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Patient experiences and the influence on health literacy and self-care using mHealth to manage symptoms during radiotherapy for prostate cancer



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**PATIENT EXPERIENCES AND THE
INFLUENCE ON HEALTH LITERACY AND
SELF-CARE USING MHEALTH TO MANAGE
SYMPTOMS DURING RADIOTHERAPY
FOR PROSTATE CANCER**

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Patient experiences and the influence on health literacy and self-care using mHealth to manage symptoms during radiotherapy for prostate cancer

THESIS FOR LICENTIATE DEGREE (Lic. Med. Sci.)

By

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This thesis is dedicated to my late friend Ewa Ericsson, RT, BA
who always thought I should aim for something more and better.

ABSTRACT

Introduction: Prostate cancer is a diagnosis that can affect the men's quality of life both due to the symptoms related to the disease and the treatment the men receive. Treatment with radiotherapy for prostate cancer in Sweden takes place at outpatient clinics, where the patient visits daily for radiotherapy and then returns home. Most of the time the patient is experiencing the symptoms and side-effects at home without health-care professionals easily accessible. To facilitate person-centered care and improve clinical management when hospital care is moving to outpatient care, the app (Interaktor) for smartphones and tablets was developed. Using patient-reported outcomes (PRO), the app was intended to identify symptoms early, assess them in real time, and provide symptom-management support during radiotherapy for prostate cancer.

Aims: The overall objective of the intervention described in this thesis, was to facilitate symptom management for patients with prostate cancer assisted with an interactive app during radiotherapy treatment.

Methods: The two studies included in this thesis come from one trial. A descriptive investigation evaluated the intervention group's use and perception of the using the app, and a quasi-experimental investigation compared those using the app with a historical control group not using the app to evaluate the effect on health literacy and self-care agency. The patients (n=130) were recruited consecutively from two university hospitals in Sweden between April 2012 and October 2013. The intervention group (n=66) had access to the app during 5-7 weeks of radiotherapy and three additional weeks. The intervention group's use of the app was logged. Health literacy was measured using the Swedish Functional Health Literacy Scale (FHL) and the Swedish Communicative and Critical Health Literacy Scale (CCHL), and the Appraisal of Self-care Agency scale, version A (patient's assessment) (ASA-A) for self-care agency. Transcribed notes from phone or face-to-face interviews about participants' experiences of using and reporting in the app were analyzed.

Results: In the intervention group using the app, adherence to daily reports was 87% (Md 92%, 16-100%), and generated 3,536 reports. All listed symptoms were used, where the most common being: urinary urgency, fatigue, hot flushes, and difficulties in urinating. A total of 1,566 alerts were generated, with 1/3 being severe (red alert). The app was reported in the interviews as easy to use, the reporting became routine; to report facilitated reflection over symptoms, the symptoms were relevant although some found that nuancing severity was hard. Using the app was reported as providing a sense of security. Substantial portions of the participants showed inadequate FHL and CCHL at baseline for both groups. CCHL changed significantly for the intervention group from baseline to three months after ended treatment ($p = 0.050$). Functional health literacy and self-care agency did not reveal any statistically significant differences over time for either group.

Conclusions: The conclusions to draw from this thesis are that an mHealth intervention, the app Interaktor, served as a supportive tool for the patients to assess and manage symptoms during the radiotherapy for prostate cancer. The intervention provided the patients with a sense of safety, increased awareness of own well-being and a significant improvement in communicative and critical health literacy was found.

The portions of inadequate levels of health literacy reported leave substantial groups of patients more vulnerable in assessing and managing symptoms when treated with radiotherapy for prostate cancer. Although health literacy levels include notable portions of patients in this study that have inadequate levels of both functional and communicative and critical health literacy, the adherence of using the app was high.

Keywords: prostate cancer, health literacy, self-care ability, mHealth, Communicative and Critical Health Literacy, Functional Health Literacy, patient-reported outcome, PRO

LIST OF SCIENTIFIC PAPERS

- I. Langius-Eklöf, A., **Christiansen, M.**, Lindström, V., Blomberg, K., Hälleberg Nyman, M., Wengström, Y., & Sundberg, K. (2017). Adherence to Report and Patient Perception of an Interactive App for Managing Symptoms During Radiotherapy for Prostate Cancer: Descriptive Study of Logged and Interview Data. *JMIR Cancer*, 3(2), e18. doi:10.2196/cancer.7599
- II. **Christiansen, M.**, Langius-Eklöf, A., Lindström, V., Petersson, L.-M., & Sundberg, K. Improved critical and communicative health literacy in patients when using an app for managing symptoms during radiotherapy for prostate cancer. (submitted).

LIST OF ABBREVIATIONS

ASA-A	Appraisal of Self-care Agency scale, version A (patient's assessment)
CCHL	Communicative and critical health literacy
EBT	External Beam Therapy
FHL	Functional health literacy
HRQoL	Health-Related Quality of Life
PRO	Patient-Reported Outcome
PSA	Prostate-Specific Antigen
SMT	Symptom Management Theory
TOUS	Theory of Unpleasant Symptoms
UCSF	University of California, San Francisco

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1 INTRODUCTION

Nursing science has, from the first texts on nursing, seen symptoms an important role for nurses and nursing.

The most important practical lesson that can be given to nurses is to teach them what to observe—how to observe—what symptoms indicate improvement—what the reverse—which are of importance—which are of none... (p. 59)

Florence Nightingale, *Notes on Nursing* (1859)

Men with prostate cancer is the largest cancer group in Sweden, and they are primarily a group of individuals close to or after the age of retirement. During my early training to become a nurse, I met these individuals at (then) ward 51, Östra Sjukhuset, Gothenburg.

The illness and treatments lead to symptoms for the patients where the observations made by nurses can now include information provided by the patients via an app. An app that also can provide self-care advice and evidence-based information. The patient-reported symptoms can be sent to the nurse at the clinic who can assess and react to them and when needed contact the patient.

When I got involved in this research training, I had a chance to reconnect with men receiving radiotherapy for this diagnosis and to follow their treatments from the start of radiotherapy to follow-ups some months later. I am very grateful for the stories and experiences – often very private and personal – that they shared with me in connection to the data collection I did.

2 BACKGROUND

2.1 Prostate Cancer And Its Treatment

Prostate cancer is the most common form of cancer in Sweden with more than 10,000 patients diagnosed in 2016 (Socialstyrelsen & Cancerfonden, 2018). A substantial proportion of men (1/8) will receive a diagnosis of prostate cancer before the age of 75 (Socialstyrelsen & Cancerfonden, 2018). Prostate cancer is a diagnosis that can affect the men's quality of life both due to the symptoms related to the disease and the treatment the men receive.

Treatment options for prostate cancer are hormonal treatments, external radiotherapy, external radiotherapy combined with internal radiotherapy (brachytherapy), prostatectomy or combinations thereof; or active surveillance (*National Guideline for Prostate Cancer Care*, 2015; Tyson, Penson, & Resnick, 2017). All treatments come with both effects and side-effects that can affect the quality of life for the person; these symptoms can be in conjunction with the therapy but also remain for more than a decade (Fransson & Widmark, 2007; Fridriksson et al., 2016). As of now, there is no conclusive evidence which therapy is the best to cure prostate cancer. Which treatment that is used is dependent on the individual: the man's wishes, the stage and grading of the disease, prostate-specific antigen (PSA) levels and development, and potential spread, but also other medical factors like concomitant diseases and life-expectancy (*National Guideline for Prostate Cancer Care*, 2015).

2.1.1 Patients' Symptoms Related To Radiotherapy

In Sweden, radiotherapy treatments take place at the outpatient clinic, where the patient visits daily for the radiotherapy and then returns home (Olausson, 2016). Most of the time the patient is experiencing the symptoms and side-effects at home without health-care professionals being easily accessible (Rose & Yates, 2015).

