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QUALITY OF RADIOTHERAPY CARE BY DEVELOPMENT OF e-FEEDBACK KNOWLEDGE

Mervi Siekkinen

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To Jari,
Petra and Reetta

Mervi Siekkinen

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Annales Universitatis Turkuensis, Painosalama Oy, Turku 2014

ABSTRACT

The aim of this three phase study was to develop quality of radiotherapy care by the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know). In Phase I, the purpose was to describe the quality of radiotherapy care and its deficits experienced by cancer patients. Based on the deficits in patient education in Phase II, the purpose was to describe cancer patients' e-knowledge expectations in radiotherapy. In Phase III, the purpose was to develop and evaluate the outcomes of the e-Re-Know among breast cancer patients. The ultimate aim was to develop radiotherapy care to support patients' empowerment with patient e-education.

In Phase I (2004-2005), the descriptive design was used, and 134 radiotherapy patients evaluated their experiences by Good Nursing Care Scale for Patients (GNCS-P) in the middle of RT period. In Phase II (2006-2008), the descriptive longitudinal design was used and 100 radiotherapy patients' e-knowledge expectations of RT were evaluated using open-ended questionnaire developed for this study before commencing first RT, in the middle of the treatment, and concluding RT period. In Phase III, firstly (2009-2010), the e-Re-Know intervention, i.e. knowledge test and feedback, was developed in terms of empowering knowledge and implemented with e-feedback approach based on literature and expert reviews. Secondly (2011-2014), the randomized controlled study was used to evaluate the e-Re-Know. Breast cancer patients randomized to either the intervention group (n=65) receiving the e-Re-Know by e-mail before commencing first RT and standard education or the control group (n=63) receiving standard education. The data were collected before commencing first RT, concluding last RT and 3 months after last RT using RT Knowledge Test, Spielberger's State Trait Inventory (STAI) and Functional Assessment of Cancer Therapy - Breast (FACT-B) –instruments. Data were analyzed using statistical methods and content analysis.

The study showed radiotherapy patients experienced quality of care high. However, there were deficits in patient education. Furthermore, radiotherapy patients' multidimensional e-knowledge expectations through Internet covered mainly bio-physiological and functional knowledge. Thus, the e-Re-Know was developed and evaluated. The study showed when breast cancer patients' carried out the e-Re-Know their knowledge of side effects self-care was significantly increased and quality of life (QOL) significantly improved in line with decrease in anxiety from time before radiotherapy period to three months after. In addition, the e-Re-Know has potential to have positive effects on anxiety and QOL, regardless of patient characteristics or knowledge level. The results support the theory of empowering patient education suggesting that empowerment can be supported by confirming patients' understanding of own knowledge level.

In summary, the e-Feedback knowledge of radiotherapy (e-Re-Know) intervention can be recommended in development of quality of radiotherapy care experienced by breast cancer patients. Further research is needed to assess and develop patient-centred quality of care by patient education among cancer patients.

Keywords: Quality of care, radiotherapy, patient education, e-feedback, knowledge test, breast cancer patient

Mervi Siekkinen

SÄDEHOIDON LAADUN KEHITTÄMINEN e-TIETOPALAUTTEEN AVULLA

Hoitotieteen laitos, lääketieteellinen tiedekunta, Turun yliopisto, Suomi

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TIIVISTELMÄ

Tämän kolmivaiheisen tutkimuksen tarkoituksena oli kehittää potilaslähtöistä sädehoidon laatua e-Tietopalaute -intervention avulla. I vaiheessa tarkoituksena oli potilaslähtöisesti analysoida sädehoidon laatua ja siinä olevia puutteita. Potilasohjauksessa koetuista puutteista johtuen, II vaiheessa tarkoituksena oli selvittää potilaiden tiedollisia e-odotuksia sädehoidossa. III vaiheessa tarkoituksena oli kehittää ja arvioida e-Tietopalautteen vaikuttavuutta rintasyöpäpotilaiden näkökulmasta. Tutkimuksen tavoitteena oli kehittää sädehoidon laatua tukemalla potilaan voimavaraistumista e-potilasohjauksella.

Tutkimuksen I vaiheessa (2004-2005) käytettiin kuvailevaa tutkimusmenetelmää ja 134 sädehoitopotilaan kokemuksia arvioitiin HYVÄ HOITO potilasversio -mittarilla sädehoitojakson puolivälissä. II vaiheessa (2006-2008) käytettiin kuvailevaa pitkittäistutkimusmenetelmää ja 100 sädehoitopotilaan tiedollisia e-odotuksia sädehoidosta arvioitiin käyttämällä tähän tutkimukseen kehitettyä avointa kyselylomaketta ennen ensimmäistä sädehoitoa, sädehoitojakson puolivälissä ja lopussa. III vaiheessa ensin (2009-2010) kehitettiin e-Tietopalaute -interventio, so. tietotesti sädehoidosta, ja palaute, joka sisälsi voimavaraistumista tukevaa tietoa ja joka toteutettiin käyttämällä sähköistä palautetta perustuen teoreettiseen ja asiantuntijoiden tietoon. Seuraavaksi (2011-2014) käytettiin satunnaiskontrolloitua tutkimusmenetelmää arvioimaan e-Tietopalaute. Rintasyöpäpotilaat satunnaistettiin koeryhmään (n=65), jonka potilaat saivat sähköpostitse e-Tietopalautteen ennen ensimmäistä sädehoitoa ja tavanomaisen ohjauksen tai kontrolliryhmään (n=63), jonka potilaat saivat tavanomaisen ohjauksen. Aineisto kerättiin ennen ensimmäistä sädehoitoa, sädehoitojakson lopussa ja kolme kuukautta sädehoitojakson jälkeen käyttämällä Tietotesti sädehoidosta, Speilberger’s State Trait Inventory (STAI) ja Functional Assessment of Cancer Therapy - Breast (FACT-B) -mittareita. Aineisto analysoitiin tilastollisesti ja sisällön analyysillä.

Tutkimuksen tulokset osoittivat, että sädehoitopotilaat kokivat hoidon laadun hyväksi. Puutteita oli kuitenkin potilasohjauksessa. Lisäksi sädehoitopotilaiden tiedolliset odotukset Internetistä koskivat pääasiassa bio-fysiologista ja toiminnallista tietoa. Näin ollen kehitettiin ja arvioitiin e-Tietopalaute. Tulokset osoittivat, että kun rintasyöpäpotilaat käyttivät sitä, heidän tietonsa sädehoidon sivuvaikutusten hoidosta lisääntyi merkitsevästi, elämänlaatunsa parani merkitsevästi, samoin kuin ahdistus väheni sädehoitojakson alusta kolme kuukautta sädehoidon päättymisen jälkeen. Lisäksi e-Tietopalaute vaikutti myönteisesti ahdistukseen ja elämänlaatuun riippumatta potilaan ominaisuuksista tai tiedontasosta. Tulokset tukevat voimavaraistavan potilasohjauksen teoriaa, jonka mukaan potilaan voimavaraistumista voidaan tukea vahvistamalla potilaan ymmärrystä omasta tiedon tasostaan.

Yhteenvetona voidaan todeta, että e-Tietopalautetta sädehoidosta voidaan suositella kun kehitetään rintasyöpäpotilaan kokemaa sädehoidon laatua. Jatkotutkimuksissa tulisi arvioida ja kehittää edelleen potilaslähtöistä syöpäpotilaiden hoidon laatua potilasohjauksen avulla.

Avainsanat: Hoidon laatu, sädehoito, potilasohjaus, e-palaute, tietotesti, rintasyöpäpotilas

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LIST OF ABBREVIATIONS

CVI	The content validity index
e-	Electronic
FACT-B	Functional Assessment of Cancer Therapy - Breast
GNCS-P	Good Nursing Care Scale for Patients
IGRT	Image-guided radiotherapy
IMRT	Intensity Modulated Radiation therapy
KHOS	Krantz Health Opinion Survey
NHS	Department of Health
OECD	Organisation for Economic Co-operation and Development
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RT	Radiotherapy
QOL	Quality of life
SD	Standard deviation
STAI	Spielberger's State Trait Inventory
TNM	Tumour, lymph Nodes and Metastases, breast cancer staging
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life Assessment

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications, which are referred to in the text by their Roman numerals I-IV:

I Siekkinen M, Laiho R, Ruotsalainen E, Katajisto J, Pyrhönen S & Leino-Kilpi H 2008. Quality of care experienced by Finnish cancer patients during radiotherapy. *European Journal of Cancer Care* 17(4), 387-393. (I)

II Siekkinen M, Salanterä S, Rankinen S, Pyrhönen S & Leino-Kilpi H. 2008. Internet knowledge expectations by radiotherapy patients. *Cancer Nursing* 31(6), 491-498. (II)

III Siekkinen M, Kesänen J, Vahlberg T, Pyrhönen S & Leino-Kilpi H. 2014. Randomized, controlled trial of the effect of e-feedback on breast cancer patients' knowledge of radiotherapy in Finland. *Nursing and Health Science*. Accepted for publication (10.9.2014), in press. (III)

IV Siekkinen M, Ryhänen A, Vahlberg T, Pyrhönen S & Leino-Kilpi H. 2014. Psychosocial effect of e-feedback of radiotherapy for breast cancer patients: a randomized controlled trial. *Psycho-oncology*. Published online (19.9.2014) in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.3684. (IV)

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1. INTRODUCTION

Cancer is one of the most common diseases in Western countries and also in Finland (WHO 2012). Nationally, in 2012, there were 30,132 new cases of cancer. Almost half of them were treated with radiotherapy (RT) at some stage of their care often combined with surgery and chemotherapy. Among them, breast cancer patients were the most common patient group and a majority of these 4,694 women received radiotherapy. (Finnish Cancer Registry 2012.) The cancer prevalence will rise, thus demanding higher use of radiotherapy. In addition, the innovative technical developments have enhanced the role of radiotherapy to more effective treatment for cancer patients (Murray & Robinson 2011, Halperin et al. 2013). Because the treatment has many physical (Huber 2011) and psychosocial side effects during (Halkett et al. 2010) and after radiotherapy period (Knopf 2007, Allen et al. 2009) it is the duty of professionals to ensure that the quality of care is experienced as positively as possible.

In radiotherapy, cancer patients' experiences of high quality of care are correlated with better patient education, i.e. knowledge of radiotherapy (Mackenzie et al. 2013, Njiman et al. 2012, Rogerge et al. 2013). It is important to support patients' empowerment with knowledge in order to assist decision making and understanding how to control own care in radiotherapy context of the technical issues and complexity. From this perspective, undertaking new patient education interventions to develop quality of care is essential. It is recommended in international (European Commission 2014) and national health strategies as well (Ministry of Social Affairs and Health 2001, 2013). Especially the introductions of the use of patient electronic (e-) education in health care has increased during last decades by the growth of powerful new health information technologies and better quality of care demand and recommended also National Development Programme of Social Welfare and Health Care -Kaste 2012-2015 (Ministry of Social Affairs and Health 2012).

The patient-centred evaluation of the quality of care is gaining increasing importance within 20th century in the health care system (OECD 2004, WHO 2007, 2008) in addition to the descriptions of professionals or organizations (Hiidenhovi 2001, Johansson et al. 2003, Leinonen et al. 2003, Kvist et al. 2006, Ruotsalainen 2006, Aiken et al. 2012). Because the patient-centred care emphasizes self-management and empowerment by tailoring health care responding to patients' needs and promoting patients' decision making as partners (Maizes et al. 2009) it is endorsed as a key component internationally by WHO (2007, 2008), health care strategies by Ministry of Social Affairs and Health (2001, 2009) and Finnish acts and decrees (1992/782, 2000/812, 2010/1326, 2012/980). It is also ethically justified by National Advisory Boards on Social Welfare and Health Care Ethics (2012).

Patient-centred evaluation of the quality of radiotherapy care is important as well. In Finland, the quality of cancer care is advised by the Ministry of Social Affairs and Health (2010) with proposed standards for good level of quality and improvements. The national propositions for care pathways, centralized treatment units, the utilization of electronic information systems and proceeding to increase patients' participation are included. The quality of medical radiation practices in radiotherapy is controlled by the Directive (European Union) 84/466/Euratom, 96/29/Euratom and 97/43/Euratom (MED-directive), the act of radiation (1991/592, 1142/1998, 39c §), and decree of Ministry of Social Affairs and Health (2000/423, 4 chapter). In last decades, the quality of radiotherapy is viewed in clinical audits mainly from the perspective of technical quality (Finnish advisory committee for clinical audit 2013). However, the patient-centred evaluation could contribute to the development of the care pathways, and be an important variable for benchmarking (WHO 2007, 2008). In addition, the development of quality of care by new intervention will contribute to patients' participation, and will also improve experience of care.

Essential part of quality of care is empowering patient education (Leino-Kilpi et al. 2014). The ultimate goal of patient education is to support patients' empowerment (Redman 2007). Empowerment is one of the central issues in health care, underlined in international (European Commission 2014) and national health strategies (Ministry of Social Affairs and Health 2001, 2013). Especially WHO defined empowerment as "a process through which people gain greater control over decisions and actions affecting their health". It has been suggested that as the individual's control over decisions and actions affecting health is increased, health is enhanced. In patient education, the studies concerning idea of empowerment are rooted from the critical social action, organization and social psychological theory (Kuokkanen & Leino-Kilpi 2000) and post-structuralistics (Bradbury-Jones et al. 2008).

Patients own knowledge expectations of health, health-related problems, treatment and care are in centre of empowering patient education. It is seen as an important facilitator in supporting patients' empowerment in their situation (Leino-Kilpi et al. 2005). Some earlier studies have shown positive outcomes of different educational approaches based on the empowering knowledge (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012). Two of these tested the effects of patient e-education being cognitively empowering Internet-based patient education (Heikkinen 2011) and the Breast Cancer Patient's Pathway (BCPP) -program through the web sites (Ryhänen 2012). The results were encouraging proving increase in knowledge level and decrease in difference between knowledge expected and knowledge received.

Feedback is another facilitator to improve knowledge in patient education. It is usually given informally by face-to-face or formally after an assessment with a knowledge test, but it has also been found to be effective when implemented electronically (Mason & Bruning 2003). In nursing, e-feedback in patient education is seen as a determinant of patients' empowerment (Kuijpers et al. 2013), as well, emphasizing the patient-centred idea that patients are supported in their own situation regarding knowledge level (Anderson & Funnell 2010). The e-feedback realized through web-based Internet technologies is shown to improve knowledge (Dempsey et al. 1993, Mason & Bruning 2003, Wang & Wu 2008), self-efficacy (Bangert-Drowns et al. 1991, Wang& Wu 2008) and quality of life (Nes et al. 2013, Tabac et al. 2014). Several reviews of the literature have examined the effectiveness of interventions for patient e-education (Nquyen et al. 2004, Woffold et al. 2005, Murray et al. 2005, Fox 2009, Ryhänen et al. 2010, Kuijpers et al. 2013, Paul et al. 2013, Kesänen et al. 2014). However, there is a lack of research evaluating the effects of e-feedback among cancer patients.

In this study, patient e-education was based on the content of patients' own knowledge expectation and implemented in e-feedback approach. In radiotherapy, knowledge expectations arise from misconceptions and fears of regarding radiation and treatment (Hinds & Moyer 1997, Hammick et al. 1998, Long 2001, Rosenthal 2006, Halkett et al. 2008). Thus, the positive effects not only on cognitive but also psychosocial outcomes should be evaluated. Particularly, the most common cancer patient receiving radiotherapy, a woman with breast cancer, may benefit from patient e-education. They have moderate to high level unmet knowledge deficits during (Liao et al. 2012) and after RT (Raupach & Hiller 2002) concerning disease and treatment, varying over time (Mesters et al. 2001) and they are interested in using Internet for health information search (Rutten et al. 2005, Asfhari et al. 2011).

The aim of this three phase study was to develop quality of radiotherapy care by the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know). In Phase I, the purpose was to describe the quality of radiotherapy care and its deficits experienced by cancer patients. Based on the deficits in patient education in Phase II, the purpose was to describe cancer patients' e-knowledge expectations in radiotherapy. In Phase III, the purpose was to develop and evaluate the outcomes of the e-Re-Know among breast cancer patients. The ultimate aim was to develop radiotherapy care to support patients' empowerment with patient e-education.

2. LITERATURE REVIEW

The literature review is presented in five parts: 1) the definitions of the main concepts of the study, 2) a comprehensive picture of radiotherapy, 3) description of the quality of radiotherapy care and its deficits from the perspective of cancer patients in radiotherapy, 4) the nature of empowering patient e-education in radiotherapy covering e-knowledge expectations, interventions and outcomes, and finally 5) the implementation of e-feedback approach in patient education is described.

The literature review for this study covered the period 1980 – 2014 (Appendix 1). It was carried out during the studies I, II, III and IV and updated in 2014. The searches were based on the Medline (Ovid)/MEDLINE (via PubMed) (I, II, III) and Cinahl/CHINAL (via EBSCO) (II, III); and manual searches (I, II, III). Manual searches included references of identified articles and hand searches. Cochrane and Scopus were used to verify coverage of the searches, however covering records included before. Database focused on the main concepts of the study and issues concerning patient education interventions. The search terms were used alone, interchangeably and in various combinations. If available, MeSH terms were entered into the search engines. The help of librarian was used to prevent gaps with keywords or combinations of them. If records could not be assessed by the title and abstracts, the full text of the publication was reviewed. Being included into reviews, the studies had to focus on adult (over18 years) and be in English language. (Higgins & Green 2011.)

Firstly, the literature review was carried out to gain a comprehensive overview of the quality of radiotherapy care and its deficits (I, summary). Secondly, to gain an overview of patient e-education in radiotherapy the systematic literature review included an assessment of studies of knowledge expectations of radiotherapy from the perspective of cancer patients. Only one study was describing knowledge expectations through Internet among radiotherapy patients. Thus, also the studies describing cancer patients' knowledge expectations in radiotherapy were included (II, summary). To develop the content of the intervention, the review was updated and deepened to breast cancer patients knowledge expectations (III, IV, summary.) Thereafter, to find out a patient e-education approach in radiotherapy main interest of the systematic literature review was in cognitive (knowledge level) and psychosocial (anxiety, QOL) outcomes evaluated in experimental (randomized controlled and quasi-experimental) patient education designs. The evidence was gathered from studies with the guidance of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statements (Moher et al. 2009). In addition, the evidence of e-feedback approach was carried out to develop the structure of the intervention. The studies of reviews describing patient e-education were included (III, IV, summary).

2.1 Definitions

Radiotherapy (**RT**) is the treatment of cancer with ionizing radiation given in forms of x-rays, y-rays or electrons and protons (Murray & Robinson 2011, Perez & Mutic 2013). The aim of radiotherapy is to deliver a lethal dose to the cancer cells, reduce local recurrence and improve survival. Radiotherapy is an external beam radiation or internal radiation therapy (brachytherapy), depending on the histological type, stage and location of the tumour.

Radiotherapy care is defined with concepts of nursing, environment, health and human being in clinical radiotherapy. Nursing is defined as "seamless combination of patient care and service as well as technical usage of radiation and radiation protection aimed at serving the health care field as part of a multi-professional teamwork". Environment in clinical radiotherapy is defined as "the physical and functional environment in health care, cultural environment, cognitive environment, and context of a radiographer's expertise". Health is defined as "a holistic and variable state of being that is indirectly affected by radiation" and substituted with the concept of health and illness. A human being is defined as "a dignified individual, which is also a holistic and variable being". (Sorppanen 2006.) In addition, radiotherapy patient is defined as "a patient receiving radiotherapy as treatment for cancer in radiotherapy department operating in special health care every weekday (mon-fri) extend over 4-8 weeks (radical) or 1-10 days (palliative)" (Murray & Robinson 2011).

