peer reviewed **ORIGINAL ARTICLE**

A proposed framework for "patient as a person" journey through a multi-level public healthcare system in accessing CT for localisation pre-radiation therapy treatment: a qualitative study

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ABSTRACT

Introduction. Accessing radiation therapy treatment is a complex journey in the multilevel public healthcare system in South Africa. A framework was incorporated in this study to illustrate the interplay between a patient as a person journeying through the healthcare system, to the point of the computed tomography (CT) for localisation in pre-radiation therapy treatment series.

Methods. A qualitative inquiry, underpinned by hermeneutic phenomenological philosophical interpretation and analysis through semi-structured interviews, enabled acquiring insights into patients' expectations and experiences as they transited through the health system's processes and procedures of the CT for localisation in pre-radiation therapy treatment.

Findings. The participants' (patients) expectations of their anticipated radiation therapy localisation procedure and experience thereof were shaped and re-shaped by their recent and/or previous encounters within the multilevel public healthcare system. They shared their interactions with various healthcare professionals including diagnostic imaging examinations and/or management and treatment interventions and how these impacted on their quality of life. They adopted a passive, co-operative stance; a go with the flow of the system as uncertainty and the unpredictable disease were already complex to deal with. Despite the latter, they remained hopeful to undergo their upcoming radiation treatment so that they would be able to return to normalcy.

Conclusion. The proposed framework illustrates the interdependence and interrelatedness of the public healthcare system's processes and procedures. Recommendation is to include each patient as a person's transitioning pathway through the healthcare system as part of seeking a solution to their problem in dealing with the unpredictable nature of their disease in order to regain a quality life.

Keywords radiation therapy, cancer care, life-world, biomedical world

LAY ABSTRACT

The experiences of cancer patients were sought in terms of what they encountered during their preparation stages for cancer treatment in a public sector healthcare system in South Africa.

INTRODUCTION

Cancer patients face complex challenges. They have to cope with their disease whilst navigating the diagnostic and treatment phases of the cancer care continuum.[1] The South African health system comprises public and private sectors, respectively. The former is divided into primary, secondary and tertiary levels of care; referrals between these levels are governed by specific guidelines.[2-5] The private health sector is divided into a large corporate private-for-profit hospital sector, and a smaller and more diverse private-not-for-profit sector.[2,6] According to Palmer et al.[7] this type of fragmented approach impacts on a health system and on patients financially and clinically in terms of providing optimal continuity of care.

In the Republic of South Africa, patients enter at the primary or district level to access diagnostic and cancer treatment services in the multilevel hierarchical fragmented public healthcare system.[8] In some cases patients can access regional or tertiary institutions; if they have multiple trauma or if their medical funds are depleted they then bypass the traditional access pathways.[9] In the public sector, patients may have different clinical pathways when accessing radiation oncology services. Within a radiation oncology department, patients consult with a radiation oncologist and attend a radiation therapy (RT) division where they undergo a radiation therapy (RT) computed tomography (CT) based localisation procedure pre-RT treatment series.[10]

From a cancer care perspective, Taplin et al.[11] emphasise that to improve patient care, healthcare professionals (HCPs) should be cognisant of the phases and subsequent transitions in the cancer care continuum. Patients' experiences shift between various phases and are contextually influenced. For example, RT treatment based on a localisation procedure is a transitioning phase between diagnosis and treatment. A RT treatment localisation procedure entails the use of specialised technology i.e. computed tomography (CT)[12] to plan the doses of the RT to follow. Very little attention has been given to patients' expectations and experiences of their CT for their localisation procedure. In this study we explored patients' expectations and experiences between transits of the cancer care continuum[11]

focusing on diagnostic imaging encounters. Our focus was on CT for localisation pre-RT planning within a complex multi-level public healthcare system's processes and procedures.

