



Symptoms and self-care strategies during and six months after radiotherapy for prostate cancer – Scoping the perspectives of patients, professionals and literature



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ABSTRACT

Purpose: Under-diagnosed and uncontrolled symptoms in patients with prostate cancer during radiotherapy can have a negative impact on the individual's quality of life. An opportunity for patients to report their symptoms systematically, communicate these symptoms to cancer nurses and to receive self-care advice via an application in an Information and Communication Technology-platform could overcome this risk. The content in the application must precisely capture symptoms that are significant to both patients and health care professionals. Therefore, the aim of the study was to map and describe symptoms and self-care strategies identified by patients with prostate cancer undergoing radiotherapy, by health care professionals caring for these patients, and in the literature.

Methods: The study combines data from interviews with patients (n = 8) and health care professionals (n = 10) and a scoping review of the literature (n = 26) focusing on the period during and up to 6 months after radiotherapy.

Results: There was a concordance between the patients, health care professionals, and the literature on symptoms during and after radiotherapy. Urinary symptoms, bowel problems, pain, sexual problems, fatigue, anxiety, depression, cognitive impairment and irregular symptoms were commonly described during the initial treatment period. Self-care strategies were rarely described in all three of the sources. **Conclusions:** The results show which symptoms to regularly assess using an Information and Communication Technology-platform for patients with newly-diagnosed prostate cancer during radiotherapy. The next step is to evaluate the efficacy of using the platform and the accuracy of the selected symptoms and self-care advice included in a smartphone application.

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1. Introduction

Prostate cancer is the most common cancer diagnosis among men worldwide. Through early detection and improved treatment combinations such as surgery, radiotherapy and hormonal treatment, the majority of men with prostate cancer are cured. However, all of the treatments can have significant impacts on the patients' quality of life (QoL) that can persist for a long time (Katz, 2007). Thus, effective management of symptoms and strategies for self-

management are crucial to improve quality of life, morbidity and mortality (Fu et al., 2004; Hashine et al., 2009; Hsiao et al., 2013). Despite this expressed importance, there is a lack of interventions for symptom management and self-care strategies in men treated for localized prostate cancer (Hsiao et al., 2013).

Radiotherapy is included as a main treatment modality in men with prostate cancer, either together with surgery or as an alternative to surgery, often in combination with hormonal treatment depending on the stage of tumor or the man's choice. Radiotherapy, including external beam and interstitial permanent brachytherapy, is the most common treatment (Pinkawa and Gontero, 2009), and the majority receive radiotherapy at outpatient clinics. Under-diagnosed symptoms in patients with prostate cancer undergoing

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treatment have shown to negatively influence the individual's quality of life (Pachman et al., 2012). Structured nurse-led or multidisciplinary follow-ups during or after radiotherapy have been shown to be beneficial to minimize symptom burden (Tärnhuvud et al., 2007; Dieperink et al., 2013). One solution that is suggested for early identification of patient concerns is to systematically integrate patient-reported outcome measures (PROM) in the planning, implementation, and evaluation of care (Sprangers, 2010). A patient reported outcome (PRO) is defined as the perceptions of symptoms, functioning, QoL, and satisfaction with care that come directly from the patient without the interpretation of the patient's responses by a caregiver (US Department of Health Human Services and Research, 2009). Studies show that routine use of PROM in the clinic can improve the communication process between the patient and the care provider and can help the provider to better meet the patient's needs (Snyder et al., 2010; Valderas et al., 2008). There are some promising results showing that using different Information and Communication Technology (ICT) based platforms and applications for collecting PROM for clinical routine use can increase patients' symptom control and self-care (McCann et al., 2009; Ruland et al., 2010; Seto et al., 2012). The rapidly growing market of smartphones, indeed, has implications and influence on remote health care interventions but the development of these are still in their beginnings (Wang et al., 2014). With the use of ICT, we aim to develop an evidence-based platform for collecting and managing symptoms and enhance self-care strategies among patients with localized prostate cancer during radiotherapy. Person-centered care based on increased patient involvement is an important concept in modern health care (McCance et al., 2011). Central to person-centered care is the patient perspective.

