

A qualitative study exploring patients' expectations and experiences of the localisation event as part of radiation therapy

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Abstract

The radiation therapy (RT) localization event is a temporary, yet significant, process from the perspective of the RT health care team. The significance of RT localization is that before establishing radiation dose planning for the forthcoming RT treatment series, it is important to establish the patient's parameters. These processes then form part of the second phase of the treatment within the cancer continuum framework. To provide effective care, it is important to establish how patients' expectations and experiences are shaped at the point of the localization process. Qualitative research strategy using the phenomenological hermeneutic approach is used to interpret and analyze patients' expectations and experiences before and after the localization process. The findings of this study illustrate the physical tolerance of pain and endurance up to a point when quality of life is compromised; only then does medical assistance become a necessity. The participants' tolerance of the system's processes and procedures to the point of localization was of importance because they felt that this could have resulted in a timely treatment process. Although participants wanted to be informed and better prepared for the localization event, it was just another milestone to overcome on the way to the series of RT treatments. They dwell on their everyday life activities but more so their goal to return to normalcy. An exploration of the localization process from the patients' perspective provided insight into how their lived expectations and experiences were shaped, regarding not only the process itself but also the impact it has on their desire to recover.

Keywords

Cancer care continuum; Effective care; Localization process; Radiation therapy

Introduction

The radiation therapy (RT) treatment planning of which the localization event is part of commences after referral from the radiation oncology practitioner. The event precedes the radiation dose planning processes and provides the context in which the technical preparation for RT treatment takes place (Symonds, Deenan, Meredith, & Mills, 2012). When situating the localization event within the broader context of the continuum of the cancer management framework, the points of contact and interactions at various points within the health care system cannot be ignored (Makanjee et al., 2014a, Taplin et al., 2012). These contacts and interactions form the backdrop and the context within which patients' expectations and experiences are shaped (Hewitt, Greenfield, & Stovall, 2006). Within the treatment domain, points of contact other than RT could be chemotherapy, surgery, adjuvant therapy, symptom management, and psychosocial support (Hewitt et al., 2006, Washington and Leaver, 2016).

From the perspective of implementation and the improvement of the quality of health care, Taplin et al. (2012) emphasized the importance of investigating how patients experience the events at each point of transition. For example, the localization event is one of the transition phases within the RT treatment process. Although it is a significant process from the perspective of the RT health care team, it is also important that it should be explored from the patient's perspective. According to Washington and Lever (2016) from the United States and some other countries, such as Canada (Zwine & McQuestion, 2015) and Australia (Merchant, Halkett, & Sale, 2014), the health care team regarding the RT treatment consists of radiation therapists (RTTs), radiation oncologists (ROs), medical physicists, and the radiation oncology nurse (RON). However, the roles and responsibilities of the RON in RT varies based on the regulatory bodies; for instance, in Belgium, RON and RTT are involved in planning localization procedure and RT treatment (Grube, 2010). The South African Qualifications Authority (SAQA) makes provision for specialist qualification in oncology and palliative care nursing. The core exit level outcomes for this professional group are specified as working with other team members within the health care system for the promotion of health, management of malignant conditions, and care of dying patients where the care of individuals, groups, and communities is addressed (SAQA, n.d.). However, the South African Nursing Council has yet to define the recognized competencies associated with this specialist category in alignment with SAQA. Nurses currently specialized in oncology are practicing under the 1993 teaching guidelines specified for additional qualification training within the elective of medical and surgical nursing science (South African Nursing Council, 1993). According to Halkett, Short, and Kristjanson (2008), information provision regarding the RT treatment process is a shared competency among RON, RO, and the RTT. It is recognised that the RTT is solely responsible for the radiation treatment planning of the appointment (Halkett et al., 2008). Although this planning appointment falls within the domain of the RTT, it would serve the RON well to gain insights into this process so as to enhance their information sharing with the patients.

