meaning to life, enabling them cope effectively with suffering and death (Taylor, Petersen, Oyedele, & Haase, 2015). The spiritual domain in the model comprises of hope, suffering, meaning of illness, religiosity, transcendence and inner strength.

2.1.4 Social well-being and symptoms

Social well-being is an effort to maintain strong relationships with peers, family and friends such as attending school, participating in extracurricular activities, social functions and dating (Erickson, MacPherson et al., 2013). Adolescents when faced with cancer and its treatment are forced to depend more on parents than before and often face problems establishing and maintaining their own independence. The domain is made up of financial burden, caregiver burden, roles and relationships, affection/sexual function and appearance.

The most frequent social threats experienced by adolescents are failure to achieve and maintain long lasting intimate sexual relationships, self-esteem, body image and sexual identity (Patterson, McDonald, Zebrack, & Medlow, 2015).

Figure 1: Quality-of-life model. Adapted with permission from Ferrell et. al (1999)



2.1.5 Model modification.

The Ferrell and Dow QoL model applied to cancer was developed by Ferrell, Grant and Hassey-Dow in 1995 and modified in 1999. The main constructs of the model are physical, psychological, social and spiritual dimensions. The model has also been modified to suit a wide range of needs such as the QoL model for caregivers, QoL in breast cancer survivors, pain impact on QoL, QoL in cancer survivors, QoL for Ostomy patients, QoL in cervical cancer survivors, and Cachexia impact on QoL among others.

2.1.6 Justification and Relevance of the Model

There are various quality of life models which are applied to different situations and age groups. The most popular among them used in cancer patients are the Wilson-

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Clearly Health Related QoL model developed in 1995, the Ferrans and Powers QoL model (1984) and the Ferrell and Dow QoL model (1999). The Wilson and Cleary QoL model consists of five domains which are: general health perceptions, symptom status, functional health, physiological factors and overall quality of life. The Ferrans and Powers QoL model addresses four main domains; health and functioning, socioeconomic, psychological/ spiritual and family domains. The Ferrans and Powers QoL model and the Wilson and Cleary QoL model depend on the subjective ideology of QoL stating that QoL depends on the unique subjective experiences and perceptions of the patient irrespective of the society and its influences (Lavdaniti & Tsitsis, 2015; Lis, Gupta, & Grutsch, 2008). This is in contrast to the WHO definition of QoL which is both objective and subjective, hence the Ferrell and Dow (1999) model serves a better alternative in studying QoL among adolescents with cancer since it captures both subjective and objective perceptions and experiences of the individual and thus clearly brings to the fore the experiences of adolescents receiving cancer treatment.

The study utilised the modified version of the (1999) model to elicit information on the experiences of adolescents receiving cancer treatment since the domains and their components are congruent with the experiences of adolescents with cancer. The physical well-being focused on functional ability, dyspnea/breathlessness, fatigue/strength, rest/sleep, nausea, appetite, constipation and pain. The study focused on anxiety, depression, enjoyment/leisure, happiness, attention/cognition to explore the psychological well-being of adolescents receiving cancer treatment. The social well-being in the study focused on caregiver burden, roles and relationships, sexual function and appearance. Lastly, spiritual well-being of adolescents receiving cancer treatment was explored by using hope, meaning of illness, religiosity and inner strength. In all these four domains, the study also explored other constructs that are pertinent to the well-being of adolescents

receiving cancer treatment but not found in the model.

The model and its constructs are ideal in exploring quality of life among adolescents with cancer. The classification of the constructs into the four main domains of health provide adequate background in eliciting information about the general well-being of adolescents with cancer. However, the constructs in the physical domain seems inadequate as it does not cover most of the physical symptoms experienced by patients with cancer. Also, nausea, appetite and constipation could have been modified into gastrointestinal disorders in order to explore other effects on the gastrointestinal system.

2.2 Literature review

The literature review is organised based on the objectives of the study hence the following areas were explored:

- Physical well-being of adolescents receiving cancer treatment.
- Social well-being of adolescents receiving cancer treatment.
- Psychological well-being of adolescents receiving cancer treatment.
- Spiritual well-being of adolescents receiving cancer treatment.

2.2.1 Physical well-being

The physical well-being of adolescents receiving cancer treatment discussed in the literature included functional ability, fatigue, rest and sleep, pain, mucositis, nausea and vomiting.

2.2.1.1 Functional ability

A study was conducted by Anclair, Lannering and Gustafsson, (2009) on the persistent late effects of adult survivors of childhood cancers by collecting data from 708 survivors and 708 parent proxies. They reported that adult survivors of childhood cancers had low functional ability including self-care, movement and sensation. Landier (2015) in his study on late effects of childhood cancer and its treatment reported that the most prominent effect of chemotherapy is sensorineural hearing loss particularly with higher doses of Cisplatin and carboplatin. Hearing loss due to radiation can be both sensorineural and conductive.

Lam, Li, Chiu and Chan (2016) in a study involving 76 adolescents undergoing cancer treatment revealed that, 61.8% of them had reduced physical activity in both intensity and frequency as opposed to 1.3% of their counterparts who were not on cancer treatment. The findings of the above study was supported by Speyer, Vuillemin, Herbinet, Chastagner and Briançon (2010), who reported that adolescents with chronic illnesses performed better on QoL in hospitals when they engaged in a form of physical activities that were permissible with their health status. The limitation of the study by Speyer, Vuillemin, Herbinet, Chastagner and Briançon (2010) was that participants were asked to recall their functional abilities which could affect the quality of information obtained.

2.2.1.2 Fatigue

Studies conducted by Erickson et al. (2010), Perdikaris et al. (2009), Kaleyias and Manley (2012) and Wu et al. (2010), revealed that adolescents experience fatigue during the treatment period which causes undue hardship on their daily activities, quality of life and varies throughout the period of treatment (Mcculloch, 2013). Fatigue they described as agonising, destructive and permeates through the adolescent's entire being

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and has pronounce effect on daily activities, ability to maintain relationship with others, participating in social activities and general well-being of the individual. Thus, it affects the physical, emotional and psychological well-being of adolescents. Fatigue is caused by factors such as socialisation, changes in sleep pattern, pain, worry, anxiety ,difficulty adapting to the diagnosis of cancer, inability to control and manage the side effects of therapy, and the effects of hospitalisation including passiveness and listlessness (Erickson, MacPherson, et al., 2013).

A study was conducted by (Wu et al., 2010) to examine the experience of cancer related fatigue among adolescents with Leukemia in China (n=14). It was reported that the physical sensation of fatigue could occur in the neck, head, limbs, bone and the body. Adolescents in the study described fatigue physically as being “heavy, weak, or dizzy” in quality. The description of their psychological state included: loss of interest, impatience, lack of motivation and an unenergetic or sleepy state. Some of them gave description such as “I do not want to do anything, and I only do things slowly,” “feel like lying in bed all day,” “still felt sleepy even after having slept a lot” and “unwilling to get up”. Though participants acknowledged they were fatigued, most of then refused to report because they felt that feeling tired was part of the disease and that neither parents nor care givers could offer any remedy. Older adolescents preferred to manage fatigue themselves than to put undue burden on their parents. Although the above study revealed in-depth knowledge on fatigue, the ability to generalise the findings would be difficult since the sample size used was small and the research was limited to only adolescents with Leukemia.

Rodgers, Hooke, Ward and Linder, (2016) in their study among adolescents receiving treatment for cancer reported that fatigue was greater in patients with Leukemia. Whilst this may be partly due to steroids such as Dexamethasone, the research did not provide any data to validate it. It was however reported that fatigue was still persistent in

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some adolescents after the cessation of steroid administration. The hospital environment was reported to contribute the most fatigue experienced by adolescents during treatment (Perdikaris et al., 2009). Strategies used to alleviate fatigue included talking with family and friends, getting adequate sleep, performing enjoyable and purposeful activities, performing self-care therapies such as hot baths and administration of medications that induce sleep (Olson, 2014).

2.2.1.3 Rest and sleep

Adolescents receiving cancer chemotherapy have altered sleep patterns during the day and night compared to their peers who do not have cancer or to themselves before commencement of cancer treatment (Erickson et al., 2011; Mcculloch, 2013; Walker et al., 2011). Reasons for nocturnal disturbances include pain and other symptoms such as vomiting, hunger, thirst, worry, need to use the washroom and change of bed or movement to another ward or room (Walker et al., 2011). The most frequent sleep-related disturbances reported were difficulty falling asleep, intermittent sleep pattern, disordered breathing, parasomnias, napping, sleeping during the daytime and other unspecified disturbances (Kaleyias & Manley, 2012; Olson, 2014). Sleep-related disturbances could be reduced by administration of medications, watching television or reading a book, playing games, sleeping with somebody, drinking or eating, sleeping with a favourite toy and having a caregiver who can advocate for sleep promoting hospital environment (Rodgers et al., 2016).

2.2.1.4 Pain

Pain is an integral part of cancer in children and the most common symptom experienced (Mcculloch, 2013), it is observed to have a direct impact on the quality of life. A study was conducted by Ameringer in 2010 to assess barriers to pain management

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involving 60 adolescents with cancer age between 12 and 17 years, 36.7% reported that they had experienced pain within the past month, often attributed to medical procedures and treatment. Pain frequently reported were backache and headache.

A study was conducted by (Erickson, Fiona, et al., 2013) to identify symptoms and symptom clusters in adolescents receiving cancer treatment using primary research reports from other studies that relied on methods such as self-report by adolescents and objective measurement of symptoms. They reported that at the time of diagnosis, pain was caused by cancer itself which was different from that during treatment which was mostly due to diagnostic procedures and administration of some treatments as confirmed by (Agrawal & Feusner, 2016). Pain ranged from moderate to severe and varied during the course of treatment but constant throughout a cycle of chemotherapy. However, adolescent girls reported higher pain intensity than boys (Hechler et al., 2009).

The different approaches used in the literature reviewed by Erickson, Fiona, et al., (2013) may make it difficult to synthesise the results obtained. All the studies however indicated that the presence of pain and its intensity is inversely proportional to the quality of life experienced by adolescents (Erickson, MacPherson, et al., 2013).

Pain can be managed by acupuncture, analgesics, massage, hypnosis and guided imagery (Mcculloch, 2013). Nonetheless, most studies on pain in adolescents report that pain is mostly undermanaged despite advances in pain management (Ameringer, 2010; Mcculloch, 2013). The reasons are that most adolescents refuse to acknowledge pain and some are unable to identify pain. There is also poor assessment by healthcare providers, disagreement between pain reported by adolescents and that documented, poor pain management, fear of addiction to analgesics and unwanted parental reactions. Some adolescents also feel that their activities would be restricted if they report pain (Ameringer, 2010).

2.2.1.5 Gastrointestinal disorders

The various forms of cancer management such as radiotherapy, chemotherapy and surgery result in electrolyte imbalance, constipation, dehydration and nausea (Erickson, MacPherson, et al., 2013). However, gastrointestinal mucositis is reported to be one of the most common symptoms experienced by patients receiving treatment for cancer. It presents with an inflammation, dry mouth, dry and cracked lips, pain, ulceration of oral mucosa, gums and palate and bleeding leading to reduced oral intake, increased risk of infection, long hospital stay, high economic burden and poor quality of life (Chen et al., 2015; Kuiken, Rings, & Tissing; 2015). The condition may make it difficult for patients to perform oral hygiene or to speak (Qutob, Gue, Revesz, Logan, & Keefe, 2013). Mucositis occurs more often in patients receiving radiotherapy to the head and neck, and even more severe when combined with chemotherapy (Moslemi, Mohammadi, & Taheri, 2016).

Research done in Japan using a case study of two adults with laryngeal cancer reported an improvement in radiation imposed mucositis using proton-pump inhibitors (Eguchi, Suzuki, Ida, Kudo, & Ando, 2017).

Oral hygiene however, seems to be the most effective way of managing oral mucositis as reported by (Murshid, Azizalrahman, & Aljohar, 2017). Regular oral assessment is therefore essential to detect early signs of deteriorating oral status (Mcculloch, 2013).

Nausea and vomiting are reported to be frequent symptoms in cancer and may be so severe as to prevent the adolescent from undergoing chemotherapy or possibly to postpone it (Alessandrino & Porta, 2016; Jakobsen & Herrstedt, 2009; Mcculloch, 2013; Rajapakse, 2009). Nausea and vomiting occur prior to chemotherapy in about 20% of patients (Kamen et al., 2014). Despite it being severe in patients receiving radiation therapy, it is often ignored by most radio oncologists (Feyer, Jahn, & Jordan, 2014).

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Prolonged nausea and vomiting poses a negative effect on dietary intake which increases the risk of malnutrition (Isenring, 2016), delay or discontinuation of therapy (Alessandrino & Porta, 2016), subsequently affecting quality of life (Alessandrino & Porta, 2016; Isenring, 2016).

Baggott et al., (2010) in a study administered a weekly checklist to provide further explanation into the pattern of nausea and vomiting experienced by adolescents. The results indicated that the incidence of nausea was high in the first week before chemotherapy and increased within the week in which chemotherapy was administered but may persist throughout the period of chemotherapy for some patients. However, there was no appreciable difference in the pattern of nausea in a similar study conducted by Walker et al., (2010).

Metoclopramide, haloperidol, antihistamines, anticholinergics and steroids are effective treatments against nausea and vomiting (Eghbali & Saeed, 2016; Gordon, Legrand, & Walsh, 2014; Alessandrino & Porta, 2016).

Data also suggest the use of alternative medicines such as ginger root (Kamen et al. 2014), pepper- mint oil (McCulloch, Hemsley, & Kelly, 2018), acupuncture (Kamen et al. 2014; Keeley, 2015; McCulloch et al., 2018), auricular acupressure (Eghbali & Saeed, 2016; Kamen et al., 2014; Miao et al., 2017), hypnosis, biofeedback mechanism and guided imagery (Kamen et al., 2014).

There are many treatment options employed in the management of cancer. These are chemotherapy, radiotherapy or surgery which may be used in combination or as a single treatment depending on the type of tumour and the stage at which the adolescent is diagnosed (Wainer et al., 2012).

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Studies conducted by American Cancer Society (2016), Hung et al. (2016) and Raphael et al. (2014) indicate the most common cancer types occurring in adolescents are Lymphomas, central nervous system (CNS) tumours, bone and soft tissue tumours, leukemia, thyroid cancers, ovarian and testicular tumours. Any treatment employed is associated with some form of physical effect (Reis et al., 2010; Wainer et al., 2012).

2.2.2 Social well-being

The social well-being of adolescents receiving cancer treatment discussed in the literature are financial burden, caregiver burden, sexuality, roles and relationships.

2.2.2.1 Caregiver burden

Caregiver burden is defined as the stress people go through as a result of providing care to a relative or a patient desiring such care (Young, Park, Kyung, Eun, & Lee, 2015). It encompasses all domains of health such as psychological (Mosher et al., 2013), physical financial and social (Young et al., 2015). Caring for adolescents with cancer causes fatigue, pain and inadequate sleep (Fletcher et al., 2008). Due to the prolonged treatment of cancer, frequent hospital visits and stays, caring for a cancer patient may lead to loss of other responsibilities such as marital responsibility, caring for other children (Deshields et al., 2012), staying away from work which would lead to loss of income and subsequent financial burden (Deshields et al., 2012; Song et al., 2011). Increased caregiver burden leads to low quality of life of the caregiver (Grant et al., 2013; Song et al., 2011) which leads to a decrease in quality of life of the adolescent with cancer. It is therefore necessary that the society, family members and health care professionals provide support to caregivers in order to improve the overall QoL of the adolescent on cancer treatment (Bastawrous, 2013; Young et al., 2015).

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A study was conducted to investigate whether provision of support to caregivers had a direct impact on their quality of life. Caregivers of cancer patients sampled from a university hospital were divided into two groups. The experimental group received education, supportive measures, coping strategies and resources needed to care for their patients whilst the control group received regular care. Data was collected after two to three weeks using objective and subjective assessment. The results indicated that the experimental group had increased self-efficacy and low burden as compared to the control group (Lee, Yiin, & Chao, 2016).

2.2.2.2 Financial burden.

Cancer diagnosis, treatment and follow-up care poses a high financial burden to the patient and family. A study conducted in Norway to determine the financial burden of various diseases rated cancer as the third disease, however, on a daily basis, financial burden due to cancer was the highest (Kinge, Sælensminde, Dieleman, Vollset, & Norheim, 2017). The financial cost of cancer burden can be both direct and indirect. Direct financial cost refers to the cost of hospital bills and cost of other services such as laboratory investigations. Indirect cost applies to losses due to absenteeism from work and other sources of income (Foster et al., 2011). A study conducted in Taiwan revealed that, Leukemia had the highest annual financial cost whilst breast cancer had the highest total life time cost (Chu, Hwang, Wang, & Chang, 2008).

Statistics gathered from 37 hospitals in China to determine the financial burden of cancer revealed that cost of medical services was problematic for most patients. Financial cost was found to be related to the type of cancer, type of medical insurance, age, duration of hospital stay and type and level of hospital providing medical services. Patients using private insurance had the least financial burden compared to those on Government

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insurance. The cost of cancer treatment in the study was found to be about 5% -10% greater than the household income (Huang et al., 2016).

A study conducted in Taiwan to assess the financial burden of patients with cancer of the head and neck revealed that, most patients have financial problems after cancer diagnosis. It was reported that the high cost of cancer treatment and diagnosis results in financial problems at home leading to high unmet needs that affected all domains of health of these patients (Brien et al., 2017).

2.2.2.3 Roles and relationships

Issues related to infertility and sexual functioning is a concern for adolescents especially, females undergoing cancer treatment (Aubin & Perez, 2015). However, adolescents lack knowledge on this issue, often leading to compromised fertility since it is less talked about (Patterson et al., 2015). Adolescents often asked questions relating to the desire for sexual arousal, to engage in sex and problems with orgasm. The various forms of cancer treatment are likely to cause oligospermia or azoospermia, low or absent production of semen, delayed development of secondary sexual characteristics, hypogonadism, impotence, delayed ejaculation for males, amenorrhoea, ovarian dysfunction and early menopause in females (Landier, 2015), precarious puberty, osteoporosis, depression and delayed puberty (Vern-Gross, Bradley, Rotondo, & Indelicato, 2015).

