

**Exploring Perceptions of Social Support Among Individuals With Cancer
in eThekweni, South Africa**

By

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COLLEGE OF HUMANITIES

DECLARATION - PLAGIARISM

I, Noliwe Vimbai Gwiza, declare that

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Signed

NV. Gwiza

.....

DEDICATION

I would like to dedicate this study to my family who supported me in every step of the way, thank you for your prayers, and constantly motivating me.

To all the patients who participated in this study I could have never done this without your love and contribution, God bless you all.

ABSTRACT

The study aimed to explore the perceptions of social support among individuals with cancer in eThekweni, South Africa. However, studies that qualitatively explore this area of study in South Africa are limited. Cancer remains a global public health problem, and it is one of the leading causes of death worldwide, with most cancer deaths now reportedly occurring in low-and-middle-income countries.

This study draws on social support theory which suggests that social support is paramount when one is going through a stressful event as it acts as a stress-buffer. In-depth interviews were conducted with twelve cancer patients and two social workers at the Cancer Association of South Africa (CANSA) Mkhuhla Care Home in Durban, to gain an understanding about perceptions of social support among individuals with cancer.

The study findings revealed that social support is a vital resource for individuals with cancer, and it promotes health well being. Participants expressed that cancer diagnosis was a life changing experience which did not only affected them psychologically but they also felt it was a burden on their relationships. Psychological factors such as anxiety, and depression were reported by most participants. Social support was found to come from a patient's social network, mostly family, friends ,neighbours, church, health professionals, and social media. The study highlighted that social support systems such as emotional support, informational, and tangible support play a crucial role in reducing the burden of cancer diagnosis among patients. The findings revealed that emotional, informational and tangible support were crucial in protecting patients from traumatic experiences caused by cancer diagnosis.

The findings also revealed that lack of social support increases stress, and anxiety which negatively impact an individual diagnosed with cancer. The study found that cancer stigma still exists in society as some patients experienced them, and there is a lack of cancer awareness to educate people about the disease.

Keywords: social support, social capital, health management, non-communicable diseases, eThekweni

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List of Acronyms

CANSA	Cancer Association of South Africa
GLOBOCAN	Global Burden of Cancer Study
IARC	International Agency for Research on Cancer
NCDs	Non-Communicable Diseases
WHO	World Health Organisation

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CHAPTER 1: INTRODUCTION

“Giving and receiving kindness are easy ways to feel good and to help others feel good too. People, organisations, and societies thrive when they are grounded in a culture of kindness. We all have the power to be kind”

Vivek Murthy

1.1 Introduction

Non-communicable diseases (NCDs) are responsible for approximately 71 percent of deaths worldwide, and 41 million people die each year because of **NCDs** (WHO, 2021). In Sub-Saharan Africa, **NCDs** pose an increasing challenge for health systems (Gouda et al., 2019). The burden of **NCDs** increased from 18.6 per cent in 1990 to 29.8 percent in 2017 in Sub-Saharan Africa. This increase can be attributed to an increase in population size and an ageing population (Mpando et al., 2021). **NCDs** include cancer, diabetes, heart disease, and chronic lung disease. Among **NCDs**, cancer has been the leading cause of death, accounting for approximately 10 million deaths in 2020 globally (WHO, 2022). Associated mortalities are higher in low- and middle-income countries, probably due to poor public health systems, whereas mortality rates are declining in high-income countries (IARC, 2020). According to Hamdi et al. (2021) of all new cancer cases being reported, 57 percent of these cases occur in low income countries due to lack of awareness, and lack of preventative strategies. It is imperative to note that in low-and middle-income countries the population which fall under the belt of low income group is high. Andersen et al., (2002) notes that there is large inequities in access of health services for low-income groups, they lack health insurance coverage, access to regular source of care, they experience delays in needed care hence they have poor health care and increased mortality rate.

The World Health Organisation defines cancer as a generic term for many diseases that can affect any body part (WHO, 2022). These are malignant tumours and neoplasms which can rapidly develop in the body. Many factors can cause cancer, and these factors includes genetics (family history of cancer), some viruses and bacteria, ageing, tobacco and alcohol, poor diet, and lack of physical activities (Cunha, 2021). Some of the causes of cancer can be prevented,

such as quitting alcohol and smoking, eating healthy, and physically exercising, whereas others cannot, for example, ageing and genetics. Globally, cancer cases are expected to increase to 28.4 million in 2040, a 47 percent increase from 19.3 cases in 2020 due to demographic changes and risk factors associated with globalisation (Sung et al, 2021: para 1).

Cancer is one of the most feared diseases due to the illness nature, painful treatment, side effects, and statistics (incidence rates and mortality rate). Previous studies have shown that most people fear cancer more than other life-threatening illnesses, for instance, heart disease, stroke, and Alzheimer's (Cancer Research UK, 2011, and Vrinten et al, 2017). Park et al. (2020:993), claim that "the physical, mental, social, and economic problems caused by cancer have a significant impact on the patient and the caregiver's family." Studies have also demonstrated that cancer illness brings out negative emotions such as anxiety and depression, which may affect the patient's recovery without immediate intervention, resulting in reduced quality of life. Hence, social support is imperative when going through this type of illness (Park, Park, and Lee, 2020 and American Cancer Society, 2022).

1.2 Background

Cancer remains the illness of the century, and its burden remains a significant public health and economic issue, especially in developing countries. Most cancer deaths are reportedly occurring in low-and-middle-income countries. WHO (2018) reports that more than 70 per cent of cancer deaths occur in low-and-middle-income countries where there is public health crisis due to the unavailability of resources to appropriately and efficiently address cancer illness and other **NCDs**. The rise in cancer cases is a public health crisis, but its impact is also felt economically.

In Sub-Saharan Africa, cancer cases are rising, and medical professionals often blame the lack of treatment facilities, cancer awareness, and political fragility (Mules and Mwakideu, 2022). Many countries suffer from the shortage of medical personnel that specialises in cancer care. Most countries have few hospitals that offer cancer therapies with less equipment for treatment, making these hospitals overbooked, resulting in many patients experiencing delays in diagnosis or treatment (Mules and Mwakideu, 2022). This is compared to wealthy nations or developed countries, where there is more awareness, more screening, personalised medicine, better diagnostics, and novel treatments such as immunotherapy, reducing cancer rates and improving survival rates (Bollyky, 2020).

In Africa, cancer and other **non-communicable diseases** are often blamed on population growth and ageing, and the continent is viewed as a place which is ill-prepared to handle these diseases (Bollyky, 2020). According to WHO (2022), cancer care has significantly improved in Africa over the past decade, but the challenges in prevention, detection, treatment services, and financing remain an obstacle that is limiting access to quality and good care for millions of patients. Most people in Africa are diagnosed with advanced cancers, and most do not have a chance to complete their treatment. The main reason for this being that cancer treatment is costly, and many people pay out of their pockets to access care which can be financially overwhelming, and there are also poor support services (WHO, 2022). Therefore, poor cancer care and support services mean a continued increase in premature deaths, whereas better services would significantly impact health and reduce mortality.

Medical professionals have labelled cancer “a national crisis” in South Africa, with early cancer diagnosis remaining a colossal obstacle within the public healthcare system (Mukwevho, 2021). South Africa is a relatively wealthy country with good health policies which have not been appropriately implemented. Most cancers are detected at an advanced stage, whereas others go undetected. South Africa still requires an urgent need to improve cancer awareness at the primary care level across the country (Mukwevho, 2021). Cancer incidences and mortality remain a challenge in South Africa. Research shows that in South Africa, cancer causes more deaths compared to HIV/AIDS, tuberculosis, and malaria combined (Hesse, 2018). Cancer affects one in four South Africans through the diagnosis of a friend, self, family members or colleagues (CANSAs, 2022). Despite efforts by the government to improve cancer services, socio-economic challenges, and lack of awareness and education, especially in the rural population, remain an issue (Cairncross et al., 2021).

The concept of social support has been variously defined and widely used in public health. Social support in relation to cancer is described as the perception that one is accepted, cared for, and provided with assistance from different people or one’s social network (Strom, 2012). Social support continues to gain attention in health literacy, and it is often linked with improved health outcomes (Ncama et al., 2008). However, Palant and Himmel (2019) argue that although social support is perceived as a positive resource, it can also bring negative experiences, and a patient may end in social isolation and deterioration of health. Positive social support can enhance the resilience to stress and help with individuals’ psychological and physical well-being (Ozybay et al., 2007). For Adam and Koranteng (2020), the availability of social support significantly determines cancer patients’ prognosis and quality of life. Social networks such as

family, friends, health professionals, and support organisations are the major players in organising social support for cancer patients. Social relationships can provide guidance, emotional connections, reassurance and a sense of security to cancer patients.

1.3 Problem Statement

In South Africa, cancer remains a public health problem despite the government having a number of cancer control initiatives in place to address this burden (Cairncross et al., 2021). Research predicts that South Africa's cancer burden will increase in the coming decade estimating with the current data, and growing and ageing of the country's population (Cairncross et al., 2021 and Finestone, Wishnia, and Ranchod, 2021). In South Africa, cancer is also a crisis that families, communities, and workplaces should be educated about because society still perceives that cancer cannot be beaten. This kind of mentality has become a cancer itself in society, and those affected by cancer become isolated and are left alone to suffer and die. There is an absence of a welcoming social environment for people with an illness such as cancer, which negatively affects a patient's ability to control their condition. This is mostly due to the fact that people see cancer as a death sentence, an illness that is nearly impossible to cure. People who have cancer are in constant need of social support for their psychological health, social and financial well-being to help manage their illness better. Considerable research has been conducted and published over the years and has established the link between social support and health (Ungar et al., 2016). Therapy, support groups, social media and communities should be available to help people cope with issues related to this illness. Hence the importance of social support to individuals with cancer because it helps educate patients, families, and the society at large on how to deal with the illness. There is need for society to recognise the impact of social support on people diagnosed with cancer, and to understand what cancer is. There are relatively few studies that were qualitatively done in this area of study. This study will add to the existing body of knowledge and shed insight on the significance of social support among individuals with cancer.

1.4 Significance/Motivation of the Study

The study is relevant because the nature of the study created a forum for people to talk about their feelings during the data collection period. The interview sessions were a form of support because all participants (patients) felt like they were venting. This process of talking to someone was crucial for patients as they could communicate important issues to them that no one had ever asked them such as talking about their feelings regarding their illness, the

challenges they experience, and the assistance they desire to have. However, there were times I skipped questions rushing so that I let patients go and rest since most of them were undergoing chemotherapy and radiation treatments. I had to put patients' needs first. Apart from conducting interviews, I was allowed at the Care Home to attend patient support groups, which allowed me to know the participants better and do my observations which helped me gain more insight into the patients' daily experiences. Also, most people cannot afford therapy, so the interviews were some sort of support/therapy session for some participants. Some participants even acknowledged that they were excited to answer the research questions because no one had ever asked them these questions. They also wished and hoped that by contributing to the study and sharing their lived experiences, people would be able to learn about essential issues individuals with cancer go through.

1.5 Aim

The study aims to explore the role of social support among individuals with cancer in eThekweni, South Africa.

1.6 Objectives

The study's overall objective is to explore the perceptions of social support among individuals with cancer in eThekweni, South Africa and:

- To explore perceptions of what social support in relation to their condition (means to people with cancer).
- To explore the experiences of social support received by people with cancer.
- To explore challenges experienced by people living with cancer with regards to social support.
- To explore the challenges experienced by people living with cancer.
- To explore how social support may influence self-management behaviours of those living with cancer.

1.7 Research Questions

The study seeks to answer the following specific questions:

- How is social support perceived by people with cancer?
- How has social support impacted on people with cancer?
- What are the main challenges with regards to social support that are faced by people with cancer?

- What are the main challenges that are faced by people with cancer?
- How does social support influence the self-management behaviours of those living with cancer?

1.8 Organisation of the Dissertation

This dissertation is organised into five chapters. The first chapter gives an introduction and the background of the study, the problem statement, and aims and objectives of the study. The second chapter reviews the relevant literature on cancer and the impact of social support on health, particularly cancer related illness, and it discusses the theoretical framework utilised in the study. The third chapter provides a detailed explanation of the methodology employed by the study. The fourth chapter presents the main findings of the study. The final chapter provides a discussion of the key findings, and the conclusion.

CHAPTER 2:

LITERATURE REVIEW & THEORETICAL FRAMEWORK

2.1 Introduction

This chapter reviews previous studies on social support and health, and more broadly the perceptions of social support among individuals with cancer and how social support influences self-management behaviour, and it also discusses the theoretical framework utilised in this study. There is inadequate research in this area of study in South Africa as existing studies are limited to educating people about cancer prevention and awareness with emphasis placed on prostate cancer, cervical cancer and breast cancer while neglecting other kinds of cancer and the impact of social support. It is important to identify the contributions made by previous studies on social support and cancer. Social support systems can significantly mediate against perplexities of people with cancer and enhance the quality of life.

2.2 Definition of Cancer

The term cancer is said to have originated from the father of medicine, Doctor Hippocrates, a Greek physician (460-370 B.C.E). Hippocrates is credited with the word cancer because he used the words carcinos and carcinoma to describe the disease as ulcers or growths that appeared to be malignant tumours (Gronning and Colditz, 2015).

The word cancer evokes strong feelings and is one of the most feared diseases. Being diagnosed with cancer is widely regarded as synonymous with a death sentence. Weinberg (1996) defines cancer as the 100 forms of disease stating that each cancer has a unique feature. The American Cancer Society (2015) states that cancer is a complex **non-communicable disease (NCDs)** which can develop anywhere in the body. Its manifestation in the body occurs when a cell grows out of control and crowds out normal cells which makes it hard for the body to function the way it should. CANSA (2017), defines the term cancer as a group of over hundred solid tumours and haematological cancers which includes malignant tumours of different sites. Cancer is a complex group of diseases which means it can have many possible causes such as lifestyle habits, genetics, environmental factors, and sometimes there is no obvious cause (The American Cancer Society, 2015). According to WHO Africa (2017), incidence of cancer rises

dramatically with age which mean ageing is another fundamental cause for the development of cancer.

Cancer incidences continue to rise at an alarming rate in the 21st century probably due to changing of lifestyle, habits, and increased life expectancy. According to Roy and Saikia (2016), all types of cancers are curable if they are caught at a very early stage when they tend to be smaller which can be easier to remove surgically or likely to shrink in response to radiation or chemotherapy. On the other hand, Herbst (2014), notes that some tumours are not cancerous as benign tumours do not invade neighbouring tissues and do not spread throughout the body. WHO (2018) states that a correct cancer diagnosis is fundamental for appropriate and effective treatment because every cancer type requires a certain treatment regimen. The American Cancer Society (2015) reported that there are over 200 types of cancer which include lung cancer, stomach cancer, breast cancer, liver cancer, colony cancer, cervical cancer, prostate cancer, and blood cancer to mention just a few.

2.3 Global Overview of Cancer

There is an increasing concern about the global burden of cancer. Cancer is one of the leading causes of death worldwide and an important barrier to increasing life expectancy in every country around the world (Sung et al., 2021). Cancer deaths are projected to be rising with more than 70 percent of cancer deaths occurring in low- and middle-income countries where there is no adequate availability of resources to appropriately attend to and manage cases diagnosed (WHO, 2018 and Shah et al., 2019). Traditionally cancer has been considered a disease mostly affecting high income countries. Nonetheless, cancer incidence rates are rapidly increasing in low-and-middle income countries with high portion of the cancers being diagnosed at advanced stage (Hall et al., 2019). This requires effort from authorities to help reduce the burden of cancer especially in low-and -middle income countries as large portion of cancers are preventable.

According to Sung et al., (2021), Global cancer statistics of 2020 (GLOBOCAN) estimates shows that prostate cancer is the most diagnosed cancer in males in 112 countries, followed by lung cancer in 36 countries, and liver cancer and colorectal cancer in 11 countries. More so, in 93 countries, lung cancer is the leading cause of deaths in males followed by prostate cancer in 48 countries and liver cancer in 23 countries. On the other hand, the most common cancers in females are breast cancer which dominates 159 countries, and cervical cancer in 23 countries. These two types of cancers are the leading causes of cancer mortality in 110 countries with

breast cancer leading and 36 countries with cervical cancer, followed by lung cancer in 25 countries (Sung et al., 2021:3).

