

PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS DIAGNOSED WITH  
CANCER IN WINDHOEK

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## **ABSTRACT**

This research study aimed at exploring and describing psychosocial experiences of adolescents diagnosed with cancer. A cancer diagnosis is known to be a life-altering experience which disrupts normal development. Often, adolescents bring to the cancer experience a different dimension of psychosocial circumstances because of their developmental life stage.

This research study employed an exploratory qualitative research design to explore the psychosocial effects of a cancer diagnosis during adolescence. Nine adolescents with cancer were identified through purposive sampling. Adolescents were between the ages of 13 to 19 years, were undergoing cancer treatment and were not critically ill. A semi-structured interview guide was used. It consisted of socio-demographic questions, psychological, social and self-assessing questions. Tesch's coding steps was used to analyze the data to identify and describe the themes and subthemes.

The phenomenological approach was used to describe the experiences of the adolescents living with cancer in Windhoek. The results show that participants reacted differently towards their diagnosis. Feelings of extreme sadness and relentless fear were observed. The adolescents also experienced good peer relations which allowed them to have good support and helped them with adjusting to the illness. Another theme that emerged was the perception of the adolescents on how they view themselves as well as dealing with a changing body image. The findings of this study may allow mental health professionals to create tailored interventions that cater for the needs of adolescents with cancer. Furthermore, this study may pave the way for health care providers to understand and equip adolescents with information regarding their developmental stage and health.

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## **LIST OF ABBREVIATIONS**

CAN	Cancer Association of Namibia
IARC	International Agency for Research on Cancer
MoHSS	Ministry of Health and Social Services
NCI	National Cancer Institute
NNCR	Namibian National Cancer Registry
WHO	World Health Organisation

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## **DEDICATION**

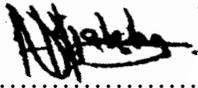
*“To every Namibian Child-the future belongs to you.”*

## DECLARATIONS

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.....  
Hambeleleni Nashikale Ndjaleka

MARCH 2018

.....  
Date

# CHAPTER ONE

## MOTIVATION AND ORIENTATION OF STUDY

### 1.1 Introduction

This research study aimed at exploring and describing psychosocial experiences of adolescents diagnosed with cancer. For this research study, the term adolescent refers to children between the ages of 10 to 19 years who are diagnosed with cancer. The diagnosis of cancer can be a life-altering experience for anyone diagnosed with the illness as well as their families (Ward, Desantis, Robbins, Kohler, & Jemal, 2014). A cancer diagnosis during adolescence is known to disrupt normal adolescent development. It is during this stage that adolescents preoccupy themselves with their body image, establishing their identity, making decisions about their future in terms of relationships and careers, trying to find independence and give in to peer gatherings (Muuss, 1996; Santrock, 2011; Zebrack, 2011).

Griggs and Walker (2016) noted that adolescents with a chronic illness involving physical symptoms such as pain (often experienced by cancer patients) fluctuate between hope and despair, which may disrupt their lives and thus cause high levels of stress and increase dependence on their caregivers. Hatherill (2007) found that adolescents with a chronic illness experience difficulties with coping with their illness which impacts development, quality of life, treatment adherence and mortality.

It is with this background that findings from this research study may spark further interest in research on adolescents living with cancer and may also contribute to a creation of a

tailor-made intervention that would help to provide psychosocial care for adolescents in Namibia. Furthermore, a better understanding of the development of an adolescent could place healthcare providers, families and peers in a better position to empower the adolescent to cope during their illness.

## **1.2 Orientation of the study**

The research study is embedded within the field of psycho-oncology. The formal beginnings of psycho-oncology started in the mid-1970s when the word '*cancer*' was often associated with stigmatization (Holland, 2002). Psycho-oncology then made provisions for patients diagnosed with cancer to talk about the diagnosis and reveal their feelings about their illness and explanations thereof (Holland, 2002). Psycho-oncology deals with the psychological reactions of patients and families to cancer and its treatment, as well as the psychological and behavioural factors that influence cancer risk and survival (Dolbeault, Szporn & Holland, 1999; Van Oers & Schlebusch, 2013). Holland (2002) reported that the late development of interest in the psychological dimension of cancer, negative attitudes attached to mental illness and psychological problems have contributed to the stigmatisation of cancer. Studies across the world began exploring issues on psycho-oncology, and created programmes that would cater for the psychosocial needs of cancer patients (Dolbeault et al. 1999).

According to the International Agency for Research on Cancer (IARC) (2012), GLOBOCAN reports that cancer is the second leading cause of death in developed countries and third cause of death in developing countries. According to IARC (2012) there are approximately 32.6 million people living with cancer worldwide of which about

715 000 are new cases reported in Africa. Furthermore, it is estimated that by the year 2020, there will be over 16 million new cancer cases, of which over 60 percent is predicted to be in developing countries as reported by the World Health Organisation (WHO, 2015).

However, Ward et al., (2014) reported the annual incidence rate of cancer in children and adolescents to be at 186.6 per 1 million children ages zero to 19 years in 2014. They further noted that approximately 1 in 285 children will be diagnosed with cancer before the age of 20 in the United States of America. Despite the figures, adolescents still appear to be an understudied population (Juth, Silver & Sender, 2015).

It appears that the availability of epidemiological data on the prevalence of cancer in Africa may be limited as stated in the Cancer Association of Namibia [CAN], 2011; Kruger et al. 2014 and Ward et al. 2011. Thus the reported incidence rates from African registries may present below the actual figures. CAN (2011) reported an increasing prevalence of cancer in Namibia. CAN (2011) further explained that the number of cancer cases reported by the Namibian National Cancer Registry (NNCR) which operates under the CAN during the measurement period 2006-2009 doubled compared to the previous measurement period of 2000-2005. However, a decline compared to the measurement period 1995-1998 could be seen. During the period of 2006-2009, CAN (2011) reported approximately 6 300 cases of cancer (malignant neoplasm), of which about 48 cases were in children below the age of 15.

Cancer is reputable for being regarded as a fatal condition (Lekhuleni & Mathiba, 2013; Syrjala, Jensen, Mendoza, Yi, Fisher & Keefe, 2014). Being diagnosed with cancer has the potential to burden people in all spheres of their lives. Zebrack (2011) noted that

widespread instabilities may be caused by cancer and these vary by the age-related life stages of the individual. To add, he explained the psychosocial adjustment depends on the ability of cancer patients to deal with the effects of this life disturbances on a daily basis.

The diagnosis of cancer in children and adolescents may be encountered as a life-altering event for them as well as their families (Ward et al. 2014). Despite having to go through the prominent physical and emotional developmental transition during the adolescence phase, they are often forced to face and live with this medical condition simultaneously. It is against this background that the proposed study aims to explore and describe the psychosocial effects of a cancer diagnosis during adolescence.

### **1.3 Statement of the problem**

Adolescents bring to the cancer experience a different dimension of psychosocial circumstances (Eiser, Hill & Vance, 2000). Juth et al. (2015) noted that in addition to illness-related stressors which are typically experienced by cancer patients, adolescents are simultaneously faced with rapid social, biological and cognitive changes because of the developmental life stage (Zebrack, 2011). During the critical developmental transition from childhood to adulthood, adolescents and young adults in particular have been thought to experience typical concerns such as establishing identity, developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating and beginning to make decisions about careers or employment, higher education and family (Phillips, 2014; Santrock, 2011; Zebrack 2011).

Research studies on cancer among adolescents have been carried out worldwide (i.e. Flavelle, 2011; Griggs & Walker, 2016; Hatherill, 2007; and others). However, it appears

as if there are no studies on the psychosocial experiences of children and adolescents carried out in Africa and that necessitates this research. The studies carried out in other contexts may be useful to the African context however, a study focusing on the adolescents in Namibia good be useful to understand the unique nature of how adolescents experience the illness.

Shino (2010) carried out a comparative study among Oshiwambo-speaking and Sesotho-speaking women living with breast and/or cervical cancer in Namibia and South Africa, respectively. Tjiroze (2013) conducted a study which explored the relationship between distress and coping styles of informal caregivers of cancer patients in Namibia. There are, however, no studies focusing on children and adolescents in Namibia and therefore, a knowledge gap exists in this area.

Thus, being diagnosed with a life-altering illness such as cancer may interfere with this transition and adolescents may be impacted developmentally. The purpose of this study is therefore to explore and describe the psychosocial experiences of adolescents living with cancer in Windhoek.

#### **1.4 Research questions**

The global aim of this research study is to explore the psychosocial experiences of adolescents diagnosed with cancer.

This study is guided by the following research questions:

- i. What are the psychological effects of being diagnosed with cancer during adolescence?
- ii. What are the social experiences of adolescents living with cancer?
- iii. How does living with cancer impact the adolescents' sense of self?

#### **1.5 Significance of the study**

The proposed study will expand literature on psycho-oncology in Africa and especially in Namibia. This study intends to study adolescents because of the minimal recognition of the threats to development of adolescents and that of their psychosocial needs. An in-depth understanding of adolescents dealing with cancer will also allow critical thinkers and researchers to understand the impact that cancer may have on adolescents and possibly spark curiosity fuelling future research in this understudied population in Africa. This study may also allow those caring for, living with and rendering services to adolescents living with cancer to understand the inner feelings of adolescents when confronted with a possible terminal illness. The findings of this study will also enable mental health professionals to make practical clinical decisions and plan interventions tailored to the needs of this special population. Furthermore, the study also hopes to inform, support

and/or challenge policy and actions directed to addressing the psychosocial needs of adolescents and children with a terminal illness.

## **1.6 Definition of key concepts**

### **1.6.1 Psychosocial experiences**

Psychosocial impact is defined as the effect caused by environmental or biological factors on the individual's social or psychological aspects (Vizzotto, de Oliveira, Elkins, Cordeiro, & Buchain, 2013). It relates to the combination of psychological and social behaviour. Psychosocial experiences will be attributed to how the individual is impacted by cancer in their social lives as well as psychological (feelings, thoughts and emotions).

### **1.6.2 Adolescence**

WHO (2016) defined adolescence as a period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19 years. Adolescence is defined as a period of transition “between childhood and adulthood that prepares the young person for occupation, marriage, and mature social roles” (Muuss, 1996, p. 366). Muuss (1996) further stated that adolescence is often defined according to social roles, expectations; level of maturity and the ability to function independently and not according to age per se (Santrock, 2011).

