A STUDY TO UNDERSTAND THE EXPERIENCES OF ADOLESCENTS AND YOUNG ADULTS LIVING WITH CANCER IN A NORTHERN CAPE PUBLIC HEALTH SETTING

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DECLARATION

I, Leana Spies, hereby declare that the work on which this thesis is based is my original work and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome
AYA: Adolescents and young adults
CEO: Chief Executive Officer
CINAHL: Cumulative Index to Nursing and Allied Health Literature
FHS: Faculty of Health Sciences
HCP: Healthcare Professional
HIV: Human Immunodeficiency Virus
HPV: Human Papilloma Virus
HREC: Human Research Ethics Committee
HRQoL: Health Related Quality of Life
HSH: Harry Surtie Hospital
LMIC: Low- and middle-income countries
MEDLINE: Medical Literature Analysis and Retrieval System Online
MeSH: Medical Subject Headings
NGO: Non-governmental organization
PubMED: “Pub” Public/ Publisher; “Med” refers to MEDLINE database
RMSH: Robert Mangaliso Sobukwe Hospital
SAYAO: Society for Adolescent and Young Adult Oncology
TB: Tuberculosis
UCT: University of Cape Town
WHA: World Health Assembly
WHO: World Health Organization

ABSTRACT

Introduction: The challenges and holistic care needs of adolescents and young adults (AYAs) with cancer in low- and middle-income countries are under-researched. This limits evidence-based information regarding their experiences related to palliative care and quality healthcare services, resulting in a neglect in planning services for this population.

Aim: The aim of the research study was to explore and identify the challenges experienced by AYAs with cancer in a Northern Cape public health setting.

Objectives: The objectives were to describe the key concerns and priorities experienced by AYAs with cancer, to determine their holistic care needs and to identify the current limitations of healthcare resources that influence the provision of appropriate palliative care for AYAs with cancer in the Northern Cape.

Methodology: In this qualitative study, purposive sampling was utilized to select AYAs with cancer and between the ages of 18 and 39 years. The participants recruited were patients from the Northern Cape public health setting who received curative or non-curative cancer treatment at either Robert Mangaliso Sobukwe Hospital or Harry Surtie Hospital oncology centres. Their experiences were explored using individual, open-ended semi-structured interviews. Data were analysed using thematic analysis.

Results: A total of twelve participants between the ages of 22 and 39 were identified. Male and female participants were equally representative of the sample and their cancer diagnosis included many diverse tumour types that ranged from Hodgkin's lymphoma, breast cancer, testicular cancer, larynx cancer, melanoma, and colon cancer, to Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome-related malignancies such as Kaposi's sarcoma, cervical cancer, and non-Hodgkin's lymphoma. Six key themes emerged that provided insight into the challenges experienced by AYAs with cancer. These challenges were interrelated on a physical, psychosocial, spiritual and healthcare level, and they included the physical impact of cancer, additional illness burdens such as Human Immunodeficiency Virus and Tuberculosis, health system issues such as poor communication, delayed diagnosis, negative nursing attitudes, poor health services, inadequate resources, and transport problems. Apart from similar challenges experienced by AYAs with cancer in developed countries, such as overwhelming emotional responses, threatened dreams and hopes, a need for emotional counselling and better support systems, participants from this study also reported the impact of socio-cultural influences such as stigmatization, cultural beliefs, socio-demographics, poverty, unemployment, and a lack of cancer awareness and education within communities.

Conclusion: AYAs with cancer experience complex, multidimensional, interrelated challenges that include many health system issues. In a middle-income country, these challenges are amplified by additional factors such as communicable diseases, sociocultural influences, and poverty. Consequently, their holistic care needs are largely unmet. Even though the findings may only be generalizable to limited settings, they can be transferred to form specific recommendations on how to improve the quality of life of AYAs with cancer and that of their families in the Northern Cape public health setting. As reflected by these findings, higher interventions on a National Health level in order to implement the current national palliative care policy, are required. Advancements in AYA oncology care that acknowledge their unique developmental age, emotional capacity, distinct life stage, and social background are also pivotal. Notwithstanding the significant challenges that plague quality healthcare delivery in the Northern Cape, further research to elucidate the meaning of age-appropriate care and the development of comprehensive, integrated oncology and palliative care guidelines for AYAs with cancer in South Africa, is necessary in order to acknowledge and address their total pain.

CHAPTER 1

Introduction

1.1 The current global cancer burden of adolescents and young adults (AYAs)

The impact of cancer is devastating and even more so in the vulnerable population of adolescents and young adults (AYA) (1). Worldwide it is estimated that the AYA group (15–39 years) constitutes approximately 3 billion people and 40% of the global population (2). Globally, an increase in cancer prevalence among adolescents and young adults has been clearly apparent (3). This is supported by statistics that showed an incidence of more than a million new global cancer cases per year in the AYA group, representing the fastest-growing annual incidence of 0.6%–1.4% new cancer cases, compared to younger and older age groups (4). This cancer burden is significantly greater than any other age group, especially considering the affected number of healthy life years (4, 5). In high-income countries (HIC) cancer is known to be the leading cause of death in the AYA group (4). In addition, despite some improvement in survival for most cancer types of AYAs living in HIC, survival rate in this group is still much worse in comparison to the survival in the paediatric oncology group (6). Mortality statistics of 2018 revealed an estimated total of 9,555,027 global cancer deaths of which the AYA group accounted for 399,329 (4.2%) deaths, equating to an overall mortality rate of 13.7 per 100,000 patients (4). Even though a decline in mortality has been evident in HIC (excluding rarer cancers such as sarcomas and brain tumours), the progress in low- and middle-income countries (LMIC) is not known and the mortality rate is likely to be considerably different (4).

1.2 The current cancer burden of AYAs in low- and middle-income countries (LMIC)

Literature reveals a strong association between cancer mortality and the socio-economic status of a country (4). This is supported by evidence that worldwide 75% of all cancer deaths occur in LMICs, while the cancer prevalence in these countries is approximately 60% (7). Additional problems in LMICs include the inadequacy of population-based cancer registries that leads to inaccurate estimates related to the cancer burden among AYAs (5). In South Africa, cancer statistics of the AYA group are also not clear. Epidemiologists are expecting to see a 78% increase in the overall cancer incidence by 2030 (8). Factors influencing this sharp rise in new cancer cases include endemic infections such as Human Immunodeficiency Virus (HIV) and Human Papilloma Virus (HPV), over urbanisation, pollution, obesity, and unhealthy lifestyles (8).

Within LMIC, lower survival rates in AYAs with cancer also exist. Factors affecting survival rate include limited diagnostic accuracy, poor adherence to treatment, or patients presenting late to healthcare facilities. Consequently, there is an increase in cancer burden and suffering (4, 5).

Unfortunately, current healthcare systems in LMICs are incapable of keeping up with the profound increase in cancer burden. Considerable deficiencies that further contribute to these challenges, include inadequate financial budgeting and allocation of globally controlled resources (7). Thus, deficient healthcare systems with poor local health services and inequalities in health, relating to cancer care access in LMICs, not only have detrimental consequences related to the physical, emotional, and social well-being of patients and their families, but may also involve significant economic repercussions (7).

1.3 AYAs with cancer as a distinct population and a "lost tribe"

Many controversies regarding the age range of the AYA oncology population exist. When considering their different biological and developmental factors, the standard definition used by the United States National Cancer Institute is individuals diagnosed with cancer between the ages of 15–39 years old. This age range for AYAs with cancer is also used by the European population-based cancer registry, EUROCARE (2, 4).

The multiple life challenges that AYAs (in the absence of cancer) may encounter, especially on a psychosocial level are significant, unique, and dynamic, compared to both their younger and older counterparts (5). These consist not only of major life transitions, but also involves many fundamental tasks that are crucial for adulthood, for example, establishing individual identity, becoming independent, and forming intimate relationships including social support networks (9). Therefore, a diagnosis of cancer at the threshold of professional and/or family life, could have a profound impact on the quality of life of AYAs, as it may result in discontinuing education, sacrificing employment opportunities, and subsequently a loss of income and life goals (9). Consequently, the quality of life of their loved ones may also be affected. Moreover, as their coping skills are still emerging (10) and they have a higher tendency to develop mental health disorders (11), AYAs are rendered emotionally more vulnerable than any other age group.

Besides the challenge of providing holistic cancer care to AYAs, the consequences when failing to do so, are clearly reflected by the description, the "lost tribe", first described by Michelagnoli. (12). Considering the complex developmental stage and multifactorial needs of AYAs with cancer, it is also vital to acknowledge and successfully bridge the transition from the paediatric stage to adulthood, by providing care that uniquely address their multifaceted needs. However, as this gap in AYA oncology care still exists, AYAs often feel distressed and poorly equipped when appropriate AYA cancer care is affected by different treatment settings and it is further complicated by the wide age span within this group (10). When treated in adult cancer facilities, AYAs experience many barriers, for example, age and the different ways in which AYAs and adults perceive the impact of cancer. They also feel intimidated by adult-related problems such as dementia. This may lead to significant levels of distress among AYAs and increase their awareness of death. Moreover, healthcare providers working in the adult environment, lack necessary communication skills and are unable to identify the specific needs of AYAs with cancer (10, 13). Consequently, AYAs often perceive their treatment environment as negative and lonely, and they regard the attending personnel as uninvolved, unsupportive and difficult to trust (10). Thus, the need for greater knowledge and cognizance regarding the specific needs of AYAs is essential. For instance, establishing meaningful relationships with peer cancer patients may not only improve their coping skills, self-concept and emotional health (5, 14), but the support from peers is also regarded as superior to that of family members and friends (5, 14). In AYAs with advanced cancer that may progress to death, discovering the meaning in life and leaving a legacy behind are often in accordance with religious beliefs and has shown to be an important coping mechanism (9). Furthermore, existential distress may contribute to significant suffering among AYAs with terminal cancer. Therefore, equipping caregivers to support and deal with these spiritual concerns is paramount (14).

1.4 Progress made in developed countries regarding cancer care for AYAs

A rapidly growing international interest in AYA oncology is clearly apparent, especially when considering the formation of the Society for Adolescent and Young Adult Oncology (SAYAO), two journals dedicated to AYA cancer care, together with the publication of a textbook in its second edition (2). Many future opportunities for progress in cancer care for AYAs have also been proposed, some of which include the establishment of an oncology discipline that is tailored to the care of AYAs (15). This does not only relate to educational programs to provide dedicated AYA services, essentially tailored to resources and the promotion of their involvement in clinical trials, but also include strong advocacy campaigns and adequate financial coverage (5).

At present, many developed countries have formulated and implemented national initiatives that address the increasing challenges and needs of AYAs with cancer (6). In particular, Australia and the United Kingdom have shown vigorous attempts to bring fundamental change to cancer treatment and patient-centred care for AYAs. Other developed countries like Canada are not far behind in their strategies to provide equal comprehensive AYA oncology care, especially when considering the resultant economic benefits (2).

A pressing need to focus on AYA cancer care beyond high-income countries also exists and should be a high priority. However, this is currently a major challenge and will require powerful networks and committed stakeholders to initiate this strategy in a coordinated way (15). Notwithstanding these efforts and advances in AYA cancer care, many limitations related to the accessibility of age-appropriate multidisciplinary teams for AYAs with cancer exist (9). Contributing factors may be the many gaps in scientific knowledge related to holistic cancer care in AYAs. This includes the limited extent of literature that aims to identify the unique experiences of AYAs with terminal illness (9, 11). In addition, the distinct cancer spectrum and biology of AYAs has also been understudied globally. As a result, there are insufficient cancer services (5) and a lack of consistent treatment and quality care provided by healthcare providers and caregivers across the world (5). Furthermore, these consequences may be detrimental to the prognosis and survival of AYAs (5).

1.5 Progress made in developing countries regarding cancer care for AYAs

In the current literature, inconsistent age ranges and different developmental stages within the AYA group, make it extremely difficult to generalize current findings regarding their cancer experiences and apply it across the AYA population worldwide. Subsequently, little knowledge and understanding regarding many unique concerns and issues within the context of developing countries may exist and may lead to the provision of inadequate and unsatisfactory care, that may result in distressing outcomes for AYAs and their families (16).

There are many factors that impede the progress of cancer care in developing countries (17). The different and often interrelated categories may consist of systemic, socio-economic and healthcare related factors (5). For example, the state of global economic affairs may greatly impact the socio-economic status of a developing country, leading to resource restrictions and an increase in poverty, as well as a potential widening of the disparity in access and quality of cancer care between the wealthy and the poor, and especially those living in rural communities (17). Other current problems linked to healthcare resources in developing countries, include a lack of adequate healthcare staff and radiotherapy services. In particular, it is evident that radiotherapy does not exist in 30 LMIC countries, and as a result 80% of African patients are unable to access this treatment (5). These deficits magnifies the challenge to progress and provide appropriate cancer care that are in accordance with the latest treatment protocols (5). Furthermore, evidence has shown that less than half of essential cytotoxic drugs as stipulated by the World Health Organisation (WHO) for children with cancer, appeared in the national essential medicine lists of low-income countries leading to further increases in morbidity and mortality (5). Additional factors affecting the progress of cancer care in developing countries may include unhealthy lifestyles, for example, smoking, alcohol and drug abuse, deficient health literacy, different cultural groups with unique traditional beliefs and behaviours, as well as insufficient funding for cancer prevention and screening programmes (17).

1.6 The integration of palliative care into AYA cancer care

According to the WHO, palliative care is described as a key element of cancer care. It focuses on improving quality of life and reducing suffering of patients and their families from the diagnosis of a life-threatening illness by providing comprehensive care through an interdisciplinary team effort. Therefore, the misconception that palliative care is equivalent to end-of-life care, should be corrected, as end-of-life care constitutes only a component of palliative care, during which the emphasis shifts more towards comfort and symptom control. The World Health Assembly resolution (WHA67.19) adopted in 2014, recognizes palliative care as an essential component of health systems, and it should also be incorporated into primary health and home-based care (18). The need to recognize and appreciate the fundamental benefits of early integration of palliative care into oncology care, is also of utmost importance.

The positive outcomes that may result from individualized care when addressing the holistic needs and expectations of AYAs, their families and involved healthcare professionals, even in the long-term, is profound (18, 19). Additionally, the provision of patient-centred care in accordance with tumour-directed cancer treatment, has proven to increase survival, optimize symptom relief, minimize the use of futile treatment in the terminal phase, reduce anxiety levels and depression, contribute to greater caregiver satisfaction and utilize healthcare resources with better knowledge and judgement (18). Yet, in developing countries, fully integrated oncology and palliative care services for AYAs with cancer, has not been described and guidelines to refer AYAs with palliative care needs are lacking (14, 20). When considering the complex bio-psychosocial and spiritual needs of this distinct group, it creates an alarming gap (16).

1.7 Challenges within the South African context regarding appropriate cancer care for AYAs

In South Africa, many other challenges may contribute to the existing burden of AYAs with cancer. This includes poor infrastructure, low socio-economic status among the majority of patients and their families, as well as inequitable healthcare (5, 15). The current two-tiered health system of South Africa originated prior to the election of the democratic government in 1994, and consists of a public and private sector. As this health system is based on socio-economic wealth, great disparities between public and private healthcare exist (21, 22, 23). In the public sector, healthcare is government funded and available to all citizens at no cost. As the 84% of the population (approximately 40 million citizens), are uninsured and unable to afford private healthcare, they utilize public health services that are provided by only 30% of doctors in the country. In addition, these citizens often experience poor health outcomes as a result of poor health service managerial skills, negligence, poor resource allocation, and service delivery (21).

The Northern Cape is the largest province in South Africa and distances between towns are great. For example, the distance between Kimberley and Upington is approximately 400 km. Robert Mangaliso Sobukwe Hospital (RMSH), situated in Kimberley (the capital of the Northern Cape), is the main oncology referral centre in the public setting, and also the only hospital in the province that has two oncologists to provide specialist oncology services (See Figure 1). Limited oncology services are also provided at two other government hospitals in the province, namely in Upington and Kuruman. These services are mainly provided by experienced nursing personnel. This is not adequate and does not cover the need for proper cancer treatment for the whole province. Even though chemotherapy is administered in Kimberley, Upington and Kuruman, access to the necessary chemotherapy drugs is often limited. Radiotherapy services for patients in the public setting are currently offered only to a limited extent in Kimberley, but mainly in Bloemfontein, the neighbouring Free State Province, and which is more than 150 km away from Kimberley.

Public health services are mostly provided free of charge to patients without a medical aid and who have little or no income. However, AYA oncology patients may experience many other significant barriers regarding adequate public healthcare. Examples include the limited number and quality of medical healthcare facilities and services, as well as a shortage of oncology healthcare professionals. In addition, there are individual factors such as poverty, and financial and time costs when required to travel far distances to access healthcare, as well as subsequent delays in diagnosis and treatment initiation (24). Consequently, this may lead to poor health outcomes and an increase in their morbidity and mortality burden (25, 26).

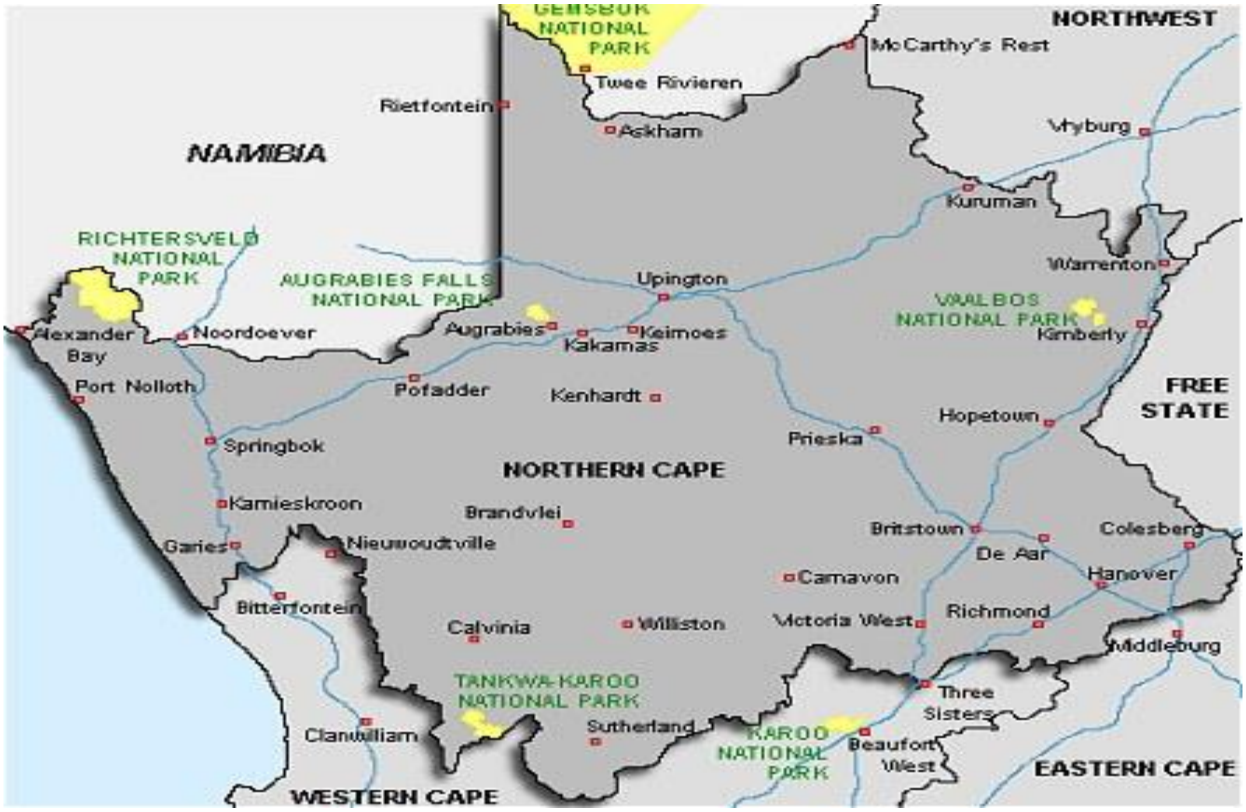

Figure 1: Map of Northern Cape showing the location of Kimberley and Upington

1.8 Conclusion

The current lack of information regarding the challenges and subsequent holistic care needs of AYAs with cancer in low- and middle-income countries, is unacceptable and the consequences for these patients are therefore tremendous, as it impacts various dimensions of their well-being (4, 27, 28). Furthermore, the lack of knowledge regarding the experiences of AYAs related to palliative care, healthcare systems and quality of service delivery, are also major gaps in informing health service planning to provide tailored patient-centred care (9). This lack of valuable information is also compounded by the uncertainty whether the experiences of AYAs living in developed countries are comparable to those living in developing countries, where the socio-demographics are exceedingly different, and where publicly-funded healthcare exists (9). Therefore, defining and providing age-appropriate palliative and cancer care and improving the quality of life for AYAs with cancer in South Africa, cannot occur without evidence that portrays a clear picture and reflect an adequate understanding of the unique experiences of this “lost tribe” (4, 27).

CHAPTER 2

Literature Review

2.1 Introduction

A literature search was undertaken using the keywords listed below in a Boolean structure to search for literature in PUBMED, Clinical Key, Medline, CINHAL and Google Scholar. The keywords and phrases used to conduct a thematic search included: “adolescent”, “young adult” “adolescents and young adults”, “AYA”, “cancer”, “oncology” “palliative care” “end-of-life care” “terminal care”, “needs”, “experiences”, “challenges”, “africa”, “south africa”, “middle-income countries”, “low-income countries”, “resource-limited countries”. Keywords were not present simultaneously during a search, as the body of literature would have been too limited. A hand search using the reference lists of articles found in the initial search was also performed to obtain additional references. Other resources that were consulted to broaden the knowledge of AYAs with cancer, included the second edition of the Blueprint of Care for Teenagers and Young Adults with Cancer, December 2016.

Articles included in this literature review were in English and published since 2003. The particular article by Michelagnoli et al. that was published in 2003, was the first article to use the term “lost tribe”. The latter term was repeatedly used in the dissertation to describe adolescents and young adults with cancer. Studies that acknowledged AYAs with cancer as a vulnerable and distinct group, explored their experiences, challenges and healthcare needs, and identified the benefits and barriers to palliative care in the context of AYAs with cancer were included. In addition, articles that focused on the need for holistic assessment and management of this group in developed and developing countries, were also selected. Due to the limited availability of literature regarding palliative care in AYAs with cancer in low- and middle-income countries, some relevant studies that were focussing more on the child and adult population, were also used.

2.2 The impact of cancer on AYAs

The term “lost tribe” has regularly been used in the literature to describe AYAs as a distinct population, and to reflect on the often unnoticed, confounding and vulnerable transition they undergo from childhood to adulthood. In an author manuscript by Rosenberg and Wolfe, focussing on palliative care for AYAs with cancer, the authors described AYAs as a complex group of patients with different levels of maturity and who often has limited capacity to understand and effectively deal with the impact of cancer on various life domains (16). Furthermore, this life-stage is characterised by many important developmental factors, such as self-identity, independence, intimate relationships, sexuality and striving towards personal and professional goals (16). The negative impact of a cancer diagnosis on the important developmental stages of AYAs, is well recognized and thus, Rosenberg and Wolfe concluded that this may result in a delay in or failure to reach certain fundamental milestones that may have a far-reaching detrimental impact on the future of AYAs (16).

Considering Rosenberg and Wolfe's recognition of AYAs as a unique and challenging group, Soanes and Gibson also collected important data in a qualitative study using a constructivist grounded theory approach to explore the experience and purpose of supportive care to young adults with cancer in the United Kingdom (27). The theory of "protecting an adult identity" was formulated after collating data arising from 11 in-depth individual interviews with young adults between the ages of 19–24 years, receiving cancer care (27). These findings were consistent with the findings of Rosenberg and Wolfe, and emphasized the impact of cancer on an emerging adult identity that not only disturbed important life experiences, relationships and events, but also affected important duties and careers such as work or education that led to an even greater need to retain their identity (16, 27). Despite the fact that the study was conducted in a developed country with a limited age range (young adults aged 25–39 years were excluded) and included only participants receiving curative treatment, these findings highlight the universal importance of AYAs sense of self. Furthermore, by using a grounded-theory approach, the authors were able to elicit and clearly understand the in-depth experiences, individual priorities and goals of participants in order to tailor the purpose and meaning given to supportive care (27).