Cancer treatments around the world continue to rise. According to the American Cancer Society (2010) cancer has the most devastating economic impact in the world. The American Cancer Society (2010) reported that cancer costs the world approximately US\$895 billion per year which one can assume without a doubt that the cost has risen since that period due to new innovative cancer treatments, innovative surgical procedures and advancing technologies. Cancer Research UK reported that the cost of cancer drugs is increasing by 10 percent per year and so as the cost of diagnosis, chemotherapy and radiation, surgery, pathology, and life care (American Cancer Society, 2010). This means that while there is an advancement in treatment of cancer the cost of treatment is rising exponentially. Goldstein et al., (2017), states that while the cost and value of cancer drugs continue to rise across the globe it is paramount to consider the factor of economic importance namely affordability. As the cost of cancer drugs continue to rise, these high-cost places a financial burden to patients and their families, and society at large. Goldstein et al., (2017:2) reported that the USA has the highest price of cancer drugs globally with a median price of \$8694, while India has \$ 6709, China \$5954, and South Africa \$5748.

Cancer diagnosis is perceived as one of the most stressful events that can happen in one's life and inevitably cause serious long-term psychological consequences (Velikova-Tzonkova, 2013). Yawman (2019), notes that the individual perceptions, understanding and responses to the implications of cancer diagnosis are a significant part of a patient's disease process. Being diagnosed with cancer is widely regarded as synonymous with a death sentence. Cancer diagnoses can be an extremely traumatic experience that affects almost every aspect of individual's everyday life and their environment (Velikova-Tzonkova, 2013).

2.4 Cancer in Africa

The cancer incidence rate continues to rise in Africa as **NCDs** become difficult to control. Africa is the second largest and second most populous continent in the world with a population of over 1 billion people. The survival of people with cancer in Africa is far lower than that in high income countries and other continents (Stefan, 2015). Primary prevention remains key in Sub-Saharan Africa where there is need to prioritize the most cost-effective means of reducing the cancer burden in health systems compared to wealthy nations where treatments like immunotherapy are reducing the rates of cancer and improving survival among all

demographical populations (Lambert, 2020). **NCDs** in Africa for instance cancer are creating overwhelming effects that will need to be halted before they overpower the continent. In 2011 the Brazzaville Declaration on Non-communicable Disease Prevention and Control policy was adopted in the WHO African region and it declared the awareness of governments about the growth of health danger from **NCDs**, especially cancer. The Brazzaville Declaration was adopted to develop strategies for control and prevention, to strengthen the African health systems and enable them to reduce the burden of **NCDs**, and raise funds required for fighting **NCDs** (Stefan, 2015). Nonetheless, despite the efforts to bring **NCDs** under control in Africa, the progress in this direction remains slow.

The control of cancer in Africa is still a challenge for many countries due to inadequate resources required to treat the disease. According to Lambert (2020), treating cancer requires more health infrastructure, clinics, hospitals, laboratories, MRI machines and X-ray machines, and health professionals who can make accurate diagnosis and perform treatments. Morhason-Bello *et al.* (2013) reported that the changing spectrum of cancer disease is changing Africa's care needs. In trying to help reduce the cancer burden that is upon many African countries the American Cancer Society had an agreement with Pfizer and Cipla pharmaceutical companies to provide six Sub-Saharan countries with sixteen chemotherapy drugs at reduced cost (Morhason-Bello *et al.*, 2013). However, this agreement has since been contested on the basis that such philanthropic agreements are not new to Africa. In 2016, GlaxoSmithKline pharmaceuticals extended the medicines patents pool to poor countries which was established in 2009 to help manufactures in these countries manufacture HIV, tuberculosis and hepatitis C drugs without patents and planned to put all its future cancer drugs into the pool to improve access to effective health care (BBC News, 2016). Prof Raymond Hill, former president of Pharmacological Society argued that this was a brave move towards broadening the access to important medicine in developing countries but the impact of this move on the treatment of cancer and other diseases in each country would depend on the healthcare infrastructure that will allow safe use of these powerful drugs (BBC News, 2016). Pascal Soriot, head of AstraZeneca states that giving out free cancer drugs to Africa is pointless because it is not only a question of medicine, but a question of infrastructure as well (Gallagher, 2016). Therefore, lack of healthcare infrastructure remains a huge stumbling block to better treatment of cancer in Africa.

Despite many challenges that are faced by African countries in controlling cancer, many of these challenges are not impossible to address. Jamal *et al.*, (2012) is of the view that population

growth and aging, as well as increased prevalence of risk factors that are associated with economic transition which includes reproductive behavior, physical inactivity, smoking, and obesity plays a massive role in the increasing of cancer burden in Africa. Therefore, most cancers that occur in the African region are largely preventable because they are largely related to infections (Stefan, 2015).

According to Bollyky (2020), cancer is spreading very fast in sub-saharan Africa and it has already affected hundreds of thousands of people and if governments do not act fast, millions will pay the price. There has been an increase of 45 percent in cancer deaths in Sub-Saharan Africa since 2000 and it now kills more than half a million people per year (Bollyky, 2020). Most cancer cases that occur in Africa hit women hard, with a third of cervical cancer deaths occur in Sub-Saharan Africa and the region represents 14 percent of the world's female population (The Cancer Atlas, 2018). Cancer incidence rates have been rising for major cancer sites for instance in Zimbabwe cervical cancer rates increased by 80 percent, and 36 percent in South Africa, however, they dropped in Uganda after a slight increase. Breast cancer and prostate cancer cases have been seeing major increases in the continent with doubling cases in Zimbabwe and South Africa (The Cancer Atlas, 2018). However, it is important to note that most of the statistics reports on cancer in Africa are estimates because of the absence of reliable data from national cancer registries.

Cancer continues to receive very low public healthy priority in Sub-Saharan Africa despite the growing cancer burden, largely because of limited resources and other pressing public health problems which include diseases such as HIV/AIDS, tuberculosis, and malaria (Jamal et al, 2012). Jamal et al., (2012), further elaborates that there is general lack of awareness among policy makers, the public, and international private or public health agencies concerning the magnitude of current and future cancer burden and its economic impact in Africa

According to Addai and Ngwa (2021), cancer prevention and control have been immensely affected by the impact of COVID-19 which reached the continent when it was already battling to deal with the growing burden of cancer. The response to Covid-19 pandemic by African governments immediately augmented the challenges in oncology at different levels, including treatment, prevention, and palliative care which will undoubtedly result to increased late-stage presentation of cancer and a surge in mortality (Addai and Ngwa, 2021).

Knowledge and awareness about cancer crisis enables the development, implementation, monitoring and evaluation of cancer strategies that prevent, cure, and care. This kind of

knowledge is lacking in many low- and middle-income countries making cancer control efforts less effective. The American Cancer Society (2011) reported that majority of cancers in Africa are diagnosed at an advanced stage due to lack of screening and early detection services, and limited awareness of the early signs and symptoms of the diseases among health care providers and the public. Cancer patients in Sub-Saharan Africa are twice likely to die compared to those in United States of America, mostly due to late diagnosis, lack of access to treatment, and not being able to afford the expensive treatments (American Cancer Society, 2020). The annual cancer deaths in this region are projected to double by 2030 (American Cancer Society, 2020).

According to Berer (2008), in instances where cancer cases are detected early and there is availability of good quality timely treatment with a combination of drugs, surgery and radiotherapy it increases the survival rates. This means that it is imperative there is more awareness among people so that they can be made conscious about the disease and encouraged to go for screening for early detection.

2.5 South Africa Cancer Overview

According to Hesse (2018), in South Africa cancer causes more deaths in the country compared to HIV/AIDS, tuberculosis, and malaria combined. Made et al., (2017), claims that there have been minimal efforts to combat **NCDs** such as cancer in South Africa due to the competing burden of HIV/AIDS epidemic in the country. Ignoring the burden of cancer in the country has resulted in several Health Medical Schemes in South Africa spending more on cancer related claims and they have reinforced the need for greater cancer awareness (Hesse, 2018). In 2016 the IOL reported that the rate at which cancer burden is increasing in South Africa will result in the health infrastructure of the country and allocation of resources not being capable of dealing with the burden unless substantial changes are made and more dedicated fundraising realised (IOL, 2016). The South African Civil Society advocates have been working tirelessly fighting for breakthrough to see the cancer afforded priority in the healthcare system. This yielded results in 2017 through the official launch of two national cancer treatment policies by the former Health Minister, Dr Aaron Motsoaledi (WHO Africa, 2019).

CANSA (2017), reported that oncology drugs are very expensive in South Africa despite the South African Constitutional right to have access to healthcare services. The oncology lifesaving drugs are out of reach for most South Africans due to higher pricing of the drugs. Many people do not have access to the drugs they need due to South African patent law which lags behind than that of other economies for example Brazil, Argentina, and India in terms of

how it protects public health (CANSA, 2017). According to Made et al., (2017), access to quality healthcare remains expensive and unavailable for many South Africans.

According to reports by CANSA, in South Africa, about 115 000 South Africans are diagnosed with cancer each year (CANSA, 2021). The Global Cancer Observatory (2020) reported that in 2020 South Africa cancer statistics showed that breast cancer constituted 14.3 percent of the cancer cases followed by prostate cancer (12.2 percent), cervix uteri (9.9 percent), lung cancer (8.3 percent), colorectum (6.8 percent), and other cancers (48.6 percent). According to Made et al., (2017) Gauteng and KwaZulu-Natal which are the most populous provinces in the country account for the highest number of cancer deaths in the country.

2.6 Social Support

Concept of Social Support

Social support is a multifaceted experience that involves voluntary associations, and formal and informal relationships with others (Strom, 2012). It results in a perception that one is accepted, cared for, and provided with assistance from different groups of people. According to Edmonds, Paul, & Sibley (2011), social support is a mechanism through which social networks are thought to impact on health. Edmonds, Paul, & Sibley (2011) further argue that social support is not a fixed set of resources, it is a situation issue and context specific, and it can be conceptualized as the function of one's network. Cohen, Gottlieb and Underwood, (2000) cited in Hether et al., (2014) define social support as the process by which social relationships promote health and well-being. Social support relationships are based on interactions and connections, they can be implied, virtual, real momentary, imagined, and ongoing. According to Strom (2012) Social support can be negative or positive and it can come from different sources including friends, peers, family members, healthcare professionals, and organisations.

Strom (2012) states that there are four different types of social support and they are catergorised as tangible support, emotional support, companionship support, and informational support. Tangible support refers to financial assistance, services, and material goods. Emotional support includes demonstration of feelings such as love, care, esteem, and sympathy, indicating value and worth (Strom, 2012 and Marisa, 2013). Companionship support encompasses a sense of belonging and the presence of companions for engagement in shared social activities, whereas informational support is the use of information, advice, constructive encouragement, guidance, and suggestions to help others solve problems (Strom, 2012). Dragest (2021), mentions that

social support can be described as structurally and functionally, as well as formally and informally. Structurally social support entails the existence of social network and the depth to which a person is connected for instance the number of social ties and the features of social exchanges between individuals within a social network. On the other hand, functionally social support means a person's appraisal of the social support that they experience and how integrated a person is within their social networks (Dragest, 2021). That is, the depth and quality of relationships. Formal support refers to "the material and spiritual assistance provided by formal organisations in accordance with relevant policies or laws. This kind of assistance has characteristics of regularity and stability, which shows the support relationship between organisations and individuals" (Lu et al., 2020:2) .While informal support refers to the assistance provided by individuals or informal organisations such as family members, friends, relatives and neighbors which is normally characterised by uncertainty (Lu et al., 2020)

2.7 Social Support and Health

Researchers continue to investigate the link between social support and health (physical and mental health) as it continues to gain attention in health literature since the lack of social support is regarded as a fundamental cause of health deterioration (Link and Phelan, 1995 cited in Song et al., 2011). Lino (2013) claims that social support has a strong impact on health, especially in the elderly. Social support may influence factors which contribute to physical health at the time when an individual is adjusting to the effect of a severe illness in their daily life. Social support may operate in complex ways affecting health in both direct and indirect ways by regulating psychological behaviour, and biological processes (Lemons 2011). Lino (2013) postulates that satisfactory relationships are important as they affect physiological responses to stress, reducing the activation of the autonomic nervous systems. Studies have shown that individuals with lower levels of social support are more likely to be adversely affected by stressful situations.

According to Dragest (2021), social support has proven in many different populations of both healthy and sick people, to be an important factor by strengthening a person's coping abilities, quality health life while facing stress. Dragest (2021), mentions that when discussing social support, and health and well-being it is important to note that there are two social support models which are used by researchers to explain social support and health promotion. The two models are buffering support and main support. Buffering support is a type of social support that is beneficial under conditions of high-level stress which means that high levels of perceived support will have less negative health effects on individuals following stressful

events than those with low levels of perceived social support (Dragest, 2021). On the other hand, the main support model reveals that social support is beneficial despite an individual's level of stress and it predicts positive influences of social support on physical and mental health (Dragest, 2021).

Lemons (2013), states that social support influences factors which contribute to physical health at the time when a person is adjusting the impact of **NCDs**. The burden of **non-communicable diseases** is well known and normally care for those affected by the diseases goes beyond patient engagement, extending to their friends, family, and acquaintances to help alleviate the harmful effects caused by stress and other health risks (Vianna and Barbosa, 2017). The provision of effective social support helps motivate patients to cope better with difficult conditions. Dragest's (2021) study highlights that people with depression who perceive their social support as poor experience worse outcomes in terms of recovery, depressive symptoms, and social functions.

2.7.1 Social support and cancer

Cancer affects patients' lives and those of their loved ones in many ways and having people with whom to share the burden with can foster a patient's engagement, hope and positivity. It is associated with high levels of patient psychological stress as the diagnosis and treatment brings about changes in personal paths of life, in their daily activities, work, relationships, and family roles (Usta, 2012). Studies have shown that the majority of cancer patients receive maximum social support from friends, family, and relatives. According to Naseri and Taleghani (2012), cancer patients receiving social support have more survival chances and higher quality of life, and higher adaptability and mental health, whereas inadequate social support leads to negative outcomes such as more psychological pressure, communication disorder, more stress, and increased mortality rate.

Additionally, Cincotta-Eichenfield (2019), is of the view that the need for social support after cancer diagnosis depends on the individual and can manifest differently depending on a variety of illness factors such as socio-economic dimension, cultural context, and individual's social and emotional strengths. Benson (2020) found substantial evidence that positive social support plays a huge role in health promotion. Benson (2020), states that research conducted in Ghana revealed that the majority of women who have been diagnosed with breast cancer reported unpleasant thoughts about their illness including fear of recurrence of the disease and were often anxious and depressed, felt vulnerable, struggled to sleep and struggled with partner

communication. In trying to deal with the health and psychological issues relating to their diagnosis these women adopted coping strategies with religion most frequently used, stating that the religious community provided them with reliable source of support (Benson, 2020).

Cancer diagnosis can signal a shift from what a patient knows as normal to a new reality, an unfamiliar network of healthcare professionals, doctors, and an exhausting schedule of appointments, treatments, and scans, which can be too much for a person and this requires full attention, support and mobilization of social networks surrounding the individual diagnosed (Cincotta-Eichenfield, 2019). The symptoms and side effects from cancer treatment decreases patients' physical well-being and quality of life (Dehkordi and Kahangi, 2018). Therefore, a person's social support network provides a means of coping with daily challenges of illness and mediating against the burdens associated with cancer. The act of positive social support allows an individual the energy to focus on treatment and coping with the illness.

Dehkordi and Kahangi's (2018) study about "The Relationship between Perception of Social Support and Fatigue in Patients with Cancer", reported that cancer patients experiencing fatigue reported significant impairment in their ability to complete various daily activities, including cleaning the house, preparing food, light lifting, and doing social activities with family and friends. These findings show that effective interventions such as social support are urgently needed, and they have potential of improving one's emotional and physical functioning and improving psychological health. Dehkordi and Kahangi (2018), found substantial evidence from research that most cancer patients received more emotional support compared to informational, and instrumental support, and family, relatives, and health personnel provided most of this emotional support, they functioned as important resources at these patients' disposal when needed. Emotional support involves empathy, providing a sense of comfort, listening, and communicating love and affection (Dragest 2021). This suggests that cancer patients were forced to face and fight the diseases alone without having informational support, and instrumental support from their loved ones.