Quality of care is a multidimensional concept (Palmer 1991). Quality is "care that is effective, safe and provides as positive an experience as possible" (NHS 2013). WHO defines the quality of care as "a process for making strategic choices in health systems" (WHO 2006). In nursing, it has different characterises as safe, effective, patient-centred, timely, efficient, equitable.

Quality of radiotherapy care experienced by patients has aspects as information provision, patient-centred approach, professional competence, planning and waiting times, accessibility, co-operation and communication, and follow-up care (Njiman et al. 2012, Rogerge et al. 2013) and environment (Rogerge et al. 2013). Here, the quality is expressed in terms of the concept of GOOD CARE and it has six main categories: staff characteristics, caring activities and preconditions for care, caring environment, caring process and patients' empowerment strategies (Leino-Kilpi et al. 1994).

Patient-centred is a widely used concept in nursing and health care. Also the concepts as person-centred, patient-centredness, person-centredness, and in Finnish potilaslähtöisyys and asiakaslähtöisyys are used. In nursing, the conditions to patient-centred are the attributes of the nurses, the care environment, person-centred processes, and outcomes from the perspective of patients. (McCormack & McCance 2006, McCance et al. 2009.)

Patient-centred care is a fundamental characteristic in high quality of care and defined as “being respectful of, and responsive to, patients’ physical, social and emotional preferences and needs” (Institute of Medicine 2001).

The **patient-centred quality of radiotherapy care** have domains such as information and communication about their cancer, emotional and spiritual support, management of physical symptoms and involvement of friends and family (Mackenzie et al. 2013, Dong et al. 2014).

The **empowering patient e-education** is defined by the concepts of “empowerment”, “patient education” and “e-“.

Empowerment is a multidimensional concept and seen differently in various settings as a process and outcome (Rappaport et al. 1984). It is associated with psychology, community psychology, social work, education and nursing (Ellis-Stoll & Popkess-Vawter 1998) and used in the context of individual, organizational and community development (Rappaport et al. 1984, Ellis-Stoll & Popkess-Vawter 1998, Kuokkanen & Leino-Kilpi 2000). Among cancer patients empowerment issues are relevant because of the numerous ways in which they come to lose control after diagnosis. The empowered cancer patients initiated an active and participatory role in controlling health and treatment related aspects of their lives. (Mok & Martinson 2000, Chang et al. 2004.)

The process of empowerment requires knowledge (Ellis-Stoll & Popkess-Vawter 1998). Multidimensional **empowering knowledge** includes overall bio-physiological (i.e., illness, symptoms, treatment and complications), functional (i.e., self-care, mobility, rest and nutrition), experiential (i.e., emotions and hospital experiences), ethical (i.e., rights, duties and participation in decision-making), social (i.e., families, other patients and patient associations) and financial (i.e., costs and financial benefits) dimensions (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012). In this study, patients own knowledge expectations are seen as a basis of empowering patient education.

The concept of ”**patient education**” is used to refer to nursing care in health care context requiring coordination, implementation, evaluation aiming to increase the knowledge of health problems and care (Funnell et al. 1991, Redman 2007). Also the concepts as patient counseling, patient teaching, patient learning, patient guidance and patient informing are used. The patient education varies according to patients’ situation while different contents and approaches are used (Redman 2003). The ultimate goal of patient education is to increase patients’ empowerment (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Funnell 2004, Leino-Kilpi et al. 2005). In this study, patient education is seen as a part of high quality of care.

In patient education, empowerment cannot be measured in itself and has to be evaluated by outcomes (Rappaport et al. 1984). The improvement in knowledge level and decreased difference between knowledge expected and knowledge received seems to facilitate patients' empowerment (Johansson 2006, Klemetti et al. 2010, Heikkinen et al. 2008, Ryhänen et al. 2012). The other outcomes are decrease in anxiety and increase in self-care (Chandler 1992) and increase in quality of life (QOL) (Funnell et al. 1991, Gibson 1991, Falk-Rafael 2001, Leino-Kilpi et al. 2005).

Patient education in radiotherapy is focused to reduce the treatment physical and psychosocial side effects, to improve the QOL, and to improve the effectiveness of treatment with knowledge (Long 2001). In this study, the interest is in the effects on radiotherapy patients' cognitive (knowledge level) and psychosocial (anxiety and QOL) outcomes defined as follows:

Cognitive is referring to processing information, applying knowledge and changing preferences. Additionally, it focuses to the mental process by witch knowledge is required, i.e. cognitive constructivism. Constructivism is a theory of knowledge that argues that human generate knowledge and meaning from an interaction between experiences and their ideas (Piaget 1967). *Knowledge level* is defined as level of facts, skills, and personal understanding about subject.

Psychosocial is referring to the mind's ability to, consciously or unconsciously, adjust and relate the body to its social environment. *Anxiety* is defined as "a multisystem response to a perceived threat or danger." In radiotherapy care anxiety can be seen as a state of apprehension, uncertainty, and fear resulting from the anticipation of a realistic or fantasized threatening event or situation, often impairing physical and psychological functioning. These psychological problems often effect on quality of life emerging also after end of treatments. *QOL* is defined according to WH0QOL (1995) as "the individual's perception of their position in life in the context of the culture and value systems in which they live and relation to their goals, expectations, standards and concerns. It is a broad concept affected in a complex way a person's physical health, psychological state, level of independence, and their relationships to sailent features of their environment."

Electronic (e-) is defined as "of, pertaining to, or controlled by computers, or computer products and services". In patient education e- is seen as an access to own medical records through web portals, "chat" online with peers, changing health data through the telephone or wireless technologies, and use the Internet to find knowledge related to health (Dansky et al. 2006). It is available in multiple languages and visually (Fox 2009) when face-to-face appointments are replaced with Internet (McMullan 2006) using advantage of digital devices as smart phones, and applications as texting, e-mail, and Skype (Reis et al. 2013). It underlines individuals' expanding access to health knowledge and discourse across time, place and cultures (Neuhauser & Kreps 2003) and supporting role of patient from passive recipient to active consumer of health knowledge and encouraging patient-centred approach (McMullan 2006, Fox 2009).

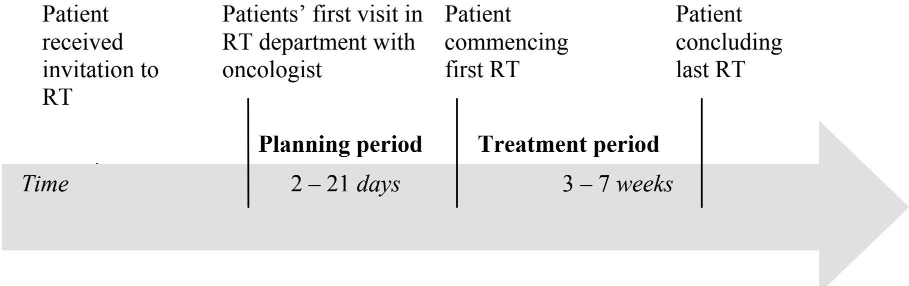
The **e-feedback** is defined as “a message electronically generated response to a learners’s action” (Mason & Bruning 2003). Here, e- means that feedback is generated through Internet. The idea of feedback has been rooted from the writings of Hippocrates and has a long history (Puschmann 1966). There were definitions since 1920’s where feedback was defined with terms as information, a reaction where information is included and a cycle, involving information and reaction (van de Ridder et al. 2008). In general, feedback is defined as “information about the result of the performance and this is often about a consultation and/or skill that has been performed by the learner and observed by the teacher”. Usually the feedback was given after answering a knowledge test. In this study, the e-feedback after response to the knowledge test is seen as a facilitator for patients to know their knowledge level, and consequently improve it and support patients’ empowerment. The knowledge test is defined as “a measurement tool to assess patients’ knowledge, mainly addressing the facts associated with their health problem” (McDonald 2007).

2.2 Quality of radiotherapy care

This chapter consists of the description of radiotherapy containing the view of delivery and side effects and the studies of quality of radiotherapy care in terms of GOOD CARE from the perspective of cancer patients in radiotherapy.

2.2.1 Description of radiotherapy

Radiotherapy has had an important role in the management of cancer either alone or in combination with surgery and/or chemotherapy for 100 years (Murray & Robinson 2011). Radiotherapy process comprises the planning and treatment periods in which many different healthcare personnel are involved (Halperin et al. 2013, Figure 1.). The planning includes the immobilization of the patient, localization of the tumour and verification patients’ treatment plan with x-rays to ensure that the treatment field is in the correct position within respect to the patient and tumour. The tumour is localized with palpation, spiral computer tomography, magnetic resonance imaging and positron emission tomography scanning. Treatment is carried out with conventional linear accelerators governed by the overall beam-on-time, or it can be image-based to complex three-dimensional treatment planning and delivery of radiation therapy, using 3D-Conformal or Intensity Modulated Radiation therapy (IMRT). (Mundt & Roeske 2011.) Different techniques of radiotherapy such as image-guided radiotherapy (IGRT) are used to compensate dose in moving targets. Stereotactic radiotherapy and CyberKnife is used to deliver very high doses precisely in a small area of cranial lesions. The patients can be treated with normal dose or hypo-fractionated (high dose per fraction with shorter treatment period) schemas. (Murray & Robinson 2011, Halperin et al. 2013.)



RT: Radiotherapy

Figure 1. Radiotherapy process.

Although technological development during last 20 years has led to optimal delivery of radiation therapy to the target and lower doses to surrounding organs, the treatment has several side effects. Treatment side effects on radiotherapy patients' quality of life and daily life are psychological and physical. All patients have a risk to experience psychosocial side effects as anxiety, depression and fatigue (Shimotsu et al. 2010, Huber et al. 2011, Poirier 2013.) The other physical side effects are related to the area of the body being treated. A common physical side effect is skin reaction at treated area. Radiotherapy to head and neck could lead to patients' oral dryness, mucositis and difficulties in nutrition. Patients treated to breast and chest may have swallowing or eating deficits. Treatment to pelvis often causes diarrhoea. However, more damage is caused on tumour than on normal cells because of the tumour radiosensitivity. The recovery of damaged normal tissue is possible because of repopulation of cell and tissue kinetics. (Steel 2002, Tyler & Hanna 2008, Huber et al. 2011.) However, the side effects could play a significant role of patients' health during and after treatments (Poirier 2013).

Radiotherapy for breast cancer depends on primary treatment; i.e. breast surgery. Adjuvant radiotherapy of whole breast is followed for patients who have had the breast conserving surgery. Patients having mastectomy are treated with radiotherapy to chest wall and regional lymph nodes. In both cases the external beam radiation is used to damage residual disease in the breast, chest wall or regional lymph node area. Palliative radiotherapy is indicated in the localized symptomatic metastasis. In Finland, women with breast cancer have been treated with different combinations of treatments comprised of surgery, chemotherapy, radiotherapy and hormonal treatments based on the recommendations of Current Care Guidelines for Breast Cancer Care. (Finnish Breast Cancer Group 2012.)

2.2.2 Patient-centred evaluations of the quality of radiotherapy care

The evaluations of the quality of care were focused to describe radiotherapy patients' evaluations of their perceptions (Rogerge et al. 2013) and overall satisfaction (Gamble 1998, Momm et al. 2011, Geinitz et al. 2012); and to explore the aspects determining the quality of RT care (Hinds & Moyer 1997, Long 2001, Karhu-Hämäläinen 2002, Ekfors & Peterson 2004, Kelsey et al. 2004, Nijman et al. 2012). In addition, the studies were especially focused to show the relations between the experiences of quality of radiotherapy care and information received (Zissiadis et al. 2006) and support (Hinds & Moyer 1997, McPhail & Wilson 2000, Dubois & Loiselle 2008).

The studies were describing the experiences from the perspective of radiotherapy patients with diverse cancer types (Hinds & Moyer 1997, Long 2001, Karhu-Hämäläinen 2002, Zissiadis et al. 2006, Momm et al. 2011, Nijman 2012, Roberge et al. 2013), and patients with breast (McPhail & Wilson 2000, Dubois & Loiselle 2008, Geinitz et al. 2012), lung (Gamble 1998, Ekfors & Peterson 2004), prostate (Kelsey et al. 2004, Dubois & Loiselle 2008), urogenital (Geinitz et al. 2012) or head and neck cancer (Gamble 1998).

The descriptions were investigated in focus groups (Kelsey et al. 2004, Nijman et al. 2012), interviews (Hinds & Moyer 1997, Ekfors & Peterson 2004), in-depth unstructured interviews (Long 2001) or semi-structured audio-taped interviews (Gamble 1998). Questionnaires used were Information Satisfaction Questionnaire (Zissiadis et al. 2006), Questions on Patient Satisfaction FPZ (Geinitz et al. 2012), Satisfaction Questionnaire ZUF-8 (Geinitz et al. 2012) and self-admistered questionnaires to evaluate the experiences of with diverse cancer types (Karhu-Hämäläinen 2002) and breast cancer conserving treatment (McPhail & Wilson 2000), the potential improvements during radiotherapy course (Momm et al. 2011), and perceptions of the quality of care (Roberge et al. 2013).

In general, patients' perceptions (Long 2001, Karhu-Hämäläinen 2002, Nijman et al. 2012, Roberge et al. 2013) and satisfaction (Gamble 1998, McPhail & Wilson 2000, Momm et al. 2011, Geinitz et al. 2012, Nijman et al. 2012) of quality of radiotherapy care were largely positive.

However, in terms of GOOD CARE, also deficits were mentioned. Radiotherapy patients' mentions of staff characteristics were positive. Patients emphasized the importance of staff friendliness (Momm et al. 2011), statements of understanding (Gamble 1998), and kindness (Momm et al. 2011). However, varying coping styles of patients were not clearly identified and assisted by professionals (Long 2001). The perceptions of the caring activities were experienced from the aspects of patient-centred care (Kelsey et al. 2004, Nijman et al. 2012, Roberge et al. 2013) and professionals competence and communication (Momm et al. 2011, Geinitz et al. 2012, Nijman et al. 2012, Roberge et al. 2013). The communication with professionals was viewed as being there, giving help and giving information (Hinds & Moyer 1997) and was valued high (Kelsey et al. 2004, Geinitz et al. 2012). Possibility to ask questions, being taken seriously and respect for privacy were greatly appreciated (Nijman et al. 2012). Although the satisfaction with the knowledge received was evaluated high (Ekfors & Peterson 2004, Zissiadis et al. 2006), the results showed some deficits in patient education (Gamble 1998, McPhail & Wilson 2000, Long 2001, Karhu-Hämäläinen 2002, Kelsey et al. 2004, Zissiadis et al. 2006).

The cognitive support in health care was experienced tangible, paralyzing and limiting (Dubois 2008) and was not fulfilled at concluding treatment (McPhail & Wilson 2000). The importance of the quality of the caring environment was also mentioned (Karhu-Hämäläinen 2002, Roberge et al. 2013). It could be improved by music and daylight in the therapy room (Momm et al. 2011), while waiting room was not rated as important aspect (Nijman et al. 2012). The caring process considering the organization of the course of radiotherapy was also valued high (Momm et al. 2011, Nijman et al. 2012). One point of criticism was schedules (Roberge et al. 2013) as waiting times to first treatment (Kelsey et al. 2004) or delays caused by servicing or machine failures (Momm et al. 2011, Nijman et al. 2012). The patients also disliked the continuous change of radiotherapists (Nijman et al. 2012) and the problems with coordination of care between various professionals resulted in confusion (Long 2001).

The results covered internationally cancer patients' experiences of the quality of radiotherapy care. The descriptions were reported in Australia (Long 2001), Canada (Hinds & Moyer 1997, Dubois & Loiselle 2008, Roberge et al. 2013), Finland (Karhu-Hämäläinen 2002), Germany (Momm et al. 2011, Geinitz et al. 2012), Netherlands (Njiman et al. 2012), UK (Gamble 1998, McPhail & Wilson 2000, Kelsey et al. 2004) and Sweden (Ekfors & Peterson 2004). The national results in one hospital were according to international results underlining the development of the radiotherapy care by patient education. However, further evaluation was needed with reliable instruments.

2.3 Patient e-education in radiotherapy

This chapter consists of a description of studies of knowledge expectations of radiotherapy and cognitive (knowledge level) and psychosocial (anxiety and QOL) outcomes of patient e-education in radiotherapy in terms of empowering patient education from the perspective of radiotherapy patients.

2.3.1 e-Knowledge expectations in radiotherapy

There was lack of earlier studies describing the e-knowledge expectation from the perspective of cancer patients undergoing radiotherapy. Only one study by Metz et al. (2003) reported the information that radiotherapy patients were most interested in searching for on the Internet. The e-knowledge expectations were evaluated with a questionnaire. Patients reported that they were interested in bio-physiological knowledge particularly of their cancer treatment and functional knowledge of symptom management.

However, the knowledge expectations have been reported in number of studies in general, describing importance of the content (Hinds & Moyer 1995, Galloway et al. 1997, Harrison et al. 1999, Mesters et al. 2001, Salminen et al. 2004, Skalla et al. 2004, Bolderstom 2008, Halkett et al. 2010, Douma et al. 2012, Halkett et al. 2012, Zeguers et al. 2012, Matsuyama et al. 2013) and time-point of delivery (Harrison et al. 1999, Mesters et al. 2001, Halkett et al. 2010, Douma et al. 2012, Halkett et al. 2012, Matsuyama et al. 2013) in radiotherapy care. One study reported knowledge expectations during breast cancer care pathway in terms of empowering knowledge (Ryhänen et al. 2012). The studies were explored among diverse cancer patients (Hinds & Moyer 1995, Mesters et al. 2001, Metz et al. 2004, Skalla et al. 2004, Bolderstom 2008, Douma et al. 2012, Zeguers et al. 2012, Matsuyama et al. 2013) and patients with breast cancer (Galloway et al. 1997, Harrison et al. 1999, Salminen et al. 2004, Halkett et al. 2010, 2012, Ryhänen et al. 2012) and breast cancer or Hodgkin disease (Mesters et al. 2001).

The descriptions of specific knowledge expectations were evaluated in interviews (Hinds & Moyer 1995), in focus-group (Skalla et al. 2004) and semi-structured interviews (Halkett et al. 2010) and visits from the OncoLink-web-sites (Metz et al. 2004). Questionnaires used to evaluate the radiotherapy-related knowledge expectations were Information Preferences of Radiotherapy Patients Questionnaire (IPRP) (Douma et al. 2012, Zeguers et al. 2012) and the RT information needs scale (Halkett et al. 2012). Other questionnaires used were modified versions of the Toronto Informational Needs Questionnaire for cancer patients (Galloway et al. 1997, Harrison et al. 1999, Bolderstom 2008, Matsuyama et al. 2013), the Information Subscale of the Health Opinion Survey (Harrison et al. 1999), the PINQ instrument (Mesters et al. 2001), the Hospital Patient's Knowledge Expectations scale (HPKE) (Ryhänen et al. 2012) and a self-administered questionnaire of breast cancer patients and relatives knowledge needs (Salminen et al. 2004). The knowledge expectations were evaluated before (Zeguers et al. 2012) and during (Bolderstom 2008), or longitudinally before, during and after (Halkett et al. 2010, 2012, Ryhänen et al. 2012), before and during (Galloway et al. 1997, Douma et al. 2012, Ryhänen et al. 2012), before and after (Hinds & Moyer 1995, Matsuyama et al. 2013), and during and after (Harrison et al. 1999, Salminen et al. 2004, Skalla et al. 2004) the RT period.

The most expected knowledge was bio-physiological knowledge of disease, cancer treatment and side effects (Galloway et al. 1997, Harrison et al. 1999, Mesters et al. 2001, Metz et al. 2004, Salminen et al. 2004, Bolderstom 2008, Douma et al. 2012, Ryhänen et al. 2012, Matsuyama et al. 2013), and also special issues of RT (Skalla et al. 2004, Bolderstom 2008, Halkett et al. 2010, Douma et al. 2012, Halkett et al. 2012, Zeguers et al. 2012). The functional knowledge of how to manage practical problems during RT period and self-care in everyday life was also highly expected (Mesters et al. 2001, Salminen et al. 2004, Skalla et al. 2004, Halkett et al. 2010, 2012, Ryhänen et al. 2012). In addition, other knowledge expected was social, experiential such as fellow patients' experiences, and economical as costs of treatment (Halkett et al. 2010, 2012, Ryhänen et al. 2012, Zeguers et al. 2012), and ethical (Ryhänen et al. 2012), however, not as much as other types of knowledge.

