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INTERNET-BASED BREAST CANCER PATIENT'S PATHWAY AS AN EMPOWERING PATIENT EDUCATIONAL TOOL

by

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enkä kirjastostakaan.

Irene Kuusimäki, Matkalla uuteen minuuteen, Painola, Kaarina 2006.

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Internet-based breast cancer patient’s pathway as an empowering patient educational tool
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ABSTRACT

This three-phase study was conducted to examine the effect of the Breast Cancer Patient’s Pathway program (BCPP) on breast cancer patients’ empowering process from the viewpoint of the difference between knowledge expectations and perceptions of received knowledge, knowledge level, quality of life, anxiety and treatment-related side effects during the breast cancer treatment process. The BCPP is an Internet-based patient education tool describing a flow chart of the patient pathway during the breast treatment process, from breast cancer diagnostic tests to the follow-up after treatments. The ultimate goal of this study was to evaluate the effect of the BCPP to the breast cancer patient’s empowerment by using the patient pathway as a patient education tool. In phase I, a systematic literature review was carried out to chart the solutions and outcomes of Internet-based educational programs for breast cancer patients. In phase II, a Delphi study was conducted to evaluate the usability of web pages and adequacy of their content. In phase III, the BCPP program was piloted with 10 patients and patients were randomised to an intervention group (n=50) and control group (n=48).
According to the results of this study, the Internet is an effective patient education tool for increasing knowledge, and BCPP can be used as a patient education method supporting other education methods. However, breast cancer patients’ perceptions of received knowledge were not fulfilled; their knowledge expectations exceed the perceived amount of received knowledge. Although control group patients’ knowledge expectations were met better with the knowledge they received in hospital compared to the patients in the intervention group, no statistical differences were found between the groups in terms of quality of life, anxiety and treatment-related side effects. However, anxiety decreased faster in the intervention group when looking at internal differences between the groups at different measurement times. In the intervention group the relationship between the difference between knowledge expectations and perceptions of received knowledge correlated significantly with quality of life and anxiety. Their knowledge level was also significant higher than in the control group. These results support the theory that the empowering process requires patient’s awareness of knowledge expectations and perceptions of received knowledge.
There is a need to develop patient education to meet patients’ perceptions of received knowledge, including oral and written education and BCPP, to fulfil patient’s knowledge expectations and facilitate the empowering process. Further research is needed on the process of cognitive empowerment with breast cancer patients. There is a need for new patient education methods to increase breast cancer patients’ awareness of knowing.

Keywords: empowerment, patient education, pathway, Internet, breast cancer patient

Anne M Ryhänen
Internet-pohjainen rintasyöpäpotilaanpolku voimavaraistavan potilasohjauksen välineenä
Hoitotieteen laitos, Lääketieteellinen tiedekunta, Turun yliopisto, Turku
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TIIVISTELMÄ

Tässä kolmivaiheisessa tutkimuksessa tarkasteltiin Rintasyöpäpotilaanpolku (RSPP) -ohjelman vaikuttavuutta rintasyöpäpotilaan tiedollisen voimavaraistumisen, tiedontason, elämänlaadun, ahdistuneisuuden ja hoitoon liittyvien sivuvaikutusten näkökulmista rintasyövän hoitoprosessin aikana. RSPP-ohjelma on Internet-pohjainen potilasohjausmenetelmä, joka perustuu vuokaavioon rintasyövän hoitoprosessista. Menetelmä kattaa hoitoprosessin rintasyövän diagnostisista testeistä aina hoitojen jälkeiseen seurantaan. Tutkimuksen tavoitteena oli selvittää RSPP-ohjelman vaikuttavuutta rintasyöpäpotilaan tiedollista voimavaraistumista tukevana potilasohjausvälineenä.

Tutkimuksen ensimmäisessä vaiheessa tehtiin systemoitu kirjallisuuskatsaus aiempien Internet pohjaisten potilasohjausohjelmien ja niiden vaikuttavuuden selvittämiseksi. Tutkimuksen toisessa vaiheessa RSPP-ohjelman käytettävyyttä ja sisältöä arvioitiin delfi-tutkimuksella. Tutkimuksen kolmannessa vaiheessa tutkimusasetelma pilotoitiin (n=10) ja rintasyöpään sairastuneet potilaat satunnaistettiin koe- ja kontrolliryhmiin (n=50 ja n=48).

Tutkimustulosten mukaan Internet voi olla tehokas potilasohjausväline tiedon lisäämiseksi ja RSPP-ohjelma sopii potilasohjausvälineeksi muiden ohjausmenetelmien tueksi. Rintasyöpäpotilaiden tiedolliset odotukset eivät täyttyneet, vaan heidän tiedolliset odotuksensa ovat suuremmat kuin kokemuksensa heille välitetystä tiedosta. Vaikka kontrolliryhmän potilaat kokivat tiedollisten odotusten täyttyvän paremmin sairaalassa saamastaan tiedosta kuin koeryhmän potilaat, tilastollisesti merkittäviä eroja ryhmien välillä ei löytynyt elämänlaadun, ahdistuksen ja hoidoista johtuvien sivuvaikutusten osalta Kuitenkin ahdistus väheni nopeammin koeryhmässä tarkasteltaessa ahdistuneisuutta eri mittauskertojen välillä. Koeryhmässä tiedollinen voimavaraistuneisuus korreloi tilastollisesti merkittävästi elämänlaadun ja ahdistuksen kanssa. Koeryhmässä rintasyöpään liittyvän tiedon taso oli merkittävästi korkeampi hoidon päättymisen jälkeen kuin kontrolliryhmässä. Tulokset tukevat teoriaa voimavaraistumisen prosessista, mikä edellyttää potilaan tietoisuutta tiedollisista odotuksistaan ja niiden täyttymisestä.

Potilaiden tiedollisessa ohjauksessa on kuitenkin vielä parannettavaa sekä suullisen ja kirjallisen että RSPP-ohjelman osalta, jotta potilaiden tiedolliset odotukset täyttyisivät ja mahdollistaisivat potilaan voimavaraistumisen. Lisätutkimusta tarvitaan tiedollisen voimavaraistumisen prosessista rintasyöpäpotilailla. Uusia potilasohjaus-menetelmiä tarvitaan potilaan tietoisuuden lisäämiseksi.

Avainsanat: voimavaraistuminen, potilasohjaus, hoitopolku, Internet, rintasyöpäpotilas

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LIST OF ABBREVIATIONS

ANOVA	Analysis of Variance
BCPP	Breast Cancer Patient Pathway
EIPPE	Evaluating Internet Page of Patient Education
HPKE	Hospital Patient Knowledge Expectations
HPRK	Hospital Patient Received Knowledge
KTBC	Knowledge Test for Breast Cancer Patient
PRKE	Pathway-Related Knowledge Expectations
PRRK	Pathway-Related Received Knowledge
QOL	Quality of Life
RCT	Randomised Controlled Trial
RSPP	Rintasyöpäpotilaanpolku-ohjelma
SAI	State Anxiety Inventory
SAT	Satisfaction of Patient education
STAI	State-Trait Anxiety Inventory

LIST OF APPENDICES

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 Ryhänen AM, Siekkinen M, Rankinen S, Korvenranta H & Leino-Kilpi H. 2010. The effects of Internet or interactive computer-based patient education in the field of breast cancer: a systematic literature review. Patient Education and Counseling. Volume 79, Issue 1, 5–13.

II Ryhänen AM, Rankinen S, Tulus K, Korvenranta H & Leino-Kilpi H. 2012. Internet based patient pathway as an educational tool for breast cancer patients. International Journal of Medical Informatics. Volume 81, Issue 4, 270–278.

III Ryhänen AM, Rankinen S, Siekkinen M, Saarinen M, Korvenranta H & Leino-Kilpi H. 2012. The impact of an empowering Internet based Breast Cancer Patient Pathway program to breast cancer patients' knowledge: A randomised control trial. Patient Education and Counseling. Volume 88, Issue 2, 224–231.

IV Ryhänen AM, Rankinen S, Siekkinen M, Saarinen M, Korvenranta H & Leino-Kilpi H. 2012.The impact of an empowering Internet based Breast Cancer Patient Pathway program on breast cancer patients' clinical outcomes. A randomized controlled trial. Journal of Clinical Nursing. Accepted.

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1 INTRODUCTION

Breast cancer has the highest incidence rate among women's cancers and it is the second leading cause of women's cancer deaths (DeSantis et al. 2011a, 2011b). In 2008 it was estimated that worldwide, 1.38 million women were diagnosed with breast cancer, accounting for around a tenth (10.9%) of all new cancers and nearly a quarter (23%) of all female cancer cases (Globocan 2008). In Finland, more than 4,400 women are diagnosed with breast cancer annually, its incidence being 89.3 per 100,000. Breast cancer is strongly related to age, with only 3% of all breast cancers occurring in women under 40 years of age. The incidence of breast cancer is 13% in women aged 40–50 years, 27% in those aged 50–60, 28% in those aged 60–70, 17% in those aged 70–80, and 12% in those aged 80 or more. (Finnish Cancer Registry 2011.) Breast cancer patients experience a loss of control of life after breast cancer diagnosis, which is why patient education is needed to support patients' empowering process (Lacey 2002, Bulsara et al. 2006).

Today, people demand knowledge about health, disease and health care. This situation requires healthcare organisations to develop continuously new methods to improve patient education (Commission of the European Communities 2007). The National Institute for Health and Welfare recommends that information technology should be used increasingly in the area of health care (Ministry of Social Affairs and Health 2001, 2003). Earlier studies show that the less patients' perceptions of received knowledge are met the more likely they are to seek information from the Internet (Lee & Hawkins 2010). In this study a new patient education method, the Breast Cancer Patient Pathway (BCPP) program, was developed and tested with newly diagnosed breast cancer patients.

With patient education, patients can be enabled to influence their own lives. The aim of patient education is to increase patients' knowledge about their health problems. Patients can be supported by patient education methods, helping them to become empowered (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999, Falk-Rafael 2001). Empowerment can be seen as a sense and overall capacity to control health problems and factors related to them, as well as feeling well-balanced and strong, and able to act in problem situations. With empowering knowledge, the patient can be empowered with her health problems and be enabled to participate actively in decisions about her care. (Leino-Kilpi et al. 1999.)

The empowering process is based on cognitive knowledge (Leino-Kilpi et al. 2005, Heikkinen 2011). The results of the empowering process include better quality of life (Funnell et al. 2004, Corrigan et al. 1999, Falk-Rafael 2001, Leino-Kilpi et al. 2005), self-management (Ellis-Stoll & Popkess-Vawter 1998, Anderson et al. 2000), a sense of self-control (Kettunen et al. 2001), less anxiety and control over life situation in spite of illness (Treacy & Mayer 2000). For example, breast cancer patients can be more empowered and have a better quality of life if they receive knowledge that helps them manage the side effects of treatment (Golant et al. 2003).

This study is based on the theory of cognitive empowerment, which includes bio-physiological, functional, experiential, ethical, social and financial dimensions (Leino-Kilpi et al. 1998, 1999, 2005, Heikkinen 2011). The study population comprised breast cancer patients, because in Finland the treatment of breast cancer is based on a common regime and breast cancer patient's pathway was well suited to this study. Earlier studies show that breast cancer patients seek knowledge from the Internet (Pereira et al. 2000, Meric et al. 2002, Satterlund et al. 2003, Teo et al. 2005, Dolinsky et al. 2006, Shaw et al. 2006a, Dubois & Loiselle 2009, Balka et al. 2010, Afshari et al. 2011, Leino 2011), which is why breast cancer patients should also be able to educate via the Internet. The use of the Internet is one possible patient education method to empower patients (Gustafson et al. 1999, Rager 2003, Høybye et al. 2005, eHealth ERA 2007a, 2007b, 2007c).

The research process consisted of three phases. In the first phase (2007), a systematic literature review for clarifying the outcomes of interactive computer and Internet-based educational programmes for breast cancer patients was carried out. In the second phase (2007–2008), a Delphi study was carried out and the BCPP programme was given its final form based on the Delphi study. In the third phase the study design was piloted and a randomised control trial of patient education was implemented testing the outcomes of an empowering education intervention from January 2008 to December 2010.

The purpose of this study was to find out how the usage of the BCPP program affects breast cancer patients' empowering process from the viewpoint of cognitive outcomes (knowledge expectations, perceptions of received knowledge, the difference between knowledge expectations and perceptions of received knowledge, knowledge level) and clinical outcomes (quality of life, anxiety and treatment-related side effects). The ultimate goal of this study was to evaluate the effect of the BCPP program to the breast cancer patient's empowerment by using the patient pathway as a patient education tool.

2 BACKGROUND

In the following paragraphs the main concepts of the study and literature in the field will be reviewed (Figure 1). First, patients undergoing breast cancer treatment, patient pathway, empowerment, patient education and empowering patient education will be defined as the main concepts of the study. Second, the results of the literature review will be reviewed (up to 2008 in Paper I) and updated (from 2009 to 2012) in this chapter.

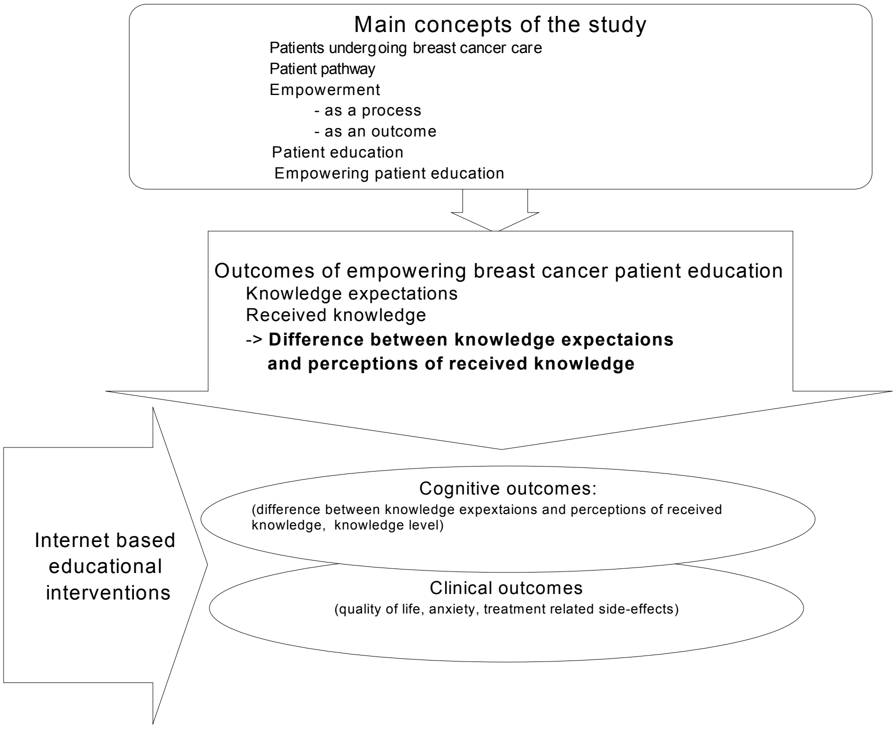


Figure 1. The theoretical background of the study.

2.1 Main concepts of the study

In Finland the **treatment of breast cancer** is based on a uniform set of national recommendations of the Current Care Guidelines, known as “rintasyövän käypähoitosuositus” in Finnish (Finnish Breast Cancer Group (FBCG) 2009). Surgery is usually the first treatment for early breast cancer. Breast-conserving surgery ranges from lumpectomy or wide local excision to quadrantectomy, in which about a quarter of the breast is removed. Total mastectomy means that all breast tissue is removed. After surgery a treatment plan is drawn up with one or more specific treatments intended to target the cancer cells in different ways and reduce the risk of future breast cancer recurrence. If chemotherapy is going to be part of the care, it is often given following surgery. Chemotherapy for breast cancer is usually given as a series of treatments every two to four weeks over a period of four to six months. It is given to weaken and destroy cancer cells in the body, including cells at the original cancer site and any cancer cells that may have spread to another part of the body. (FBCG 2009.) Radiation therapy usually follows surgery and chemotherapy. Treatment is given regularly over a period of time to have the greatest effect on the cancer cells while limiting the damage to normal cells. It is a highly targeted and effective way to destroy cancer cells in the breast that may stick around after surgery (Goldhirsch et al. 2001, 2003, FBCG 2009). Hormonal therapy is often started after the other treatments have been given if the cancer is hormone-receptor positive. It works in two ways: by lowering the amount of the hormone oestrogen in the body and by blocking the action of oestrogen on breast cancer cells. Hormone therapy can be used alone as a treatment for breast cancer, for example for women who have other illnesses or who are unable to have surgery or radiotherapy. (FBCG 2009.) Targeting therapy is the name for a group of drugs that block the growth and spread of cancer by interfering with the biology of the cancer cells; they are usually given in combination with chemotherapy (FBCG 2009, Goldhirsch et al. 2007, Goldhirsch et al. 2009).

There are substantial short-term side effects from breast cancer treatments. The most frequently encountered short-term side effects during chemotherapy treatment are emesis, nausea, stomatitis, alopecia, myelosuppression, thromboembolism, neuropathy and fatigue (Partridge et al. 2001, Ridner 2005, Mulders et al. 2008, Fu & Rosedale 2009, Rosedale & Fu 2010, Tofthagen 2010, Cantarero-Villanueva et al. 2011). Subjective breast pain, hyperpigmentation of the skin, breast tissue fibrosis and telangiectasia are side effects of radiotherapy. Skin reactions and tiredness are also common. (Porock et al. 1998, Ott et al. 2007, Sharp et al. 2011, Binkley et al. 2012.) Breast cancer patients are afraid of treatments because of the side effects (Halkett et al. 2010). Wengstrom et al. (2001) found that breast cancer patients actively sought information to reduce the fears they had about radiotherapy. Breast cancer patients express strong, unmet needs for education, information, and intervention for side effects (Collins et al. 2004, Lee & Hawkins 2010, Levangie et al. 2010, Binkley et al. 2012).

A concept of "**pathway**" has been described by 17 different terms (De Luc 2001). The most common terms are care pathway, clinical pathway, critical pathway, integrated care pathway and care map. In addition, many other terms are used to indicate this concept, such as clinical progression, clinical outcomes, care protocol, anticipated recovery pathway, care profile, and collaborative care plan. In their study de Bleser et al. (2006) later found 84 different definitions that were used to describe the concept of pathways.