METHODS

A qualitative methodology, using a hermeneutic phenomenological approach[13] was used in this study to explore specific transitions for patients diagnosed with cancer. A phenomenological approach requires reading, reflecting and interpreting the texts of the oral accounts of personal expectations and experiences. These are then described by linguistically transforming the texts into thematic statements.[14] A hermeneutic circle method was used to interpret and analyse the participants' personal accounts during their semi-structured interviews. It was used to develop codes and contrast the qualitative data with the interpretation of subsequent interviews.[13]

This study was conducted within a radiation oncology department located in a district hospital that shares services with an adjacent tertiary academic hospital building complex, and a primary healthcare (PHC) clinic.

The Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria approved the study. Approval to conduct the study was also obtained from the relevant authorities of the tertiary public hospital complex, the respective clinical head of the radiation oncology department, and the manager of the RT division.

Purposive sampling was used to invite patients who attended the tertiary public health radiation oncology department to participate in the study.[15,16] The inclusion criteria were as follows: Potential participants had to be 18 years of age or older. They had to have already been evaluated by radiation oncologists as having a performance status score of 0-3 with the use of the Union for International Cancer Control (UICC) performance grading system.[12] A total of 10 (n=10) participants who met all the inclusion criteria were interviewed during a period of approximately six months. Most participants (n=7) spoke English. Interpreters assisted during the recruitment and interviews with Zulu (non-English) speaking participants (n=3). Data saturation was determined when no new information was being gained.[17] Theme saturation was determined at the point when no further themes and sub-themes emerged.[18]

Two sets of data were collected immediately prior to and post CT based localisation procedure pre-RT planning. The data collection entailed semi-structured interviews commencing with a casual conversation with the question.

- How has your day been so far?

This was followed by the opening question: Could you please describe your expectations and experiences that have lead you to this appointment today? Based on their responses, the participants were asked two more questions.

- So what are you feeling like at the moment?
- What are you expecting will happen today?

Their responses were then probed to gain insight and/or clarification. The exit interviews (after the RT CT localisation procedure) mainly focused on their experiences of the localisation procedure in an attempt to establish the met and unmet expectations they shared during their respective entry interviews. They were asked the following opening question at their exit interview.

- Please can you share with me what you have experienced during the time that you were in the room that you have just come out from?

The duration of the entry and exit interviews averaged to 30 minutes. Interviews were recorded with a digital audio recorder and transcribed verbatim.

The main author, as the researcher, with almost 30 years of clinical experience in the field of RT conducted the interviews. In keeping with the Heidegger philosophy of hermeneutic phenomenology, the need for reflexivity and positioning one's self in the process of the study was followed.[14,19] The main author's values, beliefs, and perceptions as an academic and an experienced RT professional in the clinical field shaped the interviewing of patients' CT localisation procedure encounter pre-RT planning. Her professional background made it possible to make sense of and contextualise some texts, bracketed in the participants' quotes. A hermeneutic circle of content analysis and interpretation of the data was followed.[13]

Data interpretation and analysis entailed a reiterative process of 're-thinking, reflecting, and re-recognising' and included preliminary interpretation of the transcribed texts and immanent texts, and coordinated interpretation.[14] This process was managed with the use of the AtlasTi7© software programme.[20] The codes and categories were developed independently by each researcher, and agreement was reached in identifying common themes until thematic saturation was reached. The verbatim responses of the participants are presented in italics in the findings section. For further clarification and/or the context or meaning the researchers used square brackets with the appropriate wording or phrases where applicable.

FINDINGS

Based on the interpretation and analysis the themes that emerged together with only the most relevant and significant quotes are presented. There were three main themes and seven sub-themes as shown in Table 1. The comments of the participants pertaining to the themes and

Table 1. Themes and sub-themes

Main themes	Sub-themes
Pre-localisation procedure expectations	• Person to patient role • Situational events within the health system pathways leading to the localisation process as the patient • Communication and interactions prior to and at point of referral to the CT localisation procedure pre-radiation therapy
The actual CT localisation procedure	• Familiar CT of the past with a difference • Communication and interaction during localisation
Post-localisation procedure	• Instructions from they: the radiation therapists • Just looking forward

sub-themes are presented below. Their verbatim comments are in italics. The authors used square brackets to include their clarification and/or the context or meaning for the verbatim comments.