In general, the studies reported that cancer patients expected knowledge in radiotherapy as much as possible, except some patients avoided information completely (Hinds & Moyer 1995, Skalla et al. 2004, Zeguers et al. 2012). The amount of knowledge expectations from the diagnosis to time after treatments declined but remained high (Harrison et al. 1999, Mesters et al. 2001, Douma et al. 2012, Zeguers et al. 2012, Matsuyama et al. 2013). Several studies indicated that the knowledge of psychosocial issues was expected least (Galloway et al. 1997, Harrison et al. 1999, Salminen et al. 2004, Bolderstom 2008, Douma et al. 2012, Matsuyama et al. 2013), while the expectations did not decline during RT period (Douma et al. 2012). The expectations were the highest before commencing RT (Halkett et al. 2010, Douma et al. 2012, Zeguers et al. 2012); while the knowledge of the time after radiotherapy was also expected (Halkett et al. 2010).

2.3.2 Outcomes of patient e-education in radiotherapy

2.3.2.1 Cognitive outcomes

Knowledge level is seen as cognitive outcome referring to acquired knowledge about cognitive processes. In order to improve knowledge level, several earlier studies have focused on to evaluate the effects of patient education interventions (Rainey 1985, Hagopian 1991, 1996, Dunn et al. 2004, Cartledge Hoff & Haaga 2005, Halkett et al. 2013, Jones et al. 2013) and understanding of radiotherapy (Gonzalez-Arriagada 2013). The studies concerned cancer patients with diverse cancer types (Rainey 1985, Hagopian 1991, 1996, Cartledge Hoff & Haaga 2005), patients with breast (Dunn et al. 2004, Halkett et al. 2013, Jones et al. 2013) or head and neck cancer (Dunn et al. 2004, Gonzalez-Arriagada 2013) undergoing radiotherapy.

Diverse interventions as the weekly newsletter (Hagopian 1991, 1996), informational audiotapes (Rainey 1985, Hagopian 1991, 1996), video (Dunn et al. 2004), the video shown on laptop (Gonzalez-Arriagada 2013), group education intervention (Jones et al. 2013) and the orientation education program with oral and written form (Cartledge Hoff & Haaga 2005) have been implemented to improve knowledge level. In addition, one radiation therapist -led face-to-face intervention was conducted (Halkett et al. 2013). It was based on the theoretical framework of sensory and procedural information (Suls & Wan 1989). None of these interventions was based on the framework of empowering knowledge.

The knowledge was evaluated with questionnaires developed and delivered to measure the effect of the study intervention of the current study on knowledge level (Rainey 1985, Hagopian 1991, 1996, Dunn et al. 2004, Halkett et al. 2013, Jones et al. 2013) and understanding of radiotherapy (Gonzalez-Arriagada 2013). One knowledge test was based on the content of the RT Information Needs Scale with high internal consistency (Halkett et al. 2013), while in the other studies the quality measurement and reliability of the other knowledge tests were not always sufficiently reported.

Almost all results showed improvement in knowledge level (Rainey 1985, Hagopian 1991, 1996, Halkett et al. 2013, Jones et al. 2013) and understanding (Gonzalez-Arriagada 2013). There were beneficial results prior to first radiotherapy session and at first day of radiotherapy period (Halkett et al. 2013), during first week of radiotherapy but not in the end of radiotherapy period (Rayney 1985). Moreover, the outcomes of interventions evaluated after radiotherapy period were controversial. In one study by Gonzalez-Arriagada (2013) it was shown that intervention with oral and written education had positive effects on understanding and it improved knowledge of side effects one week after last radiotherapy. On the other hand, the knowledge levels of breast cancer and head and neck cancer patients' who saw the video in the end of treatments were not improved at 3 and 6 months after concluding radiotherapy. However, the patients were satisfied for preparing for future. (Benor et al.1998.) Although some patient education approaches were beneficial, the e-education was missing, as well as interventions to address the time after treatments.

2.3.2.2 Psychosocial outcomes

Psychosocial wellbeing of cancer patients is undermined by its treatments. During radiotherapy period it was shown to appear (Hammick et al. 1998, Long 2001, Halkett et al. 2008) affecting on quality of life (Novais et al. 2005, Shimotsu 2010, Huber et al. 2011, Poirier 2013).

Anxiety

The effects of patient education interventions for radiotherapy patients on anxiety were evaluated in several earlier studies (Rainey 1985, Hagopian 1990, Poroch 1995, Benor et al. 1998, D'haese et al. 2000, Häggmark et al. 2001, Christman & Cain 2004, Cartledge Hoff & Haaga 2005, Jones et al. 2006, Zissiadis et al. 2010, Canil et al. 2012, Guo 2013, Halkett et al. 2013). There was only one study specially focused on the effects of empowering patient e-education intervention, called an Internet-based Breast Cancer Patient Pathway program (Ryhänen et al. 2013). The effects on anxiety were described from the perspective of radiotherapy patients with diverse cancer types (Benor et al. 1998, Canil et al. 2012, Dunn et al. 2004, Hagopian 1990, Häggmark et al. 2001, Guo 2013, Poroch 1995, Rainey 1985, Zissiadis et al. 2010); breast (Halkett et al. 2013, Ryhänen et al. 2013), breast or prostate (Jones et al. 2006), breast, lung, head, and neck or the pelvic region (D'haese et al. 2000) and gynaecologic, head and neck or lung (Christman & Cain 2004) cancer patients; and patients and family members (Cartledge Hoff & Haaga 2005).

Most of the interventions were conducted with professionals: i.e. the nursing intervention (Benor et al. 1998), preparatory patient education of sensory and procedural information (Poroch 1995), radiation therapist-led educational intervention (Halkett et al. 2013), telephone call interventions by a collaborative team (Hagopian GA 1990), educational class (Canil et al. 2012) and combination of psychosocial interventions (Guo 2013). The other interventions were written information (D'haese et al. 2000, Jones et al. 2006), audiovisual program of procedural and sensory information (Rainey 1985), audiotape messages of objective information and relaxation instruction (Christman & Cain 2004) and videotapes (Dunn et al. 2004). The multidimensional education interventions used were often combinations of oral and written education such as education/orientation program (Cartledge Hoff & Haaga 2005), an intervention including standard information plus group and repeated individual information or standard information plus brochure (Häggmark et al. 2001), and intensive information including written information and a telephone call from the research nurse (Zissiadis et al. 2010). One study had multiple combinations of written and electronic education combined of printed booklets of CancerBACUP or patient's medical record or selected general information or information chosen interactively by the patient or automatically with a larger volume of material or additional advice on anxiety management (Jones et al. 2006).

Different theoretical frameworks were used to design the interventions. The preparatory patient education of sensory and procedural information was based on the framework from Johnson's work (1996) on preparing patients for threatening events (Poroch 1995, Cartledge Hoff & Haaga 2005). The radiation therapist -led intervention was based on the framework of sensory and procedural information (Halkett et al. 2013). Cognitive-behavioral therapy (CBT) part of the psychosocial intervention was based on the cognitive theory of Beck (1967) (Guo et al. 2013). Moreover, the Internet-based program available from the beginning of the care pathway was based on empowering knowledge framework (Ryhänen et al. 2013).

Anxiety was mostly measured with Spielberger's State Trait Inventory (STAI) (Cartledge Hoff & Haaga 2005, Canil et al. 2012, Hagopian 1990, Poroch 1995, Rainey 1985, Ryhänen et al. 2013, Zissiadis et al. 2010) and Hospital Anxiety and Depression Scale (HADS) (Jones et al. 2006, Halkett et al. 2013, Häggmark et al. 2001). Also the Psychosocial Adjustment to Illness Scale (PAIS-SR) (Dunn et al. 2004), Profile of Moods Scale (POMS) (Christman & Cain 2004), the Self-rating Anxiety Scale (SAS) (Guo 2013) and Symptom Control Assessment (SCA) (Benor et al. 1998) were used. Almost all studies measured the baseline before commencing radiotherapy (Zissiadis et al. 2010, Guo 2013, Hallkett et al. 2013, Canil et al. 2012, D'Haese et al. 2000, Dunn et al. 2004, Poroch 1995, Rainey 1985, Zissiadis et al. 2010).

It has been found that face-to-face interventions were effective on reducing anxiety among radiotherapy patients at first day of treatment (Halkett et al. 2013), at first week (Poroch 1995), at conclusion (Poroch 1995, Canil et al. 2012), at three visits at home during three months (Benor et al. 1998) and also after concluding radiotherapy period at two weeks (Guo 2013). In addition, radiotherapy patients who received stepwise-information by written material were less anxious before simulation radiotherapy (D'haese et al. 2000). Furthermore, audiovisual program had positive results at conclusion of radiotherapy

(Rainey 1985). However, weekly telephone call interventions had no positive results during radiotherapy (Hagopian 1990) or at conclusion (Zissiadis et al. 2010) and written material at three months after the material was selected (Jones et al. 2006). In addition, the Internet-based program reported no beneficial effects on anxiety at commencing, concluding or one year after radiotherapy period (Ryhänen et al. 2013). Thus, although face-to-face interventions provided beneficial result on anxiety, there is still lack of effective patient e-education interventions.

Quality of life (QOL)

The QOL was evaluated in some earlier studies of patient education interventions for radiotherapy patients (Wengström et al. 1999, Häggmark et al. 2001, Lee et al. 2011, Guo 2013, Ryhänen et al. 2013). The participants were mostly patients with breast cancer (Wengström et al. 1999, Lee et al. 2011, et al. Ryhänen 2013) and in two studies radiotherapy patients with diverse cancer types (Häggmark et al. 2001, Guo 2013).

The results were mainly describing the effects of face-to-face interventions: i.e. an intervention including standard information plus group and repeated individual information or standard information plus brochure (Häggmark et al. 2001) or combination of psychosocial interventions (Guo 2013) or a nurse-led cognitive-behaviour therapy (Lee et al. 2011). One study evaluated the effects of Internet-based Breast Cancer Patient Pathway program on QOL during care pathway of women with breast cancer (Ryhänen et al. 2013). Almost all of the interventions were based on theoretical framework. The nursing intervention was structured according to Orem's model for self-care during the radiotherapy period (Wengström et al. 1999). The Cognitive-behavioural therapy (CBT) part of the psychosocial intervention was based on the cognitive theory of Beck (1967) (Lee et al. 2011, Guo 2013). In addition, the Internet-based program was based on empowering knowledge framework (Ryhänen et al. 2013).

The questionnaires used to measure QOL were the Cancer Inventory of Problem Situations (CIPS II) (Häggmark et al. 2001) and Cancer Rehabilitation Evaluation System (CARES-sf) (Wengström et al. 1999), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) (Guo 2013), QOL scale for Korean Patients With Cancer (Lee et al. 2011) and Quality of Life Instrument – Breast cancer Patient version (Ryhänen et al. 2013).

There were only two studies shown to be effective on QOL of radiotherapy patients. The 6-week intervention program from the beginning of the first day of radiotherapy that included cognitive restructuring, education about the disease and medical treatment, relaxation therapy, and rehabilitation exercise was beneficial at six weeks after the radiotherapy was completed (Lee et al. 2011). In addition, a set of psychosocial interventions combined of psycho-education, cognitive-behavioural therapy and supportive-expressive therapy provided in small groups each week during radiotherapy period improved QOL at two weeks after concluding radiotherapy (Guo 2013). On the other hand, neither the nursing intervention during the radiotherapy period (Wengström et al. 1999) nor Internet-based program available from the beginning of the care pathway (Ryhänen et al. 2013) had positive effects at three months (Wengström et al. 1999) or one year after concluding radiotherapy (Ryhänen et al. 2013). However, there is a need for effective interventions on QOL for radiotherapy patients not only during but also after radiotherapy period.

2.4 e-Feedback in patient education

This chapter consists of a description of studies of e-feedback approach in order to develop patient e-education.

The e-feedback is seen as a determinant to deepen learners understanding of their own knowledge (Mason & Bruning 2003). The advantage of the use of e-feedback after a knowledge test is the ability to provide immediate, unbiased, accurate, and non-judgmental, irrespective of learners characteristics or the nature of the response feedback. (Mason & Bruning 2003). In general, three e-feedback structures could be used; firstly, feedback is given according to knowledge of results the knowledge test and is a simple verification feedback, such as “You are right.”, secondly, knowledge of correct response informs the content of correct answers and thirdly, elaborated feedback explains why the learners’ responses or answers are correct or incorrect, or provides relevant information to inspire learners to reason or judge correct responses or results. (Dempsey et al. 1993, Mason & Bruning 2003, van de Ridder et al. 2008). It has been shown that particularly knowledge of correct response improved results significantly after receiving e-feedback (Dempsey et al 1993, Wang & Wu 2008.). On the other hand, students who received elaborated feedback improved self-efficacy by deepening their conceptual understanding (Bangert-Drowns et al. 1991, Wang & Wu 2008.).

The different e-feedback approaches in patient education were described in some reviews (Woffold et al. 2005, Fox 2009, Kuijpers et al. 2013). There were evaluated outcomes of multimedia computer for office-based patient education (Wofford et al. 2005), interactive, computer-based patient education programs (Fox 2009) and web-based interventions for patient empowerment and physical activity in chronic diseases (Kuijpers et al. 2013) including multidimensional approaches of different programs were evaluated in the studies. The studies were conducted among patients with astma (Huss et al. 2003, Krishna et al. 2003), cardiac diseases (Jenny & Fai 2001, Meyer et al. 2003, Linne et al. 2006, Lorig et al. 2006, Strömberg et al. 2006, Artinian et al. 2003, Tomita et al. 2009), COPD (Nguyen et al. 2012), diabetes (McKay et al. 2001, Gerber et al. 2005, Kim & Kang 2006, Lorig et al. 2006, Richardson et al. 2007), HIV/ drug users (Evans et al. 2000, Neafsey et al. 2002, Marsch & Bicket 2004), schizophrenia (Jones et al. 2001), surgery (Keulers et al. 2007), and for patients' and their examinations (Shaw et al. 2001, Reis et al. 2004).

The description of supporting the patient actively in their learning process by providing questions and answers within or after lessons completed in hospital was described in several studies. The feedback was shown to promote knowledge gains (Evans et al. 2000, Jenny & Fai 2001, Jones et al. 2001, Shaw et al. 2001, Neafsey et al. 2002, Krishna et al. 2004, Marsch et al. 2004, Reis et al. 2004, Linne et al. 2006, Strömberg et al. 2006, Keulers et al. 2007), dietary behaviour (Glasgow et al. 1997), motivation (Evans et al. 2000), psychological state and costs (Jones et al. 2001), drug use (Krishna et al. 2004), satisfaction (Glasgow et al. 1997, Shaw et al. 2001), self-care (Artinian et al. 2007) and self-efficacy (Neafsey et al. 2002, Reis et al. 2004). Once program was viewed at home it has had positive impact on knowledge, decision making and preventive behaviour (Meyer et al. 2003).

The outcomes of e-feedback followed after self-monitoring, based on uploaded individual data were also monitored. Patients received individual e-feedback through the medical record, medication reminders and tips for overcoming self-care (McKay et al. 2001, Glasgow et al 2003, 2010, 2011, Lorig et al 2006, Richardson et al. 2007, Artinian et al. 2007, Nguyen et al. 2008, Tomita et al. 2009, Nguyen et al. 2012). The programs have been successful on self-care (Artinian et al. 2007) and self-efficacy (Artinian et al. 2007, Nguyen et al. 2008, Glasgow et al. 2010) and number of exercises (Lorig et al. 2006, Richardson et al. 2007, Tomita et al. 2009, Glasgow et al. 2010, 2011). However, no studies were describing the use of e-feedback in radiotherapy.

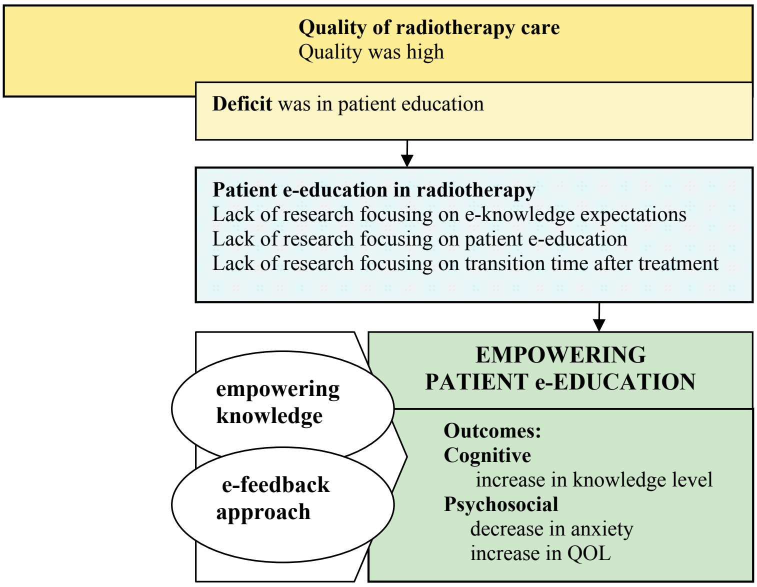
The e-feedback in patient education is of great importance supporting the patients' empowerment with knowledge. So far, the use of knowledge tests in patient education was concluded in one review by Kesänen et al. (2013). Although the knowledge test was valued highly, there was no study showing the outcomes of intervention where e-feedback after knowledge test were used alone without additional education (Kesänen et al. 2013). These findings highlight the need for more approaches that would be easily integrated into clinical care in order to overcome the challenges to support patients' empowerment.

2.5 Summary

The aim of the literature review was to gain a comprehensive picture of the quality of radiotherapy care and its deficits, and the nature of empowering patient e-education in radiotherapy in order to develop and test intervention based on e-knowledge expectations and implemented with e-feedback approach.

The radiotherapy is a technical and complex treatment often combined with physical and psychosocial side effects. Although the quality of care was rated high, the patient education seems to be the critical point and development is needed. Empowering knowledge according to patients own expectations was suggested to be the basis of patient education. Previous research reviews patients' knowledge expectations in radiotherapy and acknowledges the importance of the timing patient education before commencing radiotherapy. However, in order to develop empowering patient e-education there was only one study describing the e-knowledge expectations considering radiotherapy patient (Figure 2.).

In addition, in the literature studies with multiple combinations of different patient education approaches were shown, but they, however, failed to be implemented in terms of patient e-education (Figure 2.). Focusing the development of patient e-education for breast cancer patients seems to be noteworthy. Although earlier studies have reviewed beneficial empowering outcomes among them, there is a need to evaluate the effects on cognitive and psychosocial outcomes in radiotherapy context (Figure 2.). The studies of the use of e-feedback approach in patient education provided an overview of applications which were implemented in different fields of health care. The studies provided a description how patients were positively supported by providing questions and answers within or after different education in several health care contexts. However, the results suggested need for easily integrated applications into clinical care in order to support patients' empowerment. Moreover, there was a lack of studies where e-feedback after response to the knowledge test was a patient education approach itself (Figure 2.).



e-: electronic; QOL: quality of life

Figure 2. Theoretical background.