Pathways are seen as a tool to improve the quality of care, streamline the care given, and ensure that clinical care is based on the latest evidence and research (De Luc 2000). A clinical pathway can be seen as a method for patient care management of a well-defined group of patients during a well-defined period of time (de Bleser et al. 2006). In this study a **patient pathway** is a patient education tool that maps or charts the expected course of treatment from diagnosis to the end of the treatment period. Patient pathways are similar to critical pathways but differ in their purpose and goals. The purpose of patient pathway is to provide knowledge related to patient care and treatment. The primary goal of patient pathway is to facilitate patient education. (Clarke 2002.) In this study patient pathway (BCPP) is an Internet-based educational program that includes knowledge to empower the patient during the breast cancer caring and treatment process, starting at diagnosis and ending with the follow-up of breast cancer. BCPP gives an outline of what is likely to happen on the patient's journey and is used for patient education. In the start page of BCPP this is illustrated by a diagrammatic picture from hospital visits including time information and links to relevant web pages. The BCPP helps patients to orientate towards the future with breast cancer care. Breast cancer patients find it important to know what is going to happen next in their treatment (Saares & Suominen 2005, Leino 2011). This program is based on the idea that knowing their pathway after cancer diagnosis helps patients to understand the content of patient education and to use the knowledge in their own treatment and care, i.e., supports the empowerment of patients.

The **concept of empowerment** is multidimensional and has been used in different ways, perspectives and disciplines since the 1980s. A few concept analyses have been conducted in nursing science, but they have been made from different perspectives, as a composite of attributes relating to the client, the nurse or attributes relating to both the client and the nurse. (Gibson 1991, Hawks 1992, Skelton 1994, Rodwell 1996, Ellis-Stoll & Popkess-Wawter 1998, Ryles 1999, Kuokkanen & Leino-Kilpi 2000, Powers 2003, Finfgeld 2004, Leino-Kilpi et al. 2005, Aujoulat et al. 2007, Bradbury-Jones et al. 2008.)

The concept of empowerment can be classified into four groups on the basis of their theoretical orientation: critical social theory, social psychological theory and organisation theory - theories underpinning most studies on empowerment - and poststructuralism (Kuokkanen & Leino-Kilpi 2000, Kuokkanen 2003, Bradbury-Jones et al. 2008). In critical social theory and psychological theory empowerment emphasizes individuals' acts towards themselves in order to increase empowerment, while in dialogue people reflect the intentionality and meaning of phenomena, such as sickness, to be able to make conscious choices (Rappaport 1984, Wallerstein & Bernstain 1988). In organisational theory power is based on the structure of organisation (Kuokkanen & Leino-Kilpi 2000). From a poststructural perspective disciplinary power and knowledge/power relationships are crucial in critiquing power and empowerment (Bradbury-Jones et al. 2008). However, there are some attributes to define empowerment in all theoretical orientations from the viewpoint of nursing science.

Empowerment can be seen as being associated as a process with growth and development (Feste & Anderson 1995, Funnell 2004), being a process of recognizing, promoting and enhancing patients' abilities to meet their own needs, solving their own problems and mobilising the necessary resources in order to feel being in control of their own lives. (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al.

1999, Björklund et al. 2008.) The process requires accurate knowledge, active listening and participation to facilitate the opportunity for health orientated behaviour and self-determination (Ellis-Stoll & Popkess-Vawter 1998). In the active development process, patients attempt to use their unused resources. This calls for awareness, competence, knowledge and active participation on the part of the patients. (Falk-Rafael 2001). Empowerment can be seen both as a process and an outcome (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999), and it cannot be measured in and of itself (Rappaport 1984).

Knowledge is the key for gaining control over one's situation. The patient understands with knowledge and consciousness his/her state of change, which improves his/her experience of self-control (Kettunen et al. 2001, 2002a, 2002b, 2006). Empowering knowledge helps patients to be cognitively empowered. An increased knowledge level (Wong et al. 2004, Suhonen & Leino-Kilpi 2006, Johansson et al. 2007, Heikkinen 2011) leads to better sufficiency of knowledge, which is the outcome of empowering patient education (Heikkinen 2011) as well as positive learning experiences (Johansson et al. 2007), and an experience of being better informed (Under-Kraan et al. 2009). Empowering knowledge increases patient's capacity to think critically and make informed decisions (Anderson & Funnell 2010); however, this requires awareness, freedom, choice and responsibility on the part of the patient (Feste & Anderson 1995). Patients have a possibility to be cognitively empowered when the difference between knowledge expectations and perceptions of received knowledge is positive (Leino-Kilpi et al. 2005, Rankinen et al. 2007).

Cognitively empowered patients are able to reframe situations in a positive way and take more ownership for their health. They are ready to make healthier choices themselves based on their increased knowledge and skills, to assume responsibility for their choices (Funnell et al. 1991, Rodwell 1996, Falk-Rafael 2001, Viklund & Wikblad 2007) and have control over their life situation in spite of illness (Treacy et al. 2000). This promotes patient's independent health promoting behaviours, well-being and self-management (Feste & Anderson 1995, Ellis-Stoll & Popkess-Vawter 1998, Anderson et al. 2000, 2001, 2003, Tsay &Hung 2004, Wong et al. 2004, Anderson & Funnell 2005, 2010), enabling them to take control over the factors affecting their health (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999, Viklund & Wikblad 2007, Björklund et al. 2008). Empowerment can be seen as sense and overall capacity to control health problems and things related to them, and of feeling strong and self-reliant, with the ability to reinterpret the illness (Mok 2001). With empowerment, the patient is able to parse her/his healthiness and healthcare (Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999). The positive result of empowering patient education can be a better quality of life (Funnell et al. 1991, Gibson 1991, Corrigan 1999, Falk-Rafael 2001, Leino-Kilpi et al. 2005), less anxiety and increased self-care (Chandler 1992).

The concept of **patient education** has many related concepts, such as patient teaching, learning, counselling, guiding and informing. According to the Encyclopaedia of Nursing & Allied Health (2002), "Patient education involves helping patients become better informed about their condition, medical procedures, and choices they have regarding treatment." Patient education helps individuals to take better care of themselves and make informed decisions regarding their health problem (Leino-Kilpi et al. 1993, Bellamy 2004). Patient education is the process of informing a patient about a health matter to secure informed consent, patient cooperation, and a high level of patient compliance. Patient education is based on patient's need and motivation to learn, and goals are mutually set with the patient (Redman 2007).

The concept of patient education has shifted from narrowly focused and medically oriented patient teaching to support of patient empowerment and participation in more comprehensive domains of health promotion and disease prevention, and from unplanned, fragmented and informal delivery of information to well-planned and carefully implemented systematic programmes that complement informal teaching of doctors and nurses. (Yoon et al. 2005.) The aim of patient education is to improve patient's knowledge and competence about her health problems. With knowledge and competence, the patient can be empowered with her health problems and be enabled to participate in decisions about her care. (Leino-Kilpi et al. 1999, Dodson et al. 2008.) Knowledge can thus be understood as a basic element in the empowering process (Leino-Kilpi et al. 2005, Heikkinen 2011).

Interventions are constructed to improve the effectiveness of patient education. Face-to-face interventions are a commonly used method to educate patients, but they are not cost-effective (Redman 1997). However, interventions usually include different educational methods, such as group interventions, lectures, videos, written educational material (Loveman et al. 2003, Durbin et al. 2010, Sakellari et al. 2010), educational programmes (Weingarten et al. 2002, Jonker et al. 2009, Du & Yuan 2010, May 2010) and computer-based interventions, e.g. the Internet (Fox 2009, Samoocha et al. 2010). The duration of interventions or the number of sessions can also differ from one session to ten sessions, or even years (Loveman et al. 2003, Johansson et al. 2004a, Suhonen & Leino-Kilpi 2006, Conn et al. 2008, Wofford et al. 2008, Walters et al. 2010).

In **empowering patient education** the patient is in the focus of the education process (Poskiparta et al. 2001), and the patient's role is subject as learner (Wallenstain & Bernstain 1988). The need for patient education arises from the patient's own knowledge expectations (Poskiparta et al. 2001). Health professionals cannot empower the patient; they can only facilitate the patient's empowerment with patient education. Empowerment underlines patient's resources and health professionals' role in supporting it (Gibson 1991, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999, Falk-Rafael 2001, Kettunen 2001, Kettunen et al. 2002, Hage & Lorensen 2005, Homan-Helenius 2005). The aim of empowering patient education is to help patients to increase and develop their knowledge, competence and skills so they can make decisions about their own health care. The ultimate goal of patient education is to increase patients' empowerment. (Gibson 1991, Feste & Anderson 1995, Ellis-Stoll & Popkess-Vawter 1998, Leino-Kilpi et al. 1999, Funnell 2004, Hage & Lorensen 2005, Leino-Kilpi et al. 2005.) However, empowerment approaches to patient's freedom of choice (Funell et al. 1991).

2.2 Literature review

This literature review has been compiled from the perspective of empowering patient education. The concept empowerment takes different forms in different contexts. (Rappaport 1984, Gibson 1991, Hawks 1992, Rodwell 1996, Ellis-Stoll & Popkess-Vawter 1998, Ryles 1999, Kuokkanen & Leino-Kilpi 2000, Hage & Lorensen 2005, Bradbury-Jones et al. 2008.) In this literature review, empowering patient education has been studied by cognitive and clinical outcomes. Based on theory of empowering education, one cognitive outcome is the difference between knowledge expectations and perceptions of received knowledge (Leino-Kilpi et al. 2005, Heikkinen 2011).

The review of the literature for this study covered the period 1950–2008 (Paper I), later updated from 2009 to 2012. The systematic review was carried out in phase I to describe Internet-based and interactive computer-based patient educational programs developed for the patient education of breast cancer patients and to analyse the effectiveness of those programs. This review of the literature precedes a discussion of strategies for increasing knowledge about breast cancer and increasing efficiency in patient education through the use of Internet- or interactive computer-based programs (Paper I). The database searches for the systematic review were based on the Cochrane Database (Issue 4, 2008), CINAHL (1982–2008) and MEDLINE (1950–2008), PsycINFO (1995–2008), Eric (1966–2008), Science Direct (1994–2008), Social Science Citation Index (1956–2008) and Educational Research Complete (1990–2008) electronic databases for abstracts using the keywords "breast neoplasms or cancer$ or tumor$ or carcinoma$ ti,ab." and "patient education or counsel$ or guid$ or support or instruction$ or teaching. mp.". For articles related to the Internet the keywords "web or internet or www or computer or world wide web. mp" were used. The searches were conducted in November 2008. In this search a total of fourteen papers were identified for the review. In this review Internet-based patient education was defined as the use of the World Wide Web or modem connections to a central server for communication for patient education. Studies examining the use of the computer with CD-ROMs were accepted when these programs were interactive, because these programs can be considered predecessors of Internet-based patient education programs at the time when Internet connections were uncommon and inconvenient to use. Fourteen papers were identified for the review (Davison & Denger 2002, Fogel et al. 2002, 2003, Green et al. 2004, Gustafson et al. 2001, 2005, Jibaja et al. 2000, Owen et al. 2005, Ozanne et al. 2007, Shaw et al. 2007a, Street et al. 2005, Shawn et al. 2007b, Wise et al. 2008, Heller et al. 2008). All these database searches were updated in May 2012 (from 2009) to find the most recent Internet-based interventions and outcomes; three more studies were found (Loiselle et al. 2010, Jibaja-Weiss et al. 2011, Albada et al. 2012b). The results of those three studies are added to this literature review results.

No studies were found related to breast cancer patients' knowledge expectations or received knowledge in relation to Internet-based patient education. Breast cancer patient knowledge expectations and received knowledge are therefore examined from the point of breast cancer care process.

The initial reviews in phase I and III are partly included in this review: the description of empowerment and the outcomes of empowering patient education (Paper II–IV), the description of pathway (Paper II), breast cancer-related knowledge expectations (Paper III), and the solutions and outcomes of Internet-based education (Paper I).

2.2.1 Breast cancer patients' knowledge expectations and received knowledge

Based on theory of empowering education, one cognitive outcome is the difference between knowledge expectations and perceptions of received knowledge. The lower the difference between knowledge expectations and perceptions of received knowledge, the more possible it is for patients to be cognitively empowered. (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007, Heikkinen 2011). In the next paragraph knowledge expectations and perceptions of received knowledge will be reviewed from the viewpoint of the breast cancer patient.

2.2.1.1 Breast cancer patients' knowledge expectations

The base of breast cancer patient education is patient's knowledge expectations. In the following paragraphs these expectations are reviewed by way of the patient care process; first prior to breast biopsy, then after diagnosis, prior to chemotherapy and radiotherapy and at the end of treatments. Knowledge expectations during the breast cancer care process vary over time; for example, closer to diagnosis patients want to know about the chances for a cure, while later they want more information about self-care. (Rees & Bath 2003, Rutten et al. 2005, O'Leary et al. 2007). (Table 1.)

Breast cancer patients' knowledge expectations prior to breast biopsy are related to knowledge concerning the diagnosis as well as the biopsy procedure, disease processes, treatment options, prognosis and physical and psychological aspects of breast cancer (Shaw et al. 1994, Northouse et al. 1997). Newly diagnosed cancer patient's priority knowledge expectations are focused on short-term effects (Mills & Sullivan 1999), knowledge related to treatment and diagnosis being the most important topics (Vogel et al. 2008). With Thurstone's scaling (Thurstone 1974) the greatest knowledge expectations of newly diagnosed breast cancer patients were related to information concerning the likelihood of cure, treatment options and the stage of the disease (Luker et al. 1995, Bilodeau et al. 1996, Denger & Bilodeau 1996, Denger et al. 1997, Wallberg et al. 2000). With self-developed instruments or interviews patients and their families expected to receive knowledge related to hospital care, treatments, prognosis and further cancer prevention and risks to family members (Hilton 1993, Raupach & Hiller 2002).

Table 1. Knowledge expectations during breast cancer care.

Timing	Study	Sample size	Instrument	Knowledge expectations
prior to breast biopsy	Shaw et al. 1994 Northouse et al. 1997	n=11 n=265	Thurstone's scaling (Thurstone 1974)	diagnosis, biopsy procedure, disease processes, treatment options, prognosis physical and psychological aspects of breast cancer
after diagnosis	Bilodeau et al. 1996 Luker et al. 1995 Denger et al. 1997	n=74 n=150 n=278	Thurstone's scaling (Thurstone 1974)	likelihood of cure treatment options stage of the disease
	Wallberg et al. 2000	n=201	Thurstone's scaling (Thurstone 1974)	disease cure, disease state treatment risks
	Gopul et al. 2005	n=100	Thurstone's scaling (Thurstone 1974)	likelihood of cure sexual attractiveness
	Hilton 1993	n=30	interview	hospital care, treatments prognosis, further cancer prevention
	Vogel et al. 2008	n=135	modified from Schofield et al. 2001	treatment and diagnosis (most important), prognosis, mediation and side effects, examinations and medical tests, and aftercare information (second important)
	Raupach and Hiller 2002	n=217	self developed questionnaire	recognizing recurrence chances of cure risks to family members
	Molenaar et al. 2007	n=106	use of cd-rom	treatment-related knowledge (breast conserving therapy 99%, followed by mastectomy 79%)
prior to or during chemotherapy	Lee et al. 2004	n=52	self developed questionnaire	cancer and its spread side effects of treatment side effects management
	Galloway et al. 1997 Graydon et al. 1997	n=70 n=70	Toronto Informational Needs Questionnaire – Breast Cancer (Galloway et al. 1997, Graydon et al. 1997)	disease treatment investigative tests
prior to or during radiotherapy	Metz et al. 2003	n=120	self developed questionnaire	treatment symptom management
	Harrison et al. 1999	n=125	Toronto Informational Needs Questionnaire – Breast Cancer	disease treatment
	Halkett et al. 2009 Halkett et al. 2012	n=17 n=123	semi-structured interview RT information needs scale	varying needs (what treatment would involve, what to expect, the treatment machines that would be used, side effects and how their treatment was planned) side effects, impact to health and life
after treatments	Li et al. 2010	n=374	Information Needs Questionnaire (Denger et al. 1998)	likelihood of cure, spread of the disease treatment options, family risk adverse effects of treatment
	Bock et al. 2004	n=116	self developed questionnaire	long-term effects of treatment prognosis, discussion of prevention hereditary factors changes in the untreated breast
	Luker et al. 1996	n=105	Thurstone's scaling (Thurstone 1974)	likelihood of cure risks to other family members

Breast cancer patients' knowledge expectations prior to chemotherapy were related to cancer and its spread, side effects of treatment and their management. Knowledge related to treatments and the disease were priorities at the beginning of chemotherapy (Cowan & Hoskins 2007, Galloway et al. 1997, Graydon et al. 1997, Lee et al. 2004). At the end of chemotherapy the information related to treatment had decreased in importance, although it still remained a priority (Lee et al. 2004.)

In the field of radiotherapy some studies have been conducted to explain patients' knowledge expectations. Patients were most interested in knowledge related to disease (Harrison-Woermke & Graydon 1993, Harrison et al. 1999), treatment (Harrison-Woermke & Graydon 1993, Harrison et al. 1999, Metz et al. 2003) and symptom management (Metz et al. 2003). Patients had varying needs for knowledge. Some patients were able to manage smaller amounts of knowledge than others due to their diagnosis, and their knowledge expectations became different as they proceeded from meeting their radiation oncologist to treatment completion. (Halkett et al. 2009, 2012.)

Breast cancer patients' knowledge expectations after treatments have also been studied. Patients want knowledge about the long-term effects of treatment (Bock et al. 2004, Li et al. 2010) as well as prognosis, discussion of prevention of breast cancer and changes in the untreated breast (Bock et al. 2004). Knowledge related to hereditary factors, such as the risks to other family member, was also considered important (Luker et al. 1996, Bock et al. 2004, Li et al. 2010).

