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**Experiences of Patients with Cancer regarding
Decentralization of Oncology Services at a selected Tertiary
Hospital in the Eastern Cape**



By

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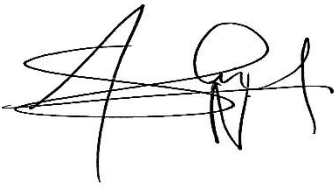
**A mini dissertation submitted as partial fulfilment of the requirements for
Master's in Public Health (ASELPH)
In the Faculty of Health Sciences
In the Department of Public Health, The University of Fort Hare**

Supervisor: Dr N.T. Nkutu

DECLARATION

I, Dr Lumkile Wilmot Jojo, declare that the study “**Experiences of Patients with Cancer regarding Decentralization of Oncology Services at a selected Tertiary Hospital in the Eastern Cape**” in submission for the degree of Master of Public Health at the Fort Hare University is my own work. All the sources used in the study were give due acknowledgements by means of complete reference list. I further declare that this work has not been submitted to any university before.

Name: Lumkile Wilmot Jojo



Signature.....

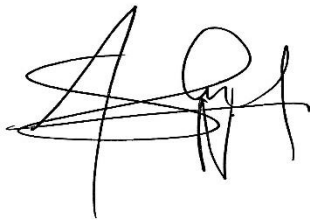
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DECLARATION ON PLAGIARISM

I, Dr Lumkile Wilmot Jojo, student number 201920210, declare that contents of this document are my own work. Where somebody's works has been used, appropriate references have been given.

Name: Lumkile Wilmot Jojo



Signature.....

Date: 05 September 2021



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CERTIFICATION

This mini dissertation entitled “**Experiences of Patients Diagnosed with Cancer regarding the Decentralization of Oncology Services at a Tertiary Hospital in the Eastern Cape**” meets the guidelines outlining the award of the postgraduate degree, **MASTER OF PUBLIC HEALTH**, at the Fort Hare University and is approved for contribution to scientific knowledge and literary presentation.

SUPERVISOR ...Dr....Nonyaniso Trustina Nkutu.....



SIGNATURE:

DATE : 10th October 2021



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DEDICATION

I dedicate this study to my late mother Ntomb'fikile “MaMadiba” Jojo. You may be gone but not forgotten. How I wish you were here to reap the fruits of your hard work. You showed character when you rose to occasion after the passing of our father, the love of your life, Sandile Samson Jojo. I will never forget the day you called me and convinced me to go to medical school. The conversation we had changed my life for better. I know how you believed in me. You saw potential in me when the world had written me off. I will forever love you dear mama.

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ABSTRACT

Background: Cancer burden is a global public health concern. It is associated with high morbidities and mortalities worldwide. Over the past decade, there has been a constant increase in the incidence of cancer cases affecting mostly low-income countries and middle-income countries. South Africa as a middle-income country is also affected by this cancer rise. The limited access to oncology services contributed to the late presentation and late diagnosis. In the Eastern Cape, oncology services were previously offered in Port Elizabeth and East London only. Oncology unit was recently opened in Mthatha to decentralize oncology services in the province.

The **purpose** of the study was to explore the experiences of patients with cancer regarding decentralization of oncology services at a public tertiary hospital in the Eastern Cape province of South Africa.

Objectives were to describe experiences of patients with cancer regarding decentralization of oncology services at a public tertiary hospital in the Eastern Cape, and to describe the quality of oncology services provided by a public tertiary hospital in the Eastern Cape.

Methods: a qualitative research approach with a descriptive, explorative, and contextual design was undertaken in this study, to get the perspective of the oncology healthcare service recipients on the decentralization of oncology services at a public tertiary hospital. An interview guide was used to get experiences of the cancer patients attending oncology clinic. Interviews were conducted to 19 participants on a one-to-one basis. With ethical consideration, all COVID-19 protocols were observed. All interviews were transcribed carefully against their audio-recordings. Field notes were also taken by the researcher on what was heard, observed, thought and experienced during the interview process. The concept of trustworthiness was used to ensure rigour throughout this study. Data was analysed by means of thematic analysis. Data was organized into themes using the Tesch's approach to open coding in qualitative research.

Results: seven themes emerged: 1) experience related to a high level of satisfaction with services provided and desired expectations, 2) waiting time, 3) availability of human and

material resources, 4) attitude of health care workers, 5) appropriate treatment and care, 6) access to services, and 7) need for improved infrastructural facilities

Many patients had positive experiences about decentralization of oncology services in the province. Most patients were happy about travelling short distances, a smaller number of days, using less money and the time it takes to see a doctor. They also expressed their satisfaction on the quality of oncology services rendered in the unit. The waiting times were acceptable, medicines available and staff had positive attitudes towards the patients. The study revealed that, there were complaints about infrastructure, poor hospital record keeping, and lack of resources.

The themes which emanated from the recordings of the study showed that patients with cancer, attending oncology clinic at a public tertiary hospital had positive experiences in this decentralized oncology unit. The services rendered at the facility were of acceptable quality. Staff had positive attitude towards their patients. All patients were seen by the doctors within acceptable waiting time, and they all got their prescribed medication. Access to services was much improved in terms of distance, number of days travelled by patients to access the service and time taken to see the doctor for appointments.

Conclusion: The hospital must improve its infrastructure, record keeping, security, and expand the services. Put more focus on cancer awareness programs.

Key words: Experiences, decentralization, oncology services, quality, distance, access

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CHAPTER 1

1.1 background

Cancer burden is a global public health concern. Worldwide, the estimated incidence of cancer is around 14 million new cases per year and is expected to expand to 22 million annually within the next 20 years (McGuire, 2016). Cancer deaths are also expected to rise at the same time (Ferlay, Colombet, Soerjomataram, Mathers, Parkin, Piñeros, Znaor, & Bray, 2019; McGuire, 2016). It is associated with high morbidities and mortalities. The disadvantaged and minority population suffers worse outcomes compared with white people from Western societies (Jemal & Torre, 2018; Wild, 2019). It is estimated that by the year 2030, more than 70% of the global cancer burden will be in low- including middle-income countries such as South Africa (Lince-Deroche, Rayne, van Rensburg, Benn, Masuku, & Holele, 2017; World Health Organization, 2020). Without significant interventions in screening and treatment efforts and substantial advances to make cancer services more accessible, the burden of cancer morbidity and mortality is more likely to increase (Lince-Deroche et al., 2017). The staging of cancer and treatment options play a crucial role in cancer treatment outcomes (Smith, Keegan, Hamilton, Lynch, Wu, Schwartz, Kato, Cress, Harlan, & Group, 2019).

Cancer care services are usually costly and centralized, making it difficult for poorly resourced settings to achieve the best possible treatment outcomes. South Africa has embraced a process of decentralization in the rearrangement of health care and oncology services (Hendricks, Buch, Seekoe, Bossert, & Roberts, 2014; Lateef, 2011). Decentralization is meant to bring services closer to the users, thereby making services more accessible to the underprivileged communities. However, decentralization has its challenges, and if dealing with those challenges is not effective, managed clients might not reap the full benefits of decentralized healthcare.

Oncology services are offered in three centers in the Eastern Cape. These services are offered in Livingston Hospital in Port Elizabeth, Frere Hospital in East London, and at a public tertiary hospital in Mthatha. Livingston Hospital and Frere Hospital provide both radiotherapy and chemotherapy whereas; the selected public tertiary hospital only offers chemotherapy. The Department of Health in the Eastern Cape Province entered into a partnership with private companies providing oncology services (Public-Private Partnership). These companies are the Cancer Association of South Africa (CANSA) and Cancer care. They work with centers in Port Elizabeth and East London. The recent opening of the oncology unit in Mthatha was part of the decentralization of oncology services in the Eastern Cape Province (Health e-News, 2017).

There has been a need for decentralization of oncology services in the Eastern Cape, more especially the eastern region (former Transkei). People would travel for a week to access oncology services from as far as Lusikisiki to Frere Hospital in East London. The first day they would sleepover in their local hospital. The following morning, they would be transferred to a public tertiary hospital in Mthatha by the patient transport vehicle. In Mthatha, they would sleep on the chairs till the next morning reference. Then, they would be transported to Frere Hospital in East London where they would be seen by oncologists. Sometimes these patients are not seen on the same day because Frere Hospital has its patients, and it has only one laboratory. After they are seen by the oncologist, they would take three days to get back home (Health e-News, 2017).

The opening of the oncology unit at a public tertiary hospital in Mthatha reduced the number of patients going to Frere Hospital for treatment and offered hope to cancer patients. All patients who need chemotherapy are seen in Mthatha, and only those that need radiotherapy are referred to Frere Hospital. The oncology unit at this public tertiary hospital received R46 million from an international donor (Bristol-Myers Squibb Foundation). At least R31 millions of this donation was allocated for hospital-based clinical services and the remaining R15 millions for community-based programs (Health e-News, 2017). At this public tertiary hospital there is only one oncologist who is the head of the oncology department and four medical officers in the department. Therefore, this has prompted the researcher to conduct this study. This study sought to explore the experiences of patients in a decentralized oncology center.

Low-income and mid-income countries are involved in an ongoing attempt to decentralized oncology services. A study conducted in Rwanda in its development of a decentralized national cancer program by designing an integrated, comprehensive framework of care, building local human resource capacity through partnerships, and delivering equitable, rights-based care from 2011. Oncology services were successfully decentralized (Stulac, Binagwaho, Tapela, Wagner, Muhimpundu, Ngabo, Nsanzimana, Kayonde, Bigirimana, & Lessard, 2015).

In another study conducted in Gauteng found that decentralization of colposcopy services to a primary care facility could reduce the time to colposcopy and decrease the workload of tertiary hospitals (Maimela, Nene, Mvundla, Sawry, Smith, Rees, Kachingwe, & Chersich, 2019). The study concluded that decentralization did not compromise the quality of services and that this model could be extended to similar settings in South Africa and elsewhere (Maimela, Nene, Mvundla, Sawry, Smith, Rees, Kachingwe, & Chersich, 2019).



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1.2 Problem statement

Over the past decade, there has been a constant increase in the incidence of cancer cases affecting mostly middle- income and low-income countries. With the high numbers of patients that come to the hospital it has been found that clients present late when cancerous cells have spread to other systems in the body (Mwaka, Orach, Were, Lyratzopoulos, Wabinga, & Roland, 2016). Cancerous cell can spread from the primary tumor via bloodstream or lymphatic system to another organ to form secondary tumors. This process is called metastasis. Amongst these patients, it has been identified that women are the most affected when they also do not know the early signs and symptoms of cancer (Berraho, Obtel, Bendahhou, Zidouh, Errihani, Benider, & Nejari, 2012). The diagnosis of cancer and treatment poses a major public health challenge as clients are frightened of the dreadfulness of the disease and, thus, decide to buy over-counter medicines to relieve symptoms instead of seeking medical opinion immediately. Lack of

knowledge regarding the early signs of cancer and late presentation to the health facility creates complexity in the treatment outcomes once clients are diagnosed with cancer (Dey, 2014). Researchers submit contributory factors to the late presentation include among others, socio-economic factors, cultural factors and beliefs, fear of diagnosis and cancer treatment, belief in prayer houses and traditional treatment (Ibrahim & Oludara, 2012). According to Awofeso, Roberts, Salako, Balogun, & Okediji, (2018), amongst the stated contributory factors there are others like lack of advanced technology for diagnosis and treatment

Furthermore, there is also shortage of oncology services to rural communities especially in the Eastern Cape Province which is the area of concern for the researcher. The limited access to oncology services might be contributory to the late presentation and late diagnosis. Because of the rising numbers of cancer patients in South Africa, there has been a need to revitalize oncology services in the Country. The vast rural communities of the Eastern Cape Province are more affected than the urban communities in as far as the shortage of oncology services are concerned. The Eastern Cape Province with a population of about 6,562 million, is hard hit with limited or no access to oncology services (Frere Hospital Cancer Registry Report October 2017). To mitigate the late cancer diagnosis in the vast Eastern Cape, a new oncology unit was recently opened in the OR Tambo District in Mthatha to decentralize oncology services in the province. Previously, the oncology services were offered in East London and Port Elizabeth, in the Buffalo City Metropolitan Municipality and Nelson Mandela Bay Metropolitan Municipality, respectively. Residents from the eastern region of the province would travel long distances for almost three days to access oncology services. The long-distance is possibly strenuous to the patients and their relatives, evidenced by some patients missing their review dates. It was in 2017 when a functional oncology unit was opened at a public tertiary hospital in OR Tambo District Municipality in the Mthatha region. Even though patients still travel to Frere Hospital in East London for radiation therapy, all those patients for chemotherapy are seen and treated at this public tertiary hospital (Health e-News, 2017). Since the opening of the new oncology unit, it would be interesting to understand how the oncology patients view the unit and the services they receive. No studies have

been conducted to that end. This has prompted the researcher to explore the experiences of patients attending the oncology clinic in Mthatha now that the new oncology unit is opened closer to them.