Pre-localisation procedure expectations and sub-themes

Patients as persons (people) tended to self-evaluate signs and symptoms of their condition that had been with them for a considerable while, and then decided to seek medical help. Pain or severe external changes seemed to be the 'thing' that made them to approach the healthcare system.

> *So, I start feeling that lump. So, I stayed for more than 6 years with that lump for because it was not painful. I had no knowledge that it be, can cause cancer. Then it started paining after 6 years. Then I went to the clinic at A* [primary health care clinic] *and then they referred me to B hospital* [tertiary hospital]. *And I didn't waste time and I went to the hospital because it was paining. I couldn't even sleep with my side, it was very, very sore. (P1)*

> *I had pain I had pains for years and years. I worked through all the pains. Then I couldn't walk anymore, and my legs were paining. And then I decided I had to go the doctors. (P6)*

Their circumstances compelled them to seek help at the permitted access point in the Republic of South Africa public healthcare system, where the local clinic is the first port of call for patients. This was their intermediary contact with the point of diagnosis and treatment management strategies This contact gave rise to the experience of being directed through the system whilst carrying worries for the condition and forming some understanding of what was 'wrong' and 'what is to come'.

> *So, she* [referring to her daughter] *see I go to the clinic. And when I come to this clinic, I explain to them I was so sick and my womb here, and I that am bleeding, and my back is so sore. So, then the nurses say, this is not for us. So eventually they say, I must go to the hospital, T hospital* [district level hospital]. *And then we go in there, we go to the hospital. Then they started there. They check me, checking me there.* [pointing to her pelvis] *(P2)*

> *I go to the clinic* [primary healthcare clinic]. *Yah, then they transfer me to the hospital* [regional level hospital]. *At the hospital* [regional level hospital] *they look at me in my breast. Then they take me to the …. After that they give me my results. That I've got breast cancer. So, I appreciate, so I go to the hospital* [regional level hospital] *and then they put me up for, for …I go to the hospital and they do the operation and send me to C* [tertiary hospital]. *(P7)*

The actual CT localisation procedure and sub-themes

Complexity of healthcare system's processes and procedures affects looming uncertainties on their health outcomes. In other words despite receiving information from healthcare providers, patients remain uncertain with the health system's processes and procedures. This is evident in the below verbatim comment. For example, this participant did not understand the fragmented approach of what happened after initial treatment, prior to the CT for localisation procedure, and was left fearful of outcomes.

> *I was admitted* [for] *my first surgery on the 23rd March. After the surgery they told me it's alright. After they told me it's alright, after six months I came to follow up treatment. They saw these nodes here* [pointing to his neck]. *They asked for something there, some tumour is there. Medication* [chemotherapy]. *But after treatment* [chemotherapy] *they didn't uh do the surgery. They go to surgery. That's six months I was there. They do CT scan* [diagnostic CT scan] *there, admission there, everything. They don't do nothing after. I think surgery told to consult cardiothoracic. After every month I came. But they took the blood and last month I went to cardiothoracic* [in] *that six months they didn't do* [the operation]. *They admitted [me] three times* [in the] *hospital but they don't do nothing….suffer. I am bitter and disappointed of the hospital. There're huge clinical nodes. No more time as it is growing to my head now. (P8)*

Another was also afraid of outcomes due to lack of understanding of the unfamiliar localisation procedure, and beyond.

> *She's* [I'm] *not sure, but she* [I] *thought they told her* [me] *that she* [I] *will be here for six weeks. No, she* [I] *has* [had] *no understanding of what is going to happen today. Nobody told her* [me] *what is going to happen. She is* [I am] *very scared because she* [I] *doesn't actually know what is going to happen. (P5)*

The ongoing anxiety and uncertainty of the localisation procedure was partly resolved by the participants trying to construct their understanding and make meaning of the procedure by comparing it to previous procedures. This re-shaped their understanding.

