



Feasibility of an interactive ICT-platform for early assessment and management of patient-reported symptoms during radiotherapy for prostate cancer



Kay Sundberg^{a, *}, Ann Langius Eklöf^a, Karin Blomberg^b, Ann-Kristin Isaksson^b,
Yvonne Wengström^b

^a Department of NVS, Division of Nursing, Karolinska Institutet, Stockholm, Sweden

^b School of Health and Medical Sciences, Örebro University, Örebro, Sweden

A B S T R A C T

Keywords:

Information and communication technology (ICT)
Patient reported outcomes
Nursing care
Self-care
Symptom management
Prostate cancer
Radiotherapy

Purpose: The aim of this study was to test the feasibility and acceptability of an Information and Communication Technology platform for assessing and managing patient reported symptoms during radiotherapy for prostate cancer.

Methods: In cooperation with a health management company, using a patient experience co-design, we developed the platform operated by an interactive application for reporting and managing symptoms in real time. Nine patients diagnosed with prostate cancer and receiving radiotherapy were recruited from two university hospitals in Sweden. Evidence-based symptoms and related self-care advice specific to prostate cancer were implemented in the application based on a literature review and interviews with patients and health care professionals. In the test of the platform the patients reported symptoms, via a mobile phone, daily for two weeks and were afterwards interviewed about their experiences.

Results: Overall, the patients found the symptom questionnaire and the self-care advice relevant and the application user friendly. The alert system was activated on several occasions when the symptoms were severe leading to a nurse contact and support so the patients felt safe and well cared for.

Conclusions: The platform enabled increased patient involvement and facilitated symptom assessment and communication between the patient and the health care provider. The study's results support further development of the platform, as well as tests in full-scale studies and in other populations.

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Introduction

At the heart of person-centered care delivery is the development of services in health care that enable patients to have the most efficient and effective care, which is also experienced as respectful and promoting patient involvement in the therapeutic relationships (Leplege et al., 2007). Patients with cancer cared for as outpatients, frequently experience multiple symptoms and problems that, when not diagnosed, influence the patients' quality of life (QoL) and recovery (Pachman et al., 2012). For immediate and continuous dialogue between patients and health care professionals, innovative e-health services using Information and

Communication Technologies (ICT) are encouraged. Appropriate tools for communication are needed to enable patients to report events that health care providers may respond to effectively (Mazor et al., 2012). There is a broad market for technology and devices for the self-monitoring of symptoms and problems. Some of these solutions are evidence-based and others not, and few include interactive components for immediate clinical management. Hence, the objective of our research program is to develop and evaluate an interactive ICT-platform for reporting and managing symptoms in real time during treatment for cancer. The ICT-platform, for use in smartphones and tablets, was developed in cooperation with a Swedish company, Health Navigator (specialized in health care management consulting and new innovative care solutions) responsible for the technical development and support. The platform is generic and the idea for the future is to test it for several diagnoses and in larger trials. In this first study, patients with prostate cancer during radiotherapy were included.

* Corresponding author. Department of NVS, Division of Nursing 23 300, S-14183 Huddinge, Sweden. Tel.: +46 852483572; fax: +46 19 30 36 01.

E-mail address: kay.sundberg@ki.se (K. Sundberg).

Patient-reported outcomes (PROs) may be defined as any aspect of a patient's health status (including disease symptoms, functioning, and health-related quality of life) that is directly reported by the patient with no interpretation of the patient's responses by a caregiver or anyone else (U.S. Department of Health Human Services and Research, 2006). Routine clinical use of PROs in real time may facilitate the assessment of problems, provide information on the effects of treatment, facilitate patient–clinician communication, promote shared decision making, improve patient satisfaction, and monitor quality improvement (Snyder and Aaronson, 2009; Valderas et al., 2008). Traditionally, PROs have been collected using pen and paper, but now more frequently a broad range of ICT solutions have been employed, including mobile phones, web-based systems and applications for smartphones and touch screens (Rose and Bezjak, 2009). In the UK, patients using a mobile phone-based system reported improved communication with health care professionals and improved symptom management when their symptoms were being monitored (Maguire et al., 2008; McCann et al., 2009). Moreover, a mobile phone-based monitoring system for heart failure patients developed and tested in a Canadian setting provided some evidence for improved self-care and clinic management (Seto et al., 2012a). In a recent RCT a web-based interactive health communication application monitoring symptoms and providing self-management support and access to e-communication with expert cancer nurses and other patients was tested by patients with breast and prostate cancer during any treatment (Ruland et al., 2013). The results showed a slight favor in the intervention group overall but additional research is needed. Mobile phone systems and applications have just begun to offer great opportunities in health care settings however, data showing sufficient evidence of feasibility and efficacy of these solutions has so far not been concluded. The importance of integrating the patients into the process (Donaldson, 2008) and to ensure user friendly data for both patients and health care professionals has been emphasized (Rose and Bezjak, 2009; Snyder and Aaronson, 2009).