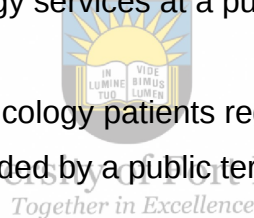
1.3 Aim of the study

The aim of the study was to explore the experiences of patients with cancer regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape province of South Africa.

1.4 Specific objectives of the study

The study objectives were

- To describe experiences of patients diagnosed with cancer regarding decentralization of oncology services at a public tertiary hospital in the Eastern Cape.
- To explore the views of oncology patients regarding decentralization (the quality) of oncology services provided by a public tertiary hospital in the Eastern Cape.



1.5 Research Questions

- What are the experiences of patients diagnosed with cancer regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape?
- What are the views (opinions) of oncology patients regarding decentralization of oncology services provided by a public tertiary hospital in the Eastern Cape?

1.6 Significance of the Study

The study would inform health professionals regarding the experiences of clients with cancer at a selected tertiary hospital in the Eastern Cape. This would assist the policy makers of the Department of Health in the district and province to develop client-centered approaches in the management of cancer, by putting the patients in the center. This study would also contribute to the body of knowledge (research) within the Department of Health locally, nationally and worldwide.

1.7 Delimitations of the Study

The study was conducted at the oncology Unit of a public tertiary Hospital. It was focusing on experiences of patients with cancer that are receiving treatment in the unit.

1.8 Limitations of the study

The study was conducted in one hospital only and among active oncology care service recipients. However, the finding of this study could be used in similar setting somewhere else.

1.9 Operational definitions

Cancer: is the uncontrolled growth of abnormal cells anywhere in a body (Kashyap, Tiwari, Arya, & Saxena, 2019).

Cancer patients: In this study, cancer patients mean all the patients that have been diagnosed with malignant tumors irrespective of site and are treated at a selected public tertiary hospital.

Oncology: is the study or science dealing with the physical, chemical, and biologic properties and features of neoplasms, including causation, pathogenesis and treatment (Farlex Partner Medical Dictionary, 2012).

Oncology services: Oncology services will include all clinical services offered to cancer patients for the management of cancer. In this study Oncology services mean all the treatment given to cancer patients in the unit.

Decentralization: health systems decentralization involves moving decision making away from centralized control and closer to the users of health services (WHO, 2020). Decentralization: in this study refers to the transfer of oncology services from Frere Hospital to the selected public tertiary hospital.

Experience: an event or activity that has an effect on you (Oxford English Dictionary, 2019). In this study, experiences mean the general treatment of patients by the institution.

Quality: how good something is in relation to others of the same kind (Oxford English Dictionary, 2019). Quality care is to be effective, safe, centered on the patient's needs and given timely (WHO, 2010). In this study quality of services refers to comprehensive treatment given to oncology patients, which includes staff attitude, waiting time and availability of medicines.

Distance: length of space between one point and another (Oxford English Dictionary, 2019). In this study, distance means length of space travelled by patients in order to access oncology services. From home to the selected public tertiary hospital and back home.

Access: the right or opportunity of reaching or using something (Oxford English Dictionary, 2019). According to Batho Pele principles, access means bringing services to the people especially to the previously disadvantaged communities and people with special needs. People should get services within short distance, speaking their own language and good staff attitude.



1.10 Research methodology and design

A qualitative approach was selected for this study in order to describe and explore the experiences of patients diagnosed with cancer regarding the decentralization of oncology services at a tertiary hospital in the Eastern Cape Province of South Africa (Brink, van der Walt & van Rensburg, 2012). This approach was appropriate for this study because it allowed the researcher to get a deeper understanding of the experiences and perceptions that cancer patients have about the decentralized oncology services at Nelson Mandela Academic Hospital.

1.11 Design

A qualitative descriptive explorative and contextual design was employed in this research study. This design was relevant to explore and describe the experiences of patients diagnosed with cancer regarding the decentralization of oncology services at a tertiary hospital in the Eastern Cape province of South Africa. The design will be explained in detail in chapter 3.

1.12. Research setting

The research was conducted at the oncology unit of public tertiary hospital, in OR Tambo Municipality of the Eastern Cape of South Africa. This public tertiary hospital is located in Mthatha.

1.13 Study population

The population consisted of oncology patients from 35-85 years of age from OR Tambo District Municipality, which sets boundaries on those participating in the study (Brink, van der Walt & van Rensburg, 2012).

1.13.1 Target population

The target population was black women and men between the ages of 35 to 85 years.

1.14 Study sampling

A non-probability purposive sampling method was used to select the participants in this research study. This sample was used in the individual interview discussions.

- **Inclusion criteria**

The sample included cancer patients who were managed at this public tertiary hospital, both male and female patients diagnosed with cancer, from the ages of 35 years to 85 years old. Only clinically stable patients were included.

- **Exclusion criteria**

The oncology patients receiving care from private providers and those who were receiving treatment from other public hospitals were excluded. Extremely ill patients and those who were not clinically stable were excluded as well.

1.15. Data collection

Data were collected through semi-structured, one-on-one interviews. An interview guide with open-ended questions was developed as a research instrument. The benefit of this process was that people could voice their opinions freely without being uncomfortable (Brink, van der Walt & van Rensburg, 2012).

An interview schedule was designed with questions that were aimed at exploring and describing the experiences and perceptions of oncology patients regarding the decentralization of oncology services. This schedule also enabled the researcher to explore how to probe by using follow-up questions (Brink, van der Walt & van Rensburg, 2012). A voice recorder was used with the permission of the participants to record all the discussions for transcription until saturation was reached. Because the common means of communication used by adults is through the verbal rather than the written medium, the interview process was an ideal tool to gather data. All interviews were conducted at convenient times for the participants and did not obstruct or interfere with any work obligations of the participants (Brink, van der Walt & Van Rensburg, 2012). Data collection will be explained in detail in chapter 3.

1.16. Data Analysis

The results of interviews were discussed and grouped into themes to identify specific areas. In this study, the data analysis was done by interpreting handwritten documentation and the voice recorded interviews. The recorded data was transcribed verbatim into text. An independent coder who is also a researcher was used to identify various themes. These themes were listed and populated to get a good understanding of the phenomenon. Tesch's eight steps approach was used to guide the data analysis process (as stated by Creswell, 2014), namely:

- Get a sense of the whole. Read all the transcripts and handwritten data carefully.
- Choose one interview and examine it once more. Ask, "What is this about?" Write the findings in the margin of the document.
- Compile a list all the topics. Compare and group similar topics together and arrange them in major topics, unique topics and leftovers.
- Abbreviate these topics as codes and write the codes next to the appropriate segments of the text.
- Check if fresh themes have developed.
- Put the codes in alphabetical order to ensure that no duplication occurs.

- Convert topics into descriptive categories. Use clustering of similar topics to try to reduce categories.
- Record existing data if necessary.

1.17 Trustworthiness

Ensuring accuracy throughout the process of collecting data and the correctness of the results requires the presence of elements such as credibility, dependability, transferability and confirmability. Lincoln and Guba's model were used to promote trustworthiness, as cited by Polit and Beck (2017).

1.17.1 Credibility

A voice recorder was used during the interviews to record all the discussions for quality and security purposes, thus ensuring the truth of the data (Brink, van der Walt & van Rensburg, 2012).

1.17.2 Dependability

The researcher used an audio recorder, and all handwritten documentation of the discussions was kept to ensure the existence of evidence, which could be used if the study were to be repeated (Brink, van der Walt & van Rensburg, 2012). Interviews continued until new participants gave no new information, meaning that saturation was reached (Brink, van der Walt & van Rensburg, 2012).

1.17.3 Confirmability

The researcher endeavored to achieve confirmability using a data audit measure to make sure of the impartiality of the results.

1.17.4 Transferability

In this study, transferability was accomplished by continuing with the interview process until saturation of data had occurred (Brink, van der Walt & van Rensburg, 2012). These concepts will be discussed in detail in chapter 3.

1.18 Ethical considerations

Ethical clearance was obtained from the University of Fort Hare Ethics Review Committee (Ref # 2021=03=07=JojoL). Permission to conduct the study was obtained from the Eastern Cape Department of Health (EC_202103_007) and from the management of a selected public tertiary hospital in OR Tambo District Municipality in the Mthatha region.

1.18.1 Informed consent

Each participant was requested to sign an informed consent form before participating in the study. The ethical principles of voluntary participation and protecting the participants from harm were formalized in the informed consent. Explanations about the purpose of the research were given before participating in the study. All study participants were requested to sign an informed consent.

1.18.2 Respect for person

This principle of respect for persons is about the right to self-determination. In this study, human dignity was ensured by giving participants an option to decide voluntarily whether to participate in the study or not. The participants were informed that they have the right to refuse or withdraw from the study, if they felt discomfort and that they would not be penalized for withdrawing from the study.

1.18.3 Anonymity and confidentiality

Participants' right to anonymity was ensured by assigning numbers on their transcripts, instead of their names. Participants were interviewed in a private room to maintain privacy. To maintain strict confidentiality, the researcher kept the research records in a safe place under lock-and-key to prevent unauthorized access to information by other people. The transcript is stored in locked shelves in a lockable room for safekeeping and adhering to privacy and confidentiality. All transcripts will be destroyed after 3 years post the completion of the study. The principles of beneficence, autonomy, and justice were strictly adhered to.

1.18.4 Beneficence / non-maleficence

Participants have a right to be protected from discomfort and harm - whether physical, psychological, emotional, economic, social, or legal (Brink et al., 2012). Beneficence was ensured by preventing any discomfort resulting from data collection and by ensuring privacy. The researcher arranged with a psychologist and a medical doctor from the selected public tertiary hospital to be on standby in case of unlikely events or emergencies. It was a hospital protocol to test all the patients for COVID-19 before they are attended to by healthcare workers during this pandemic. All participants were done COVID-19 rapid test before the interview. Extra precautions were taken during the interviews. A well-ventilated room was used for interviews. The use of sanitizers, wearing of masks, and keeping social distance were observed all the time.

1.18.5 Autonomy

Participation was voluntary, and all the study participants were requested to sign a written informed consent. All transcripts were coded with unique identifiers to allow for autonomy, and participants were not identifiable from the study report.

1.18.6 Justice

The principle of justice is about the participant's right to fair selection and treatment (Brink et al., 2012). The researcher ensured that participants freely participated in this study, and that they are not forced to participate, and the selection was fair for everyone who met the selection criteria using the sampling criteria defined.

1.19. Conclusion

This study sought to explore and describe the experiences of patients diagnosed with cancer regarding the decentralization of oncology services at a tertiary hospital in the Eastern Cape Province of South Africa in order to assist the Department of Health in the district and province to develop client-centered approaches in the management of cancer.

1.20. Chapter outline

This mini dissertation has five chapters, which are outlined as follows:

Chapter 1: Introduction and background

This chapter introduced the research topic and discussed the motivation for this study, background to the study; approach to the study, purpose, and research questions for the study were outlined. The chapter also described the problem and clarified specific terms regarding the study and research methodology used.

Chapter 2: A literature review

Relevant literature on the experiences of patients diagnosed with cancer regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape Province of South Africa was sourced and discussed in this chapter.

Chapter 3: Research Methodology

This chapter discussed the research process, research paradigm, approach, research design, sample and sampling, access to the research site and research methods. The choice of the qualitative approach was discussed, and reasons for choosing the approach were provided. Ethical considerations and principles were also ensured.

Chapter 4: Presentation of results and discussions

In this chapter, the results of the interviews were analyzed and interpreted. Data collected from the participants were presented as themes and subthemes. And findings were discussed.

Chapter 5: Summary, Conclusions and Recommendations

In this chapter, the study was summarized. The chapter also gave conclusions of the complete mini dissertation, based on the findings as well as recommendations.

The next chapter will review, analyze and synthesize related literature.

CHAPTER 2: LITERATURE REVIEW

The previous chapter described the route that the mini dissertation followed and outlined what each chapter would look like. This chapter reviewed, analyzed and synthesized related literature on the experiences of oncology patients regarding decentralization of services to the OR Tambo District.

Review is discussed under the following headings:

2.1. Purpose of the literature review

The purpose of the review was to gather related studies that have been conducted on decentralization of oncology services. Literature from 2010 to 2020 was reviewed from Google Scholar, Ebsco host, Pubmed and other search engines using the following key words: experiences, decentralization, oncology services, quality, distance, access.