3. AIMS, PURPOSES AND RESEARCH QUESTIONS OF THE STUDY

The aim of this three phase study was to develop quality of radiotherapy care by the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know). In Phase I, the purpose was to describe the quality of radiotherapy care and its deficits experienced by cancer patients. Based on the deficits in patient education in Phase II, the purpose was to describe cancer patients' e-knowledge expectations in radiotherapy. In Phase III, the purpose was to develop and evaluate the outcomes of the e-Re-Know among breast cancer patients. The ultimate aim was to develop radiotherapy care to support patients' empowerment with patient e-education. The following research questions of Phases I, II and III were addressed:

Phase I:

1 What is the quality of radiotherapy care experienced by cancer patients (I)?

2 What are the deficits in the quality of radiotherapy care experienced by cancer patients (I)?

Phase II:

3 What e-knowledge expectations cancer patients have (II)?

Phase III:

4 What are the outcomes of the e-Re-Know for women with breast cancer? (III, IV)

The following hypotheses were tested:

The e-Re-Know increases knowledge level

The e-Re-Know reduces anxiety and improves QOL

4. MATERIALS AND METHODS

This chapter consists of study design (Figure 3. and 4.), samples, data collection (Figure 5.), instruments, intervention (Figure 6.), data analysis and ethical consideration investigating the research questions.

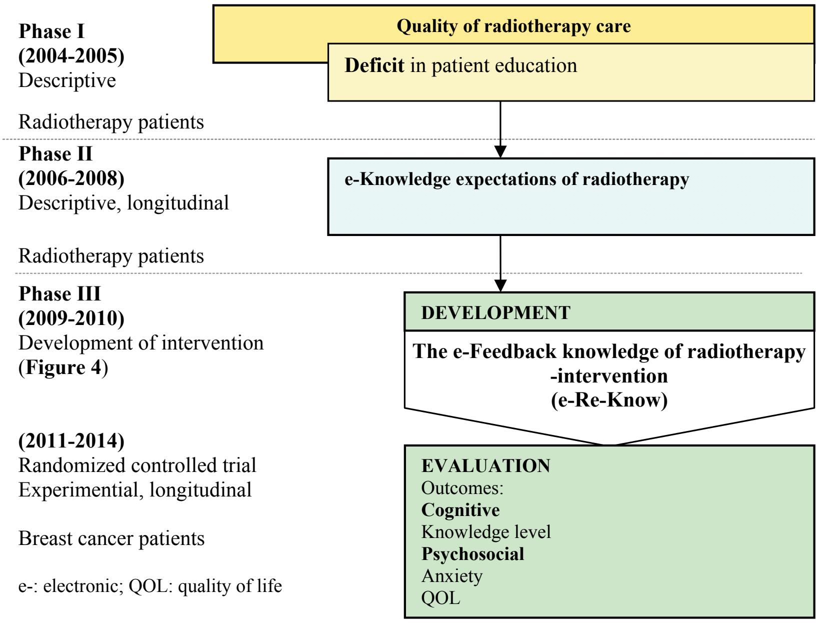


Figure 3. Study design.

4.1 Study design and samples

Phase I (I)

The descriptive design was used to explore the cancer patients' experiences of the quality of radiotherapy care and its deficits (Figure 3.). The data were collected at one university hospital in Southwest Finland during March-May 2004. The target population consisted of radiotherapy patients admitted for treatment during the study period. Inclusion criteria were patients having their primary radiotherapy treatment and age over 18 years. Out of 150 eligible patients asked to participate in the study, 134 (89 %) participated (I).

Phase II (II)

The descriptive follow up (from commencing to concluding RT period) design was used to identify cancer patients' knowledge expectations in radiotherapy through Internet during RT (Figure 3.). The data were collected at one university hospital in Southwest Finland during January-April 2006. The target population consisted of radiotherapy patients who were admitted for treatment during the study period. Inclusion criteria were patients having primary radiotherapy treatment and age over 18 years. Out of 150 eligible patients who were asked to participate in the study, 100 (67 %) patients pre RT period, 75 (=n) patients in the middle of RT period and 73 (=n) patients post RT period included (II).

Phase III (III and IV)

Phase III was conducted in two parts. In the first part, the development of the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know), i.e. knowledge test and feedback, to deliver for women with breast cancer was explored. The RT Knowledge Test development was carried out simultaneously as e-feedback development and finally the e-Re-Know was pilot tested (Bloom et al. 1971, McDonald 2007, Pittman & Bakas 2010, Figure 4.).

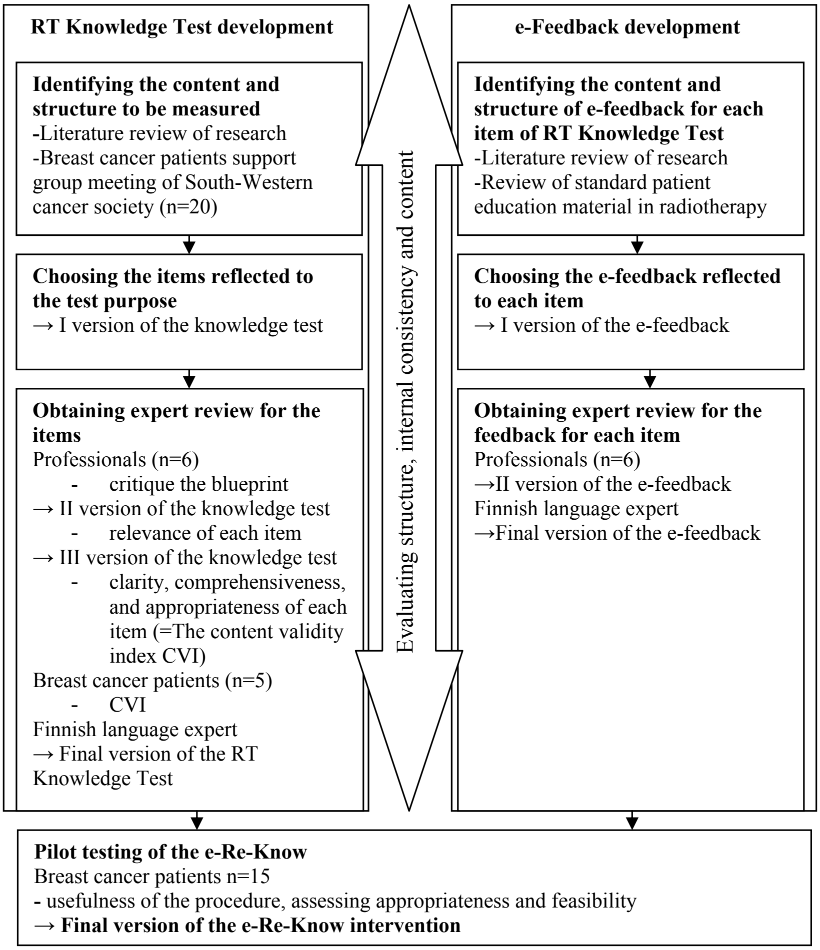


Figure 4. Development of the e-Re-Know i.e. RT Knowledge Test and feedback (modified according to Pitman & Bakas 2010).

Firstly, the data for RT Knowledge Test development was collected with literature reviews (Appendix 1.) and with expert reviews. In March - September 2010 the group of professionals (n=6) including radiation therapist, registered nurse, breast cancer nurse, medical oncologist, radiation oncologist and physicist were asked to participate in Turku university hospital. In September 2010 women with breast cancer during the support group meeting of South-Western cancer society (n=20) were met, and 5 of them were asked to participate in October 2010. Secondly, data for e-feedback development was collected in Turku university hospital with expert reviews of professionals (n=6) including radiation therapist, registered nurse, sexual therapist, dietician, radiation oncologist and physicist. Finally, the data of pilot test of e-Re-Know was collected in Turku university hospital during January 2011. The participants were primary breast cancer patients aged over 18 years at RT department during that period. Out of 16 eligible patients, 15 participated.

In the second part of Phase III, a randomized controlled trial was used to evaluate the outcomes of the e-Re-Know implemented before first RT session (Figure 3.). The data were collected at a university hospital in Southwest Finland during January 2011-September 2012. The participants were women with breast cancer. Inclusion criteria were patients who were 18 - 75-years, e-mail users, and provided written consent. All 364 patients who were invited to radiotherapy care received information of the study. The information contained a request to participate, to those patients who were e-mail users. Eligible patients 133 were randomized and finally 128 (=n) patients allocated to two groups (n = 65 in the intervention group and n = 63 in the control group). Two out of the intervention group lost interest to answer psychosocial questionnaires (n=63). Sample size was determined via preliminary power calculations on the basis of the study of minimally important difference for Functional Assessment of Cancer Therapy–Breast (FACT-B), for breast cancer patients (Eton et al. 2004). An alpha of .05 and power of 0.80 was used to detect 8 points mean difference (assuming a standard deviation of 15.5 points) in the change of FACT-B between the intervention and control groups; 60 patients were required with a potential dropout rate of about 10% in both groups. With the exception of N in TNM -classification of breast cancer, there were no statistically significant differences between the two groups in terms of their characteristics: i.e. preference for information, socio-demographical and medical. Mean age of target population was 59 years and participants 57 years (III, IV).

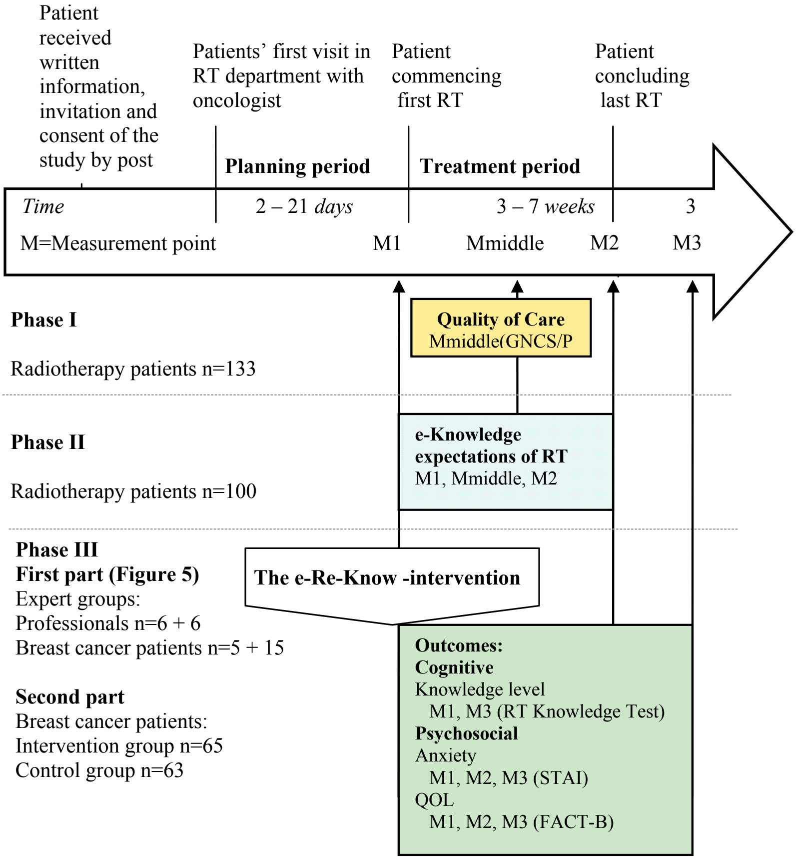
4.2 Data collection

In Phase I, the data were collected at the RT department (Figure 5.). The patients were asked to participate to the study by radiographers. The information of the study were handed to, with instructions to fill the questionnaire after the session in the middle of their RT period (Mmiddle), and then to leave it to the RT office in sealed envelope. (I)

In Phase II, the patients received a letter with information and invitation to participate to the study (Figure 5.). Patients were asked to complete open-ended questionnaire at three time points: 1) the questionnaire was received with the invitation and at the first appointment pre RT period (M1) asked to fill and leave it to RT office in sealed envelope, 2) in the middle of RT period (Mmiddle) the questionnaire was handed out and 3) post RT period (M2) by radiographers with instructions to fill the questionnaire after the session, and then to leave it to the office in sealed envelope. (II)

In Phase III, in the first part, to develop the e-Re-Know several expert reviews were made for data collections (Figure 4.): During the RT Knowledge Test development the group of professionals invited were asked to develop the items three times (see section 4.1.1) to: 1) review and critique the blueprint I version (21 items), 2) complete revised II version (36 items) and rate each item as to its degree of relevancy to the concept of knowledge expectations of radiotherapy 3) review and complete each item of III version (28 items) to ensure clarity, comprehensiveness, and appropriateness. Additionally a Finnish language expert filled grammatical changes to the items. Thereafter, women with breast cancer invited from the support group were asked to complete the final version by e-mail and comment it. During the e-feedback development the professionals invited were asked to review and comment the content of e-feedback. Finally, during the pilot test of the intervention, breast cancer patients invited were asked to ensure the adequacy of the e-Re-Know content and delivery at the first week of their RT period.

In the second part of Phase III, to implement and evaluate the e-Re-Know in the randomized controlled trial the patients were informed and asked to sign the consent form with an invitation letter (Figure 5.). Patients were asked to complete questionnaires at three time points: 1) pre RT period (M1) before commencing first radiotherapy the women in the intervention group were asked to respond to a knowledge test during intervention session with e-mailed message and women in the control group were asked to fill it at radiotherapy department; in addition, in radiotherapy department, both groups were asked to fill other questionnaires by the personnel in radiotherapy office and return before commencing first radiotherapy to the office in sealed envelope, 2) post RT period (M2) after concluding last radiotherapy questionnaires were handed out by radiographers, asked to complete after the session and return at office in sealed envelope and 3) three months post RT period (M3), the women received questionnaires by mail, with instructions to fill and mail them back to the researcher (ms) (III and IV).



FACT-B: The Functional Assessment of Cancer Therapy – Breast; GNCS/P: Good Nursing Care Scale for Patients¸KTrt: The Knowledge Test of Radiotherapy; M1: pre RT period; M2: post RT period; M3: 3 months post RT period; Mmiddle: in the middle of RT period; QOL: quality of life; RT: Radiotherapy; STAI: The State Anxiety scale of the State Anxiety Inventory; the e-Re-Know intervention: e-Feedback Knowledge of radiotherapy intervention;

Figure 5. Data collection.

4.3 Instruments

In the Phase I, quality of radiotherapy care was measured by Good Nursing Care Scale for Patients (GNCS-P, Leino-Kilpi et al. 1994), which was modified for the present study. GNCS-P comprised statement (41) of four quality categories: the characteristics of radiotherapy staff (7), caring activities (19), environment (10) and caring process (5) scored 1 - 4. In the conversion of the index scores to a scale describing the quality of care, average scores of 1.0–2.0 indicate very good, 2.1–3.0 good, 3.1–4.0 rather weak and 4.1–5.0 weak quality of care.

In the Phase II, the e-knowledge expectations were examined using open-ended questionnaire designed for the study. Radiotherapy patients were requested to give a description of their expectations: “What kind of health knowledge do you expect on an Internet site at this radiotherapy stage before commencing / in the middle of/ concluding RT period?” to cover the radiotherapy pathway.

In the Phase III in the second part, knowledge level of radiotherapy was measured by using the RT Knowledge Test designed for the study with the e-Re-Know -intervention development (Figure 4.). The RT Knowledge Test included 28 items operationalized according to essential concepts concerning breast cancer patients’ e-knowledge expectations of RT: RT process (7 items) and possible side effects (7 items) (bio-physiological empowering knowledge), side effects self-care (7 items) and lifestyles and RT (7 items) (functional empowering knowledge) (Table 1.). Each statement (true/false scale) gives score of 0-1 (correct answer=1 / incorrect or missing answer=0), maximum 28 in total/ 7 in one group. The higher the score, the more knowledgeable the patient was.

Table 1. Operationalization of the concepts of the RT Knowledge Test.

Consept	**Operationalization**	**Empowering knowledge dimension**
RT process (Harrison et al 1999, Halkett et al 2008, Halkett et al 2009, Paper II)	1. Effect on cancer cells 2. Personnel at radiation session 3. Effect on body’s radioactivity 4. Use of different beams 5. Use of different beam directions 6. Pain sensation during the session 7. Movement during the session	Bio-physiological (knowledge of bio-physiological aspects of disease, treatment, symptoms and signs) (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012).
Possible side-effects (Harrison et al 1999, Halkett et al 2008, Halkett et al 2009, Sjövall et al 2010, Paper II)	8. Individual appearance 9. Individual treatment planning 10. Time of appearance 11. Place of appearance 12. Loss of hair 13. Mucosa 14. Pneumonia	
Side effects self-care (Harrison et al 1999, Halkett et al 2008, Halkett et al 2009, Sjövall et al 2010, Paper II)	15. Washing with soap 16. Taking a sauna 17. Using deodorant 18. Using lotion 19. Taking painkillers 20. Taking antihistamines 21. Using salt compress	Functional (knowledge of functional aspects controlling the situation and acting to treat the health problem) (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012).
Life style and RT (Harrison et al 1999, Halkett et al 2008, Halkett et al 2009, Paper II)	22. Rest 23. Exercise 24. Sexual life 25. Use of alcohol 26. Smoking 27. Vitamin supplements 28. Teeth brushing	

Anxiety was measured by using the State Anxiety Inventory (STAI) (Spielberger 1972). The STAI is a widely used generic instrument to measure both state and trait anxiety. Its reliability and validity has been demonstrated in number of studies (Spielbeger & State-Trait Anxiety Inventory for Adults 1983). We used the Finnish version of State Anxiety scale of STAI (www.mindgarden.com). The scoring of this a 20-item ordinal scale instrument based on the intensity of a patient's feelings; from not at all (1) to very much so (4), total score 20 – 80. Higher scores on the subscale reflected greater level of anxiety. The norm is established to 35.2 (n=451) with healthy women aged 19 – 69 (Spielberger 1989).

QOL was measured by using the Functional Assessment of Cancer Therapy - Breast (FACT-B) scale (Brady et al. 1997), which is a breast cancer-specific instrument (36 items) to assess multidimensional quality of life: breast (9) emotional (6), functional (7), physical (7), and social well-being (7) subscales. The FACT-B is scored with a 5-point Likert scale (not at all, 0; a little bit, 1; somewhat, 2; quite a bit, 3; and very much, 4), total score 0 – 144. Higher scores indicated better quality of life. The normative value of total score is 112.8 (n=295) among women with breast cancer aged 28 – 86.

Patients' background variables were evaluated by using questionnaires. In Phase I and II, patients characteristics requested were socio-demographic (gender, age, marital status, education, employment status, type of cancer). In Phase III, preference for information was measured using the Krantz Health Opinion Survey (KHOS, Krantz et al. 1980). KHOS is a valid two subscale questionnaire of Preference for Information (7) and Behavioral Involvement (9). In present study used The KHOS Preference for Information scale (KHOS-I) reflects the tendency of patients to actively seek health-related information and to participate in treatment-related decision making. The binary response format (yes/no) yielded 7 in maximum, high scores indicated strong preference for information. In addition, patients characteristics requested were socio-demographic (age, marital status, education, employment status, having children at home, family/ nearby history of BC, discussion partner, influence on economical situation, amount of Internet use, computer literacy). Medical characteristics (way to discover tumour, TNM classification, surgery option, chemotherapy, health problems) were collected from the patient records of hospital.

4.4 The e-Feedback knowledge of radiotherapy -intervention (e-Re-Know)

In this study, the e-feedback after response to the knowledge test is seen as a facilitator for patients to know their knowledge level, and consequently improve it and support patients' empowerment (Funnell 2004, Anderson & Funnell 2010). The e-Feedback knowledge of radiotherapy -intervention (e-Re-Know) was intended to base on the content of breast cancer patients' knowledge expectations and to implement with e-feedback approach.

The content of the e-Re-Know (Table 1.) was guided by empowering knowledge (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012). It based on expert reviews and the results of literature review of breast cancer patients' knowledge expectations of RT (Figure 4). In order to cover the main knowledge expectations, the RT Knowledge Test included two dimensions of empowering knowledge: bio-physiological consisting 2 subcategories; RT process (7 items) and possible side effects (7 items) and functional consisting 2 subcategories; side effects and self-care (7 items) and lifestyles and RT (7 items) (Harrison et al. 1999, Halkett et al. 2008, 2009, Sjövall et al. 2010). The content of e-feedback knowledge for each item of the RT Knowledge Test based on literature of radiotherapy care (Murray & Robinson 2011, Halperin et al. 2013) and standard patient education material in radiotherapy. Finally, the e-Re-Know consisted knowledge of radiotherapy for breast cancer patients to support empowerment (Leino-Kilpi et al. 1999, Anderson & Funnell 2010, Appendix 2.).