2.8 Self-Management Support

There is no universally accepted definition of self-management, the definition of the term depends on the context and focus of the discussion (McGowan, 2005). Self-management is the decisions, behaviours, and daily process in which individuals engage to manage long term illness (Green et al., 2012). Gallant, (2003) and Grady and Gough (2014), define self-management as the day-to-day activities that individuals undertake to manage illness, keeping

it under control, and to minimise the disease impact on physical health over the course of time. According to Gallant (2003), social support significantly contributes to self-management of chronic illness that individuals undertake to keep illness under control and minimize its impact on physical health status and cope with the psychosocial sequences of the illness.

Supporting self-management for people with long-term conditions has been a key aim for global health policy. People with chronic conditions must cope with their diseases for many years and the face-to-face doctor's visit may not always be the best way to teach patients' necessary knowledge and skills for disease management therefore, quality social support can make a significant difference in helping patients to self-manage their disease. For instance, taking medication, making appointments, recording vital signs, doing physical activities, and managing their mental health which, however, at times depend on social network members having relevant knowledge to help the patient (Li, 2013 and Vassilev et al., 2013).

According to Jones et al., (2011), self-management support does not only focus on the medical management of the medical condition or illness, it also facilitates role management, negotiation of behaviour change needed by chronic illness and management of the emotional effect of living with a chronic illness. Green et al., (2012), states that living with a long-term illness is a self-management process that involves tasks and skills related to coping with the illness and growing as a person. Improving health outcomes is the most important aspect of self-management. Demographic factors for instance socio-economic status and culture, clinical factors such as complexity of the treatment regimen and comorbidities, and systems factors for example quality of relationships and the communication with care providers' influences self-management behaviours (Green et al., 2012). Jalilian et al., (2014), reported that in patients with diabetes the management of the illness is mainly dependant on the patient's compliance which therefore means that improvement of patients' knowledge and self-care skills are a vital strategy for controlling diabetes and its complications. According to Jalilian et al., (2014), the most common reason for the poor outcome in individuals with diabetes is the patients' lack of participation in the treatment of the disease. Hence, social support is an important aspect in the self-management of chronic illness as patients will need encouragement and emotional support. Self-management support can be delivered through standardized programmatic interventions which generally target the way a person with the chronic illness thinks or represents their feelings from family and friends and other sources of support to help them keep going with the treatment for good health outcome (Jones et al., 2008).

2.9 Theoretical Framework

2.9.1 Social Support Theory

The term social support was coined in the second half of the 20th century, and its inherent properties have been written about and extolled for centuries (Williams, 2005). Social support is considered a middle-range theory that focuses on relationships and the interactions within those relationships (Leahy-Warren, 2014). The major contributors to social support theory are Drennon Gala and Francis Cullen, who drew on insights from several theoretical traditions (Kort-Butler, 2017). Social support is a phrase that can refer to a wide variety of phenomena that characterise the social environment or the people surrounding individuals in their network (Helgeson, 2003). Williams (2005) mentions that social support is a multifaceted concept that has been difficult to conceptualise, define and measure. Some scholars claim that the social support function is to provide information to an individual that they are loved, cared for, esteemed, valued and belong to a mutually obliging communication network (Cobb, 1976 cited in Callaghan and Morrissey, 1993). Social support can be expressed functionally or structurally. The functionally side of social support involves offering emotional support, tangible or informational support, whereas the structurally side involves marital status of an individual, frequency of interaction or size of support network (Callaghan and Morrissey, 1993). This implies that if a person has some quantity of social relationships, and high quality relationships it can be predicted a person with higher structural support is more likely to experience higher functional support and vice versa (Li and Wang, 2021). Swarup et al. (2017) contend that there are two main conceptualisations of social support: received social support and perceived availability of social support.

Received support is the help and support provided by family, friends, organisations and other supportive networks. Perceived support is the subjective perception of support available from one's family, friends, and anyone who may provide assistance if needed. (Hartley and Coffee, 2019). Previous studies have shown that perceived and received social support can weaken the effect of stressors on stress (Rui and Guo, 2021). However, some studies suggest that received social support is not always effective in stress coping, and this may be determined by the type of social support being offered and to whom it is being offered. This study looks at both perceived support (perceptions of having enough close family, and friends) and received/actual support as participants will focus on accounts about their experiences and the support they receive from their social networks. More attention will be paid on received social support.

Therefore, the study will draw on social support theory's emotional, tangible, informational, and appraisal support aspects.

According to Williams (2005:33), "social relationships have the potential to provide supportive resources which include emotional resources." Some studies have revealed that people with family, friends, and spouses who provide material resources and psychological resources are in better health than people with fewer social networks (Cohen and Willis, 1985). Social support acts as a stress buffer. When one goes through a threatening or demanding situation and does not have an appropriate coping response, it raises stress in an individual (Cohen and Willis, 1985). Social support theory will be utilised in this study to explore how social support impacts individuals with cancer. Social support promotes health by shielding people from the adverse effects of stress, and it does so by promoting adapting appraisals (making one believe that they are loved and respected by family, friends, and their other social networks) and more effective coping (Lakey, 2010). Social support derives from social networks for example, family, friends, neighbors, coworkers, and social organisations (Kim, Kreps, and Shin, 2015). However, it is the individual's perception of support as available is consistently linked with positive health outcomes (Lynch, 2012).

Social support takes on different forms such as emotional, tangible, informational, and appraisal support (Strom, 2012). Emotional support involves support like esteem, trust, concern, and listening. Tangible support consists of aid in kind, money, labour, and time. Informational support involves support such as advice, suggestions for problem solving, information, and directives. Appraisal support is the support that enhances an individual's self-esteem (Usta, 2012). People with satisfying social support have greater functional, social, and family well-being (Usta, 2012). Social support is one of the effective strategies utilized to help cancer patients cope better with the disease and improve their quality of life even in low resource settings (Usta, 2012). Cancer treatments are not always curative; therefore, using other strategies to improve the illness is crucial.

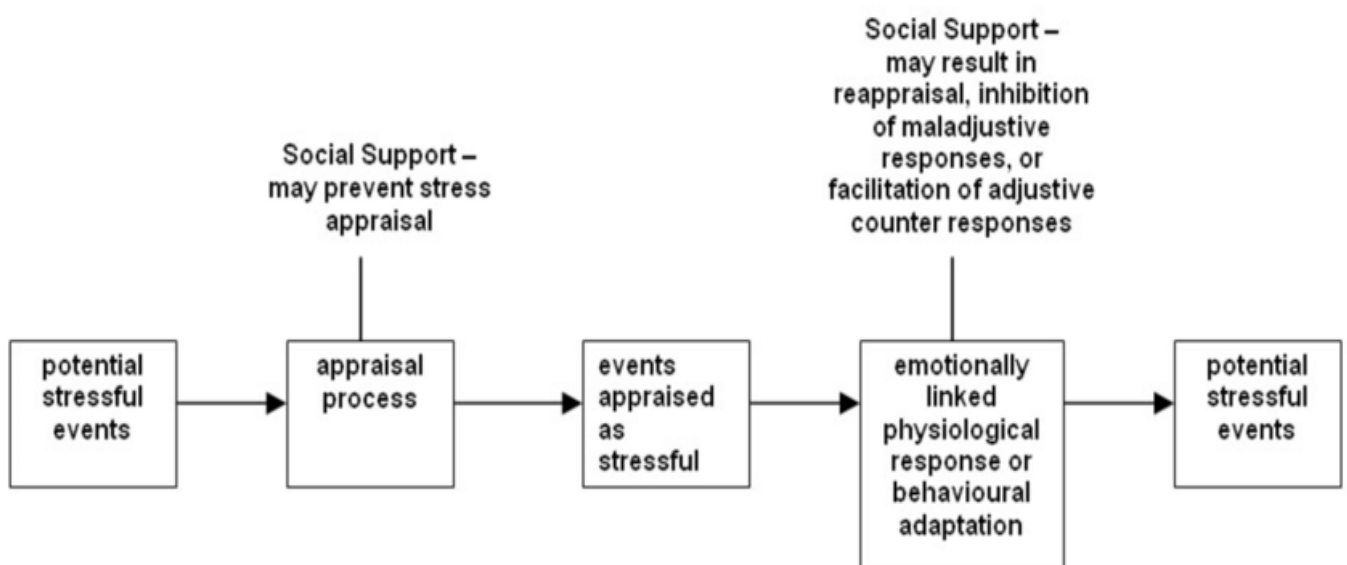
This theory is significant to the study because social networks are an asset, bringing benefits to people. Social support in the health literature has focused on health outcomes which are how the theory will be applied to this study. The theory applies in circumstances where one is going through some difficulties in life. Social interaction enables people to build communities, commit themselves to each other, and knit the social fabric (Field, 2003). Social support framework also applies in societies where there is health care inequities. Bardach et al., (2011)

mentions that social support is considered a valuable asset that may compensate for inadequate health services among low-income groups. Bardach et al., (2011) also argues that low-income groups may draw valuable assets of social support in instances where they face health challenges as it serves as a stress buffer. However, it is important to highlight that the support that may be available may not accurately fit the needs of a person. Moreover, Lino (2013) postulates that good relationships affect physiological responses to stress, decreasing the activation of the autonomic nervous system and other complications associated with chronic illnesses. People with cancer go through some difficult moments that require them to cope by accessing social support from people around them.

The Stress-Buffering Model

Social support gained research attention as a buffer in the association of stressors with mental health (Song et al., 2011). Jackson (1992:363) suggests that “social support can reduce the psychological impact of exposure to stress, especially when support is operationalised as perceived availability of support or as having at least one person in which to confide.” When one is going through undesirable life events such as a cancer diagnosis, they are expected to receive support from their social networks which can help reduce the adverse health effects of this illness (Song et al., 2011).

Figure 1. Social Support and the Buffering Hypothesis



Source: Cohen and Willis (1985:310). *Two points at which social support may interfere with hypothesized causal link between stressful events and illness*

Figure 2. The Buffering Hypothesis

1	2	3	4
Support Source	Stress Domain	Type of Support	Type of Stressor
Friend	Cancer	Emotional	Physical effects
Spouse		Informational	Emotional effects
Relative		Instrumental/Tangible	Socio-economic effects
Neighbour			
Health professional			

Source: Pamela B. Jackson (1992:367). The Four Key Components

According to Jackson (1992) the type of social support available, whether instrumental, emotional, or informational support, must match the recipient’s needs for the support to effectively reduce stress appraisals among the recipients. The stress-buffering model indicates that social support can reduce the stressor-stress relationship to the extent that individuals with limited social support are likely to report higher stress levels than those with more social support (Rui and Guo, 2022). A person diagnosed with cancer is not only affected by the physical manifestation of the illness; there are also probable effects that can affect the patient, such as the mental, socio-economical, and low social capital aspects. These are some stressors that can, directly and indirectly affect a cancer patient. Using the stress-buffering model of social support, the study utilised a sample group of cancer patients and caregivers to explore the relationship between cancer illness and stress.

2.10 The Role of Social Capital in Social Support

The social capital framework stresses that social relationships are resources that can lead to the development and accumulation of human capital (Machalek and Martin, 2015). The major contributors to social capital theory are Coleman, Bourdieu, Putnam, Burt and Loury. Coleman

(1990) defined social capital as any facet of structure that generates value and facilitates the action of individuals within that structure. Adam and Roncevic (2003) state that the theory is linked to concepts such as civil society and social connectedness. There are three dimensions of social capital which are bonding, bridging, and linking social capital (Yamaguchi, 2013). Bonding social capital refers to “trusting and cooperative relations among members of a network who see themselves as sharing identity” (Yamaguchi, 2013:154). Bridging social capital refers to relations of mutual respect between people of different socio-demography, whereas, linking social capital is the individual’s overall portfolio of social networks (Yamaguchi, 2013).

Social capital gained prominence as a means to comprehend how communities might operate to become safer and more productive and where positive identities and lifestyles might be forged (Ostrom and Ahn, 2007). Health and well-being have received substantial/significant attention in social capital field. Social capital is relevant to the study because social networks are a valuable asset, and they bring benefits to people. Social capital in the health literature has focused on health outcomes which is how the theory will be applied to this study. Social interaction enables people to build communities, to commit themselves to each other and to knit the social fabric (Field, 2003). In the context of this study the ‘social fabric’ is the support network impacting on the lived experiences of cancer patients.

Social capital is a vital resource that enables patient participation in social activities and a sense of cohesion/interconnection with others. It provides hope for the future and trust in others in supporting and coping with chronic illness conditions. According to Grootaert and Van Bastlaer (2002), the social capital framework lends itself to diverse applications as it is vast, and one may apply it in any social situation. Relationships are paramount and social networks are important assets. Social relations enable people to build communities to commit themselves to each other and build the social fabric.

Studies have shown that there is a strong link between social capital and social support. Some scholars agree that social capital is a source of social support. According to Christian et al. (2020), social capital and other network characteristics may act as a proximate measure of social support. This study highlights the link between social support and social capital. Social capital facilitates social support which has shown to influence health through emotional support, instrumental support, and informational support (Christian *et al.*, 2020)

According to Nieminen et al. (2013) social capital can have collective meaning as it is seen to arise in neighbourhoods, and communities, and it can be at individual level whereby it is seen as a personal resource that develops from social networks where individuals have access to services, information and support. Nieminen et al. (2013), argue that social support has at times been considered to be an element of social capital at the individual level, but there have been different views on whether it should be included in the concept of social capital.

2.11 Conclusion

The literature has shown that cancer is one of the most feared and devastating diseases which has contributed to high mortality across the globe. Cancer remains a global burden which does not only affect economies but affects patients and those that care for them. Despite the devastating effects of cancer, studies have shown that there is lack of attention to the diseases mostly in low-and middle-income countries due to poor economies and lack of quality healthcare infrastructure. However, social support was found to be vital to health promotion stating that it influences factors which contribute to physical health and mental health at the time when a person is adjusting the impact of **non-communicable diseases**. The literature has identified the importance and the need of social support among cancer patients and how it impacts on patient's self-management behaviours. The study has identified that there is limited literature about the role played by social support among individuals with cancer in South Africa.

