



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

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ABSTRACT

Background: The cancer burden is a global public health concern associated with high morbidities and mortalities. Low and middle-income countries are more affected including South Africa. Limited access to oncology services contributes to the late presentation, late diagnosis, and treatment of cancer. In the Eastern Cape, oncology services were previously centralized with negative effects on the quality of life of the already compromised health status of the oncology patients. To mitigate the situation, a new oncology unit was opened to decentralize oncology services in the province. Little is known about the experiences of consumers after this transformation. That prompted this inquiry.

Objective: This study aims to explore the experiences of cancer patients regarding the decentralization of oncology services to enhance the quality of life of these patients.

Methodology: A qualitative approach with a descriptive, explorative, and contextual design was undertaken, to get the perspective of oncology recipients following the decentralization of oncology services at a selected public tertiary hospital in the Eastern Cape. After obtaining ethical clearance and permission to conduct the study, interviews were conducted with 19 participants. All interviews were transcribed verbatim against their audio recordings. Field notes were taken by the researcher. The concept of trustworthiness was used to ensure rigor throughout this study. Thematic analysis was done using Tesch's approach to open coding in qualitative research.

Results: Seven themes emerged: 1) level of satisfaction; 2) waiting time; 3) human and material resources; 4) attitude of health care workers; 5) appropriate treatment and care, 6) access; and 7) improved infrastructural resources.

Conclusion: The majority of patients had positive experiences with the unit. The waiting time was acceptable, and medication was available. Access to services was improved. The staff had a positive attitude.

Keywords: Decentralization; Health care; Cancer; Mortality; Morbidity

INTRODUCTION

The cancer burden is a global public health concern with an estimated incidence of around 14 million new cases per year, expected to expand to 22 million annually within the next 20 years [1,2]. The disadvantaged and minority population suffer worse outcomes compared with white people from Western societies [3,4]. 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 [5].

The staging of cancer and treatment options plays a crucial role in cancer treatment outcomes [6]. 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 transformation of health

care and oncology services [7]. Decentralization is meant to bring services closer to the users, thereby making services more accessible to 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.

There has been a need for the 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 a distance of 356 km. This distance travelled with halfway stops added much strain on the already compromised quality of life of the cancer patients. To reduce the strain on traveling, a decentralized oncology department was built so that cancer patients could get their services closer home without having

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to sleep on benches halfway before they could be reviewed. Since the opening of the Centre, no studies have been conducted to assess how cancer patients feel now that the services are brought closer to their doorstep. Therefore, this has prompted the researcher to conduct this study.

Aim of the study

The paper aimed 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.

Objectives of the study

To determine and describe how patients diagnosed with cancer experience decentralization of oncology services at a public tertiary hospital in the Eastern Cape. Province, South Africa.

Research question

What are the experiences of cancer patients regarding the decentralization of oncology services at a public tertiary hospital in the Eastern Cape Province, South Africa?

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 also excluded.

Research setting

The research was conducted at the oncology unit of a public tertiary hospital, in OR Tambo Municipality of the Eastern Cape Province of South Africa. The unit 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 appears quite busy although it only has 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.

MATERIALS AND METHODS

Ethical clearance

Ethical clearance to conduct the study was obtained from the University of Fort Hare ethics review committee (Ref#2021=03=07=JojoL) followed by the acquisition of permission from the Department of Health epidemiological research unit.

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 hypotheses, and evaluate outcomes [8]. In this study, data were collected through semi-structured, one-on-one interviews until the data saturation point was reached. An interview guide with open-ended, semistructured questions was developed as a research instrument. 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 was used to promote trustworthiness, as cited by Polit and Beck (2017).

Research instrument

A research instrument is a tool or a method by which a researcher obtains data from the participants for his research project [9]. 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 the 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.

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, and 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 that the researcher recruited the participants after the observations and was 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 were 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 audiorecorded 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.

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 [10]. 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 [11]. 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 [12]. 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 labeled '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 recorded where necessary [13].

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.

RESULTS AND DISCUSSION

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. Most of the participants were females. Out of the 19 participants, 18 were female and only one was male (Table 1). Below shows themes and subthemes that emerged from the analysis.

Table 1: Showing themes and subthemes.