The structure of the e-Re-Know (Figure 6.) was guided by the literature of e-feedback approach suggesting that the most effective feedback structure is so called elaborated e-feedback after responding the knowledge test explaining the correct answer and providing relevant knowledge to inspire learners understanding (Dempsey et al 1993, Mason & Bruning 2003, van de Ridder et al. 2008, Wang & Wu 2008). The structure of the knowledge test was designed to be well-constructed and easy to answer true/false format (McDonald 2007).

The e-Re-Know was delivered to breast cancer patients in the intervention group via an e-mailed link after their first visit at the RT department (during their RT planning period). Patients were asked to open the link and response to 28 items of RT Knowledge Test using the options 'true' or 'false' to receive e-feedback after every answer. After responding for example to the item e.g. "During a radiotherapy session, the patient is alone in the therapy room" patients automatically received e-feedback: 1) e.g. "The correct answer is TRUE and 2) e.g. "During radiation the patient is alone in the treatment room. However, radiotherapists can see, hear and talk with the patient through cameras and computers". After that, there was no other option than continue to the next item and receive e-feedback until all 28 items were responded. The e-Re-Know link could be opened only once. Webropol© software was utilised to create the delivered link.

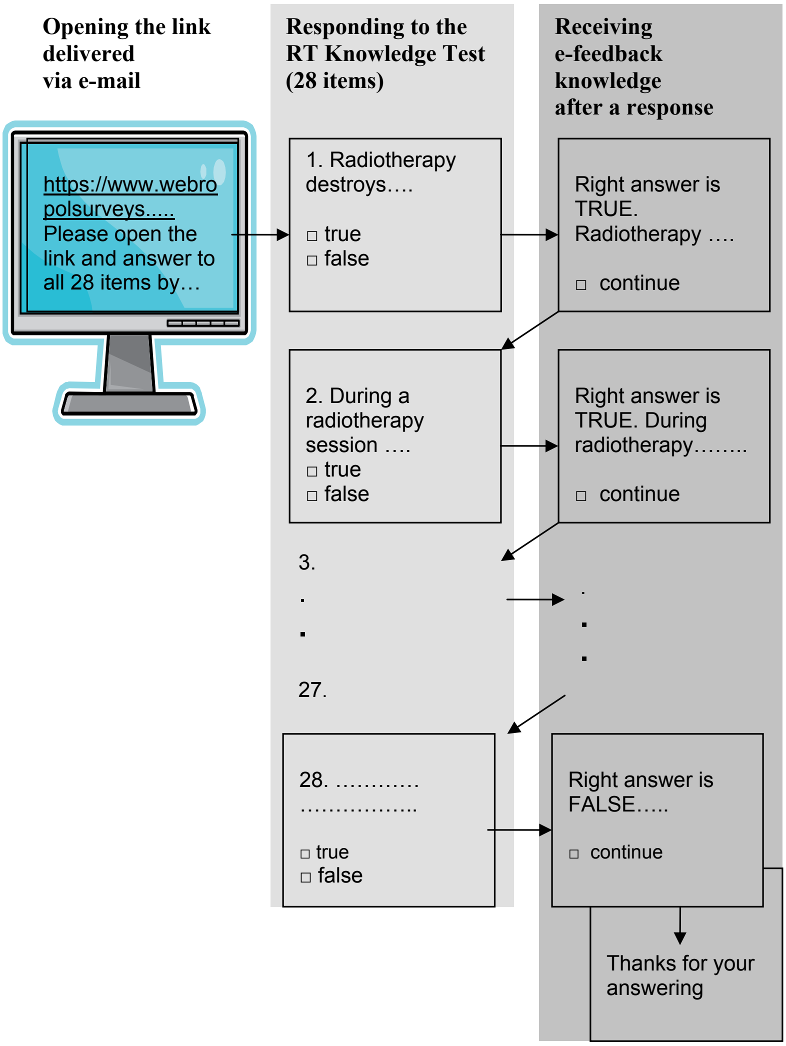


Figure 6. Structure of the e-Re-Know.

4.5 Data analyses

In Phase I, descriptive statistical analysis and frequency tables were used. Four sum variables were constructed out of the main instrument categories. The reliability of the sum variables was estimated by calculating Cronbach's alpha coefficients and by using item analysis to check the compatibility of single items with the instrument. Parametric tests were performed to examine statistically significant differences or associations between groups. Independent samples T-test was used to compare the mean scores of the sum variables containing two categories (contrasting groups), and one-way analysis of variance (ANOVA, paired comparisons with Tukey's HSD test or Tamhane test) with variables containing more than two categories. Associations between two sum variables were examined with Pearson's correlation coefficient. Statistical significance was set at <0.05, exact p-values are reported in the text. Statistical analysis was carried out using SPSS 12.0. (I)

In the Phase II, the statistical analysis was done with mixed methods. First inductive content analysis was used with the text of open-ended questions by grouping patients mentions into four main categories using abstraction, open coding and creating categories by researcher (MS) (Neuendorf 2005, Polit & Beck 2010). Secondly deductive content analysis was used with the data of "I want specific e-knowledge from different issues" category. The analysis based on the theoretical framework of empowering knowledge (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012) and the content of the text resolved the dimension (Krippendorff 2004, Grove et al. 2012, Neuendorf 2005). This analysis was done separately by two researchers in order to add validity (MS, AR). All six dimensions of empowering knowledge were derived. Finally, the statistical analyses were used to describe frequencies and percentages of the four categories and six empowering knowledge dimensions. Associations of patient characteristics with empowering knowledge dimensions were examined with contingency tables and Pearson's chi-square test. P-values less than 0.05 were considered statistically significant. Statistical analysis was carried out using SAS System for Windows, version 9.1 (SAS Institute Inc., Cary, NC). (II)

In the Phase III, in the first part the deepened literature review of breast cancer patient knowledge expectation of RT was done by systematic narrative analysis. First the abstracts of the included papers were checked against the inclusion criteria with regard to breast cancer patients and knowledge expectations of radiotherapy. The full texts acquired. The final articles included were analyzed using deductive content analysis. The framework of the analysis was the empowering knowledge (Leino-Kilpi et al. 2005, Johansson et al. 2007, Heikkinen et al. 2008, Ryhänen et al. 2012). The relative mentions of RT knowledge expectations discussed across the entire body of article were summarized to each of the six dimensions and thereafter subcategories were created. The intelligibility and consistency of each item of the RT Knowledge Test were described by statistical analysis, and as well as the degree to its relevancy to the concept of knowledge expectations of radiotherapy. (Krippendorff 2004, Neuendorf 2005, Grove et al. 2012.)

In the second part of Phase III of the randomized controlled trial, a power analysis was performed to define the sample size needed (Eton et al. 2004) (see chapter 4.1.1). Analyses were performed using intention to treat, regardless of whether intervention group participants had logged on to the e-Re-Know or not. The differences in continuous variables (patient characteristics, knowledge level, anxiety and QOL) between intervention and control groups were analysed with two-sample t-test or Mann-Whitney U-test. Chi-square test or Fisher's exact test was used to compare categorical variables (socio-demographic and medical characteristics) between the groups. P-values lower than 0.05 were considered statistically significant. Statistical analyses were performed using SAS System for Windows, version 9.1.3. (SAS Institute Inc. Cary, NC). (III, IV)

The changes in mean knowledge level within groups were tested using paired t-test. The difference in change in knowledge level between groups was tested with two-sample t-test. Because of the significant difference in knowledge level between the groups at baseline the difference in change in knowledge level between the groups was also analysed after adjustment for baseline knowledge level using analysis of covariance. The associations of patient characteristics with knowledge level at the baseline and the change in the knowledge level were analysed using linear models. Pairwise comparisons among the classes of the categorical variables were done with Tukey's method. In the first step each independent variable, baseline knowledge level and group was included in the model, with the change in the knowledge level as the outcome. Finally, variables significantly ($p <.05$) associated with the change in the knowledge level were included in the multivariable linear model. The modifying effect of patient characteristics on the difference in the change between the groups was tested using two-way interaction between characteristic variable and group. (III)

The changes in mean anxiety and QOL within groups were tested using analysis of variance for repeated measurements. Bonferroni correction was used in pair wise comparisons between time points. The difference in change in anxiety and QOL between groups was tested with interaction term group × time. Unstructured covariance structure was used to account for correlation between repeated measurements. The modifying effect of patient characteristics on the difference in the change between groups (=the effectiveness of intervention) was analyzed using analysis of variance for repeated measurements. All three-way interactions between characteristic variable, group and time were analyzed to test the significance of modifying effects. (IV)

4.6 Ethical considerations

Ethical concerns apply in all stages of the study. Central ethical questions in this study concerns how to protect research subject (respect for autonomy of patients, non-maleficent, justice and beneficence) and research process. Ethical considerations and the general principles of research ethics were complied with at every stage of the study (The National Advisory Board on Research Ethics 2012, the Declaration of Helsinki 2011).

The relevant approval of the joint Ethical Committee of the University of Turku, The South Western Hospital District obtained to perform the study. Permission to collect data were obtained from the hospital's chief physician and director of nursing (Committee of Nursing Research). In addition, approval was granted by the hospital ethics committee to access patient records to gather the radiotherapy-related data. The appropriate approval from instrument copyright owners was obtained in the Phase I at January 2004 and in the

Phase III at October 2010. Patients' socio-demographical factors collected from patients and medical factors from patients' records (see chapter 4.3.). The researcher gathered information from those who agreed to participate in study.

Ethical questions concerning the research subjects of the study were taken into account by making sure that participation in the study was voluntary (Grove et al. 2012). Fear of the illness and limited understanding of medical research in general, compounded by unhelpful explanations of the study purpose and process by health professionals could lead to patients decline especially into randomised trials. Some patients had persisting guilt about their decision not to take part (Ellis 2000, Stevens & Ahmedzai 2004). In this study, before the informed consent were emphasized: purpose, methods, analysis methods, use of results, confidentially, anonymity (all patients were coded by number, names of the patients will not be used together with data, the data will be handled only by the researcher) possibility to refuse or withdraw from the study at any time, name and contact number of the researcher.

Autonomy requires competence and ability to make decisions concerning one's own life. Ethical challenge in this study was that the patients might have had limited time to get familiar with to the information of the study before they gave their informed consent, if it was posted only few days before the first appointment in radiotherapy department. In the Phase I and II, written questionnaires were also understood as consent. In the Phase III patients returned informed consent containing their e-mail address in order to receive the intervention. Thus, a non- maleficent ethical challenge was to ensure that participants perceived the privacy perspective of responding to intervention, because also relatives e-mail addresses was used if patient wanted. Consequently, all patients were given the name and a contact number of the researcher and had the possibility to ask questions and discuss the study in general, and an e-mailed intervention or ethical questions at any time. The study was not found to cause harm to patients. Researcher was contacted during the research process only twice. The reasons were the technical problems with computers during the intervention session at home.

There were no ethical problems in beneficence of the study, with respect to non-treatment, e.g. standard education in hospital. In the intervention study, both groups received same standard patient education. Conversely, also patient without e-mail address gave their informed consent and wanted to participate to the study in spite of detailed account of the claim of internet usage. Ethical questions concerning the research process is noticed in this study by avoiding misconduct in data collection process, data protection and publishing (the National Advisory Board on Research Ethics 2012, World Medical Association Declaration of Helsinki 2013). Longitudinal designs in the Phase II and III required subject commitment over a long period of time, and thus the data collection may cause temporary discomfort as it takes time. This was avoided by contacting the personnel in radiotherapy department regularly. The explanation of the purpose of the study was done in order to ensure the willingness to assist with data collection and personal agreement to participate in the study. During data collection period the researcher visited and phoned to radiotherapy department at least once a week to discuss that the data were collected and the research was processed without ethical problems.

The protection of the data followed Finnish acts and decrees. It was carefully planned and handled by the researcher with the permission of the participants. The registered Webropol-firm defined the confidentiality of the intervention data. The written data and memory stick of e-data were saved to Nursing Department of University of Turku. The results were published in doctoral thesis, in international scientific papers and conferences. The report of the study followed confidentiality and anonymity (the National Advisory Board on Research Ethics 2012, World Medical Association Declaration of Helsinki 2013). This research was beneficial and the ethical analysis was done. This research will develop the patient education of cancer patients. More effective and patient-centred patient education may be more empowering and lead to the better quality of radiotherapy care. All patients during the research process were informed about the publication of the research results.

5. RESULTS

The results are reported according to the study questions in three parts. The first part describes cancer patients' experiences of the quality of radiotherapy care and its deficits (I). The second part describes cancer patients' e-knowledge expectations in radiotherapy (II). The third part presents the outcomes of the randomized controlled trial containing the effects of the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know) on breast cancer patients' cognitive (knowledge level) (III) and psychosocial (anxiety and quality of life) outcomes (IV). In addition, associations between background variables and main results are presented.

5.1 Quality of radiotherapy care (I)

Cancer patients' evaluations of the quality of radiotherapy care were quite high (mean 1,33, range 1-4) in the middle of their RT period (Mmiddle). In average patients perceived very good quality of care in all evaluated categories. Patients evaluated the highest points to staff characteristics (1,15), near next was caring process (1,37) and caring activities (1,38), and the lowest was in caring environment (1,42). In the item level, the highest perceived staff characteristic was the staff tidiness and politeness (1,05). In the caring process reasonable daily waiting times (1,01) and in caring activities professional skills during treatments (1,03) were evaluated highest. The radiotherapy environment was experienced really clean and tidy (1,01). The correlations between the different quality categories varied between 0.301-0.649 and were significant (p= .001). Good quality in one category thus correlates with good quality in all other categories.

The main deficits were scored in items of patient education. The highest deficits were mentioned in caring activities; the planning of treatment together with patients and relatives (2,04), discussions about the patient's prognosis and treatment results (1.84) and information on the situation (1,73). In the radiotherapy environment the notice board for written patient education material (1,61) and in staff characteristics interest of patients' well-being (1,40) was scored lowest. In the caring process, the deficits were in possibility to choose the treatment time (1,19).

Patient background variables as higher vocational education, younger age and being retired showed statistically significant correlations with high quality of radiotherapy care categories.

5.2 e-Knowledge expectations of radiotherapy (II)

In development of patient e-education, the e-knowledge expected by cancer patients in radiotherapy was identified into four main categories. Patients mentioned highest “I want specific knowledge from different issues” (46 %), next “I want all possible available knowledge” (20 %) and “I don’t know what I want” (11 %) and lowest “I have no expectations” (3 %). One fifth of the patients did not mention expectations.

Most of patients reported “I want specific e-knowledge from different issues” including multidimensional mentions of e-knowledge expectations in terms of empowering knowledge (Figure 7.). The highest were bio-physiological (42 %) and functional (30 %) e-knowledge expectations. The other mentions included social (9 %), ethical (8 %) financial (4 %) and experiential (3 %) expectations. Bio-physiological dimension included patients e-knowledge expectations of such as cancer as a disease and its treatments in general, treatment, RT in general, RT realization as why, how, past, planning, treatment area, efficacy and side-effects during and after RT period, benefits, survival rates, further treatments, laboratory tests and examinations. Functional dimension included expectations that were important for own participating such as self-care of side effects, skincare, other care, observation of side-effects and contacting with the physician, nutrition and exercise. Social dimension included e-knowledge expectations of how to deal with daily life and nearby others, support persons, collaboration with personnel in hospital and possibility to participate hobbies and trips. Ethical dimension included mentions of importance of individual knowledge. Financial dimension included mentions of payment, work and employment. Experiential knowledge dimension included mentions of sensations during laboratory visits and avoidance of horror stories.

Patients’ expectations varied across time. Before commencing RT period (M1) patients mentioned five dimensions: bio-physiological (23 %), functional (12%), social (4 %), ethical (4 %) and financial (1 %); while any of experiential knowledge. Only in the middle of RT period (Mmiddle) all six dimensions were reported: bio-physiological (27 %), functional (12 %), social (7 %), ethical (5 %), experiential (4 %), and financial (1 %). When concluding RT period (M2) patients expectations were the lowest. They expected e-knowledge of four dimensions: bio-physiological (27 %), functional (18 %), social (6 %) and financial (3 %). Knowledge concerning time after RT period was expected already before commencing RT period and in the middle of RT period.

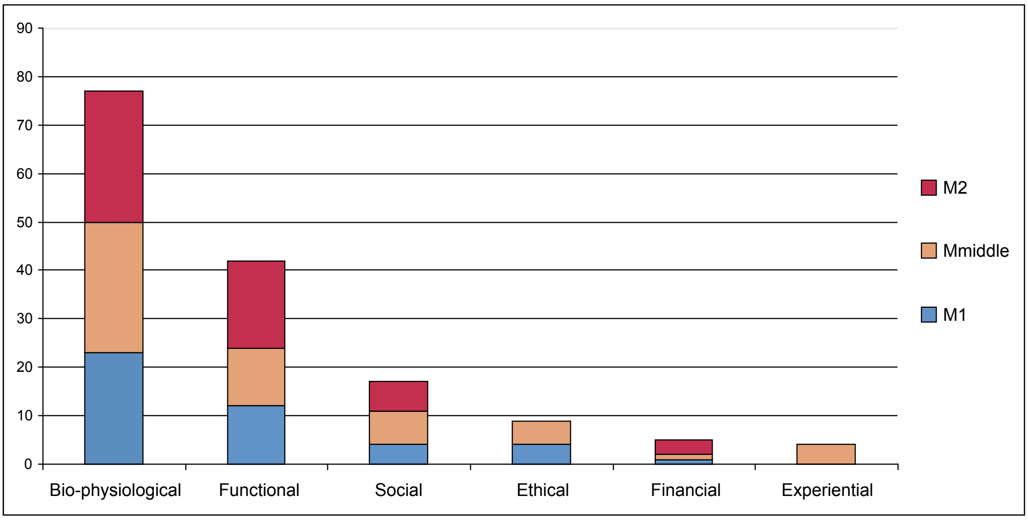


Figure 7. Cancer patients' mentions of "I want specific e-knowledge from different issues" in terms of empowering knowledge in radiotherapy.

Some patient background variables showed statistically significant correlations with mentions of specific e-knowledge expectations of bio-physiological, functional, experiential and ethical dimensions. Being female, 51-60 years of age, higher education, being in work-life or using Internet were correlated at least with higher knowledge expectations of bio-physiological knowledge. There were no correlations with mentions of social of financial e-knowledge expectations.

5.3 Outcomes of the e-Re-Know (III, IV)

This chapter describes first the cognitive outcome (knowledge level) of e-Re-Know education for breast cancer patients (III) followed by the psychosocial outcomes (anxiety and QOL) tested in this study (IV).

5.3.1 Cognitive outcomes (III)

In the intervention group (n=65) knowledge level at baseline, before commencing first RT session (M1), was scored 21.8 (range 0-28). Three months after RT period (M3) their knowledge level was increased significantly 1.9 points (p< .0001, Figure 8.)

At the subdomain level, patients' knowledge level increased mostly in side effects self-care category (1.7 points), next RT process (0.2 points) and possible side effects (0.2 points) categories and decreased in lifestyle and RT category (0.1 points).

In the control group (n=63) knowledge level at baseline (M1) scored 20.1 (range 0-28). Three months after RT period (M3) patients knowledge level was increased significantly 1.3 points (p= .0011, Figure 8.).

At the subdomain level, patients' knowledge level increased mostly in side effects self-care category (1.0 points), and next RT process (0.3 points) and possible side effects (0.1 points) categories, and decreased in lifestyle and RT category (0.2 points).