2.2.3 Psychological well-being

The psychological well-being of adolescents highlighted in the literature include emotional concerns such as fear and sadness, body image and cognitive dysfunction. These are presented in the sections that follow.

2.2.3.1 Emotional concerns

Developmental changes experienced by the adolescent are often characterised by anxiety as well as excitement or pride for the individual whose body is undergoing the transformation (United Nations & Unicef, 2011). The interaction of environmental factors such as stress, cancer and cancer treatment with these developmental changes places the adolescent at risk for psychiatric disorders (Gomes, Rincón-cortés, & Grace, 2016).

It is therefore not surprising that adolescents receiving cancer treatment often express emotional concerns such as problems adjusting to situations, depression and anxiety (McCulloch, 2013) which may lead to anger, guilt, fear, further preventing adolescents from expressing their emotions (Anderzén-carlsson, Sörlie, & Kihlgren, 2012; Carlsson et al., 2008).

A content analysis of emotional concerns was carried out by Korsvold, Viktoria, Finset, Ruud and Cathrine (2017) in Norway among adolescents with breast cancer (n=9). The most common emotional concerns expressed were sadness and fear related to loss of hair and eyebrows which according to the adolescents, make them appear different from their colleagues. Sadness was expressed in forms such as sighing, crying, non-verbal cues and sometimes from the tone of voice. Some adolescents also expressed that they had low self-esteem and often complained about why they were different from their peers. Expressions such as “Why me?”, “It’s not fair!” were often used. The low self-esteem, according to some adolescents has resulted in their inability to go back to or start school and to maintain close relationships (Tippy, 2016).

2.2.3.2 Body image

Female adolescents particularly experience fear related to their body image and how this will affect their social interactions (Anderzén-carlsson, Sörlie, & Kihlgren, 2012; Carlsson et al., 2008). Body image and appearance are particularly important to adolescents but majority of people within this age group fail to report changes in their body image but rather adapt to them (David, Williamson, & Tilsley, 2012). Others adopt various mechanisms to make up for the changes in body image. A report on adolescents by United Nations & Unicef, (2011) indicate that adolescent girls are particularly prone to eating disorders such as anorexia nervosa and bulimia in an attempt to achieve and maintain a desired body image and figure as expected by culture and the media. Some adolescents however, feel ashamed of the altered body image (Tippy, 2016). The most common changes in body image experienced by adolescents with cancer include hair loss and weight gain or loss (Aubin & Perez, 2015; Mcculloch, 2013).

A systematic review was conducted by Fan and Eiser (2009) to assess the body image of adolescents with cancer. Out of the 32 articles reviewed, 9 reported that, there is no difference in body image between adolescents with cancer and their healthy peers. Whilst 3 reported a low body image in adolescents with cancer, 7 reported no difference in age and body image between boys and girls. In addition, 2 reported a greater body image for girls older than 16 years compared to males of the same age with cancer. One study reported that females had overall high body image than males, 5 reported the reverse whilst the remaining 5 showed no difference between males and females.

The results of another study conducted to evaluate the quality of life of adolescents and young adult survivors of childhood cancer reported that, adolescent females were concerned that the side effects of cancer made them less attractive which prevented them from engaging in social relationships, but this concern is only a perception as adolescents

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expressed the same problem even in the absence of any disruption or changes in body image (Servitzoglou, Papadatou, Tsiantis, & Vasilatou-Kosmidis, 2009).

Unwarranted effects of body image can be alleviated by providing the adolescent with support from health professionals, family and friends. These support if not accessed can predispose the adolescent to increased levels of depression, anxiety and problems with behaviour.

2.2.3.3 Cognitive function

Cognitive function encompasses a wide range of domains that show that the brain is performing normally. These domains include speech, visual-spatial defect, processing information, psychomotor function, learning, memory, attention span and executive functioning (Moore, Hockenberry, & Krull, 2013; Landier, 2015). Cognitive changes prevent adolescents from returning to their status before diagnosis and commencement of treatment such as returning to school, work or even engaging in their daily activities (Patterson et al., 2015; Landier, 2015) and achieving social integration such as marriage.

A study was conducted on children diagnosed and treated for medulloblastoma, (n=8) at a Swedish rehabilitation facility to determine their cognitive function using the Wechsler Intelligence Scale for Children-Third Edition. The results revealed a decline in their psychomotor skills, understanding, perceptual organisation and social perception. The study had no control group and the sample size was also small hence the generalisation of the results cannot be emphasised (Saury & Emanuelson, 2011). However, the findings can serve as a foundation for further studies.

Radiation to the brain is a major contributor to cognitive impairment. However, other factors such as corticosteroids, some chemotherapeutic agents, fatigue and impaired

sleep also contribute to cognitive impairment, progressing steadily after one to two years (Landier, 2015).

2.2.4 Spiritual well-being

Issues related to spiritual well-being discussed are spirituality/religiosity and hope.

2.2.4.1 Spirituality/ religiosity

The diagnosis of cancer carries the probability of premature death irrespective of the outcome or prognosis. Adolescents have special health needs which in addition to cancer diagnosis places them in a state of distress and a greater need for spiritual care (Taylor, Petersen, Oyedele, & Haase, 2015).

Spirituality and religiosity are important aspects of cancer care which help patients cope with illness leading to improved QoL (Best, Butow, & Olver, 2015 ; Delgado-guay, Hui, Parsons, & Bruera, 2011). It helps individuals maintain a sense of well-being, peace and hope (Lucette et al., 2016). Most patients recognise the essence of spirituality in their care hence this supportive measure should be discussed with them.

According to Taylor, Petersen, Oyedele and Haase (2015), spirituality and religiosity are often used interchangeably but denote two different concepts. Spirituality refers to humans seeking meaning and the experience connected to oneself, others, nature and the supernatural forces whilst religiosity refers to an immersion of the self into spirituality as evidenced by expression through association, knowledge and holiness.

A study was carried out to assess the level of spirituality and health behaviour among adolescents using “The Spiritual Well-Being Scale”, “The Children’s Depression Inventory–Short Form”, and “The Pediatric Quality of life inventory” at a hospital in

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Ohio (n=155). Adolescents with higher levels of religiosity were observed to have better health behaviours. They reported that a supreme authority was concerned about them and this has contributed tremendously to their overall health status (Cotton et al., 2009) . The above study is criticised for not examining how factors such as social support mediates the relationship between spirituality and well-being. The study is however supported by (Delgado-guay et al., 2011), who examined the prevalence and intensity of spirituality among cancer patients (n=100). About 98% reported that they were both spiritual and religious and that it helped them to cope with their illness

2.2.4.2 Hope

Hope has been identified to have a positive correlation with quality of life, health and general well-being when experiencing the effects of cancer and its treatment, whilst hopelessness is a threat to well-being (Duggleby, Ghosh, Cooper, & Dwernychuk, 2013).

A study was conducted to describe hope from adolescents' perspective (n=6) in Finland using convenient sampling methods. Two definitions of hope emerged; hope towards something and hope as an inner strength. Social network and factors related to the adolescent's experience were found to promote hope whilst issues of how the adolescent feels, concern about knowledge and body image were detrimental to experiencing hope (Juvakka & Kylma, 2009). All the adolescents in the above study were hopeful of a future, occupation, engaging in relationships and even travelling overseas. Hope was manifested as wishes, dreams, humour and belief in God. However, hope has been identified to be inversely proportional to age as adolescents with cancer express more hope than the elderly (Duggleby et al., 2013) .

Jafari, Najafi, Sohrabi and Reza, (2010) in their study on the influence of spirituality and hope among cancer patients (n=120) using spiritual well-being, hope and

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life satisfaction scales reported that, spirituality and hope lead to high life satisfaction and was important in helping cancer patients adjust psychologically. The participants in the study felt that they have a God who sees them through every hardship and provided for their needs which contributed to their happiness.

Findings from the above study revealed that spirituality should be integrated into the care of patients with cancer in order to improve their psychological well-being (Lucette et al., 2016) as studies have revealed that patients feel more content when their clinicians did discuss spirituality with them (Best et al., 2015; Surbone & Baider, 2010).

2.3 Summary of the Review

The literature review has looked at the physical, social, psychological and spiritual well-being of adolescents receiving cancer treatment using the Quality of Life Mode of cancer developed by Ferrel, Grant and Hassey-Dow (1999) as an organising framework. The framework has helped to holistically review literature on the well-being of adolescents receiving cancer treatment and its treatment permeates through the entire being of the adolescent.

The physical well-being of adolescents reviewed in the literature included functional ability, fatigue, rest and sleep, pain, mucositis and nausea and vomiting. The social well-being of adolescents receiving cancer treatment discussed in the literature covered financial burden, caregiver burden, sexuality, roles and relationships. The psychological well-being of adolescents highlighted emotional concerns such as fear and sadness, body image and cognitive dysfunction. Lastly, the spiritual well-being discussed were spirituality/religiosity and hope.

Most of the research were done in the high income countries with few or none in low-middle income countries such as Africa. There is therefore the need for more research

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to be done in the low- middle income countries. The review indicates that adolescents receiving cancer treatment have poor overall quality of life.

CHAPTER THREE

METHODOLOGY

This section encompasses a detailed description of the methods that were used in achieving the aims and objectives of the study. It also explains the type of research design that was used as well as the research setting, target population, sampling methods, sample size, instruments for data collection, procedure for administering the instrument, data analysis, data management, rigour and information on how ethical requirements were met.

3.1 Research design

The research design of a study deals with an in-depth explanation of the basic strategies that researchers adopt to answer their questions, test hypothesis and the methods through which data collection would be done (Polit & Beck, 2010).

Research in social science falls under two main types; qualitative and quantitative or a mixture of both methods.

Quantitative research deals with formal, objective and deductive approach for solving problem and it is often considered more rigorous. It expounds the description and understanding of reality through discovery of laws that can be generalised. Statistical techniques employed in quantitative studies allow a true focus on description and interpretation leading to the development of new concepts and theories (Hancock, Ockleford, & Windridge, 2009).

Qualitative research deals with subjective, individual experiences in real life context. Data gathered is in the form of rich verbal descriptions which are usually not quantifiable. The process involved is flexible and systematic but needs to be planned in advance (Hancock et al., 2009).

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In scientific body of knowledge, both methods are appropriate for conducting research but its selection depends on the problem statement, purpose of the study and the research questions. The research design chosen forms the basis for sampling and sample size, data collection and analysis which are the blue prints of the study (Hancock et al., 2009).

The research design used in conducting the study was qualitative, exploratory, descriptive approach. Exploratory studies are carried out to investigate the full nature of a phenomenon when there is paucity of information in the area. Descriptive studies on the other hand, help provide answers to the questions of who, what, when, where, and how associated with a particular research problem or to obtain a picture of a phenomenon in its natural environment (Polit & Beck, 2010). The research design chosen therefore helped the researcher to describe in an in-depth manner, the experiences of adolescents receiving cancer treatment.

3.2 Research setting

The research was conducted at the Paediatric Oncology Unit of the Korle-bu Teaching Hospital in Accra, Ghana.

Korle-bu Teaching Hospital is situated at Guggisberg Avenue in the greater Accra region, in the Ablekuma south district. It shares boundaries with Korle-gonno on the south, Mamprobi on the west, Bukom on the east and Laterbiorkorshie on the north. “Korle-bu” which means the “valley of the Korle lagoon” was established on October 9th, 1923 by Sir Gordon Guggisberg as a General Hospital to address the health needs of the people of Gold- Coast. It is the premier health care facility in Ghana, offering both specialist and referral services and the third largest hospital in Africa.

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The hospital has 17 clinical departments and diagnostic centres which include Medicine, Child Health, Obstetrics and Gynaecology, Pathology, Laboratories, Radiology, Anaesthesia, Surgery, Polyclinic, Accident Centre and the Surgical/Medical Emergency and Pharmacy. The hospital has about 2,000 beds with a daily outpatient attendance of about 1,500 and about 250 admissions per day.

The Child Health Department is located on the immediate left hand side, next to the administration block upon entering the hospital and faces the Guggisberg statue in front of the old administration block. The department is made up of the Out patients' Department, the Emergency Room, PS1, P2A, P2C, P3B, Babies Unit and the Neonatal Intensive Care Unit (NICU) which is situated on the third floor of the maternity block. The unit has about 197 bed capacity.

The Paediatric Oncology Unit (POU) receives all paediatric cancer referrals from the southern part of the country and other neighbouring countries. It has a yearly admission of about 160 patients and comprises an inpatient department (P3B) and the Outpatient Day care Unit.

P3B is located on the third floor of the Child Health Department and has a total bed capacity of 26. The Day Care unit is located on the ground floor of the department and a few metres to the right of the Child Health Emergency Room. It has four nurses and one records officer. Children are booked on daily basis to receive their chemotherapy at the Day Care Unit. The unit has about 8 beds and attends to about ten children on weekdays, except on Thursdays where Staff of the unit visit patients and relatives in their homes to provide appropriate supportive and palliative care.

3.3 Target population

The target population is defined as the total number of people who meet all the criteria specified for the research or the entire population in which a researcher is interested (Alvi, 2016; Polit & Beck, 2010). Adolescents diagnosed with cancer and are receiving treatment at the paediatric oncology unit of the Korle-bu Teaching hospital were the target population for the study.

3.4 Sample size and sampling method

Sample size is the number of people to be involved in a study (Khan, 2012). The determination of sample size in qualitative research depends on the information needed. The guiding principle in sampling in qualitative studies is data saturation. Thus, sampling ends at a point where no new information is obtained and additional information does not modify your coding frame (Hancock et al., 2009).

The sample size for the study was fourteen (14) adolescents with cancer and receiving cancer treatment.

The selection of a fraction from a total population is known as Sampling. It is easier to work with samples rather than the entire population in research due to its economical and practical merits (Polit & Beck, 2010).

Purposive or judgmental sampling was employed. It involves choosing subjects who are believed to have fair knowledge about the content of the study or who possess certain characteristics in which the researcher is interested in studying (Polit & Beck, 2010). The researcher therefore selected adolescents receiving cancer treatment at the Paediatric Oncology Unit, KBTH, who were willing to share the experiences they had been going through at the time of the study.

3.5 Inclusion criteria

The inclusion criteria for this study consisted of (a) adolescents between the ages of 13 -19 years, (b) adolescents who could speak Twi and English language which the researcher understands, (c) adolescents who were receiving cancer treatment and had had treatment for at least the past six months based on their records (d) adolescents who were willing to participate in the research.

3.6 Exclusion criteria

The following adolescents with cancer were not involved in the study (a) adolescents who were too ill to participate, (b) adolescents who had been receiving treatment for less than six months.

3.7 Procedure for data collection

A proposal was sent for review and was approved by the Institutional Review Boards of the Noguchi Memorial Institute for Medical Research (NMIMR-IRB) and Korle-bu Teaching Hospital (KBTH-IRB). A Copy of the approval letter was then sent to the head of the Paediatric Oncology Unit.

Recruitment of participants was done on week days by the researcher. An information sheet was given to participants and or their guardians. The researcher carefully and thoroughly explained the purpose of the study to those participants and or their guardians who could not read.

3.8 Tool for data collection

The research employed a background information sheet and an interview guide to collect data. The background information sheet contained information on participants such as age, sex, residence, educational level, number of siblings, relationship to guardian, type of cancer, duration of disease and how long the child had been on treatment. A semi-structured interview guide was developed using constructs from the Quality of Life Model of cancer patients developed by Dow and Ferrell (1999). The interview guide had open ended questions which provided opportunity for the interviewer and the interviewee to delve deep into the subject area being discussed (Hancock et al., 2009).

3.9 Pretesting the interview guide

Pretesting is a process of determining the strengths, weaknesses, opportunities and threats of research questions based on questioning appearance and text construction. It aims at modifying the instrument before it is administered (Khan, 2012).

The instrument was pretested on two adolescents receiving cancer treatment at The Komfo Anokye Teaching Hospital. The time and venue of the interview was decided by the participants. An information sheet and two child assent forms and two parental consent forms were given to respondents and their guardians. One consent form was kept by the respondents whilst the researcher kept one after they were signed by the respondents and their guardians. The first recorded interview was transcribed immediately and errors rectified which led to the modification of the research questions for the subsequent ones. Data collected from the pretesting was not included in the main study.

3.10 Procedure for data collection

Data collection is a systematic process by which the researcher collects the necessary information that would enable him or her to accomplish the stated objectives of the research (Polit & Beck, 2010). Data collection was done between January and February 2018. It took the form of audiotape interviews which were carried out in “Twi” (local dialect in Ghana) or English language. At the beginning of each interview, each participant was allowed to read and fill the information sheet. This enabled the researcher to gain some knowledge about the respondent, which helped the researcher to interact with respondents in the best way possible. The questions were clear, simple and suited the developmental age and comprehension ability of the adolescents. The use of open ended questions were also employed, allowing respondents the opportunity to express themselves in detail. Questions pertaining to the adolescent’s experiences in terms of physical, social, spiritual and psychological effects of cancer treatment were asked. The questions were reframed or the respondents redirected where necessary which helped to achieve the objectives for the research. Respondents were made aware that they were free to express their opinions and views and were at liberty not to answer any question if they wished to do so. They were also told that they could withdraw from the research at any time. They were further assured that, data gathered from them was for research purposes only and the confidentiality of the information provided would not be compromised. Furthermore, they were informed that their responses would not affect the care given at the hospital and would not in any way also influence the quality of care they were receiving. Each interview session lasted between forty-five and ninety minutes.

The researcher kept a field diary during the process of data collection. The information written in the diary was arranged sequentially according to the day and time of each interview. Data gathered in the field diary was obtained through observing the

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participant's facial expressions and other non-verbal cues. Other happenings that took place during the data collection process that impacted on the information gathered were also recorded. Information gathered in the field diary helped to form general impressions that served as important basis for data analysis.

3.11 Data Analysis

“Data analysis in qualitative study is an inductive process that involves putting segments together into meaningful conceptual pattern” (Polit & Beck, 2010.p 469).

Data analysis was done alongside the process of collecting data. The researcher provided numbers to each respondent in the order of recruitment into the study. At the end of each interview, the audiotaped interviews were transcribed verbatim. Interviews conducted in “Twi” were translated into English by the researcher during transcription. However, an individual fluent in the local language was asked to carry out a back translation of the transcripts. The transcribed audiotaped interviews and the field notes were used in analysing the data.