> *No, it wasn't the same. The one* [the prior CT scan] *that I went for before was the one that they* [radiology service providers] *use to, view what was happening in my head. Then this one, they* [radiation therapist] *creating the mask, so you can get, they* [radiation therapist] *can go through and, then yah. So, they are totally different." (P4)*

> *They* [radiation therapist] *put something here, like uh bandages, patches. And then they* [radiation therapist] *press the machine and* [I] *go into the machine. And then the machine does the scan. Then when you, they* [radiation therapist] *take you get out of the machine, and they* [radiation therapist] *mark the places where the machine, where to come…feeling normal. (P10)*

Even where there was a clear understanding of the process, there was a vagueness regarding the procedure and its outcomes.

> *She* [the chemotherapy doctor] *told me that I am gonna attend chemo, first. And when I am done with chemo, they* [chemotherapy service providers] *going to take me to radiation where have to burn the side that make sure the part of cancer does not spread anywhere else. She, the radiation doctor* [the radiation oncologist], *the one who gave me the date to come for planning scan today. And she told me they* [radiation therapist] *are going to check and mark how where they* [radiation therapist] *are going like burn the skin* [referring to the RT treatment]. *(P1)*

Participants mentioned a need to engage

in a two-way information sharing process during face-to-face encounters with health professionals to be able to get a better understanding of the whole picture. Participants felt that sharing their experiences with HCPs would create awareness and allow them to plan appropriate treatment.

> *I don't expect much from people* [other health care providers] *who are helping the doctor because they* [other health care providers] *don't know much more than the doctor. Everything that they know* [other health care providers] *in studying they have; they can also share with me and so I can be open to them. If I have problems, I can share with them (P1)*

Where there was a lack of clarity, some participants used the internet to make meaning, albeit unsuccessfully.

> *While it is my problem that I have and probably so very frustrated. We* [patient and spouse] *just don't have enough information. And to try, and it is no good looking up on the internet because that is just terrifies the life out of me. (P7)*

Despite not knowing and struggling to understand, the participants complied throughout the initial contact with the system and with their diagnosis in terms of treatment decision-making, the related procedures and treatments, and went with the 'flow' as described by a participant. This was passive cooperation during management, treatment, and associated procedures.

> *Yes, but then you make your life difficult. If you, I just go with the flow. If they say I must do this, I'll do this. If you say, lay down, I'll lay down. If you want to put a long needle in your arm, then put a needle in …Whatever happens. I don't know this path that I have to go now. I doesn't help I want know how long your needle is, and how long is this and the things you are going to use and whatever. (P6)*

Post-localisation procedure and subthemes

During their CT for localisation procedure, they described their experiences as instructional and passively cooperated in most instances.

> *So, they* [radiation therapist] *um, they just did marks on her* [me] *and they pricked* [tattoo marking] *her* [me]. *They* [radiation therapist] *didn't necessarily say anything. Uh, that's all they did.* [markings for RT]. *(P3)*

> *But then they* [radiation therapist] *said, 'I mustn't…, I must sleep still'. Then I did as she* [radiation therapist] *told me. Yes, but they say don't move around, and sleep still. I just sleep still, and they* [radiation therapist] *could do the preparation* [non-descript localisation procedure/s]. *(P10)*

The instructions that participants receive during the procedure, including 'not to move' resulted in them taking a mentally inert stance. For instance, a participant claimed, while talking through a translator, that while being spoken to, she was also being 'pricked (tattooed)' in the marking procedure.

> *She* [I] *wasn't thinking much. (P2)*

Most participants expressed a sigh of relief after the CT for localisation procedure and accepted the next phase, namely, the RT treatment procedure. This pertained to keep going until you feel better.

> *I feel a little bit better because they* [radiation therapist] *told me that this was the preparation. And they* [radiation therapist] *will call me again after three weeks, three to four weeks. Then they* [radiation therapist] *took my phone numbers, two phone numbers, I come and do the treatment. Because today there was the preparation, just do the preparation. (P10)*

Most participants recognised that their diagnosis could not be altered, and the treatment had to be followed if they wanted to be helped. Most were eager.