Congruent with the findings of Soanes and Gibson, an interruption or threat to an evolving identity resulting from a cancer diagnosis in AYAs, was also an important finding of Knox et al. after performing a qualitative study in 2017 in a large cancer facility in Toronto, Ontario, Canada. The authors explored the experiences of 10 young adults aged 18–39 years with advanced cancer and they identified that isolation, alienation and a lack of belonging were important challenges experienced by participants (29). Not only did they feel markedly different from their peers or other young patients who had a curable cancer diagnosis, but they also felt poorly understood by loved ones. Additionally, AYAs experienced high levels of psychosocial distress and grief, and they had many unspoken fears, especially those who were new parents with small children, who feared the loss of their role as a parent. Many participants felt uncertain regarding future goals and experienced difficulty in understanding the meaning of their life (29). Findings also revealed that their underdeveloped logic reasoning and abstract thought processes may influence the way they cope, as thoughts pertaining to the possibility of death went against the progression of normal life (29).

The Knox study was culturally representative of only a single comprehensive cancer centre in Toronto, Canada. Moreover, challenges in identifying participants willing to take part in the study existed. Considering the latter, in addition to the fact that all participants were well-educated, English speaking and of whom only three were males, caution must be taken in generalizing study findings to young adults from other cultural or socio-economic backgrounds. Especially within the South African context, additional factors like poor leadership, unequal resource distribution, poor access to quality healthcare and high communicable disease burden also need to be considered, as it may influence the cancer experiences of young adults in a unique way (23).

Further work on the impact of cancer on AYAs was conducted through a meta-synthesis by Kim et al. Their study included literature published between January 2004 and March 2014 and a total of 51 articles met specified criteria. Qualitative articles from original papers that reflected AYAs own accounts of their experiences with cancer, were selected. In addition, the age range included AYAs between the ages 10–40. This meta-synthesis did not include childhood cancer survivors, the experiences of families or friends, or articles with poorly articulated methodology (30). Interpretation of results was done by the primary author and consisted of a two-level analysis followed by discussions and a final consensus between the first, second and third author. After a comprehensive review of literature, they concluded that the nature of physical, emotional, social and spiritual challenges experienced by AYAs with cancer, were interrelated (30). As stated by the authors, the impact of emotional responses such as fear, guilt and a longing to feel normal, influenced AYAs social roles, relationships and identity. Conversely, the inability to fulfil their social responsibilities and pursue future dreams such as being a good parent, striving to reach certain career goals or being financially self-sufficient, often led to anger, distress, and feeling constricted. Moreover, spiritual distress related to the possibility of death and this further contributed to their emotional burden.

Building on the findings of Kim et al., Belpame et al. found that physical challenges such as pain, fatigue, hair loss, weight change or post-surgical scars often increased emotional challenges such as anger, uncertainty, an altered body image, low self-confidence, and their sense of normality and control (3). The Belpame study was a qualitative study that aimed to understand the meaning of psychosocial challenges experienced by AYAs with cancer and the authors recognized the frustration of AYAs due to a loss of freedom that made them feel powerless and which led to a longing for independence (3). The impact of cancer on social relationships was significant (3, 29, 30). Feeling different from their peers, AYAs often experienced feelings of loneliness and isolation (3). According to Kim et al., some peers became distant as they lacked the ability to communicate within the unfamiliar context of cancer. Kim et al. also highlighted the importance of acknowledging the strong correlation between the specific challenges, needs, and the unique developmental phase of each AYA with cancer, in order to provide holistic, age-appropriate care (30).

Kim et al. acknowledged that even though their study aimed to focus on AYAs, some articles potentially included childhood cancer survivors and therefore the identified themes may be impacted by the unique challenges of this group (30). Similar to Soanes and Gibson and the study of Belpame et al. the meta-synthesis of Kim et al. also lacked detailed information on cancer patients in the age group 25–39 (3, 27, 30). In contrast to the study of Knox et al. that focus on AYAs with advanced cancer, participants from the studies of Soanes and Gibson, Belpame et al. and Kim et al. mostly included survivors or patients treated with curative intent. In addition, little mention is made regarding the importance of influences such as ethnicity, culture and geographical variability which may affect the way AYAs perceive their illness and the oncology care they will receive. However, despite these limitations, the major need for individualized, developmentally sensitive care among AYAs with cancer, was clearly evident (30).

2.3 The global lack of age-appropriate palliative care for AYAs with cancer

According to the World Health Organization, the global number of adults and children in need of palliative care per year, is estimated to be 40 million, of which 78% live in low- and middle-income countries. Yet, only 14% of those in need of palliative care have access to these services (31). At the sixty-seventh World Health Assembly in 2014, palliative care was recognized as an ethical responsibility across all age groups and levels of care and therefore includes the AYA oncology population (18). Furthermore, Rosenberg Wolfe, stated that the significant increase in cancer burden among AYAs calls for a strong need to improve access to palliative care services for this group (16). The authors assert that in practice, a clear description regarding evidence-based guidelines and the extent to which adequate palliative care services should be provided within the AYA oncology group, is lacking.

This statement by Rosenberg and Wolfe is further developed in a review article by Pinkerton et al. regarding the need for palliative care in AYAs. The authors reported positive progress in age-appropriate cancer care provision in many developed countries (32). However, according to the authors, many shortfalls including adequate symptom control, having difficult conversations, and end-of-life planning still exist.

A qualitative study was performed by Kenten et al. in England in response to limited literature, policy, and expert practice regarding the provision of optimal palliative care to AYAs with a poor cancer prognosis. By utilizing a realist evaluation approach, the authors aimed to understand the unmet needs and expectations of young adult cancer patients and their families during the end-of-life stage. The unique perspectives of 45 patients aged 16 to 40 years with a life expectancy of less than a year, as well as the experiences of the involved families, were explored. Congruent with the findings of Rosenberg and Wolfe and Pinkerton et al., the authors concluded that the palliative care needs of not only young adults with a poor cancer diagnosis, but also the needs of their families, were largely unmet (16, 19, 32). Describing cancer as a disruption to their daily lives, hopes and future dreams, young adults raised a significant need for support in adjusting to new changes in their disease trajectory. They expressed a need for continuity of care and building a trust relationship with the same healthcare professional, whenever possible (19). It was found that poor information-sharing by the involved healthcare professionals, in conjunction with a lack of the necessary communication skills, often left young adults feeling abandoned, distressed, and unable to adequately prepare for their end-of-life. In addition, family members expressed the need to feel better equipped with physical and psychosocial skills, in order to adequately support their loved ones throughout their cancer path (19). Study limitations were recognised by the authors. One of the biggest limitations is the low representation of haematological patients that generally constitutes a great proportion of cancer cases in this group. In addition, as healthcare professionals were often reluctant to communicate the non-curative nature of cancer to participants between the ages of 16–24. Their representation in this study was insufficient. Thus, there might be an uncertainty regarding an accurate reflection of data within this study (19).

In the South African setting, a recent study by Ngwenya et al. aimed to evaluate palliative care referral pathways for AYAs with cancer and HIV in South Africa. In their literature search, the authors emphasized the inconsistency of palliative care service provision and an increase in the unmet palliative care needs of patients in resource-limited countries. They mentioned that despite the published South African National Policy Framework and Strategy for Palliative Care in 2017, which stated the importance of available and accessible palliative care to all patients in need, the only established government-funded palliative care facility in South Africa is in Soweto, Gauteng, while the majority of palliative care is delivered by non-governmental organizations (NGOs). By utilizing a qualitative approach, face-to-face, semi-structured interviews were conducted from November 2016 – March 2017 with 30 health and social care professionals. They are involved in AYA palliative care in all care settings within three of the most populous provinces in South Africa namely, KwaZulu Natal, Gauteng and Western Cape (14). Supporting the findings of Rosenberg and Wolfe, the authors also concluded that in South Africa, no referral pathway for AYAs with palliative care needs exists. With limited resources across all settings in the country, access to palliative care was even more problematic in the rural areas where there were factors such as poverty, access to essential medicines such as morphine, and a shortage of healthcare professionals. A need for palliative care education among healthcare professionals, and the initiation of earlier serious illness conversations, were also identified, which is consistent with the findings of Kenten et al. (14, 19). The study findings of Ngwenya et al. were possibly limited by professional bias as only the perspectives and preferences of healthcare professionals and not those of AYAs, were included (14). In addition, HIV was the predominant diagnosis of patients cared for by these healthcare professionals, and consequently the findings may not represent a true reflection of the palliative care needs of AYA patients with cancer (14). Since the global age range for AYAs is not clearly defined, a lack of mentioning the age ranges of AYAs in the care setting of the interviewed healthcare workers, may also influence the reliability of results regarding palliative care in AYAs with cancer (14).

2.4 The fundamental role of palliative care in AYAs with cancer

In a 2017 feature article by Daunov and Cornett entitled *"Can the Early Introduction of Palliative Care Alleviate the Disease Burden in Adolescents and Young Adults with Cancer?",* palliative care was recognized as a medical speciality in its own right. According to the authors, the palliative care needs of AYAs diagnosed with any type of cancer, were not appropriately addressed during routine oncology care alone. Early palliative care referral concurrent with standard oncology care throughout the trajectory of an illness, was seen as paramount (33). Daunov and Cornett also stated that early palliative care intervention did not only help to relieve physical, psychosocial and spiritual suffering, but also increased quality of life, decreased healthcare costs, and in some cases improved survival. The authors also emphasized that the scope of palliative care provision was not only limited to AYAs and their families in the non-curative setting (including bereavement care to the family), but also to cancer survivors with palliative care needs (33).

Considering that early palliative care aims to improve quality of life of patients and their families (18), reference to the study of Sodergren et al. is important as the authors aimed to describe different health-related quality of life (HRQoL) issues experienced by AYAs with cancer and receiving treatment that includes palliative care. By conducting semi-structured interviews with 45 AYAs with cancer between 14–25 years, across different cultural settings namely, the Netherlands, Poland, United Kingdom, Israel, Norway and France, a multitude of interconnected HRQoL issues (as also stated by Kim et al.), such as treatment burden, activity limitations, limited financial reserves, and concerns relating to challenging topics such fertility or sexuality, were identified. The importance of cancer care that is specific to address every quality-of-life issue among AYAs with cancer, was emphasized by the authors. Despite the fact that this study involved a great diversity of cultural settings and provided a comprehensive overview of HRQoL concerns of AYAs with cancer, the quality of life issues of AYAs older than 25 years, were not explored and subsequently their concerns remain unknown. In addition, the incorporation of the EORTC core questionnaire (EORTC QLQ-C30) during interviews to promote further discussion among AYAs aged 14–25 years, may have influenced the type and number of quality-of-life issues elicited. Subsequently, it may also impact the prevalence and generalizability of these findings (34).

Zebrack et al. conducted a Delphi study that aimed to identify important health and supportive care needs for AYA patients and survivors. Forty health professionals in the field of oncology and 37 young adults (aged 18–44 years) were included in the study and surveys were emailed to them over three iterative rounds. Significant data reported by the authors included that engaging with other young adults with cancer, was regarded more valuable than the support received from family and friends (35). Not only did the opportunity to meet other young adult cancer patients lead to better coping skills, but by sharing experiences and comparing themselves with AYAs who were experiencing more severe and distressing circumstances, an improvement in psychosocial health and a sense of group identity was promoted (35).

Beyin conducted a meta-synthesis entitled, *“Experiences of Supportive and Palliative Care of Adolescents with Life Threatening Illness: from the perspectives of adolescents, family and nurses as providers”,* identifying many key multidimensional palliative care needs of adolescents with life-threatening illness as well the needs of their families. After a comprehensive search in the PubMed and CINAHL databases, 16 of the 1066 qualitative studies with a high and moderate academic quality, peer-reviewed and published in English from 2006–2016, were selected (36). The authors also identified AYAs need for social support that consisted of not only the unique contributions of peers, but also of family and the involved healthcare professionals. Congruent with the findings of Zebrack et al., peer relationships and support did not only help them to feel a sense of belonging, being acknowledged as a person, and confident, but also promoted fellowship, joy, and sharing life experiences that fostered a sense of normality (35, 36). In addition, the need for an age-appropriate care setting was clearly evident in conjunction with healthcare professionals that were able to communicate effectively and that could provide a sense of comfort and positivity (36). Beyin also emphasized the importance of providing palliative care to families (19, 36). Families did not only report a need for support from friends, other family members and involved healthcare professionals, but also a need for honest and clear information to clarify uncertainties. Furthermore, to understand and acquire knowledge about their child’s illness, kind and caring attitudes of healthcare professionals towards their children, and wanting their children to be comfortable, symptom free and in the appropriate place of care, were also emphasized (36). Beyin recognized study limitations, the biggest of which was the low quantity of data sources that only used published articles and excluded unpublished studies, such as master’s theses and dissertations (36). In addition, the wide age range of 2–26 years may also have led to inappropriate conclusions regarding the experiences of AYAs. Themes and subthemes were identified by the author as this was an independent degree, however, discussions with and advice from group supervisors minimized this limitation (36).

2.5 The obstacles to proper palliative care provision to AYAs with cancer

Fernandez et al. reported on *“Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult-Aged Cancer Patients and Survivors”,* from a consensus of valuable research findings presented at the Canadian Task Force on Adolescents and Young Adults with Cancer Workshop in March 2010. One of the aims was to redress the inequities in oncology care of this group by developing or improving AYA-specific healthcare programs and models of care (37). Among the six recommendations mentioned, attention was drawn to the challenge and importance of early palliative care referral to an age-specific interdisciplinary team that is trained to explore, identify and meet the needs of AYAs with cancer. It was further suggested that the development of screening tools was necessary to identify their emotional distress and medical concerns. The initiation and facilitation of conversations regarding advance care planning that included death and dying, as well as adequate provision for hospice services and home-based care support to meet the end-of-life care needs of AYAs, were also emphasized (37).

Avery et al*.* further investigated the challenges experienced by healthcare professionals when partaking in early discussions regarding palliative care with AYAs diagnosed with advanced cancer, as well as their families. In this qualitative study, four themes emerged after performing and thematically analysing 19 semi-structured interviews with oncologists, palliative care specialists, psychiatrists and professional nurses who cared for AYAs with advanced cancer. In addition to the obstacles mentioned by Fernandez et al., Avery et al*.* demonstrated feelings of devastation and anguish that healthcare professionals have towards AYAs that are facing premature death. The emotional connection with this vulnerable group did not only leave them grief-stricken and feeling helpless, but also created considerable discomfort, difficulty, and uncertainty on how to approach and engage with AYAs and family members regarding the provision of palliative care (37, 38). Despite possible selection bias due to convenience sampling, conducting the study in only two tertiary hospitals in Toronto, Canada, and including the perspectives of mostly the primary researcher, the authors identified the critical need for HCP education and research regarding communication strategies to introduce palliative care for AYAs with advanced cancer, and how to involve the family (38).

In a review article by Osbourn et al. entitled, *"Models of care for adolescent and young adult cancer programs",* the experiences of AYA cancer clinicians from Australia, United States and United Kingdom were used to identify the reasons why routine cancer care often does not meet the needs of AYA with cancer, and to describe important aspects of models of AYA care (39). They found that current obstacles to enhance holistic cancer services for AYAs included poor collaboration between adult and paediatric units, lack of AYA-specific multidisciplinary teams, limited participation of AYAs in clinical trials, and inadequate research on the preferences and needs of AYAs at the end of life. Even though no current standardised AYA model of care exists, they concluded that the development of such a program will not only require considerable on-going effort, finances and infrastructure, but also on-going research to evaluate and compare AYA program development to promote national and international standards of quality care to AYAs with cancer (39).

In the findings of Belpame et al*.*, the authors also described a few obstacles to appropriate AYA cancer care. This included a lack of patient-centeredness, compassion, professional involvement, investment of the healthcare professional's time, and the inability to acknowledge AYA patients' identity and elicit their unique needs (3). Moreover, not being granted autonomy over the amount of information they wanted to receive regarding their illness at a time that was preferable to them, influenced AYAs' attitude towards healthcare professionals. They were often left feeling unsatisfied and uncertain regarding their illness (3).

Bibby et al*.* supported the findings of Belpame et al*.* and Osbourn et al*.* after performing a systematic review and selecting 45 articles on the experiences and needs of AYAs with cancer. The authors noted the vital importance of tailoring information to each AYAs developmental stage (3, 39, 40). Their study looked at literature published between 1990–2015 and triangulated the data based on sample representation, description of methods and results. This included the age of participants at diagnosis, their age when participating in the study, and the cancer stage. Data was scored by two authors and conflicts were resolved through a consensus approach. The authors concluded the need of AYAs to be treated at age-appropriate care facilities by healthcare professionals with AYA expertise. They also emphasized the need for information, especially relating to fertility issues and available services (40).

Silbermann et al*.* conducted a study "*Evaluating Palliative Care Needs in Middle Eastern Countries*". According to their literature review, low-income countries have shown advances in the diagnosis and treatment of cancer in all age groups. Yet, palliative care still remains a major challenge (1). In this study, the authors aimed to explore the knowledge, beliefs, barriers and resources related to palliative care, to develop strategies to improve palliative care in Middle Eastern Countries. By utilizing a descriptive survey, data was obtained from 776 healthcare professionals in 15 Middle Eastern Countries. The greatest barriers to palliative care were shown to be poor knowledge regarding the meaning of palliative care among communities, a lack of training among healthcare personnel, lack of available palliative care beds, inadequate hospice and home-based care services, and a shortage of healthcare personnel (1). Even though this study focussed on patients from all age groups in the Middle East requiring palliative care, young adults were identified as a population that requires special attention. In addition, culture was also considered as a potential obstacle to palliative care. Culture played an integral part in the way patients and families viewed and experienced illness and death, and therefore it requires a sensitive and explorative approach in the context of palliative care (1). Study limitations included possible sample bias due to the use of convenience sampling, and surveying of only healthcare professionals and not patients (1). In addition, certain sections in the surveys were only translated to Turkish that led to a decrease in the number of participants.

2.6 Additional challenges in Africa that affects palliative care provision to AYAs with cancer

A literature review performed by Kohi et al*.* clearly demonstrated that a lack of resources to provide cancer treatment and care, led to an increase in cancer burden and related challenges among AYAs in low and middle-income countries, compared to developed countries that subsequently placed these cancer patients in an even more vulnerable position (41). This qualitative study, conducted in Tanzania, included two focus group discussions with 8 young adults (18–25 years) and 14 children (9–17 years) that explored their cancer-related concerns and needs of care and support during their cancer treatment. Having analysed the discussions of the 22 participants by using content analysis, the authors identified many challenges that were unique from that of developed countries, such as feeling stigmatized due to assumptions that weight loss was due to HIV, a wrong or delayed diagnosis, receiving treatment far from home, transport issues, financial difficulties, inadequate governmental funds causing limited access to the necessary medication like chemotherapy, broken or a lack of equipment, poor hospital conditions, long waiting periods for appointments, a lack of quality and compassionate care by hospital staff, lack of community support, and a major need for health education among patients, families and the community (41). AYAs expressed an urgent need for higher quality of care and improved support. This study was only limited to patients between 9–25 years, of which the majority fell into the 9–17 years age group, and therefore, the challenges experienced by young adults between 26–39 years in developing countries, remain unknown and require further exploration.

Edwards and Greeff conducted a study, entitled *"A descriptive qualitative study of childhood cancer challenges in South Africa: Thematic analysis of 68 photovoice contributions"* (42). The authors focussed on exploring, documenting and analysing childhood cancer-related challenges in South Africa by recruiting a total of 58 patient-participants (including patients between 11 and 17 years, parents and guardians), and 10 paediatric oncology workers from tertiary oncology centres and from the Childhood Cancer Foundation of South Africa (CHOC) interim care homes across South Africa. By utilizing photovoice methodology, face-to-face interviews were conducted by multilingual and multiracial psychologists and social workers to promote a patient-centred approach. The cancer challenges reported by the authors, such as poor service delivery (consistent with the findings of Kohi et al.) contrasted with the findings from studies conducted in developed countries (42). Other challenges included a delayed or incorrect diagnosis that intensified the patients' and families' fears that were due to worsening symptoms, poor referral pathways, and the distance to a tertiary hospital that limited access and which resulted in delays to care with late presentation or delayed follow-up, and as a consequence advanced disease. Transport also created unique challenges as some patients from the Northern Cape had to travel distances as far as 800 km to reach a tertiary hospital (42). Limited transport vehicles and difficulties with bookings, long waiting periods that led to sleeping on benches at pick-up points, or a lack of money, contributed to additional distress and anxiety for patients and their families (42). Moreover, congruent with the findings of Silbermann et al. the authors also identified the importance of acknowledging traditional culture-related challenges (1, 42). Within the South African context, this included distorted beliefs that cancer-related complications reflected bewitchment, is associated with evil spirits, and that such a diagnosis of a child was often denied by parents. Subsequently, being diagnosed with cancer led to feelings of shame and embarrassment among family members and consequently such a diagnosis was often kept a secret. These findings did not only reflect the need for improved public awareness of cancer, but also raised the need for respectful collaboration with and education of traditional healers within the context of cancer and palliative care (42). Lastly, illiteracy and the absence of information transfer in a patient's home language, led to poor communication, feelings of powerlessness and uncertainty regarding the cancer treatment plan (42).

Edwards and Greeff demonstrated a lack of appropriate psychosocial support and culturally sensitive palliative care services to patients and their families. Even though the study focused only on children and not AYAs with cancer, many of the challenges continues into the AYA stage, therefore raising the need for the development of advocacy strategies and policies related to palliative care. Other limitations of the study included a small sample size, the unequal representation of the participants across the country, and limited feedback regarding palliative care.

2.7 Conclusion

Following this comprehensive search, it was evident that despite existing literature that identified and described the challenges and perspectives of AYAs with cancer, and in particular those with advanced/metastatic disease, (9) the majority of studies were conducted in developed countries. In contrast, advancements in age-appropriate AYA oncology care in the majority of developing countries, still remain a major challenge (5, 15). There is also a general paucity of guidelines for palliative care in AYAs in the oncology field (16). The researcher noted that an increased awareness and understanding of the holistic care needs and provision of palliative care in AYAs with cancer is an important research priority (16). Furthermore, it was found that a lack of age-appropriate care for AYAs with cancer, places considerable long-term health and social burden not only on patients and their families, but also on healthcare systems. Considering their psychosocial and palliative care needs that tend to exceed those of children and older adults (40), factors that may exacerbate these needs include limited AYA healthcare expertise and a middle-income country like South Africa. As a consequence, tremendous suffering and impaired quality of life for these patients and their families may ensue. This makes the provision of appropriate palliative care to AYAs an extremely difficult task for healthcare workers, families, caregivers and for the community.

2.8 Rationale for the study

Experience at Robert Mangaliso Sobukwe Hospital in addition to a review of the literature, shows that AYAs have particular needs when diagnosed with a serious illness. In South Africa, there is a paucity of evidence regarding the experiences of the AYA population receiving cancer treatment and care. The unique multidimensional challenges experienced by this distinct group, may be magnified in a middle-income resource-limited setting. Understanding the first-hand experiences of these individuals, is imperative for creating awareness regarding their unique healthcare needs. The information and knowledge gathered from this study will lay the foundation and may contribute to the development of individualized and age-specific oncology and integrated palliative care strategies, policies and interventions, to appropriately address the needs and provide better quality-of-life outcomes for AYAs with cancer.

Research Question

What are the challenges experienced by AYAs with cancer in a Northern Cape public health setting?

Aim

To explore and identify the challenges experienced by AYAs with cancer in a Northern Cape public health setting.

Objectives

- To describe the key concerns and priorities experienced by AYAs with cancer.
- To determine the holistic care needs of AYAs with cancer.
- To identify the current limitations of healthcare resources that influence the provision of appropriate palliative care for AYAs with cancer in the Northern Cape.

CHAPTER 3

Methodology

3.1 Introduction

This chapter will discuss the system of methods that was utilized to implement the study.

3.2 Study design

A qualitative study design was conducted through individual semi-structured interviews. This method was used in order to get the index understanding and in-depth information of the lived experiences of participants. It also allowed a more systematic and comprehensive approach, while still conversational, flexible and personal to explore, detect, clarify and understand the experiences of AYAs with cancer. In this way, a unique depth of detailed information regarding the thoughts, opinions, priorities and feelings of participants was discovered. Other study designs were considered, for example using a survey of a larger number of patients. However, the reason for not including a survey was based on the influence it may have on the reliability of the data. In addition, it may negatively influence the exploration and collection of detailed information from participants as they may be reluctant to provide accurate, honest answers and feel uncomfortable when having to share sensitive information.

3.3 Study sites

This study was conducted at two public hospitals that provide oncology services in the Northern Cape in South Africa. Robert Mangaliso Sobukwe Hospital (RMSH) is situated in Kimberley and is the main oncology referral centre for the whole province. Harry Surtie Hospital (HSH) is a secondary hospital situated in Upington, approximately 400 km from Kimberley, that also provides oncology services that are mainly run by nursing personnel and supervised by RMSH oncology department (See page 17 for a map of the Northern Cape).

3.4 Study population

The study population was adolescents and young adults attending oncology services in the Northern Cape.