In addition to breast cancer care process, breast cancer patient's knowledge expectations were influenced by some background variables. Younger patients want as much knowledge as possible and they seek alternative information sources (Mills & Davison 2002, Block et al. 2004, Molnear et al. 2007, Leary et al. 2007, Moumjid et al. 2009). On the contrary, older people are satisfied with the knowledge received from the physician. More highly educated patients also seek knowledge more actively than those with lower education. (O'Leary et al. 2007, Moumjid et al. 2009.) Younger patients also react more critically to patient education material, such as the brochures they receive from the nursing staff and physicians (Whelan et al. 2001). Decision-making preferences also play a role: active patients want more information than passive ones (Hack et al. 1994, Denger et al. 1997).

2.2.1.2 Breast cancer patients' received knowledge

Breast cancer patients' perception of received knowledge has been studied from the point of view of physical qualities (Suominen 1994, Hack et al. 2003, Salminen et al. 2004, Mallinger et al. 2005, Griggs et al. 2007, Landmark et al. 2008), while hardly any attention has been given to patients' mental skills and abilities (Suominen 1994). Perception of received knowledge has been assessed with the Informed Communication Scale, which measured perception of having been informed with an audiotape of breast cancer patient's primary adjuvant treatment consultation. This instrument includes categories of illness- and treatment-related information with the oncologist during the consultation: treatment alternatives, side effects of treatment, likelihood of cure, extent of disease spread, and alternative forms of illness information. (Hack et al. 2003.) Suominen has studied the level of received information with 109 breast cancer patients during hospitalisation. Variables for patients receiving information were disease, treatment, operations, and internal and external prosthesis. Only a few patients considered that breast cancer patients are sufficiently informed. (Suominen 1992, 1994, Suominen et al. 1994.) Furthermore, the received information had not been as individual as the patients had wished (Brown et al. 2000, Arora et al. 2001, Wolf 2004, Oskay-Ozcelik et al. 2007) and their knowledge expectations are higher than perceptions of received knowledge (Moumjid et al. 2009, Salonen et al. 2011).

2.2.2 Internet-based educational interventions for breast cancer patients

Some Internet-based interventions have been developed for breast cancer patients. These have been described as interactive computer or multimedia programs (Street et al. 1995, Gustafson et al. 2001, Davison & Denger 2002, Green et al. 2004, Green et al. 2005, Heller et al. 2008, Jibaja et al. 2000, Jibaja-Weiss et al. 2011, Loiselle et al. 2010, Ozanne et al. 2007, Shaw et al. 2007a, 2007b, Whelan et al. 2004) and use of Internet (Fogel et al. 2002b, Fogel et al. 2003, Owen et al. 2005, Clayman et al. 2008, Wise et al. 2008, Hawkins et al. 2010, Albada et al. 2009, 2012a, 2012b).

Some interactive computer-based programs have been made to educate women about breast cancer: the Breast Cancer Genetics Computer Program (Green et al. 2004, 2005), Options for Treating Breast Cancer (Street et al. 1995), The Information and Decision Profiles (Davison & Denger 2002), Retratos de la Vida Real (Jibaja et al. 2000, Jibaja-Weiss et al. 2011), The Compurized Decision Aid (Ozanne et al. 2007), Interactive Digital Education Aid (Heller et al. 2008), and The Decision Board (Whelan et al. 2004). The specific aim of these programs has been to educate women on early detection of breast cancer (Jibaja et al. 2000, Jibaja-Weiss et al. 2011), to help women make informed decisions (Green et al. 2004, Green et al. 2005, Ozanne et al. 2007, Heller et al. 2008), or to increase patient involvement (Street et al. 1995, Davison & Denger 2002). These programs included information about breast cancer in general, breast cancer treatments as well as specific information depending on the purpose of the program.

Internet-based interventions are based on the common use of the Internet (Fogel et al. 2002, 2003) or purposely developed programs. The “Comprehensive Health Enhancement Support System” (CHESS) was at first a home-based computer system, evolving later into a web-based system providing information, decision-making, and emotional support. CHESS offers four basic types of services: information services, communication services with two conceptually different subcategories (discussion group and ask an expert service) and interactive service. (McTavish et al. 1994, 1995, Gustafson et al. 2001, Shaw et al. 2000, 2006b, 2007, Wise et al. 2008, Hawkins et al. 2010.) ”A self-guided Internet-based coping-skills training program” is a bulletin board for asynchronous group discussion, a dictionary of medical terminology, a database of breast cancer resources and Web sites, information and coping advice for management of common physical symptoms, a forum for sharing artwork and poetry, and six structured coping-skills training exercises. (Owen et al. 2005.) “Cancer Care Links” is a website dedicated to the needs expressed by patients and providers to learn about breast cancer feel in control and communicate with doctors (Clayman et al. 2008). E-info gene^{ca} is developed to provide computer-tailored information concerning counselees’ pre-visit needs for counselees who were the first in their family to request breast cancer genetic counselling (Albada et al. 2009, 2011, 2012a, 2012b).

2.2.3 The outcomes of Internet-based educational interventions for breast cancer patients

The following paragraphs will examine the outcomes of Internet-based educational interventions for breast cancer patients. The outcomes have been divided into cognitive (knowledge-based) and clinical (symptoms, well being and emotions) outcomes. Cognitive has been defined as the mental process of knowing, including e.g. awareness, perception, reasoning, and judgment (TheFreeDictionary, MedicineNet.com). In patient education cognitive outcome can be seen as the result of the process of knowing what facilitates the empowerment process. Positive clinical outcomes can be seen as outcomes of the empowerment process. (Funnell et al. 1991, Gibson 1991, Chandler 1992, Feste & Anderson 1995, Ellis-Stoll & Popkess-Vawter 1998, Corrigan 1999, Leino-Kilpi et al. 1999, Anderson et al. 2000, Falk-Rafael 2001, Leino-Kilpi et al. 2005, Heikkinen 2011.)

2.2.3.1 Cognitive outcomes

The impact of Internet or interactive computer-based patient education programs are studied in relation to breast cancer knowledge. Internet- or interactive computer-based patient education programs seem to be effective in increasing patients’ knowledge level (Street et al. 1995, Jibaja et al. 2000, Gustafson et al. 2001, Green et al. 2004, Whelan et al. 2004, Ozanne et al. 2007, Heller et al. 2008, Jibaja-Weiss et al. 2011, Albada et al. 2012b) or competence (Shaw et al. 2007a).

2.2.3.2 Clinical outcomes

Internet- or interactive computer-based patient education programs did not affect patients’ quality of life. The quality of life was measured (Gustafson et al. 2001, Owen et al. 2005, Loiselle et al. 2010) using the Functional Assessment of Cancer Therapy Breast Cancer Form (FACT-B) (Cella 1995) and the EuroQoL-5D (Brooks 1996) in Gustafson et al. (2001) and in Owen et al. (2005) and SF-36 (Helgeson et al. 2001), and well-being using the Index of Well-Being (Campbell et al. 1976) in Loiselle et al. (2010). Physical well-being was assessed using the Memorial Symptom Assessment Scale (Portenoy et al. 1994, Owen 2005.) Only one study (Loiselle et al. 2010) reported prevention of deterioration in functional quality of life while others reported that the intervention did not have any effect (Gustafson et al. 2001, Owen et al. 2005).

Anxiety was measured with Spielberger’s STAI (Spielberger 1972), which is the most commonly used instrument to measure anxiety in health sciences (Green et al. 2004, Whelan et al. 2004, Heller et al. 2008, Loiselle et al. 2010, Albada et al. 2012b). Interventions did not decrease patients' anxiety level (Green et al. 2004, Whelan et al. 2004, Heller et al. 2008, Loiselle et al. 2010), although one study described a situation where patients' anxiety level was stable following an interactive educational program while being higher after face-to-face counselling (Green et al. 2004).

Factors such as coping, stress, distress, support, loneliness, depression, and decisional conflict have been studied to find out the effectiveness of patient education using a computer or Internet (Street et al. 1995, Gustafson et al. 2001, Davison & Denger 2002, Fogel et al. 2002, Fogel et al. 2003, Green et al. 2004, Whelan et al. 2004, Green et al. 2005, Owen et al. 2005, Shaw et al. 2007a, 2007b, Heller et al. 2008, Loiselle et al. 2010). Coping has been tested with the Brief Cope questionnaire (Carver 1997, Fogel et al. 2002, 2003). Stress has been measured by the Percival Stress Scale (Cohen et al. 1983, Fogel et al. 2002, 2003), and distress with the Impact of Events scale (Horowitz et al. 1979, Owen et al. 2005). Social support has been measured using a purposely designed questionnaire (Gustafson et al. 2001) and the Interpersonal Support Evaluation List (ISEL) (Cohen and Hoberman 1983, Fogel et al. 2002, 2003) to find out Internet supportiveness. Loneliness and depression have been measured with the UCLA Loneliness Scale version 3 by Russell in 1996, and depression with the Depression Mood Scale (CES-D) developed by Radloff et al. in 1977, or by the Centre for Epidemiologic Studies Depression Scale (Devins et al. 1988). However, these instruments have failed to demonstrate the effectiveness of the interventions, with the exception of social support and loneliness. The use of the Internet was associated with social support (Gustafson et al. 2001, Fogel et al. 2002, 2003) and less loneliness (Fogel et al. 2003).

Decision-making and decisional conflict have been measured with self-developed instruments (Green et al. 2004, Ozanne et al. 2007) and with The Decisional Conflict Scale (DCS) (O'Connor 1995, Whelan et al. 2004, Jibaja-Weiss et al. 2011). No differences were found between the experimental and control group in decision-making. Patients had less decisional conflict in the study by Whelan et al. (2004), while no significant difference was found in the study by Jibaja-Weiss et al. (2011).

Participation activity and other behavioural measures have also been studied (Street et al. 1995, Gustafson et al. 2001, Davison & Denger 2002, Fogel et al. 2002, Fogel et al. 2003, Green et al. 2004, Green et al. 2005, Shaw et al. 2007a, 2007b, Wise et al. 2008). Although Internet- or interactive computer-based patient education programs increased patients' knowledge level (Street et al. 1995, Jibaja et al. 2000, Gustafson et al. 2001, Green et al. 2004, Whelan et al. 2004, Ozanne et al. 2007, Heller et al. 2008, Jibaja-Weiss et al. 2011) they did not lead to a more active role in the doctor-patient relationship, contrary to what was expected; instead, the patients might even have a more passive role (Davison & Denger 2002, Green et al. 2004, Ozanne et al. 2007, Shaw et al. 2007b).

Satisfaction-related issues have been measured with self-made questionnaires (Jibaja et al. 2000, Davison & Denger 2002, Green et al. 2004, Whelan et al. 2004, Owen et al.

2005, Ozanne et al. 2007, Heller et al. 2008, Loiselle et al. 2010, Jibaja-Weiss et al. 2011). Patients were usually satisfied with the educational programs (Jibaja et al. 2000, Whelan et al. 2004, Heller et al. 2008) and found them useful (Whelan et al. 2004, Ozanne et al. 2007).

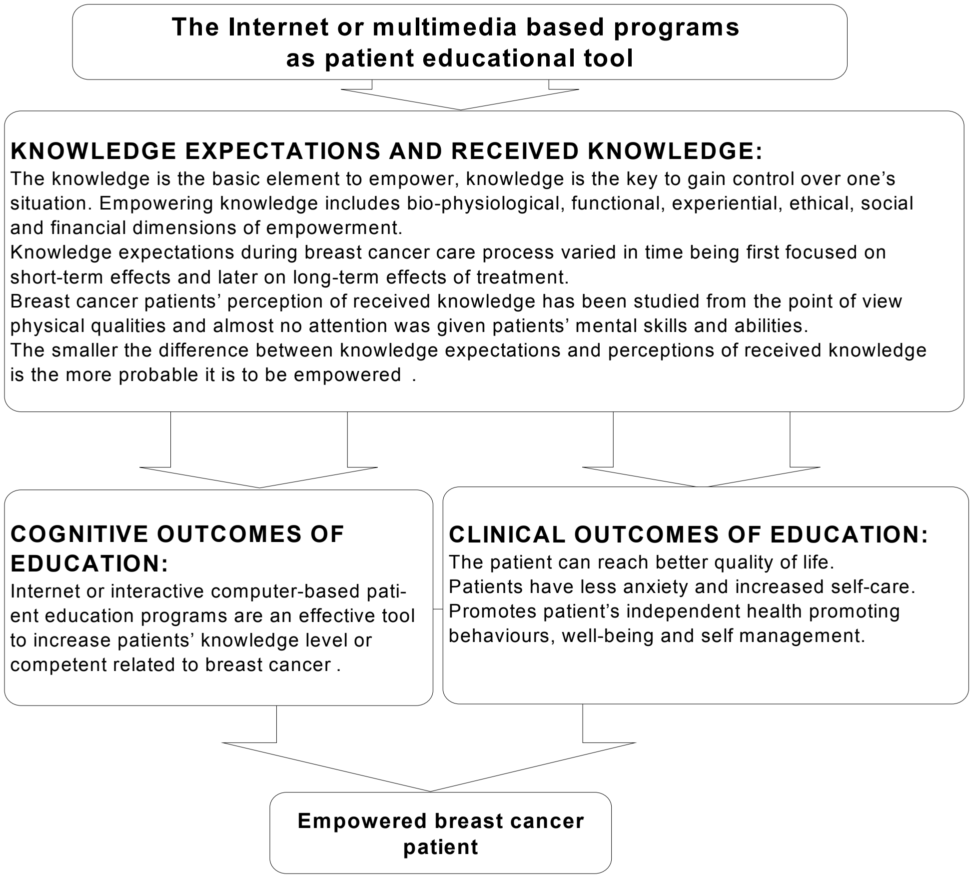
2.2.4 Summary of literature review

This literature review has been made from the perspective of empowering patient education. The concept empowerment takes different forms in different contexts. (Rappaport 1984, Gibson 1991, Hawks 1992, Rodwell 1996, Ellis-Stoll & Popkess-Vawter 1998, Ryles 1999, Kuokkanen & Leino-Kilpi 2000, Bradbury-Jones et al. 2008.) In this literature review the effects of empowering patient education have been measured by cognitive and clinical outcomes.

The aim of this literature review was to examine patients' knowledge expectations, cognitive and clinical outcomes of Internet- or computer-based patient education and Internet-based educational interventions from the point of view of the breast cancer patient. Patient education was based on patient's knowledge expectations and patient's perceptions of received knowledge.

Breast cancer patient's knowledge expectations vary during the treatment period. After diagnosis patients expect knowledge related to likelihood of cure, treatment options, stage of the disease and risks of treatment. Prognosis, medication and side effects, examinations and medical tests as well as aftercare information are also very important at this stage. Newly diagnosed cancer patient's priority knowledge expectations are focused on short-term effects. Following treatment, the most important knowledge expectations are related to long-term effects of treatment and prognosis, discussion of prevention of breast cancer, hereditary factors and changes in the untreated breast and risks of breast cancer to family members.

Internet- or multimedia-based programs have been developed for breast cancer patients. These programs have usually been made for a specific purpose. Only one of them has been developed further and is currently in clinical use. Interventions of this kind seem to be effective in increasing knowledge level, but other outcomes are rare. A summary of the results of the literature review is presented in Figure 2.



The Internet or multimedia based programs as patient educational tool

KNOWLEDGE EXPECTATIONS AND RECEIVED KNOWLEDGE:
The knowledge is the basic element to empower, knowledge is the key to gain control over one’s situation. Empowering knowledge includes bio-physiological, functional, experiential, ethical, social and financial dimensions of empowerment.
Knowledge expectations during breast cancer care process varied in time being first focused on short-term effects and later on long-term effects of treatment.
Breast cancer patients’ perception of received knowledge has been studied from the point of view physical qualities and almost no attention was given patients’ mental skills and abilities.
The smaller the difference between knowledge expectations and perceptions of received knowledge is the more probable it is to be empowered .

COGNITIVE OUTCOMES OF EDUCATION:
Internet or interactive computer-based patient education programs are an effective tool to increase patients’ knowledge level or competent related to breast cancer .

CLINICAL OUTCOMES OF EDUCATION:
The patient can reach better quality of life.
Patients have less anxiety and increased self-care.
Promotes patient’s independent health promoting behaviours, well-being and self management.

Empowered breast cancer patient

Figure 2. Summary of the results of the literature review.

3 PURPOSE OF THE STUDY, RESEARCH QUESTIONS AND HYPOTHESIS

The purpose of this study was to examine the effect of the BCPP program to breast cancer patients' empowering process from the viewpoint of cognitive outcomes (knowledge expectations, perceptions of received knowledge, the difference between knowledge expectations and perceptions of received knowledge, knowledge level) and clinical outcomes (quality of life, anxiety and treatment related side-effects). In addition, in this study the BCPP program was evaluated from the point of view of content, external appearance, instructiveness, language and structure. The ultimate goal of this study was to evaluate the effect of the BCPP program to the breast cancer patient's empowerment by using the patient pathway as a patient education tool. The phases of the study are shown in Figure 3.