Patients with prostate cancer report symptoms stemming from both the illness *per se* and its treatment, where primarily adverse bowel and urinary problems, and sexual dysfunction have been reported (Blomberg et al., 2016; Carvalho et al., 2018). Perceived symptoms related to the treatment can be long-term, since substantial proportions of men were found to experience problems a decade after the treatment, irrespective of methods (Carlsson et al., 2016). Prostate cancer has been described as both stressful and stigmatizing (Gilbert et al., 2013; Rising, Bol, Burke-Garcia, Rains, & Wright, 2017), and urinary symptoms have been found to affect the relationship with a spouse (Chien et al., 2017). For instance, urinary urgency can make the men at risk for the inability to remain continent and force them to be vigilant about where the nearest restroom is, to use pads, or experience disturbances of their night's sleep (Blomberg et al., 2016). Radiotherapy treatment requires different self-management strategies to manage the symptoms, such as

having access to pads or using Kegel exercises for urinary problems, and resting for bowel-related symptoms, but also finding ways to express affection and sexuality other than penetrative sexual intercourse (Blomberg et al., 2016; Hsiao, Moore, Insel, & Merkle, 2014). Self-management strategies for symptoms have been found to be rarely discussed with patients (Blomberg et al., 2016). The treatment is also known to negatively affect the patients' health-related quality of life (HRQoL) (Budäus et al., 2012). Patients with prostate cancer report unmet information and care needs relating to physical and emotional concerns during and after treatment (Moore et al., 2015; Paterson, Robertson, Smith, & Nabi, 2015).

2.2 Understanding Patients' Symptoms

Symptoms are the problems or discomfort the patient experiences and can be measured using patient-reported outcomes (PROs). PROs includes any aspect of a patient's health status (including disease symptoms, functioning, and HRQoL) that are directly reported by the patient without the interpretation of the patient's responses by a caregiver or anyone else (U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research, & U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health, 2006).

2.2.1 Patient Reported Outcomes for Symptom Assessment

For symptom assessment, it is necessary to use the patient's experiences, and one way is the use of PROs. These have been described as "*seek to ascertain patients' views of their symptoms, their functional status, and their health related quality of life*" (Black, 2013, p. 1) where "patients' views" are the crucial words. For clinical trials, PROs have been discussed as an opportunity to comprehensively assess the impact of an intervention (Mercieca-Bebber, King, Calvert, Stockler, & Friedlander, 2018).

Reviews have found PROs, in clinical routine, to improve patient-provider communication and patient satisfaction, but also affect the patient's symptom experience and treatment response (Chen, Ou, & Hollis, 2013; Yang, Manhas, Howard, & Olson, 2018). Assessing symptoms by routine use of PROs in clinical care has been shown to facilitate identification of current problems and increase supportive care activities and communication with the healthcare providers (Kotronoulas et al., 2014). The use of PROs can improve the patient-provider communication through the understanding of patient experiences, with prompt discussions on relevant topics that can both improve symptom management and increase quality of life, and, finally, increase survival (Yang et al., 2018).

2.2.2 Theories and Models of Symptom Management

There have been theories and conceptual models published regarding symptoms and self-care. They range from describing the individuals' self-care actions in response to symptoms (Sorofman, Tripp-Reimer, Lauer, & Martin, 1990), to the theory of unpleasant symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997), and to models that describe symptoms as more complex and dynamic (Brant, Beck, & Miaskowski, 2010; Brant, Dudley, Beck, & Miaskowski, 2016).

Sorofman et al.'s conceptual model identifies the following stages: 1) recognition of the symptom, 2) its evaluation, 3) consultation with family or a healthcare professional, 4) treatment consideration, and 5) treatment implementation (Sorofman et al., 1990). Eventually, this leads to an outcome. Sorofman et al.'s model has many strong components but lacks description and consideration of the individual's capacities and traits. Furthermore, it takes into account neither fluctuations over time nor synchrony of symptoms.

The theory of unpleasant symptoms (TOUS) is a middle-range theory that has three major components: the symptoms and the individual experience of the symptom that includes the timing, distress, quality, and intensity; the influencing physiologic, psychologic, and situational factors that create the symptom experience; and the consequences of the symptom experiences referred to as performance (Lenz et al., 1997). A review of studies using TOUS has found that the influencing factors have been studied the most (Blakeman, 2018). When looking at the symptoms, focus has mostly been on the severity and distress of the symptoms, but seldom looks at all four aspects described in the model (timing, distress, quality, and intensity).

2.3 The UCSF Symptom Management Theory

In this thesis frame, the UCSF Symptom Management Theory (SMT) will be used to discuss the findings from the studies (Figure 1). The SMT has been described as a middle range theory that has focused on how patients perceive and manage their symptoms (Bender, Janson, Franck, & Lee, 2018; Dodd et al., 2001; "A model for symptom management. The University of California, San Francisco School of Nursing Symptom Management Faculty Group," 1994). It was developed in the early 1990s by faculty at the School of Nursing, UCSF, and stems from the conceptual approach that has focused on physiological phenomena in nursing (Carrieri-Kohlman, Lindsey, & West, 2003). The model has been developed from its first publication in 1994, particularly in 2001 when symptom management was revised and the model was situated in nursing science domains, adding the domains person, environment, and health and illness (Linder, 2010). Different populations have been studied over the years, which has evolved the SMT. The theory has been used with people living with different cancer diagnoses, HIV, and respiratory problems. In Swedish nursing research, the SMT model has been used in studies of symptoms in chronic disease (Eckerblad, 2015) and lung cancer (Hench, 2007).

The SMT consists of three major interacting components: 1) symptom experience, 2) symptom management strategies, and 3) outcomes and symptom status. These components are situated within the nursing science domains of person, environment, and health and illness that few other theories have and therefore creates a stronger nursing foundation.

Symptom experience includes the individual's perception of the symptoms, how they are evaluated by the individual, and how the individual responds to the symptom experienced. For patients with prostate cancer undergoing radiotherapy, urinary urgency is a prevalent symptom. The question will be how distressing the symptom is perceived to be and how it is evaluated. Maybe the symptom is perceived more as annoying and a nuisance than concerning, although very common. In this thesis, symptom experience has been assessed using patient-reported outcomes by asking about the occurrence of symptoms, their frequency and distress; and then how the risk-assessment model in the app (described below) assisted in evaluating the symptoms.

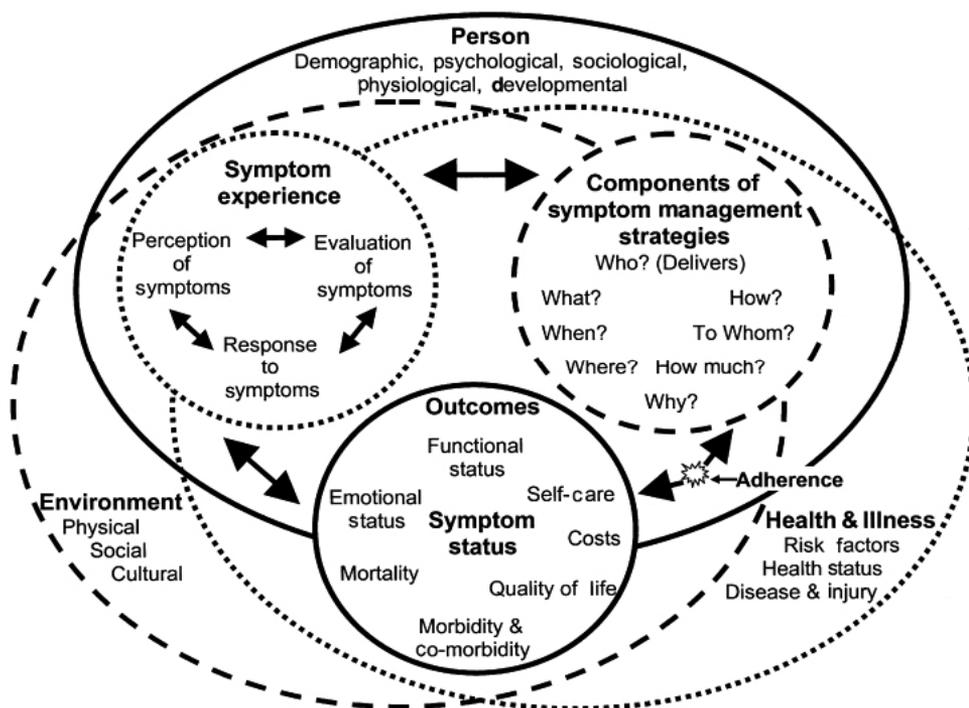


Figure 1. The middle-range theory UCSF Symptom Management Theory (SMT) with its components. Dodd, M. et al., *Journal of Advanced Nursing*, 33, 668-676 (2001). Copyright Blackwell Science Ltd. Reproduced with permission.