> *I* [am] *just waiting for my treatment… As soon as possible (P8).*

Participants were positive and hopeful of being healed through treatment despite the anticipated negative experiences shared by others.

> *Now I just want to get better. And I just want to go through, if they* [radiation therapist] *can start the radiation on Monday, it will be fine. I just want to get through and see for myself. I don't want to listen to other people and you getting this sick, and your hair not falling out, and this and that. I don't care about all the other things. I want to get healthy again. (P6)*

DISCUSSION

This discussion is based on the findings of the study and a proposed framework to capture a patient in terms of a journey of a person through the fragmented multi-level public health system complex in accessing RT treatment at the point of CT for localisation procedure pre-RT planning. As illustrated in Figure 1 patients, as persons, from a life-world perspective experience and/or become aware of their illness when they observe and/or experience out of the ordinary signs and/or symptoms that reduced their function and/or ability to perform their daily function and unable to cope. Similar to the findings of this study from the lifeworld perspective Petri and Berthelsen describe "a quest and struggle for acceptance of limited physical and social abilities pervades everyday life and as a consequence structure and predictability becomes necessary". (p3)[21] Their desire or outcome is to return to normalcy.

To achieve desired outcomes or goal cannot be actualised without seeking medical help where a person wants to know what is happening to their body. To access this service is depended on the healthcare system's processes and procedures. For instance, to make contact with a medical professional within the public health system requires one to start at the first level of care: primary care. As previously mentioned, in other instances there is a jump to the tertiary or regional level of care (see Figure 1). These transitional pathways, within the fragmented public health system, depends on the geographical location of the various level of care, the respective specialised services such as the oncology department in this study. This is also interrelated and dependent on the expertise of the various HCPs and cannot be isolated from the conditions that a person presents with.

The complexity of the interdependent and interrelated nature of the system's pathway and its distributed care services the transitions are fluid and not predictable as evident in the shared experiences presented in the findings of this study. HCPs play a crucial role in mediating the navigation of a person's healthcare continuity within the various levels of care within the multi-level heath system. For a person, as a patient, irrespective of the level of entry

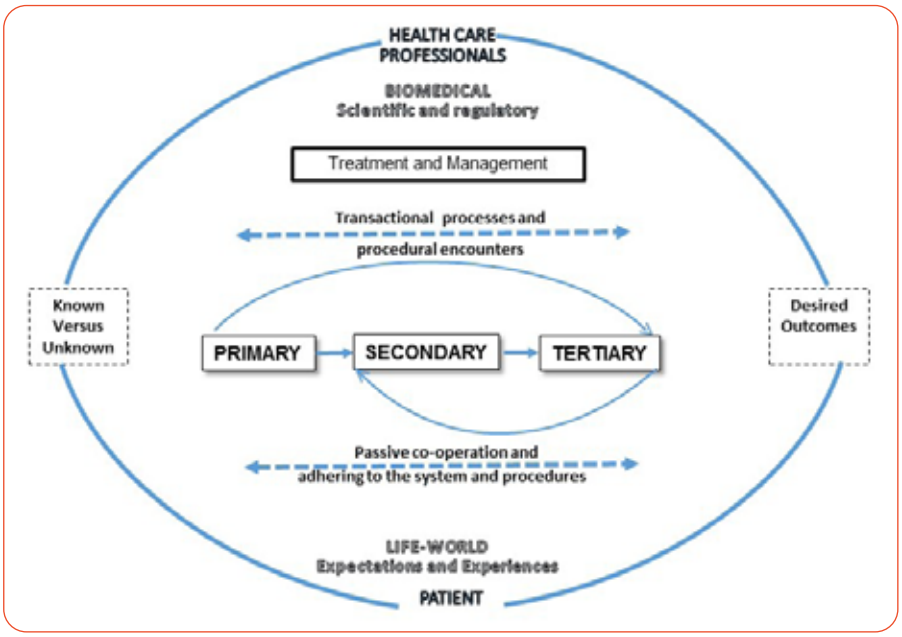

Figure 1. Framework for person-to-patient journey accessing radiation therapy in multi-level public healthcare system