In the South African context, the RT localization process is located in the RT department. The radiation oncology services are delivered by specified tertiary-level hospitals in the public sectors and in some private sectors within the health care system (Dreosti, 2015, Basu). Patients gain access to tertiary-level hospitals through a multilevel hierarchical

referral system that commences with patients consulting at the primary health care clinic and subsequent referral to district-level and regional-level hospitals (Dickens et al., 2014, Dreosti, 2015, Makanjee et al., 2014b, van Rensburg, 2004). Patients' point of contact with the radiation oncology department in the public tertiary hospital entails a consultation with the RO, who refers the patient to the RT division for the RT localization procedure, followed by the RT treatment series. The standards of service delivery within these environments are underpinned by the national core standards that are guided by the Batho Pele (People First) principles and the Patient Rights Charter (Moleko et al., 2014, van Rensburg, 2004).

Kenten, Bowling, Lambert, Howe, and Rowe (2010) emphasized the importance of eliciting expectations and experiences of health practice from the patients' viewpoint rather than from the traditional expert-driven perspectives regarding the quality of care. This study therefore explored patients' expectations and experiences at the point of transition to the localization event and before commencing the therapy treatment within a public hierarchical health system to establish the type of care the patients' desire.

Research design

Cancer in itself is a complex disease (Ose et al., 2017). There are issues around treatment-related aspects that are interrelated to the lived experience of the disease itself. A qualitative research design was chosen instead of a quantitative design after an intense literature review specific to the localization process and, to gain insights into how patients' expectations shape their experiences of undergoing the localization process. Qualitative research design is a well-accepted and practiced approach for exploring and understanding meaning which individuals or groups ascribe to a social or human problem (Creswell, 2014).

Research methods

A phenomenological methodological strategy was chosen on the basis of the exploratory nature of this study (Creswell, 2014). The hermeneutic phenomenological approach, which is based on Heidegger's philosophical theories, made it possible to interpret the lived expectations and experiences of participants undergoing the RT localization process and procedures within the health system, both from a patient and life world perspective (Lavery, 2003). The study was conducted at a public tertiary-level hospital in an urban geographical location. The reason for choosing this location was ease of access for a diverse range of patients and the fact that the referring clinical sites are in close proximity. Permission to conduct the study was obtained from the head of the radiation oncology department and the chief executive officer of the hospital. Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committee at the University of Pretoria (which is an authority similar to the institutional review board in the United States, which vets research proposals for ethical approval). All 10 participants who agreed to sign consent forms were recruited by means of purposive sampling.

Inclusion criteria for an invitation to be interviewed included the patients' general performance status score of zero or one, using the Union for International Cancer Control (UICC) performance status score (Symonds et al., 2012), sometimes referred to as the

European Cooperative Oncology Group (ECOG) performance status (Washington & Lever, 2016). Table 1 provides the UICC/ECOG performance status rating scale.

Table 1. UICC/ECOG performance status rating scale (Symonds et al., 2012, Washington and Leaver, 2016)

Grade	Patient performance
0	Fully active, able to carry on all predisease activities without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of light and sedentary nature (e.g., light house work and office work)
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry out self-care. Totally confined to bed or chair
5	Dead

The performance status assessments conducted by the ROs during the initial radiation oncology consultations classified these patients as asymptomatic or symptomatic but ambulatory. The record of the performance status in the patients' radiation oncology files served as a baseline indication to the interviewer that the patient was in an acceptable physical state to participate in the interviews. Patients who had previously undergone an RT localization process were excluded. All participants had the purpose of the study explained to them. The reason for conducting this study was to gain insights to the participants' expectations before and after localization process experiences to improve on the care aspect from a person-centered approach. These participants were reassured that their privacy and confidentiality would be protected by the use of codes. Data were collected by means of semistructured interviews in a location close to the localization examination room within the RT department convenient both for the researchers and participants with a do not disturb sign. The main researcher conducted all the interviews with the aid of an interpreter in the preferred language before and after the localization process. Three of the participants required interpreters. The interpreters were required to sign an undertaking of confidentiality. Table 2 provides the demographic profile of the diverse range of participants.