Symptom management describes what is done, by and to whom, and the dose (how much), but also when and where it is done. In the patient group studied here, this may be descriptions of interventions patients do to avoid urinary urgency, such as cutting down on fluids and making sure that toilets are available, but also may be pharmacological interventions initiated by nurses or physicians.

The component *Symptom outcomes* describes not only the changes in the individual symptom, but also how the person is affected. The outcome in the model is influenced by the individual's adherence to the symptom management strategies. In the present study, the outcomes have been presented to patients in the graphs in the app but also in generated alerts. The Symptom Outcomes component has been described as the least developed component in the SMT (Linder, 2010).

Furthermore, Linder has critiqued that the relationships among the three components have not been elaborated. These three, which included nursing domains, have not been fully described and seem less empirically tested, but also are not clearly defined. Brant et al. (2010) have described an overlap in some of the domains.

Patients often do not experience merely one symptom but several, simultaneously; symptoms that are dynamic, and therefore changing, may differ over time, and thus the effectiveness of symptom management and advice may differ (Brant et al., 2010). The co-occurrence and perhaps interaction of different symptoms, like clusters, have not been described in the SMT (Brant et al., 2010). However, there is no exclusion of other symptoms occurring simultaneously.

Time is a factor that often can be harder to describe and present in a model, but it is, however, less described in the SMT. In patients treated for prostate cancer with radiotherapy, symptoms may increase over time, peak, and then gradually decrease throughout the treatment (Dirksen, Belyea, Wong, & Epstein, 2016; Kim et al., 2009).

2.4 The Concepts of Health Literacy and Self-Care

As mentioned, SMT is situated in the domains of nursing; particularly the domains person, health and illness, and environment. Here, aspects of demographic and clinical site will be important, but also the outcomes like ability to access and comprehend information that is given, i.e. health literacy, but also the ability to engage in self-care.

2.4.1 Health Literacy

Health literacy is a broad concept with many conceptualizations, where the different conceptualizations can have different effects on policy (Guzys, Kenny, Dickson-Swift, & Threlkeld, 2015; Malloy-Weir, Charles, Gafni, & Entwistle,

2016). Therefore there is a plethora of measures and scales to assess patients' health literacy with different foci and conceptualizations (Altin, Finke, Kautz-Freimuth, & Stock, 2014; Haun, Luther, Dodd, & Donaldson, 2012; Mackert, Champlin, Su, & Guadagno, 2015; Malloy-Weir et al., 2016; Mårtensson & Hensing, 2012; Nguyen, Paasche-Orlow, Kim, Han, & Chan, 2015; Nguyen, Paasche-Orlow, & McCormack, 2017); some have reported more than 50 different instruments (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014). There is, however, no gold standard for how to measure nor how to discriminate between levels of health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Measures can view health literacy as either a risk or an asset; viewing health literacy as an asset sees health literacy as an outcome to patient information and health, while the risk model views it as a "prior status" (Nutbeam, 2008, p 2076f), not hoping to affect or change the individual but make him more compliant to rules.

Health literacy has been defined by the WHO as:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course (Kickbusch, Pelikan, Apfel, & Tsouros, 2013, p. 4).

It is therefore an individual's ability to seek, evaluate, and comprehend health information and make informed decisions accordingly (Sørensen et al., 2012). Health literacy has been described as a social determinant of health, but where a person's literacy or educational level does not equal his health literacy (Kickbusch, 2001). Later studies have nuanced the picture and have described health literacy as a mediator between the level of education and health (Jansen et al., 2018; Yamashita & Kunkel, 2015). Patients with adequate skills in self-care are reported to have a higher health literacy and are consuming less health care (Hasanpour-Dehkordi, 2016).

The ability to self-monitor symptoms and concerns and to engage in self-care activities can be seen as dependent upon the patient's health literacy levels (Mårtensson & Hensing, 2012). Historically, health literacy has focused on the functional aspects of literacy (being able to read and count) but has later widened in scope also to include critical and cognitive aspects of health literacy, i.e., the ability to comprehend and appraise what is communicated regarding health aspects and to apply it in various circumstances (Berkman, Davis, & McCormack, 2010; Chinn, 2011). Communicative and critical health literacy (CCHL) includes advanced personal skills, information skills, and knowledge about health, as well as effective interaction between providers and users (Sykes, Wills, Rowlands, & Popple, 2013).

In patients with cancer, health literacy has been shown to affect patients' well-being and HRQoL (Halverson et al., 2015). Prostate cancer treatment requires many decisions by the patients about their care (Appleton et al., 2015), and will be affected by the individual's health literacy and understanding; men with lower levels of health literacy report a lower HRQoL (Song et al., 2012). Patients with low functional health literacy, or lower levels of health literacy, have been found to have worse health (Easton, Entwistle, & Williams, 2010). Patients' lower health literacy may result in them not paying attention to critical symptoms and signs as may be warranted (Paasche-Orlow & Wolf, 2007), which in turn could affect the patients' ability to manage their symptoms and self-care (Mårtensson & Hensing, 2012). A structured approach to individually support patients with low health literacy is needed (Smith et al., 2013).

In this study, the goal has been to look at both the FHL and the CCHL, since both have been perceived as important for patients to understand their illness, treatment, and side-effects.

2.4.2 Self-Care

Self-care aims to maintain, restore, and promote health and well-being by regulating patient's functioning. It seeks practical results and resolutions to problems and may include contacts with health care providers (Söderhamn, 2013). It has been noted that there is not one, single definition of self-care (Godfrey et al., 2011; Richard & Shea, 2011). The concept self-care has in nursing been described by Orem, and self-care agency refers to the capabilities the person has to engage in self-care, and particularly the "productive operations" of self-care (Gast et al., 1989, p. 34). The capabilities are dependent on power components like self-care skills and the valuing of health, and the foundational capabilities like perception and memory the individual has.

A systematic review of the literature showed that men with prostate cancer perceived that engaging in self-care gave an empowering feeling, providing a sense of control, mainly since the individual took an active role in solving problems and made lifestyle changes (King et al., 2015). The men differed in how they preferred to receive support and care. Some wanted oral and written information in a face-to-face meeting with a professional. However, others wanted other forms of support and care, where web-based discussion with peers was preferable since it provided safety with anonymity with fewer inhibitions (King et al., 2015).

2.5 e-Health and m-health interventions in oncology to support symptom reporting and symptom management

Interventions and services that use the Internet have been here been defined as eHealth, while the ones using apps and mobile communication are referred to as mHealth. From initially being called telemedicine, neologisms like eHealth and mHealth have been presented and used in the literature, but the definitions vary and they are sometimes unprecise (Fiordelli, Diviani, & Schulz, 2013; Showell & Nohr, 2012).

Cancer survivors have reported to be positive about eHealth interventions and self-management, and a higher level of education was associated with a positive attitude toward eHealth (Jansen, van Uden-Kraan, van Zwieten, Witte, & Verdonck-de Leeuw, 2015). Furthermore, there are examples of internet-based programs to manage symptoms like anxiety (Hauffman et al., 2017). A web-based interface for interactions with healthcare providers showed that patients with prostate cancer had a better outcome on symptom distress after treatment than the control group (Ruland et al., 2013). In a study where patients reported their chemotherapy-related symptoms, via a web-based system, these patients had better ratings on well-being and quality of life and had fewer emergency department visits than patients receiving standard care (Basch et al., 2016). Weekly, web-mediated follow-ups by patients with advanced lung cancer reported longer survival, which has been attributed to earlier identification of problems with adverse consequences (Denis et al., 2017). Different eHealth and mHealth interventions have been tested in oncology (Fridriksdottir, Gunnarsdottir, Zoega, Ingadottir, & Hafsteinsdottir, 2018; Nasi, Cucciniello, & Guerrazzi, 2015). Apps for smartphones and tablets have been found to be useful for aiding in the self-management of symptoms in long-term conditions, and that apps required little familiarity with technological interventions to be successful (Whitehead & Seaton, 2016).

2.5.1 An App for Symptom Assessment and Management

To facilitate person-centered care and improve clinical management when hospital care is moving to outpatient care, the app (Interaktor) for smartphones and tablets was developed. The idea was to assess PROs in real time, to identify symptoms early, and provide symptom-management support during radiotherapy for prostate cancer (Sundberg, Langius-Eklöf, Blomberg, Isaksson, & Wengström, 2015). Its content was created collaboratively with patients and healthcare providers and was scientifically based in the literature (Blomberg et al., 2016).