### **1.6.3 Cancer**

Cancer is defined as a rapid creation of abnormal cells that grow beyond their usual boundaries (WHO, 2015). The abnormal process of development can lead to the accumulation of cancer cells which leads to the formation of tumors, if the propagation of

cancer cells continues unchecked, it could spread through the body and metastasize to form tumors, the spreading of abnormal cells could hinder body organs from functioning optimally which may cause fatal results.

#### **1.6.4 Sense of self**

A sense of self is defined as how one perceives oneself (Woodgate, 2005). It was further defined as a way one thinks about and views their traits, beliefs and the purpose within the world, noted Blatt and Zuroff (1992) and Peck (1986). It is a term used in psychology that makes up a person self-esteem and self-image. It entails having an understanding of how we see ourselves and our positions in the world.

#### **1.7 Overview of the chapters**

Above is the motivation and orientation of the research study. Following is chapter Two which will focus on the psychosocial aspects of a cancer diagnosis during adolescence. The prevalence of cancer among children and adolescents with the common types of cancers will be presented. This will be followed by a brief discussion on the common symptoms of cancer. Thereafter, the psychosocial experiences of adolescents will be explored, followed by an outline of identified coping strategies.

Chapter Three outlines the research methods and procedures employed by the researcher, which includes the research design, participant's selection, data gathering techniques and the methods of data analysis. Chapter Four outlines the results and discussions of the data analysis.

Chapter Five focuses on the relevant conclusions. The limitations of the study and recommendations are also outlined in the final chapter.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

A cancer diagnosis can be a disruptive and stressful event. According to human development theories, cancer patients experience similar set of life disruptions. But depending on the stage of development when the diagnosis is made, cancer patients will experience the illness differently. They will focus on different aspects and would each attach different levels of importance to these aspects (Zebrack 2011).

Adolescence is a stage of human development at which one is undergoing multiple changes such as physical, cognitive and social-emotional/psychological changes. It is a period which heightens awareness about oneself and one begins to differentiate from others. Adolescents are preoccupied with establishing their identity, finding independence from their parents, increasing involvement with peers, dating and making decisions about careers and higher education (Muuss, 1996; Santrock, 2011; Zebrack, 2011).

Being diagnosed with a chronic illness such as cancer during the adolescence stage affects the individual and their families. Adolescents have to deal with the changes being caused by development as well as those being caused by the illness and coping with the illness. Thus, a cancer diagnosis which may mean heightened awareness of mortality, changes in physical appearance, disruptions in social lives, loss of reproductive capacity and other health-related concerns, may be distressing for the adolescent (Zebrack, 2011). In addition, adolescents with a chronic illness have been found to have difficulties coping

with their illness, which may have an impact on their development, quality of life, treatment adherence and mortality (Hatherill, 2007).

In this chapter, an outline of the adolescence phase will be provided to illustrate a broader understanding of the physical, cognitive and social-emotional/psychological development of the adolescent as staged in literature. Next, a presentation on the prevalence of paediatric and adolescent cancers as well as an outline of the common types of adolescent cancers will be provided. This presentation will offer a foundation for understanding the adolescent and the common cancers diagnosed during this stage. Thereafter, a presentation of the common psychosocial aspects of cancer on older patients will be outlined. Lastly, a closer look at the psychosocial effects of cancer on adolescents and identified coping strategies according to literature reviewed will be explored.

## **2.2 Development of the adolescent**

An adolescent is commonly known to be young men and women between the ages of 10 and 19 years (WHO, 2016). Different human developmental theories have extensively researched on the adolescent stage. It is during the adolescence stage that the body is undergoing rapid physical changes, accompanied by cognitive and psychological changes. These physical developments are commonly caused by the interaction of hormones which marks the onset of puberty (Shaffer, Kipp, Wood & Willoughby, 2010). Below is a brief discussion of the developments expected during the adolescence stage.

### **2.2.1 Physical developments**

The onset of puberty is characterized by the appearance of secondary sexual characteristics (Santrock, 2011; Shaffer et al. 2010). These characteristics usually begin during early adolescence between 11-13 years of age. It includes growing of body hair, increased perspiration and oil production in the hair and skin, tremendous physical growth (i.e. height and weight gain), growth of the testicles and penis for males and development of breast and hips for females (Santrock, 2011; Shaffer et al. 2010).

During middle (14-18 years) and late (19-21 years) adolescence, puberty may be completed but young men continue to experience physical growth. However, girls and boys may begin to develop a greater sexual interest which marks the onset of sexual role exploration.

### **2.2.2 Cognitive developments**

Simultaneously, the adolescent experiences cognitive development which includes a growing capacity for abstract thought, deeper moral thinking, thinking about the meaning of life and creates an ability to think about ideas thoroughly and showing interest and concern about the future (Santrock, 2011; Shaffer et al. 2010).

During early adolescence, the adolescent is mostly interested in the present time and they begin to expand their intellectual interests. They continue to show increased capacity for abstract thought and begin to set goals during middle adolescence. In late adolescence, they began to question and try to understand their inner experiences and their interest in moral reasoning continues (Muuss, 1996; Santrock, 2011; Shaffer et al. 2010).

### **2.2.3 Social-emotional/psychological developments**

The social-emotional/psychological development of the adolescent is important when studying the adolescent population (Eiser et al. 2000).

According to Muuss (1996) the onset of puberty ‘destabilizes’ the hormonal system of the adolescent. It is during the early adolescence phase that adolescents struggle with their sense of identity and begins to feel strange about their body because of the physical growth; they develop an interest in privacy and start to have a strong desire for independence. It is also characterized by an increased influence from their peers which may cause conflict with their parents and they begin to test rules and limits set by their parents.

During middle adolescence, adolescents continue to adjust to body changes and self-involvement intensifies. They begin to experience feelings of love and compassion and they are driven to make friends and rely on them greatly. In Erik Erikson’s psychosocial theory of development (1950), he identified the adolescence stage as the ‘identity vs role confusion’ stage (Muuss, 1996; Santrock, 2011). Erikson believed that the primary psychosocial task of adolescence would be the formation of identity. For one to effectively form an identity at the end of this period, the adolescent is expected to integrate their sense of self, what one wants to do and be, and identify an appropriate sex role (Bee, 1992; Hoare, 2002; Sokol, 2009). This may be achieved when the individual begins to acquire new found cognitive skills and physical abilities because of the onset of puberty. On the other hand, when the adolescent fails to achieve a sense of self it may lead to identity confusion according to Erikson’s Psychosocial stages of development as stated in Santrock (2011). Santrock (2011) and Sokol (2009) concur that an adolescent is likely to

experience self-doubt regarding the meaning and purpose of their existence, which may lead to a sense of confusion and subsequently “role confusion can lead to a very different human experience” (Sokol, 2009, p. 4).

In late adolescence, a firmer sense of identity is usually observed (Santrock, 2011). Adolescents are likely to experience increased emotional stability, independence and self-reliance. Peer relationships continue to remain important and their social and cultural traditions regain some importance.

These developments are expected to be experienced by all adolescents under normal circumstances. However, the onset and diagnosis of a chronic illness interrupts this development and thus the psychosocial care of adolescents diagnosed with cancer becomes important (Hendrick & Cobos, 2010). Having knowledge about the adolescence phase allows one to understand the effects that a cancer diagnosis may have on this unique development. Dashiff (2001) in an article on data collection with adolescents urged researchers to be mindful about the unique developmental stage of adolescents so as to not compromise the integrity of the study. To add, Eiser et al. (2000) assert that adolescents’ perception should be studied differently to fully grasp their particular experiences as they may be very different from those of younger children.

### **2.3 Prevalence of paediatric and adolescent cancers**

Cancer is regarded as a public health concern and is reported to be increasing worldwide (American Cancer Society, 2011; Siegel, Miller & Jemal, 2016). Firstly, it may be attributed to the growing and aging populations around the world which are at high risk of developing cancers and secondly, individuals are reported to be engaging in behaviours

and lifestyles that put them at risk for developing cancer (Toure, Bray, Siegel, Ferlay, Lortet-Tieulant & Jemal, 2015). This research study intends to study the population of paediatric cancers which are also on the rise among African countries with a particular interest in cancers affecting adolescents.

According to available reports (IARC, 2012; Siegel et al. 2016; Torre et al. 2015), there are approximately 32.6 million people living with cancer worldwide of which approximately 715 000 are new cases reported in Africa in 2012. Ward et al. (2014) estimated that 15 780 new cases of cancer will be reported in the United States of which approximately 1 960 may end up fatal among children and adolescents aged birth to nineteen (0-19) years in 2014. GLOBOCAN (2008) estimated that about 148 000 children (0-14) are living with cancer in Africa as stated in Kruger et al. (2014). These reports do however acknowledge that the limited availability of epidemiological data on the prevalence of cancer in African countries may account for figures below the actual numbers (Kruger et al. 2014; Ward et al. 2014).

According to Siegel et al. (2016) cancer is the second leading cause of death in the United States in children between ages one to fourteen years. They estimated that in 2016 10 380 children between ages one to fourteen will be diagnosed with cancer, and an estimated 1 250 will die from the disease. In the same article which provided the expected numbers of new cancer cases and deaths in 2016 in the United States, Siegel et al. (2016) stated that the type and distribution of cancers in older adolescents (15-19 years) differ slightly from those in children (0-14). CAN (2011) noted and concur that adolescents in Namibia also tend to develop a different set of cancers compared to adults or children.

In a publication by the American Cancer Society (2014), they reported that recent studies found that accelerated foetal growth and higher birth weight were associated with increased risk for some paediatric cancers such as acute lymphocytic leukemia, central nervous system tumors, Wilms' tumor, non-Hodgkin lymphoma and rhabdomyosarcoma. They further stated that lower birth weight has been associated with acute myeloid leukemia and some central nervous system tumor subtypes. Genetic factors were also attributed to some paediatric cancers such as Wilms tumor and retinoblastoma.

Siegel, Miller and Jemal (2016) further revealed that adolescents in the United States are most commonly diagnosed with brain and other nervous system cancers which account for 20% followed by leukemia (14%), Hodgkin lymphoma (13%), gonadal germ cell tumors (12%) and thyroid carcinoma (11%). However in Namibia, during the period of 2006-2009 a total number of 48 cancer cases were reported in children below the age of fifteen (CAN, 2011). The most commonly diagnosed cancer were Kaposi Sarcoma which accounted for 22.7%, followed by connective tissue cancers (20.5%), then Wilm's tumor and non-Hodgkin lymphoma (9.1%) and a single case of retinoblastoma (2.3%).