CHAPTER 3:

RESEARCH METHODOLOGY

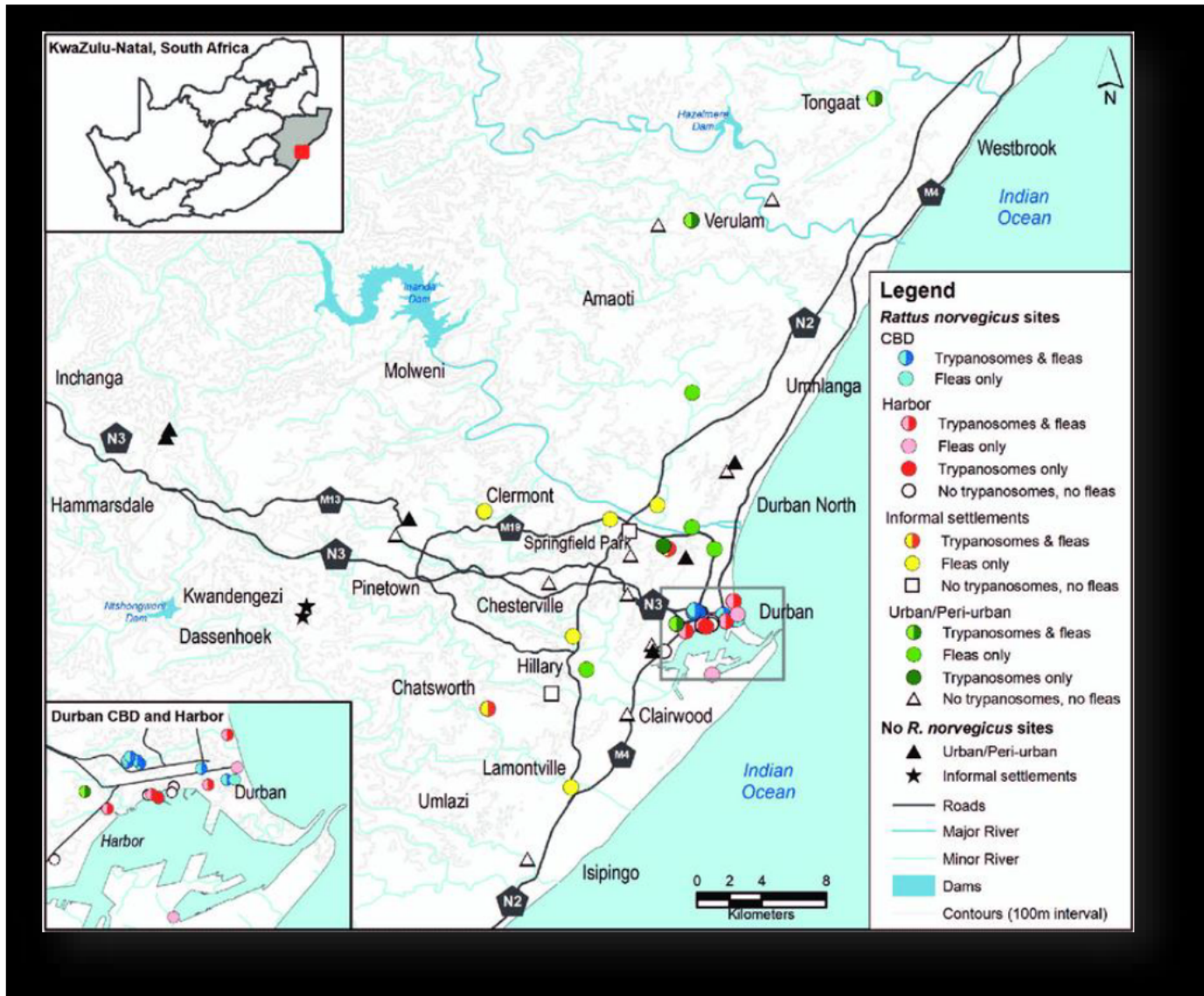
3.1 Introduction

This chapter describes the nature of the study and the methodology employed. The study was designed to explore perceptions of social support among individuals with cancer, the experiences of social support received by people with cancer, the challenges experienced by people living with cancer, and how social support may influence self-management behaviours of those living with cancer. Hence, the study is qualitative. The researcher primarily used in-depth interviews to gather data. According to Cleland (2017:68), “qualitative research is critical in educational research as it addresses the how and why research questions to enable a deeper understanding of experiences, phenomena, and context.” Hence a qualitative approach was fundamental in this study in exploring perceptions of social support among individuals with cancer in eThekweni, South Africa. This chapter will discuss the study area, study design, sampling, data collection, data analysis, ethical considerations, and limitations of the study.

3.2 Study Area

The study was conducted at the Cancer Association of South Africa (CANSA) Mkhuhla Care Home in Durban, South Africa. Durban is the largest city in KwaZulu-Natal province, and it falls under the eThekweni Metropolitan Municipality. eThekweni is described as a sophisticated, cosmopolitan city and it is well known as the home of Africa’s best-managed, busiest port (SAHO,2019). It is a major tourism centre because of its warm weather, subtropical climate, and extensive beaches (SAHO,2019). It is, therefore, ranked the second largest among the most populous urban areas in South Africa. In 2019 the population of eThekweni was at 3 987 648 (eThekweni Metropolitan KZN, 2020). In terms of health care facilities, eThekweni has 31 clinics, 3 district hospitals, 5 regional hospitals (Mahatma Gandhi, Addington, King DiniZulu, Prince Mshiyeni Memorial and RK Khan), one provincial tertiary hospital and one national central hospital; Inkosi Albert Luthuli Centre Hospital (eThekweni Metropolitan KZN,

2020). CANSA was chosen on the basis that it is one of the major non-profit organizations in South Africa that deals with cancer patients and offers support services.



eThekweni Municipality: Source Google

3.3 CANSA Organisation

The Cancer Association of South Africa (CANSA) is a non-profit organization that deals with cancer patients. It was founded in 1931 by a group of medical professionals who were concerned about the high incidence of cancer and has since become a leading cancer control organization in Southern Africa. It offers a unique, integrated service to the public and people affected by cancer. It is an organization committed to connecting people facing cancer with information, day-to-day help, and emotional support they need in the communities where they live. CANSA's mission is to be a non-profit leader that enables research with regards to lower

cancer risk, educating the public regarding symptoms, screening, and risk reduction, and providing care and support to people affected by cancer. CANSA is regarded as a leading role-player in cancer research, and it is in partnership with the Medical Research Council and National Health Laboratory Services through the Cancer Research Initiative in South Africa funds more than R4.5 million on various types of cancer research in South Africa every year. CANSA provides home-from-home accommodation to patients undergoing cancer treatment at oncology clinics far from home. It further provides accommodation facilities to parents for the duration of their children's cancer treatment period (CANSA, 2021).

3.4 Research Design

The study utilised the qualitative research methodology. According to Denzin and Lincoln (2005 cited in Aspers and Corte, 2019), qualitative research involves the studied use and collection of a variety of empirical materials, which includes personal experience, life story, case study, interview, observational, and interactional that describes routine and problematic moments and meanings in individuals. Mohajan (2018), defines qualitative study as a systematic and subjective approach highlighting and explaining daily life experiences and giving them proper sense. A qualitative research method is usually used for understanding views, and perceptions, and its methods are exploratory, seeking to find out the opinions, thoughts, and feelings of respondents. Qualitative research is different from quantitative research, which involves collecting and analysing data for statistical analysis.

A qualitative approach involves asking participants about their experiences of things that transpire in their lives. Therefore, it enables researchers to gain insights into what it feels like to be another person and understand the world as other experience it (Austin, 2014). According to Austin (2014), qualitative data are a source of well-grounded rich descriptions and explanations of processes in identifiable local contexts. The essence of qualitative research is to comprehend a phenomenon in a natural environment as opposed to an experimental setting in quantitative research, in which all variables are examined under experimental conditions (Alhamdani, 2016). A qualitative approach is concerned with how human behaviour can be explained within the framework of social structures in which that behaviour takes place. Qualitative research uses data instruments such as observations, documents, interviews (audio and video), and field notes to collect data from participants in their natural settings (Suter, 2012 and Eyisi, 2016).

3.5 Sampling

When conducting research, one cannot study everyone everywhere to get valid findings. In qualitative research, only a subset of the population is selected for any given study. The study's research objectives and characteristics of the study population determine which and how many people to choose. Qualitative researchers usually work with samples of people nested in their context and studied in-depth (Miles and Huberman, 1994). The study employed a non-probability sampling method but more specifically criterion sampling.

3.5.1 Criterion Sampling

According to Cohen (2006), criterion sampling involves the selection of cases that meet some predetermined criterion of importance. In criterion sampling, the researcher selects individuals, groups, or settings with information and study cases that meet the criteria of the study (Omona, 2013). According to Miles and Huberman (1994), the criterion sampling technique is typically utilized for quality assurance. In criterion sampling, participants are selected because they have knowledge and experience with the phenomenon of interest and, therefore will be able to provide information (Cohen and Crabtree, 2006). According to Cohen and Crabtree (2006), criterion sampling can help identify and comprehend cases that are information rich. It can provide a crucial qualitative component to qualitative data. This sampling technique also helps identify the weakness or problems in a system and find ways for improvement.

The nature of the study required the use of criterion sampling technique because participants needed to meet a certain criterion to be included in the study. Therefore, the participants in this study were diagnosed with cancer and they live in eThekweni which is the study area for the research. The sample size for this study was made up of twelve participants who access support services from CANSA and two Social Workers at the organisation. Therefore, the study was made up of fourteen participants in total. All patients who participated in the study were between the ages of 18-71. Participation depended on the availability of patients therefore, no one was excluded based on their sex and gender. CANSA provided the researcher with a list of people who were willing to participate in the study.

3.6 Data Collection Process

The fieldwork for the study took place in September to October 2021, and permission to conduct the interviews and collect data was obtained from the University of KwaZulu-Natal and CANSA organization in Durban. The researcher collected data through interviews with the study participants using an interview schedule. CANSA helped with the recruitment of

participants by sending out recruitment letters on the researcher's behalf. Data was tape-recorded, and notes were taken during the interviews. There was also observing of the body language, expression, reactions to some of the questions by participants. The researcher presented herself to each participant before the interview began, and described the purpose of the study as well as the significance of their contribution to the study.

The interviews were held at times that were convenient to each of the participants. Interviews were held in face-to-face conversations while observing the Covid-19 social distancing rules. Fourteen interviews in total were conducted, and each interview lasted between fifteen to forty minutes on average. The researcher conducted at least two interviews per day, and participants were not always available. Sometimes it would take two to three days to access participants. The researcher provided participants with an interview guide that indicated the direction of the interview and its sequence. The questions asked focused mainly on the themes surrounding the experiences of cancer survivors.

An in-depth interview was used to gather information using open-ended questions. In-depth interviews are one of the main methods of data collection used in qualitative studies, and they are usually done on a one-on-one basis (Legard et al., 2003 and Allmark et al., 2009). In-depth interviews are often described as a form of conversation with a purpose as it reproduces a fundamental process through which knowledge about the social world is constructed in everyday human interaction (Legard et al., 2003). According to (Boyce and Neale, 2006), in-depth interviews are useful when one wants detailed information about a person's thoughts and behaviors and wants to explore new issues in detail. Open-ended questions were utilized to enable respondents explain their experiences freely and in their own words. Open-ended questions allow respondents to articulate responses in their own words and express it verbally or in writing (Zull, 2016). They can be employed to gather information and to motivate respondents.

3.7 Data Analysis

Qualitative data analysis is one of the most important steps in the qualitative process because it helps researchers to make sense of their data (Ngulube, 2015). According to Kawulich (2004:97), data analysis is "the process a researcher uses to reduce data to a story and its interpretation." It is the process of reducing a large quantity of gathered data to make sense of them. According to Irwin (2008), data analysis aims to extract valuable information from data

and make decisions based upon the data analysis. Data analysis involves interpreting participant experiences to understand the study that was chosen.

A thematic data analytical tool was employed in this study to analyse the data. Thematic analysis is a process of identifying, analysing, organising, describing, and reporting themes found within a dataset (Braun and Clarke, 2012). It is commonly used because of the wide variety of research questions and topics that can be addressed with this method of data analysis. The rationale of utilising this method is its capability to permit the researcher to identify the need to be important in relation to the topic and research being exploited. Its flexibility and accessibility allows the researcher to focus on the data in many ways, and it offers a way into qualitative research that teaches the mechanics of coding and analysing qualitative data systematically.

The researcher transcribed the audio-taped interviews word-for-word for each interviews and familiarised herself with the data. The researcher studied all data and generated codes by taking notes on a printed transcript to identify patterns of the themes in the data collected. When coding the researcher always referred back to the theoretical framework utilised in this study, the literature review, and the objectives of the study in order to get sense of the themes that emerged from the collected data. The researcher finally organised the main themes of the study and used these themes to address the research.

3.8 Ethical Considerations

According to Aguinis and Henle (2002), the word ethics refers to a branch of philosophy concerned with how a person should act, judgments about those actions, and developing rules for justifying actions. Aguinis and Henle (2002:35) postulate that “in the context of research, ethics focuses on providing guidelines for the researcher, reviewing and evaluating research, and establishing enforcement mechanisms to ensure ethical research.” Research often involves a great deal of cooperation and coordination among different people in different disciplines and institutions, and therefore, ethical standards promote the values that are essential to collaborative work, for instance, accountability, trust, fairness, and mutual respect (David and Resnik, 2011). In research that involves human participants, it is fundamentally crucial that research ethics approval is obtained before the commencement of data gathering from participants (Fleming and Zegwaard, 2018). Hammer (2017) asserts that it is also important that a researcher seeks permission from participants’, and they should be made aware that their involvement in the study is strictly voluntary and that they are free to withdraw from any active

data collection program anytime without pressure or any form of coercion. According to Hammer (2017), researchers must work to protect participants' autonomy while ensuring full disclosure of factors surrounding the study, including potential benefits and harms. Participants' need to be protected from harm; their psychological well-being, health, values, and consideration cannot continue as ethics are a very important aspect of any scientific research exercise.

Before the commencement of interviews, participants in this study were made aware that participation was voluntary and may withdraw participation at any point. The researcher explained to the participants the background of the research, what is involved in the research, its nature, and the purpose of the research. Participants were provided with consent form with detailed information about the purpose of the study, the researcher contact details: email address and cellphone number. Informed consent was obtained from participants through them signing the consent form voluntarily. The consent form served as a legal binding to respect anonymity and confidentiality of the participants' and that the researcher will not share the participants' identity under any circumstances considering the participants' vulnerability and their need for greater protection. Alahmad and Dierickx (2012), asserts that confidentiality is an essential and shared human value, therefore it is important to establish positive, trusting relationships between researcher and participants and it encourage participants to disclose confidential information. Ethical clearance for this study was obtained from the University of KwaZulu-Natal Ethics Committee and a gate keeper's letter was obtained from CANSA Care Durban.

3.9 Validity and Reliability

The method in which data is gathered is an important consideration in establishing validity, reliability, and rigour. According to Shenton (2004), some researchers have proposed four criteria that is believed should be considered by qualitative researchers in pursuit of a trustworthy study. The four criteria employed include credibility, transferability, dependability, and confirmability. Validity in qualitative research means appropriateness of the tools, processes, and data whereas reliability refers to the exact replicability of the processes and the results (Leung, 2015).

Credibility is the most important aspect in establishing trustworthiness in research. Credibility establishes whether the research findings represent plausible information drawn from the

participant's original data (Korstjens and Moser, 2017). To ensure credibility of the study, two techniques were utilised in this study which are triangulation and tactics to help ensure honesty in participants. Data for this study was gathered through individual in-depth interviews. The interviews were audio taped and transcribed. To help ensure honesty in participants, each participant approached was given opportunity to refuse to participate in the study. To ensure that the data collection involved only participants who were genuinely willing to take part in the study and offer data freely, a consent form with background information about the study and the interview protocol was provided to the participants. Each participant was required to sign the form willingly.

3.10 Limitations of the study

Due to the nature of the study and being in the midst of the Covid-19 pandemic, it was challenging to find participants (cancer patients) for the study during the period the researcher anticipated to collect data. Therefore, the study lacked equal representation of gender. There were more women than men because more women than men lived in the Care Home. Also, participation depended on the availability of the participant. There were times the researcher had to leave some questions unanswered to let the patient go and rest. As a researcher, it is crucial that participants' needs are put first. It should be noted that in as much as the researcher strived to achieve the study objectives, the data obtained is not representative of the wider population. The findings of this study are based on the experiences of people living in eThekweni, one of the major cities in the province of KwaZulu-Natal, South Africa. The experiences of the study participants may differ from the experiences of people living in other towns and rural areas in KwaZulu-Natal. Therefore, one cannot generalise these experiences to a wider population. More so, there are relatively few studies qualitatively exploring the topic in the African context, which means qualitative literature for this study in the African context is limited.

3.11 Conclusion

This chapter has provided detailed and clear information on the methods used to conduct this study. The study is a qualitative study in which data on the perceptions of social support among individuals with cancer in eThekweni, South Africa was obtained by means of in-depth interviews with people accessing cancer support services from NGO CANSA. Data was thematically analysed and an ethical protocol was followed.

CHAPTER 4:

FINDINGS

4.1 Introduction

This chapter discusses the key findings from in-depth interviews with participants who are currently undergoing cancer treatment and receiving care at the CANSA Makhuhla Care Home, it also includes findings from interviews with social workers. The study aimed to explore perceptions of social support among individuals with cancer in eThekweni, South Africa. The findings of this study were obtained through one-on-one interviews with all the participants. The interviews were audio recorded with full consent from the participants. The recordings were later transcribed and in no way has the researcher distorted or altered the direct recording from the interviews, the information disclosed is solely that of the subject matter of the interviews. This chapter begins by exploring the key characteristics of the sample, and then discusses how social support impacts individuals being treated for cancer. Results are presented through identifying the main themes.

4.2 Sample characteristics

All the participants in this study were residing at CANSA Makhuhla Care Home in Durban/eThekweni with majority of the participants being women. All participants were cancer patients from the age of eighteen years and above, with the youngest being eighteen and the oldest seventy one years, except the two social workers from CANSA organization.