Between the groups the change of knowledge level between M1 and M3 was in the intervention group significantly higher than the control group (p< .0001); the increase in the intervention group was 2.5 points (p< .0001) and in the control group 0.8 points (p= .0036) after adjustment the baseline knowledge level (Figure 8.).

At the subdomain level, the change was significantly higher in the intervention group than in the control group in one category; side effects self-care (p= .018).

No significant interaction between background factors, group and time (characteristics × group × time interaction effects) on knowledge level was found.

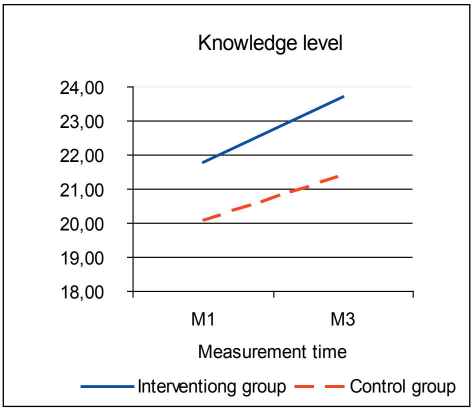


Figure 8. Knowledge level (min 0 – max 28) in the intervention and in the control group during the follow-up

5.3.2 Psychosocial outcomes (IV)

Anxiety

In the intervention group (n=63) at concluding RT period (M2) significant decrease in anxiety was found (mean change -4.1, 95% -7.2 to -1.1, p= .004) and at three months after RT period (M3) there was further decrease (mean change -1.3, 95% CI -4.2 to 1.6, p= .840). Between time before commencing first RT (M1) and three months after RT period (M3) decrease in anxiety was significant (mean change -5.4, 95% CI -8.0 to -2.9, p< .0001, Figure 9.).

In the control group (n=63) at concluding RT period (M2) significant decrease was found in anxiety (mean change -5.4, 95% CI -8.4 to -2.5, p< .0001) but at three months after RT period (M3) there was increase (mean change 2.3, 95% CI -0.5 to 5.1, p= .145). Between time before commencing first RT (M1) and three months after RT period (M3) decrease in anxiety was not significant (mean change -3.1, 95% CI -6.7 to 0.5, p= .108, Figure 9.).

Between the groups during the follow-up the change of anxiety was marginally significantly different (group x time interaction effect p= .083, Figure 9.).

No significant interaction between background factors or knowledge level (baseline), group and time (characteristics/knowledge level × group × time interaction effects) on anxiety was found.

Quality of life (QOL)

In the intervention group (n=63) at concluding RT period (M2) non-significant increase in QOL was found (mean change 3.5, 95% CI -0.7 to 7.4, p= .135) and at three months after RT period (M3) there was further significant increase (mean change 4.3, 95% CI 0.6 to 8.6, p= .046). Between time before commencing first RT (M1) and three months after RT period (M3) increase in QOL was significant (mean change 7.7, 95% CI 4.0 to 11.3, p< .0001, Figure 10.).

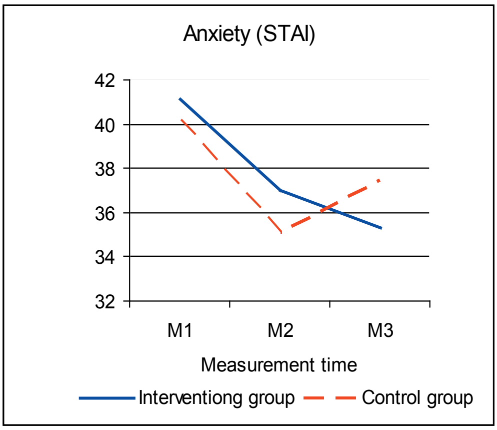


Figure 9. Anxiety (min 20 – max 80) in the intervention and in the control group during follow-up. (modified from IV, Figure 3.)

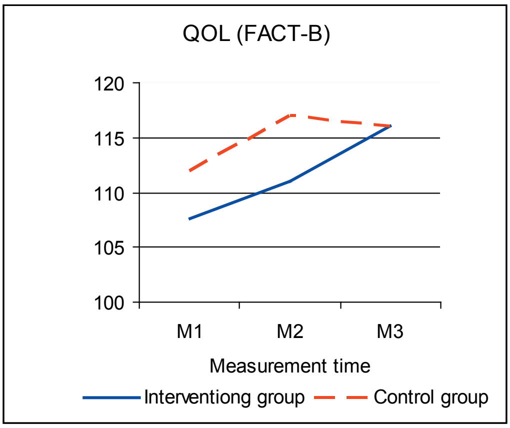


Figure 10. QOL (min 0 – max 144) in the intervention and in the control group during follow-up. (modified from IV, Figure 4.)

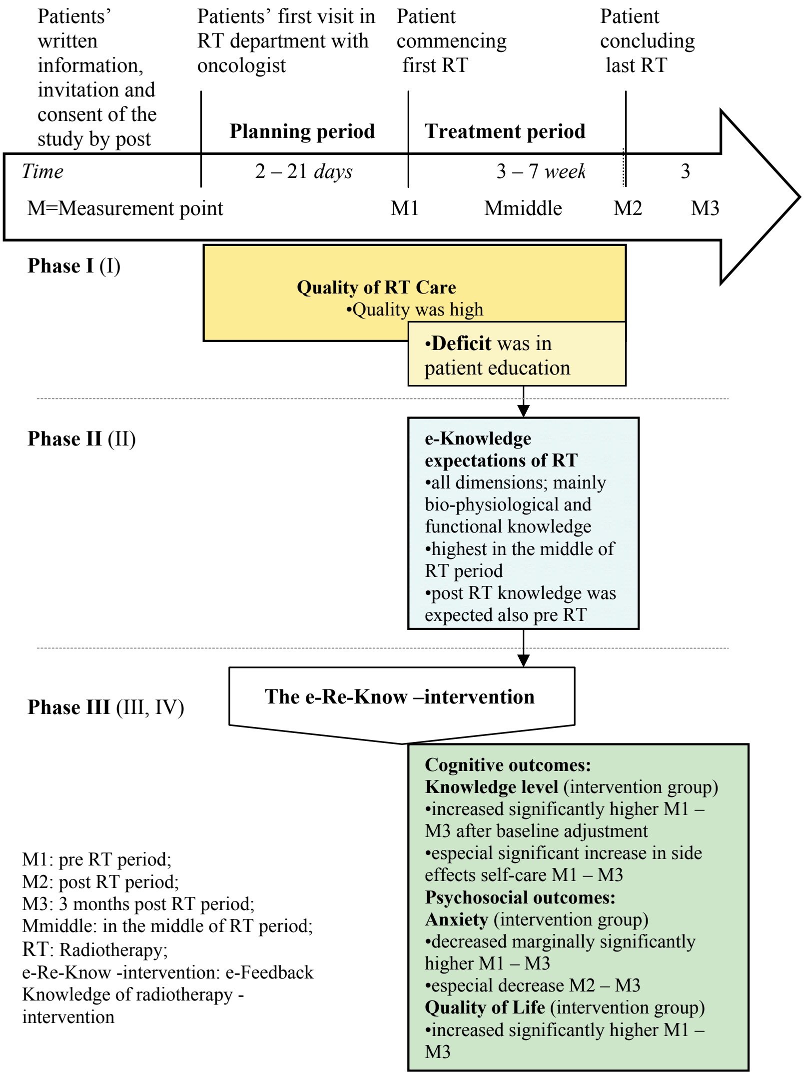
In the control group (n=63) significant increase in QOL was found at concluding RT period (M2) (mean change 6.0, 95% CI 1.8 to 10.1, p= .002) but decrease at three months after RT period (M3) (mean change 1.2, 95% CI -2.53 to 4.9, p= 1.0). Between time before commencing first RT (M1) and three months after RT period (M3) increase in QOL was not significant (mean change 4.8, 95% CI -0.4 to 9.9, p= .078, Figure 10.).

Between the groups during the follow-up the change of QOL was significantly different (group x time interaction effect p= .046, Figure 10.).

No significant interaction between background factors or knowledge level (baseline), group and time (characteristics/knowledge level × group × time interaction effects) on QOL was found.

5.4 Summary of the study results

Based on the studies following result are presented (Figure 11):



Quality of RT Care
- Quality was high
- **Deficit** was in patient education

e-Knowledge expectations of RT
- all dimensions; mainly bio-physiological and functional knowledge
- highest in the middle of RT period
- post RT knowledge was expected also pre RT

The e-Re-Know –intervention

Cognitive outcomes:
Knowledge level (intervention group)
- increased significantly higher M1 – M3 after baseline adjustment
- especial significant increase in side effects self-care M1 – M3

Psychosocial outcomes:
Anxiety (intervention group)
- decreased marginally significantly higher M1 – M3
- especial decrease M2 – M3

Quality of Life (intervention group)
- increased significantly higher M1 – M3

M1: pre RT period;
M2: post RT period;
M3: 3 months post RT period;
Mmiddle: in the middle of RT period;
RT: Radiotherapy;
e-Re-Know -intervention: e-Feedback Knowledge of radiotherapy - intervention

Figure 11. Summary of the study results (I, II, III, IV)

6. DISCUSSION

The aim of this three phase study was to develop quality of radiotherapy care by the e-Feedback knowledge of radiotherapy -intervention (e-Re-Know). To achieve this, the research process was conducted by following phases: Phase I to describe the quality of radiotherapy care and its deficits experienced by cancer patients, based on the deficits in patient education Phase II to identify cancer patients' e-knowledge expectations in radiotherapy, and finally Phase III to develop and evaluate the outcomes of the e-Re-Know among breast cancer patients. The e-Re-Know is seen as a determinant for patients to know their knowledge level, and consequently improve it and support patients' empowerment. The ultimate aim was to develop radiotherapy care to support patients' empowerment with patient e-education. In this discussion, firstly, the validity and reliability of the study will be discussed. Secondly, the main findings will be discussed in light of previous research results (Figure 10.). Finally, the implications for nursing practice, management and research are presented.

6.1 Validity and reliability of the study

The validity and reliability of the phases are here discussed in terms of the quality of the method; design, data, analysis, intervention and instruments employed. Validity represents a measure of truthfulness and accuracy in relation to the concept under study. Reliability refers to the quality of the measurement of consistency, stability and repeatability of the measures obtained (Dane 2011).

6.1.1 Design, data and analysis

The choice of the design is important to ensure that the evidence produced is valid and reliable. In this study, in order to answer the research questions, the descriptive (I, II), longitudinal (II) and experimental randomized controlled trial (III) designs were included (Polit & Beck 2006, 2010, Dane 2011). Descriptive design was selected to reach the extent the variables occurs and longitudinal design to measure them repeatedly over time with respect to the same variables (Grove et al. 2012, Dane 2011). Randomized controlled trial was chosen to test cause-effect hypotheses under highly controlled conditions, however, in order to minimise the problems and the risks of the design in natural setting (Morris & Nelson 2007).

In Phase I, to describe the quality of radiotherapy care and its deficits the data were collected at one measurement point from radiotherapy patients. To ensure the validity data were representative enough (89%) to population in one hospital. In further research to achieve greater generalizations, national or even international data should be collected. Additionally, quality evaluation requires further research after reactions to results.

In Phase II, to identify the e-knowledge expectations in radiotherapy the data collection was conducted longitudinally from radiotherapy patients. The drop-out was 25% (Mmiddle) and 27% (M2) being in acceptable rates (Badger & Werrett 2005). Although the data were collected also among the patients who were not Internet users, the data were found to be wide-ranging and covering sample from all ages. However, it is noteworthy that nearly half of the patients could not name their expectations. If the study had been conducted as an interview study the researcher could have an opportunity to specify with open questions.

In Phase III, at first part the e-Re-Know was developed in different parts (Figure 4.). The data collection based on carefully planned literature review and inclusion criteria of participants. The content validity was evaluated with multiple professionals (radiation therapist, registered nurse, breast cancer nurse, medical oncologist, radiation oncologist, physicist, sex therapist and dietician in hospital) and women with breast cancer in different stages of their disease (in radiotherapy, from support group) and face validity with breast cancer patients at the beginning of their radiotherapy. The samples were achieved as planned.

At second part of Phase III, randomized controlled trial was performed. To implement the randomized controlled study in natural setting it is difficult to reach sample size, randomization and blinding, and to prevent manipulation (Rosenberger & Lachin 1993, Wood et al. 2008). In this study, every effort was made to reach the validity and reliability according to Consort statements (Plint et al. 2006, Zwarenstein et al. 2008, Borglin & Richards 2010).

The total sample size based on the power analysis from earlier publications measuring breast cancer patients QOL with 10 % margin to consider the drop-out (Eton et al. 2004, Grove et al. 2012) (see section 4.4.). The population of e-mail users was not achieved through patient records, thus, the information letter was mailed to all breast cancer patients invited to radiotherapy for the first time. However, the planned sample size was achieved and the dropout was under acceptable 60 % (Badger & Werrett 2005) of the 65 % of all citizens using e-mail in Finland. The risk of bias was that time between enrolment and intervention varied from two days to several weeks according to the breast cancer treatment type, obviously leaving a minimal time for implementing the intervention in some cases. However, intention to treat design was used and the sample size was as determined. Moreover, main researcher who used own expertise in radiotherapy from several decades personally delivered the intervention to patients in the intervention group, all the questionnaires to department and informed personnel about the collection of informed consents and questionnaires. The visits in radiotherapy department were necessary to minimize the risk of bias (Borglin & Richards 2010). The dropout during research follow up was in the average level 10 %. The three months follow up after RT period reached valid and reliable data for analysis. The condition of randomized controlled trial, that the causal inferences were allowed to be drawn, was met (Polit & Beck 2006).

The randomization ensured the similarity of the samples. No statistical differences between intervention and control group were found in patient characteristics, anxiety and QOL at first measurement point, which strengthened the validity of the study, even though statistical difference between groups in N of the TNM classification and in knowledge level does not undermine it. However, the difference in N was not clinically significant. Moreover, randomization based on knowledge level was not possible because of the risk of maturation. The test itself before intervention might improve knowledge generating testing bias. However, the difference of knowledge level was controlled by statistical methods using baseline adjustment, and it did not seriously undermine the reliability of the study.

The blinding was used at the time of computer-based randomization; the personnel were not allowed to know in which group each woman was assigned. On the other hand, blinding was difficult to achieve in studies in natural setting, where patients have a possibility to talk with each other and personnel during their visits in radiotherapy (Zwarenstein et al 2008). However, only patients in the intervention group improved significantly their knowledge of side effects self-care. Obviously, manipulation on the patients learning was not limited to the intervention or standard education in hospital. Thus, careful control of threat through randomization was important (Borglin & Richards 2010).

The statistical analyses and conclusions were carried out with the help of graduated statisticians. No power analysis was performed for the descriptive phases of the study. The content validity index (CVI) of the test was assessed for development phase of the intervention and it was over .80 (acceptable) (Polit & Beck 2006). The total CVI was calculated by summing the individual CVI scores (range1-4) and dividing by the number of items. The power analysis for evaluation phase of the intervention was performed on the basis of QOL (Etona et al. 2004) because former, congruent earlier study of meaningful difference score of knowledge level or anxiety using the same design and similar patient group was not available. The hypotheses were confirmed. The content analyses were concluded by researcher. The theoretical framework was used and tried not to let own perceptions to affect.

6.1.2 Instruments

In this study, the instruments used were translated valid instruments (STAI-S, FACT-B, KHOS-I), modified (GNCS-P), and new instruments (The e-knowledge expectations, RT Knowledge Test, Patients socio-demographic factors -questionnaire). The modified and new instruments were pilot tested. The internal consistency was assessed of the structured instruments.

In Phase I, the Good Nursing Care Scale for Patients (GNCS-P) modified for this study has been tested in Finland (Leino-Kilpi et al. 1994, Leinonen et al. 2003, Ruotsalainen 2006, Pelander 2008) and internationally (Ruotsalainen 2006, Rehnström et al. 2003, Kalam-Salminen et al. 2008, Zhao et al. 2008, Donmez & Ozbayir 2010, Istomina 2011, Tay Zar Mauyng 2013). Content validity of instrument based on theoretical literature and pilot test with 12 radiotherapy patients. On the basis of earlier studies the instrument has been shown to be valid (Gröndahl & Leino-Kilpi 2013). In this study the internal consistency is estimated on the basis of Cronbach's alpha (0.79) indicating that the parameters measured have good internal consistency, and the test–retest correlation (0.75) showed good stability (Grove et al. 2012). In this study, the instrument was used for first time for cancer patients in radiotherapy. Factor analysis was used to test the construct validity and to identify the main patterns and factors within a questionnaire for possible item reductions (Ketokivi 2009). According to factor analysis, special attention should be given to the quality categories where the Cronbach's alphas were low, such as the caring process and environment. Further testing in radiotherapy is still needed.

In Phase II, the e-knowledge expectations were collected with open-ended questionnaire developed for the study to cover the radiotherapy process. It is useful in seeking to understand the particular topic from the perspective of patients (Grove et al. 2012). This questionnaire assessed the knowledge expectations on an Internet site at before commencing, in the middle of and at concluding radiotherapy period. The content validity was guided by theoretical literature and pilot test with 20 cancer patients in radiotherapy. The limitation was that there was no possibility to do additional questions to deepen the understanding as in focused interview. However, the data were representative enough to perform statistical analysis to compare the expectations at different measurement points.

In Phase III, the outcomes were measured with three questionnaires. Knowledge level was assessed with RT Knowledge Test, which is a true/false questionnaire developed for the e-Re-Know intervention in this study (see chapter 4.). The reliability (internal consistency) of the RT Knowledge Test was tested with the Kuder-Richardson formula (KR-20). Although the reliability was moderate .45 (Cortina 1993) the validity was strengthened by high CVI index score and face validity. Further testing of this instrument should be considered with bigger sample size.

Anxiety was assessed with the State Anxiety scale of The State Anxiety Inventory (STAI). Its reliability and validity has been demonstrated in number of studies (Spielberger 1972, 1983). It has also been used with breast cancer patients in patient e-education approach internationally (Green et al. 2004, Heller et al. 2008) and nationally (Ryhänen et al. 2013). The Finnish version of the instrument includes Trait anxiety (T-anxiety) and State anxiety (S-anxiety) questionnaires. In this study, the S-anxiety was used. It has been shown be valid among women in mammography screening (Aro 1996) and during their breast cancer care pathway (Ryhänen et al. 2012, 2013). In this study, the

Cronbach’s alpha coefficient ranged from 0.94 to 0.95 between different measurement points showing high reliability (Grove et al. 2012).

QOL was assessed with the Functional Assessment of Cancer Therapy - Breast (FACT-B) scale (Brady et al. 1997). FACT-B includes five subscales; breast, emotional, functional, physical, and social well-being. The QOL have different definitions depending on context (Ferrans et al. 2005). Thus, in earlier studies different questionnaires were used to measure the QOL concerning radiotherapy patients (Wengström et al. 1999, Häggmark et al. 2001, Lee et al. 2011, Guo 2013, Ryhänen et al. 2013). The FACT-B was used because it is appropriate for use in oncology clinical trials concerning breast cancer patients, as well as in clinical practice (Brady et al. 1997). In earlier studies the reliability of the instruments were tested and included internal consistency shown to be valid (Arora et al. 2002, Avis et al. 2005, Montazeri 2008). In this study, reliability of the Finnish version was assessed using Chronbach’s alpha, which ranged from 0.92 to 0.93 between different measurement points.

In addition, background variables in all phases were collected with questionnaires developed for the studies, except in Phase III preference for information was measured using the Krantz Health Opinion Survey (KHOS, Krantz et al. 1980) two subscale questionnaire of Preference for Information and Behavioral Involvement. In this study the KHOS Preference for Information scale (KHOS-I) was used. The reliability and validity of KHOS have been evaluated in a number of studies Cronbach’s alfa resulting .57–.87 (Christensen et al. 2000, Garvin & Kim 2000) and the consistency (KR20) was .76 (Krantz et al. 1980). The test–retest of KHOS is also satisfactory (Krantz et al. 1980, Christensen et al. 2000).