The app consists of five different parts (Figure 2):

1. assessment of self-reported symptoms and concerns regarding occurrence (yes/no), frequency (never [1], sometimes [2], rather often [3], or very often [4]), and distress (not at all [1], a little [2], rather much [3], or very much [4]);
2. connection to a web-interface for monitoring;
3. a risk assessment model for alerts;
4. continuous access to evidence-based self-care advice; and
5. graphs for the patient to view a history of their reported symptoms and the frequency and distress.

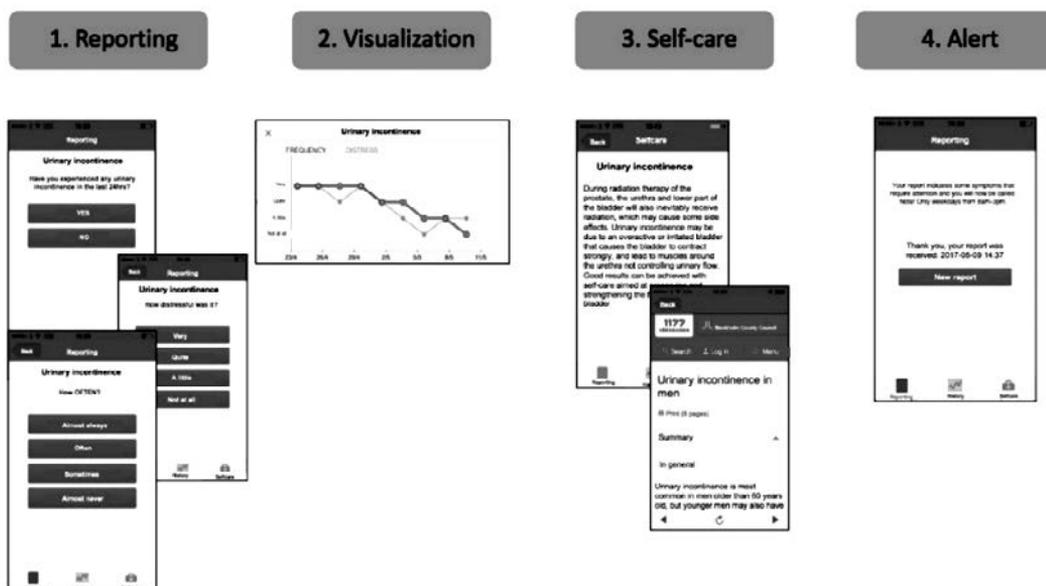


Figure 2. Screenshots from the app Interaktor for patients with prostate cancer showing the four main features of the app: 1) reporting symptoms, 2) visualizing the temporal perspective of symptoms, 3) evidence-based self-care advice, and 4) the alert function. Langius-Eklöf, A., et al. *JMIR Cancer*, 3(2), e18 (2017) [Study I]. Copyright authors. Reproduced with permission.

There are 15 symptoms and concerns reported and 16 pieces of self-care advice provided in Interaktor described in detail in Study I. The risk assessment model generates alerts that are directly sent to a nurse via a text message indicating that a yellow or red alert has been reported (Sundberg et al., 2017). The nurse can look at the alerts via a web-interface, phone the patient and follow up, and then make a note in the web-based system. Yellow alerts should be managed during the day, and red alerts within an hour's time. Results from a study of the effects on symptom burden when using the app have shown that patients in the intervention group report a better emotional functioning, lower levels of fatigue and nausea, fewer urinary symptoms, and less insomnia (Sundberg et al., 2017). Patients have considered the app to be a facilitator for participation in their care (Hälleberg Nyman et al., 2017).

The structure of the app is generic, and, besides prostate cancer, it has been developed for other diagnoses: patients with breast cancer (Langius-Eklöf, Crafoord, Christiansen, Fjell, & Sundberg, 2017), pancreatic cancer (Gustavell, Langius-Eklöf, Wengström, Segersvärd, & Sundberg, 2018; Gustavell et al., 2017); and also for support of older, home-dwelling adults (Algilani, Langius-Eklöf, Kihlgren, & Blomberg, 2017; Göransson et al., 2018).

3 RATIONALE AND AIM

The literature shows reports of patients treated for prostate cancer describing unmet care needs during treatment. Undergoing radiotherapy for prostate cancer, patients experience several distressful symptoms that they need to manage on their own at home. To manage their symptoms, they may need support; it has been shown that mHealth interventions using PROs may be a suitable way forward. The ability to successfully engage in self-care is influenced by the patient's health literacy levels and self-care agency.

The overall objective of the intervention described in this thesis was to facilitate symptom management for patients with prostate cancer, assisted by an interactive app during radiotherapy treatment. The thesis includes two studies and the specific aims were:

- I. to investigate user behavior, adherence to reporting, and the patients' experiences of using Interaktor during radiotherapy for localized advanced prostate cancer.
- II. to compare levels of health literacy and self-care agency in men with prostate cancer undergoing radiotherapy when an intervention group used an app, Interaktor, for symptom management.

4 METHODOLOGY

4.1 Design

The two studies included in this thesis come from one trial. The study design was (I) a descriptive investigation of the intervention group's use and perception of the using the app (Study I), and (II) a quasi-experimental investigation comparing the experimental participants using the app (intervention group) with control participants (historical group) not using the app to evaluate the effect on health literacy and self-care agency (Study II).

Table 1. Overview of the methodology of the two studies.

Study	Design	Data sources	Data analysis	Setting
I	Descriptive design; describing the intervention group's app use and perceptions of using the app	Logged data of app use, alerts; interviews	Quantitative (descriptive) and qualitative (content analysis)	Two university clinics, one in a rural area and one in an urban area
II	Quasi-experimental design comparing the intervention group with a historical control group	Questionnaires (baseline and 3 months after ended treatment)	Descriptive and analytic analyses	Two university clinics, one in a rural area and one in an urban area

4.2 Settings and Sample

The patients (n=130) were recruited consecutively from two university hospitals in Sweden between April 2012 and October 2013; one in a rural area and one in an urban area. Participants had a diagnosed localized prostate cancer, were eligible for curative radiotherapy, were able to read and understand Swedish, and were considered physically, psychologically, and cognitively capable of participating based on the contact nurses and medical records. Demographic data was collected at baseline (Table 2).

Table 2. Demographic data for the participants in the intervention (n=66) and control (n=64) groups.

	Intervention		Control		P-value
Age					$p = 0.805^a$
Mean (SD)	69	(5.8)	69	(6.2)	
Marital status, n (%)					$p = 0.289^b$
Single	9	(14)	13	(21)	
Married/in a relationship	56	(86)	49	(79)	
Education, n (%)					$p = 0.017^{b*}$
elementary/middle school	9	(14)	22	(36)	
high school	23	(36)	17	(28)	
college/university	32	(50)	22	(36)	
Occupation, n (%)					$p = 0.290^b$
in the workforce	17	(25)	12	(19)	
retired	51	(75)	51	(81)	

a) t-test

b) χ^2

* $p < 0.05$

Clinical data were collected by the researchers from the participants' medical records regarding the Gleason grading of the tumor, cancer staging, and the treatment prescribed (Table 3).

The control group was recruited from April 2012. The data collection was completed in December 2012. Participants in the control group (n=64) received standard care per the national guidelines (*National Guideline for Prostate Cancer Care, 2015*), and data were collected before participants in the intervention group were included. Standard care meant that patients were treated with radiotherapy for 5-7 weeks, where they met a nurse daily during the treatment phase. Patients were during the entire period also able to call his contact nurse for additional questions or support.

When all data was collected from the control group, the recruitment and inclusion for the intervention group was started (December 2012 to October 2013). Participants in the intervention group received the same standard care, i.e. were treated with radiotherapy for 5-7 weeks, where they met a nurse daily during the treatment phase (*National Guideline for Prostate Cancer Care, 2015*). Patients were during the entire period also able to call his contact nurse for additional questions or support. In addition to standard care, the intervention group (n=66) had access to the app Interaktor during 5-7 weeks of radiotherapy and three additional weeks.

The participation rate was 77% for the intervention group and 80% for the control group.

Table 3. Clinical data for the participants in the intervention (n=66) and control (n=64) groups.