Table 2. Demographics of participants interviewed

Patient number	Gender	Age	Cancer sites	Zubrod performance status	Participant language in the interview
1	Female	33	Left breast	1	English
2	Female	64	Endometrium	1	Zulu
3	Female	60	Left breast	1	Zulu
4	Male	33	Left ear	1	English
5	Female	39	Cervix	1	Zulu
6	Male	55	Rectum	1	English
7	Female	34	Left breast	1	English
8	Male	63	Thyroid	1	English
9	Male	72	Unknown primary—left axilla	1	English
10	Female	65	Cervix	1	English

The interviews were digitally recorded with note taking by the second researcher. The interview commenced with casual conversation with the question: *“Can you tell me about yourself,”* followed by the opening question: *“Could you please describe what led you to this appointment today?”* Based on the participants responses, they were further asked, *“What are you expecting will happen today?”* The participants' responses were then probed to gain insight and/or clarification. For example, the researcher probed further: *“You say, ‘you want to be treated well’. Can you perhaps explain a bit more on the wanting to be treated well.”* The exit interviews were mainly focused on participants' experiences of the localization procedure and attempted to establish the met and unmet expectations the participants shared during the entry interview. The opening question commenced with a question, *“Could you kindly share with me the examination that you just had?”* Based on the responses, probes followed on *“How different was this procedure from other examinations you had before?”* The expectations and/or anticipated experiences they shared prior to the localization to establish if there was a change in or both followed. For example, some participants did undergo computed tomography (CT) investigations but were uncertain as to what this procedure entailed. During the exit interview, participants were posed with the following: *“Before going for this procedure you were not sure what's going to happen. How are feeling now?”* The entrance interviews lasted on average for 13 min, whereas the exit interviews' average duration was 8 min. It was decided that data saturation had been reached after 10 interviews. No additional information was being gathered because of the brevity of sharing by the participants. Unlike interviews undertaken in western health care settings, the difficulty in participants sharing in depth might be attributed to the apparent lack of understanding and information.

The data collection and analysis

Data capturing entailed digital recording and the verbatim transcriptions by the second researcher immediately after each interview. The transcripts were checked by the first researcher and interpreter for authenticity. Data capturing entailed identities of the participants and the names of health care institutions and health care professionals mentioned in the interviews deidentified by using alphabetical coding. The hermeneutic circle suggested by Laverly (2003) guided the interpretative process through reading, reflective writing, and interpretation. Both the researchers read and reread. Both the researchers immersed in the interpretation and analysis throughout. The first researcher undertook the initial coding process and identified broad categories from the transcripts. Data was digitally managed using the AtlasTi[®] program, the prototype of which was developed in Berlin. The method of coding was guided by Saldaña (2009). The second researcher used the manual coding and identification of categories. The two researchers then compared until agreement was reached. This method of the iterative interpretation and analysis processes between categories and subthemes was conducted until patterns emerged to identify themes (Creswell, 2013).

The trustworthiness of the qualitative research was ensured in accordance with the work of Lincoln and Guba (1985). The credibility of this study was addressed by selecting recommended strategies, namely frequent debriefing sessions, as well as through the researcher's reflective notes and a statement on the researcher's background, that is, qualifications and experience. Credibility was enhanced through member checks by

participants to confirm the initial interpretation of the findings. Confirmability of the study was addressed through an audit trail.

Findings

The findings are presented in the following order. See Table 3 for, the themes that emerged from the initial or entry interviews followed by the themes that emerged from exit interviews after the localization procedure.

Table 3. Themes of expectations and experiences of the RT localization event

Before localization procedure (entry interview themes)	After localization procedure (exit interview themes)
<ul style="list-style-type: none"> • Going back and forth within the system • <i>Cannot stay in pain all the time</i> • <i>To be back to normal</i> • <i>Do not know what to expect vs. what they were going to do</i> • <i>Going to do the way they wanted me to do</i> • Bridging the knowledge gap 	<ul style="list-style-type: none"> • It was not the same • Patterns of interactions during the localization process • Just looking forward • The unanswered questions

RT = radiation therapy.

The following themes emerged during the first interview and exit interviews for the localization process.