6.1.3 The e-Feedback knowledge of radiotherapy -intervention (e-Re-Know)

It is suggested that the valid and reliable structure and content of the intervention can be achieved by careful design and testing. Issues considered in the development of the e-Re-Know -intervention contained conceptual basis, previous descriptive research, related intervention literature and experts, intervention population, specificity/generalitity and single/bundled, intervention delivery and dose. (Conn et al. 2001.)

At first, to ensure that the RT Knowledge Test measures what it was intended to measure the items were chosen to reflect the intervention purpose (Fayers & Machin 2000, Downing & Haladyna 2006, Pitman & Pakas 2010). In this study, several literature reviews were conducted to gain a deeper understanding of e-knowledge expectations of RT, knowledge tests and e-feedback approach to link the key concepts to the proposed outcomes. Expert reviews were made with professionals and patients several times. Additionally to deepen the specificity of the population and understanding of knowledge expectations, the researcher attended to the breast cancer patients’ support group meeting. Secondly, the intervention was determined in order to deliver adequate e-feedback knowledge (Pitman

& Pakas 2010). The structure of the intervention ensured single delivery e-mail and it was easy to answer without personnel. The amount of the items was low and designed to be answered during a reasonable time. Additionally, it was designed to be delivered at the appropriate timing according to literature (Halkett et al. 2013).

Pilot testing of the intervention was done with breast cancer patients who already had received few radiotherapy sessions, and who were familiar with radiotherapy as well as remembered the knowledge gaps of interface. They did not propose changes suggesting the e-Re-Know to be suitable for intervention. Furthermore, patients expressed interest to take part of the development and pilot testing the intervention. However, while testing the effectiveness of the intervention in a randomized controlled trial extraneous variations and intervention environment in natural setting are important to control (Fogg & Gross 2000, Polit & Beck 2006).

The strength of the e-Re-Know -intervention was that the content of the e-Re-Know was always same to all patients. Additionally, it was implemented always the same way via e-mail by the researcher after the inform consent was received to the radiotherapy office. To ensure the consistency, all patients receiving the intervention were informed of the purpose and structure of it, when and how to respond to it and to whom to call for help. As often in the interventions delivered via Internet, it would be difficult to determine whether it was the content or approach of the delivery that was important (Conn et al. 2001). However, the e-Re-Know was shown to be beneficial itself. Moreover, the threat regarding similar standard education of both groups was controlled by blinding. The personnel were not allowed to know the structure and the content of the intervention or group assignment of patients. It was important to follow the latest updated recommendations of the radiotherapy care in order to maintain the consistency between the intervention and standard education. However, because of the reasonable time of the study design no updating was needed.

6.2 Discussion of results

6.2.1 Quality of radiotherapy care

The evaluation and development of the patient-centred quality of care is gaining increasing importance in the health care system in the 21th century (OECD 2004, WHO 2007, 2008). The results of this study confirm the fact that cancer patients evaluated the overall quality of care in the middle of their radiotherapy very high, in line with earlier studies (Gamble 1998, McPhail & Wilson 2000, Momm et al. 2011, Geinitz et al. 2012, Njiman et al. 2012, Roberge et al. 2013).

The results of this study confirmed the fact that main quality deficits in quality of radiotherapy care were in patient education. In caring activities several items applying knowledge of treatment received were evaluated low. The results were in line with earlier studies shown patients' dissatisfaction with it (Gamble 1998, McPhail & Wilson 2000, Long 2001, Karhu-Hämäläinen 2002, Kelsey et al. 2004, Zissiadis et al. 2006). It has been observed that varying coping styles as seeking information were not always assisted by professionals (Long 2001, Dubois & Louiselle 2008). In this study, although the nursing characteristics were evaluated high, patients assessed that radiotherapist were not always interest in patients' well-being possibly concluding lack of knowledge of prognosis, treatment results or patient's situation in general. The results are in line with earlier studies shown that personnel is considering different knowledge important than patients (Halkett et al. 2008, 2009). In addition, uninformative notice-board experienced by patients was indicating deficits in patient education. Therefore, although radiotherapy patients preferred the face-to-face appointments or written material to receive knowledge of radiotherapy (Dodd 1987, Hinds & Moyer 1995, Jahraus 2002, Skalla et al. 2005, Halkett et al. 2012) other patient education approaches are needed. The rapid increase in the web accessibility among the public has increased the use of Internet (Internet world stats 2013). Especially breast cancer patients are motivated to use Internet (Yli-Uotila 2013) to better understand knowledge received from oncologist and written material (Ziedland et al. 2004). Obviously, new interventions were needed.

6.2.2 e-Knowledge expectations of radiotherapy

The e-knowledge expectations identified by radiotherapy patients were a study interest, because the development of quality of radiotherapy care was focused on patient e-education. However, the number of earlier studies reporting knowledge expected on the Internet among radiotherapy patients is limited. Thus, the results are discussed through radiotherapy patients' knowledge expectation in general.

In this study, the e-knowledge expectations varied during radiotherapy period evaluated at commencing, in the middle and at concluding radiotherapy. Almost all patients expected some knowledge, and half of them identified specific knowledge expectations throughout their radiotherapy. The results were similar with earlier studies shown that patients expected knowledge as much as possible, except some patients avoided it (Hinds & Moyer 1995, Skalla et al. 2004, Zeguers et al. 2012). One reason might be that some patients who answered to the questionnaire were not Internet users and thus not interested in searching knowledge electronically.

The e-knowledge expectations of radiotherapy were multidimensional covering all dimensions of empowering knowledge. Most crucial was bio-physiological and functional knowledge trough the radiotherapy period. The results were in line with earlier studies of radiotherapy patients' expectations underlining the knowledge of disease, cancer treatment and side effects (Galloway et al. 1997, Harrison et al. 1999, Mesters et al. 2001, Salminen et al. 2004, Bolderstom 2008, Douma et al. 2012, Ryhänen et al. 2012, Matsuyama et al. 2013) and how to manage practical problems during radiotherapy period and self-care in everyday life (Mesters et al. 2001, Salminen et al. 2004, Skalla et al. 2004, Halkett et al. 2010, 2012, Ryhänen et al. 2012). The results were similar with the study by Metz et al. (2003) describing that the radiotherapy patients were most interested to find on the Internet knowledge of their particular cancer treatment and symptom management. This might be explained with the unfamiliar nature of radiotherapy context with technical issues and complexity of side effects.

According to earlier studies (Halkett et al. 2010, 2012, Ryhänen et al. 2012, Zeguers et al. 2012), the present study showed that patients were interested in social, ethical and financial knowledge as well, however, not as much as the others. The expectations on experiential knowledge was mentioned rare, in line with earlier studies shown that knowledge of psychosocial issues as feelings was expected least (Galloway et al. 1997, Harrison et al. 1999, Salminen et al. 2004, Bolderstom 2008, Douma et al. 2012, Matsuyama et al. 2013). This was supported by the study of Hardyman et al. (2005), shown that patients prefer realistic and factual knowledge more than emotional and personnel through Internet. In this study, patients with most experiential knowledge expectations were higher educated and Internet users; and less interested were prostate and lung cancer patients. A possible reason for the differences could be that patients' expectations appear if they are seen to be related to sense of control (Ter Hoeven et al. 2011). On the other hand, patients rejected knowledge because of avoidance. Perhaps, patients prefer to contact the hospital personnel face to face with their individual matters.

The amount of the radiotherapy patients' e-knowledge expectations in this study were the highest in the middle of the treatment period. In addition, particularly functional and financial knowledge was expected at concluding radiotherapy. However, in earlier studies the time-point for highest knowledge expectations was before commencing RT (Halkett et al. 2010, Douma et al. 2012, Zeguers et al. 2012) when knowledge of issues considering time after radiotherapy period was also expected (Halkett et al. 2010). Thus, one might determine that patients could benefit of patient e-education because of expanding possibility to receive health knowledge and discourse across time, place and cultures according their own preferences (Neuhauser 2003).

Based on the result, empowering knowledge of radiotherapy should be considered when developing patient e-education and focused at least on mainly expected knowledge dimensions. In addition, to meet the expectation through the whole radiotherapy period, it should be offered before commencing it.

6.2.3 Outcomes of the e-Re-Know

In radiotherapy context, there is a lack of studies of patient e-education based on the patients' own knowledge expectations and implemented with e-feedback approach. In this study, we developed the e-Re-Know for breast cancer patients to meet the deficits in patient education. The cancer diagnoses, treatments, and the transition from completion of treatment to life as a cancer survivor is involving lack of knowledge and psychosocial wellbeing (Allen et al. 2009). Therefore, the interest was to evaluate whether the e-Re-Know patients had positive effects on cognitive (knowledge level) and psychosocial (anxiety and QOL) outcomes as empowering outcomes for women with breast cancer at before commencing RT, at concluding RT and 3 months after last RT.

Firstly, the results confirm the hypothesis that with the e-Re-Know it is possible to increase knowledge level from first RT to 3 months after last RT with a significant difference. In this study showed significantly higher increase in knowledge level in one subdomain, i.e. functional knowledge, especially in side effect self-care, compared to the control group after treatments. The results are in line with earlier studies showing positive effects of empowering patient e-education (Heikkinen et al. 2008, Ryhänen et al. 2012). It is noteworthy that although almost all earlier studies among radiotherapy patients have indicated improvement in knowledge level (Rainey 1985, Hagopian 1991, Hagopian 1996, Cartledge Hoff & Haaga 2005, Halkett et al. 2013, Jones et al. 2013) and understanding among radiotherapy patients (Gonzalez-Arriagada et al. 2013), they were not implemented in patient e-education approach. However, in present study, the hypothesis that the electronic intervention, the e-Re-Know, will support patients' cognitive empowerment was confirmed. One reason might be that the content of an intervention guided by patients' own knowledge expectations was relevant. The earlier study of radiotherapy patients' knowledge expectations has underlined the importance of the knowledge of side effects and self-care also after treatments (Harrison et al. 1999). Today it is important that patients have a possibility to manage without health care personnel by gaining greater control over self-care with empowering knowledge. According to earlier studies the e-feedback has increased knowledge gain after patient education intervention (Evans et al. 2000, Jenny & Fai 2001, Jones et al. 2001, Shaw et al. 2001, Neafsey et al. 2002, Krishna et al. 2004, Marsch et al. 2004, Reis et al. 2004, Linne et al. 2006, Strömberg et al. 2006, Keulers et al. 2007). In this study, additional lessons or uploaded patient education data was not needed and knowledge of correct answer and additional knowledge after an e-test might have facilitated patients' learning. However, the e-Re-Know did not cover all dimensions of empowering knowledge. It might be that some patients already had knowledge about bio-physiological and functional knowledge but were not aware of the possibilities to social support and rehabilitation groups of patient associations. Thus, more research is needed to develop content and test the e-Re-Know further.

Secondly, the hypothesis that the e-Re-Know will improve psychosocial outcomes among women with breast cancer was confirmed at least partially. The e-Re-Know did have positive effects on anxiety and QOL. The results indicated a marginally significant improvement in anxiety and significant improvement in QOL over time compared to the control group. The intervention was decreasing anxiety and increasing QOL especially during the time from concluding RT to 3 months after last RT. Several earlier intervention studies among radiotherapy patients have also found decrease in anxiety (Rainey 1985, D'haese et al. 2000, O'Connor 2013) and some interventions have increased QOL as well (Lee et al. 2011, Guo 2013). However, the patient education approaches have been multidimensional combined with different methods requiring personnel, and there are few studies concerning patient e-education. In earlier studies, the barrier to the patient-centred education has shown to be the personnel's missing ability to inquire and respond to the patients' anxieties and general feelings regarding radiotherapy (Dong et al. 2014). In this study, the e-Re-Know simply containing knowledge test and feedback delivered via e-mail has shown to support breast cancer patients' psychosocial well-being. In line with earlier studies among patients with chronic illness, the e-feedback has had positive effects on QOL (Nes et al. 2013, Tabac et al. 2014). The main strength of the e-Re-Know is its positive psychosocial effects after treatment. The benefits were essential, because the transition time from concluding radiotherapy to full recovery often involves not only cognitive but also psychosocial problems (Hakala 2005, Allen et al. 2009). In this study, it was shown that patients had a possibility to manage without personnel by gaining greater control over their lives and thus to be empowered.

Thirdly, patient characteristics or knowledge level at baseline were not associated with the efficacy of the e-Re-Know. Earlier studies have shown the challenge to tailor patient education to all patient groups in radiotherapy despite their characteristics (Douma et al. 2012, Zeguers et al. 2012, Matsuyama et al. 2013). However, the results in present study were promising since the e-Re-Know was shown be appropriate not only for young, educated and knowledgeable but also for older patients and patients with low computer-literacy and knowledge level. It is noteworthy, that during data collection also patients who were not e-mail users were interested to participate to the study. It might be in line with the trend of today, while different kinds of e-tests have been become more popular among citizens. Especially journals all over the world have noticed the increasing interest in narrative by electronic tests in addition to traditional written story. However, further development and research is needed. The e-Re-Know was linked to the objective true/false measurement and all patients received e-feedback similarly. Patients' might benefit even more of the opportunity to respond more subjectively and personally. Also the connections to personnel in hospital or patient associations might be needed to receive emotional support in addition to knowledge.

6.3 Conclusion

The main conclusions are summarized as follows:

1. Quality of radiotherapy care was experienced high among cancer patients. However, it challenges to develop new patient e-education interventions as a part of the quality of care development.
2. Cancer patients in radiotherapy expected to receive knowledge through Internet. Majority of the patients had multiple expectations covering all the dimensions that were shown to support patients' empowerment. Moreover, patients' expectations varied across time. From this perspective, it is important to focus the development on patient e-education based on expectations.
3. The development of the e-Re-Know, i.e. knowledge test and feedback, carried out with patients themselves via e-mail was shown to be a valid and reliable process underlining patient-centeredness. It was experienced easy to use in real-life setting. Thus, the e-Re-Know might have shifted women role from passive recipient in a hospital to active participant.
4. Women with breast cancer in radiotherapy might gain additional value from the e-Re-Know over a longer period of time from the beginning of radiotherapy to three months after treatment period. Knowledge of RT side effects self-care was significantly improved and QOL significantly increased in line with decrease in anxiety. Moreover, the e-Re-Know has potential to have positive effects regardless of patient characteristics or knowledge level. The results supported the hypothesis that when patient carried out the e-Re-Know facilitating her understanding of own knowledge level she will be empowered.

6.4 Implications

The implications of results should be considered in clinical practice, management and research in nursing science.

Implications for clinical practice

- In health care practice, there is a need for patients' perspective of quality of radiotherapy care. Personnel should be aware of the critical points in order to take part in development and implementation in practice.
- The results show that there are patients with high e-knowledge expectations and in turn patients avoiding knowledge. On the other hand it is important to educate all the patients of essential issues related to radiotherapy. This dilemma is a challenge in patient education. Therefore, in order to fulfill their expectations

it might be considered to develop new interventions together with patients. They seem to be prepared to join in development and testing processes in health care.

- Although the radiotherapy period is several weeks long, the time for one session is mainly under fifteen minutes. When time for face-to-face discussion is limited patients might benefit of additional knowledge through the e-Re-Know. In addition, it might be appropriate to exploit results in daily face-to-face appointments to direct education to the knowledge gaps. However, the continuous updating of the e-Re-Know according to the change of clinical practice in hospital could not be too much recalled.
- Moreover, the positive psychosocial effects of the e-Re-Know over a longer period of time should be considered. Patients should be encouraged to carry out the e-Re-Know to be able to manage without personnel in their daily life after treatments. It might be useful during whole care pathway from diagnosis in orientating patients for future.
- Based on results, the e-Re-Know is suitable to use regardless of breast cancer patient characteristics and knowledge level. Thus, the e-Re-Know should be systematically delivered if they are e-mail users.

Implications for management

- In order to implement the e-Re-Know in clinical care practice the e-Health in hospital supporting the use is required. Testing the knowledge not only by e-mail but in hospital as well might be appreciated by patients.
- Breast cancer patients in radiotherapy are only one part of health care customers. It might be appropriate to make it available through Internet to all citizens interested in the subjects. Thereafter, it might be valuable in benchmarking of the hospital.
- The e-Re-Know was used to improve knowledge of radiotherapy among patients. It might be essential in orientating new personnel or students in radiotherapy care as well.

Implications for further research

- Further research is needed to develop the evaluation of quality of RT care. The Good Nursing Care Scale for Patients (GNCS-P) instrument was used for the first time in radiotherapy. It could be recommended as an evaluation tool of quality of RT care for further testing. Repeating measures in different points might be able to show time effects in quality of care. In addition, national and international comparative research is needed.

- Further research is needed to develop the RT Knowledge Test. The test-retest data should be collected also at concluding the RT period and with bigger sample size to ensure the validity and reliability. The national and international comparative data is needed as well. Additionally it should be developed and tested to cover also the other dimensions of empowering knowledge.
- Although breast cancer patients treatments are often concluding to radiotherapy, time after might raise new knowledge expectations during follow up. Further research is needed to develop and test the e-Re-Know not only covering knowledge of radiotherapy but also other knowledge expectations during whole care pathway of breast cancer from diagnosis to follow up in primary health care and to rehabilitation in patient association.
- More research is needed to determine whether the effects of the e-Re-Know can be reproduced among people with different cancer types, diverse backgrounds and varying cultures.
- Today patients wish to interact with health care via new Internet technologies in the same way as with banks, travelling and social media. More research is needed in giving e-feedback knowledge more personally. New solutions as using voice, picture and interactivity should be developed and tested.

This study provided new knowledge of patient-centred quality of radiotherapy care and empowering patient e-education among cancer patients. Especially the e-Feedback knowledge of radiotherapy –intervention (e-Re-Know), i.e. knowledge test and feedback, was effective among patients with breast cancer. In health care, the growing number of cancer patients requires effective care. At the same time the population is aging, patients' knowledge level and their demands increase. Also the development of e-Health imposes challenges for future. Improving quality of care by new interventions and research among cancer patients should be continuous.

