ARTICLE IN PRESS

Journal of Radiology Nursing xxx (2017) 1–6

Contents lists available at ScienceDirect

Journal of Radiology Nursing

journal homepage: www.radiologynursing.org

A Qualitative Study Exploring Patients' Expectations and Experiences of the Localization Event as Part of Radiation Therapy

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Keywords:
Cancer care continuum
Effective care
Localization process
Radiation therapy

A B S T R A C T

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 becomes 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.

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, Bergh, & Hofmann, 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 & 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

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https://doi.org/10.1016/j.jradnu.2017.11.004
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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 (Basu, Andrews, Kishore, Panjabi, & Stuckler, 2012; Dreosti, 2015). 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., 2014a; 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, Msibi, & Marshall, 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 (Laverty, 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.

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.

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