Before localization (entrance interviews)

Participants focused on the uncertainties experienced along their health care pathway, which lead them to attend the localization appointment. They also gave voice to their concerns with regard to the symptoms and ambiguities surrounding cancer and how they were going to respond to the localization process.

Going Back and Forth Within the System

The RT department located within the public tertiary hospital was accessed by patients who had traveled down the various pathways, including going back and forth within the health institution itself. A typical example of this kind of experience was shared by Participant 8:

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. That six months I was in the hospital ... they didn't do. They admitted three times hospital ... But I'm suffer[erring]. I am *bitter* and disappointed of the hospital. There's huge clinical nodes (pointing to nodes in right side of neck). ... *No more time as it is growing to my head now.*

Cannot Stay in Pain All the Time

Most participants sought medical help when experiencing pain. Some were prompt in deciding to seek help because of the discomfort they were experiencing, whereas others endured the pain until it was intolerable.

So I start feeling that lump. So I stayed for more than six 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 six years. Then I went to the clinic at C P and then they referred me to T H. And I didn't wasted time and I went to the hospital because it was paining ... I couldn't even sleep with my side, it was very, very sore.

One participant went past the initial pain stage and endured the pain until no longer able to conduct day-to-day activities.

Those pains I couldn't stand it. Till I get in the taxi and I go back home. I go home, I didn't feel well at all. I couldn't even stand. I must, just when I cook my food, the pains from my *back pains* hurts too much ... So I couldn't, stand straight. And my husband come and ask me "what happened?" I say "I don't know what happened. I feel shakened. My body's very shakened, even my stomach. I don't know what's happened." ... He tells me go and rest Monday it will be better. ... So Monday, I couldn't wake up the pain was so terrible....

To Be Back to Normal

After the opening question, the next question was, *What do you expect to happen today?* The typical desire shared by most participants wanted to ... *feel better*. Some, like Participant 4, described the dominant characteristic or nature of the illness as a barrier: *Then this thing in me, at least to be controlled, and then like after treatment maybe I will focus on my life and move on, and forget about this.*

Do Not Know What to Expect Versus What They Were Going to Do?

Based on the inclusion criteria, this was their first encounter with the localization process. Participant 4 shared what was going to happen.

I am here today because I had uh surgery ... 21st April. They removed it and then they trying to give me radiation. ... probably I am going to do a CT scan and from there I think, they will be planning for my treatment how they will start and when.

It was interesting that Participant 4 shared a bit more detail, based on the oncologist's reason for the referral for the localization process and its purpose.

... The radiation doctor ... the one who gave me the date to come [h]er[e] for planning the scan today ... And she told me they (unidentified professional group) are going to check and mark how where they are going like *burn* the skin.

Participant 7 even highlighted the value of undergoing the localization process as part of the RT treatment by explaining that the benefits outweigh the risk of metastatic spread.

... They (the informing healthcare provider) said to me, they want to protect. If they (radiation therapists) do irradiation they want to protect my lungs [and] ... heart. They (unidentified healthcare worker) go[ing] to protect my heart, like taking tablets or like drinking some pain medication or else.

So with the lack of knowledge, I cannot say, the lack of knowledge of not knowing what I came here for. I really don't know what to expect. As I know what it is, when they say, 'they going to do an operation.' I know, they just cut here (pointing to abdomen). The operation, that I know. [Be]cause now the scan thing that I don't know, I'm just confused and scared. [Be]cause I don't know what I'm going to.

Going to Do the Way They Want Me to Do

The complexity of the illness and the complicated systems processes and procedures discussed in the previous section resulted in participants like Participant 6 feeling overwhelmed because she did not know what the localization process entailed and how it would impact on her coping: *I don't know how I'm going to cope ... So that stress. Too many things at once.*

... I really, really don't know what is happening. ... and by going through it now, I think what I'm going to say, it is difficult and hard.

When the participants were asked about their readiness to undergo the process itself, most of them expressed a wish to cooperate: *No it's like, I don't care as long I am going to do the way they want me to do.* The reason for this approach was shared by Participant 6.