On the other hand, in a study by Stefan, Baadjies and Kruger (2014) focusing on the incidence of childhood cancer in Namibia between the years 2003-2010, they found that leukemia was the most frequently diagnosed cancer at 22.5% followed by retinoblastomas (16.2%), then Renal tumors, soft tissue sarcomas and lymphomas followed. They warned that the figures may be low because of the lack of a formal registry in Namibia.

## **2.4 Common effects of cancer among adolescents**

Cancer is reported to have effects on the physical body of its patients. Adolescents often experience common effects that are associated with being diagnosed with cancer. Daniel, Brumley and Schwartz (2013) carried out a study focusing on fatigue in adolescents with cancer compared to healthy adolescents. They found that adolescents with cancer and their caregivers reported more clinically significant fatigue compared to healthy adolescents. These significant fatigue subsequently lead to reporting of more symptoms of depression, lower quality of life and higher negative affect.

Richter et al. (2015) acknowledge that adolescents and young adults suffer from particularly high levels of distress during the different stages of cancer (diagnosis, treatment and survivorship).

Wallace, Harcourt, Rumsey and Foot (2007) looked at how adolescent females managed their appearance changes resulting from cancer treatment. They found that adolescents with cancer have significant concerns with their altered appearance which served a constant reminder of the 'difference' and of a present illness.

Different cancer treatments are known to affect adolescents' body image (Larouche & Chin-Peuckert, 2006). In a qualitative study by Larouche and Chin-Peuckert (2006) focusing on how adolescents with cancer experienced changes in their body image, they found that adolescents preoccupied themselves with the perception of their body image. However, looking at healthy adolescents this body image preoccupation is often known as the norm during this stage. But the physical changes in cancer patients due to treatment

often increase suffering and distress and cause interpretations to the body which hinders normal development.

## **2.5 Experiences of cancer patients**

There are studies that found diagnosis and adjusting to treatment to be the most emotionally distressing event (Hatherill, 2007; Lekhuleni & Mothiba, 2013; Portnoy, Girling & Fredman, 2016; Richter et al., 2016; Zebrack, 2011). This section is going to discuss how other cancer patients from different age groups and stages of life experience cancer as document by literature.

In a study by Lekhuleni and Mothiba (2013), they found that newly diagnosed cancer patients experienced problems such as challenging consultations processes, lack of resources in peripheral hospitals, experienced frustration and difficulties adjusting to new dietary patterns. Based on this study, they recommend that health care providers should help newly diagnosed patients by promoting good interpersonal relationships to alleviate suffering of the patients, and help with adjustment.

Chirico et al. (2015) found that there are various indicators of distress in patients early in the cancer diagnosis. Syrjala and colleagues (2014) in a study conducted to explore the psychological and behavioural approaches to pain management agree that evidence is convincing that emotional distress, depression, anxiety, uncertainty and hopelessness interact with pain which makes adjustment to treatment a painful process.

In a study by Ninu, Bulli, De Massimi, Muraca, Franchi and Saraceno (2015) patients reported significantly high levels of distress following a year of post-treatment in head and neck cancer patients. They also reported high levels of suffering related to sensory

problems, social eating, and dry mouth. These problems are commonly attributed to cancer treatment and they affect the patients' quality of life.

Shino (2010) carried out a study exploring and comparing different psychosocial aspects among breast and cervical cancer patients in Namibia and South Africa. She found that half of these patients reported to experience psychological distress. On the total, about 30% South African and 20% Namibian patients met the depression case criteria, and about a third scored above the Hospital Anxiety and Depression Scale anxiety cut-off. These results highlight the presence of psychological morbidity in breast and cervical cancer patients in southern Africa (Shino, 2010).

## **2.6 Psychosocial effects of cancer on adolescents**

Shino (2010) reported that research regarding the psychosocial effects of cancer is still in its early stages in the African continent but is gradually and consistently emerging. With the exception of some studies done in South Africa and Namibia (such as Lekhuleni & Mothiba, 2013; Shino, 2010; Tjiroze 2013), the psychosocial effects and distress associated with cancer in southern Africa have not been fully explored.

There is however, substantial literature in most parts of the developed world on how cancer affects adults and studies have been carried out to measure levels of psychological distress, quality of life, adjustment and coping styles of adults, levels of anxiety and other variables pertaining to the psychological dimension of cancer (e.g. Chirico et al. 2015; Shino, 2010; Syrjala et al. 2014) and coping strategies of caregivers and parents of children with cancer (Katz et al. 2013; Phillips, 2014; Tjiroze, 2013).

In an article by Evans et al. (2008), they acknowledge that adolescents and young adults with cancer face greater challenges compared to the normal population. They noted that depending on the stage of development of the adolescents or young adult and the stage of treatment, the prognosis of the disease may differ. They looked at different domains such as family factors, psychological/emotional factors and social factors.

Barrera and colleagues as stated in Evans et al. (2008) found that maternal adjustments and the child's temperament were best predictors of psychological adjustment to the new diagnosis in the family factors domain. Juth et al. (2015) also concur that young cancer patients and their caregivers experience illness-related posttraumatic stress symptoms which include repeated disturbing thoughts about the illness, avoidance of illness-related discussions and hyperarousal. This may be a further indication that adolescents and caregivers relationship factors would influence the progress of this illness in adolescents.

In the psychological/emotional factors domain, Evans et al. (2008) reported that age would be a risk or protective factor of the adolescents and young adults. Chirico et al. (2015) supports that age should be considered as a crucial precursor of patient's distress based mainly on deficits in knowledge. Chirico et al. (2015), Evans et al. (2008) and Richter et al. (2015) concur that higher cognitive ability associated with the development age may be a resource or hindrance of the prognosis as it leads to lack of confidence in coping efficacy and distress. Yet, Evans et al. (2008) reason that adolescents diagnosed in a later stage are likely to have perceived control such as a personal sense of control over the stressor when they are coping with the illness.

In the social factors domain, Evans et al. (2008) noted that these adolescents were most likely to feel anxious about fitting into social peers (Flavelle, 2011). After analysing a 15-

year-old boy's journal, who was living and dying from cancer, Flavelle (2011) found five themes that emerged from the analysis. These themes include issues with adolescent development, a need to escape from illness, a consideration of changing of relationships with peers and family, ongoing fighting off symptoms, and exploring and learning about spirituality these themes may have emerged because of the developmental stage (middle adolescence) that he was at during the time of his illness.

According to Larouche & Chin-Peuckert (2006), adolescents often adopted coping strategies that helped them deal and manage with their physical appearances and social interactions. The coping strategies identified included 'avoiding' social situations, 'maintaining normality' by using enhancers such as make-up and wigs, 'testing the waters' which included going back to familiar places after treatment to experience the reaction of society members and lastly 'peer-shielding' which they used friends to communicate with other groups of people.

Carlsson, Kihlgren and Sorlie (2008) carried out a study to illuminate fear in adolescents with personal experience of cancer. A major theme of embodied fear -a threat to the personal self-emerged. This theme was built up by three intertwined themes, which include: firstly, experiencing fear related to the body'. Adolescents in this study expressed fear when features of their body began to change due to treatment or surgery that caused alterations on the body.

Secondly, experiencing existential fear' which mainly included the perceived fear of the unknown, fear of losing control, fear of dying and fear of reoccurrence of the cancer. Adolescents experienced this fear when they mostly felt extreme discomforting pain or

when treatment had to be intensified. It caused uncertainty about the future and the fear of dying often became a strong thought.

Thirdly, adolescents experienced fear relating to the social self. These adolescents reported that they feared being different to others and being left out by friends. Carlsson et al. (2008) found that they alienated themselves and experienced a sense of isolation which was often brought by altered appearance relieving the presence of a life-altering illness.

In a review by Griggs and Walker (2016) looking at the role of hope for adolescents with a chronic illness, they observed that adolescents with a chronic illness fluctuate between hope and despair. They found that it may interrupt their lives, and may create an increased dependency on caregivers. They further noted that hope promotes health, facilitates coping and adjustment, enhances quality of life, hope is essential in finding a purpose in life and illness, it improves self-esteem and affects maturation (Griggs & Walker, 2016). These are important aspects of coping with a chronic illness and are vital during the development period of an adolescent to help them adhere to treatment and subsequently have a better quality of life.

## **2.7 Assessing the need for psychosocial services among adolescents**

With all the above mentioned studies carried out around the world on the aspect of psychosocial oncology especially in the United States, researchers are at the stage of identifying coping strategies and assessing the need for psychosocial support among adolescents and young adults with cancer (Hendrick & Cobos, 2010; Zebrack, 2011).

Zebrack et al. (2014) carried out a study to identify trajectories of clinical distress throughout the first year of a cancer diagnosis and to distinguish factors that predict the extent to which adolescents and young adults report distress. They found that about a quarter of adolescents and young adults reported clinically significant chronic distress throughout the first year while another quarter reported delayed distress. They found that it was attributed to needs for information, counselling and practical support remained unmet during the first year following a diagnosis.

Zebrack et al. (2014) also found that adolescents and young adults are not utilizing psychosocial support services especially those of mental health service providers. He noted that it is important for health care providers to identify psychologically distressed adolescents and young adults and refer them to appropriate counselling services.

In another study by Zebrack (2011), he warned that age-appropriate programs and services have the potential to minimize negative impacts and promote positive psychosocial adjustment. However, the availability of these services may prove challenging although they are emerging in some parts of the world.

Griggs and Walker (2016) suggested that health care providers should consider developmental stage and gender when planning interventions to foster hope as adolescents adapt to their experience of chronic illness.

Other psychological interventions such as narrative therapy have also been considered (Portnoy, Girling & Fredman, 2016) to help children adjust and cope with a cancer diagnosis.

Hendrick and Cobos (2009) recognized the provision of psychosocial care for patients with cancer. After a five year period, a counselling program was introduced at a community hospital and they found that patients utilized the counselling services more at the hospital during multidisciplinary consultations.

## **2.8 Summary**

This chapter has outlined the development of the adolescent to illustrate the growth and changes experienced during adolescence. A discussion on the prevalence of common cancers among adolescents has been highlighted to gain insight into the number of cancers among adolescents in Namibia. Common symptoms experienced by adolescents and typical experiences of cancer patients have been reviewed to gain understanding of cancer patients. Emphasis was placed on the psychosocial experiences of adolescents diagnosed with cancer around the world to gain insight on how they experience cancer. Lastly a brief discussion on the identified psychosocial care was explored.