and support from a healthcare system in terms of the care and services, is having the ability to come to terms with that was is happening regarding their continuity of care journey. Patients as persons have to simultaneously cope and deal with their diseased bodies with their known or unknown unpredictable nature of the complex illness which impacts on their quality of life and life style. The tendency of a the person is to draw from their own 'lived' experience, a life-world that is guided by their natural, socially constructed beliefs and values (see Figure 1).

HCPs within a healthcare system's processes and procedures also have beliefs, values and social constructs but these are dominated by a biomedical framework including a technological component. From a person's perspective, according to Marcum (p54)[22] "[t]his everyday world or life-world is the ground or foundation upon which the meaning of human existence rests." A decision to seek medical help entails a person, as the patient, entering into the realm of the biomedical world. In this study there was a technological world reliant on HCPs with a diverse range of expertise to aid in the management and treatment journey of the patient to a quality health outcomes. In this study HCPs included the radiation therapists in the provision of care and treatment services within the cancer care continuum such as the commencement of the CT for localisation procedure pre-RT treatment. They interact with patients from a dominantly bio-medical and technical perspective governed by the values and beliefs of that are scientific, technological and individualistic in terms of the profession and institution.[23] The desired quality health outcomes, both from a patient and HCPs, occurs through transactional processes and procedural encounters enabling patients in accessing the appropriate care and services throughout their cancer care continuity (see Figure 1). Maintaining continuity of care, within the ambit of the continuum of cancer care management and treatment processes and procedures, cannot be done in isolation or a silo approach.

There is a need for reemphasis on the interdependent and interrelatedness nature to achieve a quality health outcomes for the person. Throughout this process, the expectations and experiences of patients as people are shaped and reshaped by a tussle of coming to grips with their complex disease while seeking answers to their prognosis.

The question is: How is this disease is going to impact on their journey to their desired outcomes and their quality of life? Similar to other studies[24, 25] participants in this study expressed fear of recurrence of their cancer with familiar and/or new signs and symptoms. This awareness makes a situation unstable and triggers a patient to be on the alert and vigilant. Decision-making entails making that complicated judgment call not to seek or to seek medical help. If the decision is to seek help, then the issue is the timing, namely, to avoid disruptions of their daily life activities and obligations. However, the reality within a fragmented public health system, due their new symptoms, the treatment pathways for subsequent diagnoses may differ from their initial encounter which they had just come to terms with.

This new or unfamiliar pathway reshapes their experiences and expectations. This often extended and fragmented nature of the new diagnostic and planning pathways as an 'add on' leads to uncertainty and the inability to make sense and coming to terms with what is happening. This gap, as highlighted by the participants in this study, could be filled with effective two way communication with HCPs about their treatment and management. There was a plea for an interactional space between a provider and patient to voice their lived and life-world experiences, be reassured, feel safe and have support. The reality, in the absence of the aforementioned, is a typical life world approach to resort to their peers to seeking answers which often lead to more uncertainty. While the internet may be helpful to some extent, a gap remains for patients as persons to seek a definite answer regarding their personal situation.[26-27]

The impact of the uncertainty of their condition within their life context may lead to distress. Once distressed and with the uncertainty of their care pathway within the fragmented health system's processes and procedures could result in getting lost in an attempt to make sense of what is happening. At this point the tendency of the participants in this study was often to draw from their life-world experiences in adopting a wait and see into the next stage of the health system's process of the RT treatment series as their hope of a likely positive outcome (see Figure 1).