... 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. It doesn't help I want know how long is your needle, and how long is this and the things you are going to use and whatever.

Bridging the Knowledge Gap

To bridge the knowledge gap in anticipation of the localization process, participants relied on their fellow patients who were undergoing RT. An example of this was shared by Participant 01:

No it's only patients that you, I'm travelling with from T (inter hospital transport) [with] those who attended radiotherapy before. They (the patients) not saying what the radiation is for, they just say you are going to be in the machine for 15 to 20 minutes and then that's it.

Participant 7 was still grappling with questions about the cause of the cancer and attempting to seek answers; turning to electronic sources did not yield the desired answers, as the patient described:

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

The desire to be kept in the loop, regarding not only the treatment but also the disease and the outcome, was emphasized by Participant 1:

So what is that cause? Is this going to happen to me? Or, I'm asking lots of questions but so far I don't have answers ... Ok, I would appreciate just be honest to me. Tell me what to expect ... within this process. And like try to be aware. Not like waking up early in the morning and be surprised, like how my breast's sore or swollen, even though no one told you about. So I would appreciate to what is going to happen. If you see something like this and do this, and this. Just advise ... They must try to tell me about the machine, how does it do, how does it work, and then what are the side effects

Exit interview

At this juncture, the participants tried to make sense of what they had just experienced, by relating to prior experiences of clinical and radiological procedures. They tried to explain the localization event and the associated interactions with the RTs during the process. There was an anticipation for what would follow after this process while carrying uncertainties for various cancer-related issues that they still did not understand.

The Actual Localization Process: “It Was Not the Same”

Participants shared their actual experiences in relation to their previous CT examinations. They described the CT investigation as the same but the localization procedure as something different. The following two examples illustrate their experiences.

No it wasn't the same. The one that I went for before was the one that they use to, to, to, to view what was happening in my head ... then this one, they creating the mask, so you can get, they can go through and, then yah. So they are totally different.

I didn't take that thing (referring to contrast). It is just the difference on the previous ... CT scan and the uh, this radio radiology ... And other things are the same.

Participant 5 recalled the tattooing aspect of the localization process and went on to describe both the unfamiliar environment and the machine. *It was feeling like a normal injection ... feeling the prick, when they were doing the prick. ... in an unfamiliar place. In a machine that I have has never been in. So that was different for me.*

Like Participant 5, Participant 10 shared the sequence of events that made up the localization process.

They (radiation therapists) put something here, like uh bandages, patches. And then they (the unnamed healthcare professionals) press the machine, and go into the machine. And then the machine does the scan. Then when you, they take you get out of the machine, and they mark the places where the machine, where to come.

The tattooing was not clear and neither was the scanning procedure. Participant 9 explained the uncertainty experienced during the scanning process:

... The various plotting points that they put on my body. There's some way over here (indicating where the marks were made) that I'm just uncertain why. ... I wasn't quite sure how the scan was when it was working, or when it wasn't ... Part of it was like the lasers, should I close my eyes, you know when the radiation is on.

Patterns of Interactions During the Localization Process

The knowledge gap experienced during the localization process could be attributed to the pattern of interaction and communication processes between the radiation therapist and the patient. In most instances, it was task focused, as Participant 7 describes. *... They do something that they know It's like they do their job and then they know how to do their job, on me. ... They just talk to me, ... show me, lay down. ... 'now we are going to mark, now we do one, two, three ... "relax", I relax.*

Also, like Participants 9 and 2, most participants were aware of the need to cooperate rather than to distract the providers in performing their tasks.

Because they said don't move your head. So I didn't want to sort talk while I was there ... Er well I thought they were busy you know so [don't] ... disturb them.

I just told myself that only God can help me. I just lie there and sleeping like the doctors, the nurses [referring to the radiation therapists] are telling me here.

Just Looking Forward

During the exit interviews, participants spoke very briefly about their experiences and focused mainly on the upcoming treatment, like Participant 7:

Ja, I'm feeling fine. Just looking forward, ... so ... they want[ed] to see me, on how they mark. Where they can, where they going to burn (colloquially referring to radiation treatment) me.