2.2 Cancer epidemiology

Cancer is a generic term for a large collection of diseases characterized by the abnormal, cells' growth beyond usual boundaries. Cancer is also called malignancy, with the characteristic of invading adjacent parts of the body and/or spread to other bodily organs (Thun, Linet, Cerhan, Haiman, & Schottenfeld, 2017). There are various cancer types, depending on the affected organs, with the common ones including skin cancer, breast cancer, cervical cancer, lung cancer, colon cancer, prostate cancer, and lymphoma, among the most prominent ones (Barta, Powell, & Wisnivesky, 2019; Benson, Venook, Cederquist, Chan, Chen, Cooper, Deming, Engstrom, Enzinger, & Fichera, 2017; Kelsey & Hildreth, 2019; Leiter, Eigentler, & Garbe, 2014). There are various cancer treatment options; radiation therapy, chemotherapy, surgery, stem cell transplant are the classical cancer treatment (Baskar & Itahana, 2017; Chen, Chang, & Cheng, 2017; Tohme, Simmons, & Tsung, 2017). Immunotherapy, hormone therapy, targeted therapy other available cancer treatment options. Risk factors associated with cancer are high body mass index (overweight and obesity); low fruit and vegetable intake, inactive lifestyle, tobacco use, alcohol use, exposure to carcinogenic elements, and genetic

factors (Grosso, Bella, Godos, Sciacca, Del Rio, Ray, Galvano, & Giovannucci, 2017; Rojas & Stuckey, 2016; Sitarz, Skierucha, Mielko, Offerhaus, Maciejewski, & Polkowski, 2018). Some cancers are caused by infectious agents such as viruses, such as hepatitis and human papillomavirus (Viens, Henley, Watson, Markowitz, Thomas, D. Thompson, Razzaghi, & Saraiya, 2016)

2.3 The global burden of cancer

World Health Organization global report of 2018, state that cancer is the second leading cause of death globally, with a case fatality ratio projected at 9.6 million deaths. The incidence rate of cancer is roughly 14 million new cases per year and is estimated to increase to 22 million per annum within the next 20 years. Cancer fatalities are also expected to increase within the same period. Furthermore, the WHO recorded that globally, around 1 in 6 deaths is due to cancer (Bray, Ferlay, Soerjomataram, Siegel, Torre, & Jemal, 2018; World Health Organization, 2018)

Kama (2017) argues that developing countries such as in Africa, Asia, and parts of Central and South America as are more affected by this upsurge. These countries account for over 60% of global cancer cases and 70% of cancer mortalities. It has been argued that the entire annual cost of cancer care reached the US \$ 1.16 trillion in 2010 and has been rising (Kama, 2017). This increase in economic problems is one of the underlying barriers to the effective management of cancer patients in developing countries.

The increasing complexity of cancer care requires the organization of clinical and operational decision-making. These are crucial key elements in high-quality oncology care. Generally, low-income, and middle-income countries have the greatest differences, while even those from non-Western high-income countries such as Oman and the United Arab Emirates are diagnosed with cancer at later stages and suffer increased mortality (Rodriguez, Brant, Pendharkar, Arreola-Ornelas, Bhadelia, de Lima Lopes Jr, & Knaul, 2017).

2.4 Challenges in Cancer Management

Infrastructure, medical services, managerial skills, and skilled health care workers have been identified as major challenges in cancer management in various settings. (Haileselassie, Mulugeta, Tigeneh, Kaba, & Labisso, 2019; Neupane, 2019; Schlemmer, Bittencourt, D'Anastasi, Domingues, Khong, Lockhat, Muellner, Reiser, Schilsky, & Hricak, 2017; Steward, Shackelford, Carvalheiro, Benton, Garibaldi, & Sait, 2014). All this is manifested by inequity in the health-care provision and massive inconsistencies in the quality of oncology services carried out in the different types of health facilities. According to Kama (2017) oncologist in developing countries face additional challenges in cancer management including the limited resources, changing levels of knowledge and medical skills among oncologists and the lack of integrity of health care systems (Kama, 2017; Steward, Shackelford, Carvalheiro, Benton, Garibaldi, & Sait, 2014). The progressive problem of cancer leads to a growing need for a more synchronized strategy to manage such oncology problems.



2.5 Decentralization of oncology services

Decentralization is defined as the “transfer of power or authority from higher to lower levels of government or from national to sub-national levels” (Rondineli, 2017). The rationale of decentralization is based on an essentially powerful idea; that smaller organizational units, properly structured and directed, are integrally accountable and more responsive than are larger organizations. In a healthcare setting, the possibility of establishing more locally operated, locally responsible institutions, holds out great desirability compared to centralized services (Azfar, Kahkonen, Lanyi, Meagher, & Rutherford, 2018).

In developed countries, the decentralization of cancer services had led to improved patient outcomes, where clinicians had fewer patients to attend to, thus increasing provider-patient interaction and reducing workload at higher facilities (Arenas, Gomez, Sabater, Rovirosa, Biete, & Colomer, 2015; Wilkens, Thulesius, Schmidt, & Carlsson, 2016). The decentralization also led to increases in access by removing the impediment of travelling a long distance to obtain cancer care services.

Craighead, and Dunscombe (2011), sought opinions from several external experts on decentralization. In addition, the study sought input from internal staff on their perspectives and experiences on the resources needed for a small-city radiotherapy department. Three core themes for effective decentralization; (i) *the importance of transparent connections between smaller centers and tertiary*, (ii) *The essence of balancing the complexity of oncology care with access to quality when decentralizing to small-city departments* and (iii) *The importance of training future staff and retaining current staff on oncology services* (Craighead & Dunscombe, 2011).

Greenup, Obeng-Gyasi, Thomas, Houck, Lane, Blitzblau, & Hwang, (2018), revealed that higher physician volume at decentralized centers was associated with increases in selected measures of quality of surgical care among breast cancer clients (Greenup, Obeng-Gyasi, Thomas, Houck, Lane, Blitzblau, Hyslop, & Hwang, 2018). Furthermore, individual surgeons' volumes of breast cancer operations were quite low, easing the burden at centralized centers. The physicians at decentralized centers were likely to perform on average, ≤ 6 operations surgical procedures annually on women of all ages, easing the burden at central facilities.

In Finland, the use of telemedicine and qualified decentralized cancer treatment was enshrined as a binding target, especially where the travel distance to the specialist health service was substantial references. Decentralization of oncology services improved patient care, access to treatment and had positive outcomes, especially where clients found it difficult to travel to centralized centers (Khatrri, Peterson, Kyriazokos, & Prasad, 2011).

healthcare professionals revealed that oncology service provision was hindered by a lack of resources both in relation to skilled healthcare providers and health infrastructure for the management of cancer. In this setting, access to timely diagnosis and treatment was limited due to services only being available at the central levels, indicating the challenges of centralizing these services. Recommendations were that provision of services such as clinical breast examination, advice on self-examination, and conducting ultrasound tests at lower health care levels could reduce the burden of overcrowding and service-delivery

experienced in provincial and national-level hospitals (Jenkins, Ngan, Ngoc, Phuong, Lohfeld, Donnelly, Van Minh, & Murray, 2019).

a model of decentralized care was planned to ease the challenges faced in cancer care. The model tested outreach using existing infrastructure. The number of cancer patients registering for care in district hospitals increased at a high pace, indicating the increasing level of confidence in lower-level hospitals. The outreach model involved skills building of physicians and nurses from district hospitals in groups, and peer-reviewing competencies by an independent board to assess competency to start practicing oncology services at the district hospital level. The districts also established counselling camps to advocate the cause of cancer (Pendharkar, Agarwal, & Tripathi, 2016)

2.6 Decentralization of oncology services in Africa

In Kenya, seven barriers to cancer testing and treatment were identified; which were (i) the cost of testing and treatment, (ii) poor communication, (iii) low level of knowledge about cancer among population and clinicians, (iv) lack of better cancer policy development and implementation, (v) poor health-seeking behaviors among the population, (vi) long distances to access diagnostic and treatment services and (vii) lack of decentralized diagnostic and treatment facilities (Makau-Barasa, Greene, Othieno-Abinya, Wheeler, Skinner, & Bennett, 2017).

Zimbabwe reported that access to cancer screening services, early detection, and diagnostic and palliative care services is restricted due to resource constraints. In this setting, cancer treatment services are centralized at two government hospitals in Harare and Bulawayo. Private chemotherapy services are also available, mainly in the cities. The recommendation was that the financial gap needs to be filled to make cancer management and treatment “free” for the ordinary Zimbabwean patient, and services should be decentralized to improve access (Nyakabau, 2014).

In Egypt, decentralized initiatives allowed facilities to properly assess their customized needs, to develop and build their infrastructure more efficiently and to rapidly adopt new technologies. In these decentralized facilities in this setting, (i) central chemotherapy independent unit was established, (ii) a whole department of oncology electronic medical

record was developed, (iii) Radiotherapy e-learning program was established for capacity improvement, and (iv) radiotherapy infrastructure was installed (Saad, 2015)

Rwanda developed a decentralized national cancer program by designing an integrated, comprehensive framework of care, building local human resource capacity through partnerships, *and delivering equitable, rights-based care* from 2011. Within the first 2 years since the inauguration of Rwanda's first cancer center, more than 2500 patients had been enrolled, including patients from every district in Rwanda. The authors recommended their model to be applied in other low-resource settings (Stulac, Binagwaho, Tapela, Wagner, Muhimpundu, Ngabo, Nsanzimana, Kayonde, Bigirimana, & Lessard, 2015).

Senegal reported the cervical cancer incidence rate of 41.1% in 2015, placing the country on the 15th position in the world in the age-standardized cervical cancer incidence rate. The investigators in this study undertook a literature review to identify program evaluation or policy-relevant publications with a focus on decentralized program implementation in settings similar to the context of the rural Senegal region. This study found that the literature lacks policy-specific publications focused on the decentralized low-resource settings within low-income countries in Africa. The unavailability of this type of knowledge sharing is of high concern given the critical need to develop efficient, sustainable solutions in these settings (Rahman, Clark, Collins, Traore, Dioukhane, Thiam, Ndiaye, De Jesus, Danfakha, & Peters, 2019).

2.7 Decentralization of oncology services in South Africa

South Africa has embraced a process of decentralization in the rearrangement of health care and oncology services as mentioned by various authors (Hendricks, Buch, Seekoei, Bossert, & Roberts, 2014; Lateef, 2011; Winchester & King, 2018). The health care system in South Africa is systematized government namely: the national, provincial and local sphere of government. reviewed literature on the reimbursements and challenges of decentralization, particularly in the health oncology services, shows varied findings (Alves, Peralta, & Perelman, 2013). Furthermore, numerous studies by (Maimela, Nene, Mvundla, Sawry, Smith, Rees, Kachingwe, & Chersich, 2019; Blanckenberg, Oettle,

Conradie, & Krige, 2013; Regmi, Naidoo, Pilkington, & Greer, 2010; Fonn, Ray, & Blaauw, 2011; Kahn, 2011), described below revealed that decentralization of oncology service has produced positive effects in South Africa.

Decentralization of oncology services in different sites in South Africa strengthened the volume of local organizations to negotiate with central government structures for improved resource allocation to previously abandoned groups (Alves, Peralta, & Perelman, 2013). In another study conducted in Gauteng found that decentralization of colposcopy services to a primary care facility could reduce the time to colposcopy and decrease the workload of tertiary hospitals (Maimela, Nene, Mvundla, Sawry, Smith, Rees, Kachingwe, & Chersich, 2019). The study concluded that decentralization did not compromise the quality of services and that this model could be extended to similar settings in South Africa and elsewhere (Maimela, Nene, Mvundla, Sawry, Smith, Rees, Kachingwe, & Chersich, 2019).

The colposcopy services were decentralized to the district hospital in a rural sub-district reference. An assessment was done to evaluate the uptake of colposcopy services and the impact this had on the referral hospitals. The study revealed that the establishment of a colposcopy service in a rural sub-district led to an increase in accessing colposcopy services. This establishment decreased the time from cervical smear to colposcopy, from 170 to 141 days. Moreover, the decentralized service eased the burden from the referral hospitals, by removing 202 booked patients in one year from the colposcopy load from the referral hospitals (Blanckenberg, Oettle, Conradie, & Krige, 2013).

Nevertheless, Regmi, Naidoo, Pilkington, & Greer, (2010), highlighted that the decentralization of oncology services has intensified glitches of discrepancy in vulnerable populations, leading to poor quality health care delivery (Regmi, Naidoo, Pilkington, & Greer, 2010). Malherbe, (2013), argues that separating policy factors from policy implementers in South Africa and other African countries have led to a catastrophe of effective and efficient health delivery. Policy implementers failed to restrict health funds at the provincial level, which has led to health funds being readdressed to other outlay based on political priorities (Malherbe, 2013).

Chemotherapy is directly prescribed by various specialized clinics in the department of health and referred to as a written protocol to the management office, where nurses and oncologist prepare and deliver the treatments. Chemotherapy toxicity evaluation and quality of life assessment data are very scarce and imperfect. Instruments for the avoidance of medicinal faults are almost absent or dependent on personal effort (Fonn, Ray, & Blaauw, 2011; Kahn, 2011).