# **CHAPTER THREE**

## **RESEARCH METHODOLOGY**

### **3.1 Introduction**

Chapter Two outlined the literature review. It gave an overview of the adolescence stage and how a cancer diagnosis affects the individual during the adolescence stage. The prevalence of common cancers among adolescents have been highlighted to gain insight into the cancers that are more prevalent during adolescence. An overview of the psychosocial effects of cancer on adolescents as well as their experiences was presented in the previous chapter.

Given this background, Chapter Three aims at providing a description of the philosophy and approach which informed this study. This chapter outlines the research methodology and research design employed. The sample and sampling frame are presented. This chapter also provides an overview of the data collection and data analysis techniques employed for the study. Additionally, ethical considerations are deliberated on.

Furthermore, the global aim of this research study is to explore the psychosocial experiences of adolescents diagnosed with cancer. This study was guided by the following questions:

- i) What are the psychological effects of being diagnosed with cancer during adolescence?
- ii) What are the social experiences of adolescents living with cancer?
- iii) How does living with cancer impact the adolescents' sense of self?

Given this background, below is a discussion on the research methodology the researcher employed to carry out the study.

### **3.2 Philosophical paradigm and approach**

This research study is guided by the constructivism philosophical paradigm. This paradigm aims to understand, deduce multiple participant meanings and works for studies that would be grounded in theory generation (Creswell 2014). This paradigm was specifically chosen because of the assumption that “individuals develop subjective meanings of their experiences ...” which is often a reaction towards objects or things (Creswell, 2014, p.8). The constructivism paradigm postulates that the researcher’s intent is to make sense of the participant’s understanding of the world or how they create meaning of the world. This philosophical paradigm postulates that people are active in their perceiving- of making sense of the world. Smith (2008) outlined how people search, pay attention, and make choices selectively according to the meaning they are making of their worlds. This approach particularly fits in with the researcher’s intent to study adolescents (in the context of developmental stage) who are living with cancer in Windhoek.

In addition to the approach, this study is also phenomenological in nature. Phenomenology is interested in how we experience and perceive our worlds through our conscious states (Breakwell, Smith & Wright, 2012). Creswell (2014) further stated that in phenomenological research, the actual experiences of individuals about a phenomenon is described by participants and reported by the researcher. This approach would further pave way for the researcher to understand the participant’s perceptions and experiences.

To expand, as stated by Breakwell et al. (2012, p. 328) “phenomenology aims to clarify, illuminate and elucidate...” the person’s understanding of their experiences. As a result of the nature of this research, the aforementioned research designs were chosen because it makes provision for in depth information to be obtained.

Furthermore, the research approach employed in this study is the qualitative research approach. A qualitative approach allows participants to be studied in their natural environments and word-based information is gathered (Beins & McCarthy, 2012). This approach was chosen because the researcher is able to obtain in-depth information regarding the perception and experiences of the participants and their experiences of the world (Coolican, 2014; Creswell, 2014).

Qualitative studies are done by asking participants to provide the researcher with information through interviews. This information is gathered to gain an understanding of their views and how they create meaning. These studies may be carried out in natural environments or in areas that allow for confidentiality (Smith, 2003). According to Breakwell et al. (2012) the benefits of doing qualitative studies are that the researcher acquires in-depth information about the participants experiences compared to quantitative studies. This information may form a basis on which further investigations/research can be based on. As presented in Chapter Two, information on Psycho-oncology in Namibia is non-existent thus a study of this nature would provide the psycho-oncology field with knowledge on adolescents’ psychosocial experiences of cancer.

### **3.3 Participants**

#### **3.3.1 Population**

The target population for this study were all adolescents between the ages of 10 and 19 years, both females and males, who are living with cancer. The researcher decided to have an age cut off because of the operational definition of adolescents given by the WHO (2016). Statistics from the NNCR registered approximately 296 new cases between the years 2010 to 2015 of adolescents diagnosed with cancer. Of this total, 61 adolescents resided in Windhoek.

#### **3.3.2 Sample and sampling techniques**

A sample is often used in studies because of the unpracticality of studying all the participants that are of interest to the researcher. For this study, the researcher employed a non-probability sampling technique (Beins & McCarthy, 2012; Kothari, 2004). The purposive sampling method was used. This sampling method entailed selecting participants according to the desirable characteristics required by the researcher (Beins & McCarty 2012, Kothari, 2004). These desirable characteristics such as understanding the developmental changes of being an adolescents, understanding and knowing that one is diagnosed with cancer as well.

The research sample was made up of adolescents (13 years to 19 years old) living with cancer in Windhoek. The researcher opted to study the age group of 13 to 19 years old because of their ability to cognitively start thinking in abstract form. The age group of 13-19 years are considered to have a better understanding of expressing feelings. The researcher also chose this age group because of their desirable characteristics and

development stage which is part of the phenomenon being studied. They were from different ethnic groups and they should have knowledge of their cancer diagnosis. These adolescents were required to have been recipients of cancer treatment prior to interview.

The study will focus on both in and out patients. Critically-ill patients were excluded from the study. The participants from the sample of this study were chosen according to the purpose of the study (Creswell, 2014) and a total of nine participants were employed.

### **3.4 Research instruments**

To obtain information to answer the research questions, a self-designed interview guide was used. The guide was used to create a uniform line of questioning to assure that all participants were asked similar questions (Creswell, 2014). The interview guide consisted of socio-demographic questions, psychological, social and self-assessing questions. The interview guide was semi-structured and contained open and closed ended questions (see Appendix A). In addition, the researcher also took field notes that were used during data analysis.

### **3.5 Procedure**

The researcher collected data by firstly approaching the Dr. A. B. May Cancer Care Centre staff at the Windhoek Central Hospital as well as the Cancer Association of Namibia staff dealing with patients at the Windhoek Central Hospital oncology wards. The researcher explained the objective of the study to the staff and they were asked to identify possible participants that would like to take part in the study.

Thereafter, the researcher approached the identified potential research participants and explained the objectives of the study where an information letter (see Appendix B) was also provided. When the possible participant agreed to partake in the study, the accompanying parent, guardian or healthcare provider was also given an overview of the study as well as a parental consent form (see Appendix C) to be able to provide informed consent for their child to participate in the study. The participant was also given an assent form (see Appendix D) to fill in to gain consent. Once informed consent was granted, the researcher asked verbal permission to record the interviews and a one-on-one interview was then carried out at the Psycho-oncology office situated at Dr A. B. May Cancer Care Centre at the Windhoek Central Hospital which allowed for confidentiality.

The researcher asked questions that surrounded the overall experiences of the adolescent since their diagnosis up to the day the interview took place. Questions about their psychological experiences, social experiences as well as perceptions about the self were inquired. Of note, the researcher asked these questions in context of being an adolescent and what that meant for the participants. These questions have guided the interviews and were able to yield satisfactory information to answer the research questions and to understand the main objective of the study.

### **3.6 Research setting**

The research setting is the physical location at which the study is undertaken such as a school, community hall, hospital or clinic (Holloway & Wheeler, 2010). This research study was carried out at the Psycho-oncology office situated at Dr. A. B. May Cancer Care Centre at the Windhoek Central Hospital. One of the interviews was carried out at the

participant's home in Hochland Park, Windhoek. The Psycho-oncology office is situated between the medical oncology and the nuclear medicine departments. The psycho-oncology office is conveniently situated to allow for oncology patients to see a mental health worker while waiting for treatment and consultations with the medical team.

### **3.7 Data analysis methods**

The researcher also made use of an audio recorder to capture the interview. This allowed for the interviews to be transcribed verbatim to ease coding. In qualitative studies, data is usually analysed during data collection. Phenomenological analysis according to Smith (2008) uses significant statements to create meaning from the data collected.

The data collected was analysed using Tesch's open coding method as outlined in Creswell (2014). It is an eight steps coding process which entails breaking down, comparing and examining the transcribed interviews (Creswell, 2014). Table 3.1 shows the various stages of the coding method and the specific actions taken by the researcher as applied to the study (see Table 3.1).

Table 3.1 Tesch's steps and applicability to study

Tesch's coding steps	Applicability to study
<b>1. Make sense of the whole. Read all the transcriptions carefully and write down some ideas as they come to mind while reading.</b>	The researcher went through all the transcripts to familiarize herself with the content of the interviews and began to make notes of the transcripts.
<b>2. Pick one interesting document and go through it. Consider looking at the underlying meaning of the text.</b>	The researcher focused on the transcript with the most relevant information and began analyzing the text.
<b>3. Make a list of all the topics gathered. Group similar topics together in columns of major, unique and leftover topics.</b>	The researcher made notes on the margins that she used to group the information together. These groups formed the basis of drafted themes and subthemes.
<b>4. Assign each topic a code, compare it to the text and see if new categories and codes emerge.</b>	After the groups were arranged, the researcher went back to the text to identify and code the information. This process allows for credibility.
<b>5. Find descriptive wording for the topics and turn them into categories. To reduce total list of categories, consider grouping topics that relate to each other.</b>	The researcher made use of the coding process to generate descriptive words.
<b>6. Make a final decision on the abbreviation for each category and alphabetize the codes.</b>	A table of the themes and subthemes was created.
<b>7. Group the data material belonging to each category in one place and perform a preliminary analysis.</b>	By coding and creating the themes, the researcher groups the material and the data was reduced.
<b>8. Recode your existing data if necessary.</b>	The researcher went through the data again and made the necessary changes.

Source: Creswell (2014), p. 198.

In addition to coding, Creswell (2014) and Smith (2008) concur that there are qualitative techniques for data analysis. This entails *reading*: it provides the general sense of the

information and an opportunity to reflect on the study. Secondly is *coding*: as described above the researcher attaches codes to the text to identify themes and subthemes. Thirdly, *displaying*: exploring the text further after coding. Fourthly, *reducing*: this entails reducing the themes and subthemes from the list to essential points. And lastly, *interpretation*: this means making sense out of the data. The researcher gives a final interpretation of the findings.

Themes and concept descriptions will be evaluated as outlined in the coding method which will be outlined and explained from a phenomenological approach. Interpretations of the meaning of themes and description will then be made and validated by going through the data.

### **3.8 Validity strategies**

One of the strengths of qualitative research is validity. It is based on the accuracy of the information from the standpoint of the researcher, the participant or the readers of the account (Creswell, 2014). The researcher made use of the following strategies to validate the findings:

- *Triangulation* was used to validate the information provided through the different platforms. Creswell (2014) and Holloway and Wheeler (2010) concur that the researcher triangulates different data sources of information by examining the information from the sources and using it to build a coherent justification for themes. For this research study, the researcher used the interviews, field notes as well as the audio recorded material as methods of data collection. The researcher

then compared the information from the different methods to build a coherent justification of the information.