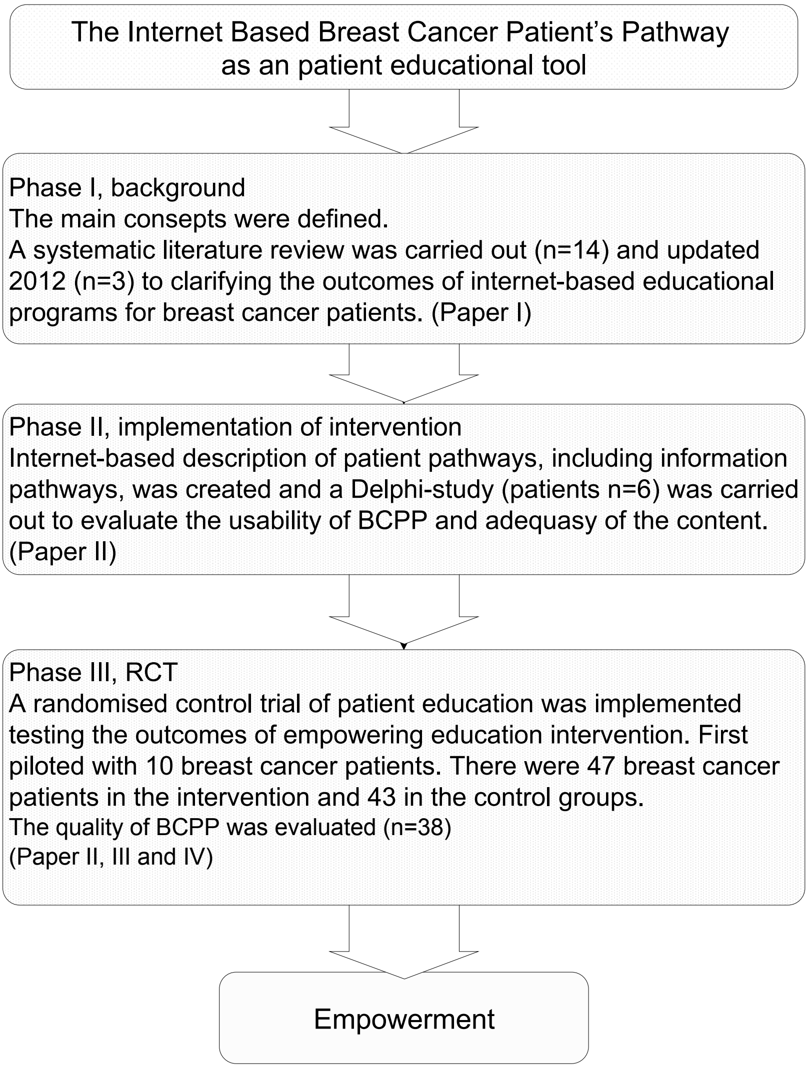
The following research questions were addressed:

1. What is the effect of Internet- or interactive computer-based patient education programs in the field of breast cancer (Paper I and in chapter 2.2 Literature review)
2. How does the BCPP program affect breast cancer patients' cognitive outcomes? (Paper III)
3. How does the BCPP program affect breast cancer patients' clinical outcomes? (Paper IV)
4. What were the relationships between the difference between knowledge expectations and perceptions of received knowledge and other outcomes? (reported in chapter 5.2 Outcomes of BCPP education)
5. What was the educational quality of the BCPP program evaluated by users? (Paper II)

The following hypotheses were tested:

I Patients using the BCPP program as a complement to standard care demonstrate higher cognitive outcomes (lesser difference between knowledge expectations and perceptions of received knowledge, higher knowledge level) than those exposed to standard patient education.

II Patients who used the BCPP program as a complement to usual care demonstrate higher clinical outcomes (higher quality of life, less anxiety and treatment related side-effects) than those exposed to standard patient education.



The Internet Based Breast Cancer Patient’s Pathway
as an patient educational tool

Phase I, background
The main consepts were defined.
A systematic literature review was carried out (n=14) and updated 2012 (n=3) to clarifying the outcomes of internet-based educational programs for breast cancer patients. (Paper I)

Phase II, implementation of intervention
Internet-based description of patient pathways, including information pathways, was created and a Delphi-study (patients n=6) was carried out to evaluate the usability of BCPP and adequasy of the content. (Paper II)

Phase III, RCT
A randomised control trial of patient education was implemented testing the outcomes of empowering education intervention. First piloted with 10 breast cancer patients. There were 47 breast cancer patients in the intervention and 43 in the control groups.
The quality of BCPP was evaluated (n=38)
(Paper II, III and IV)

Empowerment

Figure 3. The study design

4 METHODOLOGY

4.1 Sampling and settings

In the first phase, a systematic review was conducted in order to find out the effectiveness of Internet- or interactive computer-based patient education programs in the field of breast cancer. The Cochrane, CINAHL, MEDLINE, PsycINFO, Eric, Science Direct, Social Science Citation Index and Educational Research Complete databases were searched covering the period from the beginning of each database to November 2008. Studies were included if they concerned patient education for breast cancer patients using the Internet or interactive computer programs and were based on randomized controlled trials, clinical trials or quasi-experimental studies. The design in the included studies was randomized controlled trial (RCT) in nine studies, clinical trial (CT) in two and quasi-experimental (QE) in three. Seven of the studies were randomized to experimental and control groups as well as pre- and post-tests after using interactive computer programs or the Internet. (Figure 3, Paper I).

In addition, the BCPP program was structured and a Delphi study was performed for evaluation of usability of web pages and exhaustiveness of content (Appendix 1) among six breast cancer patients. Five of the patients returned the questionnaire, the response rate being 83%. (Paper II.)

In the second phase, the BCPP program was developed to its final form according to the Delphi study. The process of the development of the program had already been started in 2005 with a cancer nurse, a chemotherapy nurse, a radiographer, a member of a breast cancer support group and a patient education designer. (Paper II.)

In the third phase, the target population consisted of all breast cancer patients who were Internet users in one Finnish university hospital from January 2008 to December 2010. A power analysis was performed to ascertain the necessary sample size. Using psychological well-being scores of a quality of life instrument as a gauge power analysis assuming an ability to detect one unit difference between the groups was performed, showing that 40 patients were needed for a power level of 0.80 and a probability level 0.05 when standard deviation is 1.59 units. The randomised sample comprised 98 patients (50 in the intervention group and 48 in the control group), who had just received breast cancer diagnosis, whose language was Finnish, who were able to fill in the questionnaires by themselves, and who consented to participate. They were randomised according to age and professional education with the help of a randomisation table. We lost 8 patients in follow-up, which gave a response rate of 92%. The final sample consisted of 47 patients in the intervention group and 43 in the control group. (Paper II, Paper III, Paper IV.) Patients who did not consent to participate in the study (n=22) were however asked to complete a background questionnaire (Table 2, Appendix 2).

Table 2. Sociodemographic data on patients in phase III.

Demographic variables	**Control group (n=43) n (%)**	**Intervention group (n=47) n (%)**	**p-value* between control and intervention groups**	**Refusing patients[a] (n=22) n (%)**	**p-value* between participating and refusing patients**
Age in years mean (range)	55.7 (41–69)	54.4 (40–67)	.460	58.7 (46–65)	.083
40 - 45	2 (4.7)	6 (12.8)		0	
45 - 60	28 (65.1)	29 (61.7)		16 (59.1)	
60 - 69	13 (30.2)	12 (25.5)		9 (40.9)	
Marital status			.128		.189
married	30 (69.8)	41 (87.2)		13 (59.1)	
single, divorced or widow	13 (25.6)	6 (12.8)		9 (40.9)	
Basic education years			.009*		.140
6	15 (34.9)	4 (8.5)		10 (45.5)	
9	9 (20.9)	20 (42.6)		4 (18.2)	
12	19 (44.2)	23 (48.9)		8 (36.4)	
Professional education			.130		.523
none	10 (23.3)	4 (8.5)		7 (36.8)	
secondary level	10 (23.3)	10 (21.3)		3 (15.8)	
upper secondary/college/ polytechnic	13 (30.2)	24 (51.1)		2 (10.5)	
university	10 (23.3)	9 (19.1)		7 (36.8)	
Employment status			.403		. 224
employed	27 (62.8)	36 (76.6)		9 (40.9)	
retired	12 (27.9)	10 (21)		10 (45.5)	
unemployed	3 (7)	1 (2.1)		0	
others	1 (2.3)	1 (2.1)		1 (4.5)	
Number of children, mean (range)	1.6 (0–4)	1.6 (0–4)	.812	1.7 (0-3)	. 968
age range	8–42	4–46	.163	5–48	. 495
Monthly income[b] (Euros)			.526		.424
none	1 (2.3)	1 (2.1)		0	
under 1000	12 (27.9)	17 (36.2)		9 (42,9)	
1000-2000	23 (53.5)	31 (66)		8 (38.1)	
over 2000	7 (16.3)	8 (17)		4 (19)	

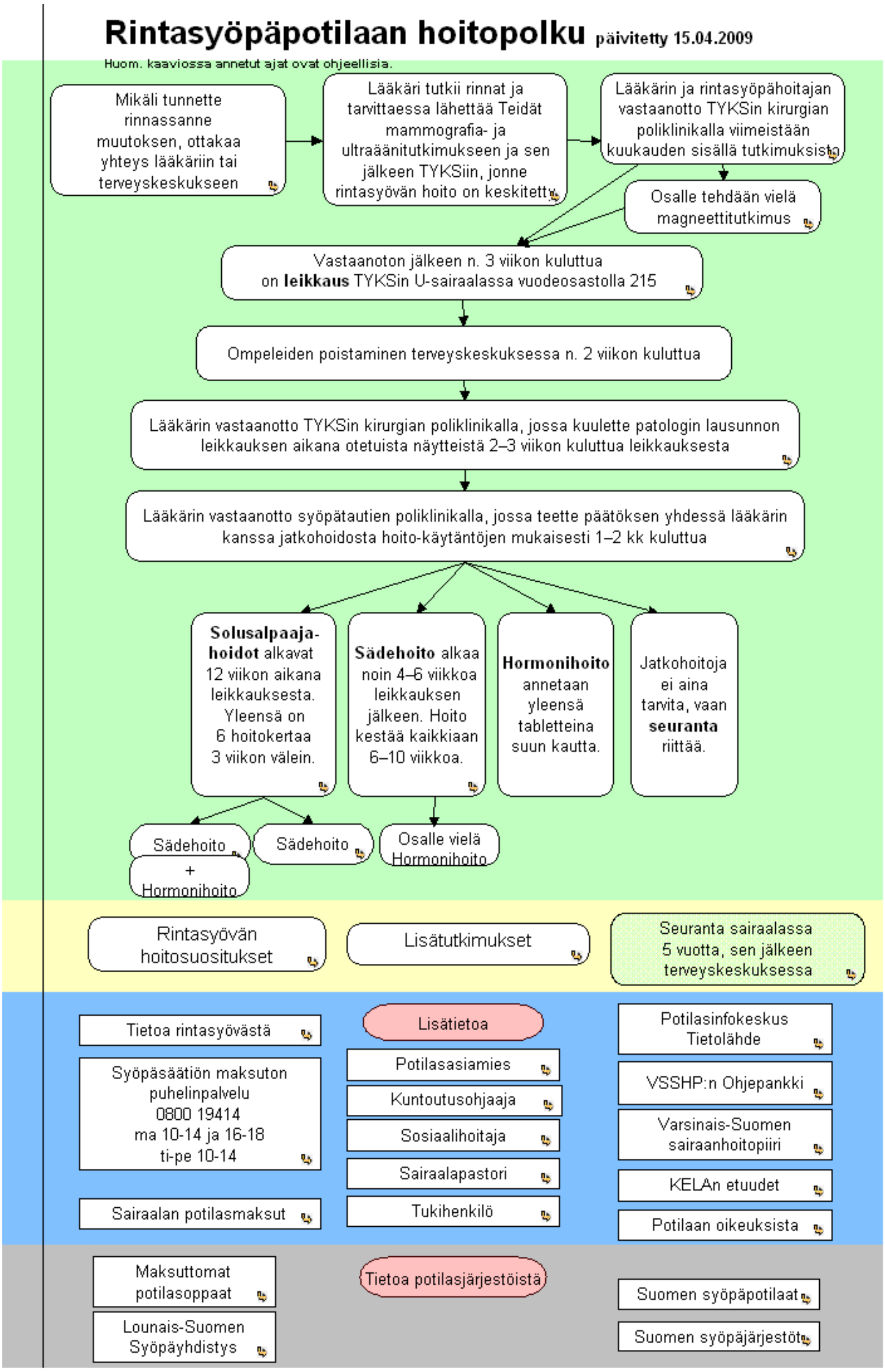
*p-value statistically significant, p-value examined by Pearson chi-square

[a] Refusing patients who returned questionnaire but did not want to participate, [b] In 2009 women's average earnings in Finland were 2,667 Euros per month (Statistics Finland 2011).

4.2 Implementation of BCPP program education

The BCPP program is an Internet-based patient education program designed for breast cancer patients. This program is based on the idea that knowing their pathway after the cancer diagnosis would help patients to understand the content of patient education and use the knowledge in their own treatment and care, *i.e.,* support the empowerment of patients. BCPP program facilitates grasping the wholeness of breast cancer care and it is based on the theory of empowering knowledge (Leino-Kilpi et al. 1998, 1999, Heikkinen et al. 2007). The structure of the BCPP program is based on a flow chart diagram of the patient pathway during the breast cancer caring and treatment process from diagnosis to the follow-up of recovery. The BCPP program includes more specific patient pathways about surgery, chemotherapy and radiotherapy. From the diagram there are links to relevant web pages containing appropriate timely information. The BCPP program differs from clinical pathway from the point of content. Items of BCPP main page are linked to patient education material. (Figure 4, Paper II.)

The results of the literature review (Phase I) indicate that an educational method of this kind has not previously been used among breast cancer patients or any other groups of patients. Clarke et al. (2002) had developed a pathway for head and neck cancer surgery patients, but the structure of this paper pathway was more like a clinical guideline to patient education. In phase II, this educational program was tested with six breast cancer patients before piloting. This Delphi study was conducted to evaluate the usability of the web pages and the validity of content. Firstly, eight health care professionals working with breast cancer patients commented the BCPP program. Secondly, data were collected using a structured instrument in one Delphi round in which breast cancer patients both answered the questionnaire and commented and pretested the web page evaluation instrument. Only one round was needed because the patients did not propose changes to the program (Rowe & Wright 1999). The instrument, Evaluating Internet Pages of Patient Education, was developed for the study by the research team in collaboration with nurses in clinical practice. The instrument is based on an instrument developed earlier to evaluate written educational material (Johansson et al. 2004b, Johansson 2006, Ryhänen et al. 2009).



Rintasyöpäpotilaan hoitopolku päivitetty 15.04.2009

Huom. kaaviossa annetut ajat ovat ohjeellisia.

Mikäli tunnette rinnassanne muutoksen, ottakaa yhteys lääkäriin tai terveyskeskukseen

Lääkäri tutkii rinnat ja tarvittaessa lähettää Teidät mammografia- ja ultraäänitutkimukseen ja sen jälkeen TYKSiin, jonne rintasyövän hoito on keskitetty

Lääkärin ja rintasyöpähoitajan vastaanotto TYKSin kirurgian poliklinikalla viimeistään kuukauden sisällä tutkimuksista

Osalle tehdään vielä magneettitutkimus

Vastaanoton jälkeen n. 3 viikon kuluttua on **leikkaus** TYKSin U-sairaalassa vuodeosastolla 215

Ompeleiden poistaminen terveyskeskuksessa n. 2 viikon kuluttua

Lääkärin vastaanotto TYKSin kirurgian poliklinikalla, jossa kuulette patologin lausunnon leikkauksen aikana otetuista näytteistä 2–3 viikon kuluttua leikkauksesta

Lääkärin vastaanotto syöpätautien poliklinikalla, jossa teette päätöksen yhdessä lääkärin kanssa jatkohoidosta hoito-käytäntöjen mukaisesti 1–2 kk kuluttua

Solusalpaaja-hoidot alkavat 12 viikon aikana leikkauksesta. Yleensä on 6 hoitokertaa 3 viikon välein.

Sädehoito alkaa noin 4–6 viikkoa leikkauksen jälkeen. Hoito kestää kaikkiaan 6–10 viikkoa.

Hormonihoito annetaan yleensä tabletteina suun kautta.

Jatkohoitoja ei aina tarvita, vaan **seuranta** riittää.

Sädehoito + Hormonihoito

Sädehoito

Osalle vielä Hormonihoito

Rintasyövän hoitosuositukset

Lisätutkimukset

Seuranta sairaalassa 5 vuotta, sen jälkeen terveyskeskuksessa

Tietoa rintasyövästä

Syöpäsäätiön maksuton puhelinpalvelu
0800 19414
ma 10-14 ja 16-18
ti-pe 10-14

Sairaalan potilasmaksut

Lisätietoa

Potilasasiamies

Kuntoutusohjaaja

Sosiaalihoitaja

Sairaalapastori

Tukihenkilö

Potilasinfokeskus Tietolähde

VSSHP:n Ohjepankki

Varsinais-Suomen sairaanhoitopiiri

KELAn etuudet

Potilaan oikeuksista

Maksuttomat potilasoppaat

Lounais-Suomen Syöpäyhdistys

Tietoa potilasjärjestöistä

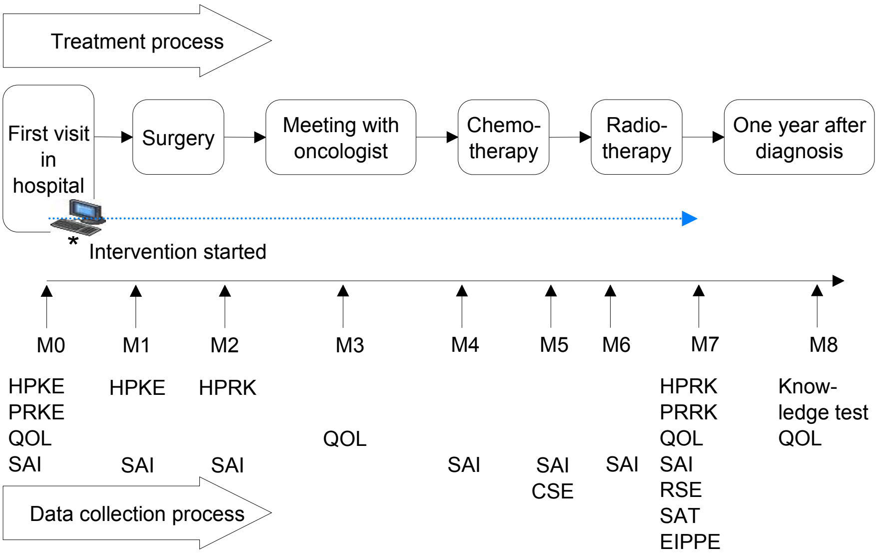
Suomen syöpäpotilaat

Suomen syöpäjärjestöt

Figure 4. The picture of the main page of the BCPP program (in Finnish).

