



Living through pelvic radiotherapy: A mixed method study of self-care activities and distressful symptoms



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ABSTRACT

Keywords:

Nursing: illness and disease
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Purpose: To explore patients' experience of their illness when undergoing pelvic radiotherapy by describing the presence and severity of distressful symptoms and to explore initiated self-care activities in response to illness and symptoms.

Methods: A mixed-method study was performed which included a core qualitative dataset and a supplementary quantitative dataset. Twenty-nine women undergoing five weeks of radiotherapy were prospectively interviewed during five weeks of treatment in order to capture experiences, distressful symptoms and quality of life during treatment. Grounded theory formed collection and analysis of the qualitative dataset and statistics were used to analyze the quantitative dataset.

Results: A maintained self-identity was concluded as being central during the trajectory of treatment. Initiated self-care activities served to alleviate physical, emotional, and social suffering; helping the respondents keep their integrity and sense of self. Previous life experiences influenced the process of being able to maintain self-identity. The gastrointestinal symptoms and pain caused most distress.

Conclusions: In order to be able to maintain self-identity patients endure treatment by focusing on symptoms, on getting cured and on their self-image. Several distressful symptoms implied social limitations and a sense that the body would not take the strain. The result of this study can help health care professionals to gain a better understanding of the struggle to endure pelvic radiotherapy. Further, health care professionals should be more proactive in alleviating their patients' distressful symptoms. The results imply that previous life experiences should precede initiated interventions because these life experiences affect the patients' self-care activities.

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Introduction

Patients undergoing pelvic radiotherapy report an increased incidence and intensity of fatigue during treatment (Ahlberg et al., 2005a; Poirier, 2006; Purcell et al., 2010) and state that their fatigue affects their physical and social well-being (Ahlberg et al., 2005b; Magnusson et al., 1999). Patients also report frequent gastrointestinal symptoms including diarrhea, nausea, and pain, as highlighted in several studies (Ahlberg et al., 2005a; Christman et al., 2001; Guren et al., 2003; Khalid et al., 2006).

Alleviating symptoms is an intentional activity, initiated by the person who is experiencing a symptom or by the health care professional (Dodd et al., 2001; Fu et al., 2004). Orem et al. (2001)

describes self-care as the activities that a person initiates and performs to sustain health, well-being, and life. In a study by Magnusson et al. (1999), patients reported reading, listening to music, taking a nap, and planning ahead as strategies to alleviate fatigue. Similar activities were reported by Fitch et al. (2008) and by Williams et al. (2010). Abayomi et al. (2005) showed that, in order to alleviate gastrointestinal symptoms, women initiated several food restrictions during and after pelvic radiotherapy, including eating less and decreasing their intake of fibers, vegetables, and fruit. The study reported in this paper is part of a research program concerning the alleviation of fatigue and other distressful symptoms in patients who undergo treatment for pelvic radiotherapy. The program includes a new intervention to alleviate distressful symptoms, based on a link between fatigue and intestinal injury (Jakobsson et al., 2010). Before introducing a new intervention for alleviating symptoms during pelvic radiotherapy we wanted to explore patients' experience of their illness when undergoing pelvic radiotherapy; we aimed to describe the presence and severity of

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distressful symptoms and to explore initiated self-care activities in response to illness and symptoms.

Methods

Design

We performed a study with a mixed-method approach comprising both qualitative and quantitative data. With reference to Morse's (2003) definition of mixed-method designs, this study has a QUAL + quan design, which indicates that the qualitative data is the core component (QUAL) and the quantitative data (quan) serves as a supplemental dataset to inform the core component. The design involves collecting the two different components simultaneously, with the core component directing data collection, analysis and interpretation of the data (Morse et al., 2006). The reason for collecting different datasets in our study was to expand and better understand the experience of undergoing pelvic radiotherapy; the different datasets represent two different perspectives on the same problem (Morse et al., 2006). The QUAL + quan design with simultaneously collected data included both open and structured interviews, which involved the first author (SJ) meeting with and interviewing each respondent three to four times during their

five weeks of radiotherapy. For a study to be performed with a mixed-method approach there should be an integration of data at one or more stages of the research process. Having simultaneously collected all data and separately analyzed the different datasets, we made an overall interpretation of the findings (Fig. 1).