3.4.1 Inclusion criteria

- Patients between 18–39 years.
- Patients diagnosed, registered and receiving curative or non-curative treatment for any solid malignant cancer at RMSH or HSH.
- All participants had to be able to understand and speak English, Afrikaans or Tswana.

3.4.2 Exclusion criteria

- Cognitive condition: Any cognitive impairment that deems a patient not to have the capacity to provide informed consent for cancer treatment (assessed as not being orientated to person, time and place).
- Physical condition: Poor symptom control, high levels of fatigue and a clinical condition that is generally poor.

3.5 Sample size and sampling method

Purposive sampling was used to generate a diverse study sample in terms of age, gender, type of cancers, treatment and demographics. The sample size was not linked to a fixed number of participants. The reason for this is complicated and consequently, besides a paucity in the literature regarding guidelines for sample size in qualitative studies, the number of interviews conducted may also be influenced by many additional elements such as the number of authors, or the country of publication (43). Therefore, the number of participants in this study corresponded to the number required for data saturation. This was defined as the inability to gain new theoretical insight that contributes to existing knowledge and themes that have already been identified (44).

3.6 Data collection tools

3.6.1 Demographic questionnaire

A brief demographic questionnaire (Appendix 6 and 7), developed by the researcher and reviewed and refined in discussion with supervisors, consisted of basic questions to obtain information regarding each participant’s age, gender, language preference, marital status, number and ages of their children, highest level of education, the year in which the cancer was diagnosed, type of cancer, current treatment, and the distance (in kilometres) to the nearest oncology facility. During the first interview, two categories were added namely, employment status and cultural background, to provide a more complete psychosocial background of the participants. Participants were not forced to provide a specific answer. Rather, they were approached in a non-judgemental way and they were all comfortable and open to share their cultural background.

3.6.2 Semi-structured interview guide

A semi-structured interview guide (Appendix 8 and 9) was developed by the researcher and reviewed and refined in discussion with supervisors to help guide interviews. All the questions were based on a questionnaire used by Knox et al. (29) that originated from themes that were identified in the existing AYA literature. The questions selected for the purpose of this study encompassed physical, emotional, social, and spiritual domains and they were discussed with colleagues and the principal investigator. Subsequently, some questions underwent minimal reconstruction to make them more relevant to the South African setting. The questions appropriately addressed the research question and they were arranged in the most suitable sequence. The first two open-ended interview questions were: “What was your life like before you were diagnosed with cancer?” and “What is your life like since you’ve being diagnosed with cancer?” The aim of these questions was to encourage participants to provide answers and to promote the collection of personal experiences and detailed data. After conducting the first two interviews, redundant questions were removed, and a few spiritual questions were added such as: “Why do you think this happened to you?” and “What helps to encourage you during this difficult time?”

3.7 Recruitment and training of research assistant

One research assistant was recruited based on her extensive knowledge and experience in the field of cancer. This included palliative care training, experience, good communication skills, a flexible schedule, and her availability for the whole duration of the data collection period. The research assistant was informed of the aim of the study and the questionnaire and received training by the primary researcher. The training session involved comprehensive information and discussion regarding:

- Research ethics to assist the research assistant to understand the issues of voluntary informed consent and to be able to pay attention to the vulnerabilities of the potential participants during data collection.
- The goals of the interview to answer the research question and to achieve the study objectives.
- A review of interview techniques that included the use of open-ended questions and an explorative approach during facilitation of interviews to obtain rich and valuable data.
- A thorough review of the topic guide of the interview.

- Practice to use the questionnaires.
- Skill-building exercises regarding interviewing and interpersonal communication.
- Clarification of uncertainties and answering any questions.

Prior to data collection, the research assistant felt prepared and confident to conduct the individual interviews.

3.8 Recruitment of participants

Following the approval from the Human Research Ethical Committee (HREC) of the Faculty of Health Sciences (FHS) at the University of Cape Town, further approval from the Northern Cape Department of Health and subsequent permission from the Chief Executive Officer (CEO) at RMSH and HSH respectively, were obtained prior to the onset of the study (Appendix 3).

The study was introduced through discussion with colleagues at the RMSH and HSH oncology study sites, respectively. Awareness of the study was created by means of posters in each of the oncology clinics, as well as verbally by the attending oncology doctor or nurse during clinic consultation with patients who were eligible. Patients between 18–39 years of age who received oncology care at the time of recruitment and who were willing to participate after being informed of the study, were asked permission to give their contact details to the primary researcher. Thereafter, patients who met the inclusion and exclusion criteria were identified by the primary researcher and subsequently, approval by them was sought to further discuss the study personally or telephonically. Each patient who showed interest and agreed to participate following this discussion, was scheduled for an individual face-to-face interview session.

Written informed consent was obtained by the research assistant in person prior to each interview. Detailed information regarding individual interviews including audiotaping of the interview, was provided in writing and verbally in a language that was well understood by each potential participant. There was ample opportunity for questions from the research participant and uncertainties were concisely clarified to confirm full comprehension of what the study entailed. To ensure voluntary informed consent, potential participants were not coerced to participate in any way. They were assured of confidentiality and that their right to choose not to take part or to withdraw from the study at any stage (including if they became distressed), would not have a negative impact on the quality of their care. This was fully explained in the informed consent document (Appendix 4 and 5). In addition, maintaining honesty and integrity towards participants was a high priority at all times. This was also documented in a carefully constructed participant information sheet (Appendix 4.1 and 5.1). Recruitment of participants continued until data saturation was reached.

3.9 Data collection process

Every participant was asked to complete a brief demographic questionnaire (Appendix 6 and 7) before the onset of their interview. The answer to each question was written down by the researcher in the presence of the research assistant. The individual interviews consisted of an open-ended, explorative approach and lasted between 30–75 minutes. All interviews were conducted by the research assistant in the participant's language of choice and it took place in the hospital in a quiet, private and comfortable setting to minimize any disruptions. Before initiating the interview, the researcher and research assistant were introduced to the participant. This was followed by a description of the research aims that was an indication that the discussion will be tape-recorded. Further opportunity was provided for participants to ask questions before commencing with data collection. The researcher ensured that every participant felt able to fully participate on that particular day.

A semi-structured interview guide was used by the research assistant to collect data (Appendix 8 and 9). To discover personal in-depth experiences of participants, flexibility and deviation from questions was allowed where necessary to follow the answers of participants. The participants' beliefs and values were respected at all times while collecting and analysing data. Before closing the interview, participants' perception of the healthcare needs among AYAs and current resource limitations experienced during their oncology care were explored. This included the scope of services that would help to improve their quality of life and to lessen their suffering. Simple, clear language was used, and when needed adequate clarification was offered throughout the interview to reduce any uncertainty regarding particular questions or concepts. Interviews were audiotaped and professionally transcribed, verbatim, after each interview to promote an accurate transcription of the interview and to reduce the possibility of researcher interpretation and memory bias. At the end of the interview, participants were thanked for their involvement in the study and they were given the opportunity to raise any other comments or questions if desired. All Afrikaans interviews were also translated into English. As all participants with a Tswana background chose to have the interview in Afrikaans or English, no Tswana interviews were conducted.

Dependability and credibility of data were promoted by using a standard semi-structured interview guide for all participants, as described under data collection tools. This interview guide contained questions that originated from themes that were identified in the existing AYA literature and it encompassed the same domains (physical, emotional, social and spiritual) for all participants. The collected data, including the transcribed and translated transcripts, were re-evaluated by the primary researcher and also underwent peer examination by discussing all findings with the principal investigator who is experienced in the field of qualitative research.

Transferability of data was promoted by using the above described methodological methods, including purposive sampling that allowed the selection of those participants to generate a rich and robust presentation of findings.

3.10 Distress protocol

During data collection, acting in the participants' best interest and not inflicting any physical or emotional harm on them, was valued as a high priority at all times. Any emotions associated with sensitive issues during deep conversations, were recognized. Those participants who appeared to be distressed in any way were asked if they want to stop the interview or if they want to continue at a later stage - either after a short break, or on another occasion. In this way, recognition was given to the fact that the narrative of the individual's experience was sometimes of therapeutic benefit emotionally. None of the participants chose any of these options. The promotion of emotional integrity was ensured by obtaining permission from the social work and psychology departments to be available for referrals as needed. However, no participant required urgent referral during any of the interviews. Further details to access these services were also in the participant information sheets (Appendix 4.1 and 5.1).

3.11 Data storage & confidentiality

Strict confidentiality and anonymity was maintained at all times by anonymising each questionnaire and transcript without compromising accuracy of data. No personal identifiers were used on study documentation and only study identification numbers were used. The storage of the master copy identifying participants and study numbers, as well as both electronic and hard copy data, were kept safe by using both password protection (electronic data) and keeping the hard copies in a fire-proof filing cabinet that is access-controlled. Hard copies of participant documents and transcripts shall be safely stored for five years prior to being suitably destroyed.

3.12 Ethical considerations

The study was funded by the SAMA Research Masters Supplementary Scholarship for 2020 and was undertaken to fulfil requirements for the University of Cape Town (UCT) Master of Philosophy in Palliative Medicine. The study involved human participants and required strict adherence to ethical standards in all aspects. Ethical approval was received from the Human Research Ethical Committee (HREC) of the Faculty of Health Sciences (FHS) at UCT. The research proposal was submitted on 14/06/19 (HREC REF: 447/2019) and formal approval was granted on 04/07/19 (Appendix 1). Ethics approval was received by the Northern Cape Department of Health to conduct the study (Appendix 2). Subsequently, permission was obtained from the Chief Executive Officer from each study site - Robert Mangaliso Sobukwe Hospital and Harry Surtie Hospital (Appendix 3).

Adhering to ethical guidelines, assisted the researchers to weigh the value of advancing knowledge against the value of non-interference in the lives of research participants. Research participants were well-informed verbally and in writing regarding the goals, procedures and importance of the study, the possible benefits and risks involved, plans for dissemination of the findings, as well as the measures taken to ensure confidentiality and anonymity.
Voluntary participation and informed consent were obtained in the participant's language of choice and participants had a sound understanding of these elements, outlined in their informed consent document (Appendix 4 and 5).

Fair selection of participants was ensured by purposive sampling which included available and willing participants that met the scientific study requirements and complied with inclusion and exclusion criteria. Study participants were not given any incentives during their participation in the study.

Bias was avoided and reflexivity was ensured by adhering to the principles and processes of a thematic analysis as described above. Attention was dedicated to the role of the primary researcher in knowledge generation through self-reflection, and by keeping a reflexive journal throughout the study.

3.13 Data analysis

During the data collection process, one interview had to be discarded, due to poor audio quality. Transcribing and analysing data occurred concurrently with new data collection, as this led to the generating of new questions for subsequent participants. For the analysis procedure, one transcriber and one translator were selected, based on their previous academic transcribing and translating experiences, as well as on their professionalism, diligence, attention to detail and familiarity with participants' cultural background. Their positions were confirmed by the primary researcher after their transcription and translation abilities were assessed by means of a mock recording. Subsequently, specific instructions were provided, in particular data representation, certain levels of detail and abiding to strict patient confidentiality regarding participants' personal information. All transcribed interviews and recordings were reviewed by the primary researcher to ensure that high accuracy and quality were maintained. Thereafter, Afrikaans interviews were translated into English by the translator. Thus, it enabled regular checking of transcripts against translated versions during analysis. Furthermore, all translated interviews were also reviewed by the primary researcher to confirm the integrity of interpretive insights and conceptual evidence. Data obtained from all other interviews were analysed using thematic analysis. The researchers adhered to the principles and processes of thematic analysis as described below. This method corresponds with the aim of the study which is to describe and promote the understanding of the experiences of AYAs with cancer, by identifying patterns and emergent themes that form the foundation of subsequent data analysis (44).

The thematic analysis process was structured yet flexible, allowing adequate interpretation of data. The primary researcher and the research assistant familiarized themselves with the data obtained by reading and rereading it until immersion occurred and an overall understanding of the content depth was discovered. The primary researcher systematically labelled data extracts with preliminary codes, based on the consistency and commonality of data by using NVivo V.12 qualitative research software. An inductive approach was utilized where key concepts, trends, meanings and themes were identified that assisted with the development of a fresh framework for analysis. Accordingly, this approach enabled the generation of primary data where no fixed relation between potential themes and interview questions existed (44). Collating data into certain categories, contributed to the development of patterns and potential themes (44). Access to original transcripts was available when reference to certain data was necessary at later stages. As the initial codes were identified, similar codes were grouped together in a meaningful way and names were given to each group. Eventually, themes and subthemes originated from specific codes, and often the theme to which certain codes belonged or the formation of a new theme, occurred at a later stage. The way in which a variety of codes can be combined to form an overarching theme, as well as the relationship between different codes and themes, were also recognised (44). The search for themes and the development of a provisional thematic map, also included that the data within each theme were meaningfully related to one other and the themes were explicitly distinguishable and conformed to the research question. Extensive reviewing and refining of all codes and themes took place in discussion with research supervisors and within the context of all collected data. The flexible and cyclic nature of this analytic stage contributed to the development of coherent and clearly apparent themes and subthemes. Defining each theme by identifying the scope and focus of each, was agreed upon by all researchers to produce a trustworthy rich and consistent description of data (44).

Results of the data analysis are described in Chapter 4.

CHAPTER 4

Results

4.1 Introduction

Chapter 4 describes the “voices” of 12 research participants that were interviewed over the period: 1 October 2019 – 3 December 2019. These participants represented young adult cancer patients from the Northern Cape public health setting who had received cancer treatment at the oncology centre of either RMSH or HSH.

4.2 Participant demographics and characteristics

The mean age of participants was 31 years (range 22–39 years). Female and male participants were equally representative of the total sample and more than half were Afrikaans speaking. Eight participants were receiving cancer treatment at the RMSH oncology facility in Kimberley, and four at the HSH oncology facility in Upington. Nine participants were single, but six of them were involved in romantic relationships. Despite only three participants being married, eight had children. The majority of children were more than six years of age. Only six participants had completed Grade 12. This was also the highest level of education achieved among all participants. Participants represented many different cancer stages and a non-curative treatment approach was being followed in the majority of participants (*n* = 7). Furthermore, the sample consisted of diverse tumour types: Hodgkin’s lymphoma (*n* = 2), breast cancer (*n* = 2), testicular cancer (*n* = 2), larynx cancer (*n* = 1), melanoma (*n* = 1), colon cancer (*n* = 1) and also included HIV/AIDS-related malignancies such as Kaposi’s sarcoma (*n* = 1), cervical cancer (*n* = 1) and non-Hodgkin’s lymphoma (*n* = 1). See Table 1 for a detailed description of participant demographics and characteristics.

Table 1 Participant demographics and characteristics (*N* = 12)

Demographics and characteristics		Description
Age	Median	31
	Range	22–39
Gender	Female	6
	Male	6
Language	Afrikaans	8

	English	4
Marital	Single	9
	Married	3
Children of participants - number	No children	4
	One child	5
	Two children	2
	Four children	1
Children of participants – age	0–12 months	1
	12–23 months	1
	2–6 years	2
	7–12 years	8
	>12 years	3
Highest level of education	Grade 12	6
	Grade 11	5
	Grade 9	1
Employment status (at diagnosis)	Unemployed	7
	Employed	5
Year of cancer diagnosis	2019	10
	2017	1
	2014	1
Cancer type	Lymphoma	3
	Breast	2
	Testicular	2
	Larynx	1
	Melanoma	1
	Kaposi's sarcoma	1
	Cervix	1
	Colon	1
Treatment modality/intent (at time of interview)	Palliative chemotherapy	7
	Chemotherapy (curative intent)	3
	Radiotherapy (curative intent)	1
	Surgery (curative intent)	1
Place of oncology care	RMSH (Kimberley)	8
	HSH (Upington)	4
Travel distance to tertiary oncology facility	Less than 50 km	6
	50–600 km	6
Cultural background (self-identified)	Tswana	5
	Coloured	5

Caucasian	2

4.3 Findings

Six key themes emerged that provided insight to the challenges experienced by AYAs with cancer: *burden of illness, health system issues, emotional responses, dreams and hopes, support, emotional counselling and socio-cultural influences*. See Table 2 for themes and subthemes.

Table 2 Table of themes and sub-themes developed in data analysis

	THEMES	SUBTHEMES
THEME ONE	Burden of illness	1.1 Activity restrictions 1.2 Losing independence 1.3 Physical effects due to cancer and cancer treatment 1.4 Influence on self-image and identity 1.5 HIV and Tuberculosis
THEME TWO	Health system issues	2.1 Communication 2.2 Delays in diagnosis 2.3 Nursing attitudes 2.4 Healthcare services 2.5 Inadequate resources 2.6 Transport and travelling
THEME THREE	Emotional responses	3.1 Distress 3.2 Fears, worries and guilt 3.3 Coping and adjustment 3.4 Building resilience and finding meaning
THEME FOUR	Dreams and Hopes	4.1 Future dreams and hopes 4.2 Uncertainty regarding dreams and hopes 4.3 Mortality is incomprehensible and a threat to future dreams and hopes
THEME FIVE	Support	5.1 Family and caregivers 5.2 Romantic partners 5.3 Peers 5.4 Healthcare services 5.5 Community and Spiritual 5.6 Emotional counselling
THEME SIX	Socio-cultural influences	6.1 Cultural beliefs, misconceptions and stigmatization 6.2 Poverty 6.3 Crime, safety and drug abuse

THEME ONE: BURDEN OF ILLNESS

1.1 Activity restrictions

From the time of cancer diagnosis, all participants reported different levels of physical restriction that led to the inability to perform various activities. These activities ranged from basic self-care, daily chores and enjoying hobbies, to carrying out work responsibilities, travelling, as well as the inability to attend religious gatherings, important family events, and having to compromise their social life. Apart from physical challenges, activity restrictions also resulted in significant psychosocial suffering that often involved emotional distress and feeling disheartened.

> My social life was good, until I found out that I have cancer. It changed dramatically, because the things that I used to do, I am no longer doing … So if I am sitting at home, they will be calling me, “Let’s go out”. Then I just think let me go out with them. But the moment when we arrive there, I will be like, I am getting bored, I want to sleep, I want to go home. And then they want to stay, they want to have fun. I will be like, I am a party pooper, something like that. So it is so difficult. [P11]
>
> Sometimes I feel disheartened, like on Sundays when I want to go to church then I don’t go to church. [P1]
>
> Financially yes, with that that I can’t work with the shortness of breath. They are now busy with a project with solar panels and I cannot go and work there, because you need to send a doctor’s pass. That is already a problem, so I will not be able to. [P4]

1.2 Losing independence

Due to limited physical capacity, many participants had to rely on family members and/or caregivers for assistance with activities such as shopping, washing, cooking, walking, mobilizing and using toilet facilities. The temporary or permanent loss of independence and freedom increased their sorrow and frustration, and for many participants it was extremely difficult to adjust.

> I cannot get to the shops. I also can’t go to the toilet by myself. Somebody must come to help me to sit on the bucket, but if they don’t come, I soil myself while I am sitting. [P1]
>
> Look it is a bit difficult to work in a hunched position. Now you just have to ask someone to help you clean and cook, because you cough and you don’t always have the cloth with you. Then the spit could maybe fall into my food, or something like this. Especially in church also to cough like that. [P4]

1.3 Physical effects due to cancer and cancer treatment

Distressing physical symptoms such as pain, insomnia, fatigue, the inability to enjoy food due to a loss of appetite, or discomfort caused by lower limb oedema, were reported by the majority of participants. These poorly controlled symptoms did not only limit AYAs in various ways and impede their quality of life, but it also caused tremendous suffering to them and their families. One young male adult shared his agony as a result of excruciating pain:

> Because sometimes when I sleep at night the pain in my back becomes very sore. Sometimes the back pain goes here into my heart. It becomes very painful and then I cry and cry ... [P2]

Another participant described that in an attempt to improve symptom control, he used non-prescribed medicinal products like cannabis oil or other innovative, nutritional immune support products, in addition to his prescribed medication. He stated that, apart from boosting his immune system, these products also enhanced his sleep quality. Besides cancer-related symptoms, many participants were burdened with intolerable side effects of chemotherapy.

> I don’t even wish chemo upon a murderer. I would rather that they bring back plain death penalty before they give me chemo. Chemo … it is evil. It is a poison. There are maybe a few changes that one can do in life, but chemo is one of those, how can I say, I don’t actually want to be here. Post it to me and I will use it in my own time, if you understand what I am talking about. [P5]

Despite the manifold negative effects of chemotherapy, many patients also shared positive experiences:

> From where I was until now, it is a huge difference, because back then I was sick, like I couldn’t speak, I couldn’t breathe, I couldn’t walk … so at least I can do these things now. I can walk by myself, I can breathe, I can talk. Things were bad. I couldn’t talk when I started with chemo. Even hearing was a problem. [P11]
>
> I was having those things on my neck. My neck was very big. So the first time I came here to the hospital, I went to M1 ward. So before chemo, when my friends looked at me they said, “Boy-boy you are very ill”. I said, “I’m here with the doctors. The doctors will help me. They need to do their work at oncology, to come and put chemo.” After two weeks then my neck became normal again. Then discharging me after three weeks, I went home. When I arrived at home, my grandmother said “Yoh, you are beautiful.” [P2]

1.4 Influence on self-image and identity

Alongside the physical consequences of cancer and/or cancer treatments, it also had a significant impact on many participants' body image, identity and their sense of normality.

> Because my breasts are large, I can't think of myself with only one breast. And at that stage I didn't think that there were options, like I can maybe put in that silicone business. For me it was only that my breast is not there anymore. I will not be a normal woman again. [P8]

Temporary or permanent body alterations included hair loss and skin changes due to chemotherapy, losing a body part such as a breast, eye, testicle, having a tracheostomy or a disfigured appearance secondary to generalized lymphadenopathy and skin changes. Apart from the need to retain their identity and feel normal, they experienced increased psychological distress, and they felt ashamed and unattractive especially when anticipating the attitudes and responses of others. Moreover, for some participants, it also led to disruptions at work, influenced social and intimate relationships, and subsequently also affected their quality of life.

> Yes the operation was successful, but the only problem was, I could not even face my family, because the eye was removed. It took me about two months to go back to my work. I was supposed to go back to work three weeks after surgery, but I could not go back, because I didn't have an eye and I was ashamed of myself. I could not even face my own family. It was not easy for me. [P10]

1.5 HIV and Tuberculosis

In addition to their cancer diagnosis, some participants were also diagnosed with HIV and/or a previous or current diagnosis of TB. One participant contracted HIV in an unexpected and traumatic way:

> I am HIV-positive, because the person who raped me was HIV-positive. [P1]

For another participant, the diagnosis of cancer subsequent to a diagnosis of TB, came as a shock and increased his current burden of illness.

> So after that they took me, after finding out that I have TB, because things were getting bad for me, the doctors decided to transfer me to Kimberley. That's where I found out that I had cancer too. So it was the most painful thing to find out that I am diagnosed with TB and cancer. And it was difficult to cope. [P11]

Participants reported feeling stigmatized, discriminated against, and rejected by friends, family and healthcare professionals. This did not only make them feel judged and shamefully different from others, but it often set them apart from the normal social order. Consequently, it had a significant impact on their self-esteem and overall psychosocial well-being.

> The cancer is fine, but the TB is something else. They expect you to everywhere you go, you have to put a mask on. So you put on a mask to protect them, but still they will look at you like this. So sometimes you are not feeling well, but still they are looking at you in a way you don't like. [P11]

Two participants reported feeling guilty and they had difficulty in disclosing their diagnosis to close family members. One participant deemed HIV as a death sentence and were also worried about the infective status of his children.