Cancer Patients

Interview Number	Sex	Age	Ethnic Group	Year of Diagnosis	Type of cancer
1	Female	58	Indian	May 2021	Breast cancer
2	Female	20	African	May 2021	Brain cancer
3	Female	38	African	March 2021	Vulvar cancer
4	Male	36	African	2009	Skin cancer
5	Male	18	African	January 2021	Ewing's sarcoma
6	Male	60	African	June 2021	Prostate cancer
7	Female	49	African	2017	Throat cancer
8	Female	58	African	January 2021	Breast cancer
9	Female	41	African	September 2014	Brain tumour
10	Male	66	African	September 2020	Prostate cancer
12	Female	71	White	May 2021	Rectum cancer
13	Female	63	African	January 2018	Breast cancer, lung cancer, brain cancer

Social Workers

Interview Number	Sex	Ethnic Group	Occupation
11	Female	African	Care Home Coordinator, and Care Giver
14	Female	African	Social Worker, and Tough Living With Cancer Leader

4.3 Themes

The data presented in this study was obtained from the transcripts of the study participants. The researcher familiarized herself with the data by transcribing the audio-taped interviews, read the transcriptions thoroughly to comprehend what the data entailed. In order to gain the meaningful parts of the data the researcher analysed the data by searching for common information between participants. This helped the researcher to interpret the data and identify underlying themes of the study.

4.4 Research Findings

4.4.1 Background information of the study

The findings for this research were obtained from the insight and experiences of fourteen participants, twelve cancer patients, and two social workers. The findings for this research were obtained by using in-depth interview as a research tool. The study respondents comprised of ten females and four males, with eight females and four males being cancer patients. These patients have different types of cancer and they receive treatment in different hospital institutions. Some receive treatment in public hospitals whereas others receive treatment in private hospitals in Durban. They all however receive care and social support at CANSA Mukhuhla Care Home.

The interview schedule was mainly concerned with the perceptions of social support among individuals with cancer, experiences of received support, challenges faced by people living

with cancer, and how social support may influence self-management behaviors of those living with cancer.

4.4.2 Responding to the news of cancer diagnosis

The information obtained from the participants suggest that they were consumed with fear, shocked and devastated when they received the news that they have cancer. Some respondents mentioned that they were shocked because at first they thought that they were suffering from other diseases which were not as severe as cancer. Some respondents indicated that they did not feel the need to see a doctor or go to the clinic until it was too late because they thought they were suffering from diseases which they thought it was not something to be worried about.

“Actually was quite shocked because I just thought it was just a normal gland which ah with some medication it could get resolved...” (Participant 1).

“Yeah, I went for something else last year towards the end of year. I was suffering with piles, so I went to the hospital. So, when you go to the hospital you know they do thorough check up on everything. They did what we call pap smear then the result came back in January they said no I’m not infected in my cervix but again I was still suffering with pains I went back in February the other doctor suggested that they were going to admit me because they want do the biopsy, then they admitted me. So, I went to theatre when I came back to theatre then March, I went back for the result that when the result came and said I have vulvar cancer. It was March” (Participant 3).

Some respondents mentioned that they were scared and thought they were going to die after they received the news of their diagnosis. In society cancer is normally perceived as synonymous with death. Some view it as a death sentence which makes one to fear death when they get diagnosed with cancer. There is a misconception that exists within our societies that anyone who get cancer dies and it is not a treatable or manageable disease.

“Obviously I was shocked and scared, I thought that I am going to die at such a young age but as time went by, I became fine I accepted the situation and realize that it’s not the end” (Participant 2).

“I was scared because I had heard that a person who has got cancer doesn’t live long. So, I kept doing check-ups hoping something good will come out of it” (Participant 7).

Some respondents admitted that when they got diagnosed with cancer they had no idea what it was and they had never heard of it before. They received all the information they needed from

doctors and other health professionals who helped enlighten them as to what cancer is and put their mind at ease. A young man with albinism, suffering from skin cancer mentioned that his parents were uneducated so he had the disease for a very long time before he finally got assistance from the doctors. His parents knew nothing about cancer or whether to seek help on time which contributed to the young man having the disease for a very long time without getting medical help.

“It was too bad for me because I didn’t know it’s a cancer. I have been long with it because of the parents who didn’t go to school, so they don’t know how, because they believe that as albinos we can’t go by the sun, they believe that it’s the sun that did this to me. So, when I found out it’s a cancer, it was too bad for me and to the family” (Participant 4).

“In the beginning I was shocked; I did not have an understanding of what it was. The doctors later on explained to me. I was scared because of the fact that it is in my brain, I was shocked. The doctors did not explain to me whether it might come back or not. So, it later came back, and I was confused as to why it is coming again then the doctors explained to me that they did not remove it all. They explained to me that if they had operated on me and remove all of it, it would come back again very fast” (Participant 9).

Being diagnosed with cancer can bring out mixed feelings in people. Some people are able to feel different emotions and others go numb. For some study participants losing a loved one to cancer or knowing someone who is suffering from the diseases can also affect one’s reaction to the news. A respondent who is an elderly woman aged 71 admitted that she went numb when she received the news of her diagnosis, she could not react and she had lost two husbands to cancer. The respondents mentioned that:

“I didn’t feel well because my aunt passed away due to cancer, but it was cervical, so, I felt scared” (Participant 8)

“I don’t know what I felt. I couldn’t react, and the doctor came to me and said to me do you understand you have got cancer and I said yes but I don’t want chemo because I lost 2 husbands with chemo” (Participant 12)

Another respondent mentioned that she lost hope when she received the news that she has cancer but the news of her diagnosis mostly affected her children than it did to her because they knew someone within their locality who had the same illness and it was awful.

“...when I was first diagnosed, I started losing hope that I will live more especially because my children were crying none stop when they realized that I’m having this cancer more especial my one and only daughter. She was so devastated having seen what cancer has done to most of the people. In our vicinity there, in our locality there is an old lady who had breast cancer, she could not take care of it. Her hand and her breast started rotting down, she started having horrible smells then when my daughter was thinking about that, she was crying everyday anyway I had to be strong for them. So, I went for the medication I went to the doctors that is how I got chemotherapy” (Participant 13).

However, although most respondents admitted to have been shocked, devastated, and scared when they received the news that they have cancer, some respondents admitted to have not been afraid. One respondent mentioned that his faith in God made him stronger and hopeful that he was going to fight the diseases. He stated that:

“I was not afraid at first because I knew God is there, I had faith that God is going to do something for me” (Participant 10).

Another respondent indicated that the news shocked her at first but she quickly adjusted to living with cancer and accepted it. She saw her illness just like any other illness and learned to live with it. Knowing that there are other people who are living with other chronic illnesses and are still living their normal life gave her some sense of comfort and it helped her with accepting the illness that she has.

“At first, I was shocked and then I quickly adjusted to living with it and accepting it just as how other people HIV, other people have whatever sorts of illnesses. So, I took that example I was like oh wow they can live with this so why can’t I. I had that type of mindset and went with it” (Participant 5).

Responses from participants shows that all cancer patients’ reactions were similar upon the time they received the news of their diagnosis. Most participants reported to be shocked and scared when they received the news but as the reality dawned on they learned to accept it whereas for others it took a longer to come to terms with the fact that they have cancer. It was observed that the shock and fear of being diagnosed with cancer shadowed them because cancer is regarded as a deadly illness and people perceive it as being a death sentence because cancer death rate around the world and in South Africa is very high. It was also observed that some

participants who came from low income households feared how they were going to afford treatment for cancer as it is very expensive in South Africa.

4.4.3 Cancer Awareness and Stigma

Most participants related strongly to the issue of lack of awareness within communities even within their families. The cancer awareness issue was mostly brought up when participants were asked about the message they would like to provide to the community regarding cancer illness. They expressed that there is also ignorance in society when it comes to cancer and other **non-communicable diseases**. This is what they had to say:

“Yes, I’m going to take back to people that don’t know about cancer, I’m going to talk about myself most probably to them and then make them understand what a patient goes through having cancer and also I will talk to them about the different types of cancers because now I have learned so much more to take back to them about the pain and suffering of a patient, they need love they need care, they need help all the time” (Participant 1).

“...especially us Africans there are so many views around cancer. So, if a person has cancer most people say it’s not cancer it has to do with ah traditional stuff. So, I will tell the community that if the doctor diagnoses a person with cancer all they need to do is to not discriminate but support and they should not make a person feel like they should be in isolation, and cancer is not contagious, and a person can finish their treatment and start over and be okay and be physically fit to do whatever. So, they no such that after you have been diagnosed with cancer it ends there, you still have a lot of potential after cancer...” (Participant 11).

“Okay, cancer is real, and cancer can happen to anyone and it’s not something that is a curse. It can happen to anyone. It’s real. And it’s manageable. It’s manageable as soon as, as long as you get help. Like, as soon as you see that there’s something wrong, and definitely screening. For the men they should do PSAs the woman must do breast exams and pap smears. They should take the precautions like wear hats when you’re in the sun. When you have a mold get like get as much as I know us Africans, we always moves towards witchcraft” (Participant 14).

Some participants expressed that HIV has been widely acknowledged in society but people with cancer are receiving a lot of negative comments because people are lacking information about cancer. Yilmaz (2020) states that health related stigma shows its effects through varied

mechanisms for example discriminating, negative attitudes and stereotypes. Responses that some participants gave indicated the negative attitude that society displays towards cancer. Stigma towards an individual with cancer affects their self-esteem and makes one feel socially excluded. Hence, the participants expressed the need of cancer awareness because once there is awareness people are able to learn about the cancer illness and stop stigmatizing those suffering from that illness. They mentioned that:

“The community should stop making fun of people who have their diseases, because we have got people who have HIV. Okay HIV has been well acknowledged in the areas but diseases like cancer I don’t know what really people have because if you have cancer someone just talk to me saying that people in your area are so much rude someone was asking me Mrs Chapita does not have the breast, is there anything wrong with that , why really why, because myself I don’t feel anything and that person does not know that cancer is not only meant for, in fact there is lack of knowledge like I was saying we people who suffer from cancer we have got to go even if we have to go to the clinic so that we can make awareness to people so that they must know that these things happen to anyone” (Participant 13).

“I like to say to the community they must accept this sickness like how they accept HIV. Yes, like how they accept HIV. People who got cancer you can sit with him, talk to him, even they can touch you there is no cancer that can come on you, yes” (Participant 4)

4.4.4 Knowledge of the concept of social support

All the study participants were asked to explain in their own view what they think social support is. All participants had different views on what they think social support is. Strom (2012), is of the view that social support is multifaceted experience and it involves voluntary association, and formal and informal relationships with others. Hence it is the perception that one is accepted, cared for, and provided with assistance from certain individuals, or from a specific group of people. Cancer patients certainly need such supportive mechanisms.

“Social support it’s something we get support from. For example, Makhuhla Home, they have actually given us support of providing for our transport, providing for meals, providing if we need medication from chemistry, they do stop and pick up from chemistry and they give us a place to stay” (Participant 1).

“I think it is the support that you receive from family, friends yeah” (Participant 2).

“...it is the support system that you have for example from family, organizations, churches. Any support you get while on your journey, it can be emotional support, financial support, or any other form of support” (Participant 6).

“Well somebody who can support you and help you, you know to keep your mind busy I think, because the mind is all over the place” (Participant 12).

Responses from participants' shows that all cancer patients had knowledge of what social support it although some found it difficult to put it in words but they do have knowledge of what it is. Based on the findings, most participants mentioned that it is the support you get from family which also shows that most of them get maximum support from family and friends.

4.4.5 Types of social support and Sources of support

According to Cincotta-Eichenfield (2015), when someone gets diagnosed with cancer it can signal a shift from what the person knows as normal to new reality which includes an unfamiliar network of doctors and health care professionals, a busy schedule of appointments, and treatments among other things. This clearly indicates the need of social support after cancer diagnosis as a person will be going through a difficult time. Lakey and Cohen (2000) states that received support can be separated into different types of support which are informational support, emotional support, and tangible support which is providing physical assistance. Strom (2012) recognises the significance of companionship support which brings a sense of belonging when going through difficult times. Most participants indicated that their social support network provides them with means of coping with their everyday challenges, helping them accept their new reality, and making them feel comfortable and belong. Participants mentioned that their sources of support were mostly family, friends, pastors, health workers, and neighbours. Some respondents mentioned that they received support right from the time they received the news of their diagnosis whereas others did not have support and they had no idea of what cancer really is.

Emotional and appraisal support

The study findings suggest that emotional and appraisal support were mostly provided by family members, followed by friends, the church and others. Participants mentioned that their strong support system was their family. Based on the study findings, participants expressed that their families have been there since day one, they listened to them, comforted them and gave them a sense of belonging by not discriminating them in any way. They also had friends and the church who would check up on them almost everyday and gave them words of support.

“My pastor has come and counselled me quite a few times, he phones me, talks to me, my friends call everyday they send me messages every day and then when I go home for the weekend ah I don’t actually take any visitors for now but we do a video call where we come to talk to each other and stuff but then all my friends will bring me certain something even if they have to come to the gate and drop it, some of them come to the gate although I can’t have them at home because of my immune system and stuff but they do come yes” (Participant 1).

“I have a very strong support base in terms of my family it has been there since day 1. I haven’t experienced and form of discrimination in the family. They all take it as if this illness is not contagious and it goes to a point where my kids do not even believe that I’m sick because I look so strong” (Participant 5).

Tangible support

Tangible support was also identified as a form of support available to some participants. It was in the form of financial assistance, material things such as small medical equipment. One participant expressed how excited he was by having this kind of support as it brought relief to some of the challenges he experienced after being diagnosed with cancer. He also explained that it brought him peace of mind knowing that some of his problems were solved by those around him.

“I had to get social support from other people like, I had people who supported me. Someone even bought me a machine to test BP, and someone also offered, he bought me a machine to test my sugar levels. Besides that, I was taken to Johannesburg in Boksburg there is a herbalist there, so the person who took me there offered to help me and paid about R12 000 for a programme which went for about 10 days” (Participant 10).

He further mentioned that:

“It has helped me. It had to let me have a peace of mind because you know one of the problems is solved you really become peace minded. It also made me to be friends with those people. Some of them would phone me, I discuss with them, and they encourage me you know especially in prayers. I have other people whom I’m praying with at night who are in Zimbabwe, at 2 o’clock they just say let us pray, we wake up and pray. That program it has kept me refreshed and strengthened” (Participant 10).

She further said:

“It helps a lot because she takes me where I must be, take me to stay with her for weekends because I still stay on my own. I don’t want to stay with someone” (Participant 12).

Informational support

The study identified health workers as an important source of support. Few participants emphasised the significance of their relationship with health workers and receiving support from them. Health workers played a significant role in providing psychosocial and informational support to the participants. One participant also indicated the importance and power of social media because that is where she got most of her support by interacting with people going through the same illness and health workers, and she receive support from her doctor as well. These findings suggests that once an individual has managed to access health care, those providing the services typically also provide social support

“My doctors, the dietician, and my daughter. That’s all I have got left” (Participant 12).

“I used to get support from Facebook. I would go through the wall on Facebook, chemotherapy support groups on Facebook, yeah from all over the world. Neuropathy support groups, cancer support groups, so, I used to get support from those, otherwise even from the lady who is the, who is my GP, yes, she used to give me support by that each time I, sometimes she just calls me when she is not having much work, we talk, we talk. She gives me support even sometimes by prayers. I used to say to my kids it is not that I like Doctor Skunyana but it is because if I am with her, I can feel that I am going to live, I’m going to live longer. She heals me medically and spiritually. Yes, I used to get support from her” (Participant 13).

She further said that:

“It helped me a lot, I realized that I was not the only one who is undergoing this. We are many and I also realized the ways of dealing with the issues that attack me when I am feeling down, when I’m sick, when I am feeling down emotionally and all that. I really, really got help from the Facebook walls” (Participant 13).

Two participants who work at the Makhuhla Care Home were also asked about the kind of support they offer to cancer patients. They explained that:

“We do have 2 social workers, 2 volunteer social workers, and 2 intern volunteers who are also social workers. So, what we offer is, first we have tele-counselling that help even people who doesn't stay at Mukhuhla. What you do is, you phone us requesting tele-counselling be it an individual counselling or family counselling or with the friends, whoever, and then after that we make an appointment. Our social worker will call you and they also do follow-ups. So, it is like having a counselor, but you do not see the person and the service is for free. Then as Mukhuhla Care Home, we have support groups, patients meet and talk about things in general and also their journey like whenever they started being diagnosed with cancer. And we also have counselling one-on-one with our patients, our social worker, others request it” (Participant 11).