- Use of *rich and thick description* of the information to convey findings. These descriptions are meant to give detailed information that will allow the reader to understand the setting of the interviews and to give the discussion a hint of shared experiences (Creswell, 2014). The aim of providing a richer description about the theme or give alternative perspectives is for the results to become more realistic and richer which in the process adds validity of the findings.
- In addition, the researcher also used *peer debriefing* to validate the accuracy of the findings. This entails identifying a person (a peer debriefer) who reviews and questions the study content so that the information will resonate with people other than the researcher (Creswell, 2014; Holloway & Wheeler, 2010). In this study, the researcher made use of a doctoral student who will go through the data.

### **3.9 Ethical considerations**

Research ethics are often important when it comes to research involving human participants. As a result, the researcher has taken the necessary precautions to ensure that all participants are protected. With that noted, the researcher went through the following steps to follow ethical protocols for this study.

Ethical clearance was granted by the Research Ethics Committee of the University of Namibia (see Appendix E) prior to commencement of the research study. The information letter, interview guide, parental consent form as well as adolescent assent form were attached to the application to gain approval from the ethics committee. Subsequently,

ethical clearance (see Appendix F) and approval/permission (see Appendix G) to carry out the study were also granted by the Ministry of Health and Social Services (MoHSS)'s research committee. This ethical clearance was sought because the researcher used participants from a public hospital which are under the jurisdiction of the Ministry of Health and Social Services.

Further than that, because the researcher used some participants that are below the age of 18, the researcher sought informed consent from their guardians/caregivers to ensure that the issue of using minors in a study are fully understood.

The researcher also ensured confidentiality and anonymity. According to Burns and Grove (2010) confidentiality refers to managing private information so that the data is not linked to the participant's responses. In addition, the research also assured anonymity. Anonymity means that the identities of the participants and their responses cannot be linked by anyone including the researcher (Burns & Grove, 2010; Coolican, 2014). For this study, the researcher coded the participant's responses so that the data remained anonymous.

The field notes as well as audio-taped recorded interviews will be kept in a safe cabinet that is only accessible to the researcher. The records are kept safe to ensure that confidentiality is maintained even after the study, and would keep unauthorised people from gaining access to the information.

All the participants were debriefed after the interviews and counselling services were provided by the Social Services department and by Dr. Shino (Clinical Psychologist) after the interviews to ensure that they were contained after the interviews.

### **3.10 Summary**

In conclusion, this chapter outlined the philosophical paradigm which formed the basis of inquiry. In addition, it also used the qualitative study approach which allowed for the research to gain in depth information from the participants. It was also phenomenological in nature meaning the participants views would be studied and described from the participants' perspective. It identified the study population used, the sampling method, the research instruments and the procedure followed to collect data. Thereafter, the steps taken for data analysis methods were discussed. This allowed for all information to be examined and coded. Furthermore, an account to ensure the validity of the study was discussed. To end, the ethical considerations that were taken into consideration during the study are explained and discussed. In the following chapter, the researcher will represent the results from the study after the data was analysed and the discussions of the results will also be presented.

# **CHAPTER FOUR**

## **RESULTS AND DISCUSSIONS**

### **4.1 Introduction**

In the previous chapter, a discussion on the research design, philosophical paradigm, and approach was given. The researcher gave an account of the data collection, described the methods of analysis as well as the ethical considerations taken into account.

This chapter will focus on giving a description of the research findings as well as providing a discussion of the findings thereof. Firstly, the researcher will provide an illustration of the demographic information of the participants. Secondly, the discussions of the findings will be described from a phenomenological writing style as supported by Smith (2008). Central themes and their subthemes will be outlined and discussed. And lastly, the researcher will incorporate the literature that supports the themes which will expand the researcher's understanding of the phenomenon identified by the participants.

Furthermore, a detailed summary will be provided at the end of the chapter.

### **4.2 Description of participants**

This study employed nine participants of which five were females and four were males. P9's interview was excluded from data analysis based on the little information produced in the interview. The participants were between the ages of 13 to 19 years. The adolescents are diagnosed with varies types of cancers of which Leukemia is the most common.

Leukemia is a cancer that affects the bone marrow and blood. There are four main groups of Leukemia, of which Acute Lymphocytic is the mostly diagnosed among patients

between zero to 19 years (American Cancer Society, 2017). Hodgkin's Lymphoma is the second mostly diagnosed cancer which accounted for two cases in this study. This is a type of cancer that affects the immune system.

One participant is diagnosed with Osteosarcoma which is a type of cancer that produces immature bones. It is often found in males more than in females (American Cancer Society, 2017). It is often diagnosed in children and young adults and the common treatment regime is usually amputation of the limb.

Another participant is diagnosed with retinoblastoma which is a rare cancer that develops from immature cells of the retina. It is only found in young children (American Cancer Society, 2017). Participant 7's (P7) eye has been removed due to the cancer and wore an eye-patch during the time of the interview.

The time since diagnosis varied from a period of two months to two years prior to the interview. Table 4.1 illustrates the demographic information of the participants. Of note, the grades of the adolescents were presented. The table illustrates the grades that the adolescents are in or attending.

Table 4.1 Description of participants (N=8)

<b>Name</b>	<b>Age</b>	<b>Sex</b>	<b>Grade</b>	<b>Diagnosis</b>	<b>Diagnosis date</b>
<b>P1</b>	19	F	10	Acute Lymphoblastic Leukemia	October 2016
<b>P2</b>	19	F	12*	Hodgkin's Lymphoma	March 2017
<b>P3</b>	17	M	9	Leukemia	June 2015
<b>P4</b>	13	F	6	Hodgkin's Lymphoma	July 2017
<b>P5</b>	17	F	11*	Leukemia	June 2017
<b>P6</b>	16	M	n/a	Conventional Osteoblastic Osteosarcoma type	October 2016
<b>P7</b>	19	F	9*	Retinoblastoma	February 2017
<b>P8</b>	15	M	7	Pharynx Cancer	October 2016
<b>P9</b>	17	M	10*	Leukemia	March 2017

(Note: M=Male, F=Female; \*=Last grade attended)

### 4.3 Description of results

The results obtained in this study are based on the data collected through interviews, field notes and transcription. This methods have permitted the researcher to gain in-depth information of the experiences of adolescents. From this in-depth information the researcher *winnows* the data, which is a process of focusing on some parts of the data and disregarding the other parts (Creswell, 2014). This process allows the researcher to identify themes that represent the dominant features of the phenomenon that is being

studied. This step is the most important step for the researcher during data analysis. Furthermore, themes are used in qualitative research to condense large amounts of information (Creswell, 2014; Lyons & Colye, 2007).

A theme is a concept used to describe pervasive expression of behaviour in data (Ryan & Bernard, 2003). In this study, the researcher identified themes through the codes that were used to identify the expressions that emerged during data analysis. The researcher illustrated these expressions by identifying and incorporating quotes that were observed in the data. This process ensures the validity of the study (Creswell, 2014).

Furthermore, the researcher also identified subthemes. Subthemes are organized branches of the themes. They are derived from the main theme presented. According to Govida (2014) subthemes inherit their parent theme's resources. One can regard them as an extension of the main theme with more detail.

In this study, the researcher explored the psychological and social experiences of the adolescents as well as the impact of cancer on their sense of self. The results below will be presented in terms of the psychological effects of the cancer diagnosis, the adolescents' social experience of living with cancer and how their sense of self was impacted by merely being diagnosed during the developmental stage of adolescence. This study identified three themes and eight subthemes. These themes and subthemes are presented in Table 4.2 below and they will be discussed in section 4.4.

Table 4.2: Identified themes and subthemes.

<b>Themes</b>	<b>Subthemes</b>
<b>4.4.1 Participants' reactions towards diagnosis</b>	4.4.1.1 Feeling extreme sadness 4.4.1.2 Relentless fear of not getting well 4.4.1.3 Indifferent towards diagnosis
<b>4.4.2 Experience of peer relations</b>	4.4.2.1 Participants experienced good social support 4.4.2.2 Adjusting to living with cancer 4.4.2.3 Maintaining normality
<b>4.4.3 Perceptions of the self</b>	4.4.3.1 View of the self 4.4.3.2 Dealing with a changing body image

#### **4.4 Discussion of the results**

##### **4.4.1 Theme 1: Participants reactions towards diagnosis**

This theme describes the reality of how the study's participants reacted towards their diagnosis. A reaction can be defined as something felt, done or thought of in response to a situation or an event. Reactions may vary in terms of behaviour, feelings and thoughts. This may be when they initially received the news or later when they had to begin treatment. The magnitude of the feelings experienced by these adolescents seemed to have been between being intense to being restricted. Most participants have identified some sort of reaction towards their diagnosis.

According to Zebrack (2011) the diagnosis of cancer can cause similar life disruptions among cancer patients but the stage of development when the diagnosis is made may cause cancer patients to focus on different aspects of the illness. The cancer patients would then each attach a different level of importance to these aspects. In a study by Richter et al. (2015) they acknowledge that adolescents and young adults experience high levels of distress depending on the different stages of cancer. This distress may often lead to

symptoms of depression, lower quality of life and then to experience higher negative affect (Daniel, Brumley & Schwartz, 2013).

The participants in this study particularly experienced feelings of negative affect as a reaction towards their diagnosis. In a study by Chirico et al. (2015) they agree that there were several indicators of distress in patients early in their cancer diagnosis.

Furthermore, the psychological effects of a cancer diagnosis can cause emotional distress, depression, anxiety, uncertainty and even hopelessness; which were some of the reactions that were observed in the participants in this study.

Moreover, the adolescents expressed different reactions towards their diagnosis. Below are the subthemes that emerged from the data analysis about the adolescent's reactions. These include feelings of sadness, relentless fear of not getting well and feeling indifferent towards diagnosis.