> I went to the clinic, then they diagnosed me with HIV. Alright, I thought this was the end of my life. [P9]

THEME TWO: HEALTH SYSTEM ISSUES

2.1 Communication

Lack of effective communication by healthcare professionals was reported by eight participants. This included insufficient and poor quality information regarding their cancer diagnosis, procedures, prognosis and treatment such as chemotherapy, radiation and related side effects that was often shared in an insensitive way. This often provoked frustration, uncertainty and led to significant misunderstandings and unrealistic expectations regarding the nature and seriousness of their cancer. Furthermore, the ability to plan and prepare for the future was limited. In an attempt to acquire information, many participants made use of internet sources like Google. One participant described the impact of a negative bad-news experience:

> Ah, it was like one of those things where the doctor arrives and then she said, "I've got the good news and the bad news for you. The bad news is that you have cancer. And the good news is, the cancer is curable". So I was like, should I cry or should I be grateful. And then I started crying the moment after she left, because cancer is cancer. It doesn't matter whether it is a curable or not. So the only thing that was running through my mind is that I am going to die. [P11]

> They didn't even tell me that they were going to do a biopsy. I just came in to check the results, then I arrived there and they said, you know what, they didn't say anything. The doctor said you must go to this doctor. And then I went to the doctor and then when I arrived

> I had to wait for him for something like half an hour. Then he came and then he said, we are going to do the biopsy today. I was like, like really? I didn't prepare myself to come and do the biopsy. And when something like that is happening, or something is going to go wrong ... We got in the consultation room, the bed was there, and then all the tools were there. Then I had to take off my shirt, lie on the bed and then he started to put a needle on my neck. So it is one of those things that you want to forget, but it is still there. [P11]
>
> There is only one doctor that I can say was friendly. The doctor who referred me to that guy who did the biopsy. She even had my file in her office. So every time when I go to the hospital, I went straight to her office. She was the only one telling me what is happening to me and all those things. And as for the rest, they didn't care. [P11]

Another participant shared his dissatisfaction with poor communication, as he received inadequate information regarding his cancer and chemotherapy treatment:

> Yes, if someone tells me: "Listen here, you have lung cancer, this and this and this. The chemo is so and so and so. And how many sessions you will get, it affects your kidneys, it affects whatever." Then I can prepare myself for it, but it was only said to me: "Chemo, sit". There goes the drip first thing. [P5]
>
> Yes, it is only that one sister, no it is a doctor who when I came here told me: "Look, you have lung cancer, you must get chemo." And then she was up and down, up and down, signed papers and said: "You must start the treatment on Monday". And she was not really open whether it is a treatable thing. Can one … or how shall I say, are there life effects, or are there side-effects that are a little different to what you are used to? [P5]

Despite many negative communication experiences, four participants reported positive encounters with healthcare professionals who met their information needs regarding surgical intervention and oncology care. Their satisfaction with and the positive impact of receiving adequate information, emphasized the critical need for clear and honest communication by healthcare professionals.

> … a doctor here in Upington. When he explained everything so nicely to me, then I understood and I was so glad for everything he did for me and said to me ... [P6]
>
> They always explain everything correctly. And maybe if I did not understand a thing, then I just ask the doctor what is that word, then the doctor tells me. [P1]

2.2 Delays in diagnosis

Within the broad scope of poor healthcare experienced at primary clinics and hospitals, the majority of participants emphasized their concern regarding diagnostic delays and the related, often detrimental, consequences. Reasons for diagnostic delays included a lack of proper physical examination, negligence, and a lack of professional competence that was described as inadequate clinical skills and large knowledge gaps. Subsequently, this did not only result in the inability to identify early signs of cancer, poor diagnostic accuracy and/or unnecessary treatment, but also led to late oncology referrals and often advanced disease. One young adult reported the long period she had to wait:

> I am very honest. I walked a long time with the pain. They made it long for me. [P6]

Another female participant with metastatic breast cancer and spinal cord compression, shared her delay in diagnosis and speculated whether her cancer could have been cured if detected earlier:

> How the breast started, it felt like a pulled muscle and I just merely rubbed it and made it warm. And the clinic sister also felt and said, “No, it is only a muscle”. And so it went on, till I saw the nipple was busy retracting. And then we started to worry … I would have liked to know what was wrong with me at the beginning. Maybe I would have still been able to walk if it had not been so … dragged out. Maybe it would not have spread so far. [P7]

Diagnostic delays often led to frustration, despair and seeking alternative healthcare routes. Two participants confessed utilizing traditional health practices. Four participants, in a desperate attempt to receive better healthcare or obtain a referral letter for tertiary healthcare services, sought help from private healthcare at a considerable expense, despite existing financial limitations. One participant waited three months for his biopsy results and described his impatience, fears, and painful journey related to the uncertainty of his diagnosis and worsening symptoms:

> I went three times to a private doctor and I was paying, so I kept on going there … It was difficult, because you have to travel to see your doctor, you have to wait for the results, and then patients when they are sick, having patience is not one of them. Because you want to know what is wrong and what is happening, because you can’t sleep at night, so painful. So when the doctor said you have to wait for the results, that waiting period feels so long, even a week is too much for you. Because you don’t know what’s wrong with you. So I was hoping for someone to say, you don’t have to wait. [P11]

2.3 Nursing attitudes

A significant challenge expressed by young adults was negative nursing attitudes at primary health clinics. Participants reported nurses as being grumpy, rude, insensitive and cold. Subsequently, these negative attitudes also led to poor behaviour such as shouting, arguing, showing a lack of compassion and respect, the inability to listen, behaving unjustly, and dishonouring the dignity of young adults. One female participant shared her negative nursing experience:

> With the hospital I don't have a problem, but the clinic, I think we must get a different sister. Or the sister's attitude towards patients must change … because sometimes one is really sick. Now you go to the clinic and then you are shouted at, or the sister is nasty or awful in other ways and I mean one is only human, you do feel sick. And then you feel to just leave everything. [P8]

The consequences of unpleasant nursing behaviours did not only leave participants feeling neglected and uncared for, but their dissatisfaction with the poor quality care made them feel discouraged and unwilling to return to clinics to receive further healthcare.

> … at the clinic, they don't really take people seriously … According to me, if it was possible, I would not even go to the clinic … because at the clinic they just take us for granted. Maybe they are just there, because they are nurses, they have to be there. But they don't treat people nicely. The nurses at the clinic are not good persons. [P10]

> It is painful, because when you are sick, you want to get help. And the people that should help you, they are giving you attitude and you are disappointed and sometimes you feel like, let me just leave them and sit at home and forget about this thing. But you can't sit at home when you are sick, because the pain will just make you stand up and do something about it. [P11]

One participant shared a demeaning experience with nursing staff in the surgical ward at RMSH and commented:

> The nurses are quite bad-tempered, but I assume they are all as bad-tempered. And the fact that it wasn't my home. I couldn't sleep well. They actually let you feel worse … They let you feel as if you are a dog. They treat people badly ... [P12]

2.4 Healthcare services

Poor quality health services were experienced by many participants at different levels of the health system. Participants highlighted the following challenges: long waiting times for appointments or consultations, the unprofessional way in which certain procedures were performed, the unavailability of necessary medication, missing or lost patient folders, unhygienic surgical wards, and a need for better home-based care. Consequently, the above issues often led to anger, impatience, feeling powerless, and losing trust in the healthcare system. One participant shared his unique experience in the surgical ward during admission:

> There was a guy, he couldn't talk, or something was wrong with him. They pushed him around. He soiled the place and they just left it like that till the next morning. I went out and sat on the terrace for hours, because they left it there on the floor and then I got nauseous. So it was quite hectic. [P12]
>
> Yes, it was painful and they left me on that bed bleeding. I thought I was dying. After they did the operation [biopsy], the nurse went, the doctor was gone and I was left there alone. Except for my girlfriend, if she was not there … I was crying. I cried and I cried ... [P11]

Positive feedback related to healthcare services was also shared by a few participants. One participant described her satisfaction with Ophthalmology services and reported that they did not only go above and beyond their call of duty to help her after clinic hours, but also assisted in expediting her CT scan and surgery dates. Another participant showed great appreciation for chemotherapy nursing personnel who prioritized patients from remote districts to prevent transport delays. Furthermore, many participants reported their satisfaction with oncology personnel (including porters) as they expressed friendliness, interest, respect and fairness that contributed to a perceived feeling of belonging to a family. One participant shared her reason for awarding the oncology department with a blue star:

> Because I think blue symbolizes love from my side. Because they really gave me that 100% love. They showed me that they really love their work. [P10]

2.5 Inadequate resources

At RMSH, young adults often encountered problems with inadequate resources such as the unavailability of beds. This did not only lead to great disappointment as participants were forced to return home after traveling long distances, but also led to worry and fearing possible negative health outcomes, as important procedures such as mastectomies had to be delayed. Moreover, a shortage of and/or broken equipment such wheelchairs, also had a considerable impact on one participant's quality of life as it limited access to important activities:

> Sometimes I feel disheartened, like on Sundays when I want to go to church, then I can't go to church … the wheelchair gives problems. [P1]

In the entire Northern Cape, there was only one mammogram machine for patients who utilized healthcare in the public setting. Consequently, one participant reported to having no alternative than to travel more than 800 km in one day to get a mammogram. She also highlighted the discrepancy and inequalities related to the accessibility of public and private healthcare:

> And everybody has to go to Kimberley for a mammogram. I think there are few people like me. I have not yet gone for a mammogram … Then I heard about E-clinic. So there are few people who know about E-clinic, or few people who have money to go private. [P8]

Furthermore, the chemotherapy facility at RMSH was perceived as small, lacking entertainment such as a television, and was often too overcrowded for relatives to support participants during their chemotherapy session. One young male adult also shared his need for more privacy and the ability to recline his chair to improve comfort and to assist with sleeping while receiving chemotherapy.

> Maybe more space that one can lie properly, a little more privacy or just space. Because if someone sits next to you, they are there. [P12]

2.6 Transport and travelling

Transport was a major challenge, as ambulances were often reported to be limited in number, overcrowded and unsafe. Participants who needed to travel long distances to tertiary hospital for appointments or cancer treatment, had to endure long waiting times that included sleeping in chairs while waiting for ambulances to pick them up at their specific locations. One participant described the prolonged period of waiting from 19h00 to 01h30 in morning after travelling from Upington to Kimberley (400 km), and only returning about 18h30 that night. However, those participants who lived far from peripheral hospitals, experienced further delays as they often had to wait for different transport vehicles to take them home:

> I went home from here at 1 o'clock at night. Because many times I indeed don't have transport to go down, so it means I have to wait for the ambulance. The ambulance can't just come to pick me up. They must now perhaps bring a patient here and if they then go down, then I can go with. [P8]

During times when participants were far from home, limited financial reserves and the unavailability of public transport led to a lack of family visits, and it often added to young adults' emotional distress. Due to the poor availability, reliability and safety of ambulances, some participants relied on family members to take them to hospital. A young female adult described her dependence on her uncle who often sacrificed his work to transport her from Postmasburg to Kimberley (200 km). However, when he was unable to take her, she often considered risky alternative options such as hitchhiking:

> Most of the time I was using the transport from home. My uncle, every time when I was supposed to come to the hospital, he used to bring me. He didn't go to work at that time, so that he can bring me to the hospital ... when my uncle was not there, then I took a hike. [P10]

THEME THREE: EMOTIONAL RESPONSES

3.1 Distress

For most participants and their loved ones, the unexpected news of cancer came as an overwhelming shock, and it was often accompanied by disbelief as it didn't fit into the framework of a young adult's life. Shock experiences were described as "it hit me hard" or getting "ice cold", and the existing emotional pain was even more intense if the news of cancer was conveyed in an insensitive way. For many participants, having to process multiple new losses simultaneously, such as a loss of health accompanied by a loss of a body part during acute or elective surgical procedures, resulted in even higher levels of distress. Apart from experiencing shock, many participants also reported varying degrees of sadness which was mostly concealed. Avoiding the exposure of their emotional vulnerability was not only an attempt to protect themselves within their family-defining roles, but also to protect their loved ones, and in particular their children, from experiencing more intense emotional pain.

> It felt as if I could scream. There were times when my husband and I just screamed together. But I told myself, I don't want them [children] to see that I am sad. [P7]

> Like there are those days that I just thought a lot, then I started to cry, but I told myself, I don't ever want to cry in front of her [baby]. Because I saw what it did to her. She feels my pain. [P8]

Spiritual distress was also prevalent in most young adults. Many questioned the reason for their cancer diagnosis and considered the possibility of being punished for previous wrong-doings.

> That is the million dollar question … "Why me"? "What have I done to deserve this thing?" Because whether you eat healthy, whether you are black or white, this is a disease for all of us. And then you ask yourself, "Why am I being punished like this?" [P11]

Some reasoned that turning away from God might explain their diagnosis, while others chose not to question the Lord but rather trust Him with their future. A few young adults had uncertainty regarding life after death. Moreover, two participants confessed having previous suicidal thoughts, while one male young adult had considered hanging himself:

> Sometimes I just think of it - now and then. If I look at the band [rope] like this, then I say, "I already have this thing on me." I will just close my eyes once, write a letter and put it down there. Then I will just go to the dead people. [P9]

3.2 Fears, worries and guilt

All participants experienced worries and fears related to multiple physical and psychosocial losses as a result of their cancer. They expressed concerns that also encompassed existential worries and fears. These included uncertainties related to their cancer stage, life expectancy and disease progression, especially in the presence of delayed treatment interventions, possible failure of cancer treatment, and in particular, the fear of death, which was often exacerbated by inconsiderate remarks of acquaintances based on their past experiences. For example, the remark that the absence of pain reflects advanced cancer, or that cancer is a death sentence regardless of your age. One participant shared her understanding of cancer and its association with mortality:

> That day was not easy. I was thinking like everyone, according to the way I know people with cancer, they didn't survive for more than a year. Some of them … died before they reached the age of 26. [So] the first thing that came into my mind … I am going to die. [P10]

Significant distress was also expressed by participants with minor children and they shared their fears related to the disruption of an irreplaceable mother-child bond. Furthermore, the absence of a suitable and reliable person to take over their parenting role in future, exacerbated their underlying fear as their current babysitters during the times of their hospital visits or admissions, were often unpredictable and untrustworthy.

> … the baby stays with my aunty, but if my aunty works, then my sister comes, who is disabled, no not disabled, she is retarded. Then she looks after my child ... she is very impatient and she stresses. I don't know if she feeds the child or what. [P8]

> I am mainly worried that when I die now, what will happen to my child. Will the people treat my child like they treated him in the beginning? Because when you are not there anymore, many people will then feel I am not your mother who has spoilt you. They only pretend that they like your child, but then they do not like your child. [P1]

Guilt among many participants also existed. This was often due to negligence or poor lifestyle habits such as smoking, alcohol abuse or promiscuity. One male young adult confessed his guilt because he neglected wearing a cricket protection box, while another participant took responsibility for his promiscuous actions in the past that led to the contraction of HIV and eventually Kaposi's sarcoma. The following participant also regretted being non-compliant to his cancer work-up:

> But it was quite tragic for me. I carried on a little long with the problem with my throat. I had already been told in 2017 to go for a check-up in Kimberley, but I never went ... maybe if I had gone to the hospital earlier, it perhaps would not have been so far advanced. [P4]

3.3 Coping and adjustment

In the challenging quest to deal with the reality of their cancer diagnosis, participants reported different ways of coping with and adjusting to their illness. Despite the presence of emotional vulnerability and feeling weak, half of the participants reflected an almost immediate acceptance to the inevitability of their diagnosis and refused to let it interrupt their life. In addition, the importance of persevering by maintaining the correct mind-set and staying mentally strong ("fighting with your mind") was paramount. This also included replacing negative thoughts with positive ones, striving to maintain normality, not giving up hope and fighting till the end.

> I told myself, I will never give up hope, never. I will fight till the end. [P9]

Keeping busy by focussing on and continuing with normal life activities was also a strategy to cope:

> Yes, that is why I decided I will continue to work as well. Because if you go and lie at home now, then you automatically feel worse. So if you keep on working then you are still alright. [P1]

For another participant, denial assisted in absorbing emotional distress and trauma related to her cancer:

> I don't have pain yet … I don't feel sick yet … I don't look sick yet, because I look at my breast, it doesn't look strange to me. Because when I had the lump, the chemo made that it went away. Actually I hope that I don't really have cancer. [P8]

3.4 Building resilience and finding meaning

There was evidence that many of the young adults affected by cancer formed a meaning system that helped to build resilience. One male young adult expressed it as being a blessing in disguise:

> Yes, you know sometimes when something comes and knocks you down and then you are able to stand up, you just have to dust yourself and look at things. It is a lesson in a way that you have to … sometimes these things are a blessing in disguise. Let's say, for example, I didn't get sick, I won't know that life can be difficult sometimes. But since I got sick, I had to experience the world at its worst, to see your friends going away, some guys don't call you, others don't even visit you when you are sick. So these things, it is like a wake-up call to me, that whatever you are thinking, you have to start to think clearly in a way that you want to do better, you want to be better at these things. So I think to me being sick, it is a blessing in disguise, because I have learned a lot. [P11]

Having a deeper awareness of life also inspired some participants to educate and encourage others, by sharing valuable experiences and newly gained knowledge. On a spiritual level, having cancer led to a higher dependence on and closer relationship with God, that strengthened their faith and hope in His goodness and His greater plan for their life. One participant believed that he was granted a second chance to fulfil his spiritual purpose in life:

> But there the Lord gave me a chance not to go and die in jail and now the same with the cancer, you understand. So the Lord has a purpose with my life. I am only still busy to figure it out. [P4]

THEME FOUR: DREAMS AND HOPES

4.1 Future dreams and hopes

Even though all participants were in different phases of their life, the longing to fulfil future dreams, that were often also their ultimate life purpose, acted as a driving force and encouraged them to maintain hope that they will conquer their cancer and subsequently regain their health. As the dream of some participants to obtain a higher level of education and to pursue a career was interrupted, they were hoping to begin or resume their education shortly after completing their cancer treatment. For those who were main bread-winners prior to their diagnosis, returning to work and financially supporting their family was paramount. Participants who were single, hoped to get married, live in their own house, buy a car, have children, be a role model to them, and enjoy a contented family life. Participants who already had children, longed to resume their normal role as a parent. They described their hopes such as to dress their children again, help with homework, see them growing up, offer them a better future, and especially to see their children fulfil the dreams they as parents had planned for them.

> I want to see myself, I want to see those dreams come true. That are the things that keep me awake. That is the thing that I am living for. And I see myself holding my child in my hands …

> I am thinking that if I have a child in my life, I want my child to have a better life than the one that I had. [P11]
>
> I think of it many times. I feel if I did not have cancer now, I would have worked far in the world for my child, because I am looking for a better future for my child, because I grew up, having a difficult life. Thus, I don't want my child to grow up like I grew up. So I want to be the best mother for him. [P1]
>
> My lifestyle. I would love to go to work again, help my child with his homework, be there for him, wash him, dress him. Now he must do everything himself and must grow up so quickly. [P7]

Other dreams included being more involved with church work, growing in faith and intimacy with God, the ability to travel, to give recompense to parents, and to achieve goals regarding hobbies such as cricket or fishing on a provincial or national level.

> I see myself in my own house, happily married. There are indeed ups and downs in any family. I want to be close to God. I just feel that if I still pray every day, it just makes my faith a little stronger. [P8]

4.2 Uncertainty regarding dreams and hopes

The presence of a cancer diagnosis greatly influenced the way young adults dreamed about and planned for their future. The lack of certainty regarding their cancer prognosis and life expectancy often led to discouragement regarding certain goals and a loss of future hope. Furthermore, indecisiveness as to whether they should continue to actively follow their dreams or rather have them postponed, also affected their identity and their meaning in life. One female participant shared feelings of hopelessness regarding the unpredictability of her future:

> Then at home, they usually encourage us to do something better in life, so that we are not like other children we see that are humiliating their parents ... So I realised that I have to finish up with my studies because I only have matric now. And by that time I was thinking, I won't make it in life. I will just stay at home, doing nothing, because I was thinking it will be the end of the road for me. Maybe I will die in a few months. [P10]

A young male adult shared his uncertainty related to pursuing his dream career:

> I've always dreamed of becoming a chef, so I don't know should I continue, should I wait? [P11]

Another participant, felt disheartened as he considered the possibility of his future dreams being shattered due to cancer-related interventions and consequences:

> When we got there, they told us: "Sir this foot ...". Then I realised they are going to come and cut me. It was there that I felt, gee, my life will not be the same again, because the dream works which I have planned now, they are buried now, they will not exist anymore. [P9]

4.3 Mortality is incomprehensible and a threat to future dreams and hopes

The reaction of participants when confronted with their own mortality, was expressed in multiple ways and included feeling overwhelmed, distressed, and having difficulty in comprehending a reduced life expectancy. Despite efforts of some participants to avoid the topic of death, five provided reasons for not being ready to die. This included viewing their young lives as incomplete, due to a sudden life disruption that posed a significant threat to their future hopes and dreams. The inability to leave a legacy was also reported. One young male adult anticipated the anguish he would experience if he had to die at that moment:

> Whether I was a Christian or not, but dying now at this moment … There are still a lot of things that I have to do. I have to get married, have kids, buy myself a house, buy myself a car. So if I die now, I will die with a broken heart. [P11]

As a way of coping with the concept of possible death, one participant held on to God's grace and hoped that he will be granted more time to live. Another participant still wished to raise her child and claimed that she would be better prepared to die when she is older.

> I was not ready. I was thinking that I am still too young to die. And I still want to do something for my mom for everything that she did for me. Even after my father went away, she really stood up for us. She didn't get tired to provide for us. So I think that I owe her something big. [P10]

> But I just don't know why I think that death has to come someday and all that I ask, or pray, is that my child must just be big, or that I must be grown-up the day that I have to die. [P8]

THEME FIVE: SUPPORT

5.1 Family and caregivers

From the time of their cancer diagnosis, the experiences of participants regarding the dynamics, quality and consistency of external support systems, varied significantly. For most participants, physical, practical and psychosocial support and sacrifices from family and caregivers made them feel loved, valued, cherished and provided encouragement and comfort.

> What makes me happy is when I can unburden with my family. When I can pour my heart out. My mother is the person with whom I talk about everything. She is the one who motivates me and encourages me … [P9]

> My father only occasionally went to work, borrowed money. A lot of things happened to me. My family gave up many of their things just to support me … they helped me with doctors' fees, transport fees. They actually helped me with everything. They support me 100%. [P9]

Conversely, participants who experienced a lack of adequate support and family relationship tension, reported attributable factors such as broken families as a result of divorce, absent parents, abuse, conflictual or distant relationships, or the loss of loved ones. This made them feel neglected, rejected, lonely, poorly understood, frustrated and sometimes worthless.

> To be honest, my husband does not really support me. My husband is a person who is up to mischief. He is a naughty, he steals and abuses me and took my money and trampled and kicked me. [P1]

The impact of a young adult's cancer diagnosis on the family unit and the need for family support was also significant, and led to many disruptions and major shifts in family roles. One participant described a lack of support offered to his mother and the negative influence on their emotional well-being:

> Many have said to my mother that she must just give up hope with the foot [Kaposi's Sarcoma]. I have just always kept quiet. When they talk like that, then I just cry in my room and when I have finished crying, then I sleep. When I have finished sleeping, then I just watch TV on the side. What has actually eaten me, is that my mother should give up hope … a person who is not a doctor telling my mother to give up hope. [P9]

Young adults also reported that the needs of their children were largely unmet. These needs were mostly described as confusion, anxiety and behavioural changes. Furthermore, a major gap in support for their children, including the need to assist young adults to deal better with their children's emotions, was clearly expressed. One participant shared the way her twelve-year-old son communicated his worries regarding her cancer:

> No, he does not like it when I sleep, he takes it quite hard … and he also does not like it when I am sick. If he comes to me when I sleep, he wakes me up and tells me I must not sleep so much. [P1]

5.2 Romantic partners

Five participants emphasized the pivotal role romantic partners played in supporting them throughout their cancer journey. The support ranged from physical assistance with daily activities such as washing, cleaning and cooking, to providing emotional support. This often also led to deeper relationships and contributed to their ability to cope. One participant expressed her appreciation towards her partner's loyalty, affection and words of encouragement:

> … my boyfriend, he is the one, really I don't want to lie, he is the one who always gives me sympathy. "Please don't give up, you know you are going to be fine and I love you just the way you are. Even whether you have cancer or malaria or what, I will die with you and I will stay with you. I won't go anywhere, I will stay". [P3]

Another participant expressed his deep gratitude for his girlfriend's generous and constant support. He also emphasized the value of being served spiritually through prayer:

> She is fine, she made peace with the fact that I have cancer. She is so supportive towards me. All the way. I am one of those guys that can say, "I am blessed". It is a blessing from God that she is still around me … Sometimes when she prays I always say she must mention me in her prayers. [P11]

5.3 Peers

Peer support ranged from trusting, loyal and fun relationships, to those who disappeared due to young adults' lack of participation or their inability to keep up with social events. One male participant shared the value of his close circle of friends:

> I can at least talk to all my friends. I have a good circle of friends and we are quite close. They are like my brothers. So we have already talked about a lot, about everything. One of my friends came down after the operation, then he came to stay here for a week. [P12]

A female participant expressed the way her cancer diagnoses uncovered the superficiality of her friendships:

> The time I deteriorated so, my friends did not worry about me anymore. Then I saw more and more of my friends went away … [P1]

During difficult and challenging times, another male participant experienced abandonment by his close friends and realized that they were apathetic and unconcerned about his well-being:

> … my close friends never came to look in on me. Everybody disappeared. They say indeed, "When days are dark, friends are few". That is the thing. [P9]

5.4 Healthcare services

The quality of support and encouragement provided by healthcare professionals was reported as unique and therefore played a vital role in the way participants experienced and coped with their cancer burden:

> I have lovely doctors, every day they see me, they give my lovely words with their happy smile and happy faces. So yes that's what makes me very strong. My medical team is number one. [P3]

> And even thinking about the words that the doctors told me, while I was still in the hospital … That encouraged me a lot. [P10]

5.5 Community and Spirituality

Some participants shared the support they received from caring community members. These acts of service provided great comfort and addressed many unmet needs. One male participant shared his experience:

> Yes, they [the community] support me a lot. There are people who just send me little plates of food in the mornings and in the evenings and come and visit me. Especially in my street … the older people are very fond of me. [P4]

Conversely, one female participant also stated that community members often lacked the necessary knowledge and communication skills when engaging in conversations with her:

> Most of the people will come and talk about it, then they don't even know how one feels, or they will come and say things about something they don't know anything about. [P6]

Internal sources of support as expressed by ten young adults, were mainly religious Christian beliefs through a personal relationship with God. Placing their faith in Him, trusting that He was in control of their life, and giving Him praise did not only increase their inner strength and joy and provided a sense of peace and comfort, but also filled them with hope, helped them with meaning-making and gave them the assurance that they will never be abandoned by Him.