In Sweden, prostate cancer is the most common cancer among men, representing 36% of all cancer cases in male adults in 2011 (National Board of Health and Welfare, 2011). Through early detection and improved therapies many are cured, but a major number of men need continuous surveillance and treatment (e.g., surgery, brachytherapy, radiotherapy, hormonal therapy). All the treatments available for local and advanced prostate cancer have side effects with a significant impact on the patients' QoL (Katz, 2007). Howlett et al. (2010) highlight the importance of evaluating, during and after radiotherapy, influences of treatment on various aspects of health and QoL. Patients with prostate cancer are commonly cared for as outpatients, visiting hospitals only to receive treatment, and this arrangement places great demands on them and their significant others. The aim of this study was to test the feasibility and acceptability of an interactive ICT-platform for smartphone use which collect and manage patient reported symptoms during radiotherapy for prostate cancer.

Methods

The design of our research program is underpinned by the Medical Research Council's (MRC) complex intervention evaluation framework (Campbell et al., 2007). The framework uses a stepwise approach for; i) defining and understanding the problem and the context; ii) developing the intervention and; iii) developing and optimizing the evaluation. In the first step patients and health care professionals were interviewed and a literature review was conducted to define the problem and the context (Author blinded, submitted). Based on this, the ICT-platform was developed and in

the present feasibility study tested for optimizing before further evaluation in a larger study.

Development of the ICT-platform

The foundation for the platform's development was that it should: 1) Include symptom assessment by the patient and, via a secure server, an immediate transmission to health care professionals, 2) Be interactive and adaptable to a smartphone application, 3) Be connected to a monitoring web interface with a risk assessment model based on symptom occurrence and frequency sending alerts to nurses by text message (SMS) if any symptom readings are of concern) and 4) Offer continuous access to evidence-based self-care advice related to symptoms and links to relevant websites for more information as well as symptom history presented in graphs over time (Fig. 1).

In the first step for defining and understanding the problem symptoms and self-care advice related to the side effects of radio and hormonal treatments during the first 6 months in newly diagnosed patients with prostate cancer were identified. This was conducted through a literature review and through interviews with patients and health care professionals (Author blinded, submitted). The symptom assessment included in the ICT-platform were mainly related to bladder and bowel function, sexual function, fatigue, pain, worries and distress, sleep, and flushing. The structure of the assessments was based on a standardized symptom and QoL questionnaire (Browall et al., 2013; Portenoy et al., 1994) in which the questions address occurrence, frequency, and distress level. For example, if the question "Do you experience urinary urgency?" is responded by "yes", the patient is asked how often it occurs, rated by frequency: never, sometimes, rather often, or very often. Furthermore, the patient is asked how distressing the symptom is: not at all, a little, rather, or very much. The patients report on a daily basis via their smartphones and receive a reminder message if a report has not been submitted. Nurses view the data via the web interface and in case of an alert the interaction is initiated whereby a nurse contacts the patient by telephone to discuss the reported problems. There are two kinds of alerts; yellow and red. A yellow alert indicates that the nurse should contact the patient sometime during the day. In the case of a red alert, the priority is higher, and contact should be made within an hour. For example, a yellow alert appears if the patient reports urinary retention "rather often"; a red alert, when the patient reports hematuria "very often".

Feasibility study

Samples

A convenience sample of ten patients diagnosed with prostate cancer and receiving radiotherapy at two university hospitals in Sweden were invited to participate in the study. One of the radiotherapy centers was located in a large city in Sweden and the other in a rural area. The patients were during one week invited by the radiotherapy coordinators at the two centers to participate in the study. They were selected according to where in the treatment period they were, ranging from just starting treatment up to a period of six weeks of treatment, each of the six weeks were represented. Inclusion criteria were; a prostate cancer diagnosis; receiving first-line radiation therapy; being able to read and understand Swedish, and; being considered by the clinical team physically, psychologically, and cognitively able to participate in the study. One patient declined to participate not providing any other explanation apart from not wanting to be involved in a study. The mean age of the patients was 69 years old. Clinical characteristics of the patients are shown in Table 1. There were altogether eight nurses (four at each treatment center) who agreed to be directly

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