	Intervention		Control		P-value
Treatment, n (%)					$p = 0.130^a$
External Beam Therapy (EBT)	20	(30)	22	(34)	
Brachytherapy and EBT	40	(70)	44	(66)	
Hormonal Therapy	50	(76)	40	(62)	
Stage, n (%)					
1	16	(24)	18	(28)	
2	29	(44)	25	(39)	
3	17	(26)	20	(31)	
missing	4	(6)	1	(2)	
Gleason, n (%)					$p = 0.300^a$
6	10	(15)	5	(8)	
7	28	(42)	36	(56)	
8	13	(20)	13	(20)	
9	14	(21)	7	(11)	
10	1	(2)	1	(2)	
missing			2	(3)	

a) χ^2

4.3 Procedure

After receiving written and oral information about the study by the researchers, and consenting to participate, the baseline measures were given to the study participants in conjunction with starting their radiotherapy. Starting the radiotherapy was regarded as the baseline in the study. Self-reported data on marital status, highest level of education, working or retired were collected at baseline. Furthermore, a questionnaire with outcomes measures regarding health literacy and self-care agency were filled out.

Three months after the radiotherapy, they were sent questionnaires with outcome measures via mail with an enclosed, stamped reply-envelope. To participants who had not responded, a reminder was sent after approximately ten days.

Patients in the intervention group were equipped with a smartphone at the baseline where the app was pre-installed, and they were instructed on how to do their reporting and the functionalities of the app.

4.4 Logged data and patients' experience of using the app

The intervention group's use of the app was logged. Data consisted of the patients' reports; each report was stored at the server, enabling the assessment of symptoms experienced and their occurrence, frequency, and distress level. Reporting behaviors, sent alerts, and free-text answers that had been logged. There were no logged data on patients' use of self-care advice.

After ending their use of the app, patients were primarily called for an interview (n=53), where some were interviewed face-to-face when the phones were collected (n=9). Using a semi-structured interview guide, patients were asked about their experiences of reporting and using the app, which functionalities in the app that they had used, any technical problems experienced. The interviews lasted 10-15 minutes, and the interviewers wrote down the answers in a template.

4.5 Outcome Measures

To gain an understanding of the individual's ability to comprehend, appraise and apply what is communicated regarding health as well as engage in symptom assessment and symptom management, health literacy and self-care agency were assessed.

4.5.1 Functional and Communicative and Critical Health Literacy

Health literacy was measured using the Swedish Functional Health Literacy Scale (FHL) and the Swedish Communicative and Critical Health Literacy Scale (CCHL), adapted and translated from Japanese by Wångdahl and Mårtensson (2014, 2015).

Both the FHL and the CCHL scales have five items each. The FHL scale has items regarding visual ability, understanding words and concepts (two items), perseverance in reading, and, finally, if the person requires assistance in reading and understanding information. The CCHL assesses an individual's ability to collect, extract, understand, judge, and apply health information to maintain or improve health. The scales are self-rated on a five-point Likert scale where the FHL ratings are in a negative direction ranging from "always" (5) to "never" (1) (Mårtensson & Wångdahl, 2017a), while the CCHL is rated in a positive direction from "strongly disagree" (1) to "strongly agree" (5) (Mårtensson & Wångdahl, 2017b). According to the manual of the scales, the ratings for FHL and CCHL for each respondent should be categorized into three levels *Inadequate*, *Problematic*, and *Sufficient* functional or communicative and critical health literacy (Mårtensson & Wångdahl, 2017a, 2017b). In the FHL scale responses "never" and "seldom" correspond to *sufficient*, "sometimes" corresponds to *problematic*, and "often" and "always" correspond to *inadequate* functional health literacy (Mårtensson & Wångdahl, 2017a). In CCHL

“strongly disagree” and “disagree” correspond to *inadequate*, “sometimes” corresponds to *problematic*, and “agree” and “strongly agree” correspond to *sufficient* communicative and critical health literacy (Mårtensson & Wångdahl, 2017b).

4.5.2 Appraisal of Self-care Agency

The Appraisal of Self-care Agency scale, version A (patient’s assessment) (ASA-A) was used in this study. It measures the ability and engagement in self-care activities and has been translated into Swedish and tested in different populations (Söderhamn, Evers, & Hamrin, 1996; Söderhamn, Lindencrona, & Ek, 1996). The scale has 24 items with Likert-type responses, ranging from 1 (“totally disagree”) to 5 (“totally agree”). An example of a question is “I look for better ways to care for myself.” The nine negatively worded responses are reversed before summing the score. The sum score ranges from 24-120 and the higher score, the higher the self-care ability.

In the present study, Cronbach’s alpha was 0.62 both at baseline and three months after ended treatment. The ASA-A scale has shown reliability in Danish, Dutch, and Norwegian versions of the scale with Cronbach’s alpha varying between 0.67 (Denmark), 0.76 (Norway) and 0.90 (The Netherlands) (van Achterberg et al., 1991). The Swedish translation reported a Cronbach’s alpha of 0.59 (Söderhamn, Evers, et al., 1996), but also 0.80 (Söderhamn, Lindencrona, et al., 1996).

4.6 Data Analyses

In Study I, logged data were analyzed using descriptive statistics. Free-text answers and interview notes were analyzed using qualitative, summative content analysis (Hsieh & Shannon, 2005). The summative content analysis meant that free-text comments were both counted but also interpreted, and categorized. All answers to the open-ended question from the app were read multiple to times to first get a sense of the data by two authors. Similarly, the notes taken during the semi-structured interviews were read through by two of the authors. The authors independently started coding the texts with codes related to the aim of Study I. Codes were compared and discussed until a harmonized description was found and transferred to an Excel spreadsheet. Thereafter, the codes were organized into categories. The codes and categories that emerged from the texts were discussed and verified by all the authors of the study (Study I). Some categories were quantified to visualize additional patterns (Krippendorff, 2013; Sandelowski, 2001).

To compare the intervention and control groups at baseline and follow-up three months after the end of radiotherapy, ordinal data were analyzed using chi-square, and independent Student’s t-test was used for interval data. The relationship between self-care agency (ASA-A) and CCHL was investigated using Spearman’s

rank correlation test. To analyze item changes in CCHL, the intervention group's within-group changes on item responses were analyzed using Wilcoxon signed rank test (Altman, 1991).

To model the relationship between the level of education, shown to differ between the groups (Table 2), and the level of health literacy (CCHL), a multinomial logistic regression (Hosmer & Lemeshow, 2000) was performed.

All statistical analyses used the Statistical Package for the Social Sciences for Mac, version 25 (Armonk, NY: IBM Corp). The level of statistical significance $p \leq 0.05$ was employed for all tests.

5 ETHICAL CONSIDERATIONS

The study was approved by the Regional Ethical Review Board of Uppsala University (Dnr 2011/256).

The study was conducted in accordance with the ethical guidelines for medical research with respect for autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001; Vetenskapsrådet, 2011). Swedish legislation – the Ethical Review Act (SFS 2003:460) – further regulated the process for conducting research (Vetenskapsrådet, 2011).

Potential participants received written and oral information about the study by contact nurses at the clinic. They were later contacted by the researchers to be given more information. Patients met up with the researchers before starting their radiotherapy and, on acceptance of participation, gave their signed consent. They were informed that non-participation in the trial would not cause them any problems. Interviews were further guided by consent being a constant process where a participant at any time could decide to terminate the interview.

Questionnaires, notes, and transcribed interviews have been stored anonymously using codes. The code sheet has been stored separately to prevent the identification of the participants.

5.1 Ethics in m-Health

In this study, participants were lent a phone with the app Interaktor pre-installed to ensure that the lack of ownership of a smartphone or tablet would not prevent someone from participating in the study. This increases the social justice component of the trial (Beauchamp & Childress, 2001).

The use of an app can lead to disclosing a diagnosis the patient maybe does not want to disclose, where grandchildren etc. may ask questions about apps. This is particularly pertinent for participants who previously did not use smartphones regularly. The app in the study had an icon that was anonymous, looking like a compass rose, and not related to any healthcare or diagnosis specific.

The app had a PIN to login and no names or personal information was transmitted. Using technology to collect personal data requires a consideration of safety issues when data is transmitted and later stored on a secure server for handling patient data.

6 FINDINGS

The main findings can be found in Table 4.

Table 4. Main findings from Study I and Study II.