The transcribed interviews were read and reread, organised, integrated and interpreted and emerging themes that describe the experiences of adolescents receiving cancer treatment in terms of physical, social, psychological and spiritual well-being were identified including other themes that fell outside of the model. During the process, similar words emerging from the content analysis were put into one theme. The researcher then read and reread to identify different themes. All the themes identified were given different names and sub grouped where necessary.

3.12 Data management

Data management in qualitative research involves reducing a huge chunk of information into smaller units that can be dealt with or managed (Polit & Beck, 2010). The transcribed documents were kept separate from the consent forms. Each of the transcribed documents were coded and stored with a different file name on the researcher's computer and secured with a password known only to the researcher. The data would be kept for at least five years before they are discarded.

3.13 Rigour

Rigour can be defined as a measure of trustworthiness of a research in terms of how data is collected, analysed and interpreted (Prion & Adamson, 2014). A study's findings can be said to be trustworthy if the reader of the research report says so (Murphy & Yelder, 2010). Lincoln and Guba (1985), were the first people to outline the criteria for assessing rigour. They include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985; Prion & Adamson, 2014).

Credibility defines the extent of veracity of the data and its subsequent interpretation. This refers the extent to which information gathered represents the exact view of the respondents (Murphy & Yelder, 2010). It is achieved by validating the data and its results and by allowing respondents and other experts to review data coding and the conclusions drawn from them (Prion & Adamson, 2014). The researcher spent prolonged period in the field and thus received credible information on the ground.

The researcher therefore recruited only those participants who met all the inclusion criteria outlined. At the end of each interview, member checks were conducted to ensure that the exact views of respondents were obtained. Coding of the interviews was done separately by the researcher and the supervisor in order to identify areas of disagreement,

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discuss them and come to a consensus. Oncology experts were also allowed to review data coding and the conclusions drawn from them.

Transferability refers to the extent to which results obtained from the study can be applied to similar populations in different contexts (Lincoln & Guba, 1985). To achieve this, the researcher outlined a detailed description of the methodology that was followed in carrying out the study (Prion & Adamson, 2014). Furthermore, the process of participant selection, inclusion and exclusion criteria were outlined in detail in the study. The researcher also kept an audit trail of the transcribed documents.

“Dependability is the ease with which readers and other researchers can follow the original researcher’s decision-making process during the study and reach similar conclusions” (Prion & Adamson, 2014 p.108). Dependability was ensured by using the same interview guide to gather data from all the respondents. Also, the researcher outlined a detailed description of the research setting, sampling and sampling methods and the procedure for data collection and analysis. The researcher is keeping documentations of raw data, field notes and other summaries gathered during the data gathering process (Murphy & Yelder, 2010).

Confirmability also known as neutrality is the absence of researcher bias or the extent to which results obtained could be confirmed by others (Kusi, 2012; Murphy & Yelder, 2010; Prion & Adamson, 2014). The aim of confirmability is to ensure that the researcher’s biases and prejudices do not affect the results obtained. Confirmability of the study was ensured by bracketing the biases and prejudices of the researcher so they did not affect the results obtained. Also, experts in the area were allowed to review results of data analysis and interpretation. A clear audit trail of raw data, analysis notes and field diary were kept.

3.14 Ethical considerations

The researcher sought ethical clearance from the Institutional Review Boards of the Noguchi Memorial Institute for Medical Research (NMIMR-IRB) and the Korle-bu Teaching Hospital (KBTH-IRB). A copy of the approval letter was sent to the head of the Child Health Department of the Korle-bu Teaching Hospital.

The following ethical considerations were followed in the study: informed consent, parental consent, assent by children, confidentiality, privacy and voluntary participation.

The purpose, aims and risks of the research were explained to participants and their guardians during the recruitment process and before the interview. Also, the information sheets containing details about the research and the ethical considerations were given to the participant to sign (if he or she was above 18years) or to the guardian. For adolescents younger than 18years, the consent of their parents were sought before they were allowed to sign the child assent forms. Also, participants were informed that their participation in the research was solely voluntary and they were free to withdraw from the study at any time. They were at liberty not to answer certain questions if they did not feel comfortable. Also, respondents were informed that the research would not interfere with the care they were receiving and their responses or withdrawal from the study would not in any way compromise the standard of care that was being given.

The privacy of the respondents was ensured by allowing them to decide on the place and time for the interview. The researcher ascertained whether the place was conducive for the interview in terms of noise and intrusion by other people. Also, only the guardians were allowed to be present during the interview process. The guardians were told the essence of making the adolescent exercise some form of autonomy and why they should be allowed to express their own views without fear of any punitive measure by the

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guardian. Also, the names of respondents and other peculiar identifying features were removed so as to prevent readers from identifying the respondents.

Telephone numbers of guardians and their place of residence, audiotapes and transcribed documents have been stored with a code under lock and key to prevent others from gaining access to them. Only the researcher and the thesis supervisors have access to the raw data. The data on the researcher's computer being protected with a password known only to the researcher.

CHAPTER FOUR

FINDINGS

This chapter presents the findings of the study. It includes the demographic characteristics of participants followed by the themes and sub themes identified.

4.1 Demographic Characteristics

A total of fourteen (14) adolescents were interviewed: Five were 13 years, three; 14 years, one; fifteen years, three; 17 years and two were eighteen years. Five of the respondents were males whilst nine were females. All participants were Christians with the exception of one who was a Muslim. Eleven belonged to the Akan tribe, two were Ewes and one was a Hausa. One participant lives in the central Region, three in the Eastern Region whilst the remaining live in the Greater Accra region. At the time of data collection, two were not in school, three were in primary school, and four were in Junior High whilst five were in Senior High school. Whilst on admission, eleven of them were cared for by their mothers, two by both parents and one by the brother. Majority of participants had two siblings whilst two had one sibling, one had four and two had five siblings. Three of them had received treatment between six months and one year, three between one and two years whilst eight had been receiving treatment between two and three years. Nine of the participants had Acute Lymphoblastic Leukemia (ALL) whilst Nasopharyngeal Carcinoma, Osteosarcoma, Adrenal tumour, Renal tumour and Ovarian Carcinoma had one participant each. Four of the participants had had surgery and chemotherapy, one had had chemotherapy and radiotherapy whilst nine had had only chemotherapy. Eleven of them had both parents working, two had only their fathers working whilst one said he did not know the father and could not tell whether he was working or not.

4.2 Organisation of themes

Five major themes were obtained from the data upon analysis: Physical well-being, social well-being, psychological well-being, spiritual well-being and health system factors. The first four themes are consistent with the Quality of Life Model whilst the last theme; health related factors emerged from the data. Each of the themes had sub-themes. In all, twenty- five sub-themes emerged. Most of them were consistent with the Quality of life Model but new ones also emerged from the data. The themes and sub-themes are presented with verbatim quotations from the respondents. Anonymity of respondents is achieved by the use of pseudonyms.

Table 4.1 on page 49 and 50 shows the various themes and sub-themes that emerged from the data.

Table 4.1: Experiences of adolescents receiving cancer treatment: Synthesis of themes and sub-themes

MAJOR THEMES	SUB-THEMES
Physical well-being	<ul style="list-style-type: none"> • GIT symptoms • Pain • Appearance changes • Functional ability • Fatigue/strength • Secondary diseases
Social well-being	<ul style="list-style-type: none"> • Sexual function • Support • Socialisation • Parents/caregiver burden
Psychological well-being	<ul style="list-style-type: none"> • Worry/Anxiety/Sadness • Distress of taking medication/undergoing treatment • Distress of frequent hospital visits/long hospital stays • Affective/mood changes

Spiritual well-being	<ul style="list-style-type: none"> • Learning/Attention/Cognition • Fear • Sensory changes • Meaning of illness • Denial • Concealing disease • Acceptance and inner strength • Hope • Religiosity
Health service -related factors	<ul style="list-style-type: none"> • Attitude of health personnel • Quality

4.3 Physical well-being of adolescents receiving cancer treatment

Physical well-being is the ability to gain control over signs and symptoms and to achieve a level of independence. It comprises any effect in the physical appearance and well-being of the adolescent which is as a result or consequence of cancer and or its treatment. Six sub-themes emerged. These are: Gastrointestinal symptoms, pain, Appearance changes, Functional ability, fatigue/strength and secondary diseases.

4.3.1 Gastrointestinal symptoms

The adolescents reported experiencing GIT disorders such as appetite disorders, nausea/vomiting, diarrhea/constipation and oral mucositis as a result of the treatment they were undergoing. The problems are inserted in turns in the sections that follow.

4.3.1.1 Appetite disorders

Some of the respondents reported that the treatment they were receiving had made them either to lose appetite or to have increased appetite. They had these to say:

“When I receive the chemo I don't feel hungry, I don't feel like eating but sometimes too I eat a lot, sometimes too I don't eat.....” Nab.

*“I was not able to eat well and sometimes too I don't feel like eating”
Nae.*

“When I receive some of the drugs, I'm able to eat a lot, but some of them I am not able to eat.....” Nad.

According to a few respondents, they were unable to eat because the food tasted bitter.

Nae, said: “Sometimes if I eat, it tastes like something else, it tastes bitter in my mouth”.

4.3.1.2 Nausea and vomiting

Some of the adolescents recounted that they experienced nausea and vomiting during the period of receiving chemotherapy which affected their eating pattern. A few said the nausea and vomiting caused them to lose appetite. Nausea and vomiting, according to the respondents continued to persist after the administration of chemotherapy. Some reported that specific types of chemotherapeutic agents were responsible for the nausea and vomiting experienced. A few of them expressed:

“The first thing which happened was when they started with chemo, I was vomiting and I could not eat well.....” Naa.

“The pink one. There are two types of the medicine. There is a pink one that when they set it up, I will definitely vomit....” Nad.

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Yes, sometimes the medicine with that black cover on it, I've forgotten the name, when I take it, I lose appetite because I vomit even the food that I eat. Even after that treatment, I will still vomit again, only that medicine”
Naf.

“Sometimes too I vomit and sometimes I feel nauseated...” **Naj.**

4.3.1.3 Diarrhoea/constipation

Some of the adolescents recounted that they experienced diarrhoea and constipation during the period of chemotherapy. They described diarrhea as “pain in the stomach when you pass stools” **Naa** and **Nab** had these to say:

“When I did the surgery, after the surgery when they gave me a certain drug, Cisplatin I got constipation” **Naa.**

“It is painful if you visit the lavatory, when you eat, you feel as if there is pain in your stomach and then you start having diarrhoea” **Nab.**

4.3.1.4 Oral Mucositis

Some adolescents experienced oral mucositis during the period of chemotherapy. Mucositis was so severe that they were not able to eat or drink water. They expressed:

“When I get the sores in my mouth I don't eat at all, sometimes even if I would eat at all it will be once a day. Sometimes I'm not even able to drink water” **Nab.**

“Sometimes after the treatment, you see your mouth will be full of sore and when you are eating, it will be difficult for you to eat” **Naf.**

“Sometimes if I receive chemo, my mouth, I cannot eat. If I eat, I will be feeling pains” **Nae.**

4.3.2 Pain

Most adolescents reported experiencing pain before and after the administration of chemotherapy. Pain mostly reported were headache, backache and abdominal pains. Two of the respondents had these to say:

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“I will be feeling pains all over my body, sometimes when they give me the medicine, my back will be paining me” Nae.

“Sometimes when I bend down then I feel pain at my back” Nac.

Pain was reportedly precipitated by engaging in minor activities and was mostly relieved by sleeping. Some of them reported:

“Oh sometimes it’s only headache, sometimes if I am at home and I feel like engaging in some minor activities, then I will get headache but if I sleep it will go.....and I also experience severe pains in my leg, that is all...”Naa.

According to some of the respondents, pain was so severe that it affected their sleep.

“I wasn't able to sleep well because I was having abdominal pain” Nad.

Some of the adolescents described pain as “someone being pierced with a sharp object” and a “feeling of pepper”.

Nae reported: “But for pain, it’s feel as if I’m being pierced with a sharp object and I will be scratching myselfand the chemo too when they give me, I feel like there is pepper on my body”.

Headaches they experienced were accompanied by dizziness. One adolescent expressed:

“Hmm! Sometimes too my head will be aching, my head will ache and I will feel dizzy” Nak.

Dizziness was described as “the world that surround the earth going round” and “a feeling of falling”. Two of them had these to say:

“Sometimes I feel dizzy.....and sometimes I see the world that surround the earth goes round and I don’t see things properly” Naj.

“I would be feeling dizzy, like I should fall” Naa.

4.3.3 Changes in physical appearance

Adolescents receiving cancer treatment reported experiencing changes in their physical appearance. These changes included skin changes, hair loss and weight loss.

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4.3.3.1 Skin changes

Respondents reported that they experienced changes in their skin colour, visible black veins, peeling, stretch marks and wounds resulting in extensive scar formation.

While some adolescents reported that they became fairer as a result of the chemotherapy, others reported that their skin became darker. Two of them commented:

“Yes, it had an effect by changing the colour of my skin.... sometimes I became dark when I receive the chemo” Naa.

“Sometimes when I receive the chemo, my mum says that I have become fairer” Nab.

Few respondents also reported that their nails became black. **Naj** said:

“My skin has changed and some black marks have appeared on my fingernails”.

Some respondents said that as a result of the chemotherapy, their palm and skin peeled off. One respondent reported:

“Yes, the soles of my feet peeled off and my palms also peeled off” Nal.

Some adolescents also reported experiencing marks such as scars, wounds, stretch marks and marks from the IV cannula. Majority of them thus reported:

“And there was nothing behind my palm, but now there are marks over there. And I have also developed a lot of stretch marks” Nad.

“Some of us when they insert the cannula, later on you will see that the needle has caused some marks on your skin” Naf.

“When I took the chemo I developed ulcer at the back of my palm and so now there is a scar over there” Naa.

“The injection gave me a wound and a big scar that has still not disappeared” Naj.

4.3.3.2 Hair changes

Respondents also reported about changes in their hair such as loss of hair on various parts of the body, and change in texture of the hair as a result of the chemotherapy. Some of them reported that they experienced hair loss and regrowth several times during the period of chemotherapy. Some of them commented:

“I had not shaved my hair before I came and started chemo. So after the chemotherapy, I saw that my hair was falling off when I combed it. I told the doctor what was happening and he said that it is the reaction of the drug so I can lose my hair, I can even lose my eyebrow but I did not lose my eyebrow” Naa.

“My hair fell off completely, all my hair went away, and it has happened for about 5 times, it goes off and comes back again. Then it will fall off and comes back again” Nae.

“They gave me a certain medicine called doxorubicin which made all my hair fall off” Naj.

“Ah one day I slept, when I woke up, my hair was on the pillow” Naf.

The adolescents reported that the new hair growth was different from their usual hair. Some of them used descriptions such as “curly” and “fresh baby’s hair”. **Nad** and **Nae** had these to say:

“And my hair was hard but now it has become a bit curly” Nad.

“When my hair came back, it’s like a fresh baby’s hair” Nae.

4.3.3.3 Weight loss

Some adolescents reported that they had lost weight as a result of the treatment. **Nac** said:

“When my friends see me, they tell me that you have grown lean, you have grown lean”.

4.3.4. Functional ability

The adolescents reported that they experienced impaired functional ability mainly as a result of dyspnea/breathlessness, fatigue and pain. This made them unable to walk even a short distance, perform self-care activities and attend to household chores. Few of them reported:

“There are a lot of things I was able to do but because of the disease I can't do them” Naj.

“When I receive some of the drugs, I don't feel normal and I can't do anything” Nad.

“Now I can bath but not like how I used to bath first. Previously, I could take the water to the bathroom and bath all by myself but right now I bath in the room” Naa.

“At first I used to write in a good way but after the treatment when I'm writing then I will be shaking, I'm not able to write properly” Naf.

The adolescent girls especially, complained about their inability to perform household chores expected of them. One of them reported:

“Whenever I go to the hospital to receive the chemo and come back, I am not able to perform most of the chores at home.....the time I was not sick I was going to fetch water, I prepare banku (maize meal), I pound fufu (cassava meal) and all that but since I got sick I don't go and fetch water, I don't prepare banku again and I don't pound fufu again” Nab.

Other respondents also mentioned that they were unable to do things with enough speed as they used to. According to them, although they were able to play with their friends, they were unable to run. Two of them thus reported:

“Sometimes too, I will be able to do things fast but now I cannot do it again” Nag.

“I am able to play with my friends but now I can't run that much” Nad.

4.3.5 Fatigue/strength

Some adolescents reported experiencing fatigue during the period of chemotherapy. According to them, the feeling of fatigue made them unable to walk or perform their normal activities with adequate energy and strength as they used to. Some of them had these to say:

“The strength that I used to have to do those things that strength is no more... and when they give me the medicine sometimes I feel weak.” Nai.

“The time that my sugar went up and I came to sleep here I realised that I was not able to walk but I didn't know the reason why but when I try to walk it looks as if I am tired” Nad.

“If they give me the medicine, I will become weak, I will become weak, I cannot do anything.” Nae.

“If I walk from here to small distance how I feel tired” Naa.

Some respondents also reported that they easily became tired when writing.

“Sometimes when I write notes, I feel like I should not write again because I will be tired” Nag.

Some adolescents were unable to describe exactly how they felt and used word such as “some way” and “don't feel normal”:

“Like when they set the chemotherapy on me, my hand will be very weak, will do like all the medicine is there, so always my hands, I will be feeling some way” Nae.

Fatigue according to some adolescents, have prevented them from doing a lot of work. Some also reported that when they walk for a short distance, they had to rest and continue later. Few of the adolescents reported:

“If I do small work, I will be tired so I don't do a lot of work like that” Nal.

“If I walk a long distance, I will be tired so I will wait small before I start again” Nae.

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“Sometimes when I'm playing football with my friends, I will be tired so I will feel like stopping because I easily get tired” Nag.

4.3.6. Secondary diseases

A few of the respondents reported that the side effects of chemotherapy had given them other diseases. This was how *Naj* and *Nad* shared their experience:

“As for that one it is part of the reason why I got stroke. It gave me a certain disease called pneumococcal meningitis, which is also part of the side effects. It affected my brain and they said that the CSF that boosts and circulate in my brain is coming through my nostrils so they have to perform surgery on me so that it will all go” Naj.