2.8 Radiotherapy infrastructure

Lack of infrastructure is a common problem in developing countries. When it comes to radiotherapy equipment, the issue is exponentially more complicated when it comes to equipment acquisition, operation, and maintenance (Saad, 2015). Whenever there is a technical malfunction, maintenance is slow, partially due to budget allocations and time taken to import spare parts. These delays have the main impact on cancer patient's survival and disease control (Buccimazza, 2015).

2.9 Challenges of decentralization of oncology services at a tertiary hospital: National, Provincial and Local sphere of government in South Africa

Cancer patients in South Africa and other African countries are bearing the effect of not only the cancer disease but also the ineffective health system. The challenges are a deficiency of radiographers in hospitals, ageing equipment and a burden of high cancer patients (Stefan, 2015). In addition, the country faces immense oncologist crisis, with a liberal decrease in clinical and radiation oncologists in the academic and state sector (Balogun, Rodin, Ngwa, Grover, & Longo, 2017). The 2018 South African annual census of clinical and radiation oncologists conducted, showed that although the number of oncologists in South Africa has declined, the rate had decelerated from a 25% decrease in 2016 to 20.5% in 2018.

The South African Human Rights Commission released a critical report on how the department of health had failed its cancer patients. Not only had the number of specialist doctors declined but hospitals had a shortage of chemotherapy drugs (Kollapen, Carnelly, Jaichand, Lawrence, Oguttu, Sello, & Siwendu, 2017). The South African Human Rights

Commission indicated that academic Hospitals in South Africa are facing shortages of radiographers; ageing equipment and an overload of cancer patients thus worsening the burden of oncology services in South Africa.

Winchester & King (2018), highlighted that there are actions to deal with the accumulation of the waiting times for patients and mending health technology machinery, including a linear accelerator that is needed to be upgraded at tertiary Hospitals in South Africa (van Heerden, 2019). The regular waiting times for radiation oncology is on average three months, but that there was no waiting period for medical oncology services.

2.10 Oncology doctors and equipment in South Africa

Mokoena (2017) indicated clinical procedures backlog cause prolonged delay for some patients pending treatment, such as cancer patient. The absence of oncology doctors and equipment, and long waiting lists for surgery or diagnosis, are some of the challenges experienced in South African health care facilities. The author indicated the elongated waiting times for medical involvement potentially exposed patients to advance problems or even hospital mortalities (Mokoena, 2017). Furthermore, the oncology equipment is poorly maintained and that patients are consequently referred to other hospitals for investigations or they had to wait until the equipment is fixed, resulting in delayed diagnosis and treatment. Manyisa and Van Aswegen (2017) indicated that the lack of administrative equipment and skilled professionals unfavorably affects the quality of care offered in health institutions (Manyisa & van Aswegen, 2017).

2.11 Poor development of a whole department of oncology Electronic medical record

According to Koelble & Siddle (2014), the available medical records system is still an old-fashioned hard copy file system, housed in an archive room that no longer fits the huge number of files. This claim is also supported by authors such as Kilonzo and Ikamari (2015) who discussed poor record-keeping system has led to the loss of a quantity of valuable information and patient uneasiness due to increasing waiting times for their file retrieval (Kilonzo & Ikamari, 2015). Furthermore, data collection is not standardized, and

statistical analysis require a huge amount of effort to go through the files. Furthermore, the installation of different equipment in other health facilities has failed due to the great number of patients seen per day and a lack of experienced personnel for data entry, which is more time consuming than the conservative paper system (Ibrahim, Khaled, Mikhail, Baraka, & Kamel, 2014). The problem is not unique to South Africa, but it is evident in other developing countries as well.

2.12 Poor Central chemotherapy independent unit

One of the critical challenges that face oncology services in South Africa and developing countries is the absence of knowledge and the deficiency of knowledgeable personnel (Edwards & Greeff, 2017; Morhason-Bello, Odedina, Rebbeck, Harford, Dangou, Denny, & Adewole, 2013). In radiotherapy, it is a more persistent problem due to the price of technology related to it, the variety of specialties involved in the cancer treatment process and the migration of skilled personnel to developed countries.

2.13 Conclusion

The literature reviewed showed that various settings experienced different challenges concerning the decentralization of oncology services. In places where decentralization was coupled with capacity building and resource allocation, decentralization improved on early diagnosis and management of cancer, whereas developing countries should use innovative approaches to effectively decentralize in a resource-limited setting, The next chapter will describe the research methodology and design.



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CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

The review of literature relevant to the study was outlined in Chapter 2. In this chapter, a description of the study's research design, research setting, the study population, sampling techniques, data collection, and analysis strategy are discussed. Further to that, ethical considerations, and a chapter summary are also included.

3.2 Research paradigm

A paradigm is a basic belief system and theoretical framework with assumptions about ontology, epistemology, methodology, and methods. In other words, it is a worldview used to understand the world we live in (Rehman & Alharthi, 2016). Paradigm is also described as sets of beliefs that guide action which is embedded in all educational research (Brooke, 2013). In this study, constructivist paradigm was appropriate to explore the experiences of patients diagnosed with cancer regarding the decentralization of oncology services in the Eastern Cape. The constructivist paradigm recognizes the researcher as a subjective actor who embarks on the task of learning the meanings which participants assign to phenomena and the effect of meanings on action (Rehman & Alharthi, 2016). This paradigm is also known as the interpretive paradigm (Merriam & Tisdell, 2016). The constructivist paradigm deals with the development of subjective meanings and understandings of one's personal experience concerning a specific topic based on their social and historical background (Tavakol & Sandars, 2014). In this study, the experiences of cancer patients attending the oncology unit at a public tertiary Hospital were analyzed to give meaning to their social setting.

Ontology, epistemology, and methodology are connected to the research paradigm. The methodological explanation is further obliged by the epistemological and ontological explanations of research (Kamal, 2019).

Ontology is described as the way the researcher defines reality (Antwi & Hamza, 2015). Ontology is based on what needs to be known (Kamal, 2019). Epistemology deals with

sufficient and valid kinds of knowledge (Gray, 2014). Epistemology is the process of discovering the truth (Kamal, 2019). The methodology is defined as the method used to conduct the research (Antwi & Hamza, 2015). The fundamental question related to methodology is “How does one go about acquiring knowledge?” (Kamal, 2019). In this study, the ontological approach focused on experiences of participants in this decentralized oncology unit. The researcher looked at realities that are experienced by the recipients of oncology services at this study site. The epistemology concept was dealt with by means of capturing the views of participants regarding decentralization and quality of services at this oncology unit. On methods, interviews were used to get the experiences of patients attending the oncology clinic.

3.3 Research Approach

In this study, the researcher employed a qualitative research approach to explore and describe the experiences and perceptions of patients attending the oncology clinic at a selected public tertiary hospital regarding the decentralised oncology services. The qualitative method was used to collect in-depth details on a particular topic. This approach assumes a single person represents the group of feelings and emotions of a person and it is important to interpret (Rahi, 2017). Qualitative research involves collecting and analysing non-numerical data to understand the concepts, opinions, or experiences (Cleary, Horsfall & Hayter, 2014). Qualitative research was found to be adequate to get deeper insights of oncology patients regarding decentralisation of oncology services.

3.4. Research design

Research design is the set of methods and procedures used in collecting and analysing measures of the variables specified in the research problem (Rahi, 2017). The research design is the plan for connecting the conceptual research problems to the pertinent and

achievable empirical research. It is an inquiry that provides specific direction for procedures in research (Kamal, 2019). A descriptive, explorative, and contextual research design was undertaken in this study, to get the perspectives of the oncology healthcare service recipients on the decentralization of oncology services at a public tertiary hospital.

- **A descriptive design**

This design describes the phenomenon in its existence. It answers the questions of what, who, how, where and when in describing the current situation (Brink et al., 2018). This design was chosen for this study as it is concerned with experiences and perceptions, which was the purpose of this study.

- **An explorative design**



This type of design is used to explore a new universe that has not been studied. It is more about establishing the why factor of a phenomenon (Brink et al., 2018). An exploratory research design was seen as the most suitable design to explore and describe the experiences and perceptions of cancer patients regarding decentralization of oncology services in a public tertiary hospital.

- **A contextual design**

The contextual research design is concerned with specific actions whilst remaining in the natural setting (Burns & Grove, 2011). Brink, van der Walt & van Rensburg (2018) make

mention of a natural setting, which is an uncontrolled, real-life state or environment. This study was done in the natural setting at th

3.5 Research setting

The research was conducted at the oncology unit of a public tertiary hospital, in OR Tambo Municipality of the Eastern Cape of South Africa. The study site is a tertiary hospital located in Mthatha. In 2003, this public tertiary hospital opened its doors, replacing the old Umtata Academic Hospital. At the time of its unveiling, the Academic Hospital worked with the then University of Transkei (UNITRA), renamed to the now Walter Sisulu University, and has been providing a level one tertiary service. In 2012 the Hospital was gazetted to be a Central Hospital, with the ability to provide up to tertiary two services.

The hospital provides 19 specialties which are general surgery, ENT (ear, nose, and throat), urology, neurosurgery, ophthalmology, orthopaedic, internal medicine, dermatology, cardiology, haematology, endocrinology, pulmonology, and medical oncology. Over and above-mentioned, the hospital also provides paediatrics and neonatology, alongside supporting disciplines that include the following: radiology, anaesthesia, intensive care services, trauma and emergency services.

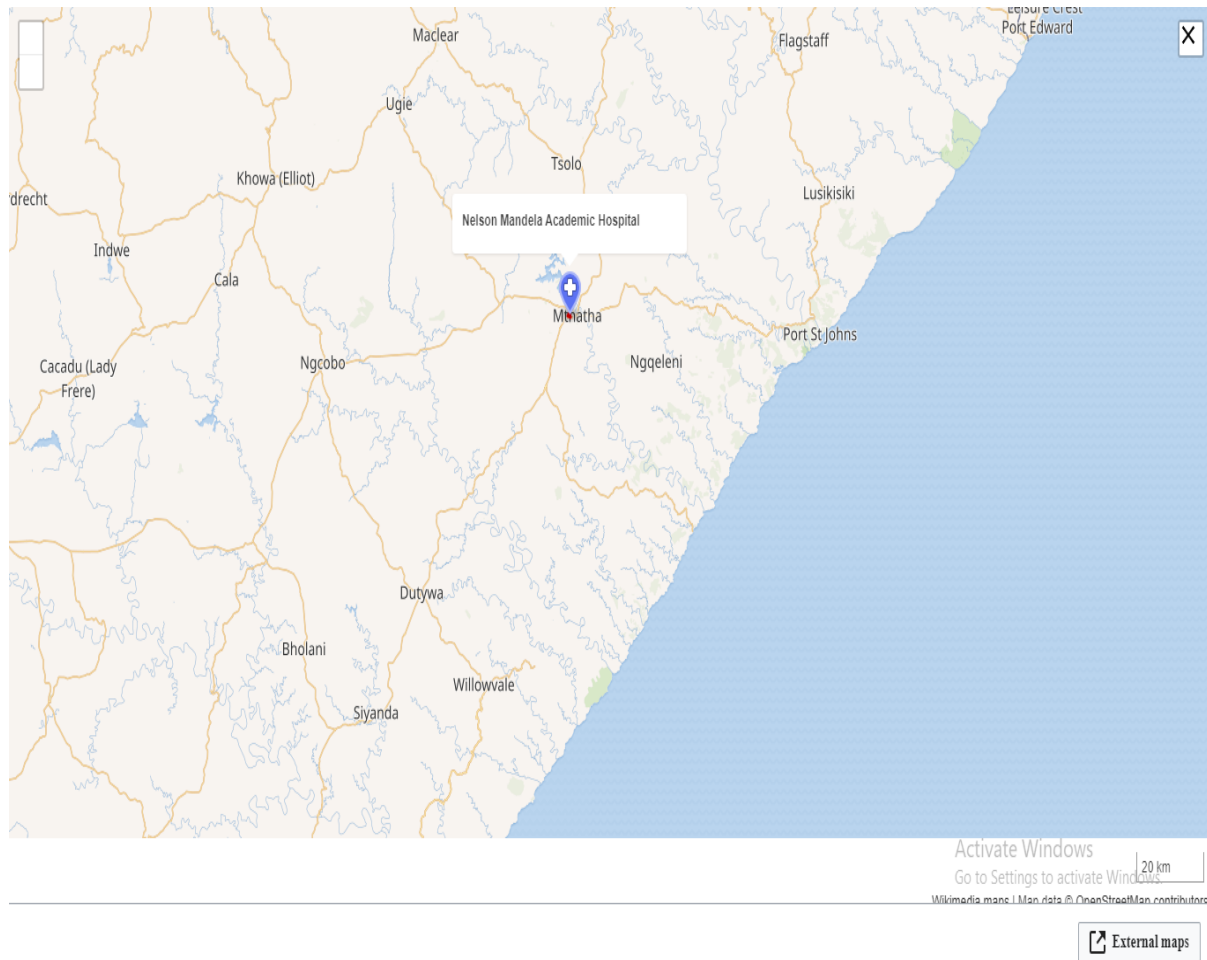


Figure 3.1: showing the setting, old Transkei map from Wikimedia Maps (March 2021).