Study	Main findings
I	<ul style="list-style-type: none">• Adherence to daily reports was 87% (Md 92%, 16-100%), and generated 3,536 reports.• All listed symptoms were used, where the most common being: urinary urgency, fatigue, hot flushes, and difficulties in urinating.• 1,566 alerts were generated, where 1/3 were severe (red alert).• The app was reported, in the interviews, as easy to use, the reporting became routine; to report facilitated reflection over symptoms, the symptoms were relevant although some found that nuancing severity was hard. Using the app was reported as providing a sense of security.
II	<ul style="list-style-type: none">• Substantial portions of the participants showed inadequate FHL and CCHL.• CCHL changed significantly for the intervention group from baseline to three months after ended treatment ($p = 0.050$).• Functional health literacy and self-care agency did not reveal any statistically significant differences over time in either group.

6.1 Using the app

In the logged data from 63 patients, adherence to daily symptom reports was on average 87% (median 92%, range 16%-100%). Three patients were excluded from analyses since they never made any reports after the introduction to the app. Overall, patients made 3,536 reports during the trial, covering the presence of 10,025 specific symptoms.

6.1.1 Reporting Symptoms

Patients used all of the 15 different symptoms that could be reported. Urinary urgency (18.7%), fatigue (18.3%), hot flushes (16.2%), and difficulties in urinating (10.5%) were the most prevalent symptoms (Table 5). The most distressing symptoms were depression, pain, difficulties in urinating, worry, insomnia, and constipation. Even though urinary urgency was a common symptom, it was neither frequent nor distressing. Depression, on the other hand, did not occur that often but was reported as the most distressing symptom and high on symptom frequency.

One thousand five hundred sixty-six (1,566) of the reported symptoms (15.6%) generated alerts that were sent to the nurses at the oncology clinics where the patient received his treatment. A third ($n=517$) of the alerts were severe (red) requiring a contact from the nurse within an hour, while the remaining 1,049 (67.0%) were

less severe (yellow) and the nurse could contact the patient within a working day. Urinary urgency was the most common alert (yellow n=359, red n=127), followed by pain (yellow n=287, red n=212), and difficulties in urinating (yellow n=274, red n=72). Alerts led to the nurses contacting the patients, adding a short, written note in the web-interface, e.g., “Called the patient – no further action,” “Pain same as before – already been taken care of,” “Extension of the patient’s prescription,” “Booked an appointment with the physician,” and “Advice given on the patient’s medication” (Study I, page 5).

Table 5. The five most occurring (per cent of reported symptoms), frequent frequency (never [1] to very often [4]), and distressing (not at all [1] to very much [4]) symptoms from the patients’ reports.

Symptom occurrence (%)	Symptom frequency (mean)	Symptom distress (mean)
Urinary urgency (18.7%)	Pain (2.30)	Depression (2.39)
Fatigue (18.3%)	Depression (2.29)	Pain (2.38)
Hot flushes (16.2%)	Difficulties in urinating (2.28)	Difficulties in urinating (2.22)
Difficulties in urinating (10.5%)	Hematuria (2.23)	Worry (2.20)
Pain (6.8%)	Fatigue (2.22)	Insomnia (2.20)

6.1.2 Perceptions of the App

The content analyses of interviews with patients resulted in six categories: 1) reporting and content, 2) self-care advice, 3) historical graphs, 4) alerts, 5) technology, and 6) safety and novelty.

Overall, the patients reported that the app was easy to use, even for those who were not accustomed to smartphones. To send reports daily was not seen as particularly time-consuming, and the patients described reporting as “becoming a routine.” Further, symptom reporting was described as making the patients reflect on their well-being.

The content in the app was described as relevant although some found the item responses “blunt,” where they wished to be able to describe the symptoms further or have more alternatives than 1-4.

Relevant questions but might be a little blunt; hard to know what is meaningful to report, hard to put the level of how to respond to such as “not at all” or “a little” distress in the beginning. [P58, age 74 years]

The self-care advice was read, but some participants described being given the same information by the nurses. Patients described the pieces of advice as providing both knowledge and a way they could decrease the symptom burden.

Historical graphs provided patients a confirmation on how they felt, but could further provide a tool to show family and friends how they were doing:

I used the graphs to show my family and friends that I actually felt good during the treatment. [P21, age 73 years]

The alerts provided a sense of safety to some, while others wanted an ability to decide if they wanted to be contacted. The latter lead some to fine tune their responses:

It took me about a week to fine tune the level at which to report symptoms. At the start the nurses called me pretty often, but then I learned how to report the symptoms so as to avoid being contacted unnecessarily. [P29, age 55 years]

The majority (70%, n=37) did not report any technological problems when using the app. Some reported issues initially when the study started, issues that required a restart of the phone and then was resolved (n=20).

6.2 Influence on Health Literacy and Self-Care Agency

6.2.1 Functional Health Literacy

The FHL levels at baseline revealed that 9.8% of the intervention group and 10.9% of the control group reported inadequate FHL, and there were no significant differences between the groups at baseline ($p = .414$). Three months after ended treatment, 9.8% of the intervention group and 3.6% in the control group reported an inadequate FHL ($p = .203$). Three months after ended treatment, no statistically significant within-group differences were found for FHL measured for either the intervention ($p = .682$) or control groups ($p = .617$).

6.2.2 Communicative and Critical Health Literacy

The CCHL levels at baseline revealed that 12.5% of the intervention group and 23.1% of the control group reported inadequate CCHL, and there were no significant differences in the groups at baseline ($p = .523$). Three months after ended treatment, 4.9% of the intervention group and 13.0% in the control group reported an inadequate CCHL with no statistically significant differences ($p = .114$). Three months after ended treatment, no statistically significant within-group differences were found for CCHL for the control group ($p = .617$). However, a statistically significant within-group improvement was found for the intervention group ($p = .050$).

Having found a statistically significant within-group difference in CCHL over time, an analysis of each item in the CCHL was performed. Statistically significant improved scores from baseline to three months after ended treatment were shown on three items in the CCHL: “I can select the particular information I need from a variety of information sources.” ($p = .020$), “I can determine if the information is credible.” ($p = .041$), and “I can, based on the information, plan and decide about what I need to do to improve my health.” ($p = .004$).

Having found a statistically significant difference in levels of education between the intervention and control groups, the multinomial logistic regression (Table 5) showed no probability that higher levels of education determined a higher level of CCHL (model $\chi^2=10.17$, $df 6$, $p = 0.118$).

Table 5. Multinomial logistic regression for communicative and critical health literacy three months after ended treatment.

	B (SE)	95% CI for Odds Ratio		
		Lower	Odds Ratio	Upper
Sufficient CCHL vs Inadequate CCHL				
Intercept	3.27 (0.89)***			
Group control	-1.38 (0.77)	.06	.25	1.15
- intervention	0			
Elementary school	-1.47 (1.03)	.03	.23	1.71
High school	-1.41 (0.91)	.04	.25	1.45
College/university	0			
Problematic CCHL vs Inadequate CCHL				
Intercept	2.96 (0.90)***			
Group control	-.82 (0.77)	.10	.44	2.00
- intervention	0			
Elementary school	-.88 (0.99)	.06	.42	2.87
High school	-1.57 (0.91)	.04	.21	1.24
College/university	0			

Note: $R^2 = .09$ (Cox & Snell), $.10$ (Nagelkerke). Model $\chi^2(6)=10.17$, $p = .118$. *** $p < .001$

6.2.3 Self-care Agency

The average score for ASA-A at baseline was 91.1 (SD 9.9) for the intervention group and 92.1 (SD 9.5) for the control group. Three months after ended treatment, the ASA-A was 91.5 (SD 9.3) and respectively 92.2 (SD 11.0). No statistically significant between-group differences were found at either baseline ($p = .602$) or three months after ended treatment ($p = .731$).

6.2.4 Association between Self-care Agency and Communicative and Critical Health Literacy

At baseline, there was a significant, positive moderate correlation between the variables self-care ability and CCHL for both the intervention group ($\rho = 0.353$, $p < 0.05$), and the control group ($\rho = 0.352$, $p < 0.01$). Thus, patients with a higher score on ASA-A reported a higher level of CCHL.

7 DISCUSSION

7.1 Methodological Considerations

The use of a historical control group in the trial can have potential weaknesses, like changes in treatment or therapy regimens. However, there were no changes in treatments and content of standard care between the groups; treatment regimens, Gleason score, and clinical staging of the disease were not statistically different between the historical controls and the intervention group. Furthermore, due to the sample size, it should be noted that some groups had become quite small in the analyses due to attrition, which opens up the risk for type II errors (Altman, 1991; Shadish, Cook, & Campbell, 2001).