“I remember that there was a time I was urinating a lot but it got to another time that I didn't see anything again. When I opened my eyes I saw that there was something at my private part that I was urinating from. When I asked I was told that my sugar level had gone up and would come down after sometime” Nad.

In summary, adolescents receiving cancer treatment have poor physical well-being in relation to the gastrointestinal tract, pain, changes in physical appearance, functional ability, fatigue/strength and the acquisition of secondary diseases.

4.4 Social well-being of adolescent receiving cancer treatment

The ability of the individual to enjoy the company of or relate to family, friends and significant others or to partake in leisure and social activities, as one experiences the effects of cancer and its treatment. Three sub-themes were identified. These were sexual function, support, caregiver burden and socialisation.

4.4.1 Sexual function

The adolescent females in the study particularly reported changes in their secondary sexual characteristics such as the size of their breast and menstruation. Some of

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them reported that their breasts were bigger but had become smaller as a result of the treatment. Others also reported changes in their menstrual cycle. Two the adolescent girls reported:

“At first, my breasts were a bit heavier but since I got sick it became smallat first I was getting my menses regularly and when I get it, it usually comes for 4 days before it stops but now it only comes once a while, sometimes it comes for two days or even one day then it stops” Nab.

“If it (menstruation) comes, it doesn't flow well, it comes bit by bit. On the first day it came a bit plenty but on the other days it did not come like that” Nad.

4.4.2 Support

The adolescents reported that they received a lot of support from friends, relatives and significant others which helped them cope with the effects of cancer and its treatment. These support came from the family, school and health care personnel.

4.4.2.1 Family support

Most of the adolescents experienced support from their family. They said that their mothers, particularly, were supportive in their care and served as a source of encouragement. Some of them reported:

“I can say that as for my mother she has done extremely well. God richly bless her because sometimes if I am admitted at the hospital and even if my mother wants my father to come he usually wouldn't want to but as for my mother whenever I am on admission she is always by me so I thank her very much” Nab.

“Oh as for my mother sometimes when we go to collect the medicine she asks me what happened to me and give me my medicine to drink. Everything I ask she buys it for me” Nae.

“She tells me encouraging words that I should not worry and that everything will be ok” Nai.

“As for my mother she is good. My father also treat me well” Nal.

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Other family members provided support in diverse ways to the adolescents. Some of them narrated:

“Hmm! my mother's relatives have done a lot for me.....if my mother or my father doesn't have money or something like that they support them in terms of help or if someone is not with me like my mother is going somewhere they will come and sit to take care of me” Naa.

“Some of them came to visit me. My grandmother even came to take care of me at the hospital” Nac.

“When I was in the hospital and lost my memory they were the ones who helped me regain my memory....They prayed for me andThey encouraged me that I can go to school” Naj.

“Hmm, the first time they told me that I was going to do surgery, everybody was crying. My sister took a picture and my mother sent it to my pastor. Even the pastors cried when he saw it..... Their reaction is that of laughter, we crack jokes and all those stuffs. We used to play and read books” Naa.

Siblings also provided support to the adolescents. **Nad** commented:

“They (siblings) are young so when I send them they go but as for the older one, whatever I say I want she does it for me...everything I want they will give it to me”.

The adolescents also mentioned that they received support in various ways from the household. **Nag** and **Nal** reported:

“They (household) always talk to me that it shall be well.... when I greet them they respond. Whenever I am talking to them they listen” Nag.

“There are a lot of people in the house. There are two ladies in my house that I have taken as my sisters so when there is nobody in the house, I go and sit by them and we talk” Nal.

4.4.2.2 Support from school

Majority of the adolescents recounted receiving support from their friends and teachers in school. They reported that they were often exempted from punishment as compared to their counterparts who were not ill. Few of them commented:

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“When I come to school late they don't do anything, they allow me to go in because they know my condition....when a teacher calls me to answer a question and I can't answer it, he will teach me the correct answer but he will not do anything, he would allow me to sit down but the next person, they will punish that person” Naj.

“They don't treat me badly at all. For example, if there is anything and I have to be punished, they don't punish me but they talk to me in a nice way” Nad.

“When they see me they smile and we crack jokes. When I come to school we play football and do everything together. Sometimes I teach them what they don't understand and we do everything together” Naa.

4.4.2.3 Support from health care personnel

Most of the adolescents in the study recounted that health personnel were very supportive which helped them cope with the illness and treatment. Some said they received encouragement and amusement from the health personnel. They said:

“Oh they've been encouraging me that it will be ok when I take the medicine” Naf.

“Some tell me that I shouldn't be sad because the sickness will go back and I will return to school” Nag.

A few of the adolescents reported that health care personnel supported them in the form of finances for their treatment. *Naa* said:

“I have seen that what the nurses and doctors are doing are good. They are supportive, they are helping people to support their families through money issues, finances and a lot more”.

A few respondents stated that the health personnel were always closer whenever they needed them. One person reported:

“Sometimes the nurses are closer, they are close..... Sometimes some of them come and stand or sit to talk with me” Nag.

4.4.3 Parents/caregiver burden

Caregivers, according to the adolescents experienced burden as a result of the adolescent's ill health and frequent hospital visits. The burden was classified as financial burden and the physical burden caregivers themselves go through as a result of providing care to the adolescent.

4.4.3.1 Financial burden

The adolescents complained that the high cost of cancer treatment which can be attributed to the cost involved in laboratory investigations, travelling cost and cost of upkeep due to prolonged hospital stays poses a high financial constraints on their parents. The frequent hospital visits also leads to loss of income due to absenteeism from work and other sources of income further resulting in financial constraints to parents and caregivers.

Two of them commented:

“If we come here too I can say I feel happy sometimes but then, they (parents) will be spending money too much” Nak.

“Mmm!... It has made my mother's work go down so she doesn't usually get money to help my father to take care of me in terms of the chemo and other treatments” Nab.

A few of the adolescents complained that their parents sometimes displaced their anger on them because they felt that they were spending a lot of money on their treatment.

Naf reported:

*“Sometimes even with my parents when they become angry, they will be saying that because of my sickness they have not been able to do anything”.
Naf.*

Due to the financial constraints, most of the adolescents called for financial support for their caregivers. **Nal** mentioned:

“I want somebody to come and help my mother so that she will buy the medicine for me because it is only my mother that buys the medicine. Then these days the man who takes care of us has traveled abroad. They gave us

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last week to come but because of money issues we couldn't come so Monday we will see whether we will come” Nal.

4.4.3.2 Caregiver burden (physical)

Respondents were of the view that their parents were experiencing a huge burden as a result of providing care for them. They recounted that their parents/caregivers had to stay with them throughout the period of treatment, bring them every time to receive treatment, help them maintain self-care, go and purchase drugs, send laboratory specimens and also collect laboratory results after specimen have been sent. *Nal* mentioned:

“As for my mother when I see her I get sad, because since I got sick, she has been taking care of me till now.....”

Respondents wished that their caregivers obtained some rest or someone came to the aid of these caregivers. Two of them commented:

“I will say that she's stressing herself, she has to rest a little....She has to release some stress and strain against her” Naj.

“If I get somebody to even take care of me so that my mother can stay at home so that, that person will take me to the hospital, I will be very happy” Nal.

4.4.4 Socialisation

From the data, the numerous effects of cancer and its treatment, according to the adolescents have impacted negatively on their socialisation. Few of them also reported that the effects of cancer and its treatment have rendered them unable to socialise with their friends and to attend school and church. Two sub-themes emerged: social isolation and absenteeism from church/school.

4.4.4.1 Social isolation

Majority of the adolescents recounted that due to the effects of cancer and its treatment, they were unable to relate to their friends as they used to. The respondents also commented that they deliberately had to stay away from people to prevent teasing and other negative comments. Few of them mentioned:

“How I use to relate to people now has reduced, like if I’m looking for someone I have to walk but because they have cut my leg, I can’t walk. So now I don’t relate to them as often as I used to” Naa.

“I was not playing with them at all. I would usually remain in the room” Nac.

“When my friends see me, they will be calling me “sakora” (alopecia). So I don’t usually get close to people as much as I used to do before” Nad.

“Sometimes if I see people I don’t feel like greeting them” Nae, age 13.

“.....and sometimes too I don’t feel like talking to anyone..... sometimes when the doctors and the nurses come in, they will be talking to me but I don’t feel like talking to them” Nag.

4.4.4.2 Absenteeism from church and school

Participants reported that they often had to absent themselves from church and school to prevent them from acquiring other infections as told by health personnel and to prevent people from staring at them. Two of them commented:

“When I started the chemo sometimes the cells (immunity) go down so I was told not to get close to people. I attend church once a while” Nad.

“Sometimes I don’t feel like going to church because when I go some of them will be looking at me” Nag.

A few of the respondents said that they were absent from church and school because of their ill health and the distressing effects of the treatment. Three of the adolescents said:

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“The last time that I got seriously sick, I was not stepping my feet at the school's premises at all” Nac.

“Yes, sometimes I'm not able to go to school because it may be time for me to come and receive the treatment “Nad.

“The time that all my hair fell off, I couldn't go to school. Since that time I've never gone to school. If I go to school, my friends would be laughing at me.....I don't go to church like the way I used to go” Nak.

The respondents reported that they were unhappy and often wished they were in school or church. Some of them said that their friends had missed them. Others complained that whilst their friends are going to school, they would be at home or hospital. A few of them said:

“Sometimes if my friends go to school I also want to go to school but because of the disease I can't go....when I go to school they ask me when I will come to school because when I was in school, I make them laugh so right now that I'm not going to school they have missed me. When they see me they tell me that I should come to school” Nal.

“I am the only one staying at home when all my friends are going to school” Nai.

“I always dream of myself going to church but now....” Naj.

In summary, the findings from the social well-being of adolescents receiving cancer treatment reveals that though the adolescents received enormous support from their family and health care workers which helped them cope with the effects of cancer and its treatment, they experienced social isolation in terms of absenteeism from church and school.

4.5 Psychological well-being

Psychological well-being refers to a state of joy and the ability to gain a sense of control in relation to fears, anxiety, emotions and death as one experiences the effects of cancer and its treatment.

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Seven Sub themes emerges: Worry/anxiety/sadness, distress of taking medication/undergoing treatment, distress of frequent hospital visits/long hospital stays, Affective/ mood changes, Learning/attention/cognition, sensory changes and fear. Distress of taking medication/undergoing treatment, distress of frequent hospital visits/long hospital stays and sensory changes emerged from the data whilst Worry/anxiety/sadness, mood disturbances, Learning/attention/cognition, and fear were found to be consistent with the psychological well-being in the QoL model. From the data, adolescents receiving cancer treatment experienced worry, anxiety and sadness relating to the effects of cancer treatment. Most of them recounted experiencing changes in attention and cognition, speech and hearing. It was revealed that the adolescents were distressed with the frequent hospital visits and the various forms of cancer treatment. Again, the adolescents expressed fear related to death and relapse of the condition.

4.5.1 Worry/Anxiety/Sadness

A vast majority of the adolescents experienced worry/anxiety/sadness related to chemotherapy, frequent hospital visits and hospital admissions with their attendant problems. Few of them reported:

“I feel sad when I will be going to the house and coming back to the hospital, going and coming back, and one day a doctor will tell me that I need to be admitted, I feel sad and even want to go home” Naf.

“It worries me that I am always coming to the hospital. It is because my classmates will be learning and I will also be in the hospital and will be receiving treatment” Nac.

“I get sad because we would wake up at dawn sometimes I don't feel like waking up but I still have to wake up and come” Nad.

“If I'm coming and my mother is having money I will feel happy, but if she's not having money I will feel sad” Nak.

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More than half of the adolescents reported that they were particularly sad due to fatigue, loss of functional ability and absenteeism from school. Two of them reported:

“Sometimes it annoys me, sometimes too I get sad. It annoys me in the sense that when all my friends are working I alone will be sitting down without doing anything.....It makes me sad because I don't get the strength to do house chores like any other adolescent girl would do.....and when I go to the ward and come home, by the time I go to school they would have written a lot of notes, that one too becomes a heavy task” Nab.

“I didn't feel fine and I was always crying.....I cry because by that time my classmates would be sitting in school learning, only me I will be sitting at home.” Nac.

A few of the respondents said they were sad because upon returning home or school after undergoing treatment, they were unable to play with their friends.

“I get sad because if I go to the hospital and they give me medicine, when I come back I'm not able to play with my friends again” Nae.

Many respondents reported they were sad to go for treatment because of the “needle”. Two of them reported:

“When it makes me sad, that is when I'm coming for review because I know I will be coming for the needle, that is all” Naf.

“I don't feel like going but if my mother says we should go and if we do so, when they say they will do bone marrow my heart will start beating” Nae.

Few adolescents also reported they experienced sadness because they see other sick people in the hospital.

“It is because of the sick people, people have been injured I do not want to see them” Naj.

The vast majority of the adolescents recounted that they were not happy because of people's reaction towards them regarding their condition and its side effects. These made them feel uncomfortable going to church or school. One of them reported:

“.....I'm used to my hair that has removed and if I go to school with it I don't feel normal walking among my friends or my classmates” Naj.

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A few respondents also reported that they were not happy because the condition and its treatment. They regarded themselves as being less privileged compared to other people. *Naa* expressed:

“I feel so not too happy, not too happy..... like how they cut my leg, I will be seeing people with two but only me with one”.

According to the adolescents, their family and friends also experienced sadness related to cancer diagnosis and its treatment. *Nag* and *Naa* had these to say:

“I was friendly and I always respected my friends so when they found out that I was sick, they weren't happy” Nag.

Naa: “Hmm the first time they told me that I was going to do the surgery, everybody was crying. My sister took a picture and my mother sent it to my pastor. Even the pastor was crying.

4.5.2 Distress of taking medications/undergoing treatment

The adolescents reported that undergoing the various kinds of treatment was a burden for them. They used descriptions such as “it is very stressful” and “difficult”. The burden experienced were related to the frequent needle pricks and anaesthesia that goes with bone marrow aspiration. Three of the respondents mentioned:

“It is very stressful. When you are going to take samples they will prick you several times before they finally get it, that is very stressful” Nab.

“Sometimes if they say they are coming to do IT (Intrathecal administration of drugs) for me, I don't like it because the children would want to sleep but as for me, I do not want to sleep so if I don't sleep then it pains me but still I will not sleep” Nad.

“....because of the injection and the medicine I will take it worries me. I don't like to take the medicine” Nal.

Due to the fact that the adolescents experienced distress of undergoing treatment, a few of them reported that one needed to be courageous in order to receive the treatment:

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“Hmm, you have to be brave to receive whatever they are giving you, you have to know more about what they are giving you, whether it is a good medicine or not. Things are easy nowadays but it was so difficult when I had to take the drugs” Naa.

A few of the adolescents reported that they became angry whenever they saw the doctors.

“Yes, at first they will say that you have to do bone marrow and sometimes they will say another thing. So sometimes when I go home and I am coming back on review, When I see the Doctors, I become angry because I don't like the needle but hmm, it is a process, you need to go through” Naf.

Most adolescent commented that they wished they were not coming for the treatment again because of its nature. One of them said:

“Every day, they give me chemo, I wish that we were not coming for the treatment again....., sometimes when we come from the house to the hospital to receive treatment, they say that I would have to take some injections so I have to stay at the hospital and finish the injections before I go home” Nad.

A few of them also reported that they agreed to undergo the treatment because they knew that they were experiencing disorders but they have rather experienced complications and unwarranted side effects from the treatment.

“It is because I don't want to have a lot of disorders that is why I decided to do the surgery..... But, it is rather helping me get more sickness into my system” Naj.

4.5.3 Distress of Frequent hospital visits /long hospital stays

The respondents complained that the frequent hospital visits was a problem for most of them. According to some, they usually are not comfortable with the hospital environments. A few of them commented that but for the doctors who asked them to be coming for their treatment, they wouldn't have done so:

“As for me, I don't like the hospital, I don't like hospitals in general, not this hospital. So when my mother calls me on phone that we will be coming

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for review, sometimes I even tell her that she will not see me in the house the next day but it's just a saying" Naf.

"It is the doctors who told me to be coming for the chemotherapy, like I won't come" Naj.

Some respondents also reported that it was stressful sitting in a vehicle and coming to the hospital every time. They would have wished that they stayed at home:

"Well it is very stressful. Every day you have to sit in a vehicle up and down like that, that one too it's stressful" Nab.

"I feel that if it's within my wish I should be at home" Nai.

"I don't feel happy over it because every blessed day I'm in the hospital. Sometimes, I'm not feeling sick but they still tell me that I have come to the hospital, hmm it's a matter of time" Naf.

Some of the participants rather reported that the frequent hospital visits will help them and that, if they continued honouring reviews and went ahead to continue with the treatment as scheduled, they would soon be done. Two respondents said:

"....When I started going for chemo every month it wasn't scary and I didn't see anything about it because I knew I was going to take it and I will go back home" Nah.

" Sometimes I feel we have to come to the hospital because when we come I can't default in treatment but when we come continuously then I can take it fast and then I will finish" Nad.

4.5.4 Affective/Mood changes

The adolescents reported changes in their mood. The vast majority of respondents reported that they became angry at the least provocation. Few also reported that they sometimes became happy or sad without any reason. They reported that they thought some of these effects would be easy to manage and persist over a short period but that has not been the case. Two of them reported:

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“As for my mood, sometimes even if you tell me something that is not annoying I easily get annoyed. Yes and sometimes too I get happy. I may not know what has happened but I still get happy” Nab.

“Hmm! They (health professional) said that sometimes some things will change in my system. For instance, I won't feel like how I used to feel at first but I thought that it will be easier so that I can go home but..... Sometimes I easily feel excited and at another time, I will be feeling very sad” Naa.

4.5.5 Learning/Attention/Cognition

Respondents reported that cancer chemotherapy had impacted negatively on their learning. Most of them reported a decline in their learning, memory and attention span. These negative effects together with absenteeism from school have made their classmates move ahead of them in class. Some claimed that they easily forget whenever they were told to do something or taught in class. According to the adolescents, they found it difficult to understand when they were taught and therefore had to “chew” (memorise) or “read every day”. Few of the reported:

“It (memory loss) has made the things I'm learning go down, it has made me stagnant in class because I'm not able to remember a lot of things.....and when the teacher teaches unless I “chew” it into my mind before it will stick. So it's as if I am now learning everything new” Naj.