Themes	Subthemes
<ul style="list-style-type: none"> • Positive experiences related to a high level of satisfaction with services provided and desired expectations • Negative experiences related to oncology 	<ul style="list-style-type: none"> • Participants were unanimous in experiencing good service delivery which was voiced by "satisfaction with services offered to them and that gave participants a high level of expectations of getting well." • Fear of dying. • Anxiety and stress about cancer and the treatment.
Waiting time	Not wait for too long, I am quickly attended to.
Availability of human and material resources	Always get prescribed medications.
An attitude of health care workers	Caring and loving people. "The doctors are all nice, but there are only nurses who are rude." (Participant 9, female).
Appropriate treatment and care	Improved health status.
Improved access to services	Facility close to home.

Need for improved infrastructural facilities	<ul style="list-style-type: none"> • Overcrowding at the center, fears of contracting COVID-19. • Insecurity, lack of warm water for bathing, lost hospital files, and delayed delivery of laboratory results.
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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. This study found that majority of participants was older than 50 years. It was only one participant who was between the ages of 41 years and 50 years; one participant between the ages of 35 years and 40 years whilst another participant between the age of 35 years. Researchers agree that cancer patients are increasingly getting older [14,15]. 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 the reason is 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 [16].

Most of the participants were females. Out of the 19 participants, 18 were female and only one was male. According to the 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 those female cancers in the country are on the rise, especially breast cancer and cervical cancer [17].

Themes

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 [18,19]. The decentralization of oncology services to this public tertiary hospital showed improved patient care and reduced workload to its referral tertiary hospital. This is confirmed by participants that they are always attended to by the healthcare workers during their appointments and the services they get from the facility are satisfactory. There is also a decrease in the 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 [18,19].

Theme 2-waiting time: According to the National Core Standards 2011, the average patient waiting time for Specialized Hospitals is one to two hours, for Public Health Centres is two to three hours, for District Hospitals is two to three hours, for Regional Hospitals is three to four hours, and for Tertiary, Hospitals is three to four hours.

In this study, most participants reported that a doctor saw them within a brief period 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 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, decentralization 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.

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 [20]. In a healthcare setting, the possibility of establishing more locally operated, locally responsible institutions, holds out great desirability compared to centralized services [21]. 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 [22]. However, it was also reported that challenges of a deficiency of radiographers in hospitals, ageing equipment and a burden of high cancer patients 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 is not rare observations [23,24]. What the recommendation for this challenge?

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. These studies found that staff attitude and knowledge are major factors that affect successful recovery of chronically and terminally ill patients [25,26].

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 was 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 increase in consultations of patients with clinicians, and improvement in healthcare service delivery [27]. 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 [28]. The shortage of specialist doctors and chemotherapy drugs harm service delivery. The quality of services is compromised by the shortage of human and material resources.

Theme 6-access to services: All the participants appreciated having this facility close to home and receiving cancer treatment. According to most 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 [20]. Decentralization also led to increase in access by removing the impediment of travelling a long distance to obtain cancer care services [18]. 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.

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 and Jenkins et al. According to Saad, 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 [29]. When it comes to radiotherapy equipment, the issue is exponentially more complicated when it comes to equipment acquisition, operation, and maintenance. A study done in Vietnam among healthcare professionals revealed that oncology service provision was hindered by a lack of resources both to skilled healthcare providers and health infrastructure for the management of cancer [30]. The participants also complained about lost hospital files. According to Koelble and 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 and Ikamari 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 [31-37].

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 (Figure 1).

CONCLUSION

The findings of the study showed that patients diagnosed with cancer, attending oncology clinic at selected public tertiary hospital had positive experiences in this decentralized oncology unit. Their positive experiences were based on the 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 counseling. They were attended to 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.

DECLARATIONS

Ethics approval and consent to participate: All methods were carried out in accordance with the Declaration of Helsinki.

Ethical clearance to conduct the study was obtained from the University of Fort Hare ethics review committee (Ref # 2021=03=07=JojoL) followed by the acquisition of permission from the Eastern Cape

Department of Health epidemiological research unit.

Informed consent was signed by all participants in accordance with Helsinki Declaration.

CONSENT FOR PUBLICATION

Not applicable.

AVAILABILITY OF DATA AND MATERIALS

All data available on request from the corresponding author.

COMPETING INTERESTS

No competing interests.

FUNDING

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AUTHORS CONTRIBUTIONS

L.W. Jojo prepared the manuscript. N.T. Nkutu guided L.W. Jojo and revised the manuscript. Both authors read and approved the final manuscript.

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