> The Lord and I have a good understanding, because I talk to Him like I would have talked to Him if I had been in the church. So, I still think the Lord does good things to me, except that I am sick now. I don't blame Him. I have no questions. All that I ask is that He will keep me strong to face whatever situation I have to. [P8]

5.6 Emotional counselling

A strong need to be offered emotional counselling at their cancer diagnosis was expressed by ten participants. Not only did they show a desire to share their deeper emotions more freely with a professional therapist who would have the necessary expertise to guide and support them on a regular basis, but also someone they can feel comfortable with and whom they can trust. One participant who was referred to an emotional counsellor at a local TB hospital in Kimberley, shared his positive experience:

> Yes, it helped me a lot, first I refused to go there, but once I got there it was a blessing in disguise, because they have a therapist there. Every Wednesday the therapist will come and they will have those sessions with me. So I think if the one therapist was not there, I don't know what would have happened to me ... because you can be fine physically, but emotionally you can be shattered ... So I am really, really grateful. [P11]

Another participant emphasized the challenge to communicate on an emotional level with family members and her preference to rather receive professional counselling:

> Yes you must talk. If you talk you feel happier and if you sit with your own family, you cannot really talk to them, because you don't feel comfortable. So you need to talk to somebody else where you can talk more comfortably with the person. [P1]

The lack of emotional counselling offered to family and caregivers of AYAs with cancer was also described by participants. As family members and caregivers struggled with their own emotional distress regarding the young adults' cancer diagnosis, it was evident that they would greatly benefit from an opportunity to express their fears, worries and uncertainties, and therefore be referred to a professional therapist who can listen, provide the necessary support, and address their needs.

> Yoh … I would like someone to talk to my mother - I would say to talk to my parents. Just a few serious words with my parents, because they also need counselling. [P9]

Moreover, the suffering experienced by family members and caregivers due to their child or loved one's cancer diagnosis, was witnessed by some participants. Subsequently this was often perceived by young adults as a lack of empathy, as it made them feel poorly understood and sometimes contributed to conflictual or distant relationships.

> From my side yes, I think they will also need someone that they can talk to. Maybe they will tell them how did they experience it while I was ill, how did they manage from their side. Because sometimes I could have seen their eyes that they were not happy. Even the time when I told them I was having eye cancer, the way they said it over the phone, I could hear they didn't take it very well. After I was at home, I could see in their eyes there was something wrong. [P10]

THEME SIX: SOCIO-CULTURAL INFLUENCES

6.1 Cultural beliefs, misconceptions and stigmatization

A lack of cancer awareness and education commonly led to fears and misconceptions among family and/or community members, and included beliefs that cancer is contagious and related to witchcraft or it is due to punishment by the ancestors. One young male adult admitted his ignorance as he assumed that cancer is only for certain cultural groups, while others thought that it is a disease only for the elderly and once it is diagnosed, death is inevitable.

> The thing is, you know, there is a difference between … how am I supposed to say this … You guys are white and I am black. So living in a black community and a white community are two different things. Like when you talk to a white person, and tell them: "I have cancer", the reaction you are going to see on his face … they will be shocked, but when you go to a black community and you tell me, "I have cancer", they will be like … sitting like this and say: "What?" And then … I think black people don't know anything about cancer. [P11]

The same participant elaborated further on the lack of cancer awareness and education in his community:

> In the villages it is a problem, when someone sees you the only thing that comes to their minds is, this person is HIV-positive. We don't know him like this, which means he must be sick. They can't think of anything else than HIV and AIDS. They can't think of any other disease like TB or cancer or something. When you lose weight, it is HIV. When you get sick of flu, or dark it is HIV. So, hence I am saying, in the village, there is no information about cancer. No awareness about cancer. [P11]

Notwithstanding the majority of participants' disbelief in the effectiveness of cultural treatment, two participants emphasized the attempts of family members pressurizing them to seek help from traditional healers such as sangomas or faith healers.

> You know us black people think maybe it's a witch craft sometimes, those things. Sometimes you think, like maybe there must be something wrong, maybe the ancestors are turning their backs on you or something. Sometimes you tend to go to a traditional doctor to see what is happening. So I tried those things. But all of them said the same thing, I was like, "No, I didn't believe what they said." So I thought I would rather go with the medical ones, instead of these ones, because they don't know the answer of cancer. They might say that they have the cure, but deep down they know, the only thing they want is your money. [P11]

Cancer-related stigma, especially related to anatomical disfigurement or physical changes, also existed and consequently led to emotional distress and feeling poorly understood, judged and/or rejected by family or community members. Furthermore, for many participants, it was a threat to their identity, it led to social isolation, and a lack of social support, and it impaired their quality of life considerably.

> In black people, rejection is very much. Some people, they tell you straight, "Wow, this thing".
> I lost a lot of friends because of this. [P3]

6.2 Poverty

Financial hardship was compounded by a low socio-economic background for the majority of participants. This aggravated their suffering and placed an increased financial burden on family members. Financial challenges included unemployment, interference with educational or work responsibilities, a loss of income, being compelled to use money from saving accounts or pension funds, as well as being dependent on monthly disability grants to purchase basic requirements such as food. In addition, participants who relied on family members for financial assistance, were often burdened with additional expenses such as for transport. One young female adult who received a monthly disability grant, was the main bread winner and described her financial worries:

> I told you, I won't go home, I will stay here until I am healed. Because I avoid that thing [home]. When I am at home, my boyfriend is not working. When I am at home on weekends, what will I eat? And my boyfriend, always, he struggles too much. He has to go to his people and ask for some food and everything ... [P3]

Conditions of extreme poverty were also reported by two participants, and it included living in informal dwellings, also known as "shanties", where access to sanitation or electricity was limited. Furthermore, the unavailability of a flush toilet facility also led to great difficulty and inconvenience. One participant described the assistance she required with a bucket toilet system:

> Yes, the toilet is still outside. When I close the door, I close it with my body. Or sometimes my boyfriend says, "You know what, there is too much wind outside, so I will leave a bucket for you. Then you can do everything there." [P3]

6.3 Crime, safety and drug abuse

Additional social stressors reported by seven young adults included the danger of crime that threatened their safety and contributed to existing fears. This was often accompanied and/or exacerbated by substance abuse. One participant was devastated and mourned the loss of a cousin's unexpected murder. Her grief was aggravated by the fact that the suspects were never found. Another participant reported being raped as a 10-year-old girl and described the destructive and lifelong psychosocial consequences of this brutal act. According to her, the rapist also never went to prison. As a consequence, she shared her anxiety and current safety precautions at night when she is alone in her shanty:

> If I am alone at night, I leave the lights on … Then I must lock myself in. Then I must lock it by inserting the chain. Then I must sit like I sit now, in the wheelchair. Then I sit and sleep like this till the next morning. [P1]

A young male adult admitted to being violent towards his partner and stabbing her with a knife:

> … I stabbed my children's mother 8–9 times with the knife: We separated and she left me … she left me with the children just like that and went to stay with her mother. After two weeks, I went to stab her. I was locked up for 20 days before I got bail and I got outside punishment. [P4]

Lastly, drug abuse among family members was also mentioned by two participants. These experiences were described as disruptive and problematic, and gave rise to significant distress and conflictual relationships. One participant's brother was a drug addict and committed suicide by hanging himself.

4.4 Conclusion:

This chapter provides a clear reflection of the multitude difficulties and complexities that AYAs with cancer experience. However, within their unique developmental life stage, these problems and concerns often remained undiscovered and unaddressed. As they experienced many unexpected, painful losses such as physical limitations, a sense of normality, unfulfilled hopes, dreams and difficulty in living up to their social roles as a result of cancer, they unveiled significant and often incomprehensible challenges that impacted on various facets of their overall well-being. Considering their poor socio-economic background, diverse cultural influences and a public healthcare system that oftentimes failed to meet their holistic needs, it gave rise to considerable physical, psychosocial and spiritual pain that contributed to their suffering and total pain.

The results of this study will be further interpreted in Chapter 5.

CHAPTER 5

Discussion

In this qualitative study, the aim was to explore and identify the challenges experienced by AYAs with cancer in the Northern Cape public health setting. The richness of this data provides a transparent reflection of the experiences, concerns and priorities of this distinct population, as demonstrated by six key themes, of which the implications will be further discussed in this chapter.

5.1 Burden of illness:

In the findings of the study, physical challenges experienced by the majority of AYAs as a result of cancer itself and/or its treatment, contributed significantly to their burden of illness and suffering. Physical challenges included uncontrolled symptoms such as excruciating pain, fatigue, severe nausea and a loss of appetite. These symptoms were aggravated in the presence of limited physical activity, especially when they were forced to rely on loved ones for basic self-care. As a result, they also lost a sense of their autonomy. The literature shows that normal developmental milestones of AYAs, such as the need to be independent and autonomous, can be interrupted by a diagnosis of cancer (11). AYAs with a life-threatening illness also tend to experience more intense pain compared to younger and older populations (11). Therefore, achieving optimal pain control may be challenging and require various pharmacological and non-pharmacological interventions (11). In addition, when considering the detrimental impact of cancer on AYAs' identity formation (11), this study also demonstrated the damaging effects of an altered physical appearance, due to surgery or cancer itself, on participants' self-image, as it often led to feelings of unattractiveness, embarrassment and social isolation. After an enucleation of the eye, one participant shared her reluctance to return to work and engage in social relationships since she feared or anticipated negative social reactions. In addition, emotional pain was also expressed by participants as frustration and sorrow, or feeling discouraged, due to functional disruptions that resulted in a loss of freedom. Participants who were unable to work as a result of cancer, often experienced great financial hardship in addition to a reduced autonomy and a high psychological burden. Especially in the presence of disease progression, the importance of maintaining control over their lives was vital. This emphasized the need to have early discussions regarding their preferences for treatment and care, and to document advanced directives which were consistent with the findings of Kenten et al. (19). Furthermore, the multidimensional and interrelated nature of pain, as demonstrated by participants and recognized by the different ways in which physical symptoms of cancer affected emotional, social and spiritual dimensions of pain, is also in accordance with prior research (3, 11, 30, 42). There is a critical need for frequent comprehensive needs assessments, where the scope of pain and distressing symptoms can be explored and adequately addressed at an early stage. Moreover, it also highlights the importance of identifying holistic support structures to build AYAs' self-esteem, help them find their identity and promote a sense of normalcy (3, 27). This includes creating a safe environment where AYAs can openly share their cancer-related pain (11). Acknowledging all the different facets of pain is therefore essential, in order to develop a needs-focussed oncology approach that will aim to improve symptom control and optimize health outcomes for AYAs with cancer (30).

As South Africa is one of the worst afflicted countries for HIV and TB (23), participants who had a concomitant communicable disease in addition to their cancer diagnosis, experienced a significantly greater burden of illness. Studies that evaluate the impact of a concomitant epidemic, such as HIV or TB in AYAs with cancer from both developed and developing countries, are scarce. This emphasizes the uniqueness and importance of the data that provided new insights into AYAs' challenges. Study findings did not only include worry, sadness, and spiritual pain relating to having a progressive, incurable disease, but also reflected the trauma of contracting HIV, for instance, after being raped. As a result, the burden caused by stigma, discrimination and negative social judgements related to having HIV or TB, often gave rise to feelings of rejection and shame, and this contributed to greater psychosocial suffering. Consistent with previous literature, the need to be acknowledged as an individual and not to be labelled by a disease, is also recognized by AYAs from this study (3, 9, 18). One participant who was diagnosed with pulmonary TB, perceived the negative attitudes and actions of healthcare professionals as an insult to his self-respect. Other participants were saddened by the rejection of friends and other acquaintances. This implies the longing of AYAs with a concomitant communicable disease to be treated equally, with respect, and with a dignified human approach.

5.2 Health system issues:

In response to major gaps in the literature regarding the health system experiences of AYAs with cancer (9), the majority of participants in this study reported poor communication by HCPs. The latter resulted in unmet information needs regarding their prognosis, procedures and treatment. The considerable dissatisfaction with the quality of information-sharing by doctors exacerbated harmful consequences, such as intense grief, uncertainty about the future, as well as a growing distrust in healthcare professionals. In response to poor communication and a lack of therapeutic alliance with HCPs, AYAs often utilized internet sources to fill existing information gaps. As stated by Avery et al., HCPs perceive honest and open discussions with AYAs as extremely uncomfortable and challenging, due to the tragic nature of a cancer diagnosis at such an early age (38). Especially in the context of AYAs with advanced disease, HCPs often provide unrealistic hope and optimism, in order to avoid emotional discomfort during difficult conversations. This may be due to limited training in communication skills. Furthermore, HCPs also neglect to involve the family of AYAs with cancer, as it may unveil the families' unaddressed support needs that are often beyond HCP's scope of practice. Thus, communicating with families of AYAs may also require extra time and lead to increased workloads (19, 38). As a result of poor communication, the involvement of AYAs in decision-making regarding cancer treatment and future expectations, is neglected, and this may disempower them (42) and undermine their need to be in control of their treatment preferences and goals of care (3, 11, 36). Consequently, they may develop unrealistic expectations and future hopes. Their current and anticipated multidimensional needs and wishes such as maximum comfort, functional goals, values and beliefs may remain unknown and unaddressed. This may restrict their ability to live as actively as possible within the constraints of their illness. Poor communication and care-experiences related to other critical topics such as sexuality and reproductive health, also existed. As emphasized in a systematic review by Bibby et al., fertility preservation and support is of great importance to AYAs with cancer (40), as it forms part of their life narrative and future goals. However, in this study, reproductive health services and fertility needs were neither probed nor explicitly mentioned by AYAs. Possible reasons for this may include their lack of awareness regarding the availability of such services, a lack of counselling by healthcare professionals regarding fertility, or being confronted with multiple other stressors such as poor social circumstances. In contrast to negative communication experiences, some study participants also reported the beneficial impact of adequate and effective communication that increased their health-related quality of life significantly. This emphasizes the use of guidelines to identify AYAs information preferences, and to tailor the delivery of information that is appropriate to their developmental phase and capacity, in order to meet their information needs (3, 30, 32, 39, 40). This also stresses the need for professional training and education in communication skills and techniques, especially when the meaning of palliative care has to be introduced to AYAs and their families (1, 32, 38). It also includes collaborating with palliative care teams who can guide important on-going discussions through good communication, co-ordinate family conferences, and affirm non-abandonment to the patient and family. Thus, palliative care teams go beyond the treatment of only physical symptoms, but also deliver care that encompasses various aspects of quality of life such psychosocial and spiritual care (16, 38, 40).

Even though an early cancer diagnosis is fundamental for prompt initiation of cancer treatment and improved survival, participants reported major obstacles to early diagnosis that caused significant emotional distress and often limited their healthy young life years. These obstacles included long waiting periods before receiving diagnostic results, negligence and a lack of professional competence that was often evident as poor cancer knowledge and skills, especially on a primary health level. Drake et al., also reported that AYAs often fail to seek early medical advice and neglect to pay urgent attention to new symptoms or signs, as having a cancer diagnosis is not part of their or their HCP's normal framework (9). Moreover, it is also reported that the enrolment of AYAs with cancer in clinical trials is limited, which may generate uncertainty about their treatment and lead to adverse health outcomes (9). As a result, in concordance with the findings of Edwards and Greeff and Kohi et al., this led to detrimental consequences for the majority of AYAs with cancer, and it included misdiagnosis, unnecessary treatment, late oncology referrals, advanced disease, as well as seeking alternative healthcare options like traditional practices or private healthcare that were often unaffordable to AYAs (41, 42). In the findings, four participants, in a response to poor public healthcare, sought help from private health services in a desperate response to address severe diagnostic delays, alleviate worsening cancer symptoms, and obtain referral letters to access public tertiary hospital care. One participant described his fears, impatience and a painful, frustrating journey after having to wait for three months in the public setting for his biopsy results. Consequently, due to his significant emotional distress and desperation, private care was delivered by HCPs at a considerable expense, despite limited financial reserves of the participant. Hence, under these circumstances, an additional burden of emotional suffering was experienced by a high percentage of AYAs that was often expressed as impatience, fear, or despair. Furthermore, the impact and consequences of inaccurate diagnosis, in particular at primary and district level, also poses a significant strain on the healthcare system (41). Improving health literacy and vigilance amongst HCPs regarding early cancer recognition and diagnostic skills, are paramount. This requires meticulous planning and urgent, drastic measures that involve training of HCPs, especially on a primary healthcare level, to use primary care guidelines that include cancer control instructions (41, 42). Moreover, due to poor leadership of the South African government and management at health facility level, non-adherence to the constitutional mandate exists, as the leaders who are involved are unable to provide South African citizens with access to and provision of the necessary healthcare, inter alia. This should also be explored when addressing issues pertaining to the improvement of health services (23).

Consistent with previous sub-Saharan African studies, the quality of healthcare as perceived by AYAs with cancer in this study, was severely impacted by negative nursing attitudes (41, 42), particularly nurses working at primary healthcare clinics. The lack of fair, compassionate and committed care often discouraged AYAs to return to clinics as they felt dissatisfied, neglected and uncared for. This may lead to non-adherence to treatment and adverse health outcomes that compromise patient-centred care. There is a great need within the South African context to explore and address the roots of harsh, often demeaning nursing behaviour (42). The critical demand to strengthen and improve nursing support and intrinsic motivation from higher managerial levels in order to monitor high-quality care and establish a value-driven environment, are also paramount (21, 42). This may include compulsory nursing programs to upskill and maintain professional norms and standards to improve patient care (42). In addition, despite the WHA resolution to encourage all HCPs including nursing staff to be trained in palliative care, this crucial field of medicine is not yet integrated into the curriculum of nursing schools in South Africa. Moreover, a lack of adequately skilled nursing staff in the public sector may emphasize the unequal distribution of healthcare workers in the current two-tiered South African health system. This strengthens the need for further progress and implementation of a unified National Health Insurance that conforms to quality-improvement programmes (21, 23).

The majority of participants also reported poor quality health services at different levels that led to feelings of anger and powerlessness. Apart from unprofessional attitudes of staff that made them feel abandoned, and the unavailability of necessary medication, many participants experienced long waiting periods that were often exacerbated by missing patient folders. One participant also reported unhygienic in-patient care facilities that posed hazardous effects on environmental health standards. This is consistent with previous evidence from Tanzania and South Africa that highlights the delivery of unacceptable quality health services (23, 41, 42). In addition, large transitional gaps exist in the post hospital discharge and out-patient care setting of AYAs with cancer. This raises concerns (42), as a lack of continued quality care may cause chronic and complex psychosocial and future developmental repercussions to AYAs with cancer (30). It also raises the critical need to advocate for and establish palliative care teams within the hospital setting. Palliative care training emphasises patient-centred care and team members who are trained and skilled to build rapport with patients and their loved ones over time. They can assist with the development of individualized care plans, support functional abilities, address total pain, and coordinate proper discharge planning. Referral to community-based or home-based care systems that are sufficiently functioning, may help to secure a safety net for and promote the well-being of AYAs and their families (1, 30). Core elements of home care include on-going symptom control, adequate psychosocial and spiritual support and making provision for anticipated problems. However, the adequacy of services delivered by community-based or home-based care systems, especially in remote areas, is questionable and they may require closer evaluation, improvement and monitoring. In the African context a strong influence of community care exists (14). Therefore, focussing on and investing in palliative care models within these settings, may be more sustainable and may help to address the current gaps in hospice and home care in order to support AYAs' future goals and preferences (1). Notwithstanding the negative responses of AYAs regarding healthcare, they also shared positive feedback regarding the attitudes of HCP that included friendliness, kindness, and being fairly treated with the patient's best interest at heart. Some participants also acknowledged the compassion and consideration of chemotherapy personnel to prioritize participants from remote areas, as well as perceiving the oncology department as a family where they could experience a sense of belonging and feel loved and cared for. This demonstrates the value of knowing what matters most to AYAs with cancer regarding health care services, in order to prioritize and focus on providing services that is patient-centred and will meet their needs.

In this work, a lack of resources such as limited hospital beds that led to delays in urgent surgery, a shortage of and/or broken equipment such as wheelchairs, and small overcrowded chemotherapy facilities that lacked privacy, were reported. Two participants also expressed the need for a television or listening to music to draw their attention away from their illness. Apart from a Pink Drive NGO service that provides mobile mammography services on a yearly basis to remote areas in the Northern Cape, one participant reported travelling more than 800 km in one day for a mammogram as only one machine was available in the Northern Cape public health setting. This emphasized the impact of long distance travelling, as a result of inadequate resources, on the quality of life of participants and also highlighted the need for governmental funding to provide the necessary equipment to hospitals (41). In addition, the inadequacy of resources in the public setting revealed the unequal distribution of resources between public and private facilities, and emphasized the notable difference in quality of care provided in the public and private sectors.

Challenges relating to transport and traveling are rarely mentioned by AYAs from developed countries, but was shown to increase the cancer burden of AYAs in this study. As ambulances were often unsafe and overcrowded, AYAs often feared missing important hospital visits and treatment. Consequently, in the absence of available and affordable means of transportation to cancer facilities, they may opt to forgo important cancer care that can reduce their chances of survival. Moreover, as the majority of AYAs did not own a motor vehicle, they often explored alternative transport options such as relying on family members to undergo significant sacrifices to assist with transport. Alternatively, one participant also reported considering risky options such as hitch-hiking. In accordance with the findings of Edwards, Greeff and Kohi et al., challenging transport experiences of AYAs from remote areas included travelling far distances to access tertiary hospital care, and long hours of waiting at peripheral hospitals that often involved sleeping in chairs overnight (41, 42). Some AYAs experienced further transport delays between peripheral hospitals and rural districts as transport vehicles were unavailable at the sought-after times. Furthermore, additional stressors for AYAs with cancer that related to traveling far away from home, included interrupted work or parenting responsibilities, worries about the well-being of their children, and a longing for familiar social support structures, which is also consistent with the literature (5). Additional financial expenses related to transport and travelling for young patients with cancer, may also impact their quality of life (42). Cleary et al., reported that South African patients from remote areas that experience the impact of extreme poverty, often need to borrow money and carry a significantly greater transport cost burden than those from urban regions (24). This illustrates that increased rates of transport and travel barriers may exist for AYAs with cancer in the presence of demographic and socio-economic factors. Considering that the majority of AYAs in this study are unemployed and under financial strain, it may aggravate their distress and result in fragmented cancer care. Strategies to address these challenges in order to prevent poor health outcomes for AYAs with cancer, may include collaborative efforts between health policy makers and urban and rural transportation management, or steering committees to discuss and implement possible solutions to address transportation barriers.

5.3 Emotional responses

In the findings, the devastating news of a cancer diagnosis was often delivered to AYAs in an insensitive or inappropriate way. This contributed to a heightened experience of dominating emotions such as overwhelming shock and disbelief as cancer did not fit in with their future life expectations. Difficulty in navigating their psychological distress was further compounded by the presence of multiple past or current losses. Furthermore, the impact of existing burdens such as having HIV or TB, or discordant family relationships, also complicated their ability to cope. Two participants reported suicidal ideation. At the cost of their own well-being, many AYAs chose to protect their loved ones and children by not exposing their emotional vulnerability. This often contributed to increased levels of emotional hardship and inadequate support from loved ones. Spiritual distress was also apparent among the majority of participants from this study. Apart from questioning the reason for their diagnosis and feeling angry and hopeless, some participants viewed their cancer as a punishment and challenged their religious beliefs. This emphasized the need for healthcare professionals to initiate meaningful conversations on the emotional and spiritual impact of the illness, and to do spiritual screening in order to identify and address their spiritual needs. Moreover, as AYAs with cancer have an increased risk of developing mental health disorders such as depression and anxiety (11, 16), the use of screening tools should be considered to detect and appropriately refer high-risk participants for specialized assistance (11, 37, 39).