“But resource is telephonic counseling, they can get that they have other devices. They have devices available for them. Some of them, they need walking frames, they need hospital beds, when they get home, they need, we have those assistive devices. We also have coping kits, we have a lot of material online that they can use even at home, like how to deal with pain at home, how to cope with cancer. There is something we call a survivor kit. It's a weekly email program. When you get diagnosed, you just start on it. And it's like you're talking to someone. And they have questions there that may relate to you like, what does this mean for me? What does this, what is this? What do I need to ask my doctor like we have those types of questions, and these were created by other cancer survivors. So, it's created for patients by patients. Yeah. We also have other support stuff like prosthesis, other people need prosthesis after having a mastectomy” (Participant 14).

“We try to find out that, and also whenever you are counselling a person, you can tell that a person still need more counselling. Oh and one more thing we have a social worker who is a survivor, so, it is easier to talk to a person who has been through the journey. So, when she calls them to follow-up, she is trying to find out if they have accepted, and how they are doing in their journey, and if they need more time and all that. So, to ensure that you leave a person in a good state of mind, a person has now accepted. It is easier to go through the healing process” (Participant 14).

All participants reported to be receiving social support. Some receive maximum support from their families and friends, others from social media, health professionals, and from church. It was noted that all cancer participants receive support from CANSA Mukhuhla Care Home

where they reside while they receive their treatments' at nearby hospitals. Therefore, none of them could actually say they do not have support even if it may not be much support but they all have one common organization which provides them with support. Most participants expressed that the support they are receiving has helped them to accept their illness, given them strength to fight the illness and gives them hope for tomorrow.

4.4.6 Patient challenges

All study participants were asked to describe the main challenges they face as go through their cancer journey. Respondents mentioned the different types of challenges they face as cancer patients. These challenges were mainly social challenges, economic challenges, and challenges related to their treatment.

Social challenges

One respondent expressed feeling frustrated with the kind of treatment offered in public hospitals. She stated that treatments are being delayed in public hospitals which affects their recuperation. This forces patients to shift from public hospitals to private hospital to seek better treatment, but it requires more money to get treatment in private hospitals and sometimes patients cannot afford it. The respondent stated that she wishes if government could intervene so that they receive better service in public hospitals. She stated that:

“....especially in public hospitals government must intervene because they are delaying the process of treating the people. As for me I was supposed to be better now because I found out early this year but I only started now because I shift from a public to a private so that is when I am getting the treatment. I think the government must do something about the date of treating us because it's very difficult to live with this thing”
(Participant 3).

Some participants mentioned that they face different social challenges which affect their day to day lives as cancer patients. One respondent who lives with albinism talked about isolating himself from other people because of what the cancer had done to his face. He felt uncomfortable to associate with others in society and the way people looked at him made him feel uncomfortable to be seen because people were always staring at him and talking behind his back. This shows that discrimination still exists in society when one becomes ill. He said that:

“I didn't have no cheek this side, left hand side and it was a big sore and in that sore it was like its rotten, so as I am saying it was hard for me to go near the people because

they, even you too couldn't come near me or near to it so I separate myself from them one time because I can't go be by the people who don't understand it..” (Participant 4).

“...you can see if people are talking bad when you coming there, they act like they wasn't talking about you but you can see and feel it too.” (Participant 4).

Another respondent indicated that a family member became mentally ill and it affects her a lot. She also mentioned that her family is unemployed and she unable to work as well due to her illness which affects her and her family financially. The respondent stated that:

“One of my family members became mentally ill during the process of my journey so, that stresses me out a lot. Also, nobody is employed in my family including me so, I rely on washing for people and cleaning but now I can't do it because of the pains in my body” (Participant 7).

The study found that many who get diagnosed with cancer find it difficult to accept that they have it. They struggle to come to terms with the fact that they have it and it also affects their healing process because when one is in denial it becomes difficult to adhere to doctors recommendations. Acceptance remains the biggest challenge when one gets diagnosed with cancer. Another respondent mentioned that their main challenge was accepting the reality that they have cancer.

“I don't know whether it's challenge or not, but it was accepting the fact that I have this thing. That was like the biggest thing that I had to overcome, accepting that this is me, this is what I have and yeah” (Participant 2).

Economic challenges

According to the study findings, lack of finances, unemployment are some of the major challenges which affected many of the study respondents. These challenges do not only impact the patients but their families as well. Some respondents reported to have stopped working once they got diagnosed due to their illness conditions, while others talked about their struggle in finding employment. This has highly affected them because they struggle to take care of their families, and even affording transport fares to doctor's appointments which result in them missing their appointments, and they also struggle to buy food for their recommended diet.

“You see currently since I found out that I am sick I'm not working so it's so hard for me especially when you are having some appointments with the doctors, the money for transport and all this stuff then at home my kids they are looking at me saying mummy

we want this, we want this. I got no money, maybe if the government can grant the people living with this, with something maybe a monthly income, I think that can help” (Participant 3).

“As a person who got cancer, sometimes I have to separate the food what I’m eating but because I have got no money to pick and choose the food, I’m eating everything, what is coming in front of me...” (Participant 4).

“The thing I can share with you, I can say I accept the cancer; I accept it but what I like is to be supported. Once I get supported, I can stand for this treatment, I can do, because sometimes I miss the dates because there is no transport money at home, so the doctors scolded me shout at me, so I try to explain to the doctor that sometimes it is the transport money” (Participant 4).

“The main issue I have is finances. Sometimes I have to come for treatment, but I do not have money to come for treatment, but I told myself I will beat cancer. I understand what it is” (Participant 9).

One participant mentioned that lack of employment and finances increased a burden of stress on her and left her with no other option but to go to money launderers to borrow money. Having cancer has not only affected her ability to work but her ability to fend for her family as well. It is impossible for her to go to the bank and ask for a loan since she is not working so she opted for going to individuals in communities who lend money and sometimes they can be dangerous if a client fails to pay their money on time. This is what she said:

“I have stress because I am not working so I went to money lenders and now I am owing that person and those people sometimes they are dangerous. So, now I am under a lot of stresses, but back at home when I was still okay, I had my own garden, and I would sell fruits and veggies but now there is no income coming in. So, it is very stressful” (Participant 7).

Another participant mentioned that being uneducated had affected her in getting a good and comfortable job, and being diagnosed with cancer makes it even harder to keep the types of jobs she can do as an uneducated person. For example being a street cleaner where she is exposed to conditions that can affect her illness. She expressed that she wishes if she can get proper treatment and become better so that she will be able to find means and ways to work and have an income to take care of herself. She mentioned that:

“Financial issues is the main one for me. It is very hard for me to get a job and also keeping a job especially being a person who is uneducated. It is very hard keeping a job because I once got a job as a street cleaner, but it was very hard keeping it because the sun was very hot, and I could not do it because of my condition. It is very hard to find something I can keep doing, something that is not hard on my health. Maybe it will be better if I can work for myself as a street vendor or something just to get some income” (Participant 9).

“Everything works around money. The fact that I have to travel for treatment I need money, buying food I need money. So, the things that can sustain my situation right now, I am sick, and everything requires me to have money” (Participant 9).

However, some respondents mentioned that although they face some financial constraints they have families and friends to lean on, who support them financially for them to get to their treatment centres, make sure they have proper food all the time, help them with everything possible for them to get better, and they expressed gratitude towards the support they are receiving from them. They stated that:

“I had people who supported me. Someone even bought me a machine to test BP, and someone also offered he bought me a machine to test my sugar levels. Besides that, I was taken to Johannesburg in Bokesburg there is a herbalist there, so the person who took me there offered to help me and paid about R12 000 for a programme which went for about 10 days” (Participant 10).

“...some could buy grocery food for me, some could send money so that food could be bought for me” (Participant 10).

“Really, really having the kids that I have was a very great pleasure to me because sometimes I go short of money then they will help, they would help that I get money for petrol for instance I usually have petrol issues, the car is there but there is no petrol. One of them would give me some cash and I get some petrol because I do have to come to Port Shepstone or Durban. Durban R1 500 petrol, Port Shepstone R1000 it takes me there and back home” (Participant 13).

4.4.7 Challenges related to cancer treatment

Most respondents indicated that part of their main challenges are the physical side effects of their treatments and it is difficult to manage them.

“There were lot of challenges because first time I went to the chemo, the chemo had some side effects, so I was nauseous, vomiting, weak, yeah, all those stuffs. It was hard” (Participant 6).

“I have not experienced any big challenges but when I was doing chemo, I would sometimes be tired and wanting to sleep every time, but other than that my routine hasn’t changed, nothing has changed” (Participant 8).

Another participant indicated that cancer did not only affect his body but also affected his daily routine, diet, and had to make some difficult adjustments.

“The challenges that I faced are that I stopped eating many different foods because some of these foods affect my illness. I shifted from eating a lot of meat to eating lots of vegetables. If I eat boiled eggs, I only eat the white part, I no longer eat the yellow part. This encouraged me to exercise. I do 1 hour exercise in the morning at home and in the evening, I do 30 minutes exercise. This helps e reduce stress and reducing my cancer, and to also maintain my sugar levels. It helped me a lot and it is still helping me” (Participant 10).

“Another challenge that I faced was losing my sleep. I would spend the whole night without sleeping. So, I went to the doctor at the clinic where I take my medicine, I told the doctor about the issue, and he gave me some tablets which I drink before I go to bed so that I can sleep” (Participant 10).

“Another challenge is that I urinate a lot at night, I even have a bottle on the side of my bed because I urinate after every 10 to 12 minutes until morning. So those are some of the challenges that I have. I even talked to my doctors, and they said we know it happens but do radiotherapy, then we see how it goes after that, and we see what we can do. So, I am still waiting to finish this program then I see how I feel after that, then we see if it is working or not” (Participant 10).

“So, the time I got here I was diagnosed with diabetes. I got diagnosed with diabetes on my first visit to the clinic, and I had a catheter, and it was removed this year in January. I had the catheter almost every time and I had challenges that it would block anytime, maybe we would be walking or doing something, and it blocks, and we have to find a hospital where I can go. So, these are the challenges I was facing but for now

I don't have the catheter anymore. The challenge that I am left with is that my bladder is now loose" (Participant 10).

4.4.8 Illness Self-Management

All the respondents explained the various daily activities they undertake to manage their illness or keep their illness under control, reduce its impact on their physical mobility. The respondents were asked to explain what they do to manage their illness and this is what they said:

"For now I just need to keep doing exercises, ah being on a good diet, trusting the Lord, and I know I am completely healed" (Participant 1).

"I talk to my family, I buy the newspaper and read just to pass time, and I used to do the garden but now because of the pain I cannot do the garden so, I tell my son to do it and I guide him on how to do it" (Participant 7).

"I keep myself busy by being around people but when I am tired, I take a break and rest. But I am always in a space where there are people around me" (Participant 9).

"...I do 1 hour exercise in the morning at home and in the evening, I do 30 minutes exercise. This helps reduce stress and reducing my cancer, and to also maintain my sugar levels. It helped me a lot and it is still helping me..." (Participant 10).

"I am trying to attend the physiotherapy like I said my illness has resulted me not being able to move. I go to the physiotherapy I get those sessions although this Covid thing disrupted that. I was already getting there then Covid came I started not attending because of some regulations. I am still going to start that after going this radiation, I'm going to get that physiotherapy so that I can be able to move again" (Participant 13).

"It is the patient's responsibility to ensure that they take their medication on time as prescribed by the doctor but what I have noticed is that, especially for pain tablets patients still don't understand what they have very well. I'm saying that because there are patients who only take pain tablets when they feeling pain while the doctor has told them that you have to take the medicine every day or every morning. So, having the support groups we also talk about treatment. Like, okay you are saying that you are taking morphine, so how often are you expected to take morphine and I think that helps them to know the importance of taking their medication but at the same time we do not have control over that because we do not have caregivers per se. I am a caregiver just to oversee everything because patients who are accommodated here are patients who

can do everything for themselves. So, it may help but sometimes it is up to a patient whether they are responsible for their medication or not” (Participant 11).

A care giver mentioned that equipping cancer patients with knowledge about the illness helps them to practice good self-management behavior. She mentioned that there are some patients who are resistant to any form of support they receive. This mostly happens when a patient is in denial and when they are still in depression. Therefore, at the end of the day it is the patient’s responsibility to ensure that they take care of themselves.

“I think with the knowledge, the knowledge and the resources that they have the support that they have, they better manage themselves. It's always better unless the person is just not interested, there are some patients who are resistant, they still in depression and in denial of everything that's happening. So, anything you tell them will not make any difference to them anything that you advise them on or they don't not come up with solutions themselves, you ask a person, okay, what do you think would be the best solution for this? And they don't have an answer because they just, they still in that bubble of why me. But definitely, what I've seen is that the resources or whatever supports resources they have, assist them with getting better, or dealing with whatever they going through at the time, whether it's pain or side effects, or denial” (Participant 14).

Gallant (2003), is of the view that illness self-management does not occur in a vacuum but rather in a context that includes health care providers, a physical environment which includes housing, and air quality, and social network support. Most participants reported that the support they are receiving helps or encourages them to take good care of themselves and fight the illness that they have. For most respondents being diagnosed with cancer caused them to change their lifestyle especially in terms of diet and exercise. On the contrary, lack of support may result in a patient losing hope and make bad choices that worsens their health condition.

4.4.9 Support Needed and Impact of Lack of Social Support for Cancer Patients

All study participants were asked to state the kind of support they are lacking and the support that they need. All participants mentioned the different types of support that they need but tangible support and emotional support were mentioned the most.

Tangible Support

Some participants expressed their struggle in accessing tangible support especially in terms of finances. One of the participants described his experiences with lacking tangible support such as financial support and housing as a painful and horrible experience. He reported that lack of money has resulted in him eating whatever food he gets even if it affect his illness because he cannot afford to buy the food he is required to eat. He also mentioned that he stays in a very bad environment and he is struggling to get RDP houses because no one in society sees him as a person because of his disability. He appealed to the councilor to get a proper house but nothing has been done. This has affected his illness badly.

“Nothing is lacking now. I am not lacking except the money” (Participant 3).

“If there is any support that comes, I will accept it. I think I have accepted myself as it is now because I know my life has changed, it’s no more like before you know I have accepted but every support that comes my way I will accept it” (Participant 3).

“As a person who got cancer, sometimes I have to separate the food that I’m eating but because I have got no money to pick and choose the food, I’m eating everything that is coming in front of me. So, the doctor try for me because he got me where I am right now. They are trying to support us; I think it’s what I can say thanks about. But it is not enough because at the end of the day I am coming out here after 6 months, I got no house I’m living on a dirty place by the Mjondolo place. So, as a person who got cancer, like me, I think the doctor used to tell me I have to be in a good place, clean place because this disease it can be spread on my body if I’m still on this kind of place where I am staying. So, even if we go by the Councilor and ask for help, they pick their friends and take their friends and give what we call these houses, government houses” (Participant 4).

“Yes RDP houses, so many times I used to apply for it. So, even, I can’t say nothing because I’m disability. When they calling for the vouchers and everything to fill up the forms, I can’t go, so they can’t come to me to so it’s very hard for me...” (Participant 4).

“Financial issues is the main one for me. It is very hard for me to get a job and also keeping a job especially being a person who is uneducated. It is very hard keeping a job because I once got a job as a street cleaner, but it was very hard keeping it because the sun was very hot, and I could not do it because of my condition. It is very hard to

find something I can keep doing, something that is not hard on my health. Maybe it will be better if I can work for myself as a street vendor or something just to get some income” (Participant 9).

Emotional support

Some respondents reported that they are lacking emotional support and if they could get someone who provide them with that kind of support, it would make their cancer journey more bearable. They mentioned that having emotional support will keep them motivated and help them reduce their stress. Lack of emotional support especially when one spends most of their time alone, can be dangerous because it can cause depression. Therefore when one is going through cancer, emotional support is paramount.

“I think to talk to somebody you know, because I am mostly alone but I don’t really have support” (Participant 12).