Therefore, one important aspect to consider when developing modern health information technology tools is that the content must be relevant to patients and their care providers (Rose and Bezjak, 2009). Our research agenda is to develop an interactive ICT-platform that allows patients with prostate cancer undergoing radiotherapy to, via a smartphone or tablet application, instantly communicate their symptoms and concerns to cancer nurses and provide access to self-care advice. Although it is well-known that common adverse side-effects of radiotherapy for men with prostate cancer are urinary problems, diarrhea, fatigue and impotence, we want to ensure that the platform is based on evidence-based knowledge regarding symptoms and self-care advice. The content in the platform must be precise enough to capture symptoms that are important for both patients and health care professionals while at the same time being simple and concise. Therefore, the aim of this study was to map and describe symptoms and self-care from the patient perspective identified by 1) newly diagnosed patients with prostate cancer during and 6 months after radiotherapy alone or in combination with hormonal treatment, 2) health care professionals caring for these patients, and 3) the literature.

2. Methods

The design for this project is underpinned by the Medical Research Council's (MRC) complex intervention evaluation framework (Campbell et al., 2007). This study combines data with a focus on the patient perspective from individual interviews and focus group discussions (FGDs) with patients and health care professionals and a scope of the literature.

2.1. Interviews with patients and health care professionals

2.1.1. Setting and participants

Patients with prostate cancer at two University hospitals in

Sweden representing both a rural and an urban environment were asked to participate in the individual interviews or FGDs respectively. The inclusion criterion was undergoing radiotherapy (external radiotherapy with or without brachytherapy) as either the only treatment or in combination with hormonal treatment. Nurses, physicians, and other professionals caring for patients with prostate cancer during radiotherapy were also recruited from the two hospitals to participate in this study. The recruitment was stratified to meet a maximum variation in the sampling (Patton, 2002), that is, the goal was to include a sufficient variation of professionals (nurses, physicians, and one medical social worker) from both oncology units and urology units and patients of different ages and at different stages of radiotherapy treatment (early in their treatment, in the middle of treatment, and nearing the end of treatment). The patients and the health care professionals received both written and oral information about the study before they gave their informed consent to participate. Ethical approval was obtained from the Regional Ethical Review Board (www.epn.se) (dnr 2011/256).

A total of eight patients (n = 3 individual interviews and n = 5 in one FGD) between 59 and 78 years of age, in stage T2 to T3 and at different stages of their radiotherapy and sometimes in combination with hormonal treatment (n = 3 external radiotherapy + hormonal treatment, n = 1 external radiotherapy, n = 4 external + internal radiotherapy + hormonal treatment) were invited to take part. Ten health care professionals (n = 1 nurse from the urology unit and n = 6 nurses from the oncology unit, n = 1 physician from the urology unit and n = 1 physician from the oncology unit, and n = 1 medical social worker from the urology unit) were also included.

2.1.2. Data collection

Individual semi-structured interviews (Kvale and Brinkmann, 2009) with three patients in the rural hospital were carried out by two experienced researchers and took place, in accordance with the patients' wishes, in connection with their hospital visit. Four FGDs were conducted, one with prostate cancer patients (n = 5) in the urban hospital and three with health care professionals (n = 2 FGDs in the rural hospital and n = 1 FGD in the urban hospital, with between four and six participants in each). Some of the health care professionals participated in two FGDs. The FGDs followed the procedure described by Barbour (Barbour and Kitzinger, 1999) and took place in a conference room at the hospitals. Each FGD was led by two experienced moderators.

The interview guide in the interviews with the patients focused on patients' experiences of symptoms during their treatment and how they managed them with the initial question: "Can you describe your symptoms and concerns during and after the radiotherapy?" This was followed by questions about how they managed the symptoms they had, and how they felt about the support they had received. The participants were encouraged to speak as freely as possible about their experiences. Probing questions were used, such as "Please could you describe more?" or "Can you give an example?" as a means of increasing the richness of the data. In the FGDs with the health care professionals, the focus was on what they perceived to be the primary symptoms among patients with prostate cancer during radiotherapy with the opening question "How, in your professional view, do the patients experience symptoms and concern during radiotherapy?" followed with questions about the self-care strategies that they recommend to their patients. The moderators' roles were to stimulate interactions between the participants and to maintain the focus of the discussion on the topics of interest.

The individual interviews and FGDs were recorded with the

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