“Like when they gave me the medicine and I feel ok, if someone tell me something like today, tomorrow, I will not remember unless the person reminds me” Nae.

“Since I got this condition, if you tell me something right now by the time I go and come back I would have forgotten. Sometimes I am able to put some of them into memory for long.....sometimes I find it very difficult and it keeps long before I am able to understand some of the subjects” Nab “At first, when I learn, it was sticking (retain) in my mind but nowadays, when I learn, unless I read the thing, I read it every day before it sticks in my mind, so I now learn little at a time” Nag.

“Since I started treatment, my classmates have moved on to another class and I am left behind” Nab.

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“I could not remember anything, I could not remember my mother, I could not remember my father, and I could not remember anybody” Naj.

4.5.6 Sensory changes

The adolescents recounted that due to cancer and the effects of its treatment, they experienced changes in their senses. Majority of them reported changes in their sight, hearing and speech.

“After the treatment, when I talk, it seems it doesn't come out..... when I'm reading, people also tell me that they cannot hear me well.....when I am talking I feel like I have been hearing it in my head so when I talk a bit under tone, some people don't hear unless I talk louder” Nag.

“At first when the disease was serious I had a swelling around my ears. Sometimes when you even talk I was finding it difficult to hear” Nab.

4.5.7 Fear

Participants experienced fear related to death, injury, possibility of cure, relapse and prolonged hospital stays. The fear of other people dying on the ward and their own death was so strong that some of the adolescents refused to sleep. Some of them commented:

“At first when the disease started the way that some people were dying, it made me panic a bit and also made me get scared.....” Nab.

“Sometimes when I see that they are taking someone (dead body) away, I don't want to sleep because I feel that when someone sleeps that is when the person feels like dying.....” Naf.

A few of the adolescents also reported that they were afraid of relapse of their condition. Their fear was attributed to lack of fund, defaulting in treatment and delay in seeking treatment. *Nab* and *Nag* reported:

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“I was afraid that the chemo, they said that you don't have to default in treatment and if it is time for us to go to clinic my mother will say that she doesn't have money so we will not go and receive the chemo. If she says that I get afraid that I may not be able to go for the chemo and that may bring another problem for me” Nab.

“..... A certain day I was talking with my mother and she said that when my neck swelling came back they said that maybe because we have delayed it can travel to other parts of the body” Nag.

The vast majority of respondents reported fear of prolonged hospital stay, injury and fear of injection. Two of them mentioned:

“Sometimes I get scared that if I play too much with my friends I may fall down and get hurt or something like that and come back to the hospital.....sometimes I am afraid that we will come on admission for a very long time before we will go back home because the first time we came, we kept a bit longer” Nad.

“.....the blood test I will do and the injection they will give me, I am scared of injection.....” Naj.

4.6 Spiritual wellbeing of adolescents receiving cancer treatment

Spiritual well-being refers to a sense of inner peace and a search for meaning and purpose as one experiences the symptoms of cancer and the side effects of treatment. The findings from the study showed that adolescents receiving cancer treatment adopted various coping mechanisms which helped them deal better with cancer and its side effects. Six Sub-themes emerged. These were meaning of illness, denial, concealing disease, acceptance and inner strength, hope and religiosity. The first three sub-themes emerged from the data whilst the last three are consistent with the Quality of life model. From the data, it was revealed that the adolescents attributed the cause of cancer to various means including physical and spiritual. Most of them coped with the condition and the side effects of treatment by either denying the existence of the disease or concealing it from their friends. Others also accepted the diagnosis and therefore

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developed an inner strength and zeal to face cancer and its challenges. The adolescents were however highly religious and had hopes of cure and growing to fulfill their dreams in life. The sub-themes are presented with relevant themes in the ensuing sections.

4.6.1 Meaning of illness

Meaning of illness is the way in which the origin of a condition is regarded, interpreted or understood. The findings of this study indicated that adolescents had various perceptions about the cause of cancer and that affected the way in which they responded or coped with the condition and its treatment. Although the adolescents were on the oncology ward and were receiving treatment, they claimed they did not know the kind of condition they were suffering from and therefore attributed the cause to various means or merely believed what they were told by parents, Clinicians or Pastors. Three sub-themes emerged. These were physical, spiritual and a combination of both physical and spiritual factors.

4.6.1.1 Physical

Most of the adolescents classified the physical cause of their condition as either environmental or nutritional. According to them, cancer is caused by living in filthy environments. Two of them reported:

“I think that the environment we live in, for example the dirty environment might have caused this cancer” Nab.

... “And the filthy environment that we stay in like where mosquitoes and other things that are not good can also bring about the sickness” Nac.

Some of the adolescents also attributed the cause of cancer to lack of nutritious diet and probably food that they claimed were not good for them. Some of them commented:

“Sometimes we don't eat healthy food that is what I think might have caused the disease” Nab.

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“I think that it is because of the bad food that we eat that can bring some of the sickness” Like I’ve eaten something that is not good for me” Nac.

“I think it was my inability to eat nutritious food” Naj.

4.6.1.2 Spiritual

Some of the adolescents were highly superstitious and therefore attributed the cause of cancer to spiritual forces. According to them, the cause of their disease was revealed to them by God through their dreams. One respondent claimed a snake bit him in his dreams and a few days later, experienced pain in the leg which was diagnosed as cancer:

“One night, I was sleeping in the house, I dreamt and saw a snake coming, the snake was very long, the place was like a forest. When I run, the snake will vanish but by the time I see it, it will be at my back. I jumped and used my left leg to hit a rock. I fell down and the snake bit one of my legs, I did not see which one it bit. I told my parents and we all started praying. Later, my leg got swollen and we started going to church. At the church, they said that all those things are spiritual and the Pastor said that some people don’t want me to be alive” Naa.

A few also attributed the spiritual cause of the disease to a cultural belief known as “the evil eye”. To them, the everyday comments people made about them regarding their physical appearance as an adolescent might have contributed to them getting cancer because they never thought they would contract a disease such as cancer. *Nal*, said:

“.....when I’m walking with my mother or my mother is walking, someone will tell my mother that as for me I’m beautiful so she should take good care of me. All that, I don’t know but I think that is part of the reason why they gave me that disease, because I have never thought that I can get this disease”.

Majority of the adolescents also attributed the cause to their school or to the school children. They claimed that the school children have no respect for authority and retaliated

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whenever they got offended by their colleagues and therefore cancer could be one of the ways of attacking those who offended them:

“...I think that the school I was attending first, I thought that it's some of the school children that might have caused it.....because they usually behave and talk and do things like adults... ..if someone does anything against them, they will not go and report to the teacher or even if someone hits the other person, that person will also hit him or her back. They will not go and report to the teacher they will not tell anybody” Nad.

Although some of the respondents had their own perception about the cause of their condition, this was confirmed by their friends and Pastors. One respondent expressed:

“Some Pastors have been telling me that it is from the school and when I went to school too, one of my friends told me that it's from our school..... they said that when I went, some of our students stopped the school and one told me that because every year someone dies in our school so when I got sick, they thought that I will die” Nag.

Some of the respondents said that they wished that the cancers which people have afflicted on them spiritually would in turn afflict those who caused it.

Nal said: *“Anybody who knows about this sickness, it should go back to that person. I think that it's somebody who gave me that sickness.”*

4.6.1.3 Both physical and spiritual

A few of the adolescents also attributed the cause of their condition to both physical and spiritual means. To them spiritual conditions could manifest themselves physically. One of them expressed:

“Hmm, when all these things started happening, I thought it was a spiritual being who was behind it or as well planned it.....but I noticed that this thing cannot be spiritual, sometimes, they (witches) can do a spiritual or physical thing, that is what I believe” Naa.

4.6.2 Denial

Although most of the adolescents stated that they were informed by health care personnel as having cancer, they denied the existence of their condition. Most of them reported:

“I don't know if I have gotten this sickness” Nae.

“I didn't know that I will get this sickness” Nag.

“I ask always ask myself this question; it is me? And sometimes I can ask God why this thing happened, I don't seem to understand” Naa.

“I often think that my siblings and I are all in the same house. We all eat the same food, we all do the same thing so how come me alone I am a sickler” Nad.

“Sometimes I ask questions like why and why did I get it?” Nah.

“Hmm, I was surprised that I have gotten this sickness but was not sure that it is possible for me to get it... It came into my mind that I do not have the sickness they are talking about” Nai.

4.6.3 Concealing disease

The vast majority of participants reported that they coped with cancer and the side effects of the treatment by either “covering up” or non-disclosure. Some of them said:

“When I receive the chemo, it makes my hair fall off, so when I see that it is beginning to fall off, I go and barber it short so that when it completely falls off nobody will even see. And sometimes when it goes very low I shave all the hair on my scalp” Nab.

“I was able to mix with people but I would usually put on the cap” Nac.

“They gave me a certain medicine, I vomited and my eyes became big. We went to the eye clinic and they pushed it back and it became like this, they told me to wear glasses so that nobody sees the eye” Naj.

“They often ask me where did I go but I often don't want to tell them so I tell them that I don't know” Nad.

“I have been absent from school and when I go, some people want to know the reason why but I don't tell them that I have been coming to the hospital” Nag.

4.6.4 Acceptance and inner strength

A few of the adolescents reported that they were aware of their condition and therefore did their best to cope. Some respondents believed that things do not happen by chance and therefore they believed that getting cancer is God's plan and purpose for their lives: One of the adolescents stated:

“Hmm, this sickness I think that it is a thing which comes to change your life from not good to bad, although is bad, it is a purpose which must happen. We don't know whether is good or bad we don't know but I think it is a good situation whereby God can transform everything bad to new.... So I put strength in me and I do everything that makes me happy, I do everything as well” Naa.

A few of the respondents who believed that the cause of their condition was spiritual, narrated that they coped with cancer and the side effects of cancer treatment by behaving in a way and manner which made it difficult for others to realise that they were ill. *Nal* said:

“I believe that I can do everything because I don't allow somebody to know that I'm sick and whatever people do, I do it so when somebody sees me, the person may think that I am not sick”.

About a quarter of the respondents reported that though they were experiencing cancer and its side effects, they felt that they were the same and that nothing had changed in their lives because there are other people who have serious and more deadly conditions than them. Two of the respondents stated:

“I don't feel like giving up because there are some people who have had the same conditions and they are now healed so I know and I believe that I will also be cured” Nab.

“I was feeling so bad but I realised that it was good to help me be healthy... even a lot of people don't have legs; now I relax” Naa.

Other participants commented that they had read on the internet and therefore were expecting that they may experience some of those side effects. To others, they simply had

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to go through the treatment so that they can be free from cancer. Some of them commented:

I've been researching on the internet on chemotherapy, the effects, side effects that why when I lost the hair, I was not afraid because I know it will be happening. I feel it's a process, it needs to happen before you can get well so I don't give up" Naf.

4.6.5 Hope

Most respondents despite the effects of cancer treatment were hopeful of growing to accomplish their dreams and fulfilling their purpose in life. They were hopeful of cure and complete resolution of the side effects of the treatment. Some of them said:

"I hope that I will one day grow to take care of my mother and my father and my younger siblings" Nac.

"I believe that in the future, I would be able to work in the hospital" Nad.

"I believe that I can grow and become a mother of somebody. I have hope that in future, I will become a Doctor and I will be taking care of people too" Nae.

"I hope that one day I will grow to become a responsible person" Nak.

"I have hope that I can do a lot of things, big things that can blow their mind..... Even I can be a pilot.....everything happens for a reason and so you can go to school, I can still go to school" Naa.

According to some of the adolescents, their hopes and aspirations would only be achieved with the help of health care personnel. They also believed that they will achieve all their aims if they continued to receive their treatment and also studied hard. Two respondents remarked:

"I believe that if I continue to receive the treatment it will come to a time that I will not come here again and the disease will go away completely.... I hope this cancer thing, this cancer sickness will be cleared off by the help of the doctors and nurses" Nad.

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“When I study, I hope it will stick and I will be able to remember.....I hope to go to the best secondary school, to the university and achieve what I want” Nah.

A few respondents hoped that by the time they grew, the side effects of the treatment would have reduced. *Naf stated:*

“I think that by the time I grow a bit older some of the marks on my skin might have gone a bit. May it will not be big like it is now”.

One respondent was hopeful that others will learn from them (adolescents with cancer) and move on in lives:

“I hope that those who are also listening to me can learn some of my experiences so that they will “ginger” (motivate) themselves and also move on” Naj.

4.6.6 Religiosity

Most participants reported that they were religious and that helped them cope to with cancer and the effects of treatment. Religiosity was exhibited through prayers and belief in God. Respondents shared the following:

“You must be prayerful too...we prayed and my uncles and everybody prayed about it.....I was praying and I slept again and God revealed a certain thing to me. He told me that He knew that this thing will happen but He said that I should not mind about my leg that has been amputated. I can still become whoever He wants me to become to the extent that, it will blow people's mind” Naa.

“Sometimes when praying, even when you are receiving the treatment, you may feel like dying or something like that so you pray to God to take care of you from dying” Naf.

“I feel that if God is my father, He should fight for me and me too I will pray” Nak.

“I will say that God is there and He also listens to our prayers so I know that one day He will be able to hear mine” Nai.

A few of the respondents reported that they did not believe in God when they were children, but after growing to this age and upon being diagnosed with cancer, and going

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through the numerous experiences, they now believed the existence and supremacy of God. They further stated that God is the Healer and would heal them so they were not afraid. Some of the respondents shared the following:

“Get afraid of...? I have faith in God that nothing will happen to me” Nae.

“Hmm, first I didn't believe in God that much when I was young, when I woke up, I knew that God was there but I didn't believe in him but now that I am alive I have faith in him that He is the person who created us so we don't have anything to do,.....I thought that I cannot walk with my two legs but I later realised that I can do everything through Christ who strengthens me. So when my family were crying I told them that it's easy but God does everything for us, as we don't know what is happening he knows and so they should give thanks to Him because I am alive and did not die through this sickness” Naa.

“I believe that God is the healer and therefore he will heal me” Nab.

“I almost died but God did not allow that to happen.....when they (family members) come to me they say God is great, God is great. They say that it is God who has made me like this” Nad.

A few of the respondents commented that God loves them so much because a lot of people have died from similar conditions but they are still alive. They therefore prayed to God for healing and complete cure of their conditions. A few respondents said:

“...The time I got the disease I did not believe that I will get well but when I took the medicine and I have become well it's as if God loves me so much” Nal.

“I often tell God that He should let this sickness go away, it shouldn't come back to me again” Nak.

Religiosity was also exhibited by reading the Bible and other related materials.

Naa commented:

“I used to read the bible, and watch motivational episodes on television to inspire me.

4.7 Health Service - related factors

Health service-related factor is any factor in the health care institution or setting that influences the experiences of the adolescent receiving cancer treatment. Two sub-themes emerged from the data. These were attitude of health personnel and Quality of care. These are presented with verbatim quotations from the respondents.

4.7.1 Attitude of health personnel

According to the adolescents, most health workers such as nurses, doctors and laboratory technicians exhibited good attitudes towards them. Most of them described the health workers as friendly, jovial or playful and were willing to give any support needed.

A few of the adolescents reported:

“They relate to me well. They talk to me in a very nice way. If I don't understand anything and I asked them they explain it to me” Nab.

“As for the doctors when they realise that the person's condition at the moment is not good, they take the person as their friend, so they are friendly” Nad.

“Sometimes they will be talking to me, they ask me how I'm feeling and they will be laughing with me” Nag.

“When they come to check anything on you, they tell you things that will make you laugh” Nai.

“They play with me before they give me the medicine” Naj.

Some of the respondents claimed that they did not feel pains during injection when they were played with by health personnel. *Nae* said:

“When they are coming to inject me they play with me and inject me so sometimes I don't feel any pains”.

Some of these adolescents reported that the attitude exhibited by health personnel towards them was cordial. Two of them commented:

“They talk to me like I am their daughter” Nac.

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*“They talk to me like their friend, they embrace me like I’m their brother”
Naj.*

Other adolescents found the attitudes of the health personnel to be normal because they felt they were doing their work. They described them as being passionate to their work. **Naf** said:

“Hmm... I have nothing to say because they are patriotic to their work. When you go there, their relationship with the patient is normal... It is like they are doing their responsibilities”.

A few of the respondents also felt that the way the health personnel talked to them was not professional. They complained about the way and manner some health personnel carried their duties toward them. **Naf** and **Nak** complained:

“Some of them when they come to you, the way they talk to human beings sometimes it is not good” Naf.

“It (intra- venous line) is very painful and when they are doing it too I don't think they feel pain in their heart that if it were to be my child, would I do this to them?” Nak.

4.7.2 Quality

Majority of the respondents said that they were satisfied with the care given. As adolescents, most of them said they were given story books to read whenever they came to receive treatment. **Nae** had this to say:

*“If I go, I learn in the hospital and sometimes they gave me story books”
Nae.*

Other respondents however reported that the care they were given at the hospital may not be of total quality since there can be errors in the administration of chemotherapy by the health personnel. Hence, they had to monitor health personnel to ensure that such errors do not occur. Others complained about health workers not getting the correct IV lines and therefore they had to be pricked several times which causes a lot of pain. **Naa** and **Nae** expressed:

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“You have to know more on what they (health personnel) are giving you, whether is it a good medicine or not. You must monitor for example some of the nurses. Some of them don't know that you are monitoring them so maybe they can give you another drug which is not the one they are supposed to give and so you have to tell them that, that's not the right drug” Naa.

“If the nurse or the doctor doesn't locate the vein well and pushes the medicine through it, it causes pain” Naf.

4.8 Summary of findings

This chapter analysed 14 interviews conducted among adolescents receiving cancer treatment at the Korle-bu Teaching Hospital. Five major themes were derived; Physical well-being, psychological well-being, social well-being, spiritual well-being and health service-related factors. The first four themes are consistent with the Quality of life model developed by Dow and Ferrel (1999) which was used as an organising framework. The last theme, health related factors emerged from the data. In all, twenty-three sub-themes were identified.

Adolescents receiving cancer treatment had a wide range of experiences in relation to the model and themes identified. The most dominant experiences obtained were the physical well-being with the following sub-themes: GIT symptoms, Pain, Appearance changes, Functional ability, Fatigue and Other effects. It was realised that adolescents receiving cancer treatment had an overall poor physical quality of life.