Others perceived the localization process as a form of assistance. For instance, Participant 5 expressed a sense of relief, *It is just that I have been helped and I feel a relief.*

The Unanswered Questions

During the exit interview, participants also shared their frustrations about trying to come to terms with the experience of this insidious illness and the associated uncertainties despite having sought medical assistance. The following are two examples of their questioning and the uncertainties they were experiencing.

So what is that cause (referring to the cause of cancer)? Is this going to happen to me? Or, I'm asking lots of questions but so far I don't have answers," and "I'm getting cold.

Like if I am at home I think about everything to do one, two, three, four. So it's like the problem with me if I got the questions but, it never be as far, if I am there what they are going to do again, and then what will happen if they finish here. I come like anybody and then.

Discussion

There have been several studies on the quality of cancer care and service delivery with specific reference to RT, including the localization process, but they have focused on the clinical interventions as confirmed by McQuestion and Fitch (2016). Apart from that, the focus has mainly been on the dominant and very significant aspect of radiation dosage planning, where the approach centers on multiproviders (Washington & Leaver, 2016). Although most participants were informed about the localization process, there were a few who were not informed regarding what the procedure entailed and the justification for undergoing the procedure. A recurring theme was the consciousness of uncertainty about when something would happen, what would happen, and what could be done (Folkman, 2010). The stance adopted by most participants is to go with the flow and cooperate rather than distract the RTT providers in performing their tasks. The procedure is a significant milestone for some in transitioning to the radiation treatment within the context of their disease status (Taplin et al., 2012). Whereas, with others, the transition was simply a nonsignificant milestone looming with uncertainty as to how they would cope from that point onward. The confounding factor was the insidious and unpredictable nature of the disease itself and the complex processes and procedures that were their only hope of returning to normal life (Walker, Szanton, & Wenzel, 2015).

This study attempted to fill in gaps in the literature on the localization event from the patients' perspective as a point of transition. Although they had interacted with their RO before their referral to the localization process, they were only vaguely able to recall what the localization process entailed and focused on the radiation treatment aspect. In most instances, patients tried to bridge the knowledge gap in the absence of communication from the health provider by relying on similar others and drawing on their previous experiences of diagnostic imaging procedures (Walshe et al., 2017). From a continuity of care perspective, the focus shifted back to the integrity of the forthcoming RT treatment and to remaining hopeful.

Study Limitations

There are several limitations to this study. Using interviews as a single data collection method enabled the researcher to obtain rich data, observations of body language, and participants' use of nonverbal cue to share their experiences and expectations. However, to capture or provide a holistic account and verify requires additional data collection strategies like observations of the actual procedure and shadowing of patients from the point of referral to the localization to strengthen the credibility of the findings by means of triangulation of data sources. Another strategy could have been to include health care

providers' perspectives. Only a single institution and low sample because of qualitative nature of research and therefore findings of the study cannot be generalized.

Conclusion

To the best of the authors' knowledge, this is one of the very few studies that focused on the point of transition from the domain of diagnostic and medical treatment to the localization process in anticipation of the RT treatment intervention. This study also provided insights into the importance on aspects of communication and interactions at a particular time although a brief but temporary encounter. A review is required on who communicates with whom during the transitioning to ensure that the patient is kept in the loop and adequately prepared (Makanjee et al., 2014b). From health system perspective, the findings also provided a glimpse into aspects of the care at the particular point within cancer continuum framework. Future studies should include other health care provider role players at the same time. There is a need to review the role of the oncology nursing professionals as part of the team within the RT context (Gosselin-Acomb, 2006, Grube, 2010). Interventions are needed to educate and inform patients in the technical aspects of the RT localization and treatment delivery and the associated medical aspects related to the cancer and treatment (Halkett et al., 2008) and to promote peer patient education in the form of cancer-specific support groups (Knott, Turnbull, Olver, & Winefield, 2012). Future studies should include more than one settings, that is, both private and public health care.

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