The hospital serves a catchment area of approximately three million people, which stretches along the North-Eastern part of the Eastern Cape Province. This public tertiary hospital is the only Tertiary hospital serving the entirety of the region. The hospital has 736 beds.



Figure 3.2 showing the oncology unit sections at Public Tertiary Hospital from Google Maps (June 2018).

It was in 2017 when a fully functional oncology unit was open at this public tertiary hospital. The oncology unit at this public tertiary hospital is a day clinic without admission beds. Patients who need admission are admitted to medical wards. There is a waiting area with 13 beds for patients with referrals for radiotherapy in East London. The unit has an average of 500 consultations per month, with 100 patients receiving chemotherapy services every month. The unit has only 1 laminar flow machine for mixing chemotherapy drugs, in addition to the basic general equipment such as blood pressure machines and body mass index scale. The researcher chose this setting because it was suitable for the data collection process. All cancer patients who are receiving their chemotherapy attend the clinic in this unit. The researcher was able to recruit and select the participants from the target population.

3.6 Population

A population is a group of individuals with specific characteristics that the researcher wants to study. (De Vos, Strydom, Schulze, & Patel, 2011; Polit & Beck, 2017). Population in this study refers to all patients diagnosed with cancer, attending oncology clinic at a selected public tertiary hospital. Our population target was both males and female patients aged 35-85 diagnosed with cancer, receiving oncology services at this public tertiary hospital from 2017 to 2020.

3.7 Sampling

A sample is a subset of individuals from the population. Sampling is a process of selecting research participants from the population (McCombes, 2019). Convenient, non-probability sampling was applied to select a sub-sample from the population identified (patients with cancer), who knew the most about their condition, and who were willing and able to articulate and explain nuances (Brink, van der Walt & Van Rensburg, 2012). Participants were recruited and selected from the waiting area before they were seen by the doctors. The researcher worked with a nurse in the unit to identify clinically stable cancer patients as participants.

3.8 Inclusion criteria

The sample included cancer patients who were managed at a selected public tertiary hospital, both male and female patients diagnosed with cancer, from the ages of 35 years to 85 years old. Only clinically stable patients were included.

3.9 Exclusion criteria

The patients receiving care from private providers and those who were receiving treatment from other public hospitals were excluded. Extremely ill patients and those who were not clinically stable were excluded.

3.10 Data collection

Data collection is a process of gathering and measuring information on variables of interest, in a systemic fashion that enables one to answer research questions, test hypothesis, and evaluate outcomes (Grove, Burns, & Gray ,2013). In this study, data were collected through semi-structured, one-on-one interviews. An interview guide with open-ended, semi-structured questions was developed as a research instrument.

3.11 Research instrument

A research instrument is a tool or a method by which a researcher obtains data from the participants for his research project (Japheth, 2014). There are different types of research instruments such as questionnaires, interviews, observations, focus group discussions, and experiments (Japheth, 2014). In this study, face to face interviews were chosen as a suitable instrument. A self-developed interview guide with open-ended, semi-structured questions was used as a research instrument for data collection. The interview guide had 2 sections namely: Section A which was demographic information of the participants and Section B which was asking questions about experiences of cancer patients who are receiving treatment from the selected public tertiary hospital oncology unit. section B was also asking questions about the views of oncology patients regarding the quality of services they receive from the unit such as waiting time, availability of medicines, staff attitude, and accessibility of oncology services now that the new unit has been opened closer to the people.

3.12 Trustworthiness

According to Stahl and King (2020), trustworthiness is a way of ensuring data quality or (rigor) in quality research. In this qualitative study, trustworthiness was measured by four criteria: credibility, dependability, conformability, and transferability.

3.12.1 Credibility

Credibility alludes to confidence in the truth of the data and the interpretation thereof (Brink et al., 2012). In this study, credibility was ensured by the reality of the findings. A detailed description of the research was provided by the researcher to the participants and credibility was achieved through a prolonged engagement between researcher and participants and matching of words with their voice. Prolonged engagement will build trust and rapport between researcher and participants (Brink et al., 2012).

3.12.2 Dependability

Dependability refers to the provision of evidence such as that if it were to be repeated with the same participants in the same context, its findings would be similar (Brink Van der Walt & Van Rensburg, 2012). In this study, dependability was ensured by stepwise replications of comparisons of similar participant findings. Inquiry audits, the supervisor, and mentors examined the steps for data collection to repeat the study.

3.12.3 Conformability

Conformability refers to the potential for congruency of data in terms of accuracy, relevance, or meaning (Brink et al., 2012). Conformability was ensured by inquiry audit, establishing participant's information represent data, the reflex voice of participants with data and triangulation was also used where the participants were asked questions in different methods about different events (Brink et al., 2012).

3.12.4 Transferability

Transferability refers to the ability to apply the findings in other contexts or to other participants (Brink et al., 2012). In this study, transferability was ensured by comparisons of findings of participants and applied it to others, safeguarding all data records, voice recordings, and the analyzed data records.



3.13 Ethical consideration

Ethical clearance was obtained from the University of Fort Hare ethics review committee (Ref # 2021=03=07=JojoL). Permission to conduct the study was obtained from the Eastern Cape Department of Health (EC_202103_007) and management of a selected public tertiary hospital in OR Tambo District Municipality in the Mthatha region. According to Botma *et al.* (2010), ethics must be considered throughout the study. In research that involves human beings, their rights must always be protected (Creswell, 2014). The researcher must observe the principle of respect for persons, right to anonymity and confidentiality, and principle of autonomy.

3.13.1 Informed consent

Each participant was requested to sign an informed consent form before participating in the study. The ethical principles of voluntary participation and protecting the participants from harm were formalized in the informed consent. Explanations about the purpose of the research were given before participating in the study. All study participants were requested to sign an informed consent.

3.13.2 Respect for person

This principle of respect for persons is about the right to self-determination. In this study, human dignity was ensured by giving participants an option to decide voluntarily whether to participate in the study or not. The participants were informed that they have the right to refuse or withdraw from the study if they felt discomfort and that they would not be penalized for withdrawing from the study.

3.13.3 Anonymity and confidentiality

Participants' right to anonymity was ensured by assigning numbers on their transcripts instead of their names. Participants were interviewed in a private room to maintain privacy. To maintain strict confidentiality, the researcher kept the research records in a safe place under lock-and-key to prevent unauthorized access to information by other people. The transcript is stored in locked shelves in a lockable room for safekeeping and

adhering to privacy and confidentiality. All transcripts will be destroyed after 3 years post completion of the study. The principle of beneficence, autonomy, non-maleficence, and justice were adhered to by all questions.

3.13.4 Beneficence / non-maleficence

Participants have a right to be protected from discomfort and harm- whether physical, psychological, emotional, economic, social, or legal (Brink et al., 2012). Beneficence was ensured by preventing any discomfort resulting from data collection and by ensuring privacy. The researcher arranged with a psychologist and medical Doctor from the selected public tertiary hospital to be on standby in case of unlikely events or emergencies. It was a hospital protocol to test every patient for COVID-19 before they are attended by healthcare workers during this pandemic. All participants were done COVID-19 rapid test before the interview. Extra precautions were taken during the interviews. A well-ventilated room was used for interviews. The use of sanitizers, wearing of masks, and keeping social distance was observed all the time.

3.13.5 Autonomy

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Participation was voluntary, and all the study participants were requested to sign a written informed consent. All transcripts were coded with unique identifiers to allow for autonomy, and participants were not identifiable from the study report.

3.13.6 Justice

The principle of justice is about the participant's right to fair selection and treatment (Brink et al., 2012). The researcher ensured participants, freely participated in this study, not forced to participate, and the selection was fair for everyone who met the selection criteria using the sampling criteria defined.

3.14 Data collection procedure

The researcher recruited the participants from the waiting area at a selected public tertiary hospital oncology unit. When patients come for their review in the unit, firstly are registered by clerks, from there they go to the observation room for vital signs. After checking vital signs, they go to the waiting room before they are seen by the doctors. It was at this stage where the researcher recruited the participants after the observations and were found to be clinically stable.

The researcher was working at a selected public tertiary hospital during the time of the study. He organized a private room in the oncology unit where interviews were conducted to maintain confidentiality. Data was collected through semi-structured, one-to-one interviews until the data saturation point was reached. A semi-structured list of questions was used to ensure that critical points were covered in every interview. Participants were given the necessary flexibility to enable them to give information on the discussion point relevant to them. That allowed participants to express their experiences regarding the decentralization of oncology services at this public tertiary hospital. The participants were sampled from the waiting room before they were seen by the doctors. The sampled participants were interviewed on a one-to-one basis for about 20 minutes. All interviews were audio-recorded with permission from the participants and transcribed verbatim in full by the data collector. Every transcript was vigorously checked against its corresponding audio record for accuracy. All transcripts were translated from isiXhosa to English. The audio recording was encrypted in the folder with biometric authentication, to allow for confidentiality. Data was collected until saturation was reached.

3.15. Data Management

The electronic and physical management of collected data is a significant aspect of the research process (Surkis & Read, 2015). Electronic data was transferred into an external hard drive and safely stored in the same safe as the hard copy interview schedules.

Electronic data was securely stored on password-protected computers, and access to the data was and is currently restricted to the researcher and supervisory team. All physical copies of the consent forms were scanned and uploaded to be stored securely electronically. After being scanned and uploaded to the password-protected University of

Fort Hare servers, the researcher saved all physical copies of the data in a locked cupboard. Not every question was used due to the relevance of the opinions of the patients. The copy of the data was also kept on an external hard drive as a backup. This backup ensured that the ink on the hard copy was protected from fading or any damages that may be caused.

3.16. Data analysis

Framework analysis, or the Framework Method, is a conventional method of analysis of the open-ended question format standard in semi-structured interviews and is regularly referred to as qualitative content analysis or thematic analysis, as these methods follow a similar approach (Polit & Beck, 2017). They emphasize that thematic analysis in generic qualitative studies' aims is to provide an in-depth and comprehensive analysis of a phenomenon by incorporating approaches that are inductive and utilize open codes and categories of a standardized method of data analysis (Joffe, 2012). In this study, after the interviews were transcribed, the transcripts were presented to the independent coder along with the methodology chapter, and a copy was made for the researcher's use of the transcribed data.

The coding process consisted of taking the recorded audio data and segmenting these words or paragraphs into themes and sub-themes (Creswell, 2014). Data analysis was done according to Tesch's eight-step method where the researcher

- Read each interview, got meaning from the information and wrote down the thoughts that came to mind.
- Similar topics were arranged in groups by forming columns labelled 'major topics.'
- The researcher then coded and wrote the codes next to the appropriate segment of the text.
- The data was then organized to check if new categories or codes emerged, and all this was done with the assistance of an independent coder.

- The most descriptive wording for the topics was found and converted into categories.
- The codes were then arranged alphabetically.
- A preliminary analysis was performed.
- Existing material was recoded where necessary (Belotto, 2018).

The data analysis progression involved data collection through individual interview discussion, field notes taken by the researcher, transcription of audio recordings, sending transcripts to an independent coder, and the researcher engaging with the data and transcripts to construct themes using Tesch's steps of data analysis. All codes generated were guided by information from the responses of the patients. The codes were grouped into themes and subthemes.

3.17. Conclusion

This chapter outlined the research design of the study. It was a qualitative study which used interview guide as a research instrument. Ethical consideration was also described. Strict COVID-19 regulations were adhered to. And furthermore, data collection procedure, data management and data analysis were described. The next chapter will be the presentation of the results.



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CHAPTER 4: RESULTS AND DISCUSSIONS

4.1 Introduction

In the previous chapter, it was explained how data was collected and also the considerations that were made to ethical standards and the trustworthiness of the entire study was discussed. In this chapter, data analysis and the findings of the study will be presented, which shows the identified themes and sub-themes with thorough explanations that emerged from the participants through the research questions asked. Each theme will be discussed in full and will be supported with relevant quotations from the participants who were interviewed during the data collection process. The results will also be discussed in this chapter.

4.2 Demographic profile of patients receiving cancer care services

4.2.1 Age

Nineteen clinically stable cancer patients of African ancestry participated in the study. The sample was an aging population from 35 years to 85 years old. The participants' largest concentration was in the 50 years and older age group with 16 participants. There was one participant under the age of 35 years, one in the age group 35-40 and one participant in the age group between 41-50 years old.

4.2.2 Gender

Most of the participants were females. Out of the 19 participants 18 were female and only one was male.