The psychological well-being was explored based on the following sub-themes: Worry/Anxiety/Sadness, distress of taking medication/undergoing treatment, distress of frequent admissions/long hospital stays, Affective/mood changes and Learning/Attention/Cognition. From the data, it was realised that adolescents receiving cancer treatment experienced a lot of distress with cancer treatment and its side effects which led to a poor psychological well-being of these adolescents.

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Social well-being was investigated using Meaning of illness, Denial, Concealing disease, Acceptance and inner strength, Hope and Religiosity as sub-themes.

It was found that the perception adolescents had regarding the cause of their illness was a contributing factor to the coping mechanisms adopted. They coped with cancer and the side effects of treatment by denial, concealing the disease and its effects and by acceptance/inner strength. Despite the effects of cancer treatment, the adolescents had hopes of growing to fulfill their future dreams. Most of these adolescents despite experiencing social isolation in terms of absenteeism from church and school, had immense support from their relatives, friends, school and from health care professionals which helped to improve their social well-being.

Health service - related factors were explored using attitude of health personnel and Quality as sub-themes. It was found that most adolescents were comfortable with the health setting.

CHAPTER FIVE

DISCUSSION OF FINDINGS

This chapter presents the discussion of the findings with related literature. The demographic characteristics of participants are discussed first followed by the main themes and sub-themes which are discussed in line with the constructs in the conceptual framework.

5.1 Demographic characteristics of participants

Most participants were within the ages of 13-16 years. Out of the 14 participants, nine of them had Acute lymphoblastic Leukemia (ALL). This finding agrees with a research conducted in Norway on children or adolescents with cancer which reported that majority of the participants had leukemia although other types of cancer were reported (Ruland & Hamilton, 2009). This finding is however in contrast to a study conducted by Ward, Desantis, Robbins, Kohler and Jemal, (2014) in the United States of America who reported that Hodgkin lymphoma, thyroid carcinoma, brain and CNS tumours and testicular germ cell tumours are the 4 most common cancers diagnosed in adolescents. Acute lymphoblastic leukemia (ALL) was found to be high among children.

Findings from the current study also revealed that most of the adolescents were from poor socio-economic backgrounds. This finding is supported by GLOBOCAN in 2012 which reported that of the predicted 20 million new cancer cases expected by 2025, the greatest increases are anticipated in the low income countries as a result of life-style factors and increased number of infectious agents (Ferlay et al., 2015).

5.2 Physical wellbeing of adolescents receiving cancer treatment

Adolescents receiving cancer treatment may have good, moderate or poor physical well-being according to their individual experiences with the type of treatment and side effects. The findings of this study suggest that adolescents have overall poor physical well-being. The symptoms most commonly reported were pain, nausea and vomiting, alopecia, decrease in functional ability and fatigue. Other studies reported poor physical well-being among adolescents and young adults with cancer (Darezzo et al., 2017), and patients with advanced cancer (Augustussen, Sjøgren, Timm, Hounsgaard, & Pedersen, 2017). This may be due to the fact that most adolescents fail to report some symptoms experienced (Ameringer, 2010). Furthermore, decisions concerning treatment such as whether or not to report to the hospital for chemotherapy, follow-up visits, when to pay and conduct laboratory investigations are all decided by their caregivers and that might have contributed to their poor physical well-being.

Pain in cancer has widely been reported in a number of studies (Agrawal & Feusner, 2016; Hechler et al., 2009). This study shows that all the adolescents had experienced pain at one point during cancer treatment. Pain is reported by most studies as an integral part of cancer and the most common symptom experienced (Garud, Oza, Gaikwad, & Kulkarni, 2017; Mcculloch, 2013) and is observed to have a direct impact on quality of life. This study also found out that pain is experienced in various parts of the body such as leg, abdomen and back. Again, this finding is similar to other studies that reported that the sensation of cancer pain could be felt in the head and neck (Jakun W. Ing, 2017), lower back (Kahn, 2017), and lower abdomen (Maree & Nqubezelo 2014). Findings from the study indicated that pain was present before chemotherapy and during diagnostic procedures. Some adolescents reported pain even before the administration of chemotherapy. Most adolescents reported pain during bone marrow aspiration and setting

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of intravenous infusion lines. This finding is in consonance with various studies which reported that at the time of diagnosis, pain was caused by cancer itself which was different form that during treatment which was mostly due to diagnostic procedures and administration of some treatments (Agrawal & Feusner, 2016; Erickson, Fiona, et al., 2013; Portenoy & Ahmed, 2018).

This study also found out that participants experienced sleep related disturbances such as difficulty in sleeping as a result of pain experienced. This is supported by a number of studies which found out that adolescents receiving cancer treatment experience altered sleep patterns during the day and night as a result of pain, vomiting and worry. (Kaleyias & Manley, 2012; Walker et al., 2011).

Gastrointestinal disorders such as nausea and vomiting, appetite disorders, diarrhea and constipation and oral mucositis were reported by the adolescents. Most adolescents experienced nausea and vomiting during the period of chemotherapy and persisted even after the administration of chemotherapy. This finding agrees with a study conducted by (Gordon et al., 2014; Zaidan, 2015) who reported that nausea and vomiting are a common symptom in cancer and may or not be related to treatment.

Furthermore, the adolescents reported increase or a decrease in appetite following treatment. This findings is supported by (Barajas et al., 2017) who stated that appetite disorders are highly prevalent among cancer patients and may contribute to nutritional disorders.

It was also found that adolescents experienced diarrhoea and constipation as a result of the treatment. Diarrhoea was commonly preceded by abdominal pains. Some participants recounted passing about five watery stools a day and persisted some days after treatment. This finding is in accordance with a similar study's findings which reported that

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chemotherapy - induced diarrhoea is often associated with ulceration of the gastrointestinal tract. Chemotherapy - induced diarrhoea was classified as uncomplicated with passage of 4-6 stools a day or complicated with passage of more than 7 stools a day (Escalante, McQuade, Stojanovska, & Nurgali, 2017).

The findings from this study also revealed that cancer treatment causes oral mucositis which is pain and inflammation of the oral mucosa, tongue and throat. This affected the eating patterns of the adolescents as they were unable to eat, swallow or drink water as a result of pain. This finding is consistent with findings of studies conducted by (Chen et al., 2015; Kuiken, Rings, & Tissing; 2015) who reported that gastrointestinal mucositis is one of the most common symptoms experienced by patients receiving cancer treatment leading to reduced oral intake, increased risk of infection, long hospital stay, high economic burden and poor quality of life.

Participants also reported experiencing fatigue which made them unable to perform self-care activities such as bathing. Adolescent females particularly were unable to perform chores expected of them at home. They frequently felt tired after walking a small distance or performing minor activities. Again, this finding corroborates with findings of studies done by Erickson et al. (2010), Perdikaris et al. (2009), Kaleyias and Manley (2012) and Wu et al. (2010) who revealed that adolescents experience fatigue during the treatment period which causes undue burden on their daily activities, quality of life and varies throughout the period of treatment. Fatigue was reported to have pronounced effect on daily activities, ability to maintain relationship with others, participating in social activities and general well-being of the individual (McCulloch, 2013). The findings of this study also revealed that male adolescents especially could not engage in leisure activities such as playing football with their friends which led to a decrease in their social

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interaction. The current study however did not find variation of fatigue during the treatment period.

Furthermore, the adolescents in this study reported changes in physical appearance such as alopecia, stretch marks, wounds and scars. This finding agrees with the findings of a study conducted in Canada on adolescents and young adults with cancer which found out that the most common changes in body image experienced by adolescents with cancer included hair loss, weight gain or loss (Aubin & Perez, 2015; Mcculloch, 2013).

Furthermore, the current study found out that cancer and the effects of cancer treatment lead to impaired functional ability in the adolescent receiving cancer treatment. The above findings are similar to findings of a study by Lam, Li, Chiu, and Chan (2016) who reported that adolescents receiving cancer treatment have reduced functional ability as opposed to their counterparts who are not on cancer treatment. Most adolescents could not engage in their usual household chores, perform self-care activities and could not engage in recreational activities. This finding is similar to findings of a study conducted by Anclair, Lannering, and Gustafsson, (2009) on the persistent late effects of adult survivors of childhood cancers. They reported that the participants had low functional ability including self-care and movement. Impaired functional ability in this study was found to be related to fatigue, dyspnoea and breathlessness.

This study also found out that adolescents receiving cancer treatment experienced sensory disturbances such as hearing loss, speech and sight problems. This is supported by findings of a study conducted by Landier (2015) who reported that the most prominent effect of chemotherapy is sensorineural hearing loss particularly with higher doses of Cisplatin and carboplatin. Hearing loss due to radiation can be both sensorineural and conductive.

In general, adolescents receiving cancer treatment have a poor physical well-being which may impact negatively on their quality of life.

5.3 Social well-being of adolescents receiving cancer treatment

This theme focus on understanding the social well-being of adolescents receiving cancer treatment. It explains how the effects of cancer treatment on the adolescent affects his or her social interaction which consequently impacts negatively on the social wellbeing of the adolescent. The study revealed that the side effects of cancer treatment impacted negatively on the adolescent's social interaction. The findings from this study revealed that participants experienced social isolation in varied forms. This included school absenteeism from school and church and poor relationships with neighbours, including friends. Absenteeism from school and church might probably be due to frequent hospital visits and prolonged hospitalisation. Also, the adolescents consciously isolated themselves in various ways to prevent being teased by their friends as a result of skin changes and other body disfigurements. This finding is similar to the findings of a study conducted in Australia which reported school re-entry was a major concern for these adolescents because of changes in their physical appearance which consequently affected their socialisation with their peers (Patterson et al., 2015).

These findings are supported by the findings of a study which revealed that absenteeism from school or work due to recovery from side effects of therapy, frequent and lengthy hospital stays place adolescents and young adults with cancer at a greater risk of social isolation (Docherty et al., 2015). The current study also reported that adolescent males, especially could not engage their friends in social activities such as playing football due to the experience of fatigue and pain. Adolescent females could also not perform simple household chores which resulted in the adolescents having feelings of anger, worry

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and sadness. This is supported by various studies which reported that pain and fatigue interrupted simple daily activities of adolescents and young adults with cancer and served as a source of social isolation (Flavelle, 2011; Keim-Malpass et al., 2013; Kim & Gillham, 2013). Other studies reported that alteration in daily activities of the adolescent with cancer and social isolation consequently became a source of distress, anger, and frustration (Hauken et al., 2013; Kim and Gillham, 2013).

Although the experiences of caregivers of the adolescents was not evaluated in this study, the adolescents reported that caregivers experienced caregiver burden and financial burden. The high cost of cancer treatment has been evaluated in a number of studies (Chu et al., 2008; Foster et al., 2011). A study conducted in Norway to determine the financial burden of various diseases rated cancer as the highest on a daily basis (Kinge et al., 2017). The financial burden on caregivers was found to be related to the cost of treatment and diagnostic procedures and additional costs due to prolonged hospitalisation and frequent hospital visits. This finding is partly supported by a study conducted in China which revealed that the financial cost of cancer was related to the type of cancer, duration of hospital stay and type and level of hospital providing medical services. Patients using private insurance had the least financial burden compared to those on Government insurance (Huang et al., 2016).

Prolonged hospital stay was found to be a cause of financial burden on caregivers due to absenteeism from work. This is supported by study findings of Deshields et al., (2012) and Song et al. (2011), who reported that prolonged cancer treatment, frequent hospital visits and stays and caring for a cancer patients may lead to absenteeism from work which would lead to loss of income and subsequent financial burden.

Additionally, caregivers experienced caregiver burden as a result of providing care to the adolescent. This finding is similar to that of Fletcher et al., (2008) who reported that

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caring for adolescents with cancer causes fatigue, pain and inadequate sleep. Caregivers of the adolescents aside providing physical care to the adolescents were the same people who had to go and collect specimen bottles from the laboratories, sent the samples back after they were taken, go back to collect results when they were ready, go to the pharmacies to purchase drugs among other responsibilities. The study also found out that caregivers of the adolescents experienced loss of income which may be due to cost associated with frequent hospital visits, prolonged hospital stays and the high cost of cancer treatment which is not included on the National Health Insurance Scheme.

The adolescents therefore expressed the need for financial assistance and caregiver respite to ease the burden on their caregivers. The findings are consistent with findings of a study conducted on adolescents and young adults with cancer or blood disorder which demonstrated that most of the participants preferred a support service that included financial aid, assistance and emotional support for themselves and for their family (Goodall et al., 2012; Olsson, Jarfelt, Pergert, & Ensk, 2015).

This study also revealed that participants received immense social support which helped them to cope better with their condition. A number of studies have also evaluated the importance of social support to patients with cancer and have found it to have a positive impact on a wide range of outcomes (Grimsbø, Finset & Ruland, 2011; Skirbekk, Korsvold, & Finset, 2018)

In this study, it was also found that adolescents received immense support from both the nuclear and extended family. Additionally, participants received support from their school teachers and friends at school. Although participants experienced learning difficulties and school absenteeism, teachers and friends were highly supportive which helped them to cope better with school work. This finding is supported by findings of a study conducted in Australia which revealed that strong social support system is a

significant resource for adolescents and children with cancer coping with the illness (Goodall et al., 2012).

Furthermore, the findings of the current study revealed that adolescents received tremendous emotional, psychological and financial support from health personnel which helped them to cope better with the illness. The study also revealed that adolescent female adolescents also experienced disruptions in their menstrual cycle. This findings corroborate with the findings of a study conducted by Aubin & Perez, (2015) which showed that issues related to infertility and sexual functioning is a concern for adolescents especially females undergoing cancer treatment.

Generally, participants had immense social support. They however experienced social isolation and disruption in the development of their secondary sexual characteristics which could impact negatively on their social well-being.

5.4 Psychological wellbeing of adolescents receiving cancer treatment

This theme covered how the effects of cancer and the side effects of cancer treatment impacted on the state of mind of the adolescent receiving cancer treatment. The findings from the study revealed that adolescents receiving cancer treatment have poor psychological well-being. The adolescents were worried, anxious and sad (Korsvold, Viktoria, Finset, Ruud, & Cathrine, 2017; Mcculloch, 2013). These emotional concerns expressed by the participants were related to cancer treatment, frequent hospital visits and admissions, absenteeism from school, loss of functional ability, loss of hair and other body disfigurements. This finding is again supported by the findings from a study conducted by Korsvold, Viktoria, Finset, Ruud, and Cathrine (2017) which reported that adolescents

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receiving cancer treatment expressed emotional concerns related to loss of hair and eyebrows which according to the adolescents make them appear different from their peers.

Another finding in relation to the psychological well-being of the adolescents was the distress of taking medications or undergoing treatment. Most of the adolescents expressed distress from taking medications most of the time or undergoing other forms of treatment which involved frequent needle pricks and undergoing anaesthesia. Findings from the study also revealed that the adolescents were distressed as a result of frequent hospital visits and long hospital stays. Most of the adolescents felt that the distance they had to travel every now and then to come to the hospital was a source of distress to them.

Mood changes/swings was found to be prevalent in the adolescents which affected the way they interacted with people around them including health personnel. The findings revealed that most of them became sad at the least provocation and sometimes without any cause or reason. This finding is partly supported by the findings of other studies which reported that mood disturbances such as depression is a common symptom in cancer patients and often occurs in combination with sleep disturbances, fatigue and pain (Kim et al., 2016; Loh et al., 2018).

Furthermore, the study found out that cancer and its treatment impacted negatively on the cognitive ability of the adolescents. Most of them experienced difficulty in learning, attention deficits and memory loss. These factors together with absenteeism from school negatively affected their school performance.

This finding corroborates with the findings by Patterson et al., (2015) and Landier (2015) who reported that adolescents with cancer experience cognitive changes which prevent them from returning to school, work or even engaging in their daily activities and achieving social integration. Again, another study conducted to determine the cognitive

function of adolescents with cancer in Sweden revealed a decline in their psychomotor skills, understanding, perceptual organisation and social perception (Saury & Emanuelson, 2011).

5.5 Spiritual well-being of adolescents receiving cancer treatment

This theme covered the spiritual well-being of the adolescents receiving cancer treatment. This spiritual well-being served as a form of coping mechanisms which the adolescents used to deal with the challenges imposed on them by cancer and its treatment. The adolescents attributed various meanings to their illness. Some of them attributed the meaning to physical factors such as poor environmental conditions and lack of nutritious diet.

Some of the adolescents felt that evil forces were responsible for their illness as some of them claimed that this was revealed to them through their dream. This finding is supported by a study conducted in South Africa on patients with cervical cancer which reported that participants in the study attributed the cause of cancer to witchcraft (Mabena and Moodley, 2012). This in a way accounted for the coping mechanisms participants adopted to deal with the distressing effects of cancer and its symptoms. Hence, they concealed their condition from their friends, colleagues and their households as a way of preventing the evil ones from getting back at them.

The participants also demonstrated acceptance of the condition claiming that although the condition has changed their lives from good to bad, it is a purpose which needed to happen in their lives. This served as a form of motivation by which they endured the effects of cancer and followed through with their treatment. Similarly a study conducted by Nedjat-Haiem et al., (2012) on women with cervical cancer revealed that the

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women accepted of their condition, which motivated them to continue with their treatment plans.

The findings from the current study showed that the adolescents had immense hope which helped them to go through cancer and its treatment. This is supported by the findings of Duggleby, Ghosh, Cooper and Dwernychuk (2013), which reported that hope is positively correlated with quality of life, health and general well-being when experiencing the effects of cancer and its treatment whilst hopelessness is a threat to well-being. The adolescents were hopeful of a future, growing to become responsible adults, having children and fulfilling their future dreams and aspirations. Again, this finding is consistent with the findings of a study conducted in Finland by Juvakka and Kylma, (2009) which revealed that adolescents receiving cancer treatment were hopeful of recovery, occupation, engaging in relationships, travelling overseas and had dreams towards the future. The adolescents in the current study were also hopeful of cure and complete resolution of cancer and its side effects.