#### *4.4.1.1 Subtheme 1: Feeling extreme sadness*

Sadness is a state of unhappiness. Sadness is often experienced as an uneasy feeling of low mood. It was a reoccurring feeling among the adolescents. Upon receipt of the news about their diagnosis, most of them reported that they responded with feelings of sadness. Most of them felt like it was the most appropriate feeling or reaction at the time. Even though they were accompanied by their caregivers (or parents, siblings), they still burst out into tears, which is a strong indication of sadness:

*“... so I went back and the lady (sic) said oh no I am so sorry but it is cancer ... because I was with my mom (starts to cry) and I just started crying.”[P2]*

This adolescent expressed great sadness in that she has been reading up her symptoms and they were indicative of cancer. Even though she ‘prepared’ herself, she was still hopeful that it would not be cancer. This behaviour may be indicative of an adolescent who is hopeful for their future and felt like it was taken away by a cancer diagnosis. Based on the findings of Evans et al. (2008) they reason that adolescents diagnosed in a later stage (which is late adolescence) are most likely to have perceived control over the stress when they are coping with the illness.

In addition, some adolescents experienced extreme sadness because of the pain that they were experiencing prior to the diagnosis. It is also indicative of emotional distress in these adolescents:

*“I was really upset but I was not actually depressed or anything. I was just really sad.”*

[P2]

*“It was really bad, really bad. It was not easy. I was just not fine at all. It was just sad news to me.”* [P1]

All in all, sadness was the common reaction towards the cancer diagnosis of most participants. Although some expressed some feelings of hopelessness, it seemed like it was an intertwined reaction of sadness and hopelessness towards the diagnosis:

*“I felt bad, I felt down (sic) because the doctor was unsure about what it was. But I didn’t cry but I was feeling very hopeless ... and when the doctor told us that there was no other option but I had to be amputated [closes eyes and looks up] then I was feeling very bad.”* [P6]

#### *4.4.1.2 Subtheme 2: Relentless fear of not getting well*

Relentless refers to something “unceasingly intense”, meaning it is something that is persistent and not going away. The participants in this study were constantly faced with fear. They experienced fear when they were diagnosed, they experienced fear when they received treatment and continuously experienced fear because of the side-effects of treatment. It became a common feeling for them during their illness. In some adolescents, they experienced a generalized fear about the prognosis of their illness. One adolescent stated that:

*“When I use to go to school I use to think that the cancer wasn’t going to finish from my blood. I thought it will just be in the blood forever. And even with the school I thought I will not go anymore I will just be at home.” [P5]*

This persistent fear of not getting well may hinder the prognosis of the illness. In a study by Flavelle (2011) she found that a 15 year old adolescent began to explore and learn about spirituality out of fear of dying and not getting well.

This findings were supported by Carlsson et al. (2008) who found that adolescents with a personal experience of cancer showed fear by making it part of themselves. This means they experienced a threat to their personal self. This usually happens when they have a misconception of the fear and it becomes a lived experiences through their body sensoria.

Additionally, adolescents expressed perceived fear of the unknown which Carlsson et al. (2008) referred to as existential fear. They had a great fear that they were going to die. When asked about what came on their mind when they learned about their diagnosis, most of them responded around the theme of dying:

*“That I am going to die!” (giggles) [P2]*

*“... I was thinking about death and that it is too danger (sic).” [P3]*

This could also be interpreted as mere reactions towards the diagnosis but that the persistent thought of death would not go away. They also acknowledge that it was uneasy for them to think about death but the thought crippled in during treatment.

With this persistent fear noted, it may be that this fear may manifest in other psychological effects that would hinder a better prognosis.

#### *4.4.1.3 Subtheme 3: Indifferent towards diagnosis*

Indifferent can be defined as having no particular interest or sympathy about something. It is a sense of being unconcerned. Feeling indifferent towards the cancer diagnosis may be attributed to many things in the case of the adolescents living with cancer in Windhoek. In this research study, some participants were not responsive to some questions. The study found that they had no emotional reactions towards their diagnosis or that they felt ambivalent of how the cancer affected them. A 17 year old adolescent could not really say how the cancer affected her psychologically. This could be attributed to the middle to late adolescence stage that she is going through.

*“It did not really affect me but it affected me because at first I wasn’t allowed near people, I had to wear a mask because my immune system was low at the time so I could pick up diseases easily.” [P1]*

*“I don’t know. There is no effect.” [P3]*

According to Evans et al. (2008) they reported that age would be a risk or protective factor of the adolescents and young adults. They maintain that age can affect how one reacts towards their diagnosis. As suggested by Chirico et al. (2015) age should be considered a key precursor of the patients' distress based mainly on deficits in knowledge. Furthermore, as noted above based on the findings of the older participants, their age allowed them to have more control on what to do with the information they received about their diagnosis and they were most likely to be active in their treatment plan which would be indicative of it being a protective factor. Compared to the younger participants, a 13 year old who took part in the study noted that she does not really understand the illness and initially thought of it as a joke:

*“First I thought there were lying to me but now I know they are telling me the truth because of the medication ...”* [P4]

Further asked about how she reacted towards the diagnosis, she stated:

*“I didn't feel anything really. I didn't really understand this cancer (sic).”* [P4]

This may also be interpreted as having a lack of knowledge or awareness about the illness. The adolescents noted that sometimes they do not know what is going on with them. They noted that they do not even know the stage of their cancer:

*“No. I don't know the stage. Nobody told me at what stage the cancer is. I just came here (pointing towards the Medical Oncology clinic) for treatment and they write for me a date to come back again.”* [P7]

In a study by Richter et al. (2015) they agree that higher cognitive ability associated with the development age may be a resource or hindrance of the prognosis as it leads to lack of

confidence in coping efficacy and distress. In this research study, it was found that the older participants took more initiative to understand their illness compare to the younger ones:

*“When I initially started to get the swollen glands, I googled it and it said it was cancer right. After the Dr’s appointment as well, I googled for two months straight everyday ... I was much calmer when I learned there is a cure for it and now here I am.” [P2]*

All in all, this subtheme illustrates the need for understanding the illness before the patient is able to identify any psychological effect caused by the illness. Feeling indifferent could also be attributed to other aspects such as the denial that the illness has an effect or to developmental age and cognitive functioning in this instance.

#### **4.4.2 Theme 2: Experience of peer relations**

This theme was derived from the findings of the question posed on the social experiences of adolescents living with cancer. Adolescents gave answers mostly relating to how they relate to their friends or peers. According to Magnusson, Stattin and Allen (1985), social development among adolescents is common. It is during this stage that the adolescent begins to place importance on having relationships with people outside of home.

Zebrack (2011) found that during the adolescence stage, adolescents are mostly increasing their involvement with peers and begin to date. This theme is supported by Muuss (1996) who stated that adolescents begin to experience feelings of love and compassion and they are driven to make friends and rely on them. This study found that adolescents maintained

their friendships with their peers even after they were diagnosed with cancer and stayed for extended periods of time (months) in the hospital.

When the participants learned about their diagnosis, most of them indicated that they had encouraging friends and they experienced positive social relations. Even though they were initially unsure about how their peers were going to react towards their diagnosis, they reported that they received support and acceptance from their peers. The above sentiments agree with a study by Evans et al. (2008) who noted that adolescents were most likely to feel anxious about fitting in with their social peers after they were diagnosed with cancer. They tend to use their friendships as safe environments to explore their feelings and experiences with cancer.

#### *4.4.2.1 Subtheme 1: Participants experienced good social support*

Social support is assistance that people receive from others. It is a perception of being cared for by other people and knowing that they will be available to offer assistance. These adolescents maintained their social relationships even after diagnosis. These can be seen in the actions of these adolescents in which they continued to pursue physical activities, other continued to go out with their friends:

*“I play netball at least twice a week with my peers. It allows me to spend some time with them.” [P1]*

One participant was rather experiencing annoyance with her friends. She felt that it was a reoccurrence of being told what not to do as opposed to what to do, thus her expression of this feeling:

*“They would tell me not to drink but I would still drink because I still wanted to be normal and but (sic) the people I went out with would be like please don’t drink, please don’t drink and I would get really frustrated and it would irritate me a lot.” [P2]*

The above expression is a clear indication that the participants still wanted to be with their friends and continue with their normal activities but could become easily irritated when friends disagree with their actions. But, besides the above mentioned concern, the adolescents maintained that their friends looked up to them and praised them for their courage and strength. This gave them some sense of meaning:

*“Some they look up to me saying I am a survivor. Like initially when I was diagnosed, I was really sick but now when they see me I am like just normal so I start to encourage them and stuff.” [P1]*

Furthermore, participants with physical body changes expressed that they were surprised about how supportive their peers were after they lost a body part:

*“The first time I went back to school after being amputated, I thought I would be treated badly from the other students but yeah, they treated me like a normal person in a normal way (sic) and they even asked me questions.” [P6]*

In a study by Larouche and Chin-Peuckert (2006) on changes in body image experienced by adolescents with cancer, they found that the adolescents expressed feelings of vulnerability which served as an emotional link between their perceptions and their actions. These sentiments can be observed in the above adolescent who thought was vulnerable due to his changed appearance and that impacted his perceptions and actions.

#### 4.4.2.2 Subtheme 2: Adjusting to living with cancer

In the aspect of the adolescent adjusting to living with cancer, this study looked at how their social experiences were different when they were diagnosed. One participant thought that she had to compromise some activities to make provision for the days she was receiving treatment for cancer:

*“...I use to go out all the time. ... Every weekend. But since I started chemo I wouldn't go out chemo weekends (sic) and then I would have chemo every second weekend so I would squeeze everything in one weekend and go out as much as possible and I would be home chemo weekends.” [P2]*

Larouche and Chin-Peuckert (2006) noted that adolescents often avoided going out when they were sick because they felt vulnerable and did not want other people to see them in their sickness state. But, this may be due to them adjusting their lifestyles as well as activities to suit their treatment plans. However, four adolescents indicated that they did not have much to adjust to after they were diagnosed with cancer besides the fact that they were out of school.

Being out of school made some participants to feel uneasy and uncertain about their futures. This was a common feeling amongst the participants especially those with Leukemia and Hodgkin's lymphoma. Some participants had to be out of school for lengthy months due to the treatment regime that the participant is prescribed. Several adolescents have expressed dissatisfaction with the fact that they are out of school:

*“It affected my studies. I was like supposed to be in grade 12 next year to finish my school but now I can't because I am out of school with cancer (sic).” [P5]*

One participant was very disappointed because she has to repeat her grade for the second time, except that it was because of the cancer this time. During the adolescence stage that these participants were supposed to be making their future plans, they are rather faced with uncertainties about the future (Santrock, 2011; Zebrack, 2011). This may cause emotional distress and anxiety to the adolescents and subsequently poor coping efficacy.