4.3 Data collection and analysis

In phase I and II, data were collected with a systematic literature review and one Delphi round (Appendix 1). In phase III baseline data (M0) were collected in the first hospital visit after breast cancer diagnosis, before breast cancer surgery (M1), one day after surgery (M2), at first meeting with oncologist (M3), before and after chemotherapy and radiotherapy treatments (M4-M7) and one year after breast cancer diagnosis (M8). (Figure 5.) Patients in both groups received oral and written patient education material according to the normal practice of the hospital. The intervention was implemented between M0 and M1. In both groups timing of data collection was based on the process of breast cancer treatment. The background variables were asked at baseline and the sources of knowledge after radiotherapy (M7, Appendix 3).



* Intervention group patients had an educational session with researcher. After that the patients had an opportunity to use the BCPP program during their treatment process until the end of all treatments

Measure times:
M0=baseline
M1=before surgery
M2=after surgery
M3=first meeting with oncologist
M4=before chemotherapy,
M5=after chemotherapy
M6=before radiotherapy
M7=after radiotherapy
M8=a year after diagnosis

Instruments:
HPKE=hospital patient knowledge expectations
HPRK=hospital patient received knowledge
PRKE=pathway related knowledge expectations
PRRK=pathway related received knowledge
EIPPE=internet page evaluation instrument
QOL= quality of life
SAI=state anxiety
CSE=chemotherapy side effects
RSE=radiotherapy side effects
SAT=satisfaction with patient education

Figure 5. Data collection process in relation to patient's treatment process and instruments used in the study in phase III.

The instruments used in this study, items, subscale items and response scales are summarised in Table 3. The possibility of cognitive empowerment was measured by the difference between Hospital Patient Knowledge Expectations (HPKE) and Hospital Patient Received Knowledge (HPRK) based on the theory of empowerment. The lower the difference between HPKE and HPRK, the higher the possibility of being cognitively empowered (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007, Heikkinen 2011). The values of the difference between HPKE and HPRK ranged from +3 (strong) to -3 (weak). (Paper III.)

Table 3. Summary of the instruments used in study.

Instrument	**Items**	**Items in subscales**		**Response scales**
Hospital patient knowledge expectations (HPKE) (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007) Modified by Ryhänen 2007.	40	bio-physiological functional experiential ethical social financial	9 7 3 9 6 6	Scale 0-4 1=fully agree 4=fully disagree 0= does not apply
Hospital patient received knowledge (HPRK) (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007) Modified by Ryhänen 2007.	40	bio-physiological functional experiential ethical social financial	9 7 3 9 6 6	Scale 0-4 1=fully agree 4=fully disagree 0= does not apply
Pathway-related knowledge expectations (PRKE) (based on literature Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007)	12			Scale 0-4 1=fully agree 4=fully disagree 0= does not apply
Pathway-related received knowledge (PRRK) (based on literature Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007)	12			Scale 0-4 1=fully agree 4=fully disagree 0= does not apply
Breast Cancer-related knowledge (KTBC) (based on Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007)	12	bio-physiological functional experiential ethical social financial	2 2 2 2 2 2	Scale 1-3 1 = correct 2 = incorrect 3 = do not know
Quality of life (QOL) (Ferrell et al. 1995a, 1995b, 1996, 1997a, 1997b, 1998a, 1998b, Dow et al. 1996)	43	physical psychological social spiritual	8 2 2 9 4	Scale 0-10 0 = worst outcome 10 = best outcome
State anxiety (SAI, S-Anxiety scale) (Spielberger 1972, 1983)	20			Scale 1-4 1=not at all 4=very much
Chemotherapy Side Effects (CSE)	14			Scale 0-4 1=fully agree 4=fully disagree 0= does not apply
Radiotherapy Side Effects (RSE)	9			Scale 0-4 1=fully agree 4=fully disagree 0= does not apply

Instrument	Items	Items in subscales		Response scales
The Source of Knowledge (SK)	15			Scale 1-3 1=most important 2=second important 3=third important
Satisfaction (SAT)	2			Scale 1-4 1=extremely satisfied 4=not at all satisfied
Evaluating Internet page of patient education (EIPPE) (based on Johansson 2004b, Ryhänen 2009)	37	content language and structure instructiveness external appearance technical characteristics	7 8 7 9 5	Scale 0-4 1=fully agree 4=fully disagree 0= don't know

All the data were analysed statistically (Table 4) using PASW® 18 (IBM Corporation, Somers, NY, USA). Hypotheses were tested with one-way ANOVA (HI) and RM-ANOVA (HII).

Table 4. Research questions, hypothesis and statistical variables used in this study.

Research question	Response variable	Statistical analyses/test used
How do Internet- or interactive computer-based patient education programs affect in the field of breast cancer?	Outcomes of Internet-based education	Descriptive statistics
How does the use of the BCPP program affect breast cancer patient's cognitive outcomes?	Expected knowledge Received knowledge Knowledge test Satisfaction with patient education	T-test Wilcoxon signed rank test One way ANOVA
How does the use of the BCPP program affect breast cancer patients' clinical outcomes?	Quality of life Control of side effects State of anxiety	T-test, X^2 Fisher exact test Wilcoxon signed rank test Pearson correlation RM-ANOVA
What were the relationships between cognitive and clinical outcomes?	Difference between knowledge expectations and perceptions of received knowledge Knowledge test Satisfaction with patient education Quality of life Control of side effects State of anxiety	Pearson correlation
What were the BCPP program's content, language and structure, instructiveness, external appearance and technical characteristics of the web-pages evaluated by users?	Content External appearance Instructiveness Language and structure Technical characteristics	Descriptive statistics Pearson correlation

The internal consistency of the instruments used in the present study assessed with Cronbach's alpha coefficients (Table 5).

Table 5. The internal consistency of the instrument used in the present study.

Instrument	Cronbach's alpha total	Cronbach's alpha in subscales	
Hospital patient knowledge expectations (HPKE)	0.94	bio-physiological	0.91
		functional	0.88
		experiential	0.81
		ethical	0.90
		social	0.90
		financial	0.91
		dimension of empowerment	
Hospital patient received knowledge (HPRK)	0.88	bio-physiological	0.89
		functional	0.89
		experiential	0.83
		ethical	0.92
		social	0.84
		financial	0.94
		dimension of empowerment	
Pathway-related knowledge expectations (PRKE)	0.80		
Pathway-related received knowledge (PRRK)	0.93		
Quality of life (QOL)	0.94–0.96	spiritual	0.53–0.70
		physical	0.71–0.78
		social	0.78–0.85
		psychological well being	0.92–0.95
State anxiety (SAI)	0.94–0.97		
Chemotherapy side effects (CSE)	0.80		
Radiotherapy side effects (RSE)	0.69		
Evaluating Internet page of patient education (EIPPE)	0.97	content	0.90
		language and structure	0.93
		instructiveness	0.90
		external appearance	0.92
		technical characteristics	0.89

4.4 Ethical questions

The general principles of research ethics were adhered to in this study (Medical Research Act 488/1999 ETENE 2001, 2002, 2009, ICN 2003, Northern Nurses´ Federation 2003, Academy of Finland 2004, Burns & Groove 2005). The permission to carry out this study and to use the data collection instruments and ethical questions concerning informed consent, voluntary participation, anonymity, confidentiality and the protection of participants from discomfort and harm are presented in the next paragraph.

Permission to carry out the study was given by from the hospital's chief physician and director of nursing (Committee of Nursing Research) after obtaining ethical approval from the Ethics Committee of the Hospital District of Southwest Finland, with the exception of the systematic review (Paper I). Permissions to use the instruments and to use, translate and modify them were obtained from the authors: The Quality of Life Instrument (QOL) Breast Cancer patient, © Ferrell BR 1993, 16 April 2007; STAI, © Spielberger CD. 1983, 22 August 2007 (Finnish translation, © Aro A. 1996, 8 May 2007); SPTT, SPTS, 27 August 2007, © Leino-Kilpi, Salanterä & Hölttä 2003.

Some of instruments were developed by the researcher and tested before use. Permission to collect the test data was approved by the hospital's chief physician. For copyright reasons, the Quality of Life Instrument (QOL) Breast Cancer patient, State Anxiety Inventory, SPTT, SPTS, PRKE and PRRK instruments, Evaluating Internet Pages of Patient Education instrument, Knowledge Test for Breast Cancer Patient, Chemotherapy and Radiotherapy side-effects instrument are not published in this dissertation.

In Phase II and III, patients were informed in writing about the aims of the study (Appendix 4) with a letter before their admission to the hospital, where they were also orally informed. Patients who decided to participate returned their signed voluntary informed consent and their sociodemographic questionnaire (Appendix 5). They were aware that their participation was voluntary and they were able to drop out whenever they wished to do so (Appendix 6 and 7). Patients were assured that their decision to participate or not would have no effect on their care. Patients in the control group received standard oral and written patient education whereas patients in the intervention group also had access to the BCPP program. All the data were handled anonymously and confidentially. The instruments needed to be coded in longitudinal study design and the person register was retained secured.

5 RESULTS

The results are reported in two parts: the first part describes the evaluation of educational interventions used to educate breast cancer patients on the Internet (Paper II, Paper I reported in background chapter). The second part describes and compares the outcomes of Internet-based empowering education for breast cancer patients; first, cognitive outcomes of Internet-based patient education for breast cancer patients (Paper I, Paper III), followed by clinical outcomes of Internet-based breast cancer patient education according to a previous research paper (Paper I) and from the point of empowerment tested in this study (Paper IV).

5.1 Evaluation of Internet-based educational interventions

The BCPP program is based on the idea that knowing their care pathway after the cancer diagnosis would help patients to understand the content of patient education and use the knowledge in their own treatment and care to be more empowered. Being based on the theory of empowering knowledge, BCPP program facilitates knowing the wholeness of breast cancer care. The patients in the intervention group had an educational session with the researcher, after which they had the opportunity to use the BCPP program as often as they wanted during their treatment process until the end of all treatments. (Paper II.)

The BCPP program was evaluated in the intervention with an Internet page evaluation instrument (EIPPE) after radiotherapy (M7). Patients evaluated the BCPP program as being well developed, the mean value of all evaluation criteria being 3.40 (4 = fully agree, 1 = fully disagree). They evaluated the content to be the weakest aspect of the BCPP program (3.13) and language and structure to be the best (3.48). Other aspects evaluated were instructiveness (3.26), external appearance (3.43) and technical characteristics of the web site (3.36). Although the mean of evaluated values was over three there is still a need to develop the content of the BCPP program because some individual criteria scored less than three, e.g. social dimension of empowering knowledge scored 2.77. (Paper II.)

5.2 Outcomes of BCPP program education

This section describes and compares first the cognitive outcomes of Internet-based patient education for breast cancer patients (Paper III) followed by the clinical outcomes tested in this study (QOL, Anxiety and side-effects) (Paper IV). The results of the literature review in Paper I are reported in the background chapter.

The demographics in the control and intervention groups were similar except for basic education. Participants in the control group had less compulsory education than participants in the intervention group. Patients who did not consent to participate in the study were however asked to complete a background questionnaire, and it was completed and returned by 22 of them. No significant differences appeared in demographic variables between patients who participated and those who refused to do so (Table 2). When completed demographic variables were compared to the outcomes of this study some differences were found between the intervention and control groups. In the intervention group marital status correlated strongly with anxiety (r=0.423, *p*=0.004) and the difference between knowledge expectations and received knowledge (r=-0.435, *p*=0.005). According to these results it can be said that women in relationship were less anxious and their knowledge expectations were fulfilled better compared to women living without partner. A weak correlation was also found between age and satisfaction with patient education (r=0.338, *p*=0.031) and between quality of life and basic education (r=0.328, *p*=0.025). Older patients were more satisfied than younger and those with more basic education had a better quality of life. One significant correlation was found in the control group. During radiotherapy patients in relationship had less side effects (r=0.571, *p*=0.001) than women living without partner. A weak correlation was also found between age and quality of life (r=0.318, *p*=0.040). Older patients' quality of life was better compared to that of younger patients.

5.2.1 Cognitive outcomes of BCPP program education

In this study the possibility of cognitive empowerment was measured by the difference between HPKE and HPRK based on the theory of empowerment. Pathway-related expected and received knowledge, satisfaction and knowledge level were also measured as cognitive outcome in this study.

HPKE was measured twice, at baseline (M0) and before surgery (M1), to find out the immediate effect of the intervention. HPRK was measured after surgery (M2) and radiotherapy (M7) to find out the state of change. The level of expected knowledge was higher than the level of received knowledge in both groups and in all dimensions of empowerment. (Table 6, Figure 6, Paper III, Table 2.) However, knowledge expectations of the patients in the control group were higher in all other dimensions except social dimension, and when comparing the differences between baseline knowledge expectations and received knowledge after radiotherapy, patients in the control group scored better on received knowledge on all dimensions of empowering knowledge (*p*=0.049). Statistically significant differences between the groups were found in the bio-physiological (*p*=0.049) and social (*p*=0.005) dimensions of empowering knowledge. (Paper III.) PRKE and PRRK were measured at baseline (M0, PRKE) and after radiotherapy (M7, PRRK). The difference between pathway-related expected and received knowledge was also statistically significantly better in the control group (*p*=0.017) (Table 3, Paper III, Table 4). The intervention did not have a positive effect on the differences between baseline knowledge expectations and received knowledge as had been expected; instead, the difference between baseline knowledge expectations and received knowledge after radiotherapy was smaller in the intervention group compared to the control group.

Table 6. Difference of knowledge expectations at baseline and received knowledge after radiotherapy.

Dimensions of knowledge	group	HPKE M0	HPRK M7	difference between HPKE and HPRK (M0-M7)		statical difference between HPKE-HPRK between groups
		mean	mean	mean	SD	*p*
Bio-physiological	control	1.20	1.53	-0.31	0.63	0.049*
	intervention	1.22	1.90	-0.64	0.82	
Functional	control	1.31	1.62	-0.22	0.76	0.215
	intervention	1.43	1.91	-0.47	0.94	
Experiential	control	1.43	1.82	-0.39	0.85	0.394
	intervention	1.61	2.20	-0.58	1.04	
Ethical	control	1.51	2.05	-0.47	0.94	0.109
	intervention	1.53	2.35	-0.82	0.91	
Social	control	1.70	1.94	-0.12	0.89	0.005*
	intervention	1.68	2.40	-0.71	0.84	
Financial	control	1.50	2.04	-0.45	1.17	0.150
	intervention	1.55	2.36	-0.82	0.95	
All	control	1.42	1.82	-0.34	0.72	0.049*
	intervention	1.47	2.17	-0.68	0.78	

M0= baseline, M7=after radiotherapy, * statistically significant

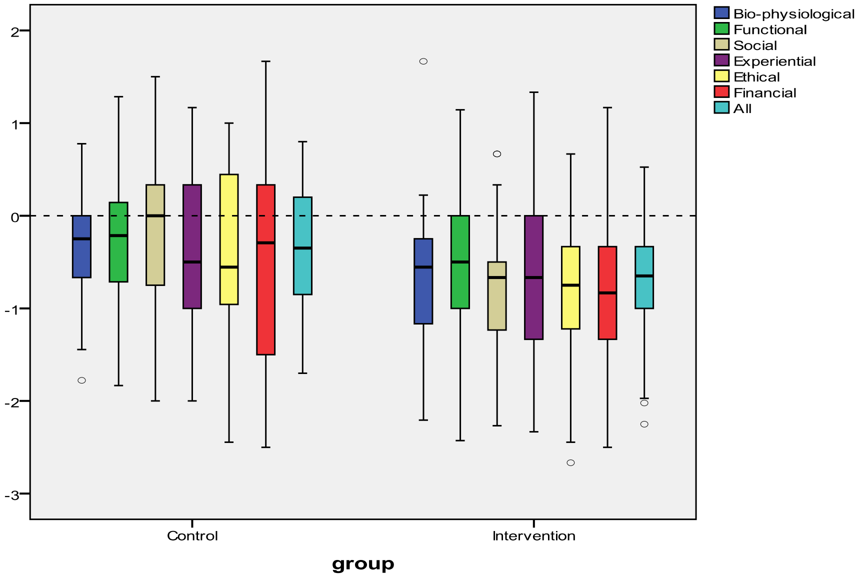


Figure 6. Box blots of the difference between knowledge expectations (M0) and perceptions of received knowledge (M7) divided into dimensions of empowerment in both groups. The figure shows the biggest and smallest value (rate +3 to -3), the upper quartiles and field quartiles and median. The higher value means a more positive relationship between knowledge expectations and perceptions of received knowledge. All quartiles are below 0 in the intervention group.

The knowledge level was measured with KTBC one year after breast cancer diagnosis (M8). All patients scored on average 8.87 points out of twelve points on knowledge level (range 4 to 11, Figure 7). Knowledge level was statistically significantly higher (mean 9.26, *p*=0.021) in the intervention group compared to the control group (8.42, Paper III). There was no statistical significant difference between the groups in the dimensions of empowering knowledge even though the total knowledge level in the intervention group was higher than in the control group (*p*=0.021). The bio-physiological dimension was the best known and social the weakest known in both groups. (Table 7.)

Table 7. Knowledge level in different dimensions of empowering knowledge one year after diagnosis.

Dimension of empowerment	Group	Mean*	SD	*p*-value between groups
Bio-physiological	Control	1.81	0.53	0.171
	Intervention	1.93	0.26	
Functional	Control	1.31	0.67	0.218
	Intervention	1.49	0.63	
Social	Control	1.03	0.17	0.110
	Intervention	1.14	0.41	
Experiential	Control	1.39	0.69	0.121
	Intervention	1.61	0.50	
Ethical	Control	1.58	0.55	0.440
	Intervention	1.67	0.47	
Financial	Control	1.31	0.58	0.360
	Intervention	1.42	0.50	
All	Control	8.42	1.68	0.021
	Intervention	9.26	1.45	

* Rate 0 to 2, in all 0 to 12

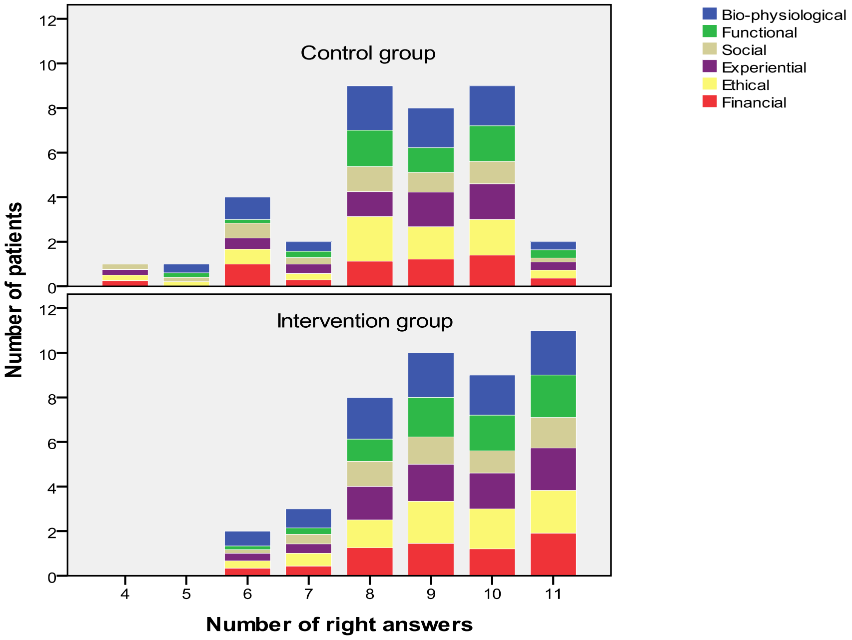


Figure 7. Histograms of the number of right answers in breast cancer knowledge test showing proportions of correct answers in different dimensions of empowering knowledge.