Furthermore, participants also displayed a high level of religiosity which was exhibited as trust and belief in God, reading the Bible and watching motivational talks on the television. The participants together with the help of their relatives also prayed to God for healing which they believed could be achieved with the help of the doctors and nurses. This finding is similar to the findings of Jafari, Najafi, Sohrabi and Reza (2010) who conducted a study on the influence of spirituality and hope among cancer patients in Iran. They reported that spirituality and hope lead to high life satisfaction and were important in helping cancer patients adjust psychologically. These individuals believed God would help them through every hardship would provide for their needs. This contributed to their happiness. Findings from the above study suggest that spirituality should be integrated into the care of patients with cancer in order to improve their psychological well-being

(Lucette et al., 2016).

In summary, adolescents receiving cancer treatment in this study applied various meanings to their illness which accounted for the coping mechanisms adopted. They did this by denying their diagnoses, concealing their condition from friends and neighbours, acceptance and reliance on their inner strength. They were hopeful of a future. They prayed to God, believed and trusted God for healing and read the Bible and other motivational books. This may be due to the fact that Ghana is a secular country “de jure” but a highly religious country “de factor”; the report of the 2010 population and housing census as with previous censuses indicated that Ghana is predominantly Christian (Ghana Statistical Service, 2012). The Ghanaian culture vividly portrays the nation’s religiosity, thus it is not surprising that Ghanaian adolescents suffering from cancer and the effects of cancer treatment rely heavily on their religious inclinations to help them cope with their predicament. These Ghanaian adolescents might have turned to religion due to socialisation by their respective families.

5.6 Health service-related factors

This theme explored the factors related to the health care system as the adolescents sought treatment from the Korle-bu Teaching Hospital. The adolescents had a wide range of experiences which either influenced their well-being negatively or positively. Even though some of the adolescents were being managed at the oncology ward, they claimed they did not know what condition they were being managed for. This could be due to the fact that most adolescents in our cultural context are considered as children hence decisions concerning their care and well-being are usually made in consultation with their parents or caregivers oblivious to them. This assertion agrees with the norms in most countries such as the United States and Britain where adolescents less than 18 years are

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considered as minors and are deemed not fully autonomous, hence decision making falls on the parents (Abrams, Hazen, Penson, & Erikson, 2007) .

This may require that adolescents and children receiving cancer treatment be provided with adequate information that commensurate with their developmental stage and comprehension ability. This recommendation agrees with the findings from a systematic review conducted to evaluate psychosocial interventions for adolescents and young adult cancer patients. It was suggested that there is the need for age-appropriate interventions in dealing with the psychological issues of adolescents and young adults with cancer (Richter et al., 2015). Majority of the adolescents in the current study recounted that they had received prior information from the doctors and Nurses about the side effects of cancer treatment and therefrom were not surprised to see some of these signs and symptoms being experienced. The adolescents were happy with the hospital environment. Most of them claimed the unit was ultra-modern as seen in the beautiful paintings on the walls. This made them comfortable to receive treatment. Participants also were given story books to read whilst on admission and during follow-up visits. Teachers were always available at the oncology day care unit to engage them in reading and other activities. This could make up for academic loss due to school absenteeism. It could be concluded that adolescents receiving cancer treatment had poor physical well-being from cancer itself and the side effects of cancer treatment. The adolescents experienced gastrointestinal disturbances, pain, loss of functional ability, loss of strength and fatigue and the acquisition of secondary diseases.

It could be inferred from the data that the adolescents had moderate social well-being. They had support from their relatives, friends, school and from health care professionals. They however experienced social isolation and absenteeism from church and school. Their caregivers also experienced caregiver burden and financial burden

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which consequently impacted negatively on the well-being of the adolescents.

The adolescents had poor psychological well-being. They were worried, sad and anxious about the cancer treatment, side effects and absenteeism from school. They experienced distress as a result of frequent hospital visits and the need to undergo treatment. There was disruption in their mental states which resulted in mood changes, attention deficits and memory loss. They had fear related to cure and relapse of their condition. The effects of cancer and its treatment also affected their speech, hearing and sight.

The adolescents were highly spiritual and attached diverse meanings to their diagnoses which impacted either negatively or positively on their coping mechanisms. They coped with the distressing effects of cancer and its treatment by denial, concealing and finally acceptance and reliance on their inner strength. They prayed to God, read the Bible and watched motivational talks on the television. They were hopeful of cure and growing old to accomplish their future dreams and aspirations. It could therefore be inferred that the adolescents had good spiritual well-being.

The adolescents were comfortable with the health care environment. Teachers were available to teach them whilst they were on admission or were receiving their treatment. They were also given story books to read which in a way could make up for school absenteeism. They however expressed mixed feelings about the attitude of health personnel.

5.7 Evaluation on the effectiveness of the theory

The theoretical framework employed in this study generally helped to unravel the experiences of adolescents receiving cancer treatment. It guided the researcher in setting

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the objectives/research questions for the study. Furthermore, the framework helped in the organisation of the literature review. The domains of the framework and their constructs provided a structure or template for designing the data collection tool used in the study. Finally, it guided the discussion of findings from the study in relation to other studies.

The model was not modified in its application in this study because it suited the study in its entirety.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

This chapter describes the summary, implications, limitations, conclusion and recommendations and of the study.

6.1 Summary of study

The study used the Quality of Life Model applied to cancer developed by Hasey Dow and Ferrel (1999) to explore the experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital. Data collection commenced after ethical approval was obtained from The Institutional Review Boards of Korle-bu Teaching Hospital (KBTH-IRB) and the Noguchi Memorial Institute for Medical Research (NMIMR-IRB). Pre-testing of the interview guide was done using two adolescents receiving cancer treatment at the Komfo Anokye Teaching Hospital after which corrections were made in the tool for gathering the actual data. Fourteen adolescents receiving cancer treatment participated in the study. Parental consent and child assent were sought from parents and adolescents who were below 18 years and consent was sought from adolescents who were 18 years and above. Recruitment of participants, data collection and transcription were carried out concurrently between February and April, 2018.

Each interview was recorded with an audio tape recorder and transcription was done verbatim. Data analysis was done in May, 2018 using thematic content analysis.

The findings showed that adolescents receiving cancer treatment experienced many physical effects from cancer itself, the side effects of the various treatments such as chemotherapy, surgery and radiotherapy and from diagnostic procedures. The adolescents

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experienced gastro-intestinal effects such as appetite disorders, nausea and vomiting, diarrhoea and constipation and oral mucositis. In addition, the adolescents experienced pain which was mostly headaches, back pain and abdominal pain. Pain was also reported during diagnostic procedures. Pain was seen to affect the sleeping pattern of these adolescents. Furthermore, the adolescents experienced changes in their physical appearance such as changes in skin colour, stretch marks, wound, scars, alopecia and weight loss. There was impairment in functional abilities of the adolescents as a result of pain, fatigue and breathlessness. Fatigue was experienced which caused a decrease in the adolescent's functional ability and the ability to associate with friends and engage in leisure activities. All these effects combined to produce poor physical well-being of the adolescent receiving cancer treatment.

Socially, adolescent females particularly experienced changes in their sexual function such as the size of their breast and disturbances in their menstrual cycle. The adolescents, due to the distressing effects of cancer treatment experienced social isolation, and absented themselves from school and church. They however, had support from their family, school and church and also from health care professionals. Caregivers of the adolescents experienced a heavy burden including financial burden as a result of providing care to the adolescents which consequently affected the social well-being of the adolescents receiving cancer treatment. Adolescent receiving cancer treatment therefore had overall poor social well-being.

It could be inferred that the psychological well-being of the adolescents was poor. The adolescents were worried, anxious and sad because of frequent absenteeism from school and loss of functional ability. They also experienced distress as a result of frequent hospital visits and undergoing frequent treatments. The side effects of cancer treatment affected their mood, learning, attention and cognition. Additionally, the adolescents

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experienced other effects such as changes in vision, hearing and speech. They were afraid of death and thoughts of the possibility of cure and relapse of their condition.

They however experienced good spiritual well-being. The adolescents attached various meanings to their illness which accounted for the various coping mechanisms adopted. They coped through denial, concealing the disease and acceptance. They had an inner strength to continue with the treatment and to fight the condition. This gave them hope of a future and growing up to accomplish their dreams. They were also highly religious by praying to God for a cure. They obtained inspiration from reading the Bible and watching motivational talks on television.

Lastly, the adolescents had various experiences with the health care system that impacted either negatively or positively on their quality of life. Most of them were comfortable with the hospital environment as they recounted that the place was ultra-modern and they were given story books to read whenever they came to receive their treatment. They however expressed mixed feelings about the attitude of health workers and the way some health workers talked to them.

6.2 Implications

The findings of this study brought to light some implications that need to be addressed in nursing practice, nursing education, nursing research, and for policy formulation.

6.2.1 Nursing practice

The findings showed that the effects of cancer and the side effects of treatment permeate through the physical, psychological, social and spiritual well-being of the

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adolescent receiving cancer treatment. It is important that a holistic approach to care be employed in the management of adolescents receiving cancer treatment. Moreover, the findings indicated that the adolescents experienced side effects related to almost all the body systems. They also experienced other challenges related to social isolation and school absenteeism. It is important that various health professional such as oral health practitioners, educational psychologists, otolaryngologists, social workers be involved in the care of these adolescents with cancer.

6.2.2 Nursing education

The findings revealed that some nurses has inadequate knowledge on cancer chemotherapy whilst some displayed negative attitude toward the adolescents. Organising more in-service education and training for nurses working in the Paediatric Oncology Unit would be beneficial. Moreover, there is the need for the Ministry of Health to train specialist oncology nurses with the needed skills and knowledge to care for cancer patients.

6.2.3 Nursing research

This study highlights the need for further research on adolescents receiving cancer treatment especially in sub-Saharan Africa and in Ghana since there is paucity of information on the subject. This present study explored the experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital. To understand and appreciate what adolescents with cancer go through, another study could be conducted at the Komfo-Anokye Teaching Hospital. Future research could be conducted to elicit the experiences of caregivers of the adolescents.

6.2.4 Policy formulation

The findings from this study revealed that the cost of treatment for adolescents with cancer is very high as caregivers experienced financial burden especially with the cost of drugs. It is essential to include the cost of cancer treatment, especially for adolescents on the National Health Insurance Scheme. It would be cost effective if the government to imports cancer chemotherapy into the country to make the drugs affordable to families who need them. The government can also eliminate import duties on these drugs into the country so that private pharmaceutical companies could dispense them to patients at affordable prices.

6.3 Limitation

Given the age of the adolescents, they might not have been able to give the nuances of their experiences as adults would have provided. Hence certain in-depth insights may have been omitted.

6.4 Conclusions

Some findings of the study were consistent with the constructs of the Quality of Life Model Applied to cancer. Other findings outside the constructs were also identified. In relation to the physical well-being of adolescents receiving cancer treatment, the findings that were consistent with the constructs in the model were functional ability, dyspnea/breathlessness, strength /fatigue, gastrointestinal disturbances such as nausea, appetite disorders and diarrhoea/constipation and pain whilst changes in physical

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appearance, changes in speech, hearing and sight problems and the acquisition of secondary diseases emerged from the data and were not part of the model's constructs.

Secondly, the social well-being of adolescents receiving cancer treatment represents the social well-being domain of the model. Caregiver burden, financial burden and changes in sexual function corroborates with the constructs in the model whilst support, absenteeism from school and church and social isolation were from the data but outside the model. Financial burden was captured under caregiver burden.

Thirdly, the psychological well-being of adolescents receiving cancer treatment represents the domain of psychological well-being of the model. It was found that fear, cognition/attention and anxiety were congruent with the model's constructs. However, anxiety was captured with sadness and worry whilst cognition/attention were captured together with learning. Happiness as found in the model was captured under mood disturbances. Distress of taking medication/undergoing treatment and distress of frequent hospital visits/prolonged hospitalisation were other factors mentioned by the participants in this study.

The spiritual well-being of adolescents receiving cancer treatment represents the spiritual well-being domain in the model. The meaning of illness, hope and religiosity were consistent with the model whilst denial, concealing disease and acceptance were coping mechanisms identified in the study but not found in the model. Inner strength found in the model was captured together with acceptance which was not part of the model's constructs but emerged from the data.

Lastly, the health service-related factors such as attitude of health personnel were factors reported by the adolescents.

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The findings showed that adolescents receiving cancer treatment experience a myriad of physical effects from cancer and the side effects of cancer treatment. These physical effects were found to have pronounced effects on their psychological well-being and social functioning. They however received support from family members, school and health care professionals which enabled them adapt or cope better with these changes. They were highly spiritual and employed many mechanisms to deal with the distressing effects of cancer. The adolescents in the study were prayed to God for healing and cure. They were hopeful of a future and long life to accomplish their future prospects.

The study also found out that some health personnel showed negative attitudes towards the adolescents. The adolescents were however comfortable with the hospital environment and were content and appreciative that they were given books to read whilst on admission which partly made up for the loss of knowledge caused by absenteeism from school.

Due to the age limits of adolescents which place them in between children and adults, managing the adolescent in either the adult department or the paediatric setting comes with its own problems. It is therefore suggested that a unique approach that is multidisciplinary in nature be employed in managing the adolescents with cancer. Also the government, non-governmental organisations and individuals should come to the aid of parents/caregivers in order to reduce the caregiver burden.

6.5 Recommendations

Based on the findings of this study, some recommendations were made to the Ministry of Health, Ghana Health Service, KBTH, KBTH's Paediatric Oncology Unit, adolescents, caregivers and the general public.

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Ministry of Health (MoH)

The MoH should:

- Train specialist oncology nurses and physicians to be able to provide effective care to the adolescent with cancer.
- Organise periodic in-service training for health care professionals to update their skills and knowledge in caring for the adolescent with cancer.
- Continuously educate the general public on the occurrence of cancer in the adolescent population, how to recognise signs and symptoms early and to report to the hospital for appropriate intervention.
- Appeal to the government for the inclusion of care and cost of adolescent cancer cases on the National Health Insurance Scheme.
- Appeal to the government to reduce import duties on cancer chemotherapy drugs into the country so as to reduce the cost on parents and caregivers.

Ghana Health Service (GHS)

The GHS should:

- Establish cancer centres in almost all the regions to facilitate care and treatment of oncology patients in order to reduce cost and burden on the adolescents and caregivers.
- Adopt a multi-disciplinary care approach in the care and management of adolescents receiving cancer treatment.
- Liaise with the Ministry of Education to include cancer education and screening into school health programmes.

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- Organise periodic in-service training for health care professionals on the early signs and management of adolescents with cancer.

KBTH (POU)

The Paediatric Oncology Unit should:

- Train and retain oncology health care professionals to provide effective care to the adolescents receiving cancer treatment.
- Organise periodic in-service training for health care professionals on the patient charter and effective communication with the patients.
- Educate patients and their caregivers on their conditions and side effects of treatment.
- Solicit for more funds from non-governmental organisations and individuals to assist with the care and cost of adolescents with cancer.
- Liaise with the hospital administration to get more teachers to teach adolescents on admission.
- Liaise with Non-Governmental Organisations and resourceful individuals to train parents and caregivers on skills and entrepreneurship that will serve as alternate sources of income to them.

Families of Adolescents with cancer

- Families of adolescents with cancer should provide all the needed support to the adolescents.

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Schools with adolescents with cancer

- Authorities, teachers and classmates of adolescents with cancer should provide emotional, psychological and physical support to these adolescents.
- Classmates and school children should be educated to show compassion to their colleagues with cancer instead of teasing or shunning their company.

General Public

The general public should show acceptance to adolescents with cancer and their families and desist from ostracising and stigmatising them.

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APPENDICES

Appendix A: Background Information Form/Demographic Data

Code Number.....

1. Age (years).....
2. Sex.....
3. Place of residence.....
4. Nationality
5. Religion.....
6. Tribe.....
7. Relationship to guardian.....
8. Educational level.....
9. Number of siblings.....
10. Mother's occupation.....
11. Father's occupation.....
12. Type of cancer.....
13. Duration of treatment
14. Type (s) of cancer treatment



1

Appendix B: Interview guide

1. Can you share with me your experiences while receiving cancer treatment?
2. Tell me how these experiences changed your life?
3. What are the physical experiences you go through as you receive cancer treatment?