On the other hand, the participants experienced being cared for by their family members as well as accommodating friends. Sometimes they did not have to go out and rather their friends come by:

*“I didn’t go out much, I just stayed at home. Because most of my friends come to me at the house that is why I don’t go out much.” [P6]*

In light of this, these adolescents have experienced the wrath of cancer but on the right track to adjusting to living with cancer. Even though some might not have major adjustments to make, others are coping well.

#### *4.4.2.3 Subtheme 3: Maintaining normality*

Maintaining normality refers to a state in which one would act like there is no change in their context or situations. Adolescents in this study tried to maintain a normal life by participating in the activities that they use to before they were diagnosed and to also go back to their normal routine. They have indicated that even though they were some challenges with receiving treatment and had to be out of school for a long period of time, they attempted to continue pursuing activities that they engaged in before their diagnosis. This is often a common experience with adolescents diagnosed with cancer. In a study by Larouche and Chin-Peuckert (2006), they found that adolescents living with cancer would

often want to look normal. They did not want to be identifiable when going out with their peers. When they experienced physical changes such as loss of hair due to cancer treatment, they would buy wigs and use make up just to look ‘normal’ and ‘fit in’ with the others. When asked about whether they still go out with their peers since they were diagnosed, one responded:

*“Yes, I still walked with my friends to and from school.” [P5]*

In addition, they also continued pursuing sports. When they were asked about their social experiences they mostly spoke of sports. They maintained that sports was a good form of exercise and it did not make them feel different from their peers. However, some reported that they had to adjust their physical activities because of the cancer as well as the treatment regimen. One participant states that:

*“Uhm, we use to cycle a lot, every Saturday. ... the streets are very steep and I could cycle on them but then when I got diagnosed I could not because the lymph nodes would swelling up around my Larynx and that caused my breathing to like become heavier. So I would not cycle, I would not run, I would walk and do yoga but yeah. I was not active at school.” [P2]*

In addition, for every question posed asking about their experiences of being an adolescent with cancer, the element of being a teenager was not elicited or spoken about. Even though they liked or seem to have enjoyed their time alone (having a need for independence and freedom), they still seem to have thought having a terminal illness as normal and not because they are going through adolescence. In the same vein, a participant who used to

be accompanied by their caregiver began to insist that the caregiver stops coming to follow-ups because she would enjoy coming alone:

*“My (caregiver) should stop coming with me here (at the hospital) because I want to start coming alone. I just want my freedom.” [P4]*

This is a typical response or feeling of an adolescent. According to Muuss (1996) adolescents develop an interest in privacy and start to have a strong desire for independence. This behaviour can also be seen in most participants as most of them come unaccompanied for their consultations.

#### **4.4.3. Theme 3: Perceptions of the self**

During the adolescence stage, one is often preoccupied with their body image, establishing their identity and trying to find independence (Santrock, 2011). Their perception about themselves is a central part of their development and thus they are bound to be thinking about how they view themselves. This was a theme that came out when the adolescents were asked if cancer impacts their sense of self. Adolescents’ are concerned about how they are viewed, may it be physical or perceived.

Sometimes adolescents may have a negative view of themselves which may disrupt their development and may cause them to experience difficulty with the illness. Their body image was something that they were not really willing to explore but were able to respond to with short answers. This may have been due to the adolescents being uncomfortable of disrupted development. Larouche and Chin-Peuckert (2006) agrees that adolescents’ perceptions about their body images were altered because of a cancer diagnosis. They also noted that their appearances reminds them of the presence of the illness.

In addition, some participants had to undergo operations that altered their physical appearances. These adolescents experienced a constant reminder of the illness and they felt they were different from the others because of the effects of the illness. These alterations of the body is known to cause suffering as well as distress in the adolescent as stated by Trask et al. (2003) in Larouche and Chin-Peuckert (2006).

#### *4.4.3.1 Subtheme 1: View of the self*

This subtheme is characterized by how adolescents viewed themselves and to what extent did they feel different from other adolescents without cancer. Generally, the participants did not view themselves different from their peers because of the cancer, this is how some have responded:

*“No, I don’t feel different.” [P4]*

*“No!” [P3]*

Further probing was done but they maintain a no response and some would shook their heads to show emphasis that they were not different from their peers.

On the other hand, the adolescents with physical changes (such as amputation and loss of an eye) explicitly noted that they left different from their peers. A 19 year old noted that it was obvious that she was different. The presence of the illness has marked the beginning if something different for the adolescent. Because of the cognitive development during late adolescence, adolescents begin to set goals and think about the meaning of life (Shaffer et al., 2010). It is with this thoughts that causes distress to the adolescent and thus disrupts development. On viewing of the self, an adolescent responded:

*“Yeah cause I feel like you need to grow up faster, become more matured ... like you cannot make stupid mistakes where you like want to smoke, people judge you.”*

[P2]

*“Yeah, being diagnosed with cancer makes you appreciate life at my age.”* [P2]

This adolescent perceived herself different because of the thought that she had to grow up faster and take more responsibility for herself.

Based on the findings of this study, this subtheme illustrates that the diagnosis of cancer itself might not have been a bigger factor than the effects of its treatment. Therefore, adolescents who did not have to lose any of their body parts felt less different compared to those who that did. Furthermore, this may be attributed to the perceptions that adolescents have and their preoccupation with their body image as stated in Larouche and Chin-Peuckert (2006).

#### *4.4.3.2 Subtheme 2: Dealing with a changing body image*

A changing body in this study refers to physical changes caused by an illness or as a result of the treatment of the illness. Cancer is associated with the vigorous treatment plans such as chemotherapy, radiation therapy and surgical procedures (National Cancer Institute [NCI], 2017). However, these cancer treatment options may cause severe side effects that may alter the physical appearance of the patients.

After some participants began treatment, they experienced hair loss which is a common side effect of most cancer treatments. This caused distress to the adolescents and they experienced difficulty dealing with hair loss. For the females, one participant continuously

had to wear a bennie, even during the interview she kept it on. She stated that she hardly removes it because she is not comfortable yet. Larouche and Chin-Peuckert (2006) concur with this finding as they found that adolescents often felt vulnerable when they revealed their body changes. They further noted that they would ‘test the waters’ by revealing their body changes in a secure environment. This action may be indicative of them trying to protect themselves. In another study by Wallace et al., (2007) they concur that adolescents with cancer have significant concerns with their altered appearance.

In the same vein, there are those that took bold steps to not hide their appearances. One stated that:

*“My hair was thinning and falling out in large portions ...but my mom and I decided to cut it and kept it short. ... but then I realized I wanted to attend the farewell and I had to just shave it off.” [P2]*

She had to attend a major event which is important for her and thus had to ‘accept’ that she had to get rid of the little hair that she had left.

In addition, some adolescents had different thoughts about how they dealt with a changed physical appearance. Sometimes the adolescent may not consider themselves different until the presence of the illness becomes obvious. It requires some adjusting to the new appearance and a lot of processing cognitively.

*“My view of myself started or became real after I got amputated. Sometimes I want to play football and then I realize that I don’t have both my legs because of the cancer and that makes me different from my peers.” [P6]*

This subtheme is based mainly on the physical ailments of the participants and how they view themselves in that light. It can be deduced from this subtheme that the presence of a loss of body part has the ability to make one feel different from their peers.

#### **4.5 Summary**

All in all, the findings are indicative of the psychosocial experiences of the adolescents. The participants had a general negative response towards their diagnosis but they had good peer interactions. This is evident in how they have experienced their friends and those people they considered important. In terms of their perception of the self, it is quite noticeable how they noted that they did not feel different after the diagnosis until the treatment side-effects were physically present.

This chapter outlined the results presented from the study. It also provided a discussion of the results supported by literature. It gave a description of the themes and subthemes that were found and elaborated further. The next chapter will provide the reader with the conclusions drawn from this study as well as the limitations and recommendations based on the results of the study.

## **CHAPTER FIVE**

### **CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

#### **5.1 Introduction**

The previous chapter looked at the data analysis. It provided a description of the participants as well as the results from the data. A discussion of the findings was provided. The themes and subthemes were identified and discussed accordingly.

This chapter will focus on the conclusions drawn from the discussions. It will also provide an account of the limitations and recommendations based on the study's findings. Conclusions will be based on the global aim as well as the research questions that informed this research study.

The recommendations are also based on the findings and they emphasise the need to study adolescents with a terminal illness such as cancer. Their developmental stage formed the basis of the research and thus a phenomenon that need further research in Namibia.

#### **5.2 Conclusions**

This study's main objective was to explore the psychosocial experiences of adolescents living with cancer. To achieve this objective one-on-one, in depth interviews were conducted with eight participants selected through a non-probability, purposive sampling set on an inclusion criteria. Participants were asked questions about their psychosocial experience with living with cancer as well as how the cancer affected their sense of self. The interviews provided information on the adolescents' experiences. They were transcribed verbatim and analysed using Tesch's data analysis methods as outlined in

Creswell (2014). Based on the research findings, the following conclusions were drawn from this research:

- The psychosocial experiences were explored and the study found that adolescents had different reactions towards their diagnosis.
- Most participants expressed extreme sadness when they were diagnosed.
- They indicated persistent fear while others experienced an indifference towards their diagnosis.
- Participants in this study revealed that they experienced good social support from their peers and friends.
- They further revealed that they had to adjust living with cancer, particularly due to changes in their physical appearances.
- Most participants continued to engage in activities such as sports in order to maintain normality.
- Some adolescents had to adjust to a new way of viewing themselves while the others maintained that they did not view themselves different because of the cancer diagnosis.
- While some adolescents were dealing with a changing body image, they still maintained a positive outlook.

In addition, based on the constructivism philosophical paradigm adapted by the researcher for this study, the researcher is aware and maintained interpretative validity by getting feedback from the participants about the information interpreted. In terms of creating meaning of the participants world, the researcher focused the study in one town (which

had similar characteristics in terms of treatment services) to fully grasp the view of the participants and how they create meaning of their experiences in this similar environment.

### **5.3 Limitations of the study**

This research study was aimed at exploring the psychosocial experiences of adolescents with cancer. Due to the limited nature of the sample, the study will only focus on the experiences of a limited number of participants. The research study was based in Windhoek and the findings may not be applicable to adolescents living elsewhere. In addition, qualitative studies only accommodate the personal views of individuals and thus the findings may not be similar to the general population of this study. This may be applicable because the study employed adolescents with different cancers compared to only studying one type of cancer and thus the essence of each experience may be lost in interpretation of results. In addition, the interviews were carried out in a hospital setting which might have an effect to response because the participants were either going for or coming from treatment.