Knowledge expectations between the groups were presumed to be similar at baseline, and the difference between baseline knowledge expectations and received knowledge after radiotherapy to be lower in the intervention group. When studying relationships between knowledge test and the difference between knowledge expectations and perceptions of received knowledge only few correlations were found. (Table 8.) Some weak correlations were found between the ethical dimension of knowledge test and bio-physiological and experiential dimensions of difference between knowledge expectations and perceptions of received knowledge in the control group (r=0.421, *p*=0.021, r=0.420, *p*=0.021). A weak correlation was also found between the functional and ethical dimensions of the knowledge test and the social and financial dimensions of the difference between knowledge expectations and perceptions of received knowledge (r=-0.345, *p*=0.036, r=0.404, *p*=0.013). Based on this finding it can be said that an increased knowledge level did not have a positive effect on the relationship of the difference between knowledge expectations and received knowledge.

Table 8. Correlations between knowledge test and the difference between knowledge expectations and perceptions of received knowledge at baseline and after radiotherapy.

Dimension of knowledge of the difference between knowledge expectations and perceptions of received knowledge			knowledge test					
			Bio-physiological	Functional	Experiential	Ethical	Social	Financial
Bio-physiological	control	Correlation	-0.221	0.330	0.274	0.421	-0.245	-0.083
		p	*0.240*	*0.075*	*0.143*	*0.021**	*0.192*	*0.663*
	intervention	Correlation	-0.305	-0.141	-0.255	0.072	0.184	0.093
		p	*0.063*	*0.398*	*0.123*	*0.667*	*0.270*	*0.579*
Functional	control	Correlation	-0.241	0.321	0.320	0.174	-0.186	0.293
		p	*0.200*	*0.083*	*0.084*	*0.357*	*0.325*	*0.117*
	intervention	Correlation	-0.124	-0.046	-0.207	0.053	0.086	0.023
		p	*0.464*	*0.785*	*0.218*	*0.795*	*0.614*	*0.891*
Experiential	control	Correlation	-0.234	0.263	0.108	0.420	-0.004	0.170
		p	*0.213*	*0.160*	*0.569*	*0.021**	*0.985*	*0.368*
	intervention	Correlation	0.022	-0.004	0.044	0.063	-0.176	0.072
		p	*0.899*	*0.980*	*0.796*	*0.713*	*0.298*	*0.674*
Ethical	control	Correlation	-0.190	0.162	-0.086	0.312	-0.096	0.106
		p	*0.316*	*0.392*	*0.650*	*0.093*	*0.614*	*0.578*
	intervention	Correlation	-0.057	-0.196	-0.146	-0.055	0.067	-0.007
		p	*0.733*	*0.239*	*0.381*	*0.744*	*0.239*	*0.967*
Social	control	Correlation	-0.298	0.427	0.199	0.171	0.084	0.201
		p	*0.109*	*0.019**	*0.291*	*0.365*	*0.659*	*0.287*
	intervention	Correlation	-0.011	-0.345	-0.254	0.030	-0.118	0.149
		p	*0.947*	*0.036**	*0.129*	*0.861*	*0.488*	*0.380*
Financial	control	Correlation	-0.181	0.309	0.220	0.163	-0.115	0.227
		p	*0.338*	*0.096*	*0.242*	*0.390*	*0.545*	*0.227*
	intervention	Correlation	-0.063	-0.163	-0.158	0.404	-0.086	0.202
		p	*0.712*	*0.335*	*0.352*	*0.013**	*0.614*	*0.230*

* Statistically significant
Correlation measured with Pearson Correlation

5.2.2 Clinical outcomes of BCPP program education

Quality of life, anxiety level and side-effects related to the treatment were selected to be measured as clinical outcomes of this study (Paper IV). The positive result of empowering patient education was expected to be manifested as better quality of life, less anxiety and increased self-care, shown as decreasing effect of treatment-related side effects. Clinical outcome measurement times were based on the process of breast cancer treatment. The effect of the intervention on the clinical outcomes is examined in the next paragraphs.

Quality of life was measured at baseline (M0), at first meeting with oncologist (M3), after radiotherapy (M7) and one year after diagnosis (M8) to indicate the effectiveness of intervention. The quality of life was divided into four domains including physical, psychological, social and spiritual well-being. Overall quality of life varied from 6.07 to 6.50 (scale from 0 to 10) in the intervention group and from 6.18 to 6.57 in the control group. There were no statistically significant differences in quality of life between the groups. Based on this it can be said that the intervention did not have an effect on the quality of life.

Table 9. The means of quality of life and the groups' internal differences between measurement times.

domain of well being	group	M0		M3		difference M0-M3	M7		difference M3-M7	M8		difference M7-M8	difference M0-M8
		mean	SD	mean	SD	*p*	mean	SD	*p*	mean	SD	*p*	*p*
physical	control	7.35	1.49	7.21	1.64	0.681	6.63	1.93	0.190	6.98	1.57	0.418	0.283
	intervention	7.32	1.46	7.50	1.36	0.547	6.26	1.62	0.001*	7.08	1.53	0.029*	0.451
psychological	control	5.79	1.70	6.03	2.11	0.565	6.03	1.93	0.997	6.37	1.88	0.478	0.156
	intervention	5.39	1.63	6.00	1.80	0.091	6.08	1.87	0.856	6.22	1.73	0.731	0.021*
social	control	7.05	1.71	6.72	1.64	0.371	6.10	1.91	0.164	6.58	1.88	0.311	0.246
	intervention	6.82	1.68	6.37	1.87	0.234	5.81	2.14	0.228	6.59	1.63	0.085	0.519
spiritual	control	6.14	1.65	6.44	1.77	0.444	6.40	1.95	0.923	6.84	1.60	0.315	0.060
	intervention	5.55	1.80	6.45	1.87	0.020*	6.76	1.72	0.457	6.70	1.77	0.871	0.003*
total	control	6.36	1.36	6.44	1.70	0.819	6.18	1.71	0.536	6.57	1.60	0.338	0.527
	intervention	6.07	1.31	6.40	1.49	0.270	6.10	1.65	0.410	6.50	1.42	0.266	0.142

* p-value statistically significant
M0= baseline, M3= first meeting with oncologist, M7= after radiotherapy, M8= one year after diagnosis

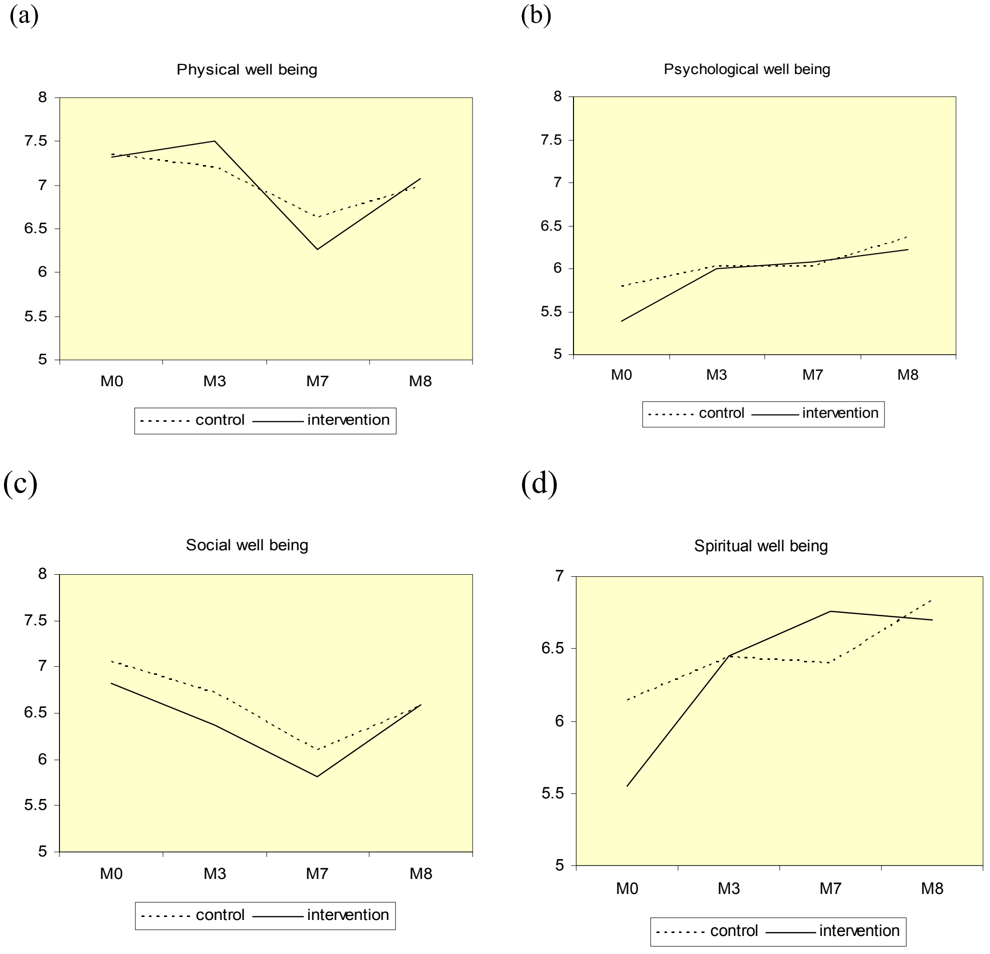


Figure 8. Physical (a), psychological (b), social (c) and spiritual (d) well-being during measurement times in the control and intervention groups on a scale 0-10 (worst to best outcome)

Overall quality of life was better in the control group, but the difference to the intervention group decreased over the course of treatment (Paper IV, Figure 2 and 3). However, there were some significant positive changes in measured variables during the treatment (Figure 8, Table 9). In the intervention group psychological (p=0.021) and spiritual well-being (p=0.003) increased between the baseline (M0) and the last (M8) measurement times, and spiritual well-being (p=0.020) increased between the baseline (M0) and the first meeting with an oncologist (M3) more than in the control group. Physical well-being in the intervention group also decreased significantly more during chemotherapy and radiotherapy treatments (p=0.001).

State of anxiety were measured at baseline (M0), before and after surgery (M1, M2), before and after chemotherapy (M4, M5) and before and after radiotherapy (M6, M7) to indicate the effectiveness of the intervention. Anxiety level was highest (mean 2.53, from scale 1 to 4) at baseline (M0) in the intervention group and before surgery (M1) in the control group (means 2.41). There were no statistically significant differences in anxiety level between the groups; based on this it can be said that the intervention did not have the expected effect. However, anxiety level decreased significantly in both groups during the measurement times, but the decrease in the anxiety was only continuous in the intervention group. The anxiety level also decreased faster among patients in the intervention group. (Table 10, Paper IV, Table 3, Figure 4.)

Table 10. The means of SAI and the groups' internal differences between measurement times.

Measure time		control group	intervention group
M0	mean	2.38	2.53
	SD	0.63	0.68
M1	mean	2.41	2.47
	SD	0.66	0.71
M0-M1	*p*	0.814	0.657
M2	mean	2.09	2.13
	SD	0.53	0.48
M1-M2	*p*	0,021*	0,012*
M4	mean	2.13	1.97
	SD	0.65	0.45
M2-M4	*p*	0.785	0.148
M5	mean	2.14	1.93
	SD	0.6	0.5
M4-M5	*p*	0.954	0.683
M6	mean	1.93	1.91
	SD	0.73	0.56
M5-M6	*p*	0.254	0.889
M7	mean	1.89	1.88
	SD	0.53	0.47
M6-M7	*p*	0.772	0.828
M0-M2	*p*	0,030*	0,002*
M0-M4	*p*	0.109	<.001*
M0-M7	*p*	<.001*	<.001*

M0=baseline, M1=before and M2=after surgery, M4=before and M5=after chemotherapy, and M6=before and M7=after radiotherapy

The side effects related to treatment were measured after chemotherapy (M5, mean control 2.26, intervention 2.28, from scale 1 to 4) and radiotherapy (M7, control 1.80, intervention 1.97). There was no significant difference in the side effects related to treatment between the groups even though patients in the control group had less side effects than those in the intervention group. The intervention did not have an effect on treatment related side effects. The most common side effect was hair loss during chemotherapy and skin reactions during radiotherapy, with fatigue as the second most common side effect during both therapies.

Patient satisfaction with patient education (M7) was better in the control group (control group 1.27, intervention group 1.60, *p*=0.016, scale 1 to 4, 1=very satisfied). The same was also true for the amount of education (1.51, 1.89, *p*=0.003). (Paper III.)

5.2.3 Relationship between outcomes of BCPP program education

This study was based on the theory of empowering knowledge, and correlations between response variables were measured to indicate the relationship between study outcomes. The empowering process is based on cognitive knowledge, which requires patient's awareness of knowledge expectations and perceptions of received knowledge. When the difference between knowledge expectations and perceptions of received knowledge is positive there is a possibility to become empowered. (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007, Heikkinen 2011.) In the next paragraph we analyse the results of the intervention and control group correlating the difference between knowledge expectations and perceptions of received knowledge and other outcomes.

Significant correlations between knowledge expectations and perceptions of received knowledge and clinical outcomes were found only in the intervention group where the relationship was significant with QOL (r=0.594, *p*<0.001) and SAI (r=-0.574, *p*<0.001) (Table 11). When knowledge expectations were fulfilled, the quality of life was better and the level of anxiety was lower. Although the relationship between the difference between knowledge expectations and perceptions of received knowledge was higher in the control group no correlation was found with clinical outcomes. Knowledge expectations and perceptions of received knowledge did not correlate with knowledge level in either of the groups.

Table 11. Relationships between measured outcomes.

	Outcome	Group		KTBC	QOL	SAI	CSE	RSE	Satisfaction
Cognitive outcomes	DIFF KE/RK	control	Correlation	**-0.131**	**-0.124**	**0.071**	**0.177**	**-0.174**	**-0.224**
			p	***0.434***	***0.470***	***0.680***	***0.420***	***0.395***	***0.243***
		intervention	Correlation	**-0.132**	**0.594**	**-0.574**	**-0.210**	**-0.247**	**0.166**
			p	***0.432***	***<0.001****	***<0.001****	***0.315***	***0.166***	***0.326***
	KTBC	control	Correlation	1	-0.134	0.054	0.017	0.185	0.121
			p		*0.428*	*0.756*	*0.936*	*0.337*	*0.509*
		intervention	Correlation	1	-0.144	0.037	0.066	0.039	-0.126
			p		*0.355*	*0.817*	*0.750*	*0.836*	*0.457*
Clinical outcomes	QOL	control	Correlation	-0.134	1	-0.609	-0.242	-0.261	0.314
			p	*0.428*		*<0.001**	*0.244*	*0.149*	*0.086*
		intervention	Correlation	-0.144	1	-0.706	-0.316	-0.298	0.271
			p	*0.355*		*<0.001**	*0.108*	*0.092*	*0.086*
	SAI	control	Correlation	0.054	-0.609	1	0.130	0.267	-0.326
			p	*0.756*	*<0.001**		*0.527*	*0.147*	*0.073*
		intervention	Correlation	0.037	-0.706	1	0.289	0.371	-0.151
			p	*0.817*	*<0.001**		*0.153*	*0.037*	*0.352*
	CSE	control	Correlation	0.017	-0.242	0.130	1	-0.245	-0.053
			p	*0.936*	*0.244*	*0.527*		*0.326*	*0.806*
		intervention	Correlation	0.066	-0.316	0.289	1	0.280	0.438
			p	*0.750*	*0.108*	*0.153*		*0.219*	*0.020**
	RSE	control	Correlation	0.185	-0.261	0.267	-0.245	1	-0.336
			p	*0.337*	*0.149*	*0.147*	*0.326*		*0.137*
		intervention	Correlation	0.039	-0.298	0.371	0.280	1	0.102
			p	*0.836*	*0.092*	*0.037**	*0.219*		*0.599*

* Statistically significant, Correlation measured with Pearson Correlation

DIFF KE/RK= difference between knowledge expectations and perceptions of received knowledge, KTBC= Breast Cancer-related knowledge, QOL= quality of life, SAI=state anxiety, CSE=chemotherapy side effects, RSE=radiotherapy side effects

6 DISCUSSION

The purpose of this study was to obtain evidence on how the usage of the BCPP program affects breast cancer patients' empowering process from the viewpoint of cognitive outcomes (knowledge expectations, perceptions of received knowledge, the difference between knowledge expectations and perceptions of received knowledge, knowledge level) and clinical outcomes (quality of life, anxiety and treatment related side-effects). In addition, in this study the BCPP program was evaluated from the point of view of content, external appearance, instructiveness, language and structure. This discussion begins by looking at the validity and reliability of the study, followed by comparing the main results of this study with earlier research. Finally, a summary and conclusions with challenges for nursing practice and educations as well as future research needs are presented.

6.1 Validity and reliability of the study

The validity of the study can be seen as a measure of the truth or accuracy of a claim, and it is an important concern throughout the research process (Burns & Groove 2005, DeVon 2007). The validity and reliability of this study is first discussed from the viewpoint of instruments and intervention, then from the viewpoint of data, data collection and data analysis, and finally from the viewpoint of results.