Participants also experienced a wide range of fears and worries related to missing treatment, cancer severity, disease progression, an expected limited lifespan, and at the back of their minds, possible death. Their fears were often heightened by accompanying losses such as those resulting from surgical procedures, a loss of independence, the inability to adequately fulfil parenting roles, and additional concerns generated by cancer myths. In addition, a few participants also expressed guilt, due to previous unhealthy lifestyles such as promiscuity, drug abuse, carrying the blame for causing shifts in family roles, or negligence for delays in seeking medical assistance. Even though AYAs seldom initiated conversations regarding their deep-rooted emotions, the study demonstrated a need among the majority of AYAs to share sensitive psychological issues, and therefore warranting prompt referral to appropriately skilled members of the team (16), as these discussions may improve their satisfaction with care, and help AYAs to feel more supported.

The burden of concerns, negative feelings and temporary and/or permanent life changes that participants experienced as a result of cancer, demanded adequate coping strategies in order to effectively deal with the new challenges they were faced with and to help them discover a new normal. Nonetheless, as AYAs have less life experiences compared to adults, their capacity to cope is underdeveloped, which can negatively influence the way they deal with challenging matters (10). Different coping perspectives revealed by participants in this study included resuming normal activities such as work, keeping busy, and maintaining a positive mindset that was often associated with fighting for their lives and hoping to attain future goals. In addition, the majority of AYAs also expressed immediate acceptance that was mostly based on religious beliefs. Similar to the findings of Kohi et al., religious beliefs and rituals such as prayers played a cardinal role in the way AYAs coped (41). This stresses the key importance of assessing their belief systems, morals and personal ethos and identifying their coping mechanisms in order to offer the necessary support (32). Moreover, adaptive denial has also been described by Knox et al. and Pinkerton et al., and was also evident in one participant who used it as a protective, internal coping mechanism to block the conscious awareness of painful thoughts, feelings and perceptions related to the overwhelming nature of a cancer diagnosis (29, 32).

Even though participants experienced the radical impact and negative ramifications of cancer on their lives, the experience led to a complete change in their outlook on life and fostered open and hopeful expectations for the future. Thus, it was apparent that the majority of participants viewed their experience as an opportunity for life appraisal, self-growth and reconciliation. This is consistent with the findings of Kim et al. and Beyin, that demonstrated how the process of adjusting to the impact of cancer, may increase AYAs capacity to cope with a new way of living (30, 36). Although the formation of a meaning system can be complex (29), data supports that it assists AYAs to better comprehend their cancer diagnosis and help to build resilience (30). In the findings, the meaning participants derived from their unique life experiences varied and included an increase in courage and self-confidence, strengthening of their relationships with loved ones, improved communication, and the ability to forgive. This eventually led to stronger support systems, as well as feeling more valued and loved. For others, a closer relationship with God and new cognizance such as the impermanence of life, led to broader perspectives and reshaped their worldviews and life goals in a beneficial way. Spiritual meaning was also reported by Drake et al. where living a life of sacrifice and giving thanks to God was apparent. According to these findings, strategic interventions to reduce the negative impact of cancer and encourage inner growth, strength and meaning-making, are paramount for long-term welfare and can significantly improve the quality of life of AYAs with cancer (9, 30, 36). This is only possible when taking into consideration each AYAs unique background and treating them as a whole (30).

5.4 Dreams and hopes

Due to the young life stage of AYAs, all participants had many different unfulfilled dreams and hopes for the future. These dreams and hopes such as building a career, getting married and having children, did not only add meaning to their life, but in the midst of cancer, also motivated and empowered them to remain hopeful and conquer cancer in order to resume these life goals. Acknowledging each AYAs life stage and future plans is imperative (19). In contrast, a diagnosis of cancer brought significant future uncertainty, and the unpredictability of their prognosis and life expectancy had a considerable impact on their quality of life as they often felt despondent, confused, lost hope, and became indecisive as to whether they should postpone or continue to pursue their life plans. Consistent with previous literature, a sudden disruption in the early life stage of participants also challenged their identity, as many adult-defining roles were jeopardized by cancer (19, 27, 29, 30). This led to feelings of alienation and losing their sense of normal as they were torn away from normal social roles.

Furthermore, building on existing evidence, the study findings confirmed the incomprehensibility of death for AYAs with cancer. This was often evident as profound emotional tension and anguish when confronted with their own mortality, as it did not fit in with their dreams and hopes for the future. Consequently, as also stated by Kim et al. and Knox et al., participants viewed their lives as incomplete. The thought of dying posed a major threat to their hopes, dreams and legacy work, such as fulfilling social roles as a parent (29, 30). Moreover, a striking feature was the way AYAs derived hope from God and held onto religious beliefs, for instance, that He will grant them more time to live. This confirms the critical need for age-appropriate palliative care teams to play an integral role in oncology care, as palliative care has value alongside curative treatment and is essential in the non-curative setting. Fundamental aspects of palliative care strategies include comprehensive needs assessment in the domains of physical suffering, psychosocial problems and spirituality, and in engaging in important conversations regarding advanced care planning and future care (32). In addition, availing relevant information resources that are tailored to the different life stages of the AYA oncology population, may aid in addressing a variety of existing and evolving cancer-related concerns and challenges and improve their overall well-being (30).

5.5 Support

In this study, as the diagnosis of cancer in the life of an AYA caused numerous disruptions within their family structure and personal life, they derived significant benefit and meaning from external and internal support systems to improve the way they cope. Important external support networks were reported to be family, romantic partners, peers, work colleagues, members from the community and religious institutions.

The strong and crucial role of parents in supporting AYAs with cancer, as described by Soanes and Gibson, was also reported by most participants in this study (27). Nevertheless, it was also clear that many disparities in quality family support existed. These differences ranged from extremely involved, supportive and compassionate family members, to distant and conflictual relationships that led to loneliness. Furthermore, honest discussions between AYAs and their families were often avoided in order to protect each other. Accordingly, as also stated by Belpame et al., this led to more torment and pain (3). AYAs from this study described many additional factors that contributed to broken family relationships, such as verbal or physical abuse, divorce, absent father figures, or the death of a primary caregiver or close loved one. The negative impact of these experiences on the quality of life outcomes of AYAs was severe. From this study it was also evident that when parental support was compromised or absent, long-term romantic partners fulfilled a significant role in the provision of emotional support. Moreover, romantic partners can also help AYAs to maintain their identity and feel normal (27). Thus, as families and loved ones act as a unique primary source of influence and fulfil a fundamental role in supporting AYAs with cancer, a greater focus on educating families on how to support AYAs, and focussing on their well-being, is essential (37). However, the physical, emotional, social and spiritual needs of family and caregivers often remained unidentified and neglected. Beyin demonstrated the appreciation and satisfaction of parents of AYAs when positive and engaging relationships with health care professionals existed (36). However, due to unique socio-demographics in the Northern Cape, family meetings were often difficult to arrange due to logistical challenges that included overcrowded ambulances, long distance traveling and household responsibilities that compelled family and loved ones to stay at home. Consequently, the limited ability to provide parents and caregivers with the necessary information may result in uncertainty, distress and poor psychosocial support. As highlighted by Drake et al., this study also affirms major gaps regarding the availability of appropriate support to the children of AYAs with cancer (9). The repercussions of inadequate support to children of AYAs with cancer is alarming as they do not only impact the overall well-being of affected children (30), but may also have detrimental effects on the welfare of AYAs who are parents. Healthcare professionals are urged to educate and provide assistance to family and loved ones of AYA cancer patients, including children. As a result, it may lead to greater satisfaction and increase the quality of life of AYAs living with cancer (39).

Consistent with the findings of Bibby et al. and Beyin, AYAs from this study also placed significant value on true, loyal, peer support as demonstrated by their appreciation for consistent friendships (36, 40). Many participants expressed great disappointment when peers withdrew, and relationships disintegrated as it reflected the superficiality of what they had hoped to be a committed friendship. Furthermore, in accordance with previous literature, feeling different from their peers did not only lead to feelings of loneliness and a loss of normal life, but also heightened the need to feel cherished and belonged (3, 29, 30). AYAs with cancer often find comfort and support from cancer peers with the same age, as they can appreciate humour and share and relate with their cancer experiences (9, 40). However, as AYA support groups in the

Northern Cape context are extremely limited, the level of benefit that AYAs derive from cancer peer relationships as reported in the literature (30, 36), is unknown in the Northern Cape setting and requires further exploration.

There is a lack of literature regarding the relationships between AYAs with cancer and the community as noted by Drake et al. (9). Even though some participants reported support from the community as satisfactory and beneficial, contradictory findings were also expressed. This included negative attitudes and poor quality support from community members or religious networks. These cold behaviours were often a reflection of their poor understanding and lack of knowledge and perspectives related to cancer. Consequently, this demands for a need to educate communities and strengthen communication and relationships between AYAs, their loved ones, and involved community members.

Moreover, healthcare professionals play an essential role in providing support to AYAs with cancer and to lessen their cancer-related grief (9, 19, 36). The special needs of participants in this study, did not only include the provision of honest, comprehensive information to improve their insight and knowledge of cancer, but the value of encouraging words, showing a positive attitude, and avoiding prognostic ambiguity, made them feel supported and empowered in a special way. Furthermore, the value of positive patient-healthcare professional alliances may lessen the grief of AYAs and improve treatment adherence (9). Nonetheless, since healthcare professionals often encounter great challenges when working alongside AYAs with cancer, especially when they approach the end of life, specialized AYA oncology and palliative care training is required (27, 29, 38, 42) to upskill interdisciplinary teams to adequately address the needs of AYAs with cancer.

Supporting the findings of Kohi et al., who reported that faith and prayer play a crucial protective and supportive role during their cancer journey, this study also demonstrated the importance of the Christian faith which was the only religion participants belonged to. Christian beliefs and associated practices were strong pillars of internal support to all AYAs with cancer (41). Through a personal relationship with God, they described finding hope in the midst of spiritual distress and were able to make sense of their cancer experience. As spiritual distress among AYAs is often less noticeable (11), exploring spiritual attitudes and providing adequate spiritual support may be of fundamental value (32). This emphasized the need to recruit and train spiritual counsellors to provide spiritual guidance and address the spiritual needs of AYAs with cancer.

As reported by previous research, the psychological impact of cancer on AYAs in this study oftentimes outweighed their capacity to effectively cope with the repercussions of this unexpected, life-threatening disease (10, 11, 29). Notwithstanding the fact that AYAs require unique age-appropriate emotional support that is in keeping with international AYA oncology standards, the majority of AYAs in this study were not offered emotional counselling from the onset of the diagnosis (28, 29, 39, 40). Consequently, they failed to benefit from the opportunity to learn essential coping skills that might have helped to address their unsatisfied emotional needs and adjust to a new normal (11, 35, 42). While previous research shows a reluctance among AYAs from developed countries to be referred for psychological therapy (29), the results of this study demonstrate that ten out of the twelve participants from both genders expressed an equally strong need for prompt referral to a professional counsellor whom they could trust. Additionally, one male participant emphasized the profound emotional benefit gained from early referral for emotional counselling, which resonates with the findings of Knox et al. (29). Among the majority of participants, professional counselling was preferred over emotional support from family members. Another notable observation that is concurrent with the findings of Osbourne et al., was the significant difference in emotional maturity that varied with age and gender (39). For younger male patients it was often more challenging to express their emotions and thoughts compared to older AYAs. This recognizes the need to appreciate diversity that exists among different developmental ages and distinct subgroups within this population. It also denotes more attention to a tailored, age-appropriate approach when facilitating emotional counselling sessions (40). Furthermore, as also recognized by previous qualitative research, the lack of opportunity to unburden their emotions was mirrored by their eagerness and dedication to attend research interviews, as they felt emotionally supported, satisfied and worthy to be listened to (29, 42).

The emotional needs of family and caregivers of AYAs are also challenged by emotional trauma and grief when their young loved one is diagnosed with cancer (42). An even greater emotional burden may be experienced by parents of AYAs as they have to come to terms with the early timing of their child's diagnoses, and they may often fear or grieve the loss of future dreams they have planned for their child. This study recognizes the need for emotional counselling of family and caregivers as it may assist in addressing their psychological challenges and distress, improve their coping skills, and alleviate their emotional burden. Consequently, this may enable them to strengthen the support they provide to AYAs and enhance their own quality of life (42). Conversely, as also evident from this study, the failure to offer emotional support services to family and caregivers, resulted in limited knowledge and understanding of AYAs’ condition. This led to either difficulties in engaging in conversations with young adults, or distant, conflictual relationships that impacted AYAs’ psychosocial health and contributed to greater suffering (16).

5.6 Sociocultural influences

In this study, the role of culture was shown to impact the perceptions of communities and perpetuated the lack of cancer information and understanding of certain populations.

Concordant with the findings of two African studies, misconceptions, fears and cultural beliefs regarding cancer, existed. For instance, that it is contagious, seen as a form of punishment by the ancestors, a death sentence, a result of witchcraft, or that it is prevalent only in certain age categories or ethnic groups (41, 42). A comment made by Edwards and Greeff further describes the influence of cancer stigma and how it may direct decisions related to medical care (42). This is demonstrated by two AYAs who were coerced by family members to seek help from traditional healers, rather than obtaining help from healthcare professionals. Consequently, this may contribute to diagnostic and treatment delays and impact cancer control (17). The impact of stigma on the experiences and quality of life of AYAs was also profound, and included feelings of judgement due to changes in their physical appearance, feeling poorly understood, rejected, or receiving inadequate support that resulted in social isolation. In view of this, the importance of cancer awareness campaigns and programs to increase health promotion and cancer knowledge within all communities, and in particular rural areas, is essential (17, 41). Acknowledging the role of culture and how it influences the conceptualization of disease, pain and suffering, is paramount, and also requires an understanding, appreciation and respect towards cultural differences in order to promote sensitive, individualized care to AYAs with cancer and their families (1, 32).

In this work, participants also reported poverty-related challenges that were experienced on various levels. This was demonstrated by their low socio-economic background, insufficient household income, and the fact that they were only able to access cancer care in the under-resourced public health sector. Consistent with prior research, it also included a shortage of basic needs, such as proper nutrition, that often took precedence over seeking medical help, being financially dependent on disability grants, and living in informal dwellings and rural areas where access to electricity, sanitation and proper cancer care were often limited (17, 42). In addition, compliance to cancer treatment, especially for AYAs from remote areas, involved additional inescapable expenses such as transport, which is also a well-known finding in the literature (42). These factors, along with existing financial hardship, increased AYAs burden of disease and as highlighted by Brookman et al., they emphasized the large gap of quality healthcare between the wealthy and the poor. This contributed to challenges that were unique for most AYAs in developed countries (17). Furthermore, a significant difference between AYAs from high- and middle-income countries, was inadequate education, as reflected by fifty percent of AYAs who failed to obtain their grade twelve qualification and that may contribute to unemployment. As AYAs are in a life-stage where they pursue educational and career goals, almost half of the participants wanted to further their education. However, their cancer diagnosis and cancer treatment led to interrupted academic studies and resulted in higher dependence and financial strain on family members. Moreover, crime and safety were also unique challenges experienced by AYAs within their communities compared to AYAs with cancer in HICs. Their exposure to violence varied from being affected directly, such as being a victim of rape, to dealing with the death of a murdered family member, or a suicide attempt of a loved one as a result of drug abuse. Not only did this add to the existing anxiety and fears of having cancer, but it also contributed to conflictual relationships and increased overall suffering.

5.7 Researcher's reflection:

To meet AYAs with cancer from different socio-cultural backgrounds and being granted permission to travel along the varying depths of their transparent emotions, real life challenges, sharing in their priorities, and what they hope for and dream about, contributed to an understanding that is significantly wide and uniquely rich.

The impact of these delicate and treasured encounters facilitated the transformation of my pre-existing theoretical constructs to actual experiential truths. Listening to different dimensions of their positive and negative lived experiences, awakened in me a deep sense of sadness, compassion, and respect for the lonely way AYAs cope with their individually perceived cancer challenges, and with life in general. This paradigm shift changed my perspective of AYAs with cancer in an exceptional way – knowing that behind these young adults' smiles and laughs lie a hidden sphere of vulnerability, unmet needs and often unheeded pain. This did not only urge me to increase awareness of the different manifold challenges that AYAs with cancer experience within the South African public health setting, but also to advocate for radical change in the quality of cancer care that is provided to them.

5.8 Limitations of study

This study aimed to explore the challenges experienced by AYAs aged 18–39 years with cancer. However, as participants were selected by purposive sampling, none of the participants recruited for the study was under the age of 22 years. Consequently, this study does not include information related to the experiences of adolescents, but only young adults between 22–39 years who may not be fully representative of the intended age group. Therefore, the results can only apply to AYAs aged 22 years and above. Nonetheless, since the majority of previous studies relating to AYAs with cancer failed to include experiences of older AYAs, this study contributes to an in-depth understanding of their key priorities and concerns within the South African context.

Another limitation is that the research findings did not explicitly explore additional prompts such as reproductive health issues and fertility needs of AYAs with cancer. Therefore, the possibility exists that the holistic pain and challenges related to reproductive health and infertility, may remain unrecognized and unaddressed.

As the primary researcher conducted the majority of the thematic analysis, the research findings may be limited to the views and perspective of the primary researcher. However, this limitation was minimized by having discussions with the research assistant and receiving objective input, guidance and supervision from the researchers throughout the analysis process.

Lastly, as the researcher was present during all interviews, there may have been participant bias during AYAs' interviews, related to their healthcare experiences and needs. However, this was minimized by counselling and reassuring participants before and during interviews that honest criticism or comments will not negatively impact their health outcome in any way. Moreover, they were encouraged that their input will be acknowledged and may be valuable to inform better healthcare systems that may benefit future AYAs with cancer.

5.9 Conclusion

This work has provided a valuable lens through which the quality of life of AYAs with cancer in the Northern Cape public health setting can be viewed. As it reflects many considerable differences in experiences between AYAs from a middle-income country compared to AYAs from high-income countries, it reinforces the critical need for improved AYA oncology care that cannot be provided without early collaboration with and support from a palliative care team (16, 18, 32). Nonetheless, due to the lack of palliative care systems, AYAs from this study report various interrelated multidimensional needs that oftentimes remain unnoticed and unaddressed. In addition, this considerably high cancer burden is further exacerbated by several unique challenges grounded in the South African context.

While research related to AYAs from HIC strongly focuses on the development of age-appropriate AYA centres and services, (40) the basic needs of AYAs with cancer in an impoverished and resource-limiting MIC are hardly met (14). This is even more pronounced in rural settings (14). Moreover, another striking observation from this work is the essential need to explore and honour the AYA behind a disease, to discover the particular way they perceive their cancer journey, and to provide care that is individualized and retains dignity. Therefore, a deep holistic needs assessment as well as an appreciation of their differences, is required to guide planning and delivery of comprehensive AYA oncology care (11). Consequently, by appropriately treating their total pain, the quality of life of this vulnerable population and their families may be impacted in a significant way (11, 16).

CHAPTER 6

Conclusion and Recommendations

6.1 Conclusion:

To the researcher’s knowledge, this is the first study in South Africa to explore the first-hand experiences of AYAs (22–39 years) with cancer in the public health setting. This qualitative study aimed to understand the complex, multidimensional, interrelated challenges experienced by AYAs with cancer, and clearly demonstrated their total pain and the cardinal importance of providing holistic treatment and patient-centred care. Compared to high-income countries that have shown significant progress in delivering age-appropriate care to AYAs with cancer, the manifold challenges described by participants in this study were largely unmet. Within the South African setting, challenges experienced by AYAs with cancer were amplified by stigmatization and rejection by community members in response to a diagnosis of HIV or TB. In addition, socio-cultural influences such as cultural beliefs, poor cancer awareness, severe poverty, unemployment, crime, and threats to personal safety, also engendered distressing feelings and increased their healthcare needs. These findings highlighted the fundamental nature of a holistic patient assessment and early recognition of AYAs’ physical, emotional, social and spiritual needs, to provide optimal palliative care through an interdisciplinary team approach. In addition, the importance of culturally-sensitive and dignified patient care was also demonstrated.

A wide range of existing healthcare system issues were identified. This was of significant concern and greatly influenced the provision of palliative care to participants and their families. Problems that had a significant impact on AYAs’ overall quality of life, included poor communication, delayed diagnosis, negative nursing attitudes, a lack of equipment, and transport and travel issues. These factors also unveiled to which extent AYAs in the public setting were affected by the divided and unequal South African health system, and they emphasize the need for change in order to promote equitable and equal healthcare to all citizens.

Similar to AYAs with cancer from HIC, participants in this study also expressed many emotional challenges that particularly pertained to the possibility of dying, and also included fears and worries related to the future care of their children. Nonetheless, these sources of tremendous concern remained mostly unaddressed, and emphasized the need to offer formal psychosocial support to AYAs and their families. As their cancer diagnosis triggered many losses and threatened their future hopes and dreams, the formation of a meaning system, gaining a new perspective on life, and holding onto religious beliefs, were among the priorities that assisted in building resilience and enabled them to cope with their cancer diagnosis. Supporting these coping mechanisms and providing encouragement and comfort through adequate social support structures are vital, in order to appropriately address the needs of AYAs with cancer.

Reflecting on the study findings, even though the findings may only be generalizable to limited settings, they can be transferred to form specific recommendations on how to improve the quality of life of AYAs with cancer and their families in the Northern Cape public health setting. This study demonstrates that higher interventions on National Health level is necessary in order to implement the current national palliative care policy. This includes advances in AYA oncology care that acknowledge their unique developmental age, emotional capacity, distinct life stage, and socio-cultural background. Notwithstanding the significant challenges that plague quality healthcare delivery in the Northern Cape, further research to elucidate the meaning of age-appropriate care and the development of comprehensive, integrated oncology and palliative care guidelines for AYAs with cancer in South Africa, is necessary to acknowledge and address their total pain.

In conclusion, within a poverty-stricken, resource-limited middle-income country, this study promoted a greater cognizance related to the complex, multidimensional challenges experienced by AYAs with cancer. It does not only contribute to a wider framework of valuable information related to the challenges and unique healthcare needs of this “lost tribe”, but also identifies that the current scope of comprehensive AYA-specific oncology care in South Africa is virtually non-existent. Therefore, these findings highlight the importance of and may set a foundation for the prioritization and development of key strategies to initiate the integration of individualized, age-specific palliative care into oncology care. Even though these future goals may seem like unattainable paradigms within the South African setting, one can strive to implement interventions that may lead to small changes and successes with time. The ultimate aim would be to appropriately address the holistic unmet needs and provide better quality of life outcomes for AYAs with cancer, and their families, in South Africa.

6.2 Recommendations

6.2.1 Research implications and recommendations:

- Training of more healthcare professionals in palliative care as recommended by the World Health Assembly resolution 2014 (WHA 67.19), is paramount. This may improve communication skills, strengthen interdisciplinary team work and promote comprehensive individualized care.

- On a tertiary, secondary and particularly primary nursing level, basic training and on-going support relating to the concept of "total pain" and the vital role it plays in palliative care may lead to significant changes in attitudes, and increase their awareness towards patients' holistic care needs. Sensitivity training of primary level nurses should also include patient-centred care, treating AYAs with respect and compassion, and upholding their sense of dignity.
- Providing early emotional support and counselling to all AYAs and their families at the time of cancer diagnosis, should be integrated into standard oncology care in order to address and reduce their emotional distress and suffering.
- Since this study demonstrated that religious beliefs are one of strongest sources of support for AYAs with cancer, empowering local religious communities and offering opportunities for education and palliative care training, may equip them to recognize and address the spiritual needs of patients and loved ones.
- As access to palliative care is a fundamental human right, establishing and facilitating proper transitions from in-hospital discharge to home-based care services is imperative to improve coordination and continuity of care including on-going communication with available resources as required.
- The implementation of community cancer awareness programs and educational campaigns with a specific focus on rural areas, is crucial, in order to address stigma and promote family and community knowledge and support to AYAs with cancer.
- It is imperative to individualize each patient in order to understand their unique challenges and provide care that is compassionate, comprehensive, dignified and patient-centred.

6.2.2 Further research:

- It was beyond the scope of this study to focus on the experiences of family and caregivers. As they play a critical role in supporting AYAs with cancer, recommendations for future research include the identification of their unmet holistic needs and an exploration of practical ways to provide support that may improve their quality of life.
- Exploring the experiences and concerns of other diverse AYA groups such as those with HIV and TB, as well as AYAs treated in the South African private sector for cancer, is crucial, as it may help to define age-appropriate care and contribute to valuable knowledge necessary for the provision of holistic, patient-centred care. In addition, comparing AYAs with cancer in the public sector with those in the private sector, may also emphasize the disparities within the South African two-tiered healthcare system, and underpin the need for change.