4.2.3 Year of diagnosis of cancer among the participants

Seven participants were recently confirmed cancer patients (in the years 2020 and 2021). The duration of living with cancer was two years. Categorically, cancer was confirmed in more than half of the participants between 2018 and 2021 and in four participants in 2014-2017. Two participants knew they had cancer more than ten years ago (2010). One participant said he was diagnosed more than five years ago, and another one was not sure of the year of diagnosis.

4.2.4 Number of months receiving therapy at the oncology unit

Half of the participants received therapy at the study site for more than 12 months. Nine patients with cancer who participated in the study have been treated in this oncology unit for more than a year. Followed by eight participants who have been treated for 0-6 months and two for 6-12 months.

4.2.5 Frequency of visits to the facility for cancer care services.

Most of the participants visit the facility to receive cancer care service once a month. Less than half of the participants visit the facility twice or more times a month.

4.3 Table 4.1. showing Themes and subthemes

Themes	Subthemes
Positive experiences related to a high level of satisfaction with services provided and desired expectations	Satisfaction with the services offered to them at the unit happy with the quality of services High expectations of getting well. <i>good service delivery</i>
Negative experiences related to oncology	Fear of dying; anxiety and stress about cancer and the treatment.
Waiting time	<i>not wait for too long</i> <i>I am quickly attended to</i>
Availability of human and material resources	<i>always get it [prescribed medications]</i>
Attitude of health care workers	caring and loving people. <i>are very nice people</i> <i>"The doctors are all nice, but there are only nurses who are rude."</i> (Participant 9, female,
Appropriate treatment and care	appropriate treatment and care. improved health status.
Improved access to services	Facility close to home
Need for improved infrastructural facilities	overcrowding at the center, fears of contracting Covid19. insecurity, lack of warm water for bathing, lost hospital files, and

	delayed delivery of laboratory results.
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4.3 Themes

Seven themes emerged from the data analysis

4.3.1 Theme 1

Positive experiences related to a high level of satisfaction with services provided and desired expectations

All the participants had positive experiences regarding the services provided to them and what they expected from the oncology unit. They expressed a high degree of satisfaction with the services offered to them at the unit. It emerged from the data that all of them were well treated.

"I am fine with everything, the nurses and the four doctors I have seen; they are treating me well." (Participant 17, female, 57 years)

"The treatment here is very good compared to the one in Frere." (Participant 9, female, 51 years)

"They have good service delivery." (Participant 7, male, 70 years)

"They treated me very well; this is my second visit since we were transferred here, and the treatment is good." (Participant 15, female, 59 years)

It was extracted from the interview that some of the participants had high expectations of getting well.

"I had hopes. I did not think I was going to die; I was hoping that I will be all right. I thought I would be given IV drips; I did not know I was going to be given a pill. I thought when I start chemo, I will be worse or maybe even having other sicknesses, but I saw myself getting better." (Participant 14, female, 69 years)

"I was expecting to live and to be treated." (Participant 17, female, 57 years)

"I did not know what to expect, I went to the doctor, and he said I had cancer, I wanted to live." (Participant 13, female, 66 years)

A substantial minority of the participants had negative experiences and thought they would die, but their encounter with the unit changed the course of their life. They expressed that they did not anticipate receiving help but are glad they met the right people, were helped, and are still alive.

"I thought I would die because I did not even know this thing called cancer, I just I came, to the people who are good to me, and I am alive." (Participant 4, female, 75 years)

"I was expecting that I was going to die, but I quickly got help." (Participant 10, female, 37 years)

Though a few participants reported suffering from post-diagnosis fears and anxiety, they indicated that nurses and doctors helped to manage their experiences of anxiety and stress about cancer and the treatment.

"I was shocked, I did not even know whether I was going to die soon, but they explained everything on cancer treatment and chemo." (Participant 9, female, 51 years)

"I was told I had cancer, and I lost hope because I knew people with cancer did not exist, but when I got here, I saw a nurse then I saw that they had helped me." (Participant 15, female, 59 years)

"I will not lie; I thought my life had ended. When I visited this facility, they explained nicely that cancer does not kill, but it can be cured". (Participant 16, female, 61 years)

Most of them admitted that their expectations were met as evidenced by improved health status.

"I got it because they [enlarged breast] are no longer the same as before." (Participant 11, female, 92 years)

"Yes, because the breast was removed, I was given treatment I have nothing now." (Participant 13, female, 66 years)

Two participants felt that their expectations were not met because of the side effects of the chemotherapy.

"No, sister, I have not yet got it [my expectations], because every time I feel I am getting better, the chemo pulls me down, and I feel myself falling." (Participant 3, female, 62 years)

"I got it, but I did not get it because I bleed; I want this bleeding to go down." (Participant 19, female, 32 years)

Quality of oncology services received by patients

All participants were happy with the quality of services during visits to the oncology unit. The data show that the waiting times were short, treatment always available, clinicians always attended to them, the clinicians were very helpful, caring, and loving towards them, and they received appropriate treatment and care.

4.3.2 Theme 2

Waiting time

The majority reported that a doctor saw them within a brief time during their last two visits. Nine participants indicated that they waited for less than 30 minutes, eight for 30 minutes to 1 hour, and only a few waited for more than 1 hour.

"13 minutes, we do not have to wait that long." (Participant 4, female, 75 years)

"Since I do not know how to count, I cannot say the exact time, but it was a few minutes." (Participant 14, female, 69 years)

"We do not wait for too long. It is just a while, I do not have to wait that long." (Participant 15, female, 59 years)

"I did not stay long; it was not more than 30 minutes." (Participant 10, female, 37 years)

"It depends on the reasons for the visit; if its chemotherapy, I am quickly attended to, but if it is for anything else, it is around 30 minutes." (Participant 9, female, 51 years)

"Over an hour." (Participant 16, female, 61 years)

4.3.3 Theme 3

Availability of human and material resources

All the participants reported that they had never visited the oncology unit and return home without being seen by a clinician.

“No, it did not happen to me, I always see a doctor.” (Participant 4, female, 75 years)

“No, I have never left without seeing a doctor.” (Participant 9, female, 51 years)

“No, it has not yet happened that I go home without seeing a doctor.” (Participant 12, female, 62 years)

Fourteen of the 15 participants with prescribed drugs stated that they had never returned home without their medications.

“Yes, I always get it [prescribed medications].” (Participant 7, male, 70 years)

“Yes, I got them [prescribed medications] all.” (Participant 9, female, 51 years)

“When I was coming here, I was told I would get them on Monday last week, but first I got them.” (Participant 11, female, 92)

The one participant who reported not having all her medications on one appointment date could not remember why she did not get them.

“One time I was seen by nurses, but I was not given the injection I came for. I do not remember the reason why I was not given the injection.” (Participant 16, female, 61 years).

Four participants had no prescribed drugs.

“I was prescribed medication in East London, where they did not make a prescription.” (Participant 19, female, 32 years).

“No, I have never been given pills here. It is only that injection.” (Participant 18, female, 63 years).

“I got the medication in East London.” (Participant 1, female, 70 years).

“Most of them did not tell me I was on treatment, so they just gave me the pills when I was there; the last time I was given pills was in eMadzikane; here in Mandela, I was not given pills. The doctor checked me then told me to go.” (Participant 2, female, 49 years).

4.3.4 Theme 4

Positive attitude of health care workers

Almost all participants described the nurses and doctors as caring and loving people. They experienced positive attitudes from the clinicians during patients' care and personally. The participants benefited from these positive attitudes and were very happy.

“I see they are very loving and very caring.” (Participant 11, female, 92 years)

“Yes, they are nice people; no one has ever shouted at me.” (Participant 8, female, 52 years)

“The nurses are right people who can talk to people well.” (Participant 19, female, 32 years)

“They are nice people that you find that I can be thinking about them even when I am home.” (Participant 13, female, 66 years)

“They are very nice people. One of the nurses gave me R20 and a lift without me asking for it.” (Participant 12, female, 62 years)

One participant added that she felt comfortable seeking advice from the nurses.

“They are nice people, who are easy to talk to or ask about things you are experiencing.” (Participant 10, female, 37 years)

On the other hand, one participant had a negative report about the attitude of nurses.

“The doctors are all nice, but there are only nurses who are rude.” (Participant 9, female, 51 years)



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4.3.5 Theme 5

Appropriate treatment and care

All the participants were satisfied with the treatment and care they were receiving at the study site. They were happy because the treatment and care they received were what is needed for cancer patients. Some of them noted that they had never left the facility stressed, and they had no complaints. Fifteen participants noted that they were receiving the appropriate treatment and care as evidenced by their improved health status.

"I would think so because as I am on treatment here, I am not sick of anything else; they said my hair may fall out, it has not fallen out; they said I will be dizzy and my colour will change." (Participant 12, female, 62 years)

"Yes, I get it...no more pain in the breast." (Participant 13, female, 66 years)

"They give me everything they said they were going to give me." (Participant 1, female, 70 years)

"Yes, I receive everything, and I take it well until it is finished. Yes, I came to do a scan this morning." (Participant 7, male, 70 years)

"Yes, I am getting chemo injections." (Participant 17, female, 57 years)

Two participants were unsure if they were getting the treatment and care they need as cancer patients.

"I do not know whether I am getting the right treatment or not; I do not know." (Participant 16, female, 61 years)

"I do not know; I just see myself being given medication." (Participant 11, female, 92 years)

4.3.6 Theme 6

Improved access to services

All the participants appreciated having this facility close to home and receiving cancer treatment. According to 89.5 percent of the participants, they can now access cancer care personnel and services with minimal delays.

“The issue with East London is it will be dated 17 May, and I will meet with a doctor again on 17 June or July and but here it takes 27 days.” (Participant 17, female, 57 years)

“It used to be a long process because I would have to sleep here, then wake up here going to East London, and when I am coming back, it is still the same process.” (Participant 10, female, 37 years)

“It has made a big difference. Since we have started being treated here, things have been easy.” (Participant 12, female, 62 years)

“Coming here is a big difference because here you see a doctor soon/early and go home early. When I go to East London, I stay at the waiting room. It is cold and be transported to East London.” (Participant 16, female, 61 years)

“Now it takes one day to see a doctor. This place is helpful.” (Participant 6, female, 55 years)

The participants are happy with the decentralized unit and prefer using this unit given the long waiting time, cost, and long-distance involved in traveling to the central hospital. Most of them specifically stated that it now takes a day to visit the facility and back home compared to two or three days and even a week when visiting the central hospital.

“Coming here, I go back from on the same day, but the time I was going to East London, I would have to sleep here first before going to East London.” (Participant 12, female, 62 years)

“It is 2days when I am going to East London, but it is a day coming here.” (Participant 17, female, 57 years)

“It was three days for East London; now it is a day.” (Participant 13, female, 66 years)

"I used to take a week to and from East London; now it is only a day to and from my home." (Participant 9, female, 51 years)

Another participant indicated that the maximum number of days it takes to visit the facility and back home was two days compared to a week when she was visiting the central hospital.

"I was taking a week to EL, now it is 2days. I sleep at my local hospital and go to Mthatha the following day and back to Matatiele same day." (Participant 10, female, 37 years)

In addition to accessing the facility within a shorter time, having the decentralized unit makes a high difference to the participant in terms of money spent during visits. Twelve participants noted that having the facility nearby is cost saving.

"I spend a small amount of money here than going to East London." (Participant 13, female, 66 years)

"Yes, before the journey was long, and I was using a larger amount than now." (Participant 10, female, 37 years)

"The money used to come to Mthatha is little, and I can prepare food for super at home and only use R60. But when going to East London, I spend more money because of the distance." (Participant 17, female, 57 years)

One participant added that travelling to the central hospital was not a good experience because they were insulted by the bus drivers. However, now, there is such experience, and she gets to spend less amount of money.

"The difference is huge; now I use 10 rands to come here. The time we were going to East London, using an ambulance was difficult; the drivers would insult us that the bus smells because of cancer wounds. Here we are given food to eat and tea; the difference is huge." (Participant 9, female, 51 years)

More than half of the participants also indicated that the decentralized unit is helpful to them since the distance travel is now shorter. The long-distance sometimes makes them sick. Considering their advanced age, they did not like the fact that they had to wake up early for the ambulance. They also did not enjoy sleeping outside of their homes.

"They are not the same because I was going to sleep here and wake up in the hospital to go to East London, now I just come from home and go back Home on the same day." (Participant 8, female, 52 years)

"A great difference, here it takes days going to East London, but here I sleep home the same day." (Participant 9, female, 51 years)

"Yes, there is a difference; I use to travel long distances that I get there sick." (Participant 16, female, 61 years)

"Great change. More especially for someone like me, we had to wake up early and wander that is difficult for someone like me." (Participant 4, female, 75 years)

However, one participant still wishes for such services to be closer to her residence, mainly citing her old age as the reason for making this request.

"I was expecting help to transfer my treatment to Matatiyela. I was expecting to be transferred to the hospital nearest to me for treatment because I am old." (Participant 5, female, 89 years)

Despite the high level of patient satisfaction with the unit, three participants expressed dissatisfaction with the infrastructural resources available.