6.1.1 Validity and reliability of the instruments and intervention tested

In this study both previously tested valid instruments as well as modified, translated and new instruments were used. Most instruments were pretested, and all instruments were piloted in phase III. In phase III seven different instruments were used. All developed instruments or those translated into Finnish were pretested with 20 breast cancer patients undergoing treatments before data collection and subsequently analysed. During pretesting patients were asked to comment on the questionnaires if necessary. The internal consistency of the instruments used in the present study assessed with Cronbach's alpha coefficients is presented in Table 5.

Knowledge expectations and perceptions of received knowledge in the hospital instruments (HPKE, HPRK) have been used earlier in Leino-Kilpi (2005), Rankinen (2007) and Heikkinen (2007, 2011). Those instruments were developed earlier based on the theory of empowering knowledge (Leino-Kilpi et al. 1998, 1999, 2005, Heikkinen et al. 2007, Rankinen et al. 2007). Content validity of instruments is estimated on the basis of theoretical literature and by an expert panel of researchers and nurses in clinical practice (Leino-Kilpi et al. 2005, Heikkinen et al. 2007, Rankinen et al. 2007). The reliability of the HPKE and HPRK instruments has been tested with Cronbach's alpha coefficients. The alpha coefficient of HPRK has varied from 0.90 to 0.93 for total scale and 0.87–0.90 for the subscales (bio-physiological, functional, experiential, ethical, social, and financial). HPRK has varied from 0.90 to 0.93 for total scale and 0.80–0.93 for the subscales among surgical patients (Leino-Kilpi et al. 2005, Heikkinen et al.

2007, Rankinen et al. 2007). A reliability coefficient of 0.80 is considered the lowest acceptable value (Burns & Groove 2005). On the basis of earlier studies these instruments have been shown to be valid. In this study HPKE and HPRK were used for the first time with breast cancer patients.

The PRKE and PRRK related to the breast cancer pathway were collected with two structured parallel questionnaires developed in this study. These questionnaires assessed knowledge related to patient's treatment process (e.g. treatment options, duration, institutions, effects on daily living). Content validity of instruments was based on theoretical literature.

Breast cancer-related knowledge level was assessed with the 'Knowledge Test for Breast Cancer Patient', which is a questionnaire developed in this study that is based on the theory of empowering knowledge (Leino-Kilpi et al. 2005, Heikkinen et al. 2007, Rankinen et al. 2007). Content validity of the instruments was estimated on the basis of theoretical literature and a panel of experts, and the instrument was pretested with 20 breast cancer patients.

Quality of life was assessed with the Quality of Life Instrument - Breast Cancer Patient Version (Ferrell et al. 1995a, 1995b, 1996). The instrument includes four subscales of quality of life including physical, psychological, social and spiritual well-being. In earlier studies the reliability of the instrument included test, re-test and internal consistency. The Cronbach's alpha co-efficient analysis revealed an overall 0.93 and alphas for physical 0.77, psychological 0.89, social 0.81, and spiritual 0.71 well-being subscales. (Ferrell et al. 1995a, 1995b, 1996.)

The instrument was first translated into Finnish, after which the translation was assessed by an expert group, followed by back-translation into English and comparison with the original instrument (Cha et al. 2007). The instrument was pretested with 20 breast cancer patients. Cronbach's alpha was also measured to validate the instrument for Finnish language and culture. Three questions were excluded from the domain of spiritual well-being because of the basis of alpha and face validity of experts. In addition to alpha, the questions did not fit to the Finnish culture. (Cha et al. 2007.)

Anxiety was assessed with the State Anxiety scale of The State Anxiety Inventory (STAI), which is a valid and widely used instrument to measure anxiety (Spielberger 1972, 1983, 1999) and also used to measure outcomes of Internet-based patient education with breast cancer patients (Green et al. 2004, Heller et al. 2008). A Finnish version of the STAI (Aro 1996) instrument includes Trait anxiety (T-Anxiety) and State anxiety (S-Anxiety, SAI) scales. S-Anxiety scale was used in this study. This version has earlier been used among women undergoing mammography screening (Aro 1996), among women having caesarean delivery (Kiviniemi 2006), among coronary patients (Koivula et al. 2001, 2002) and among total hip arthroplasty patients (Montin 2007). In earlier studies the overall median alpha coefficient for the S-Anxiety scale in the normative samples was 0.92, and it's concurrent, divergent and constructs validity has been tested in many ways.

Side effects of chemotherapy and radiotherapy treatments were assessed with two instruments designed by the researchers. The instruments were pretested with 20 patients each. Content validity of instruments was estimated on the basis of theoretical literature and by a panel of experts. The source of information and satisfaction with patient education were also measured with a questionnaire designed for the present study and asked with one multiple-choice question.

The last one was the Evaluating Internet Pages of Patient Education instrument, which is a structured instrument developed earlier to evaluate written educational material (Johansson 2004b, Ryhänen 2009) that was modified for this study. During the modifying process the items were changed to estimate web pages' suitability and one subcategory was added, the technical characteristics of the program. The instrument was modified by the research team in collaboration with nurses in clinical practice and pretested with six breast cancer patients before data collection in phase II. The content evaluation of this instrument was based on the theory of empowering knowledge (Leino-Kilpi et al.1998, 1999, Heikkinen et al. 2007). Content validity of the instrument was based on theoretical literature and it was pretested in phase II.

We tested the reliability of instruments with Cronbach's alpha coefficients to measure how well each individual item in a scale correlated with the sum of all items of the instrument or subscales. When evaluating alpha total some instruments (HPKE, QOL, SAI, EIPPE) indicated values that were too high (0.94 or more), which could be mean that items of the instrument measure the same subject. However, when studying alpha subscales the values were lower. On the other hand, some instruments had low (PRKE, CSE, RSE) or even weak alphas in the QOL spiritual subscale. However, those instruments were developed for this study and low alpha is acceptable. When using a new instrument Cronbach's alpha coefficient of 0.7 can be considered acceptable. (Burns & Groove 2005, Table 5.) The validity of knowledge test instruments needs more research.

The validity of the intervention can be discussed from some points of view. First, the intervention was pretested with six breast cancer patients who had undergone all the treatments. Second, previous studies in the systematic literature review provided evidence that Internet-based interventions have an effect on the knowledge level and varying clinical outcomes. Third, the researcher met all the participants in the intervention group and an educational session was given in the same way every time, making sure that the patients knew how to use the program by themselves. Fourth, the content of the intervention was similar to all patients. Finally, all the patients received standard oral and written patient education, and the hospital staff did not know which group the patients belonged to when they educated them.

6.1.2 Validity and reliability related to data, data collection and data analyses

In the second phase data were collected among six breast cancer patients with a Delphi study using a questionnaire. Five patients returned the questionnaire completed. (Paper II.) A systematic review was conducted in order to find out the effectiveness of Internet- or interactive computer-based patient educational programs in the field of breast cancer. The papers were searched and analysed independently and collectively by three researchers. (Paper I.)

In the third phase the target population for this study consisted of all breast cancer patients who were Internet users and met the inclusion criteria in one Finnish university hospital. A power analysis was performed to ascertain the necessary sample size. Using quality of life psychological well-being scores as a gauge power analysis assuming an ability to detect one unit difference between the groups was performed; this showed that 40 patients were needed for a power level of 0.80 and a probability level 0.05 when standard deviation is 1.59 units. However, one unit difference between the groups was not performed. (Paper III, Paper IV.)

In the third phase a randomised controlled trial was used to examine the effects of the intervention by comparing the intervention group with a control group. Randomisation means that each participant has a greater than zero chance of being selected for a sample. (Moher et al. 2001, Burns & Groove 2005, Schulz et al. 2010, Augestad et al. 2012.) Participants were randomized to the control and intervention group based on age and professional education with the help of a randomisation table by a breast cancer nurse. The randomisation table was used in an attempt to ensure similarity of the groups. Women in the control and intervention groups were comparable in terms of other demographic variables except basic education. (Paper III, Paper IV.) Participants in the control group had less basic education than participants in the intervention group. The patients were randomised to control and intervention groups according to age and professional education, because we considered professional education to be a more important and relevant background variable than basic education before adulthood. Because the age cohort in question is quite old (mean 55 years) what they have done after their basic education is more relevant. The sample size limits the amount of attention that can be given to individual factors in the final analyses without power suffering too much, which is why only professional education was taken into account as a mixer in the research plan. Although there was significant difference between the groups in basic education it did not correlate with other variables (Paper III). Patients in the intervention group were more anxious and their psychological well-being was lower at baseline. However, there was no difference between the groups during further data collection (Paper IV).

In this study the data were collected during follow-up according to the treatment process instead of time limits. The patients who answered the questionnaire were in the same situation in regard to their care. (Paper III, Paper IV.) The aim of using this method was a wish to utilise crucial moments in patient education; because the patients were at the same point of treatment when they answered the questionnaires the results can be compared.

6.1.3 *Validity and reliability of the results*

In phase II only five patients (out of six) returned the Delphi questionnaire completed. This sample is small and the results can be seen as being indicative. The methodological quality of the solutions used in the studies reviewed also varied, and none of the studies covered all the evaluated issues. (Paper I.) In phase III the response rate was 92%, which can be considered a very good result (Burns & Groove 2005). However, the sample size could have been bigger, but this would have required more time for data collection, which lasted three years in the present case. The data collection should be well-timed to make sure that the changes that take place in care do not affect the results. (Paper III, Paper IV.)

Patients who did not consent to participate in the study were asked to complete the background questionnaire, and it was returned completed by 22 patients. When comparing the three groups or participants to nonparticipants, demographic variables differed statistically significantly in terms of basic education and professional education: 45.5% of nonparticipants had basic education at the lowest level, while 36.8% had no professional education at all. (Table 3.) Based on this finding it can be said that those with less education chose not to take part in the study.

The data were collected in one university hospital and the population comprised one hospital district. The study population was substantially younger than breast cancer patients' average in Finland (Finnish Cancer Registry 2008) and one inclusion criteria was Internet use. The results can thus be generalized to younger breast cancer patients who are Internet users and who are treated in any of the university hospitals in Finland.

6.2 Comparing the findings with previous research results

In this study a new patient education tool, the BCPP program was developed and tested with newly diagnosed breast cancer patients. The purpose of this study was to obtain evidence on how the usage of the BCPP program affects breast cancer patients' empowering process from the viewpoint of cognitive outcomes (knowledge expectations, perceptions of received knowledge, the difference between knowledge expectations and perceptions of received knowledge, knowledge level) and clinical outcomes (quality of life, anxiety and treatment related side-effects).

6.2.1 *Internet-based educational interventions*

Earlier studies have reported that the educational solutions used to educate breast cancer patients via the Internet are usually created for a special purpose and are used during the nursing process for a short time or only once (Paper I). The BCPP program differs from the others in its purpose and duration. The idea of the BCPP program is that it guides the patient through the breast cancer treatment process and shows all the possible treatment options the patient can have in her pathway. The ultimate goal of the

BCPP program is to empower the patient, and it is based on the theory of empowering knowledge (Leino-Kilpi et al.1998, 1999, Heikkinen et al. 2007). The patient can use the BCPP program during the entire breast cancer treatment process as often as she wants (Paper II). According to the results of the systematic review the educational solutions to educate breast cancer patients were described as interactive computer or multimedia programs (Paper I). Also in this study BCPP is called a program. However, the solutions of BCPP can also be called an educational environment or portal for breast cancer patients.

The BCPP program was evaluated with a purpose designed instrument, which has earlier been used to evaluate written educational material (Johansson et al. 2004b, Ryhänen et al. 2009). According to the results evaluations between subcategories varied, being the highest in language and structure and lowest in content and instructiveness. In Johansson's et al. (2004b) and Ryhänen's et al. (2009) studies of written educational material there was also much room for improvement with regard to content, whereas external appearance received the best scores. Ahlers-Schmidt et al. (2006) found that language presented in breast cancer sites was too advanced for the patients. However, in this study medical jargon was avoided, or if it was used it was expounded, and language and structure were thus evaluated to be the best. This result is similar with the study of Green et al. (2004) where breast cancer patients evaluated a computer-based educational intervention as being easy to understand with 100 per cent agreement. During the Delphi round and educational meeting with the researcher many patients expressed satisfaction with the BCPP program. Also Jibaja et al. (2000) and Loiselle et al. (2010) found that patients were very satisfied with interactive programs. The BCPP program was used on all the days of the week and although mostly in the daytime the period from 1 to 3 a.m. was the only time without visitors. This result shows that this kind of patient education method is needed.

6.2.2 Outcomes of Internet-based empowering education for breast cancer patients

6.2.2.1 Cognitive outcomes of Internet-based patient education

The use of the BCPP program did not increase breast cancer patients' perceptions of received knowledge or decrease their knowledge expectations as expected. One reason for this can be the study design. Knowledge expectations were measured at the beginning and perceptions of received study at the end on data collection, on average nine months later. Another reason can be that the knowledge a patient obtains from the BCPP program may increase her knowledge expectations during breast cancer treatment process. According to studies with surgical or ambulatory patients knowledge expectations were not fulfilled when comparing knowledge expectations and perceptions of received knowledge (Heikkinen et al. 2007, Rankinen et al. 2007). The same result was found in this study with breast cancer patients. However, the difference between patients' knowledge expectations and perceptions of received knowledge was smaller in the control group. This is why the first hypothesis of this study must be rejected. When a patient's knowledge expectations are fulfilled there is a possibility to be cognitively empowered. However, this calls for awareness of knowing and knowledge expectations (Leino-Kilpi et al. 1998, 1999, 2005, Heikkinen 2011), which were not measured in this study. Therefore we cannot say that control group patients were more cognitively empowered. The patients in the control group were more satisfied with patient education and its amount while patients in the intervention group expected to have more patient education and were less satisfied with it.

According to previous research, Internet or interactive multimedia programs are effective in increasing knowledge level or higher health information competence with program users in comparison with control group patients (Street et al. 1995, Jibaja et al. 2000, Gustafson et al. 2001, Green et al. 2004, Whelan et al. 2004, Ozanne et al. 2007, Shaw et al. 2007a, Heller et al. 2008, Jibaja-Weiss et al. 2011, Albada et al. 2012b). Also in this study, the knowledge level of patients in the intervention group was significantly higher one year after diagnosis. In both groups patients were best acquainted with issues related to the bio-physiological aspects of empowerment. (Paper III.) Heikkinen et al. (2008) have studied Internet-based education with ambulatory surgery patients and found that they have best knowledge of issues related to the social dimension of empowerment two weeks after surgery, with the bio-physiological dimension coming second (control group) or third (intervention group). The KTBC includes one question about a rehabilitation nurse, and it could be that most of the patients mixed her up with a physiotherapist, because only a few patients knew the right answer, only one of them in the control group. However, when the KTBC was pretested during radiotherapy period over 33% knew the right answer. It could be that patients forgot the meeting with the rehabilitation nurse during the time from radiotherapy to one year after diagnosis. The hypothesis that the use of the BCPP program increases breast cancer patients' empowering knowledge related to breast cancer care more compared to standard patient education can be retained.

6.2.2.2 Clinical outcomes of Internet-based patient education

Empowerment cannot be measured in and of itself (Rappaport 1984). Therefore it has to be measured by its outcomes. Quality of life has been used to measure the outcome of empowerment (Funnell et al. 1991, Corrigan 1999, Falk-Rafael 2001, Leino-Kilpi et al. 2005) and as an outcome of Internet-based education for breast cancer patients (Gustafson et al. 2001, Loiselle et al. 2005, Owen et al. 2005). The effect of intervention on quality of life has been non-significant in earlier studies (Gustafson et al. 2001, Loiselle et al. 2005, Owen et al. 2005), and the same result is shown in this study, even though the quality of life in the intervention group increased more during measurement times than in the control group. Anxiety has been assessed with the State-Trait Anxiety Inventory (STAI) in many studies (Green et al. 2004, Whelan et al. 2004, Loiselle et al. 2005, Heller et al. 2008), but the findings have mostly been non-significant. No significant difference was found in this study, either, when comparing the groups. However, the anxiety level decreased faster in the intervention group than in the control group. No significant effect was found when comparing side effects between the groups. (Paper IV.) Hypothesis II therefore has to be rejected in this study.

6.2.2.3 Relationship between outcomes of Internet-based patient education

As an outcome of empowering patient education patients can reach a better quality of life (Funnell et al. 1991, Gibson 1991, Corrigan 1999, Falk-Rafael 2001, Leino-Kilpi et al. 2005) and have less anxiety and have control over their life situation in spite of illness (Treacy & Mayer 2000) as well as increased self-care (Chandler 1992). In this study significant correlations between cognitive and clinical outcomes were found in the intervention group with QOL and SAI (Table 10). This supports the theory of empowerment in which a positive difference (from 0 to +3) between knowledge expectations and perceptions of received knowledge enables the patient to become empowered (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007, Heikkinen 2011). Although the relationship between the difference between knowledge expectations and perceptions of received knowledge was higher in the control group no correlation was found with clinical outcomes. Also in the study by Leino-Kilpi et al. (2005) a positive relationship was found between received knowledge and health-related quality of life. These results support the theory that the empowering process requires patient's awareness of knowledge expectations and perceptions of received knowledge (Leino-Kilpi et al. 1998, 1999, 2005, Rankinen et al. 2007, Heikkinen 2011). The relationship between the difference between knowledge expectations and perceptions of received knowledge and anxiety was studied here for the first time, which is why evidence from earlier studies is not available.

6.3 Conclusion

According to the results of this study, the Internet is an effective patient education method for increasing knowledge, and the BCPP program can be used as a patient education tool supporting other education methods. Breast cancer patients' perceptions of received knowledge were not met; their knowledge expectations are bigger than their perception of received knowledge. Although control group patients' knowledge expectations were better fulfilled with the knowledge they received in hospital when compared to intervention group patients, no statistical differences were found between the groups in quality of life, anxiety and treatment related side effects. However, anxiety decreased faster in the intervention group when examining the groups' internal differences between measurement times. In the intervention group the relationship between the difference between knowledge expectations and perceptions of received knowledge correlated significantly with quality of life and anxiety. Their knowledge level was also significantly higher than the knowledge level in the control group. Between groups the effect of intervention was not found, contrary to the hypothesis. However, these results support the theory that the empowering process requires patient's awareness of knowledge expectations and perceptions of received knowledge, and that new patient education methods are needed to increase breast cancer patients' awareness.