- Probes:

Activities of daily living

Dyspnea/ breathlessness

Fatigue

Sleep/rest

Nausea

Appetite

Constipation/diarrhea

Pain

4. How has your spiritual life influenced your cancer treatment?

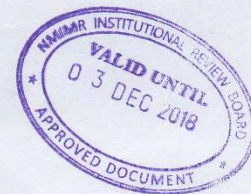
- Probes

Hope

Meaning of illness

Inner strength

5. What social problems do you face during this period of your cancer treatment?



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

- Probes
 - Financial burden
 - Caregiver burden
 - Roles and relationships
 - Affection/sexual function

6. What makes each of these a problem?


7. What are the psychological problems you encounter during the period of receiving cancer treatment?

- Probes
 - Anxiety
 - Depression
 - Enjoyment/leisure
 - Pain distress
 - Happiness
 - Fear
 - Learning difficulties

8. Are there any other experiences? Please tell me about them.

9. Can you share with me your thoughts about the following treatment processes?

- Probe
 - Laboratory investigations

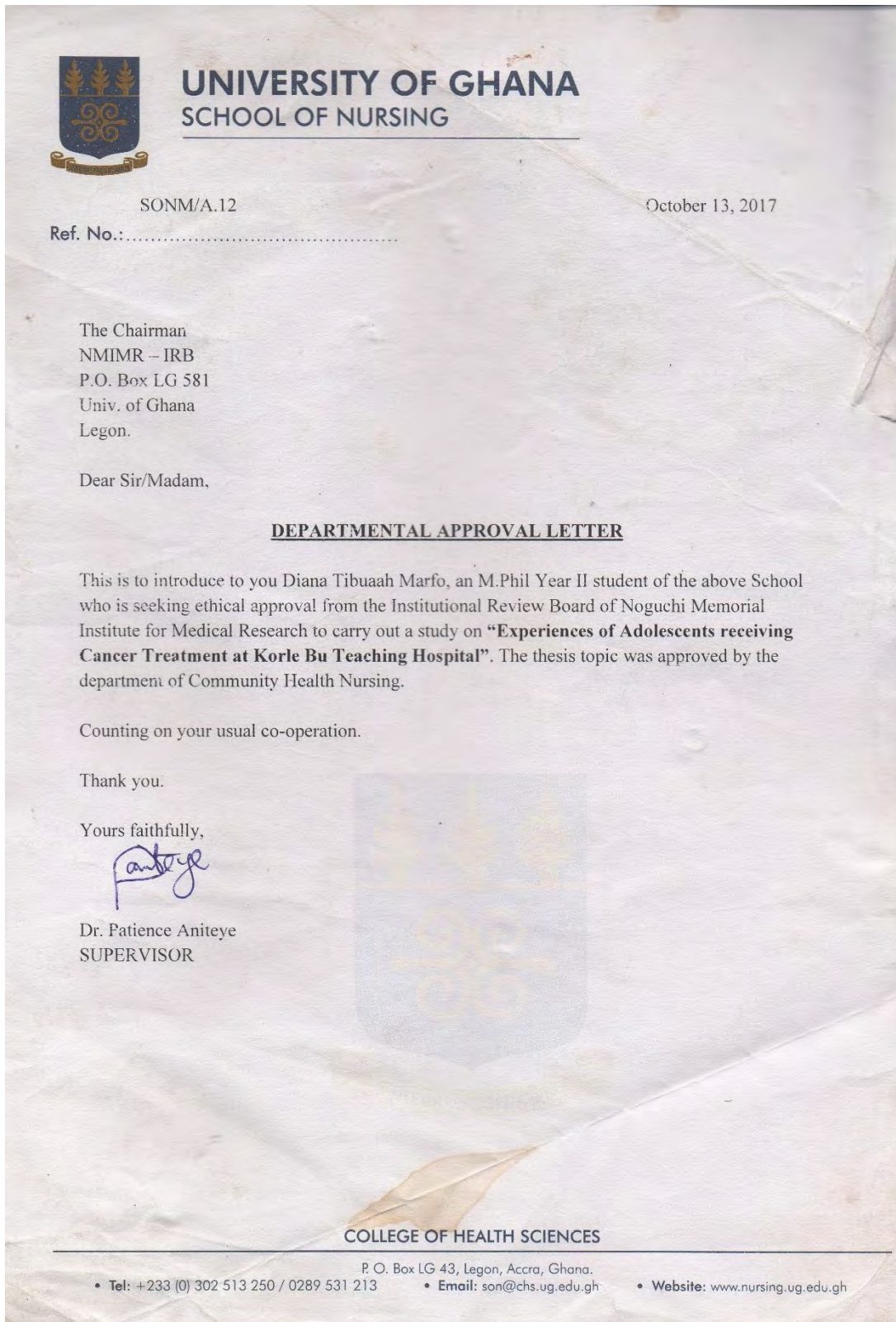


3

- Medications
- Frequent hospital visits
- Prolonged hospitalization

10. Is there any other thing you would like to share with me?


Appendix C: Introductory letter



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

In case of reply the number
And the date of this
Letter should be quoted

My Ref. No. KBTH/MD/G3/118
Your Ref. No.



KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

20th February, 2018

DIANA TIBUAH MARFO
DEPT. OF COMMUNITY HEALTH
SCHOOL OF NURSING, COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA, LEGON

**“EXPERIENCES OF ADOLESCENTS RECEIVING CANCER TREATMENT AT THE
KORLE BU TEACHING HOSPITAL”**

KBTH – IRB /00096/2017

Investigator: Diana Tibuaah Marfo

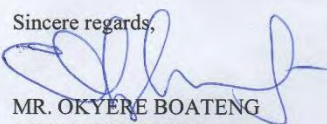
On 20th February, 2018, the Korle-Bu Teaching Hospital Institutional Review Board (KBTH-IRB) reviewed and granted approval to the study entitled **“Experiences of adolescents receiving cancer treatment at Korle Bu Teaching Hospital”**

Please note that the Board requires you to submit a final review report on completion of this study to the KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from KBTH-IRB renders this certificate invalid.

Please report all serious adverse events related to this study to KBTH-IRB within seven days verbally and fourteen days in writing.

This IRB approval is valid till 31st December, 2018. You are to submit annual report for continuing review.

Sincere regards,

MR. OKYERE BOATENG
CHAIR (KBTH-IRB)

Cc: The Chief Executive Officer
Korle Bu Teaching Hospital

The Director of Medical Affairs
Korle Bu Teaching Hospital

Appendix E: Consent Forms

Parental Consent Form

PARENTAL CONSENT FORM

Title: Experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital

Principal Investigator: Diana Tibuaah Marfo

Address: School of Nursing and Midwifery
University of Ghana
Post office box LG 43
Legon, Accra


General Information about Research

I am conducting a research study entitled *Experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital*. I am trying to learn more about *the experiences adolescents go through in the course of receiving cancer treatment at the Korle-bu Teaching Hospital*.

I will have a conversation with you and your child in either "Twi" or English on the things he / she has gone through while receiving cancer treatment. The conversation would be recorded with an audio recorder. During the interview, your child is free to say anything he/she wants to say. There are no right or wrong answers. On the other hand, he/she is also free not to speak or answer any question if he/she feel like doing so. The interview will be conducted at a place you or your child chooses. A second interview may take place if necessary. The interview will last between forty-five to ninety minutes. However, you and your child would be contacted if there is the need to seek further clarification into anything that was said during the interview. A second interview may be scheduled if necessary.

Possible Risks and Discomforts

There are no risks or discomforts that the study will have on your child. However, he/she may remember painful and unpleasant things that he/she might have gone through during the treatment



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Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

period. If such a thing becomes too much for you or your child to bear, a professional would be given to take care of you and or your child at no financial cost to you.

Possible Benefits

The study would help us to know the things your child goes through as a result of receiving cancer treatment. These things if identified, would help the hospital plan care that will meet the special needs of your child. It will also help the government so that when they are making decisions, adolescents receiving cancer treatment would be included. Other people can also use the information if they want to do their research.

Confidentiality

I will protect information about your child to the best of my ability. No one will be able to know what your child said. Also, the information will not bear your child's name. The information sheet, tape recorder and other documents would be kept under lock and key in my bedroom so that nobody can have access to them. Also, I will put a password on my computer so that even in my absence, nobody can take it and see what is on it. However, some Nurses, Doctors, Clinical Psychologists, Social workers, pharmacists and radio-oncologists may look at your child's research report.

Compensation

You and your child would be given snacks at the end of the interview.



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

Voluntary Participation and Right to Leave the Research

This research is voluntary and therefore, you or your child may decide not to take part. Even if you decide that your child should take part but your child says no, the research would not be carried out. The same applies if you agree but your child does not. You and or your child can decide to withdraw from the research at any time.

Contacts for Additional Information

If you need any information about the study you can contact

Dr. Patience Aniteye (Research supervisor) on 0244 681 352

You can also contact

Major Alphonsus Tenteh (clinical psychologist) on 0277836001 if you experience any emotional or psychological harm from the study.

Your Child's Rights as a Participant

This research has been reviewed and approved by the Noguchi Memorial Institute for Medical Research Institutional Review Board (NMIMR-IRB). If you have any questions about your child's rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh



Child Assent Form

CHILD ASSENT FORM

Introduction

My name is *Diana Tibuaah Marfo* and I am from *School of Nursing and Midwifery, University of Ghana*. I am conducting a research study entitled *Experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital*. I am asking you to take part in this research study because I am trying to learn more about *the experiences adolescents go through in the course of receiving cancer treatment at the Korle-bu Teaching Hospital*. This will take between forty-five to ninety minutes. But you can be contacted later if there is the need for you to explain further anything you said during the interview.

General Information

If you agree to be in this study, you will be asked to fill a background information sheet about yourself.

I will have a conversation with you in either "Twi" or English on the things you have gone through while receiving cancer treatment. The conversation would be recorded with an audio recorder. You will be required to thumb print or sign a form which will show that you have agreed to take part in the research. During the interview, you are free to say anything you want to say. There are no right or wrong answers. You are also free to cry or laugh if you feel like doing so. On the other hand, you are also free not to speak or answer any question if you feel like doing so. The interview will be conducted at a place you want. A second interview may take place if necessary. The conversation will be about the things you have gone through since you started cancer treatment.

Possible benefits

Your participation in the study may not benefit you at the moment. However, it would help to understand what adolescents go through during cancer treatment. This will help the health care management team to plan care that is specific to the needs of adolescents with cancer. It will also help the government to formulate policies that would benefit adolescents receiving cancer treatment.

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Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

Possible Risks and Discomforts

However, the risks associated are that you may remember painful and unpleasant experiences that you might have gone through during the process of receiving treatment. If these become more than you can cope, you would be referred to a clinical psychologist at no financial cost.

Voluntary Participation and Right to Leave the Research

You can stop participating at any time if you feel uncomfortable. No one will be angry with you if you do not want to participate. You can also ask for the interview to be discontinued and continue on another day if you want to.

Confidentiality

We would keep your information confidential to the best of our ability. No one will be able to know how you responded to the questions and your information will not bear your name. The information sheet, tape recorder and other documents would be kept under lock and key in my bedroom so that nobody can have access to them. Also, I will put a password on my computer so that even in my absence, nobody can take it and see what is on it. However, some Nurses, Doctors, Clinical Psychologists, Social workers, pharmacists and radio-oncologists may look at the report. **The information would be kept for at least five years after which they would be destroyed.**

Contacts for Additional Information

You may ask me any question about this study. You can call me at any time on 0548774269 or talk to me the next time you see me.



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

Please talk about this study with your parents before you decide whether or not to participate. I will also ask permission from your parents before you are enrolled into the study. Even if your parents say “yes” you can still decide not to participate.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

VOLUNTARY AGREEMENT

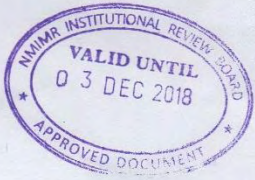
By making a mark or thumb printing below, it means that you understand and know the issues concerning this research study. If you do not want to participate in this study, please do not sign this assent form. You and your parents will be given a copy of this form after you have signed it.

This assent form which describes the benefits, risks and procedures for the research titled "*Experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital*" has been read and or explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate.

Child's Name:..... Researcher's Name.....

Child's Mark/Thumbprint..... Researcher's signature.....

Date..... Date:



4

Consent form

CONSENT FORM

Title: Experiences of adolescents receiving cancer treatment at the Korle-Bu Teaching Hospital

Principal Investigator: Diana Tibuaah Marfo

Address: School of Nursing and Midwifery
University of Ghana
Post Office Box LG 43
Legon

General Information about Research


I am conducting a research study entitled *Experiences of adolescents receiving cancer treatment at the Korle-bu Teaching Hospital*. I am trying to learn more about *the experiences adolescents go through in the course of receiving cancer treatment at the Korle-bu Teaching Hospital*.

If you agree to be in this study, you will be asked to fill a background information sheet about yourself

I will have a conversation with you and you in either "Twi" or English on the things you have gone through while receiving cancer treatment. The conversation would be recorded with an audio recorder.

You will be required to thumb print or sign a form which will show that you have agreed to take part in the research. During the interview, you are free to say anything you want to say. There are no right or wrong answers. You are also free to cry or laugh if you feel like doing so. On the other hand, you are also free not to speak or answer any question if you don't feel like doing so. The interview will be conducted at a place you want. A second interview may take place if necessary. The conversation will be about the things you have gone through since you started cancer treatment.

1



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

Possible Risks and Discomforts

However, the risks associated are that you may remember painful and unpleasant experiences that you might have gone through during the process of receiving treatment. If these become more than you can cope, you would be referred to a clinical psychologist at no financial cost.

Possible Benefits

Your participation in the study may not benefit you at the moment. However, it would help to understand what adolescents go through during cancer treatment. This will help the health care management team to plan care that is specific to the needs of adolescents with cancer. It will also help the government to formulate policies that would benefit adolescents receiving cancer treatment.

Confidentiality

We will protect information about you to the best of our ability. Your information will be kept confidential. No one will be able to know how you responded to the questions and your information will not bear your name. You will also not be named in any reports. Some health workers may sometimes look at your research records.

Compensation

You will be provided with snacks at the end of the interview.

Voluntary Participation and Right to Leave the Research

You can stop participating at any time if you feel like doing so. No one will be angry with you if you do not want to participate.



Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

Contacts for Additional Information

If you need any information about the study you can contact

Dr. Patience Aniteye (Research supervisor) on 0244 681 352

You can also contact

Major Alphonsus Tenteh (clinical psychologist) on 0277836001 if you experience any emotional or psychological harm from the study.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh



*Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital***Appendix F: Demographic data on participants**

Number/ Pseudony ms	Age	Sex	Place of residence	National ity	Religion	Tribe	Relationshi p to guardians	Educatio nal level	Num ber of siblin gs	Mother's occupatio n	Father's occupatio n	Type of cancer	Duratio n of treatme nt	Type(s) of cancer treatment
001 Naa	14	M	La palm wine, GA/R	Ghanaia n	Christian ity	Ewe	Mother	JHS2	one	Trader	Sales personnel	Osteosar coma	2-3 years	Chemother apy, surgery
002 Nab	14	F	Accra Newtown, GA/R	Ghanaia n	Christian ity	Akuap im	Mother	JHS2	five	Petty trader	Filling station attendant	ALL	1-2 years	chemother apy
003 Nac	13	F	Nii Ayi, GA/R	Ghanaia n	Christian ity	Ashant i	Mother/fat her	Primary 6	Two	Trader	Driver	Ovarian Carcino ma	1-2 years	Surgery, Chemother apy
004 Nad	13	F	Cape	Ghanaia	Christian	Fante	Mother	JHS2	Two	Seamstre	Upholster	ALL	2-3	Chemother

Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

			Coast,	n	ity					ss	y worker		years	apy
			C/R											
005 Nae	13	F	Lapaz,	Ghanaia	Christian	Ewe	Mother	Primary	Two	Caterer	Farmer	ALL	2-3	Chemother
			GA/R	n	ity			4					years	apy
006 Naf	15	M	Nsawam,	Ghanaia	Christian	Fante	Mother	SHS 1	Three	Seamstre	Building	ALL	2-3	Chemother
			E/R	n	ity					ss	contractor		years	apy
007 Nag	17	M	Akwatia,	Ghanaia	Christian	Akuap	Mother	JHS3	One	Caterer	unknown	Nasopha	2-3	Chemother
			E/R	n	ity	im						ryngeal	years	apy,
												Carcino		Radiothera
												ma		py
008 Nah	14	F	Ashaiman	Ghanaia	Christian	Hausa	Mother	SHS 2	Three	Fashion	Accounta	Adrenal	6months	Chemother
			, GA/R	n	ity					designer	nt	tumour	-1 year	apy,
														Surgery
008 Nai	13	M	Tesano,	Ghanaia	Christian	Ashant	Mother/Fat	Primary	Two	unemplo	Building	ALL	6months	Chemother
			GA/R	n	ity	i	her	6		yed	contractor		-1 years	apy

Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

010 Naj	18	M	Tema Newtown, GA/R	Ghanaia n	Christian ity	Fante	Mother	SHS3	Two	Petty trader	Unemploy ed	ALL	2-3 years	Chemother apy,
011 Nak	13	F	Mamprobi , GA/R	Ghanaia n	Christian ity	Ga	Mother	Not in school	Two	Petty trader	Carpenter	ALL	2-3 years	chemother apy
012 Nal	13	F	Teiman, GA/R	Ghanaia n	Christian ity	Fante	Mother	Not in school	Three	Unemplo yed	Artisan	ALL	2-3 years	Chemother apy
013 Nam	15	F	Kwahu, E/R	Ghanaia n	Christian ity	Akuap im	Mother	SHS1	Four	Trade	Accounta nt	Renal Tumour	6 months- 1 year	Chemother apy, surgery
014 Nan	17	F	Westland, GA/R	Ghanaia n	Christian ity	Ashant i	Brother	SHS2	Five	Trader	Driver	ALL	1-2 years	Chemother apy

Appendix G: Themes, meaning and abbreviations

THEMES AND SUB-THEMES	MEANING	ABBREVAITION
<p>Physical well-being</p> <ul style="list-style-type: none"> • GIT symptoms • Pain • Functional ability • Appearance changes • Fatigue/strength • Secondary diseases 	<p>The ability to gain control over signs and symptoms and to achieve a level of independence.</p>	<p>PW-B</p> <p><i>Git</i></p> <p><i>Pai</i></p> <p><i>Fta</i></p> <p><i>Apc</i></p> <p><i>Ft/s</i></p> <p><i>Sds</i></p>
<p>Social well-being</p> <ul style="list-style-type: none"> • Sexual function • Support • Effects on socialisation • Parents/caregiver burden 	<p>The ability of the individual to enjoy the company of or relate to family, friends or significant others or to partake in leisure and social activities as one experiences cancer treatment and its side effects.</p>	<p>SW-B</p> <p><i>Sup</i></p> <p><i>Eos</i></p> <p><i>P/cb</i></p>
<p>Psychological well-being</p> <ul style="list-style-type: none"> • Worry/Anxiety/Sadness • Distress of taking medication/undergoing treatment 	<p>A state of joy and ability to gain a sense of control in relation to fears, anxiety,</p>	<p>PW-B</p> <p><i>W/a/s</i></p> <p><i>Dtm</i></p> <p><i>Dhs</i></p>

Experiences of adolescents receiving cancer treatment at Korle-Bu Teaching Hospital

<ul style="list-style-type: none"> • Distress of frequent hospital visits/long hospital stays • Affective/mood changes • Learning/Attention/Cognition • Sensory changes • Fear 	<p>emotions and death as one experiences cancer treatment and its side effects.</p>	<p><i>A/mc</i> <i>L/a/c</i> <i>Sch</i> <i>Fer</i></p>
<p>Spiritual well-being</p> <ul style="list-style-type: none"> • Meaning of illness • Denial • Concealing disease • Acceptance/ inner strength • Hope • Religiosity 	<p>A sense of inner peace with oneself and relation with one's object of worship as one experiences cancer treatment and its side effects.</p>	<p><i>SW-B</i> <i>Moi</i> <i>Dnl</i> <i>Cds</i> <i>A/is</i> <i>Hop</i> <i>Rel</i></p>
<p>Health service-related factors</p> <ul style="list-style-type: none"> • Attitude of health personnel • Quality 	<p>Any factor in the health care institution or setting that affects the experiences and well-being of the adolescent receiving treatment</p>	<p><i>Hsf</i> <i>Ahp</i> <i>Qlt</i></p>