The samples were recruited consecutively at the two sites, and with a participation rate of 77% for the intervention group and 80% for the control group. The demographic data revealed only one statistically significant variable that differed between the intervention and control groups – the level of education – that did not show any effect on the outcome variable of CCHL, unlike other studies (Bailey et al., 2015). Previous studies have found associations between level of education and levels of health literacy (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Jansen et al., 2018). It can be argued that the sample that participated in the intervention possibly were more prone to accept new, technological interventions, potentially leading to a more select sample. It is difficult to ascertain that aspect in a study unless an analysis of the non-responders could be done.

In this study, smartphones were lent to the participants to decrease any impact of not having access to a smartphone or tablet. The trial started at a time when the use of smartphones and the internet boomed in Sweden (starting in 2011) in the young and the working population (Findahl, 2012). When the trial started, smartphones and apps were not used across all populations; 55% of the Swedish population had mobile access to the Internet (Findahl, 2012). The year the intervention group began in the trial (2013), almost two-thirds of the Swedes had access to a smartphone and mobile internet (Findahl, 2013). However, Swedes of the age group recruited here, only 8% used the Internet daily via their mobile phone, and 24% used the Internet only sometimes in 2013. In spite of this, participants reported it easy to use the app and had a high adherence to reporting. These numbers of Internet use are rapidly increasing, but a group of people older than 75 (17%) still do not have access to smartphones and Internet (Davidsson & Thoresson, 2017).

The app had previously been tested for feasibility with good results (Sundberg et al., 2015), and few technical issues were reported during the trial (Study I). Furthermore, the app contained the symptoms and areas of need for the patients, and, described as easy to use.

Interviews were conducted primarily by taking notes while interviewing over the phone, which can lead to missing some nuances in their experiences or to losing exact wordings. A few (n=9) of the interviews were tape-recorded and later transcribed. This was done in some instances when patients in the intervention group lived far away from the treatment site and the smartphone was collected at the same time as another interview was conducted. In the analyses, no differences were observed in the results from the two modes of collecting data.

When the trial was started, discussions about health literacy was a recent concept to be tested in a Swedish context, notably using a scale that included CCHL (Wångdahl & Mårtensson, 2014). During the last few years, many instruments to measure and assess eHealth literacy have been presented (Sudbury-Riley, FitzPatrick, & Schulz, 2017; van der Vaart & Drossaert, 2017), although discussions started much earlier (Norman & Skinner, 2006). Assessing eHealth literacy, which assesses individual's ability to use information technology to improve one's health (Eng, 2002), will become an even more important issue to be able to serve communities and trial participants. Patients with lower levels of health literacy have been found to be less likely to own a smartphone or have access to the Internet (Bailey et al., 2015), something that could continue to marginalize an already vulnerable group. In this trial, we avoided that risk by lending the men a smartphone.

Looking at the scales used in this trial, there is a potential issue with FHL where one item asks about the use of reading glasses (Mårtensson & Wångdahl, 2017a; Wångdahl & Mårtensson, 2015). The use of reading glasses is something that is common in this group of individuals based on age, and this item may result in older participants "easily" receiving a less favorable scores on FHL since "normal" age-changes like the use of glasses can lead to a lower score.

In Study II there were no statistically different levels of ASA-A in the intervention and control groups at either baseline or three months after ended treatment. Similar levels of self-care agency have been found in healthy older adults (Söderhamn, Lindencrona, et al., 1996). This could indicate that the measure is less successful in discriminating levels of self-care agency in a vigorous group of individuals which is visible in some of the items that asks about the ability to manage one's hygiene.

Lately models on how to evaluate eHealth interventions have been published, where a model has been presented to increase the evidence base for the interventions (Enam, Torres-Bonilla, & Eriksson, 2018). The model bears a resemblance to the framework from the randomized controlled trials for complex interventions which this trial is a part of (Campbell et al., 2007), but it details the aspects that need to be assessed at the different stages of implementing an eHealth intervention. This trial will later have to be followed up in a randomized controlled version to fully see if the use of an app decreases symptom burden and simplifies symptom management.

7.2 Discussion of the findings

7.2.1 Symptom experience

In the SMT symptom experience studies the patient's perception, evaluation and response to symptoms (Bender et al., 2018). Using PROs in the app, patients have been able to perceive and evaluate their symptoms from the list of 15 symptoms. In free text comments, additional symptoms could be reported. The patient has been given the task of describing the presence of the symptom, its occurrence, and the distress that particular symptom causes. There is nothing in the app that prevents mentioning several symptoms at once, which has been discussed in the symptom theories, although it is not a problem in SMT. Furthermore, the app did not include the interaction of symptoms in the evaluation and assessment; however, several symptoms could be reported. With more than 3,500 reports, including more than 10,000 symptoms, this indicates that the patient, on average, experiences more than one symptom.

From the assessment of the symptoms experienced, it can be seen that the most prevalent versus the most distressing symptoms vary. These results support the notion behind PROs that patients should report their experiences and not merely rely on nurses and health provider's assessments (Basch et al., 2016; Chen et al., 2013).

7.2.2 Symptom Management Strategies and Outcomes

In the evaluation, there was a risk-assessment model as part of the functionality that led the more clinically important symptoms to be assessed and treated faster by sending alerts to the nurses. With the available self-care advice and interventions in the app, there were symptom management strategies available to the patients. Some generated an alert that led to a nurse contacting the patient. Looking at the results through the prism of SMT, there was less focus on how the outcome was resolved unless it generated an alert. To some patients, that meant that the feedback on how their symptoms were developing was visible in the graphs.

The patients had access to self-care advice to manage symptoms. However, there was no possibility to assess the patients' use of them: if patients read them initially or did so when starting the trial or returned to them during their treatment, and there was no systematic way of knowing how well the pieces of advice worked. From the interviews, we learned that patients had used them.

In this study it was not possible to assess if there were any outcomes, e.g. in decreased number of emergency room visits, as has been described for other interventions but could be an interesting marker to assess (Basch et al., 2016).

7.2.3 Adherence

Adherence is in the SMT described as the factor that connects symptom management and outcomes and symptom status. Intervention participants showed a high adherence to reporting in the app during their treatment period. Of note here is that adherence is calculated on the number of days reported out of the possible days of reporting while in the trial. This is not a self-reported measure in this case but an objective measure. The adherence in this study is referring to the adherence to reporting symptoms in the app, not to the adherence to advice provided by either the nurse or Interaktor or the time spent using the app (Sieverink, Kelders, & van Gemert-Pijnen, 2017). The high adherence could be attributed to the app being easy to use, providing useful information and services which participants described in the interviews. Furthermore, the app was reported as easy to use and the reporting became a daily routine. There is of course always the issue of desirability to be aware of, where a participant does not want to disappoint the researchers or the nurses at the clinic.

In this study we have found both a high adherence and an improved CCHLA study by Miller of adherence and the use of non-medication interventions in patients with cardiovascular found that interventions to improve health literacy also resulted in improved adherence (Miller, 2016). Kim and Xie (2017) have described studies where participants with low health literacy levels found apps useful. In our sample we have a high adherence in spite of substantial proportions reporting low health literacy levels.

7.2.4 Health literacy

The health literacy levels found in this group of patients – particularly the reported low levels of both FHL and CCHL – indicate individual qualities and vulnerabilities that could affect a person's ability to manage their symptoms (Mårtensson & Hensing, 2012). From the literature, it is known that low levels of health literacy affects a person's ability to make decisions about treatment (Song et al., 2012). Similarly, levels of low FHL have been found in Swedish samples of people screened for colon cancer (Wangmar et al., 2018) and patients undergoing day surgery (Hälleberg Nyman, Nilsson, Dahlberg, & Jaensson, 2018). This indicates that there is a substantial group of patients that have vulnerabilities that can affect their ability to correctly assess and manage symptoms. Sets of clinically important areas that ought to be brought into the training of health-care professionals have been presented regarding health literacy where focus has been on clear and easy language without medical jargon, but also the realization that problematic health literacy levels are more widespread than often assumed (Karuranga, Sørensen, Coleman, & Mahmud, 2017; Toronto, 2016).