Implications for nursing practice

The Internet offers the possibility to choose the time and frequency of reading for patients as well as their significant others. It should be used as a supportive method when educating breast cancer patients. BCPP program can be used as one solution when educating patients via the Internet. From the viewpoint of breast cancer patients, the amount of information they must deal with during hospital visits is overwhelming, which is why other patient education methods are needed to support oral information (Saares & Suominen 2005, Leino 2011). Alternative patient education methods are needed because patients are not always capable of posing questions to health care professionals because they do not know, dare or remember to ask about the matters that occupy the mind (Salonen et al. 2009, 2011, Leino 2011).

Based on the results of this study the following challenges for nursing practice can be identified:

- The basis of patient education should be the patient's expectations instead of educating all patients in the same way. The assessment of breast cancer patient knowledge expectations and its evaluation should be included in patient education. Instruments to measure breast cancer patient's knowledge expectations must be developed for clinical use in order to help individual breast cancer patient education to confirm patient's informed decisions. During the breast cancer treatment process the patient has to make decisions about her care. She needs more knowledge to be able to participate in her care. It is the responsibility of the healthcare professionals to make sure that the patient has the knowledge she needs for decision-making.

- Internet-based patient education methods can be effective education methods and support oral education. The content of these methods should be based on scientific evidence.

- Breast cancer patient's knowledge expectations cover all dimensions of empowerment. In addition to bio-physiological knowledge also functional, social, experiential, ethical and financial knowledge are expected. This should be considered in oral as well as other patient education methods. From the point of clinical outcomes the patient's anxiety level needs more attention in breast cancer patient education. Anxiety has a strong effect on the patient's quality of life, which is why patient education methods aimed to decrease anxiety level are needed. More patient education is also needed to explain how to manage with treatment relate side effects.

Suggestions for nursing research:

- Future research is needed to develop the theory of empowering patient education. The relationship between knowledge level and the difference between knowledge expectations and perceptions of received knowledge needs more research, particularly how the empowering process is affected by an increasing knowledge level. Future research is needed to define what happens to patient's knowledge expectations and on its effect on perception of received knowledge when patient's knowledge level increases. Interventions with possibilities to fulfil knowledge expectations should be developed and tested from the viewpoint of empowering patient education.

- More research is needed to develop the BCPP program into a more powerful patient education method to empower breast cancer patients. The Internet offers multiform ways to create new types of applications for patient education, but there is a lack of knowledge of how to utilise them. More technical solutions and interactive programs could be used when developing the BCPP program.

- More research is needed to find out how health care professionals or organisations can utilize the BCPP program. The BCPP program can be used to increase health care professionals' competence of breast cancer patient education or to educate recently graduated nurses or doctors. This will also require readiness and time to teach patients to use the computer if there is a need to it. The BCPP program can be used as a patient education method in different points of a breast cancer patient care and treatment pathway.

- The ethical aspects of Internet-based patient education need more attention. Breast cancer patients and their significant others should be asked about their experiences of Internet-based education. More research is needed to evaluate what effect Internet pages have on breast cancer patient's fears. This emphasises the need of reliable Internet sites where knowledge is accurate and produced without any commercial purpose.

- A wide variety of instruments have been developed to measure empowerment. In this study HPKE and HPRK were used to measure the possibility of being empowered. These instruments as well as the KTBC need more validation.

Worldwide, breast cancer is the most common cancer in women, with its incidence growing yearly (Parkin et al. 2005, Globocan 2008). In Finland, in 2009 almost 4,500 women were diagnosed with breast cancer; at the same, the duration of hospital stays has become increasingly shorter (Finnish Cancer Registry 2011, OECD Health Data 2011). This poses challenges for patient education, creating a need for new patient education methods. The importance of patient education is also addressed in law (Act on the Status and Rights of Patients 785/1992) and national healthcare plans (Ministry of Social Affairs and Health 2001, 2003, 2009, National Knowledge Society Strategy 2007–2015, KASTE 2008–2011, 2012–2015), along with the importance of possibilities of finding cancer knowledge on the Internet and participating in decision-making in cancer care (Ministry of Social Affairs and Health 2010).

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Turku, 30 October 2012

APPENDICES

Appendix 1 1(1)

Turun yliopisto, Hoitotieteen laitos
Turun yliopistollinen keskussairaala
Potilasohjauksen tuloksellisuuden arviointi

Seuraavassa Teitä pyydetään arvioimaan muutaman kysymyksen avulla **koekäyttämiänne potilaanpolun Internet-sivuja**. Vastatkaa niihin kysymyksiin, jotka koette tarpeelliseksi. Kysymyksiin ei ole olemassa oikeita tai vääriä vastauksia vaan tavoitteena on kartoittaa tilannetta **juuri Teidän kohdallanne**.

1. Millaista rintasyöpään ja sen hoitoon liittyvää tietoa olisitte halunnut lisää? Luetelkaa niitä asioita, joista olisitte kaivannut lisää tietoa.

____
____
____

2. Oliko sivuilla jotakin sellaista, mitä ette olisi siellä halunneet olevan tai katsotte olevan tarpeetonta? Kertokaa lyhyesti mitä.

____
____
____

3. Oliko sivuilla jotakin sellaista, mitä oli mielestänne väärin? Kertokaa lyhyesti mitä.

____
____
____

4. Voitte vielä kommentoida vapaasti niin halutessanne potilaanpolun Internet-sivuja paperin kääntöpuolelle.

Kiitos vastauksistanne!

Appendix 2 1(2)

Turun yliopisto, Hoitotieteen laitos
Turun yliopistollinen keskussairaala
Potilasohjauksen tuloksellisuuden arviointi

Pyydämme Teitä vastaamaan joihinkin **itseänne koskeviin tietoihin.** Valitkaa rastittamalla Teille parhaiten soveltuva vaihtoehto tai kirjoittakaa vastauksenne sille varattuun tilaan.

1. Ikänne ________ vuotta

2. Siviilisäätynne
avioliitossa tai avoliitossa ☐
naimaton ☐
eronnut ☐
leski ☐

3. Peruskoulutuksenne
kansakoulu (tai vähemmän) ☐
keski- tai peruskoulu ☐
ylioppilas ☐

4. Ammattikoulutuksenne
ei ammattikoulusta ☐
kouluasteen ammattitutkinto ☐
opistoasteen ammattitutkinto ☐
korkeakoulututkinto ☐

5. Mikä seuraavista kuvaa parhaiten pääasiallista toimintaanne?
Työssä ☐
Eläkkeellä ☐
Kotityössä ☐
Opiskelija ☐
Työtön/työnhakija ☐
Muu, mikä?___________________ ☐

6. Oletteko koskaan työskennellyt sosiaali- tai terveydenhuollossa?
Kyllä ☐, missä tehtävässä _____________________
En ☐

Appendix 2 2(2)

7. Sairastatteko jotakin pitkäaikaista sairautta?

Kyllä ☐, mitä ________________________________
En ☐

8. Onko teillä lapsia?

Kyllä ☐, montako ____
minkä ikäisiä_________________________
Ei ☐

9. Mikä on kuukausittaisten tulojenne käteen jäävä määrä verotuksen jälkeen?

Ei lainkaan tuloja ☐
Alle 1000 euroa ☐
1000–2000 euroa ☐
Yli 2000 euroa ☐

10. Onko joku läheisenne sairastunut rintasyöpään (esim. äiti, sisko, ystävä tai työtoveri)?

Kyllä ☐
Ei ☐

11. Oletteko kertonut sairastumisestanne kellekään läheisellenne?

Kyllä ☐
Ei ☐

12. Onko teillä mahdollisuus halutessanne keskustella sairauteenne liittyvistä asioista jonkun kanssa luottamuksellisesti?

Kyllä, aina tai lähes aina kun tarvitsen ☐
Joskus tai joissain asioissa ☐
Ei yleensä tai ei monissakaan asioissa ☐
Ei koskaan ☐
En osaa sanoa ☐

Kiitos vastauksestanne!

Appendix 3 1(2)

Turun yliopisto, Hoitotieteen laitos
Turun yliopistollinen keskussairaala
Potilasohjauksen tuloksellisuuden arviointi

Pyydämme Teitä vastaamaan joihinkin **itseänne koskeviin tietoihin.** Valitkaa rastittamalla Teille parhaiten soveltuva vaihtoehto tai kirjoittakaa vastauksenne sille varattuun tilaan.

1. Mistä olette saanut tietoa sairastumisenne aikana? Rastittakaan kaikki ne vaihtoehdot, joista saitte tietoa ja merkitkää viivoille kolme tärkeintä lähdettä tärkeysjärjestyksessä (1 tärkein).

Lääkäriltä ☐ ___
Hoitajalta ☐ ___
Tukihenkilöltä ☐ ___
Perheenjäseniltä ☐ ___
Ystäviltä ja tutuilta ☐ ___
Toiselta rintasyöpäpotilaalta ☐ ___
Internetistä ☐ ___
Lehdistä ☐ ___
Kirjoista ☐ ___
Kirjallisista potilasohjeista ☐ ___
Oppaista ☐ ___
TYKSin potilasinfokeskus Tietolähteestä ☐ ___
Rintasyöpäpotilaan hoitopolun kuvauksesta ☐ ___
Televisiosta ☐ ___
Joku muu, mikä _______________ ☐ ___

2. Yrittäkää arvioida, miten monta kertaa otitte yhteyttä lääkäriin tai hoitajaan saadaksenne tietoa hoitoonne tai sairauteenne liittyvistä asioista

en kertaakaan ☐
__________ kertaa ☐

3. Miten tyytyväinen olette sairaalan henkilökunnalta saamaanne potilasohjaukseen?

Erittäin tyytyväinen ☐
Melko tyytyväinen ☐
En oikein tyytyväinen ☐
En ollenkaan tyytyväinen ☐
En osaa sanoa ☐

Appendix 3 2(2)

4. Miten tyytyväinen olette saamaanne potilasohjauksen määrään?

- Erittäin tyytyväinen ☐
- Melko tyytyväinen ☐
- En oikein tyytyväinen ☐
- En ollenkaan tyytyväinen ☐
- En osaa sanoa ☐

5. Oletteko kertonut sairastumisestanne kenellekään läheisellenne?

- Kyllä ☐
- En ☐

6. Onko Teillä ollut mahdollisuus halutessanne keskustella sairauteenne liittyvistä asioista jonkun kanssa luottamuksellisesti?

- Kyllä, aina tai lähes aina kun tarvitsen ☐
- Joskus tai joissain asioissa ☐
- Ei yleensä tai ei monissakaan asioissa ☐
- Ei koskaan ☐
- En osaa sanoa ☐

7. Mikäli haluatte enemmän ohjausta, mistä asioista ja miten olisitte halunnut sitä saada?

Appendix 4 1(1)

Potilastiedote
Hyvä potilas!

Haluamme kehittää antamaamme hoitoa ja potilaan saamaa ohjausta. Pyydämme Teitä osallistumaan tutkimukseen, jonka avulla pyritään kehittämään potilasohjausta vastaamaan mahdollisimman hyvin potilaiden tarpeita. Tutkimukseen pyydetään mukaan jokainen rintasyöpään sairastunut potilas, jolla on mahdollisuus käyttää Internetiä tiedon hakemiseen. Tutkimuksella pyritään selvittämään Internetin käyttömahdollisuutta potilasohjauksessa. Tämän tutkimuksen tarkoitus on selvittää antamamme potilasohjauksen vaikuttavuutta rintasyöpäpotilaan elämänlaatuun, hoitojen aiheuttamiin sivuvaikutusten, kokemukseen tiedon tarpeesta ja tiedon saannista sekä hoitotoimenpiteisiin liittyvään ahdistuneisuuteen. Keräämällä tietoa koko hoitonne ajalta voimme seurata ohjauksen vaikuttavuutta hoitonne eri vaiheissa.

Tutkimusaineiston keruu tapahtuu siten, että se aiheuttaa Teille mahdollisimman vähän haittaa. Tutkimuksen aikana Teille annetaan sairaalassa käyntien yhteydessä täytettäväksi kyselylomakkeita. Voitte täyttää lomakkeet sairaalassa käyntien yhteydessä. Lomakkeet voitte palauttaa mukana olevassa kuoressa hoitajalle tai postittaa tutkijalle.

Tutkimukseen osallistuminen on Teille vapaaehtoista eikä se vaikuta hoitoonne. Toivon Teidän suhtautuvan tutkimukseen myönteisesti, sillä se auttaa potilaan ohjauksen kehittämisessä. Tutkimukselle on saatu sairaalasta asianmukaiset tutkimusluvat. Henkilöllisyytenne ei tule ilmi missään tutkimuksen vaiheessa. Halutessanne voitte keskeyttää tutkimuksen.

Ystävällisin terveisin

Anne Ryhänen

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VSSHP, hallintokeskus

Appendix 5 1(1)

POTILAAN SUOSTUMUS

Suostun osallistumaan tutkimukseen ”**Internet-pohjaisen hoitopolun kuvaus voimavaraistavan**
potilasohjauksen välineenä”

Minulle on selvitetty tutkimuksen tarkoitus ja tiedän, että tutkimukseen osallistuminen on vapaaehtoista. Tutkimukseen osallistuminen ei vaikuta hoitooni. Halutessani voin keskeyttää tutkimuksen. Annan tutkijalle luvan kerätä tietoa potilasasiakirjoistani leikkauksesta, lääkityksestä ja hoitoihini liittyviä asioita. Henkilötietoni säilyvät salassa.

Haluan osallistua tutkimukseen

Nimi:______________________________

Syntymäaika:
____

Turussa _____, ______kuuta 200______

Osoite:
____
____

Sähköpostiosoite:
____

Puhelinnumero:
____

____
Allekirjoitus
ja nimen selvennys

____
Tutkija Anne Ryhänen

Haluan, että tutkija ottaa minuun yhteyttä tutkimustulosten valmistuttua ja kertoo tutkimuksen keskeiset tulokset

kyllä ☐
ei ☐

Tämä suostumus palautetaan kirurgian poliklinikan sairaanhoitajalle. Suostumuslomakkeet säilytetään luottamuksellisesti tutkijalla siihen asti, että aineisto on koottu ja tutkimustulokset raportoitu. Tämän jälkeen lomakkeet hävitetään asianmukaisesti.

Appendix 6 1(1)

Hyvä tutkimukseen osallistuja!

Olette antanut suostumuksenne tutkimukseen, jonka avulla pyritään kehittämään potilasohjausta vastaamaan mahdollisimman hyvin potilaiden odotuksia. Ohessa ovat tähän tutkimuksen vaiheeseen kuuluvat kyselylomakkeet. Pyydän, että täyttäisitte kaikki lomakkeet ja palauttaisitte ne mukana olevassa kuoressa hoitajalle tai niille osoitettuun laatikkoon. Halutessanne voitte myös palauttaa vastaukset palautekuoressa postitse tutkijalle, sillä palautekuoren postimaksu on maksettu.

Haluaisin muistuttaa Teille vielä, että tutkimukseen osallistuminen on Teille vapaaehtoista eikä se vaikuta hoitoonne. Pyydän Teidän suhtautuvan tutkimukseen myönteisesti, sillä se auttaa potilaan ohjauksen kehittämisessä. Henkilöllisyytenne ei tule ilmi missään tutkimuksen vaiheessa. Halutessanne voitte keskeyttää tutkimuksen. Tutkimukselle on saatu sairaalasta asianmukaiset tutkimusluvat.

Kiitos osallistumisestanne!

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Appendix 7 1(1)

Hyvä tutkimukseen osallistuva!

Olette antanut suostumuksenne tutkimukseen, jonka avulla pyritään kehittämään potilasohjausta vastaamaan mahdollisimman hyvin potilaiden tarpeita. Tämän tutkimuksen tavoitteena on selvittää Internetin käyttömahdollisuutta potilasohjauksessa. Varsinais-Suomen sairaanhoitopiirissä olemme tehneet moniammatillisessa yhteistyössä potilaille Internet-sivuston, jossa kuvataan rintasyöpäpotilaan hoitopolku aina syöpäepäilyksen syntymisestä hoitojen loppuun. Arpa on valinnut Teidät sattumanvaraisesti koeryhmään, johon kuuluvat pääsevät käyttämään rintasyöpäpotilaan hoitopolkua. Toivon Teidän tutustuvan rintasyöpäpotilaalle tarkoitettuun hoitopolun Internet-sivustoon. Ne löytyvät Internetistä osoitteesta http://hoitoreitit.vsshp.fi. Sivuston auki saamiseksi tarvitsette käyttäjätunnuksen sekä salasanan, jotka ovat kirjeen alaosassa. Tutkija opastaa Teitä rintasyöpäpotilaan hoitopolun Internet-sivuston käytössä.

Tämän tutkimuksen tavoitteena on selvittää rintasyöpäpotilaan hoitopolun vaikuttavuutta potilaan elämänlaatuun, hoitojen aiheuttamiin sivuvaikutusten, tiedon tarpeeseen ja tiedon saantiin sekä hoitotoimenpiteisiin liittyvään ahdistuneisuuteen. **Luetettavan tutkimustuloksen aikaansaamiseksi on äärimmäisen tärkeää, että ette luovuta omaa käyttäjätunnustanne ja salasanaanne muiden käyttöön**, sillä samanaikaisesti kerätään tietoa henkilöiltä, joille ei ole mahdollista tutustua hoitopolkuun. Mikäli Teitä lähestyy henkilö, joka haluaisi saada tietoonsa hoitopolkuun liittyviä asioita, voitte pyytää häntä ottamaan yhteyttä tutkijaan. **Pyydän Teitä ottamaan yhteyttä tutkijaan, mikäli havaitsette ongelmia Internet-sivuilla esim. linkki ei aukea tai Teillä on jotakin kysyttävää asiasta**.

Käyttäjätunnuksenne on _______________

Salasananne on _______________________

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