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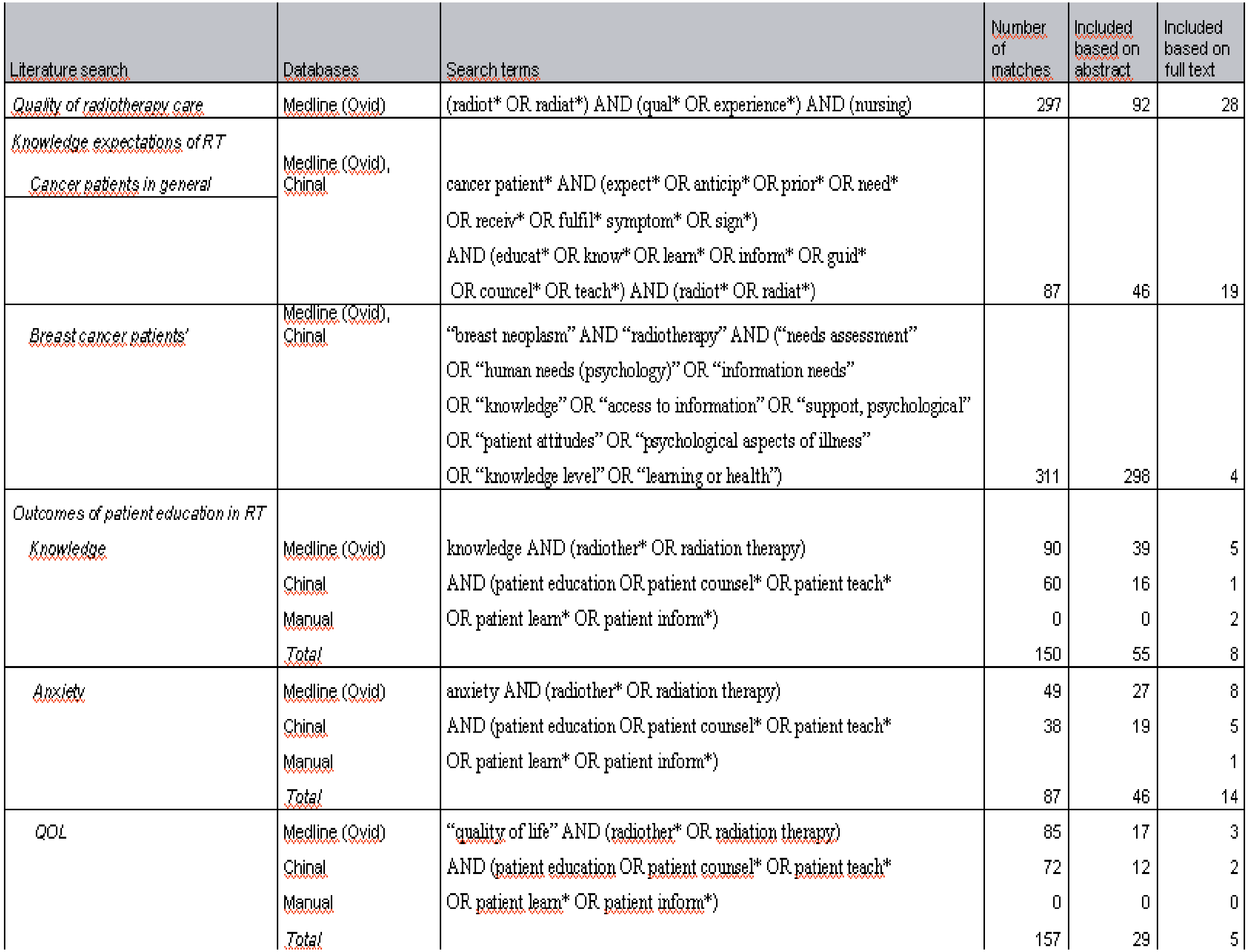
APPENDICES

Appendix 1. Literature search



Literature search	Databases	Search terms	Number of matches	Included based on abstract	Included based on full text
Quality of radiotherapy care	Medline (Ovid)	(radiot* OR radiat*) AND (qual* OR experience*) AND (nursing)	297	92	28
Knowledge expectations of RT					
Cancer patients in general	Medline (Ovid), Chinal	cancer patient* AND (expect* OR anticip* OR prior* OR need* OR receiv* OR fulfil* symptom* OR sign*) AND (educat* OR know* OR learn* OR inform* OR guid* OR councel* OR teach*) AND (radiot* OR radiat*)	87	46	19
Breast cancer patients'	Medline (Ovid), Chinal	"breast neoplasm" AND "radiotherapy" AND ("needs assessment" OR "human needs (psychology)" OR "information needs" OR "knowledge" OR "access to information" OR "support, psychological" OR "patient attitudes" OR "psychological aspects of illness" OR "knowledge level" OR "learning or health")	311	298	4
Outcomes of patient education in RT					
Knowledge	Medline (Ovid)	knowledge AND (radiother* OR radiation therapy)	90	39	5
	Chinal	AND (patient education OR patient counsel* OR patient teach*	60	16	1
	Manual	OR patient learn* OR patient inform*)	0	0	2
	Total		150	55	8
Anxiety	Medline (Ovid)	anxiety AND (radiother* OR radiation therapy)	49	27	8
	Chinal	AND (patient education OR patient counsel* OR patient teach*	38	19	5
	Manual	OR patient learn* OR patient inform*)			1
	Total		87	46	14
QOL	Medline (Ovid)	"quality of life" AND (radiother* OR radiation therapy)	85	17	3
	Chinal	AND (patient education OR patient counsel* OR patient teach*	72	12	2
	Manual	OR patient learn* OR patient inform*)	0	0	0
	Total		157	29	5

Appendix 2. The e-Re-Know

RINTASYÖPÄPOTILAAN e-TIETOPALAUTE SÄDEHOIDOSTA
Olette ystävällisesti ilmaisseet halukkuutenne osallistua tähän tutkimukseen vastaamalla e-Tietotestiin. Tämän e-Tietotestistä saadun palautteen tarkoituksena on lisätä rintasyöpäpotilaan tietoa sädehoidosta. Tavoitteena on kehittää syöpäpotilaiden ohjausta. Vastaaminen on vapaaehtoista. Tietonne pysyvät salassa ja niitä käsittelee vain tutkija. Pyytäkää tutkijalta lisätietoja, mikäli haluatte selventää jotain seikkaa.

e-Tietotestissä on sädehoitoa koskevia väittämiä, joiden oikeellisuutta toivomme Teidän arvioivan.
Pyydän kohteliaimmin Teitä osallistumaan toimimalla näin:
1. Valitkaa (klikkaamalla) alla oleva linkki ja siirrytte e-Tietotestin 1. väittämään.
2. Valitkaa mielestänne oikea vastaus; kyllä tai ei.
3. Vastattuanne saatte oikean vastauksen ja lisätietoa.
4. Valitkaa nuoli ja siirrytte seuraavaan väittämään.
5. Lopuksi kun olette vastannut 28. väittämään, vastauksenne siirtyvät automaattisesti tutkijalle.

Kiitos vastauksista! Vastausaika e-Tietotestiin päättyy päivää ennen sädehoidon aloitusta

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e-Tietopalaute sädehoidosta

Sädehoidon toteuttaminen

1 Sädehoito tuhoaa syöpäsoluja

Oikea vastaus: Kyllä

Sädehoito tuhoaa syöpäsoluja. Se vaikuttaa solujen jakautumisvaiheessa ja estää nopeasti jakautuvien syöpäsolujen kasvamisen ja jakautumisen edelleen. Sädehoito vähentää merkittävästi taudin uusiutumisen riskiä ja lisää elinaikaa.

2 Sädehoitoa annettaessa potilas on yksin hoitohuoneessa

Oikea vastaus: Kyllä

Sädetyksen aikana potilas on yksin hoitohuoneessa, mutta hoitajilla on kameroiden ja tietokoneen kautta näkö-, puhe- ja kuuloyhteys potilaaseen.

3 Sädehoito annetaan kehon radioaktiivisuuden lisäämiseksi

Oikea vastaus: Ei

Sädehoitoa ei anneta radioaktiivisuuden lisäämiseksi. Säteily ei jää potilaaseen eikä potilas ole säteilyvaarallinen ympärillään oleville.

4 Sädehoito toteutetaan laservalolla

Oikea vastaus: Ei

Sädehoitoa ei anneta laservalolla, vaan laservaloa käytetään potilaan asettelussa merkkivalona. Laservalo kohdistetaan potilaan iholla oleviin merkkeihin ja piirustuksiin oikean hoitoasennon löytämiseksi. Rintasyövän sädehoitoa annetaan kahdella eri säteilylajilla: fotoni- ja elektronisäteilyllä. Säteilyä annetaan sädehoitolaitteella eli lineaarikiihdyttimellä.

5 Sädehoitoa annetaan useammasta kuin yhdestä suunnasta

Oikea vastaus: Kyllä

Sädehoitoa annetaan useammasta kuin yhdestä suunnasta. Säteilykenttiä voi olla yksi tai useampia, ja niiden koko ja sijainti määritetään tapauskohtaisesti kasvaimen tyypin ja sairauden levinneisyyden mukaan. Antamalla hoitoa useammasta eri suunnasta, eri säteilylajeilla ja pienillä kerta-annoksilla vältetään terveen kudoksen sädettämistä ja autetaan sen paranemista.

6 Sädehoito tuntuu säteilytyksessä kipuna

Oikea vastaus: Ei

Säteilytystä ei tunne kipuna. Se ei myöskään haise tai maistu miltään.

7 Sädehoito uusitaan jos potilas on liikkunut

Oikea vastaus: Ei

Sädehoitoa ei voi uusia, jos potilas on liikkunut sädetyksen aikana. Sädehoitoa annetaan sädehoitolaitteella tarkasti laskettuina annoksina, eikä kokonaishoitoannosta voi ylittää uudella sädetyksellä. Jotta sädetys osuu suunnitellulle alueelle, on tärkeää että potilas pysyy sädehoidon aikana tarkasti paikallaan ja samassa asennossa kuin suunnittelussa. Hoidon aikana potilas voi hengittää normaalisti kevyesti. Paras hoitoasento on sellainen, jonka potilas voi toistaa jokaisella hoitokerralla.

Sädehoidon haittavaikutukset sädehoitojakson aikana

8 Haittavaikutukset esiintyvät yksilöllisesti.

Oikea vastaus: Kyllä

Haittavaikutusten esiintyminen on hyvinkin yksilöllistä. Sädehoidon haittavaikutusten fyysiseen ilmaantumiseen vaikuttaa säteilyannos, hoitoajan pituus ja se, mitä kehon osaa sädetetään. Jotkut välttyvät kokonaan haittavaikutuksilta. Haittavaikutuksien psyykkinen kokeminen ja väsyminen on myös yksilöllistä.

9 Haittavaikutukset rajoittuvat sädetettävälle alueelle.

Oikea vastaus: Kyllä

Haittavaikutukset rajoittuvat sädetettävälle alueelle eli sädehoitokenttiin, jotka on suunniteltu kasvaimen koon ja paikan mukaan. Sädehoidon tavoitteena on tuottaa kasvaimeen riittävä säteilyannos, joka saa aikaan toivotun parantavan tehon niin, että hoidon haittavaikutukset pysyvät mahdollisimman vähäisinä tai ainakin hyväksyttävinä.

10 Haittavaikutukset esiintyvät jo ensimmäisellä hoitokerralla.

Oikea vastaus: Ei

Haittavaikutuksia ei esiinny ensimmäisellä hoitokerralla. Varhaiset haittavaikutukset ilmenevät yleensä 2-3 viikkoa hoidon aloituksesta. Sen jälkeen ne voivat jatkua jonkin aikaa hoidon jälkeenkin, mutta asettuvat itsestään kuukauden kuluttua. Sädehoidon pitkäaikaiset haittavaikutukset voivat ilmaantua kuukauden tai useamman vuodenkin jälkeen sädehoidon loppumisesta.

11 Haittavaikutukset havaitaan tavallisimmin iholla.

Oikea vastaus: Kyllä

Tavallisimmin rintasyövän sädehoidon haittavaikutukset havaitaan hoitoalueen iholla. Ne ovat usein melko vähäisiä ja potilaat voivat käydä hoidon aikana työssä.

12 Haittavaikutukset havaitaan ensimmäisenä ihokarvojen lähtemisenä.

Oikea vastaus: Ei.

Ensimmäinen haittavaikutus ei ole ihokarvojen lähteminen. Ensimmäiset haittavaikutukset ilmenevät ihon nopeasti uudistuvissa soluissa pistelynä, kuumotuksena ja turvotuksena. Ihokarvat lähtevät vain sädetettävästä kainalosta. Solunsalpaajahoitojen vuoksi hiukset voivat lähteä, mutta ne kasvavat takaisin sädehoitojakson aikana.

13 Haittavaikutukset lisäävät limakalvojen kuivumista

Oikea vastaus: Ei

Haittavaikutukset eivät lisää limakalvojen kuivumista. Jos sädehoitoalue on rinnan sädetyksen lisäksi kaulan alueella sädetys vaikuttaa mahdollisesti nielun limakalvon ärtymisenä ja nielemisvaikeutena. Sukupuolielinten limakalvojen kuivuminen johtuu ennen sädehoitoa saaduista solusalpaajahoidoista tai hormonimuutoksista. Sukupuolielinten limakalvojen kuivumisongelmiin voi kysyä neuvoa seksuaalineuvojalta tai muulta hoitohenkilökunnalta.

14 Haittavaikutukset aiheuttavat keuhkokuumetta

Oikea vastaus: Ei

Haittavaikutukset eivät aiheuta keuhkokuumetta. Keuhkotulehdusta voi tulla muutaman kuukauden kuluttua hoidosta. Se ilmenee sitkeänä yskänä. Oireet ovat ohimeneviä, ja niitä voidaan lievittää lääkehoidolla. Keuhkojen ja hermojen kudoksia säästetään jakamalla kokonaishoitoannos pienempiin kerta-annoksiin. Sädehoito ei yksinään alenna veriarvoja eikä lisää sairastumista.

Sädehoidon haittavaikutusten hoito

15 Hoitoaluetta pestään saippualla

Oikea vastaus: Ei

Hoitoaluetta ei saa pestä saippualla, koska se kuivattaa ja rasittaa ihoa. Iho tulisi suihkuttaa haalealla vedellä päivittäin. Pesun jälkeen iho kannattaa kuivata kevyesti taputellen. Sädehoidossa hoitoalueen tulee olla puhdas ja kuiva. Ihoa saa rasvata (ei rasvaa, vaan kosteuttavaa perusvoidetta) vasta jokaisen sädehoitokäynnin jälkeen ohuelti.

16 Hoitoaluetta suojataan saunassa löylyltä

Oikea vastaus: Kyllä

Sädehoitojakson aikana ihoa tulisi suojata löylyltä, auringolta, voimakkaalta hikoilulta ja kloorivedeltä, kemikaaleilta ja hankaukselta. Hoitojen jälkeen ihoa tulisi suojata näiltä muutaman viikon ajan. Auringon ottamista sädehoidetulle alueelle ei suositella seuraavan vuoden aikana.

17 Hoitoalueen hikoilua vähennetään käyttämällä deodoranttia

Oikea vastaus: Ei

Hoitoalueen iholla ei saa käyttää deodoranttia tai hajuvettä. Hikoiluongelmia voi lievittää suihkuttamalla hoitoaluetta usean kerran päivässä. Myös löysät ja hengittävät vaatteet ehkäisevät hikoilua.

18 Rikkoutuneelle iholle laitetaan perusvoidetta

Oikea vastaus: Ei

Rikkoutuneelle iholle ei saa laittaa voidetta. Jos iho rikkoontuu hoidon aikana, ihon päivittäiseen hoitoon antaa ohjeet joko sädehoitokoneen omahoitaja tai toiset hoitajat, ja tarvittaessa varataan aika lääkärin vastaanotolle.

19 Ihon kuumotusta lievitetään kipulääkkeellä

Oikea vastaus: Kyllä

Ihon kuumotusta voi lievittää kipulääkkeellä. Ihon kuumotuksen rauhoittamiseksi voi aloittaa kamomillateehaudehoidon, mikäli potilaalla ei ole mykerökukka-allergiaa (päivänkakkara ja pietaryrtti). Ohjeet hoitoon saa hoitokoneen hoitajilta. Ihon kuumotusta lievittävät myös ilmakylvyt, puuvillaisten vaatteiden käyttö ja rintaliivien ja -proteesin käytön vähentäminen.

20 Ihon kutinaa helpotetaan allergialääkkeellä

Oikea vastaus: Kyllä

Ihon kutinaa voi helpottaa allergialääkkeellä. Kutisevaa ihoa ei saa raapia. Yöllä raapimista voi ehkäistä pitämällä puuvillakäsineitä.

21 Ärtynyttä ihoa hoidetaan keittosuolahauteella

Oikea vastaus: Kyllä

Ärtynyttä ihoa voi hoitaa keittosuolahauteella. Sen voi laittaa myös rakkulaiselle iholle. Hoitajat hoitokoneella neuvovat potilasta sopivan keittosuolahauteen teossa ja käytössä.

Elintavat sädehoitojakson aikana

22 Lepääminen kuuluu päivittäiseen rutiiniin

Oikea vastaus: Kyllä

Lepääminen kuuluu päivittäiseen rutiiniin sädehoitojakson aikana. Sädehoitojakson aikana useimmat potilaat ovat väsyneempiä kuin yleensä. Sairastumisen aiheuttama huoli tulevaisuudesta, mielialan vaihtelut ja tulevaisuuden pelko ovat luonnollisia reaktioita sairastumiseen. Muuten sädehoitojakson aikana tulisi elää totuttujen päivärutiinien mukaan. Lepäämiseen ja nukkumiseen liittyviin asioihin voi kysyä neuvoa henkilökunnalta.

23 Liikunta vähentää väsymystä

Oikea vastaus: Kyllä

Liikunta vähentää väsymystä ja edistää kehon paranemista. Sädehoitojakson aikana voi harrastaa liikuntaa kuten aikaisemminkin, omien voimien mukaan ja oma jaksaminen huomioonottaen. Liikunta on suositeltavaa, mutta hikinen iho tulisi kuitenkin suihkutella heti liikunnan jälkeen ja välttää uintia uimahallien klooripitoisessa vedessä.

24 Sädehoito aiheuttaa rajoituksia seksuaaliselle kanssakäymiselle

Oikea vastaus: Ei

Sädehoito ei aiheuta rajoituksia seksuaaliselle kanssakäymiselle, hellyydelle ja läheisyydelle eikä rakastelulle. Mahdollisimman täysipainoinen seksuaalinen elämä tukee selviytymistä. Sairauden aiheuttamat tunteet ja oireet, jotka aiheuttavat ongelmia seksuaalielämään, minäkuvaan, mahdolliseen parisuhteeseen tai perheeseen ovat normaaleja. Niistä on hyvä keskustella seksuaalineuvojan kanssa.

25 Alkoholin nauttiminen lisää sädehoidon aiheuttamia nielemisvaikeuksia.

Oikea vastaus: Kyllä

Alkoholin nauttiminen lisää sädehoidon aiheuttamia nielemisvaikeuksia. Se on sallittua kohtuullisesti käytettynä paitsi jos sädehoidosta on aiheutunut palan tunnetta kurkussa, jolloin kaikkia väkeviä juomia tulisi välttää. Rintasyövän uusiutumisriski on korkeampi, kohonnut säännöllisesti liikaa alkoholia käyttävillä. Alkoholin käytön riskitestin voi tehdä osoitteessa www.paihdelinkki.fi.

26 Tupakointi vähentää sädehoidon tehoa

Oikea vastaus: Kyllä

Tupakointi sädehoitojakson aikana vähentää sädehoidon tehoa, koska tupakointi alentaa solujen hapekkuutta. Sädehoito vaikuttaa hapekkaisiin soluihin aiheuttamalla solun kemiallisia muutoksia biologisesti tärkeissä makromolekyyleissä. Lisäksi tupakointi huonontaa ihon verenkiertoa ja lisää haittavaikutuksia. Tupakoinnin nikotiiniriippuvuustestin voi tehdä osoitteessa www.stumppi.fi.

27 Sädehoidon aikana on käytettävä vitamiinivalmisteita

Oikea vastaus: Ei

Sädehoidon aikana ei suositella käytettäväksi vitamiinivalmisteita vaan vitamiinit tulisi saada monipuolisesta ruokavaliosta. Vitamiinivalmisteiden käytön ei ole todettu vähentävän rintasyöpäriskiä. Monipuolisessa ruokavaliossa tulisi syödä päivittäin puoli kiloa kasviksia ja hedelmiä ja korvata kovat rasvat pehmeillä rasvoilla. Nopeasti imeytyviä sokereita voi välttää ja suosia kokojyvätuotteita, kuten puuroa ja ruisleipää sekä käyttää vähän suolaa. Runsas vedenjuominen pitää ihon aineenvaihdunnan hyvänä ja parantaa ihon kuntoa. Ruokavaliotestin voi tehdä osoitteessa www.pienipaatospaivassa.fi.

28 Hampaiden pesu lisää vastustuskykyä

Oikea vastaus: Kyllä

Hampaiden pesu lisää vastustuskykyä. Sädehoito rasittaa kehon normaalia toimintaa ja mahdolliset ongelmat hampaissa alentavat yleiskuntoa. Suutulehdusta voi ennaltaehkäistä pitämällä hyvää huolta suuhygieniasta. Hampaat harjataan pehmeällä hammasharjalla ja fluoripitoisella hammastahnalla. Myös hammaslankaa kannattaa käyttää.

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