4.3.7 Theme 7

Need for improved infrastructural facilities

These participants were clear about the need for improved infrastructural facilities. They complain about the overcrowding at the center, expressing fears of contracting Covid19. They also raised insecurity, lack of warm water for bathing, lost hospital files, and delayed delivery of laboratory results.

"I am happy, but the process is tiring. It would be better if there were beds so that I get the drip in bed." (Participant 12, female, 62 years)

"The water is cold for bathing in the morning for those who sleep here. There is also the issue of security guards. It is not safe where we are sleeping when going to East London. There is a mistake in the list that is made when we get into these ambulances going to

East London. Moreover, as there is a Covid, the place where we sleep is congested.”
(Participant 9, female, 51 years)

“The results take longer to come out, and at times they say that your file is lost, they should take note of that.” (Participant 16, female, 61 years).

4.4 Discussion of results

4.4.1 Demographics

Demographic information in this study composed of race, age, gender, year of diagnosis and number of months receiving therapy at a public tertiary hospital.

4.4.1.1 Race

In this study, all the participants were blacks. The reason for this race representation is likely to be the fact that, the study was conducted in OR Tambo district which is predominantly a black community. According to Statistic South Africa census, (2011), the population of O R Tambo District Municipality is 1 364 943. About 99 percent of this population is black.



A study conducted in the United States of America, found that the breast cancer incidence rate in age-adjusted population is higher in Non-Hispanic White women than other races (Singh et al., 2014). Another study conducted in the United States of America found that Black and Hispanic women had high incidence of cervical cancer (Yu, Sabatino, & White, 2019). Why?

4.4.1.2 Age

This study found that majority of participants were older than 50 years. It was only one participant who was between ages of 41 years and 50 years; one participant between the ages of 35 years and 40 years whilst another participant was under the age of 35 years. Researchers, agree that cancer patients are increasingly getting older (Bluthmann et al., 2016; Miller et al., 2016). As you get older you are more likely to get cancer. Old age is the biggest risk factor for cancer. Researchers are not sure what is the reason for this. It

could be the fact that elders have been exposed for longer to cancer-causing agents like sunlight, cigarette smoke, and other chemicals (Pilleron, S., Sarfati, Janssen-Heijnen, Vignat, Ferlay, Bray & Soerjomataram, 2019).

4.4.1.3 Gender

Almost all study participants were females, and only 1 participant was a male. According to Eastern Cape Cancer Registry report of 2003 to 2007, about 60% of confirmed cancer patients in the province were females. The South African National Cancer Registry report of 2018 shows that 52% of cancer patients in the country are females. Although this study could not delineate the kinds of cancers, researchers concur with these results to say that the female cancers in the country are on the rise, especially breast cancer and cervical cancer (Mbeje et al., 2021). On the other hand, it would be interesting to study why women are on the rise with cancer statistics.

4.4.1.4 Year of diagnosis of patients

Less than half of all participants were recently diagnosed between 2020 and 2021. This shows that there are still many people who come to our hospital very late when the cancer has advanced. Other researchers agree with the findings of this study that majority of cancer patients present late at the hospital when cancer has advanced (Dunyo, Effah & Udofia, 2018). They attributed this phenomenon to socio-demographic factors in the society. These factors were level of education, employment status, marital status and distance between residence and hospital.

Another study conducted in Pakistan in 2017, found that majority of patients with cancer of the cervix present late when the disease has advanced. The late presentation was attributed to unavailability of pap smear and lack of awareness (Batool et al., 2017).

4.4.1.5 Duration of treatment

Less than half of the participants have been receiving therapy at oncology clinic for less than 6 months. Few of participants have been receiving treatment at oncology clinic between 6 months and 12 months. Majority of participants have been attending the oncology clinic for more than 12 months. Of these patients less than a half visit the clinic twice or more a month because of the need for frequent monitoring. The majority of the

participants visit the clinic once a month. All these patients come by appointments and most of those appointments are reviews for patients who are already receiving treatment. This means that these patients are responding well to treatment and are clinically stable

4.4.2 Themes

4.4.2.1 Theme 1: Experiences related to satisfaction with services provided and desired expectations.

All the participants had positive experiences regarding the services provided to them and what they expected from the oncology unit. These results concur with other studies showing that decentralization of oncology services leads to positive experiences and improved patient outcomes (Arenas et al., 2015; Wilkens et al., 2016). The decentralization of oncology services to this public tertiary hospital showed improved patientcare and reduced workload to its referral tertiary hospital. This is confirmed by participants that they are always attended by the healthcare workers on their appointments and the services they get from the facility are satisfactory. There is also a decrease in number of patients that are referred to East London. In developed countries, the decentralization of cancer services led to improved patient outcomes, where clinicians had fewer patients to attend to, thus increasing provider-patient interaction and reducing workload at higher facilities (Arenas, Gomez, Sabater, Rovirosa, Biete, & Colomer, 2015; Wilkens, Thulesius, Schmidt, & Carlsson, 2016)

4.4.2.2 Theme 2: Waiting time.

Below is a table illustrating average patient waiting time per level of health institution according to the National Core Standards 2011.

Table 5.1: Showing Standardized Patient waiting time in various levels of public health facilities.

Level of a hospital	Patient waiting time (in hours) for service/s per visit	Total time (in hours) spent by a patient per visit
Specialized hospitals	1	2
PHC facilities	2	3
District Hospitals	2	3
Regional hospitals	3	4
Tertiary hospitals	3	4

In the above Table 5.1 the majority reported that a doctor saw them within a brief period of time during their last two visits. Nine participants indicated that they waited for less than 30 minutes, eight for 30 minutes to 1 hour, and only a few waited for more than 1 hour. According to the results the unit is complying with the National Core Standards and 6 priorities of former minister of health Dr Aaron Motsoaledi (2011) as displayed in Table 5.1. According to National Core Standards acceptable waiting time is up to 3 hours for a tertiary hospital. Most patients were seen by the clinicians within an hour which is the acceptable waiting time. Therefore, decentralisation of oncology services in this public tertiary hospital did not compromise the quality of services. Oncology services offered in this decentralised unit meet the criteria for National Core Standards.


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4.4.2.3 Theme 3: Availability of human and material resources.

All the participants reported that they had never visited the oncology unit and return home without being seen by a clinician. The findings of the study are in line with the purpose and rationale of decentralization where smaller organizations are integrally accountable and more responsive than larger organizations. Other study conducted in Finland show similar results. The study showed that decentralization of oncology services improved patient care, access to treatment and had positive outcomes, especially where clients found it difficult to travel to centralized centers (Khatri, Peterson, Kyriazokos, & Prasad, 2011). In a healthcare setting, the possibility of establishing more locally operated, locally responsible institutions, holds out great desirability compared to centralized services (Azfar et al., 2018). In this decentralized oncology unit, collected data showed that all patients were seen by clinicians every day they come for treatment. This has a positive impact on the services rendered by the unit. When patients come to hospital for treatment,

they always expect to be seen by a doctor. When that does not happen due to overcrowding or shortage of staff, the quality of the service rendered is negatively affected. The health system in South Africa has a crisis of staff shortage (Malakoane, Heunis, & Kruger, 2020). However, it was also reported that challenges of a deficiency of radiographers in hospitals, ageing equipment and a burden of high cancer patients (Stefan, 2015) were a negative reflection on the facility. In addition, researchers agree that the immense oncologist crisis, with a liberal decrease in clinical and radiation oncologists in the academic and state sector are not rare observations (Balogun, Rodin, Ngwa, Grover, & Longo 2017. What the recommendation for this challenge?

4.4.2.4 Theme 4: Attitude of health care workers.

Almost all participants described the nurses and doctors as caring and loving people. They experienced positive attitudes from the clinicians during patients' care and personally. The participants benefited from these positive attitudes and were very happy. Other studies concur with the findings of this study. A study was conducted in Malaysia found that positive staff attitude is an important element of good care (Tan et al., 2017). Positive staff attitude influences the recovery of the patient positively. Also, other studies found that staff attitude and knowledge are major factors that affect successful recovery of chronically and terminally ill patients (Kassa et al., 2014; Skar et al., 2014; Parveen et al., 2020). Other facilities can benchmark in this one

4.4.2.5 Theme 5: Appropriate treatment and care.

All the participants were satisfied with the treatment and care they were receiving at the facility. They were happy because the treatment and care they received were what is needed for cancer patients. Some of them noted that they had never left the facility stressed, and they had no complaints. Similar effects of health system decentralization were observed in a study conducted in Honduras. The study focused on making social services work better for the poor. There was an increase in production of preventative

women health services. There was also an increase in consultations of patients with clinicians, and improvement in healthcare service delivery (Zarychta, 2020). Fifteen participants noted that they were receiving the appropriate treatment and care as evidenced by their improved health status. Contrary to the report released by South African Human Rights Commission on how the Department of Health had failed its cancer patients, the oncology unit at this public tertiary hospital managed to provide appropriate treatment and care to its patients. The report also said that not only had the number of specialist doctors declined but hospitals had a shortage of chemotherapy drugs (Kollapen, Carnelly, Jaichand, Lawrence, Oguttu, Sello, & Siwendu, 2017). The shortage of specialist doctors and chemotherapy drugs have a negative impact on service delivery. The quality of services is compromised by the shortage of human and material resources.

4.4.2.6 Theme 6: Access to services.

All the participants appreciated having this facility close to home and receiving cancer treatment. According to the majority of the participants, they can now access cancer care personnel and services with minimal delays. The data collected from the participants showed that bringing the oncology services closer to people helped them ease the burden of travelling the long distances for treatment. Decentralization of oncology services close to reach areas improved patient care and positive outcomes, and access to treatment, especially where clients found it difficult to travel to centralized centers (Khatri, Peterson, Kyriazokos, & Prasad, 2011). Decentralization also led to an increase in access by removing the impediment of travelling a long distance to obtain cancer care services (Arenas et al., 2016). The study findings are in line with Batho-Pele principles (1997) as far as access to services is concerned. It states that all South African citizens should have access to services to which they are entitled to.

4.4.2.7 Theme 7: Need for improved infrastructural facilities.

These participants were clear about the need for improved infrastructural facilities. They complained about the overcrowding at the centre, expressing fears of contracting Covid-19. They also raised insecurity, lack of warm water for bathing, lost hospital files, and delayed delivery of laboratory results. The findings in the study are

in line with other studies conducted by other researchers such as Saad (2015), and Jenkins et al., (2019). According to Saad (2015), the major challenge in screening, diagnosis and treatment of cancer is lack of proper infrastructure and resources. Lack of infrastructure is a common challenge in developing countries (Saad, 2015). When it comes to radiotherapy equipment, the issue is exponentially more complicated when it comes to equipment acquisition, operation, and maintenance (Saad, 2015). A study done in Vietnam among healthcare professionals revealed that oncology service provision was hindered by a lack of resources both in relation to skilled healthcare providers and health infrastructure for the management of cancer. (Jenkins, Ngan, Ngoc, Phuong, Lohfeld, Donnelly, Van Minh, & Murray, 2019). The participants also complained about lost hospital files. According to Koelble & Siddle (2014), the available medical records system is still an old-fashioned hard copy file system, housed in an archive room that no longer fits the huge number of files. Kilonzo & Ikamari (2015) argues poor record-keeping system which has led to the loss of a quantity of valuable information and patient uneasiness due and increasing waiting times for their file retrieval (Kilonzo & Ikamari, 2015). Therefore, there is a need to develop a paperless based filing system. This will eliminate the risk of losing medical records. Furthermore, it will reduce waiting time taken to look for hard copy files.

4.5 Conclusion

This chapter presented results of the study and discussions. Demographic information outlined. Data collected through interviews was grouped into themes and sub-themes. Grouping was guided by the responses from the participants. Many participants were satisfied with the quality of services rendered by the oncology unit. There are still areas for improvement in terms of infrastructure, filing and security. The next chapter will give conclusion, summary, limitations, and come up with recommendations.

CHAPTER 5: CONCLUSION, SUMMARY, LIMITATIONS AND RECOMMENDATIONS

5.1. Introduction

The previous chapter presented the results of the study and discussions. This chapter will give conclusion, summary, limitations, and recommendations.

5.2 Conclusion

The purpose of this study was to explore the experiences of patients diagnosed with cancer regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape province of South Africa. With 2 objectives which were, 1) to describe experiences of patients diagnosed with cancer regarding decentralization of oncology services at a public tertiary hospital in the Eastern Cape and 2) to explore the views of oncology patients regarding the quality of oncology services provided by a public tertiary hospital in the Eastern Cape.