- By acknowledging the rich, ethnic and cultural diversity within the South African context, future studies are required to do deeper evaluations of the cultural experiences of AYAs from different backgrounds. This may not only increase awareness and provide a better understanding of AYAs' and their family's unique values, traditions and beliefs, but may also equip healthcare professionals to provide collaborated care that is culturally-sensitive, respectful, and that will address spiritual pain in more appropriate ways.
- There is a need to conduct further studies that focus on the analysis of different age groups within the population of AYAs with cancer, as they may have varying levels of emotional maturity, coping styles and unique needs.
- In South Africa, further attention should be given to the role of support groups, not only for AYAs and their cancer peers, but also for survivors. The development of support groups for AYAs with cancer may grant them the opportunity to connect and share challenges and experiences to promote psychosocial well-being. Evaluating the impact of support groups for family and caregivers should also be considered.
- Further research is needed to explore possible reasons for negative nursing attitudes in the Northern Cape, in order to appropriately address the root problem and promote better quality care and patient outcomes, such as optimal symptom control, early diagnosis, and adequate timely referral.

References

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1. Silbermann M, Fink RM, Min SJ, Mancuso MP, Brant J, Hajjar R, et al. Evaluating palliative care needs in Middle Eastern countries. J Palliat Med. 2015;18(1):18-25.

2. DePauw S, Rae C, Schacter B, Rogers P, Barr RD. Evolution of adolescent and young adult oncology in Canada. Curr Oncol. 2019;26(4):228-33.

3. Belpame N, Kars MC, Beeckman D, Decoene E, Quaghebeur M, Van Hecke A, et al. "The AYA Director": A Synthesizing Concept to Understand Psychosocial Experiences of Adolescents and Young Adults With Cancer. Cancer nursing. 2016;39(4):292-302.

4. Trama A, Botta L, Steliarova-Foucher E. Cancer Burden in Adolescents and Young Adults: A Review of Epidemiological Evidence. Cancer journal (Sudbury, Mass). 2018;24(6):256-66.

5. Bleyer A, Ferrari A, Whelan J, Barr RD. Global assessment of cancer incidence and survival in adolescents and young adults. Pediatric blood & cancer. 2017;64(9).

6. Ferrari A, Barr RD. International evolution in AYA oncology: Current status and future expectations. Pediatric blood & cancer. 2017;64(9).

7. Prager GW, Braga S, Bystricky B, Qvortrup C, Criscitiello C, Esin E, et al. Global cancer control: responding to the growing burden, rising costs and inequalities in access. ESMO Open. 2018;3(2):e000285.

8. Sartorius K, Sartorius B, Govender PS, Sharma V, Sherriff A. The future cost of cancer in South Africa: An interdisciplinary cost management strategy. S Afr Med J. 2016;106(10):949-50.

9. Drake EK, Urquhart R. The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review. J Adolesc Young Adult Oncol. 2020;9(2):145-56.

10. Marshall S, Grinyer A, Limmer M. The 'lost tribe' reconsidered: Teenagers and young adults treated for cancer in adult settings in the UK. Eur J Oncol Nurs. 2018;33:85-90.

11. Beerbower E, Winters D, Kondrat D. Bio-psycho-social-spiritual needs of adolescents and young adults with life-threatening illnesses: Implications for social work practice. Soc Work Health Care. 2018;57(4):250-66.

12. Michelagnoli MP, Pritchard J, Phillips MB. Adolescent oncology—a homeland for the “lost tribe”. Eur J Cancer. 2003;39(18):2571-2.

13. Wiener L, Weaver MS, Bell CJ, Sansom-Daly UM. Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. Clin Oncol Adolesc Young Adults. 2015;5:1-18.

14. Ngwenya N, Ambler J, Archary M. Qualitative situational analysis of palliative care for adolescents with cancer and HIV in South Africa: healthcare worker perceptions. BMJ Open. 2019;9(1):e023225.

15. Barr RD, Ferrari A, Ries L, Whelan J, Bleyer WA. Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future. JAMA Pediatr. 2016;170(5):495-501.

16. Rosenberg AR, Wolfe J. Palliative care for adolescents and young adults with cancer. Clin Oncol Adolesc Young Adults. 2013;2013(3):41-8.

17. Brookman-May SD, Rodriguez-Faba O, Langenhuijsen JF, Akdogan B, Linares E, Minervini A, et al. Challenges, hurdles and possible approaches to improve cancer care in developing countries–A short breakdown of the status quo and future perspective. 2017;3(5):204-12.

18. Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. The Lancet Oncology. 2018;19(11):e588-e653.

19. Kenten C, Ngwenya N, Gibson F, Flatley M, Jones L, Pearce S, et al. Understanding care when cure is not likely for young adults who face cancer: a realist analysis of data from patients, families and healthcare professionals. BMJ Open. 2019;9(1):e024397.

20. Delgado E, Barfield RC, Baker JN, Hinds PS, Yang J, Nambayan A, et al. Availability of palliative care services for children with cancer in economically diverse regions of the world. Eur J Cancer. 2010;46(12):2260-6.

21. Mayosi BM, Benatar SR. Health and health care in South Africa - 20 years after Mandela. N Engl J Med. 2014;371(14):1344-53.

22. South African Department of Health. National Health Insurance for South Africa: Towards Universal Health Coverage. 2015; Available at: https://www.gov.za/sites/www.gov.za/files/National_Health_Insurance WhitePaper10Dec 2015.pdf. Accessed 04/24, 2020.

23. Maphumulo WT, Bhengu BR. Challenges of quality improvement in the healthcare of South Africa post-apartheid: A critical review. J Cur. 2019;42(1):1-9.

24. Cleary S, Birch S, Chimbindi N, Silal S, McIntyre D. Investigating the affordability of key health services in South Africa. Soc Sci Med. 2013;80:37-46.

25. Pauw K. A Profile of the Northern Cape Province: Demographics, Poverty, Inequality and Unemployment. 2005.

26. Magrath I, Epelman S. Cancer in adolescents and young adults in countries with limited resources. Curr Oncol Rep. 2013;15(4):332-46.

27. Soanes L, Gibson F. Protecting an adult identity: A grounded theory of supportive care for young adults recently diagnosed with cancer. Int J Nurs Stud. 2018;81:40-8.

28. Skaczkowski G, White V, Thompson K, Bibby H, Coory M, Pinkerton R, et al. Do Australian adolescents' and young adults' experiences of cancer care influence their quality of life? Psycho-Oncology. 2018;27(3):990-7.

29. Knox MK, Hales S, Nissim R, Jung J, Lo C, Zimmermann C, et al. Lost and stranded: the experience of younger adults with advanced cancer. Support Care Cancer. 2017;25(2):399-407.

30. Kim B, White K, Patterson P. Understanding the experiences of adolescents and young adults with cancer: A meta-synthesis. Eur J Oncol Nurs. 2016;24:39-53.

31. Item WHOJS-SWHAA. Strengthening of palliative care as a component of comprehensive care throughout the life course. WHA 67.19. 2014. 2018;15.

32. Pinkerton R, Donovan L, Herbert A. Palliative Care in Adolescents and Young Adults With Cancer-Why Do Adolescents Need Special Attention? Cancer journal (Sudbury, Mass). 2018;24(6):336-41.

33. Daunov KA, Cornett SE. Can the Early Introduction of Palliative Care Alleviate the Disease Burden in Adolescents and Young Adults With Cancer? Journal of Hospice & Palliative Nursing. 2017;19(4):351-5.

34. Sodergren SC, Husson O, Rohde GE, Tomaszewska IM, Vivat B, Yarom N, et al. A Life Put on Pause: An Exploration of the Health-Related Quality of Life Issues Relevant to Adolescents and Young Adults with Cancer. J Adolesc Young Adult Oncol. 2018;7(4):453-64.

35. Zebrack B, Bleyer A, Albritton K, Medearis S, Tang J. Assessing the health care needs of adolescent and young adult cancer patients and survivors. Cancer. 2006;107(12):2915-23.

36. Beyin DR. Experiences of supportive and palliative care of adolescents with life threatening illness: from the perspectives of adolescents, family and nurses as providers: meta-synthesis. 2016.

37. Fernandez C, Fraser GA, Freeman C, Grunfeld E, Gupta A, Mery LS, et al. Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult-Aged Cancer Patients and Survivors. J Adolesc Young Adult Oncol. 2011;1(1):53-9.

38. Avery J, Geist A, D'Agostino NM, Kawaguchi SK, Mahtani R, Mazzotta P, et al. "It's More Difficult…": Clinicians' Experience Providing Palliative Care to Adolescents and Young Adults Diagnosed With Advanced Cancer. 2020;16(1):e100-e8.

39. Osborn M, Johnson R, Thompson K, Anazodo A, Albritton K, Ferrari A, et al. Models of care for adolescent and young adult cancer programs. Pediatric blood & cancer. 2019:e27991.

40. Bibby H, White V, Thompson K, Anazodo A. What Are the Unmet Needs and Care Experiences of Adolescents and Young Adults with Cancer? A Systematic Review. J Adolesc Young Adult Oncol. 2017;6(1):6-30.

41. Kohi TW, von Essen L, Masika GM, Gottvall M, Dol J. Cancer-related concerns and needs among young adults and children on cancer treatment in Tanzania: a qualitative study. BMC Cancer. 2019;19(1):82.

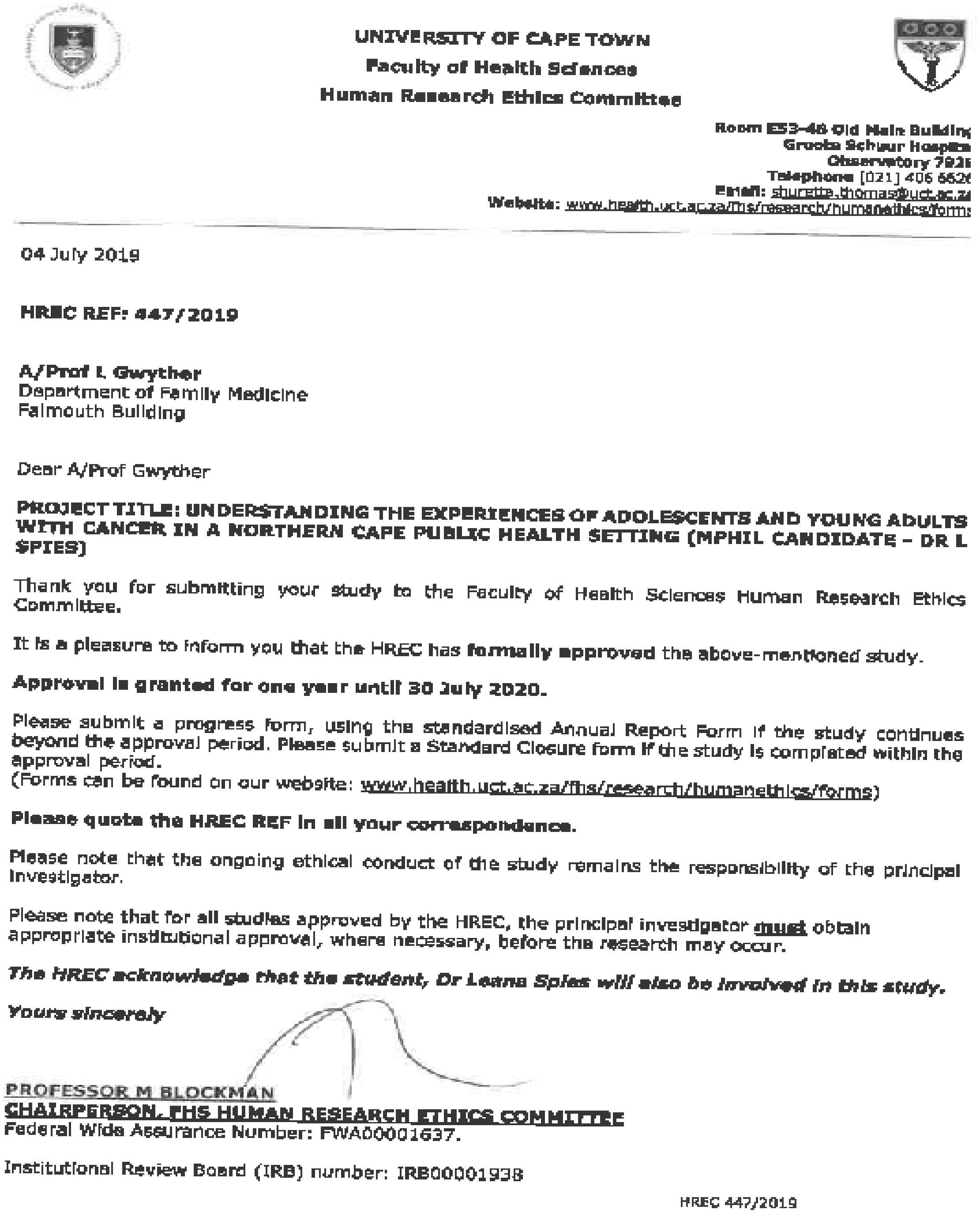
42. Edwards LB, Greeff LE. A descriptive qualitative study of childhood cancer challenges in South Africa: Thematic analysis of 68 photovoice contributions. South African Journal of Oncology. 2017;1.

43. Marshall B, Cardon P, Poddar A, Fontenot R. Does Sample Size Matter in Qualitative Research?: A Review of Qualitative Interviews in is Research. Journal of Computer Information Systems. 2015;54(1):11-22.

44. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

Appendices

APPENDIX 1: UCT Ethics Approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Buildin
Groote Schuur Hospit
Observatory 792
Telephone [021] 406 662
Email: shurette.thomas@uct.ac.z
Website: www.health.uct.ac.za/fhs/research/humanethics/form

04 July 2019

HREC REF: 447/2019

A/Prof L Gwyther
Department of Family Medicine
Falmouth Building

Dear A/Prof Gwyther

PROJECT TITLE: UNDERSTANDING THE EXPERIENCES OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER IN A NORTHERN CAPE PUBLIC HEALTH SETTING (MPHIL CANDIDATE – DR L SPIES)

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

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

Approval is granted for one year until 30 July 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

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

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Dr Leana Spies will also be involved in this study.

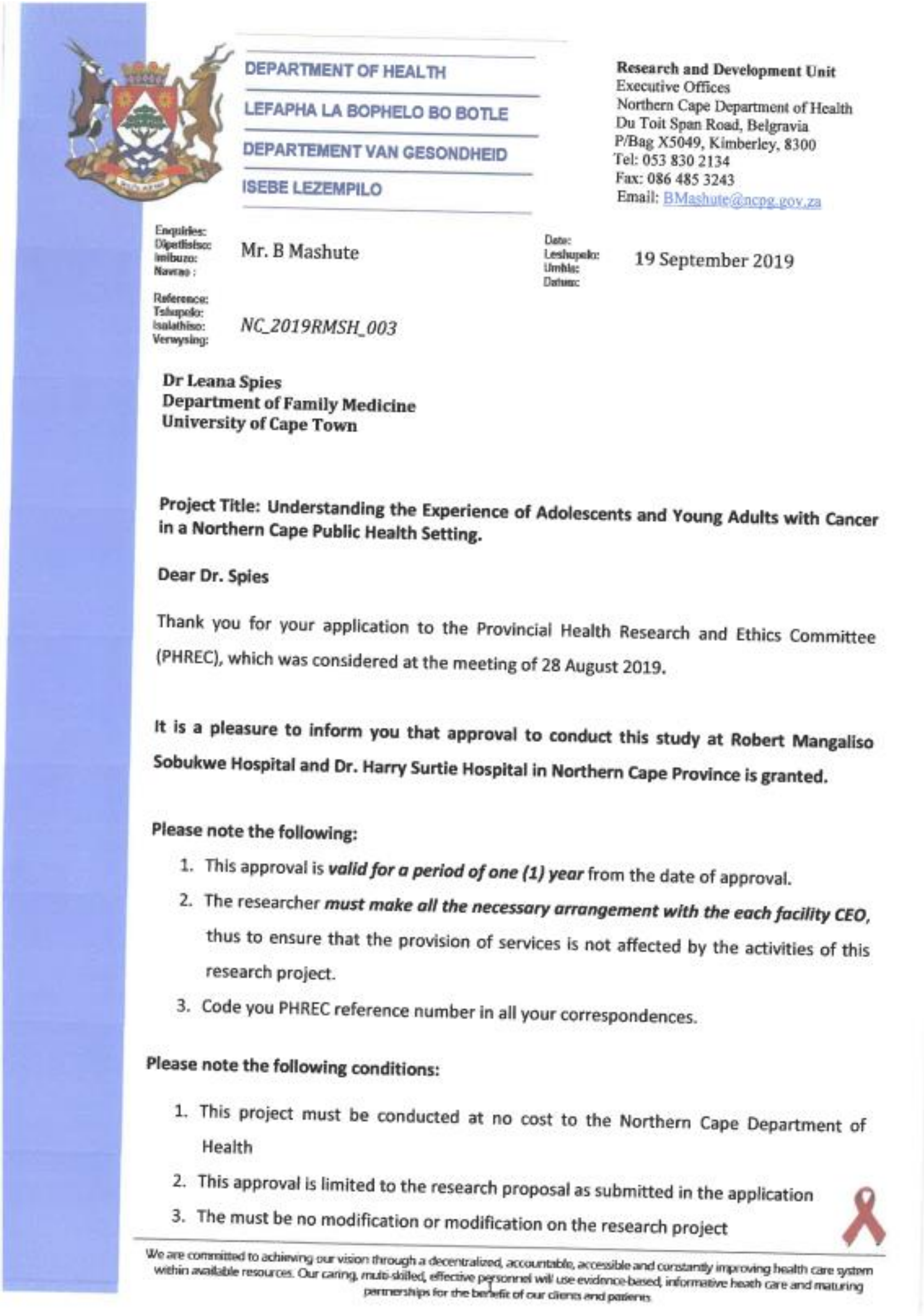
Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

HREC 447/2019

APPENDIX 2: Provincial Health Research and Ethics Committee Approval



DEPARTMENT OF HEALTH
LEFAPHA LA BOPHELO BO BOTLE
DEPARTEMENT VAN GESONDHEID
ISEBE LEZEMPILO

Research and Development Unit
Executive Offices
Northern Cape Department of Health
Du Toit Span Road, Belgravia
P/Bag X5049, Kimberley, 8300
Tel: 053 830 2134
Fax: 086 485 3243
Email: BMashute@ncpg.gov.za

Enquiries: Dipotsiso: Imibuzo: Navrae: Mr. B Mashute

Date: Leshupelo: Umhla: Datum: 19 September 2019

Reference: Tshupelo: Isalathiso: Verwysing: *NC_2019RMSH_003*

Dr Leana Spies
Department of Family Medicine
University of Cape Town

Project Title: Understanding the Experience of Adolescents and Young Adults with Cancer in a Northern Cape Public Health Setting.

Dear Dr. Spies

Thank you for your application to the Provincial Health Research and Ethics Committee (PHREC), which was considered at the meeting of 28 August 2019.

It is a pleasure to inform you that approval to conduct this study at Robert Mangaliso Sobukwe Hospital and Dr. Harry Surtie Hospital in Northern Cape Province is granted.

Please note the following:

1. This approval is ***valid for a period of one (1) year*** from the date of approval.
2. The researcher ***must make all the necessary arrangement with the each facility CEO,*** thus to ensure that the provision of services is not affected by the activities of this research project.
3. Code you PHREC reference number in all your correspondences.

Please note the following conditions:

1. This project must be conducted at no cost to the Northern Cape Department of Health
2. This approval is limited to the research proposal as submitted in the application
3. The must be no modification or modification on the research project

We are committed to achieving our vision through a decentralized, accountable, accessible and constantly improving health care system within available resources. Our caring, multi-skilled, effective personnel will use evidence-based, informative heath care and maturing partnerships for the benefit of our clients and patients

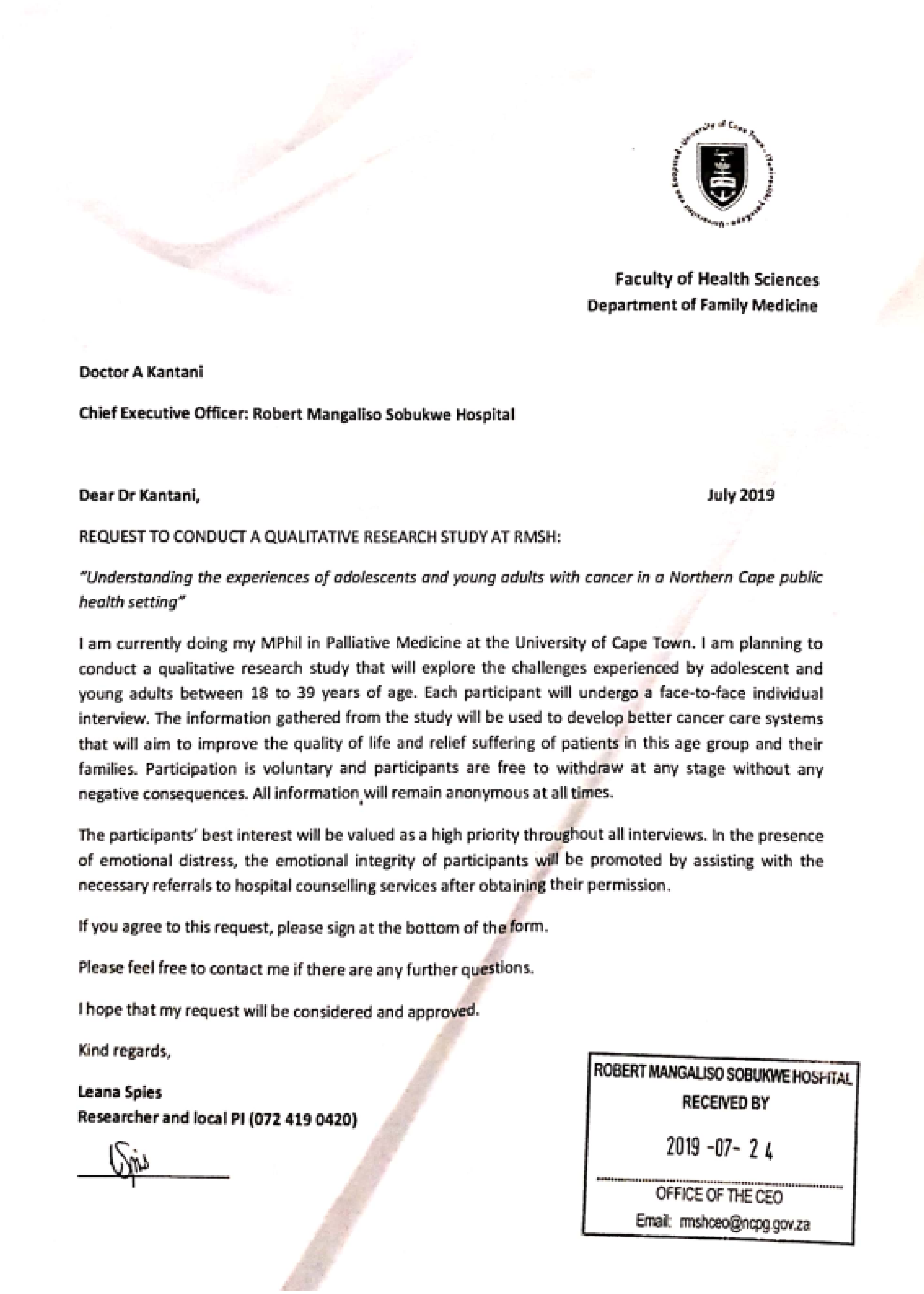
4. PHREC may monitor the research progress at anytime
5. At the completion of your study, a copy of your final report must be submitted to the Research and development Unit
6. The Northern Cape Department of Health Senior Management Committee shall be briefed on the outcome of the study prior publishing

Yours' faithfully

Dr. E Worku
Chairperson of the PHREC
Department of Health
Northern Cape Province

19/09/2019
Date

APPENDIX 3: Letters of Permission from CEO of RMSH and HSH



Faculty of Health Sciences
Department of Family Medicine

Doctor A Kantani

Chief Executive Officer: Robert Mangaliso Sobukwe Hospital

Dear Dr Kantani, **July 2019**

REQUEST TO CONDUCT A QUALITATIVE RESEARCH STUDY AT RMSH:

"Understanding the experiences of adolescents and young adults with cancer in a Northern Cape public health setting"

I am currently doing my MPhil in Palliative Medicine at the University of Cape Town. I am planning to conduct a qualitative research study that will explore the challenges experienced by adolescent and young adults between 18 to 39 years of age. Each participant will undergo a face-to-face individual interview. The information gathered from the study will be used to develop better cancer care systems that will aim to improve the quality of life and relief suffering of patients in this age group and their families. Participation is voluntary and participants are free to withdraw at any stage without any negative consequences. All information will remain anonymous at all times.