The findings were that due to the complexities, participants adopted a passive, compliant and cooperative stance while dealing with their uncertainty. They also adopted a wait and see approach at that particular point of contact/s[28] as they journeyed through the public multilevel health system. They accounted for this behaviour by describing their interactional encounters with HCPs as instructional; they therefore passively cooperated in most instances as this was

the best option.[29] As presented above the participants' reaction to a "not to move" instruction during their procedure was for them to take a mentally inert stance: referred to as cognitive avoidance.[30] Over and above the looming fact that their diagnosis could not be altered, they had to cooperate with the treatment which had to be followed if they wanted to be helped.[31]

The post-CT for localisation and a glimpse of the RT treatment series led the participants to have a sense of optimism that something may change and this could give them back their wellness. However, on the threshold of the RT treatment series, they were distressed and uncertain, often leading to an attitude of passive compliance in their treatment.

This study is one of very few that attempted to capture the journey of patients up to their CT for localisation pre-RT treatment within a complex public healthcare system. The findings of this study cannot be generalised due to its qualitative nature.

This study was limited to one point in time. Future studies should explore patients' experiences at multiple points-of-contact to enhance the rigor and recommended interventions that should improve patients' experiences.

The interviews were for 30 minutes and this short duration could possibly be that the participants were not used to being interviewed or participating in research studies. Future studies could utilise other methods such as providing questions in advance to participants so that they can prepare their responses. However, it should be noted that if this recommendation were to be considered, this would not guarantee patients returning on an agreed upon date to be interviewed in view of the unpredictable nature of their illness.

CONCLUSION

The use of a framework shows that it is not a simple process for persons as patients to navigate and transition through an unfamiliar fragmented multi-level public healthcare system's processes and procedures in terms of accessing the desired service. It is a complex process to make sense of within the greater scheme of life; to come to terms with an unpredictable disease and to cope with the happenings at each point-of-contact within the healthcare system; and to keep control, understand and make sense and meaning of what is happening.

What patients as persons value as a quality of care service experience transitioning through the brief CT for localisation procedure can be strengthened through effective communication, interventions and educational interventions to ensure that they are on the same page as their HCP at that point in time in terms of being informed on their radiation treatment series. Based on the findings it is evident that the interrelatedness and interdependent nature of a patient as a person's journey cannot be approached through a silo lens. A multiple lens approach should be used to capture a person-centred approach.

ACKNOWLEDGEMENTS

The persons who agreed to participate in this study, for their openness in sharing their perspectives that has provided these valuable insights. We thank Dr Cheryl Tosh, Scientific Editor, Faculty of Health Sciences, University of Pretoria who provided editorial support.

CONFLICT OF INTEREST

The authors declare they have no conflicts of interest.

CONTRIBUTIONS OF AUTHORS

GL (UP) was responsible for conducting the data collection, the transcription of the interviews and qualitative data analysis. CM (UC)verified the accuracy of the transcriptions and reviewed the data analysis. The initial manuscript was written by GL. CM developed the framework. The final manuscript was the product of collaborative reviewing and editing by GL and CM.

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To
The Editor
South African Radiographer

Erratum: Experiences of radiography students regarding the objective structured clinical examination (OSCE): a case of the University of Namibia (UNAM)

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We would like to notify your office about the incorrect sample size mentioned in our article that was published in the November issue in 2019.

Methods. A qualitative, exploratory, descriptive, retrospective and contextual research design with an ethnographic approach was utilised. A purposively selected sample of second, third and fourth year radiography students (n=20) participated in the study.

It should read :
Methods. A qualitative, exploratory, descriptive, retrospective and contextual research design with an ethnographic approach was utilised. A purposively selected sample of second, third and fourth year radiography students (n=30) participated in the study.

In the body of the article under **MATERIALS AND METHODS** it reads:

Four FGDs were held until data were saturated enabling group consensus to be reached. The study included twenty (n=20) participants in four focus groups: group one (n=6), group two (n=7), group 3 (n=7), and group 4 (n=10).

It should read:
Four FGDs were held until data were saturated enabling group consensus to be reached. The study included thirty (n=30) participants in four focus groups: group one (n=6), group two (n=7), group 3 (n=7), and group 4 (n=10).

Regards
Edwin R Daniels