On the findings of the study seven themes emerged: 1) high level of satisfaction with services, 2) acceptable waiting time, 3) availability human and material resources, 4) positive attitude of health care workers, 5) appropriate treatment and care, 6) access to services, and 7) need for improved infrastructural facilities. Study findings showed that patients diagnosed with cancer, attending oncology clinic at a public tertiary hospital had positive experiences in this decentralized oncology unit. Their positive experiences were based on quality of services rendered to them by the oncology unit. All their expectations were met by the unit. Their experiences and treatment journey were also made easy by positive staff attitudes. All patients were treated well by the staff, they were also given the necessary support like counselling. They were attended as soon as possible. This led to shorter waiting times. The availability of medicine was also a noted positive factor in their experience. Even though there were complaints about infrastructure, poor hospital record keeping, and lack of resources, the overall experiences of patients were positive, and the quality of services were of an acceptable standard.

5.3 Summary

The study intended to explore the experiences of patients diagnosed with cancer regarding decentralization of oncology services at a selected public tertiary hospital oncology unit. Cancer burden is a global public health concern. Worldwide, the estimated incidence of cancer is around 14 million new cases per year, and it is expected to expand to 22million annually within the next 20 years (McGuire, 2016; Bray et al.,2019).

South Africa has embraced a process of decentralization in the rearrangement of healthcare and oncology services (Roberts et al., 2014; Lateef, 2011). Decentralisation is meant to bring services to the users, thereby making them accessible.

A qualitative research approach with a descriptive, explorative, and contextual design was undertaken in this study, to get the perspective of the oncology healthcare service recipients on the decentralization of oncology services at a selected public tertiary hospital. The study's objectives were, 1) to describe experiences of patients diagnosed with cancer regarding decentralization of oncology services at a public tertiary hospital in the Eastern Cape, 2) to assess the quality of oncology services provided by a public tertiary hospital in the Eastern Cape.

The study explored the experiences of cancer patients attending the oncology unit. Many patients had positive experiences about decentralization of oncology services in the province. Most patients were happy about travelling short distances, a smaller number of days, using less money and the time it takes to see a doctor. They also expressed their satisfaction on the quality of oncology services rendered in the unit. The waiting times were acceptable, medicines available and staff had positive attitudes towards the patients. There are still areas of improvements as highlighted on the recommendations below. The study achieved its main purpose of exploring the experiences of oncology recipients regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape.

5.6 Limitations of the study

The study was limited to one hospital (selected public tertiary hospital). However, the findings of the study could be used in similar setting somewhere else. The study was conducted during COVID- 19 pandemic. These were the difficult times which proved to be a challenge and a limitation as human interaction was observed and restricted.

5.7 Recommendations

- Improve infrastructure by adding more buildings for waiting area, wards for admission and proper sleepover wards. This will help in controlling overcrowding and reduce the risk of spreading and contracting COVID-19 infection.
- Employ more skilled healthcare workers like qualified oncologists and radiographers. This will improve the quality of oncology services rendered by the unit. Now there is only one qualified oncologist in the hospital.
- Improve security level by placing a security guard at sleepover ward.
- Expand services, like adding radiotherapy services in the unit. This will help patients who still travel to East London for radiotherapy.
- Develop paperless based filing system. This will eliminate the risk of losing medical records. Furthermore, it will reduce waiting time taken to look for hard copy files.
- Engage more on cancer awareness programs as there are still many people who come to hospital late when the cancer has advanced.

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INTERVIEW GUIDE FOR PATIENTS ATTENDING ONCOLOGY CLINIC

Please supply information where necessary and tick where appropriate.

SECTION A

SOCIO-DEMOGRAPHIC INFORMATION

1. Race ☐ Black ☐ White ☐ Coloured ☐ India
2. Age ☐ 35-40 ☐ 41-50 ☐ 50 and above
3. Sex: Male ☐ Female ☐
4. Year diagnosed with cancer
5. Number of months receiving therapy in NMAH ☐ 0-6 months ☐ 6-12 months ☐ >12 months

SECTION B

EXPERIENCES OF PATIENTS

6. How often do you visit the facility to receive cancer care services?
☐ Once a month ☐ two or more times a month
7. What is your experience at this oncology unit?
8. When you came to this clinic, what were your expectations?
9. Were your expectations met by the clinic? If not, what would you have wanted to happen?

QUALITY OF ONCOLOGY SERVICES

10. In your previous two visits, how long did you have to wait to be seen by a Dr?
☐ ≤ 30 minutes ☐ 30 minutes-1 hour ☐ > 1-2 hours ☐ > 2 hours

11. In your previous two visits, did you receive all prescribed medication for your treatment?

If not please

explain _____

—

12. Have you ever been sent home without being seen by a healthcare worker in this unit? If yes, what do you think was the cause of that?

Please

explain _____

13. How nice were the Nurses and Doctors at this oncology unit?

Please
explain_____

—

14. According to your expectations, do you get treatment and care you need as patients suffering from cancer in this unit?

Please
explain_____

15. Are you happy with the services you are receiving at this facility?

Please
explain_____

16. With the services brought closer to people, what difference has the opening of the unit brought in terms of accessibility? (Time, transport money and distance)

a) - Waiting time, is there any change in the waiting time before patients are seen by doctors?

Please
explain_____

- Time taken to access the service, is there any change in time taken from home to the oncology unit?

Please
explain_____

b) - Transport money, do you find it helpful that the transport money is reduced?

Please
explain_____

c) – Distance, now that the distance has been cut short, what difference has that brought in patients?

Please
explain_____

17. Are there any other comments you would like to make about the cancer-care services at this hospital?

This is the end of the interview – thank you very much for your time.

INFORMED CONSENT FOR PARTICIPANTS

Dear Participant,

You are kindly invited to participate in a research study entitled: Experiences of Patients Diagnosed with Cancer Regarding Decentralization of Oncology Services at a Tertiary Hospital in the Eastern Cape. I am currently enrolled for the Master of Public Health (MPH); Albertina Sisulu Executive leadership Program (ASELPH), at the University of Fort Hare and I am in the process of writing my dissertation for partial fulfilment of the requirements of the degree.

Previously, the cancer care services were offered in East London and Port Elizabeth, in the Buffalo City Metropolitan Municipality and Nelson Mandela Bay Metropolitan Municipality, respectively. It was only in 2018 when a semi-functional oncology unit was opened at Nelson Mandela Academic Hospital. The unit is currently offering limited services, as it does not provide radiotherapy. The purpose of this study would be to describe experiences of patients diagnosed with cancer regarding decentralization of oncology services at a Nelson Mandela Academic Hospital.

The significance of this study is to outline the experiences of cancer patients receiving oncology services at Nelson Mandela Academic Hospital, identify challenges and come up with recommendations on how to address those challenges at the district and provincial level. The factors could be addressed to strengthen oncology services at the hospital to improve patient care and positive patient outcomes.

The interview guide has been designed to collect information on your views about the oncology services at Nelson Mandela academic hospital. The questions are open-ended, meaning that you can add any information that is relevant that might not be part of the questions.

Your participation in this research project is completely voluntary. You may decline altogether or opt-out during the interview process for any reason. There are no risks of you or your family in receiving cancer treatment at this facility. Participation will not jeopardise your or your family members cancer management at this facility. If you are part of the oncology unit staff, your participation will not jeopardise your employment or job function at the Nelson Mandela Academic hospital. Your responses will remain confidential and anonymous. Data from this research will be securely kept and reported only as a collectively combined total. No one other than the researchers will know your individual answers to this questionnaire.

If you agree to participate in this project, please answer, the questions on this face-to-face interview to the best of your knowledge. It should take approximately 30 minutes of your time to complete the interview process.

If you have any questions about this research, feel free to contact Dr Lumkile Jojo on 0718977251

Thank you for your assistance in this important endeavour.

Sincerely yours,

Principal investigator

Dr Lumkile Jojo

I agree/don't agree _____ to participate in this study

Date _____



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HEALTH RESEARCH ETHICS COMMITTEE

P.O. Box 1054
East London 5200
Tel: +27 (0) 43 704 7368
E-mail: dgoon@ufh.ac.za

ETHICAL CLEARANCE CERTIFICATE REC-100118-054

Certificate Reference Number: **Ref #2021=03=07=JojoL**
Project title: **Experiences of patients diagnosed with cancer regarding decentralization of oncology services at a Tertiary Hospital in the Eastern Cape, South Africa**
Nature of Project: **Masters of Public Health**
Principal Researcher: **Jojo L**
Student Number: **201920210**
Supervisor: **Dr N Nkutu**

On behalf of the University of Fort Hare Health Research Ethics Committee (HREC), I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instruments(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the HREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the HREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.



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HEALTH RESEARCH ETHICS COMMITTEE

P.O. Box 1054
East London 5200
Tel: +27 (0) 43 704 7368
E-mail: dgoon@ufh.ac.za

The HREC retains the right to

- **Withdraw or amend this Ethical Clearance Certificate if**
 - Any unethical principles or practices are revealed or suspected
 - relevant information has been withheld or misrepresented
 - regulatory changes of whatsoever nature so require
 - the conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.
- In addition to the need to comply with the highest level of ethical conduct principal investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to HRECmonitoring@ufh.ac.za.

The Ethics Committee wishes you well in your research endeavours.

Yours sincerely

Professor DT Goon
Chairperson: HREC
5th March 2021

Enquiries: Yvonne Gixela

Tel no: 079 074 0859

Email: Yvonne.Gixela@echealth.gov.za / yglxela@gmail.com

Date: 15 March 2021

RE: Experiences of Patients Diagnosed with Cancer regarding Decentralization of Oncology Services at a Tertiary Hospital in the Eastern Cape. (EC_202103_007)

Dear Dr L. Jojo

The department would like to inform you that your application for the abovementioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress update on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.



SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

**TOGETHER, MOVING THE HEALTH SYSTEM
FORWARD**





Province of the
EASTERN CAPE
HEALTH

11 March 2021

Clinical Governance

Nelson Mandela Central Hospital

Mthatha

5099

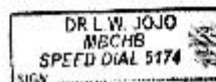
Permission to conduct a study at oncology unit in the hospital

I Dr Lumkile Jojo, would like to request a permission to conduct a study at oncology unit. I am currently doing my Masters in Public Health, and I am required to conduct a study/research to fulfil the requirements of the degree. My research topic is "Experiences of patients diagnosed with cancer regarding decentralization of oncology services at a tertiary hospital in the Eastern Cape". I have also requested permission from the Eastern Cape Department of Health.

Please find the attached supporting documents for the study.

Kind regards

Dr L.W. Jojo



MBChB (WSU), DOH (UKZN)

Cell : 071 897 7251

Email : lumkilejojo@gmail.com



Province of the
EASTERN CAPE
HEALTH

11 March 2021

Head of Department Oncology Unit
Nelson Mandela Central Hospital
Mthatha
5099

Permission to conduct a study at oncology unit in the hospital

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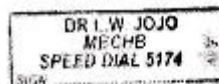
Kind regards

Dr L.W. Jojo

MBChB (WSU), DOH (UKZN)

Cell : 071 897 7251

Email : lumkilejojo@gmail.com





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Dr. LW. Jojo
Nelson Mandela Academic Hospital,
Sisson Street,
Fortgate
Mthatha,
5099

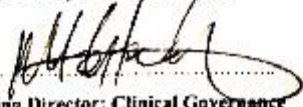
RE: APPROVAL FOR YOU TO CONDUCT RESEARCH AT NELSON MANDELA ACADEMIC HOSPITAL (NMAH).

This communicate bears reference to your application/request to conduct clinical research at NMAH.

In reference to the Human Research Committee Clearance Certificate from Eastern Cape Department of Health, would like to inform you that your request/application has been approved. The approval is based on you meeting the conditions stipulated in the certificate issued to you by the University as attached. Kindly note that the approval is strictly restricted to the study as specified in your proposal seen by the institution. Any deviation should be accompanied by pre-approval and without such it will be prohibited and this letter could nullified. The institution and the Department reserve the right to change part or whole of the condition/s when it is deemed necessary. All relevant stakeholders that you may need for this research within the institution will be notified accordingly.

Failure to adhere to such conditions will result in unconditional withdrawal of this letter with immediate effect.

Clinical Governance Office wishes you all the best of luck and if there is any further assistance you may need, you are welcome.


Acting Director: Clinical Governance
Nelson Mandela Academic Hospital
Dr. M. Ndlekisa
Date: 01/04/2021


Acting Chief Executive Officer
Nelson Mandela Academic Hospital
Dr. M. Mdledle
Date: 01/04/2021



DeColigny Mission Mthatha.
Wednesday, 4th August 2021.

To whom it may concern

Confirmation of data analysis

Ref: Student N° 201920210

This serves to confirm that I, MK Nanjoh analysed the data for the research entitled
"Experiences of Patients Diagnosed with Cancer regarding Decentralization of Oncology
Services at a tertiary hospital in the Eastern Cape".

If in need of more information, send a correspondence to mirabelnanjoh@gmail.com or
dial 0711494716.

Regards



Mirabel. K. Nanjoh
BNS, B Hons. Medical Physiology, MPH.