The participants' best interest will be valued as a high priority throughout all interviews. In the presence of emotional distress, the emotional integrity of participants will be promoted by assisting with the necessary referrals to hospital counselling services after obtaining their permission.

If you agree to this request, please sign at the bottom of the form.

Please feel free to contact me if there are any further questions.

I hope that my request will be considered and approved.

Kind regards,

Leana Spies
Researcher and local PI (072 419 0420)

ROBERT MANGALISO SOBUKWE HOSPITAL
RECEIVED BY
2019 -07- 24
OFFICE OF THE CEO
Email: rmshceo@ncpg.gov.za

Prof Liz Gwyther
Principal Investigator (021 650 1475)

Dr Daniel Osei-Fofie
Head of Oncology Department

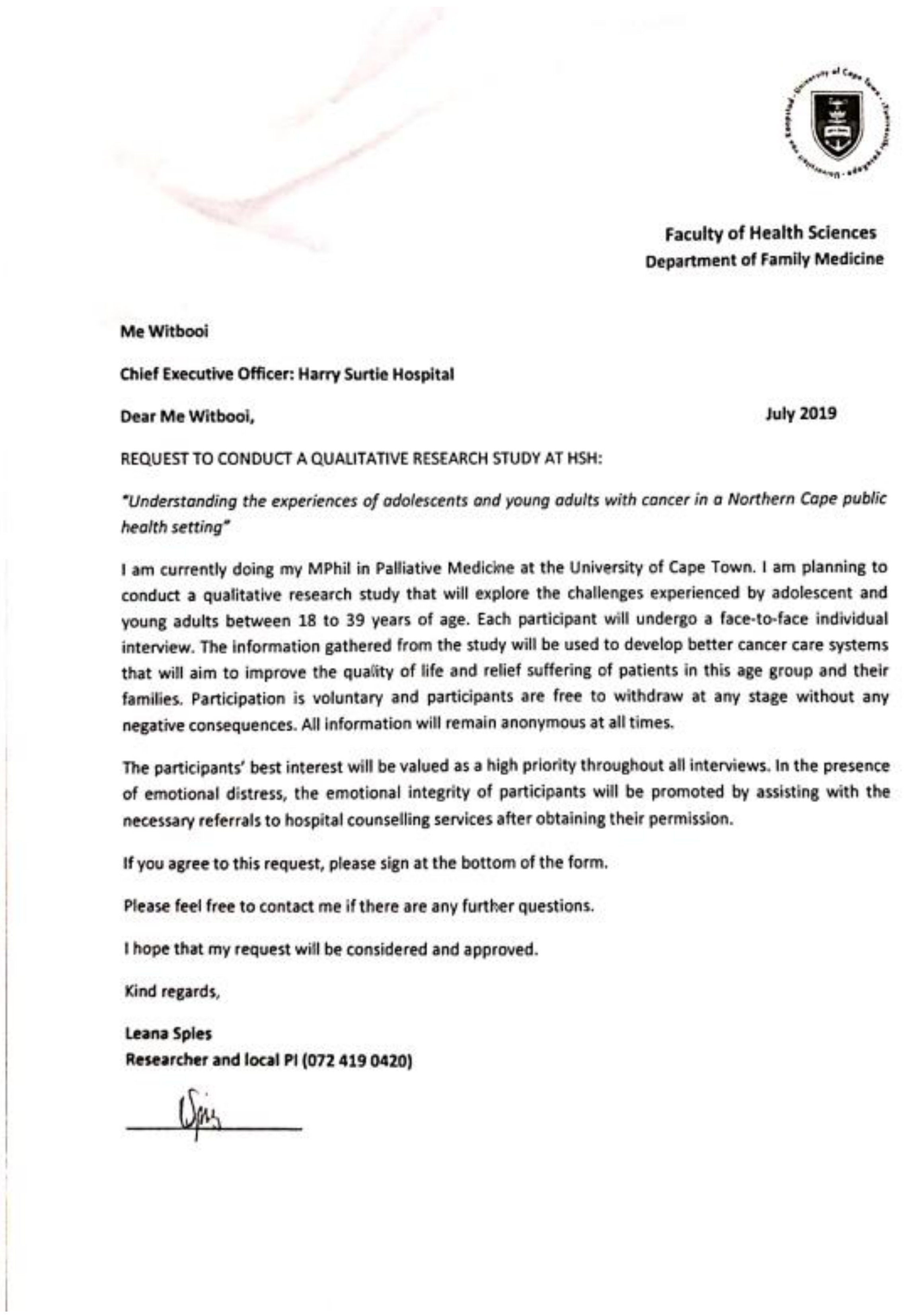
CONSENT TO CONDUCT RESEARCH AT ROBERT MANGALISO SOBUKWE HOSPITAL:

Hereby, I, **Dr A Kantani**, give consent to the conduction of a qualitative research study at RMSH:

"Understanding the experiences of adolescents and young adults with cancer in a Northern Cape public health setting"

CONSENT:

DATE: 24/07/19



Faculty of Health Sciences
Department of Family Medicine

Me Witbooi

Chief Executive Officer: Harry Surtie Hospital

Dear Me Witbooi, **July 2019**

REQUEST TO CONDUCT A QUALITATIVE RESEARCH STUDY AT HSH:

"Understanding the experiences of adolescents and young adults with cancer in a Northern Cape public health setting"

I am currently doing my MPhil in Palliative Medicine at the University of Cape Town. I am planning to conduct a qualitative research study that will explore the challenges experienced by adolescent and young adults between 18 to 39 years of age. Each participant will undergo a face-to-face individual interview. The information gathered from the study will be used to develop better cancer care systems that will aim to improve the quality of life and relief suffering of patients in this age group and their families. Participation is voluntary and participants are free to withdraw at any stage without any negative consequences. All information will remain anonymous at all times.

The participants' best interest will be valued as a high priority throughout all interviews. In the presence of emotional distress, the emotional integrity of participants will be promoted by assisting with the necessary referrals to hospital counselling services after obtaining their permission.

If you agree to this request, please sign at the bottom of the form.

Please feel free to contact me if there are any further questions.

I hope that my request will be considered and approved.

Kind regards,

Leana Spies
Researcher and local PI (072 419 0420)

Prof Liz Gwyther
Principal Investigator (021 650 1475)

Dr Daniel Osei-Fofie
Head of Oncology Department

CONSENT FOR CONDUCTING RESEARCH AT HARRY SURTIE HOSPITAL:

Hereby, I, **Me Witbooi**, give consent to the conduction of a research study at HRH:

"Understanding the experiences of adolescents and young adults with cancer in a Northern Cape public health setting"

CONSENT: Ms Gladys Witbooi
Acting CEO

DATE: 10/07/2019

APPENDIX 4: Informed Consent Document (English)

4.1 Participant information sheet

Faculty of Health Sciences
Department of Family Medicine

Dear Participant,

INFORMATION REGARDING RESEARCH PROJECT

I am a Master's degree student enrolled for the degree M.Phil in Palliative Medicine at the Department of Family Medicine, at the University of Cape Town. I have to conduct a research project and write a research dissertation on it in fulfilment of the requirements for my postgraduate qualification. The title of my research study is: Understanding the experiences of adolescents and young adults (AYA's) with cancer in a Northern Cape public health setting.

Purpose of this study:

The purpose of this study is to understand the experiences and palliative care needs of adolescents and young adults with cancer in South Africa. The study will therefore aim to explore and identify the challenges experienced by AYA's with cancer in a Northern Cape public health setting in order to inform cancer care systems and make recommendations about health service delivery in Northern Cape.

Procedure:

Participation in the study requires an individual face-to-face interview session of approximately 30-60 minutes that will be held at a time convenient to you. Informed consent is given by completing and returning the form attached to this letter.

Risks and possible discomforts:

There are no risks involved by participating in this study. If you experience any emotional discomfort during the interview and require access to social work or psychology services, the researcher will refer you to these services. The necessary referrals will be done according to need and request. This research project entails no financial implications or any other discomforts for you as participant.

Value of the study:

As a need for better understanding of the challenges of adolescents and adults with cancer in a middle-income country was evident, obtaining information regarding their experiences in the Northern Cape Province will help to identify the holistic needs of this group to inform the provision of holistic healthcare that will aim to address their needs.

Participant's rights:

Participation in the study is entirely voluntary and participants maintain the right to choose not to take part or to withdraw from the study at any stage and they will continue to receive standard care without negative consequences.

Confidentiality:

All the results obtained from the individual interview will be treated as strictly confidential. The results will be represented anonymously in a complete discussion of the findings of the research project. The data will be stored for 5 years for archiving and research purposes, where after it will be destroyed.

If you have any queries or concerns, please feel free to contact me, Leana Spies, or the principal investigator, Prof Liz Gwyther, at the contact details provided below.

Thank you in advance for your co-operation and time.

Kind regards,

____

Leana Spies
Researcher and local PI
072 419 0420

____

Liz Gwyther
Principal Investigator
021 650 1475

Contact details of Human Research Ethics Committee
Faculty of Health Sciences – University of Cape Town
Telephone: 021 650 3002

4.2 Informed Consent

Title of research:
Understanding the experiences of adolescents and young adults with cancer in a Northern Cape Public Health setting.

Researcher:
Leana Spies

Supervisor:
Prof Liz Gwyther

I understand what this study is all about, how it is going to be conducted as well as what is expected of me. I have been given the opportunity to ask questions so that I can understand the study.

I understand that the information which I supply will be treated as strictly confidential and that I have the right to withdraw at any time during the study, with no negative consequences.

I also understand that the information which I will provide by completing the questionnaire will be used anonymously for the purposes of this research study.

I consent to audiotaping of the interview.

Herewith I give voluntary consent to participate in this research study.

_______________________ _____________________

Participant **Date**

____

Leana Spies
Researcher

APPENDIX 5: Ingeligte Toestemmingsdokument (Afrikaans)

5.1 Deelnemer inligtingsblad

Fakulteit van Gesondheidswetenskappe
Departement van Huisartskunde

Geagte Deelnemer,

INLIGTING RAKENDE NAVORSINGSPROJEK

Ek is ‘n Meestersgraad-student, ingeskryf vir die graad M.Phil in Palliatiewe Geneeskunde by die Departement van Huisartskunde by die Universiteit van Kaapstad. Ek moet ‘n navorsingsprojek onderneem en ‘n navorsingsverhandeling daaroor skryf ter vervulling van my nagraadse kwalifikasie. Die titel van my navorsingstudie is: “Understanding the experiences of adolescents and young adults (AYA’s) with cancer in a Northern Cape public health setting”. [*Om die ondervindings van adolessente en jong volwassenes (AJV’s) met kanker in ‘n Noordkaapse publieke gesondheidsopset te verstaan*].

Doel van hierdie studie:

Die doel van hierdie studie is om die ondervindings en palliatiewe sorg behoeftes van adolessente en jong volwassenes met kanker in Suid-Afrika te verstaan.

Die studie sal dus daarop mik om die uitdagings wat deur AJV’s met kanker, in ‘n Noordkaapse publieke gesondheidsopset ervaar word, te ondersoek en te identifiseer ten einde kankersorgstelsels in te lig en aanbevelings oor gesondheidsdienslewering in die Noordkaap te maak.

Prosedure:

Deelname aan die studie vereis ‘n individuele van aangesig tot aangesig onderhoudsessie van ongeveer 30-60 minute wat gehou sal word op ‘n tyd wat vir u gerieflik is. Ingeligte toestemming word verleen deur voltooiing van die vorm onderaan hierdie brief.

Risiko’s en moontlike ongemak:

Daar is geen risiko’s betrokke by deelname aan hierdie studie nie. Indien u enige emosionele ongemak gedurende die onderhoud ervaar en toegang tot maatskapplike werk of sielkundige dienste verlang, sal die navorser u na hierdie dienste verwys. Die nodige verwysings sal volgens behoefte en versoek gedoen word.

Hierdie navorsingsprojek behels geen finansiële implikasies of ander ongemaklikhede vir u as deelnemer nie.

Waarde van die studie:

Aangesien die behoefte vir beter begrip van die uitdagings van adolessente en volwassenes met kanker in 'n middel-inkomste land duidelik was, sal die verkryging van inligting rakende hulle ondervindings in die Noordkaap Provinsie help om die holistiese behoeftes van hierdie groep te identifiseer ten einde holistiese gesondheidsorg in te stel wat daarop sal mik om hulle behoeftes aan te spreek.

Deelnemer se regte:

Deelname aan die studie is heeltemal vrywillig en deelnemers behou die reg om te kies om nie deel te neem nie, of in enige stadium van die studie te onttrek en hulle sal steeds standaard sorg sonder negatiewe gevolge ontvang.

Vertroulikheid:

Al die uitslae verkry uit die individuele onderhoud sal as streng vertroulik hanteer word. Die uitslae sal anoniem in 'n volledige bespreking van die bevindinge van die navorsingsprojek verteenwoordig word.

Die data sal vir 5 jaar vir argivering en navorsingsdoeleindes gestoor word, waarna dit vernietig sal word.

Indien u enige navrae of bekommernisse het, voel asseblief vry om my, Leana Spies, of die hoofnavorser, prof Liz Gwyther, te kontak by die kontakinligting hieronder verskaf.
By voorbaat dankie vir u samewerking en tyd.

Vriendelike groete,

____
Leana Spies
Navorser en plaaslike PI
072 419 0420

____

Liz Gwyther
Hoofnavorser
021 650 1475

Kontakbesonderhede van Menslike Navorsingsetiekkomitee
Fakulteit van Gesondheidswetenskappe – Universiteit van Kaapstad
Telefoon: 021 650 3002

5.2 Ingeligte toestemming

Titel van navorsing:

Understanding the experiences of adolescents and young adults with cancer in a Northern Cape Public Health setting. (*Om die ondervindings van adolessente en jong volwassenes met kanker in 'n Noordkaapse publieke gesondheidsopset te verstaan*).

Navorser:
Leana Spies

Studieleier:
Prof Liz Gwyther

Ek verstaan waaroor hierdie studie handel, hoe dit onderneem gaan word sowel as wat van my verwag word. Ek is die geleentheid gegee om vrae te vra sodat ek die studie kan verstaan.

Ek verstaan dat die inligting wat ek verskaf as streng vertroulik hanteer sal word en dat ek die reg het om te enige tyd gedurende die studie te onttrek met geen negatiewe gevolge nie.

Ek verstaan ook dat die inligting wat ek sal voorsien deur die voltooiing van die vraelys, anoniem gebruik sal word vir die doel van hierdie navorsingstudie.

Ek stem in tot die oudio-opname van die onderhoud.

Hiermee gee ek vrywillig toestemming om aan hierdie navorsingstudie deel te neem.

______________________	_________________
Deelnemer	**Datum**

____

Leana Spies
Navorser

APPENDIX 6: Questionnaire for Demographic information of participants (English)

INSTRUCTIONS:

Please read through all the questions carefully.
Please answer ALL the questions by supplying a short answer.
Please note that by completing and returning the questionnaire, you give consent that the information you are going to provide can be used for research purposes and you agree to understand:

- ✓ What this study is all about, how it is going to be conducted as well as what is expected of you.
- ✓ That the information which you supply will be treated as strictly confidential.
- ✓ That you have the right to withdraw at any time during the study, with no negative consequences.
- ✓ That the Northern Cape Department of Health, Dr Kantani, CEO of Robert Mangaliso Sobukwe Hospital and Ms Witbooi, CEO of Harry Surtie Hospital have given their consent that the research may be conducted.

DEMOGRAPHIC INFORMATION:

1. Age: ________________
2. Gender: ________________
3. Language preference: ________________
4. Marital status: _________________
5. Number and ages of children: ________________
6. Highest level of education: ________________
7. Employment status: ________________
8. Year in which you were diagnosed with cancer: _______________
9. Type of cancer: ___________________
10. Current treatment for cancer: ________________
11. Place of Oncology care: ________________
12. Distance/Time between Oncology centre and Home: ________________
13. Cultural background: ________________

APPENDIX 7: Vraelys vir Demografiese inligting van deelnemers (Afrikaans)

INSTRUKSIES:

Lees asseblief sorgvuldig deur al die vrae. Antwoord asseblief AL die vrae deur ‘n kort antwoord te verskaf.

Let asseblief dat deur die voltooiing en terugbesorging van die vraelys, u toestemming gee dat die inligting wat u gaan voorsien, vir navorsingsdoeleindes gebruik kan word en dat u toestem om te verstaan:

- ✓ Waaroor hierdie studie handel en hoe dit onderneem gaan word, sowel as wat van u verwag word.
- ✓ Dat die inligting wat u voorsien as streng vertroulik hanteer sal word.
- ✓ Dat u die reg het om te enige tyd gedurende die studie te onttrek, met geen negatiewe gevolge nie.
- ✓ Dat die Noordkaapse Departement van Gesondheid, dr Kantani, HUB van Robert Mangaliso Sobukwe Hospitaal en me Witbooi, HUB van Harry Surtie Hospitaal hulle toestemming gegee het dat die navorsing onderneem mag word.

DEMOGRAFIESE INLIGTING:

1. Ouderdom: ___________________
2. Geslag: ___________________
3. Taalvoorkeur: ___________________
4. Huwelikstatus: ___________________
5. Getal en ouderdomme van kinders: ___________________
6. Hoogste vlak van onderrig: ___________________
7. Indiensnemingstatus: ___________________
8. Jaar waarin u met kanker gediagnoseer is: ___________________
9. Tipe kanker: ___________________
10. Huidige behandeling vir kanker: ___________________
11. Plek van Onkologiesorg: ___________________
12. Afstand/Tyd tussen Onkologiesentrum en Huis: ___________________
13. Kulturele agtergrond: ___________________

APPENDIX 8: Interview Topic Guide (English)

Introduction to each participant prior to initiating the interview:

- This interview will be carried out as part of a study to explore the experiences of adolescents and young adults with cancer in the Northern Cape.
- The purpose of this interview is to learn about your challenges and experiences when living with cancer. This will help us to understand and identify your needs and may lead to future research where strategies on how to improve health care for adolescent and young adults with cancer may develop. I would like you to be comfortable and at ease during the interview. It will be a face-to-face interview and will last approximately 30 to 60 minutes. However, you are allowed to stop at any time if needed. If you don't feel ready to do the interview today we can arrange a suitable alternative time for you.
- In order to collect valuable information I would like to tape record the interview. Your answers will we kept strictly confidential and will not be shared with your loved ones or medical staff.
- If you are still willing to take part and have signed the consent document, we will start with the interview.

Question-guide:

- What was your life like before you were diagnosed with cancer?
- How did you feel when you were told about your cancer diagnosis?
- How did you deal with these emotions?
- Why do think did this happen to you?
- Have you ever encountered serious illness, losses or difficult times in the past?
- How did your family and loved ones feel and react when you were diagnosed with cancer?
- What is your life like since after being diagnosed with cancer - how has it influenced your daily life?
- What were your dreams and hopes for your future?
- What are the most significant challenges you have struggled with so far?
- How have these challenges changed over the course of your illness?
- What are your biggest fears and worries at this stage of the illness?
- What are your biggest sources of enjoyment at this moment in your life?
- What are your priorities at this moment?
- What gives meaning to your life?
- What helps to encourage you at this difficult time?
- What gets you up in the morning?
- What do you look forward to?
- What has been the highlight of your life so far?
- How do you see your future?
- What role does spirituality play in the way you cope with your current situation?
- Have you ever considered the possibility of death?
- Who are currently the greatest sources of support to you?
- What type of support do they provide?

- Has this changed from before your diagnosis?
- What has been the impact of cancer on your relationships?
- Do you feel that your current support systems are adequate?
- Looking back at your cancer journey, do you feel that the support you received since your diagnosis was adequate?
- What has your experience of the health care facility including the medical staff since your diagnosis been like?
- Were you offered any form of emotional support services since your diagnosis, for example, a social worker, spiritual care professional or a psychologist?
- If so, when? If not, what type of support would you have preferred from your diagnosis until now?
- How has your illness influenced the lives of your family and loved ones?
- What are their current sources of support?
- Do you feel that the support they are receiving from the medical system is adequate?
- What kind of support would your family members benefit from?
- How can we assist in providing such support to them?

Before completion:

- Are there any other questions you would like to ask or thoughts you would like to share before we close?
- How did you feel about taking part in this interview? Were there any questions you feel I should not have asked?
- Can you think of any other particular question you would’ve liked me to ask that will help me to get a clearer picture of your experiences with cancer?
- Do you have any questions regarding the interview?

APPENDIX 9: Onderhoud onderwerp gids (Afrikaans)

Inleiding vir elke deelnemer voor die aflê van die onderhoud:

- Hierdie onderhoud word uitgevoer as deel van n studie om die ervaringe van adolesente en jong volwassenes met kanker in die Noord-Kaap te ontdek.
- Die doel van hierdie onderhoud is om meer oor u uitdagings en ervaringe rakende hoe dit is om met n kanker saam te leef, te leer. Dit sal ons help om u behoeftes beter the verstaan en te identifiseer en mag ook tot verdere navorsing lei sodat stratgiee om gesondheidsorg vir adolesente en jong volwassens met kanker te verbeter, ontwikkel kan word. Ek wil graag hê dat jy tydens die onderhoud gemaklik moet voel. Dit sal n een-tot-een onderhoud wees en sal ongeveer 30 – 60 minute duur. U sal egter toegelaat word om die onderhoud op enige tydstip te staak indien nodig. Indien u nie gereed voel om die onderhoud vandag te doen nie, kan ons n alternatiewe tyd reel wat u beter sal pas.
- Om waardevolle inligting in te samel, sal ek graag die onderhoud wil opneem. U antwoorde sal streng konfidensieel gehou word en sal dus nie met u geliefdes of mediese personeel gedeel word nie.
- Indien u steeds gewillig is om deel te neem en u die ingeligte toestemming dokument geteken het, sal ons die onderhoud begin.

Vraelys:

- Hoe was u lewe voordat u met kanker gediagnoseer is?
- Hoe het dit gevoel toe die nuus van n nuwe kanker diagnose met u gedeel is?
- Hoe het u hierdie emosies hanteer?
- Hoekom dink jy het hierdie met jou gebeur?
- Het u ooit in die verlede met n ernstige siekte, verliese of moeilike tye te doen gekry?
- Hoe het jou familie of geliefdes gevoel en gereageer toe hulle van jou kankerdiagnose gehoor het?
- Hoe is u lewe sedert u met kanker gediagnoseer is – wat het dit alles beinvloed?
- Watter drome en hoop het u vir die toekoms gehad?
- Wat is die grootste uitdagings waarmee u tot dusver gesukkel het?
  Hoe het hierdie uitdagings verander oor die verloop van u siekte?
- Wat is u grootste vrese en bekommernisse op hierdie stadium van u siekte?
- Watter dinge bring vir u die meeste vreugde en geluk op hierdie oomblik van u lewe?
- Wat is u prioriteite op hierdie oomblik?
  Wat gee betekenis aan u lewe?
  Wat motiveer u om op staan in die oggend?
  Waarna sien u uit?
- Wat was die hoogtepunt van u lewe tot dusver?
  Hoe sien u die toekoms?
  Watter rol speel spiritualiteit in die manier hoe u met u huidige situasie?
- Het u al ooit aan die moontlikheid om te sterf gedink?
- Wie is op die oomblik u grootste bronne van ondersteuning en is dit voldoende?

Watter tipe ondersteuning het hulle gegee?
Het hierdie ondersteuning verander in vergelyking met die tyd voor u kanker diagnoseer is?
Wat is die impak van kanker tot dusver op u verhoudings gewees?

- Wat is u ervaring van die gesondheidsorg sentrum en mediese personeel sedert u kankerdiagnose?
  Is u enige vorm van emosionele ondersteuningsdienste aangebied sedert u diagnose soos byvoorbeeld n maatskaplike werker, professionele spirituele berader of n sielkundige?
- Indien wel, wanneer? Indien nie, watter tipe ondersteuning sou u verkies het sedert u diagnose tot huidiglik?
- Hoe het u siekte die lewens van u familie en geliefdes beinvloed?
  Wat is hulle huidige bronne van ondersteuning?
  Voel u dat die ondersteuning wat hulle van die mediese sisteem ontvang voldoende is?
  By watter tipe ondersteuning sal u familielede baatvind?
  Hoe kan ons help om sulke ondersteuning vir hulle te gee?

Voor die afsluiting:

- Is daar enige ander vrae wat u graag wil vra of gedagtes wat u graag wil deel voor ons afsluit?
- Hoe het dit gevoel om aan die onderhoud deel te neem?
- Was daar enige vrae wat u voel ons nie moes gevra het nie?
- Kan u dink aan enige ander spesifieke vraag wat u graag sou wou hê ons moes vra sodat ons n duideliker idee van u ervaringe met kanker kon kry?
- Het u enige vrae oor die onderhoud?