Setting

The present study was conducted in an outpatient radiotherapy unit at a university hospital in Sweden, a unit caring for approximately 2800 patients each year. This study adheres to the Declaration of Helsinki and was approved by the ethical board of the University of Gothenburg (diary no. 009-08).

Recruitment

The first five patients were informed about the study at the hospital before start of radiotherapy. However, as the researcher perceived this hospital visit to be an inappropriate occasion because the patient is already fully occupied, the procedure was changed and information was sent out to subsequent potential participants by mail. The patients were then contacted by telephone a few days later by the first author (SJ) to enquire about their

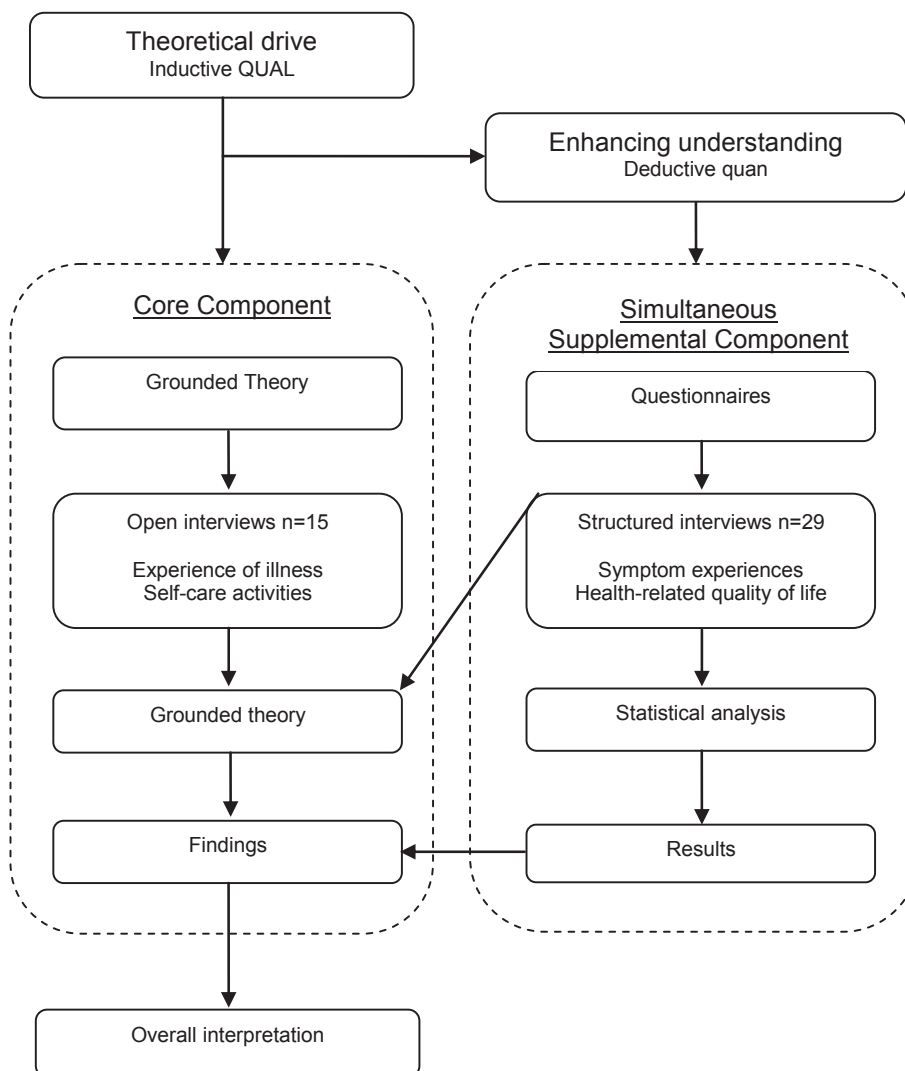


Fig. 1. Methods within the QUAL + quan design.

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