### **5.4 Recommendations**

The recommendations made from this research are based on the findings and limitations of the study. The researcher made recommendations for future research as well as for practical implementation.

For future research, a recommendation is made that the research focuses on all adolescents considering the number of adolescents diagnosed with cancer which the research can be quantitative in nature and could focus on the needs of the adolescents. The researcher may also choose to study each type of cancer to capture the unique experiences of the

adolescents with each cancer. Furthermore, the results generated in this research is has shown mostly the pain that the adolescents experience; it would be recommended that future research could look more at issues of resilience and agency to focus on the positive effects of dealing with cancer as well as how they experience social support.

Secondly, based on the conclusions made for the study, it is recommended that healthcare professionals provide adequate information that will be understandable and simple to the adolescents when they are diagnosed with cancer for better prognosis of the illness. It was found that adolescents who are equipped with more knowledge have a better coping efficacy and are able to deal with stressors.

Thirdly, the psychosocial needs of the adolescents need to be catered for and this can only be done by offering more psychosocial counselling to the adolescents. Healthcare providers are therefore urged to identify adolescents who may be in dire need of counselling services and refer them to mental health care providers (Hendrick & Cobos, 2009; Zebrack et al., 2014).

Fourthly, it is recommended that the interviews take place in another setting other than the hospital. It should also be noted that having more than one interview with the adolescent can increase the chance of attaining more information from the adolescents as they become more open and willing to share information (Larouche & Chin-Peuckert, 2006).

Lastly, it is recommended that caregivers of the adolescents are made knowledgeable about cancer and the psychosocial needs of the adolescents so that they are able to take

better care of them. This empowerment would mean better treatment adherence and active patient participation.

### **5.5 Summary**

This chapter outlined the conclusions of the study based on the findings. The limitations of the study were discussed as well as the recommendations. The experiences of these adolescents are unique due to their developmental stage. The recommendations made from this study aims to understand and provide psychosocial care to adolescents and equip them with knowledge about their diagnosis.

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## APPENDIX A: INTERVIEW GUIDE

### Interview Guide

**Research Title:** Psychosocial experiences of adolescents diagnosed with cancer in Windhoek

Date:

Place:

Age:

Sex/Gender:

Diagnosed date:

Type of cancer:

### Standard questions

#### Psychological experience

1. How did you learn about your diagnosis?
2. When did you learn about your cancer diagnosis?
3. How do you feel about the diagnosis?
4. Being a teenager, how did the cancer diagnosis affect you?
5. What came on your mind when you learned about your diagnosis?
6. How did you react towards the diagnosis?

#### Social experience

7. Do you often go out with your peers since your diagnosis?
  - a. How often?
  - b. What type of activities do you engage in?
  - c. If no, why don't you go out?
8. What do you think other people think of you as a teenager with cancer?
  - a. e.g., Friends?
  - b. School mates?
  - c. Other people?

#### Perceptions of self

9. Do you perceive yourself different from your peers?
  - a. How does being diagnosed with cancer make you feel different from your peers?

#### General questions

10. How often are your hospital visits?
11. How far is the hospital from your house?
12. Who accompanies you when you come to the oncology clinic/center for treatment or consultations?
13. Do you feel you are getting enough support?
  - a. from Family
  - b. from Nurses
  - c. Doctor
14. Do you have someone you talk to often about your feelings?
15. Do you have any questions and/or comments for me?

## **APPENDIX B: INFORMATION LETTER**

### **Informed Consent [Information] Letter**

2017

Dear esteemed parents and participants,

My name is Hambeleleni Nashikale Ndjaleka. I am an MA in Clinical Psychology student at the University of Namibia. As part of my studies, I have to complete a mini-thesis in partial fulfilment for my degree. My research topic is:

#### **Psychosocial experiences of adolescents diagnosed with cancer in Windhoek**

Research shows that many adolescents diagnosed with cancer often experience a wide range of emotions, also because of their developmental stage. It further indicates that adolescents living with cancer are often overlooked, and their needs are not explored and they are left to deal with the cancer in their own way.

The main aim of this research study is thus to explore the psychological/emotional and social experiences of these adolescents living in Windhoek. It is hoped that this study will produce information that would shed light into making provision for tailor-made psychosocial services and programs that would benefit adolescents diagnosed with cancer.

This letter serves as a kind request to you to take part in this study. Your participation is voluntary and you may withdraw from the study anytime you wish to. You will be requested to give permission to take part in this study and thus to sign a consent form. The information provided by you will remain confidential and your identity will not be disclosed to anyone. Information will be collected through one-on-one audio-taped/recorded interviews.

Should you have any questions or require clarification about this study please feel free to contact me or my supervisor. If you require counselling, also kindly feel free to contact us.

Your participation is highly appreciated.

Yours sincerely,

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**Ms. Hambeleleni N. Ndjaleka**  
MA in Clinical Psychology student  
0814796581  
[hndjaleka@gmail.com](mailto:hndjaleka@gmail.com)

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**Dr. Elizabeth Shino**  
Research Supervisor  
(061) 206 3807/  
081 250 9414  
[eshino@unam.na](mailto:eshino@unam.na)

## APPENDIX C: PARENTAL INFORMED CONSENT FORM

### Parent consent form

Dear Parent,

Your child is cordially invited to participate in this research study. Because your child is under the age of 18, your consent is required in order for your child to participate.

**Procedures:** Your child will be asked to participate in an interview with the researcher in which she/he will be asked to share his/her opinions, experiences, feelings and attitudes about being diagnosed with cancer. The interview will take approximately 50 minutes to one hour. The interview will be audio-taped/recorded.

**Agreement:**

- I agree that I have read the information letter and fully understand the nature of the research study.
- I understand that my son/daughter's participation in this research study is completely voluntary and she/he may withdraw from the study without any consequences.
- I understand and agree that information collected in this research study will be kept confidential and will only be used for the purpose of this research study.
- I understand that there is no physical harm involved.
- I understand that should my son/daughter/child require counselling, it will be provided by a social worker or psychologist.
- I understand that I may contact Hambeleleni Ndjaleka (081 479 6581, [hndjaleka@gmail.com](mailto:hndjaleka@gmail.com)) or the research supervisor, Dr. Elizabeth Shino (081 250 9414, [eshino@unam.na](mailto:eshino@unam.na)) should I have any queries.
- By agreeing, I will be given a signed copy of the information letter, consent form and assent form.

Son/daughter/child's name \_\_\_\_\_

Parent's name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher's signature \_\_\_\_\_ Date \_\_\_\_\_

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## APPENDIX D: ADOLESCENT ASSESNT FORM

### Participant assent form [For Adolescents]

**Research title:** Psychosocial experiences of adolescents diagnosed with cancer in Windhoek

I have been asked to participate in this research study and have been informed about the nature of the study. I understand that:

- My participation is voluntary and I may withdraw from the study anytime I wish to without any consequences.
- The information collected will remain confidential and my personal identity will not be disclosed.
- Information will be collected through audio-taped/recorded one-on-one interviews.
- I understand that there is no physical harm involved.
- I understand that should I require counselling, it can be provided by a social worker or psychologist.

By signing this consent form, I understand that my parents have been informed about this research study. I understand what my involvement in the research study means and I voluntarily agree to participate in this research study.

Participant            signature            \_\_\_\_\_            Date

\_\_\_\_\_

Researcher            signature            \_\_\_\_\_            Date

\_\_\_\_\_

## APPENDIX E: UNAM ETHICAL CLEARANCE CERTIFICATE



# UNAM

UNIVERSITY OF NAMIBIA

**ETHICAL CLEARANCE CERTIFICATE**

**Ethical Clearance Reference Number:** FHSS/205/2017      **Date:** 24 April, 2017

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

**Title of Project:** Psychosocial Experiences Of Adolescents Diagnosed With Cancer In Windhoek

**Nature/Level of Project:** Masters

**Researcher:** Hambeleleni N. Ndjaleka

**Student Number:** 201103426

**Faculty:** Faculty of Humanities and Social Sciences

**Supervisor:** Dr. E. N. Shino

Take note of the following:

- (a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
- (b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
- (c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
- (d) The UREC retains the right to:
  - (i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
  - (ii) Request for an ethical compliance report at any point during the course of the research.

UREC wishes you the best in your research.

**Prof. P. Odonkor:** UREC Chairperson      **Ms. P. Claassen:** UREC Secretary



## APPENDIX F: MOHSS RESEARCH APPROVAL LETTER



### REPUBLIC OF NAMIBIA

#### *Ministry of Health and Social Services*

Private Bag 13198  
Windhoek  
Namibia

Ministerial Building  
Harvey Street  
Windhoek

Tel: 061 - 203 2562  
Fax: 061 - 222558  
E-mail: [hnangombe@gmail.com](mailto:hnangombe@gmail.com)

#### OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3 HN

Enquiries: Dr. H. Nangombe

Date: 19 June 2017

**Ms. Hambeleleni N. Ndjaleka**  
University of Namibia  
PO Box 376  
Ongha  
Namibia

Dear Ms. Ndjaleka

**Re: Psychosocial experiences of adolescents diagnosed with cancer in Windhoek**

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
  - 3.1 The data to be collected must only be used for academic purpose;
  - 3.2 No other data should be collected other than the data stated in the proposal;
  - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;

## APPENDIX G: MOHSS APPROVAL LETTER



MINISTRY OF HEALTH AND SOCIAL SERVICES

Private Bag 13215 Windhoek Namibia	Harvey Street Windhoek Central Hospital	Tel. No: (061) 203 3024 Fax No: (061) 222886
Enquiries: Ms. S.lipinge	Ref.17/3/3	Date: 28 June 2017

OFFICE OF THE MEDICAL SUPERINTENDENT

Ms.H.Ndjaleka  
~~P.O. BOX 81925~~  
0811222282  
teklashiindi@gmail.com

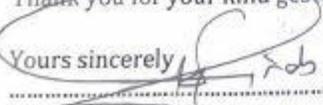
Dear Ms.Ndjaleka

**RE: PERMISSION TO RESEARCH ON THE PSYCOSOCIAL EXPERIENCE OF ADOLESCENTS DIAGNOSED WITH CANCER IN HOSPITAL WINDHOEK -NAMIBIA**

This letter serves to inform you that permission has been granted for you to conduct a study on the above mentioned subject as you have requested and does not include any remuneration.

Thank you for your kind gesture.

Yours sincerely

  
.....  
Dr.D.T. UIRAB  
CHIEF MEDICAL SUPERINTENDENT

29-06-2017