“I need emotional support, if I can get emotional support. Sometimes I become so emotional because most of the time I’m lonely, yeah most of the times I’m lonely. Sometimes kids will do their own things outside there and I become bored, I’m sitting there. If I’m bored with Facebook, then really really. Sometimes I can’t even sleep because chemo itself, it takes away the sleep. I end up thinking a lot, I wake up stressed, and if I can get the emotional support, I can be fine. Yes, that is why there is a lady here Lindelo, she is working here. Yesterday we were talking trying to give me some positive views about life in general” (Participant 13).

According to CANSA Mukhuhla Care Home worker when a patient lacks social support it makes them feel worse especially when they are not receiving support from the people closest to them. She explained based on her experience of working with cancer patients that:

“What I can tell you, if a patient lacks support be it from families, from friends, even colleagues, they are not taking it well and it makes them to be more sick. And if I need support from my mother and then she is not giving me. There won’t come an outsider and offer me support. Because what I noticed is that the person who is not doing well even not receiving the support is because she is not receiving support from the people, she needs the most. So, she is expecting her mother to give her support and if the mother does not give her support, she won’t accept your support because she thinks the person who can support her better is her mother” (Participant 11).

Based on the research findings, for some respondents lack of support did not seem to matter much but having their healthy life back is what matters the most to them. One participant responded that:

“There is nothing I need other than having a healthy life because if I am healthy, I can work for myself. I am a farmer, I know how to farm, chicken farming. So, I am always hoping that once I get better, I will be able to do something for myself and not be just someone who wait to be given a handout by others. You know as black people we need to have something that you do to take care of yourself, but because of the illness that I have and the chronic diseases that I have, I have life threatening diseases, cancer, diabetes, and BP (Blood Pressure/hypertension). So, I cannot do it all. So, I have taught myself not to be tempted to try and do something that can affect my health. I always pray to God for wisdom, and for me not to worry or stress myself all the time. I have things that worries me a lot, but God always help me to overcome, he know everything because he is my creator” (Participant 10).

However, not all participants felt that they lack support or are in need of any additional support apart from the support that they have. Some participants expressed their satisfaction with the kind of support they are receiving so far. They mentioned that:

“I don’t feel like there is anything that is lacking. I don’t feel like I need any additional support whatsoever” (Participant 2).

“I do not lack any support, but I have not really opened up to the church that I am sick. So, I have not been getting support from the church but when I go to the church it is fine only 2 people know” (Participant 7).

“It is fine we sing we worship everything is okay” (Participant 7).

“I am fine, I am satisfied with what I have right now” (Participant 8).

The researcher asked all participants about what they think those who are trying to provide social support to those fighting cancer should know. They stated various issues which people should take note of when offering support to someone with cancer.

“Cancer is a disease that can come without you knowing. Let me say in short how this disease happened. I did not follow the proper healthy lifestyle unknowingly. I used to eat too much meat, too much oil. I did not know I was causing myself some problems. I

realized I was not leading a healthy life the moment I got diagnosed. It is good that people remain aware and follow healthy lifestyles, it helps prevent some of the disease that might affect you” (Participant 10).

“Have lot of patience with people and understand. You have to empathize with people. If you are providing social support for any person you have to have empathy even though you won’t picture it as person is going through like exactly but you need to have empathy, because what I have noticed is that if you are too formal and you are offering that support as a person....Like with patients, when a patient comes to you our economy is already bad, they are sick, they stopped at work, others are not getting paid because they are not going to work they rely on UIF” (Participant 11).

“I think just to maybe put their mind at ease a bit, just to say maybe you are going to be okay but maybe tell you to be positive because you get negative easily oh I do, I don’t know if everybody is like that. It’s a big thing, anyway the doctor told me I just stared at them, and he came in and sat on my bed and he says Sue you know you got cancer ‘crying’ so I said yes” (Participant 12).

“I think we should go to them, we people who are suffering, like I was saying we should organize these places in our locality whereby we can go and talk about different sickness and cancer is going to be one of them. So, after that we can go and talk about the disease to the people so that the word can be spread” (Participant 13).

“People are different. The people are different. You’ll meet bubbly people, you meet people who are closed off, it’s just I think taking it one day at a time, like really taking it one day at a time and in social work there is person centered, you treat a person as an individual, like never think that oh, you have breast cancer. Had another breast cancer patient she was so bubbly, what’s wrong with you: we are all different. We are all brought up in a different way. We all have different characteristics. And the needs are not the same. May have breast cancer, but our needs will never be the same because it might be affecting me in a different way from you because even our psyche is not the same, even our physical body is not the same, we may have the same cancer, same everything but our bodies not fight the same” (Participant 14).

4.4.10 Lack of Institutional Support

The study respondents expressed their concern regarding lack of support from the government especially in creating more cancer treatment facilities with working equipment, providing

financial support to cancer patients, and proper housing facilities. They also reported about lack of support from hospitals workers. Some participants reported that it even takes longer periods for them to get the treatment that they need. They felt that sometimes the doctors are reluctant especially in public hospitals, they get ill treatment from the nurse practitioners, and sometimes they get scolded even when they see that they are very ill. They stated that the government has failed in terms of supporting people with cancer, and hospitals are failing them as well.

“About 6 years, 5 years I’m going in those hospitals they don’t know what I had, so I think they are not educated too about it until one of the nurses helped and said Hey you better run away from this hospital because they don’t help you, go to King Edward. So, I was supposed to take the money from my pocket, buy the letter from a private doctor to make a letter for me to go to King Edward, but I can’t talk proper English but I am trying sorry” (Participant 4).

“Sometimes you go by the nurses there, she’s angry, maybe she was fighting with her husband at home, you see. You will ask her nicely okay mama this is what I am asking. How she answer you, she answer you like she is in a hurry; you understand? At the end of the day you go there, she is just pointing, and we can’t see, we got eye problem. When you say go there, where? How many corners in this hospital, you understand, it means each day they got no time? I’m not talking bad about them but I’m saying” (Participant 4).

“I am worried you know, when this morning they said no, because I was supposed to come last month then their machines didn’t work. There was one machine at Albert Luthuli, out of 3 only 1 works. So, now I am here now, and the machine is off, and my brain says oh my God I am going to stage 4. You don’t want to wait too long, if you wait too long then it’s not going to get better but they phoned and said I could come in tomorrow” (Participant 12).

All the study participants were asked to state the message they would like to provide to people who have the same illness of cancer. It is important to note that not all participants were cancer patients. Two of the participants were a social worker, and a Care Home Coordinator and caregiver at CANSA Mukhuhla Care Home. The respondents mentioned that when one is going through an illness such as cancer they should have hope and willing to fight the illness. They

also mentioned the importance of research and to refrain from consulting Google and encourage patients to always consult their doctors.

“I think that they should have hope and be willing to fight, and even though you have been told that you have cancer be willing to do more research and get to understand it more. Be active in terms of your health and go for regular check-ups” (Participant 9).

“I will just tell them that, firstly CANSA is there for them. CANSA is an organization that is there for them. Whatever we can offer we will do without hesitation but at the same time I would like to tell them to fight the way they are fighting. Most of them they show positivity through their journey even though there are some who do not accept and who blame whoever, but I have seen people who are so positive” (Participant 11).

“I think, to be hopeful and ask questions, especially to the doctors who are treating them. Those are the people who have all the answers. Ask questions, ask a lot of questions. And diarize a lot of things that you go through. When you diarize a lot of things, you know, when you go to the doctor, you have a question or two about something you experienced, like, if you say, I'm going to ask my doctor, this. By the time he goes to the doctor's office, you will not remember what it is that you wanted to ask. But diarize all the questions, write them down and ask questions. Use all the resources available, but not Google. Google will tell you that you are dying tomorrow...” (Participant 14).

4.5 Conclusion

This chapter has presented a qualitative analysis of the information obtained from in-depth interviews conducted among participants at CANSA Mukhuhla Care Home in eThekweni, South Africa. By answering the research questions, participants were able to provide a detailed description of their lived experiences as cancer patients and the impact of social support through their journey. Social support was found to be very significant when one is going through cancer illness. It was found out that when one is supported they feel that their existence is important, and it gives them hope and courage to keep fighting to get better and get back to their normal self.

Furthermore, this study found that lack of social support such as emotional support, tangible support such as finances, and unemployment was a hindrance in patients' recovery journey. According to the research findings it was found that when one lacks support it also impacts their

illness. People who lack social support struggle to get better and sometimes their illness get worse because they lack resources which can help them recover or control their illness.

Most participants admitted that social support also influences their self-management behavior. The study found that when one is supported they adhere to treatment and try by all means to do activities which helps them get better unlike in situations whereby one lacks support. They tend to not care about taking their medication or do activities that helps them to get better. They quickly give up on themselves.

Participants reported that there is lack of cancer awareness in communities and those who lack knowledge about cancer associate it with witchcraft which result in people suffering from cancer being discriminated in society because of ignorance. Participants expressed their concern with the South African government relaxing when it comes to cancer illness and its failure to support people with cancer mostly financially. Participants also revealed that in public hospitals some health practitioners mistreat them and doctors take longer to diagnose them when they go to hospitals. Therefore, the participants requested that there should be increased cancer awareness campaigns and that the government must also assist and consider cancer departments as well the same way they do HIV/AIDS, and all they need is to be supported.

CHAPTER 5:

DISCUSSION AND CONCLUSION

5.1 Introduction

The aim of this study was to explore the impact of social support among people with cancer through the lenses of individuals who were diagnosed with cancer. The researcher managed to gain insight into the challenges cancer patients face and the impact of social support on these patients through examining the lived experiences of cancer. This chapter will provide a discussion and conclusion on the impact of social support among individuals with cancer in the eThekweni case study. The findings of this study are in line with the buffering hypothesis which stresses that social support plays a crucial role of protecting against the negative effects of stress in the existence of stressful factors.

5.2 Discussion

This study draws on the social support theory whose major contributors were Drennon Gala and Francis Cullen (Kort-Butler, 2017). This theory helps explain the fundamentals of relationships and social support especially when going through difficult times in life. This theory is relevant to the study because social networks are an asset, and they bring benefits to people especially people experiencing health challenges which may alter their normal daily lives. Previous studies support the idea that access to social support is associated with individual health and well-being.

Cancer is a devastating disease that can affect any individual. Based on the study findings, participants expressed that they were devastated, shocked, and filled with fear and disbelief when they received the news of their cancer diagnosis. For most patients, the news came as a shock and was unexpected because they never thought whatever was wrong with them could be cancer, which is what brought in the element of shock when they received the news. According to Cunha (2021), a cancer diagnosis can bring feelings that people are not used to dealing with, and those feelings can be intense. Being diagnosed with cancer can make some people feel like their lives are ending, affecting their journey to recovery. Some participants mentioned that they had the fear that they might die, and this fear mostly stems from personal experiences with the disease through either a family member or someone they know who was diagnosed with cancer. The study findings showed that participants went through some

common stages of grief, including denial, anger, sadness and depression, and acceptance. That is how most of them could come to terms with the fact that they have cancer. They mentioned that they slowly accepted their new reality and adapted and moved forward.

The participants expressed that they delayed seeing doctors for some time, attributing their illness to just a minor illness that could quickly go away. This is an attitude that commonly exists among African people. Hassan et al. (2021) states that Africans primarily seek health care services after noticing the physical manifestations of the illness and when the illness interferes with their daily activities. Some participants waited to seek proper medical care until their condition progressed too far to ignore. Other participants stated that learning about their cancer diagnoses did not scare them because they trusted their religious beliefs that they would be fine. However, Cunha (2021), argues that when a person learns the news of their cancer diagnosis, the shock may range from complete denial to just acting as if nothing is wrong. Further, not only cancer patients are affected by the news of their diagnosis; the news also affects the patients' family members as well. These findings correlate with Schaepe's (2011) study findings that, the news of cancer diagnosis affects a patient and those around them.

The study showed how clear the concept of social support was, among the participants. The accounts revealed that all participants were familiar with the term social support. Participants viewed social support as the support system that a person has, such as support from family, organisations, and churches. This shows that participants were aware of the significance of social networks and the positive role they play in a person's life. According to Helgeson (2003), social support is generally regarded as a wide variety of phenomena that characterise the social environment or the people surrounding individuals in their network. Danish and Khan (2020) state that an increase in social capital increases social support in society.

5.2.1 Sources of Social Support

The social support theory stresses that social networks are a valuable asset; they bring benefits to people. Cohen-Celiin (2018) states that social support is often divided into cognitive domains: perception of support, reciprocity, trust, and structural domains: that is, participation in social activities and support from individuals in the community. The study findings indicated the significance of social capital/social networks and social support when one is going through health challenges. Participants expressed the importance of social support on their cancer journey. Most participants indicated that their support networks provide them with assistance and helped them cope with the disease better and encouraged them. Their support networks

consisted of pastors, church members, family, friends, and neighbours, NGOs dealing with cancer, health professionals, and social media. Many studies have shown that cancer pain has a severe impact on quality of life, many cancer patients suffer from activity limitation, anxiety, helplessness, depression, avoidance behaviours, and physical disability (Hosseini et al., 2016). Therefore, social support is imperative as it promotes healthy well-being and serves as a buffering factor for stress (Christian et al., 2020). The study has also shown the power of social media and its importance in helping connect people who are going through the same predicaments and help them support one another

The study has demonstrated that cancer patients go through a lot because the disease is very aggressive, and even after treatment, the body is devastated because with the side effects of chemotherapy and radiation a person will never be the same again as the treatment weakens the immune system. These most challenging times test existing social relationships/social networks and require new arrangements in this network (Usta, 2012). In these times, social support is crucial. According to the study findings, some participants reported that they had good social support networks. Most participants expressed that they were satisfied with their social support networks who help them with psychosocial issues. However, the study findings also revealed that having low levels of social support can negatively affect a patient's physical, mental, and emotional well-being. A participant reported that he had no support from family or anyone else except for the support they receive at CANSA Mukhuhla Care Home, and from doctors only. His description of the challenges he faced because of lack of support showed that it affected him mentally and emotionally, and he yearned to get the support he needed. Lack of support is perilous for someone, especially with a chronic condition such as cancer, because it makes a patient harbour their feelings (emotions and pain), and they are likely to fall into depression which could affect their recovery.

The study found that social support is needed right from the onset of a cancer diagnosis. This helps a patient cope with the news better than when no support is available. Participants who had support from the time they got diagnosed showed better adherence to treatment and a sense of fighting to get better and have their normal lives back.

5.2.2 Forms of Social Support

Emotional Support

According to the study findings, all patients received emotional support from CANSA Association and some patients received additional emotional support from their families,

friends, health professionals, social media, and the church. Emotional support was found to have a positive impact among patients. This is seen where some patients reported to have strong support from their CANSA, family, pastor, doctor, and people from Facebook groups who they trusted to confide in. Social support theory stresses that emotional support involves trust, listening, and concern (Usta, 2012). CANSA Association also provided patients' and their families with emotional support.

Some respondents noted however that emotional support from their social networks was not always available or sufficient. Emotional support is one of the most needed forms of support when one is going through an illness such as cancer. Studies have shown that when one is going through an illness they are likely to fall into depression because of the nature of the illness (Song et al., 2011 & Lino, 2013). Though these patients had support from their social networks the emotional support element was still missing. This was perhaps due to the fact that these patients were not staying with their closest families, they mostly received support via phone calls which was not sufficient for them. Emotional support can be expressed through attentive listening and non-verbal empathy, and it can also depend on circumstances (Adler & Page, 2008). Two participants mentioned that being alone most of the time and not having someone to talk to and someone with a listening ear most of the time was depressing. Lack of emotional support is associated with greater psychological distress and increased rates of post-traumatic stress disorder (Adler & Page, 2008). Further, a CANSA Mukhuhla Care Home social worker explained that lack of support makes patients feel worse, especially when they do not receive support from people they consider closest to. Lack of emotional support among cancer patients was reported in the study by Mlaba et al. (2021) where participants experienced lack of support from some of their family members.

The study found that most participants perceived a high rate of social support from their friends and families. Families have proven to be the essential support structures for cancer patients. Emotional support was the leading support most patients had, whereas financial support was the least. However, some participants had both emotional support and financial support.