In the intervention group, we found a statistically significant improvement in CCHL. Interestingly, it was items reflecting ability to search information, judgement of information and use of information in the CCHL scale that showed improvements during the study period. These are items that could be related to the use of the app with self-care advice with links out to evidence-based information and having access to a nurse when symptoms were alarming.

There has been an increase in the use of eHealth and mHealth solutions in Swedish healthcare, where patients can contact healthcare via web or app interfaces (Lundberg et al., 2013), access their electronic healthcare records online (Hägglund & Koch, 2015; Hägglund & Scandurra, 2017). In oncology there are descriptions of patients being active online in search of information, but also to stay in contact with family and friends (Mattsson, Olsson, Johansson, & Carlsson, 2017). The app with its self-care advice and provided links to evidence-based information may have had a better content and approach than what has been described in analyses of websites with cancer information (Haase, Thomas, Gifford, & Holtslander, 2018).

At the same time, smartphones and tablets have increased in society, and 85% of the Swedes have searched for health and medical information online the last month (Davidsson & Thoresson, 2017). This is a substantial increase over the years. This further raises the need of assessing the eHealth literacy in patients (Altin et al., 2014). It is even more pertinent in a patient group belonging to an age bracket that is still evolving and increasing in its use of smartphones and other mobile services, but where other aging-related issues may influence the use of Internet, smartphones, and apps (Davidsson & Thoresson, 2017; Koch & Hägglund, 2009; Kottorp et al., 2016; Malinowsky, Fallahpour, Lund, Nygard, & Kottorp, 2017). However, interventions like an app have been described being important and helpful for patients with a low level of health literacy (Kim & Xie, 2017).

It is not just the patient that has and can change his levels of health literacy. It is crucial that nurses and other health care providers assess and adapt and person-center their information to the patients (Smith et al., 2013). However, it has been found that nurses overestimate patients health literacy levels (Dickens, Lambert, Cromwell, & Piano, 2013). Furthermore, it has been found that the information given about radiotherapy is given at a higher level than recommended (Prabhu, Hansberry, Agarwal, Clump, & Heron, 2016).

The radiotherapy that takes place at an outpatient clinic makes other parts of the environment important, which in this group of individuals could be the family, friends and other networks. Furthermore, the app becomes its own environment where interaction between patient and family or friends can be assisted with the historical graphs. There have been descriptions of the closeness technology in health care can create, for example, by creating mutual spaces (Pols, 2012).

7.3 Clinical implications

The clinical implications are that an app like this is a valuable tool for patients to assess, report and manage their symptoms, enabling individuals to use provided self-care advice to manage symptoms on their own. But also enable a quick contact with a nurse when needed, enabling a nurse's assessment and intervention.

Health literacy must be assessed, although maybe not measured, to guide nurses to give patients information at a level patients can understand.

The app worked for groups with different levels of health literacy, also the ones with inadequate levels which means that an app like this can be used by patients from all levels. Furthermore, there are signs the app even contribute to improving the health literacy levels.

7.4 Future research

Future research should be focused on using stronger designs, like conducting larger randomized, controlled trials, in which interventions using mHealth are tested and compared to control groups receiving standard care. With a stronger design, determining the influence the app can have in improving patients' health literacy can be performed with better evidence.

Health literacy is an important area to explore more in patients, particularly when a greater participation in one's care has become legally binding (The Patient Act, SFS 2014:821). Health literacy levels have potentially great impact on the patients' ability to assess and manage their symptoms. More descriptive inventories are needed to assist nurses and healthcare professionals to be able to provide the right and needed support for the patients.

E-health literacy ought to be measured in future studies that include different e-health interventions. The literature is growing and providing salient results that, albeit important, health literacy is one aspect, but the more common use of eHealth interventions need to factor in the patients' eHealth literacy levels.

8 CONCLUSION

The conclusions to draw from this thesis are that an mHealth intervention, the app Interaktor, served as a supportive tool for the patients to assess and manage symptoms during the radiotherapy for prostate cancer. The intervention provided the patients with a sense of safety, increased awareness of own well-being and a significant improvement in communicative and critical health literacy was found.

The portions of inadequate levels of health literacy reported leave substantial groups of patients more vulnerable in assessing and managing symptoms when treated with radiotherapy for prostate cancer. Although health literacy levels include notable portions of patients in this study that have inadequate levels of both functional and communicative and critical health literacy, the adherence of using the app was high.

9 SVENSK SAMMANFATTNING

Prostatacancer är en diagnos som kan påverka individers livskvalitet både på grund av symptomen relaterade till sjukdomen och behandlingen som männen får. Behandling med strålbehandling för prostatacancer i Sverige äger rum på polikliniker där patienten besöker dagligen för strålbehandling och sedan återvänder hem. För det mesta upplever patienten symtomen och biverkningar hemma utan hälsovårdspersonal lättillgänglig. För att underlätta personcentrerad vård och förbättra klinisk hantering när sjukhusvård flyttar till öppenvård, utvecklades appen (Interaktor) för smartphones och läsplattor. Med hjälp av patientrapporterade resultat (PRO) var appen avsedd att identifiera symptom tidigt, utvärdera dem i realtid och tillhandahålla symptomhanteringsstöd under strålbehandling för prostatacancer.

Mål: Det övergripande målet med interventionen som beskrivs i denna avhandling var att underlätta symptomhantering för patienter med prostatacancer som assisterades med en interaktiv app under strålbehandling.

Metoder: De två studierna som ingår i denna avhandling kommer från en studie. En beskrivande undersökning utvärderade interventionsgruppens användning och uppfattning om användningen av appen, och en kvasi-experimentell undersökning jämförde de som använder appen med en historisk kontrollgrupp som inte använde appen för att utvärdera effekten på hälsolitteracitet och egenvård. Patienterna (n = 130) rekryterades successivt från två universitetssjukhus i Sverige mellan april 2012 och oktober 2013. Interventionsgruppen (n = 66) hade tillgång till appen under 5-7 veckors strålbehandling och ytterligare tre veckor. Interventionsgruppens användning av appen loggades. Hälsolitteracitet mättes med hjälp av den svenska *Skala för Funktionell hälsolitteracitet* (FHL) och den svenska *Skala för kommunikativ & kritisk hälsolitteracitet* (CCHL) och skalan bedömning av egenvårdsförmåga skala, version A (patientens bedömning) (ASA-A) för egenvård. Utskrivna noteringar från telefonintervjuer eller dem genomförda ansikte mot ansikte om deltagarnas erfarenheter av användning och rapportering i appen analyserades.

Resultat: I interventionsgruppen som använde appen var följsamheten till dagliga rapporter 87% (Md 92%, 16-100%) och genererade 3 536 rapporter. Alla listade symptom användes, var de vanligaste var: urinträngningar, trötthet, vallningar och svårigheter med urinering. Totalt 1566 varningar genererades, varav 1/3 var allvarlig (röd alert). Appen beskrevs i intervjuerna såsom lätt att använda, rapporteringen blev rutinmässig; att rapportera underlättad reflektion över symptom var symtomen relevanta även om vissa fann att nyanser av svårighetsgrad var svåra. Användningen av appen rapporterades som att ge en känsla av säkerhet. Väsentliga delar av deltagarna visade otillräcklig FHL och CCHL vid baslinjen för båda grupperna. CCHL förändrades signifikant för interventionsgruppen från baslinjen till tre månader efter avslutad behandling (p = 0,050). Funktionell hälsolitteracitet och egenvårdsförmåga avslöjade inte några statistiskt signifikanta skillnader över tiden för någon grupp.

Slutsatser: Slutsatserna från denna avhandling är att en mHealth-intervention, app Interaktor, fungerade som ett stödjande verktyg för patienterna att bedöma och hantera symtom under strålbehandling för prostatacancer. Interventionen gav patienterna en känsla av säkerhet, ökad medvetenhet om eget välbefinnande och en signifikant förbättring av kommunikativ och kritisk hälsolitteracitet hittades.

De delar av otillräckliga nivåer av hälsolitteracitet som rapporterade lämnar väsentliga grupper av patienter som mer sårbara vid bedömning och hantering av symtom vid behandling med strålbehandling för prostatacancer. Även om hälsolitteracitetsnivåerna visar att noterbara delar av patienterna i den här studien har otillräckliga nivåer av både funktionell och kommunikativ samt kritisk hälsokompetens var följsamheten att använda appen hög.

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