Informational support

Support such as information, advice, and suggestion for problem solving is paramount when one is going through cancer illness. According to Cherry (2020) having this type of support may make some people feel less anxious about the problem they are facing. The study found that informational support was present among some patients and it was linked with a positive

health outcome. One participant reported that her church pastor would come and sometimes call her and provided her with counselling, and friends would send her encouragement messages. Some participants reported that health workers such as doctors, nurses, and dieticians supported them and it gave them strong feeling that they were going to fight the cancer. This shows those who provide treatment services also support patients by encouraging them, informing and educating them on how take care of themselves . The study also found that CANSA provided patients with individual counselling, organised support groups for patients, a space where they could vent and obtain information about cancer disease, and different types of treatments. The organisation also extended this type of support to family and friends of the patients for them to be well informed about the illness. According to a CANSA caregiver both the patients and their loved ones received this type of support because cancer does not only affect a patient but it also affects their social networks especially family members. Therefore, it is important that those close to a patient also get support such as counselling, to learn more information about the illness, the dos and don'ts, how it affects a patient, and how to care for and support someone with cancer.

Tangible Support

Tangible is a type of support that is essential when someone has immediate needs that must be addressed. In most cases an individual's social network provides this type of support. Instrumental support can be provided in the form of money, labour, kind, and other physical needs (Cherry, 2020). Family members and church members of the patients were found to be the providers of instrumental support among some respondents. These patients' reported that they received financial support, and assistance with household chores from their close support network, mostly family and church. One participant stated that he received financial support from church members and some would buy him machines to test sugar and blood pressure. Another respondent mentioned that she received financial assistance from her children especially money for fuel to travel to doctors' appointments, and others had families to lean on for house chores. It was observed from the findings that instrumental received by participants' related to less financial burden and reduced stress.

Instrumental support was noticed to be lacking among most respondents however . According to the study findings, most patients perceived low levels of instrumental support especially financial support. It was discovered from the findings that low levels of financial support had a negative impact on patients. Participants mentioned that they experienced high levels of stress due to financial constraints because most of them were breadwinners of their families and they

could not afford to provide for them anymore due to the illness. They struggled to get to their appointments on time, they could not afford to eat healthy, and to go to private hospitals where they could receive better treatments on time that in public hospitals.

5.2.3 Importance of Social Support

It was identified from the findings that participants with close and caring relationships were hopeful that they would fight cancer and be well again. Participants stated that social support helped them find inner peace and have peace of mind because if one problem is solved or taken care of, it eases the burden and helps them conquer their negative feelings. One participant mentioned that her support system cheered her up, she had not experienced any form of discrimination, and sometimes people do not believe she has cancer. Another participant expressed that support groups she attended on social media, and the support that she gets from her family and doctor have helped her realise that she is not alone in the cancer battle and that there are so many people going through the same fight. The support she gets also helps her deal with her internal tensions. Feeney and Collins (2015:1) postulate that “close and caring relationships are undeniably linked to health and well-being at all stages in lifespan.”

5.2.4 Patient Challenges

Financial Constraints

Financial constraints and unemployment were some of the main challenges faced by participants. Some participants mentioned that they had lost their ability to work normal jobs because of cancer, and it became very challenging for them to get employment while they have this illness. They mentioned that these challenges have also impacted their families. Participants expressed that it is a struggle for them to ensure that their families' immediate needs are taken care of. They struggle to eat, and sometimes they miss their doctors' appointments because of lack of money. One participant mentioned that he has a specific diet to follow as a cancer patient, but he cannot afford it. Therefore, he eats the food that is available to him. Some participants mentioned that lack of finances and unemployment had put them into debt that they could not afford to pay, which stressed them and affected their health further. Studies have shown that financial support is vital for increasing well-being because the cost of treatment and other needs for a cancer patient are expensive, and lack of finances brings massive burden on patients and their families. Patients reported experiencing higher levels of stress due to not receiving this desired support.

Treatment-Related Challenges

Despite having support from their social networks (families, friends, church members, healthy professionals, and neighbours) participants identified several challenges which are critically important to address, especially when one is going through cancer illness. Participants identified delays in diagnosis and treatment in public hospitals as a challenge. These findings are consistent with other existing South African research findings that there are long waiting lists for cancer treatments in South African hospitals, which cancer activists have declared a crisis. When a cancer diagnosis is delayed, the patient's survival rate also decreases because the chances are high that the time one is treated, the cancer could be at an advanced stage which affects the treatment process. The more the cancer treatment is delayed, the more cancer spreads. That is why cancer deaths remain high in South Africa and Sub-Saharan Africa. According to Pumpalova et al. (2022), delays in cancer diagnosis and treatment, and high cancer mortality rates in South Africa and the entire African region are due to socio-economic, cultural, and health system barriers.

It was identified from the study findings that several factors were associated with cancer treatment delays among the participants. Distance was the main factor for most participants. In South Africa, cancer treatment centres are scarce. Patients travel long distances to get treatment. Participants pleaded if the South African government could make cancer treatment accessible in all corners of the country. The study findings have shown that cancer treatment is non-existent in rural communities and small towns, and one has to travel to the city to find better treatment. According to Mukwevho (2022) patients who reside in smaller towns and rural areas have difficulties accessing cancer treatments, and some are forced to wait for months to receive the help they need. Most participants reported that they had to travel long distances to get the treatment in eThekweni. Some had to travel from province to province because of the country's scarcity of cancer treatment centres. Traveling back and forth for doctor's appointments can be critical for someone with cancer because the body is already weak with the illness itself, and the treatment makes it even worse. Cancer treatments are costly, and nowadays, for one to receive the best care they need, their bank balance has the final say. Many of the study participants received their treatments in public hospitals. They could not afford to go to private hospitals because it could cost them an arm and a leg. Those receiving treatment in private hospitals complained about how expensive it is and that they got financial assistance from their social networks; otherwise they could not afford it alone.

5.2.5 Lack of Institutional Support

The study findings revealed that; there is a lack of institutional support. Participants expressed the inadequate support from the government in creating sustainable cancer treatment facilities, providing financial support to cancer patients, and making sure that they have proper housing. Participants also raised issues that hospital staff mistreats cancer patients, and in public hospitals, health workers do not show empathy for cancer patients. Participants expressed that much attention is given to diseases like HIV/AIDS and other diseases which could be diverting focus from cancer. Studies have shown that the lack of institutional support in diseases like cancer is the reason why there is high mortality from cancer in Sub-Saharan Africa.

5.2.5 Lack of Cancer Awareness

The study findings showed that participants related strongly to the issue of lack of cancer awareness in communities and experiences of stigma in society. Previous studies have reflected the same trend of low awareness of cancer, mostly in rural communities and small towns (Mukwevho, 2022). Most participants admitted that they had no idea of what cancer was before they were diagnosed, while others claimed they had heard of cancer before but did not have an understanding of what it is. They reported that there is lack of cancer awareness campaigns even in communities they come from. People do not know what cancer is because they have not heard about it, and even in healthcare facilities there is a lack of education about cancer. Hence, awareness campaigns are essential since they raise critical consciousness among people.

5.2.6 Cancer-Related Stigma

Mandizadza and Moyo (2021) state that health related stigma was found to contribute to issues such as psychological and social morbidity, increasing stress in patients, undermines emotional well-being, and undermining of personal identity. It was clear from the findings that cancer related-stigma is an important aspect that needs to be addressed. Participants stated that stigma still exists in society against people with cancer. This stigma was found to mainly stem from ignorance among community members. Studies have also shown that stigma against people with cancer is presumably driven by fear of the illness itself, and the fear that it might happen to anyone (Mandizadza and Moyo, 2021). There is the perception that cancer is contagious, and this assumption will continue to exist as long as awareness campaigns remain limited. One participant reported that people would rather stay away from someone with cancer than be close to them. The study found that stigma was associated with lower self-esteem and depression. Cancer stigmas instigate challenges to cancer control and can have a silencing

effect whereby it negatively affects efforts to increase cancer awareness (Daher, 2012). Lack of cancer awareness and ignorance hinder social support delivery for people with cancer. There is a need for increased cancer awareness programs to learn more about cancer, be aware of the disease and stop the negative attitudes displayed by society toward people with cancer and the illness itself. Neighbourhoods', communities, and organisations are believed to play a role in the origins of stigma because stigma is often based on the norms of a social unit (Kido et al., 2013). South Africa has a well-developed economy and has the capacity to improve its health policies and programs to prioritise, enhance cancer departments, and reach communities to educate them.

5.2.7 Impact of Social Support on Patient Self-Management Behaviour

The study found that social support is positively associated with illness self-management behaviour among cancer patients. Participants shared the same thought that having social support motivated them to take care of themselves, manage their illness better, and hope for a brighter tomorrow. Some participants reported that they engage in physical exercise, attend physiotherapy, maintain a good diet, read newspapers, books, and magazines for informational purposes and keep their mind busy so that they do not consume negative energy. According to Vassilev et al. (2014) social network support contributes to long-term condition management because it provides access to wider resources that potentially improve health outcomes for cancer patients. The study found that activities undertaken by participants helped them reduce stress. It was difficult though to link self-management behaviour with physical health and determine whether the cancer was getting better because all patients were still undergoing treatment. Therefore it was too early to tell.

According to the social workers in the study, it is a patient's responsibility to ensure that they take their medication on time as prescribed by the doctor and make sure that they do small exercises to keep their bodies fit. The study found that sometimes patients do not understand how to use their medication, primarily pain medication. According to CANSA social worker patients are advised to attend support groups where they talk about cancer treatment with other patients and survivors, and how to be responsible. It was discovered from the findings that equipping cancer patients with knowledge about the illness is imperative as it helps them practice good self-management behaviour. However, some patients are resistant to any form of support they receive. According to Cunha (2021), a cancer patient may be resistant to support due to denial, and might still be in depression. When a patient is resistant to support anything you tell them will not make any difference because they struggle to accept their illness.

5.3 Conclusion

The study has reported the overall findings from the interviews and analysed them to gain a deeper understanding of perceptions of social support among individuals with cancer in eThekweni, South Africa. The study has shown that social support is crucial in societies where there is health care inequities and poor public health services, mostly the low-income groups. It acts as a stress buffer. The study has mostly shown the significance of social support in health promotion in that social support is important when one is going through an illness such as cancer. Cancer brings about psychological, physical, social, and economic burdens for patients and their loved ones. Supportive social networks are the major sources of social support for cancer patients, which contribute to a reduction of the burden a patient might have in the light of a cancer diagnosis, and the treatment and coping process. The study showed that participants felt the greatest need for social support right from the time of their cancer diagnosis and through their entire journey. However, lack of satisfactory support was linked with increased stress and negative coping skills.

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APPENDIX A: GATEKEEPERS LETTER



Toll-Free 0800 22 66 22
www.cansa.org.za

HEAD OFFICE
Bedfordview
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26 Concorde Road West Address
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13 April 2021

Noliwe Gwiza
College of Humanities
(School of Built Environment and Development Studies)
University of KwaZulu Natal

Email to: noliegwiz@gmail.com
mottiar@ukzn.ac.za

Dear Noliwe

This letter serves to confirm that CANSA will help support your study, entitled *Exploring the perceptions of social support among individuals with cancer in eThekweni, South Africa*, as a Master of Development Studies student, by allowing you to recruit people living with cancer that are being supported by CANSA.

The aim of the study to seek to explore the role of social support among people with cancer in eThekweni and the objectives are noted:

- To explore perceptions of what social support is in relation to their condition (to people with cancer)
- To explore the experiences of social support received by people with cancer.
- To explore the challenges experienced by people living with cancer.
- To explore how social support may influence self-management behaviours of those living with cancer.

CANSA permits you to recruit participants from our Care Home in eThekweni contingent on the following conditions:

- receipt of Ethical approval for the study
- an outline of strict COVID transmission prevention related protocols
- that the requirements of the POPI Act are adhered to
- that CANSA receives the report of the study at the end

We look forward to your cooperation and the successful outcome of this research.

Yours sincerely


Preethi Mistri
Head of Research

Imagine a world without cancer

Non-Executive Directors: V Memani-Sadile (Chairperson), Prof. P. Arbutnot (Vice-Chairperson),
Dr M Mendow, Dr R Mngqibisa, J Palmer, Judge D Pillay, BA Mazarura
Executive Directors: HC Joubert (CEO), P Mukhebi (CIO)

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APPENDIX B: ETHICAL CLEARANCE



21 July 2021

Miss Noliwe Vimbai Gwiza (215081751)
School Of Built Env & Dev Stud
Howard College

Dear Miss Gwiza,

Protocol reference number: HSSREC/00002947/2021

Project title: Exploring the perceptions of social support among individuals with cancer in eThekweni, South Africa.
Degree: Masters

Approval Notification – Full Committee Reviewed Protocol

This letter serves to notify you that your response received on 15 July 2021 to our letter of 07 July 2021 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

This approval is valid for one year until 21 July 2022

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours faithfully

.....
Professor Dipane Hlalele (Chair)

/dd

Humanities & Social Sciences Research Ethics Committee
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Tel: +27 31 260 8350 / 4557 / 3587
Website: <http://research.ukzn.ac.za/Research-Ethics/>

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

INSPIRING GREATNESS

APPENDIX C: INFORMED CONSENT FORM

UKZN HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE (HSSREC)

APPLICATION FOR ETHICS APPROVAL

For research with human participants

INFORMED CONSENT RESOURCE TEMPLATE

Note to researchers: Notwithstanding the need for scientific and legal accuracy, every effort should be made to produce a consent document that is as linguistically clear and simple as possible, without omitting important details as outlined below. Certified translated versions will be required once the original version is approved.

There are specific circumstances where witnessed verbal consent might be acceptable, and circumstances where individual informed consent may be waived by HSSREC.

Information Sheet and Consent to Participate in Research

Date:

Greeting: Good day

My name is Noliwe Vimbai Gwiza from University of KwaZulu Natal, Howard College; Student Number 215081751; Cellphone number 067 1262 987, email addresses 215081751@stu.ukzn.ac.za or noliegwiz@gmail.com

You are being invited to consider participating in a study that involves research titled: **Exploring perceptions of social support among individuals with cancer in eThekweni, South Africa**. The aim and purpose of this research is to **explore the role of social support among people with cancer in eThekweni**. The study is expected to enroll 10 participants provided by CANSA Durban. It will involve the following procedures an interview which takes about 30 to 45 minutes per participant. The duration of your participation if you choose to enroll and remain in the study is expected to be one day as there will be only one interview per each participant. The study is funded by (provide details if relevant) N/A.

The study may involve the following risks and/or discomforts as it involves the sharing of lived experiences and the journey of people who are living with cancer/ cancer survivors. We hope that the study will create the following benefits of giving people the opportunity to understand the challenges one can face when surviving with chronic illness, and the importance of having social support when going through that difficult time. The study will also help educate families, friends, and communities on how to live with affected people and support one another, and to raise cancer awareness. The study will contribute to existing literature and shedding more light in this area of study.

The study could potentially open feelings and emotions of the participant's challenging experiences which can be hard for them to deal with. In these circumstances they may maybe referred to CANSA Social Workers for support and counselling.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number **HSSREC/00002947/2020**).

In the event of any problems or concerns/questions you may contact the researcher at **067 126 2987** or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Participation in this research is voluntary and participants may withdraw participation at any point. In the event of refusal/withdrawal of participation the participants will not incur penalty or loss of treatment or other benefit to which they are normally entitled.

The research is for academic purposes and there is no compensation for participation. However, final report will be provided per request.

Data will be stored on a password protected computer which the supervisor will have access to. Data will be deleted after 5 years.

CONSENT (Edit as required)

I (Name) have been informed about the study entitled, **Exploring perceptions of social support among individuals with cancer in eThekweni, South Africa** by Noliwe Vimbai Gwiza.

I understand the purpose and procedures of the study (add these again if appropriate).

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at **067 126 2987**.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview

YES / NO

Signature of Participant

Date

Signature of Witness

Date

(Where applicable)

Signature of Translator

Date

(Where applicable)

APPENDIX D: INTERVIEW SCHEDULE

When were you diagnosed?

How did you feel when you received the news?

In your own view, what do you think social support is?

Did you have a support network the time you were diagnosed? If not, how did you deal with it or find support?

What kinds of social support are available to you?

How has this helped you?

What are some of your main challenges?

What kinds of support do you still need/ what do you think is lacking?

What do you do to manage your illness?

How does lack of social support you described earlier impact on:

- a. illness work,*
- b. everyday work,*
- c. emotional work and*
- d. overall health promotion*

What do you think those who are trying to provide social support to those fighting cancer should know?

What message would you like to provide to people who are going through the same fight?

What message would you like to give to the community?

