



PÄIVI SALONEN

Quality of Life in Patients
with Breast Cancer

A prospective intervention study



ACADEMIC DISSERTATION

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To Janne and Linnea

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Tampere, August 24th, 2011

Päivi Salonen

ABSTRACT

The purpose of this study was to describe the impact of two interventions on the quality of life (QOL) and the role of social support. Its aim was to generate new knowledge about QOL and social support and in this way to help health care professionals achieve a deeper understanding of QOL and social support issues. The outcome measures were QOL and social support.

The data for the research were collected by questionnaires one week and six months after breast cancer surgery. In the first phase 120 breast cancer patients took part in the telephone intervention and 108 patients were recruited into the control group. In the second phase 112 breast cancer patients took part in the face-to-face intervention and 92 patients were recruited into the control group. The third dataset comprised those breast cancer patients who were involved in both phases, i.e. in the telephone intervention and in the face-to-face intervention. The population consisted of 85 women in the intervention group and 79 women in the control group. QOL was assessed using two instruments, viz the Quality of Life Index-Cancer Version (QLI-CV) and the European Organization for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life (EORTC QLQ-BR23).

The results showed that the breast cancer patients benefited from the telephone support and counselling provided by the physiotherapist one week after surgery as well as from the face-to-face counselling six months after surgery. The breast cancer patients who took part in the telephone intervention had a statistically ($p=.036$) and clinically better body image, less postoperative side-effects ($p=.004$) and they had a better future outlook ($p=.010$) than the breast cancer patients in the control group. The breast cancer patients who took part in the face-to-face support and education intervention had statistically ($p=.011$) and clinically less arm symptoms than women in the control group. In a clinical analysis patients in the control group were not as distressed by hair loss as the patients in the intervention group. In both phases the breast cancer patients in the intervention group reported clinically better sexual functioning than those in the control group.

During the six-month follow-up body image deteriorated (intervention group $p \leq .001$, control group $p = .007$) and treatment side-effects increased statistically (intervention group $p \leq .001$, control group $p = .003$) and clinically significantly in both groups, breast and arm symptoms decreased in both groups both statistically ($p \leq .001$) and clinically significantly. Future outlook improved significantly ($p \leq .001$) over six months among patients in the control group, but not among patients in the intervention group. The improvement in future outlook was greater in the control group ($p = .014$).

Age, education, type of surgery and axillary treatment were associated with QOL and predicted poor QOL at both stages of the study. In both phases membership of the control group and at follow-up adjuvant therapies predicted poor QOL. Negative QOL changes were best predicted by education, employment status, having underage children and adjuvant therapies, as well as by support received from the social network. The patients who received more affect from the support network were at greater risk of reduced global QOL and health and functional capacity. Increased aid from nurses increased the likelihood of improved sexual functioning.

The interventions designed and tested in this study can be put to use in the care and treatment of breast cancer patients with relatively low resource input. Even short-term support and counselling after breast cancer surgery and during treatment can help to improve patients' QOL. Postoperative support and counselling should be incorporated as an integral part of the care of breast cancer patients and implemented on the basis of the existing research evidence. Early intervention after a short hospital stay is the most effective way of supporting and helping breast cancer patients cope and of enhancing their physical, psychological and social QOL. Breast cancer patients with poor QOL and at greatest risk of declining QOL during the treatment process are in greatest need of support and counselling. This must be taken into account in planning treatment interventions and in the allocation of support to breast cancer patients.

Keywords: breast cancer, quality of life, social support, patient education, intervention

TIIVISTELMÄ

Tutkimuksen tarkoituksena oli selvittää interventioden vaikutusta leikattujen rintasyöpäpotilaiden elämänlaatuun ja sosiaalisen tuen roolia. Tavoitteena oli tuottaa uutta tietoa ja syventää terveydenhuollon ammattilaisten ymmärrystä elämänlaatuun ja sosiaaliseen tukeen liittyvistä tekijöistä. Päätulomuuttujia olivat elämänlaatu ja sosiaalinen tuki.

Tutkimusaineisto kerättiin kyselylomakkeilla viikon ja puolen vuoden päästä rintasyöpäleikkauksesta tutkimukseen suostumuksensa antaneilta. Ensimmäisessä vaiheessa puhelininterventioon osallistui 120 ja kontrolliryhmään 108 rintasyöpäpotilasta. Toisessa vaiheessa, kasvokkain annettuun ohjaukseen osallistui 112 rintasyöpäpotilasta ja kontrolliryhmään 92 rintasyöpäpotilasta. Tutkimuksen kolmannen analysoidun aineiston muodostivat ne rintasyöpäpotilaat, jotka osallistuivat sekä puhelimesta että kasvokkain annettuun tukeen ja ohjaukseen. Aineisto muodostui interventioryhmästä (n=85) ja kontrolliryhmästä (n=79). Elämänlaatua arvioitiin Quality of Life Index-Cancer Version (QLI-CV) -mittarilla ja European Organization for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life -mittarilla (EORTC QLQ-BR23).

Tulokset osoittivat, että fysioterapeutin puhelimesta viikon päästä leikkauksesta antamasta tuesta ja ohjauksesta ja kuuden kuukauden päästä leikkauksesta henkilökohtaisesti antamasta ohjauksesta ja tuesta oli hyötyä rintasyöpäpotilaille. Puhelininterventioon osallistuneilla rintasyöpäpotilailla oli sekä tilastollisesti ($p=.036$) että kliinisesti parempi kehonkuva, vähemmän leikkauksen jälkeisiä sivuvaikutuksia ($p=.004$) ja he suhtautuivat myönteisemmin tulevaisuuteen ($p=.010$) verrattuna kontrolliryhmään kuuluviin rintasyöpäpotilaisiin. Rintasyöpäpotilailla, jotka osallistuivat kasvokkain annettuun henkilökohtaiseen ohjaukseen ja tukeen, oli sekä tilastollisesti ($p=.011$) että kliinisesti vähemmän yläraajan oireita verrattuna kontrolliryhmään. Kliinisesti tarkasteltuna kontrolliryhmään kuuluvista potilaista hiusten lähtö ei tuntunut yhtä pahalta kuin interventioryhmään kuuluvista potilaista. Interventioryhmään kuuluvilla rintasyöpäpotilailla oli kliinisesti parempi seksuaalinen toimintakyky molemmissa vaiheissa verrattuna kontrolliryhmään

kuuluviin rintasyöpäpotilaisiin. Kuuden kuukauden seuranta-aikana kehonkuva huononi (interventoryhmä $p \leq .001$, kontrolliryhmä $p = .007$) ja hoitojen sivuvaikutukset lisääntyivät molemmissa ryhmissä sekä tilastollisesti (interventoryhmä $p \leq .001$, kontrolliryhmä $p = .003$) että kliinisesti merkitsevästi. Rinnan alueen ja yläraajan oireet vähentyivät molemmissa ryhmissä sekä tilastollisesti ($p \leq .001$) että kliinisesti merkitsevästi. Kontrolliryhmään kuuluvilla potilailla suhtautuminen tulevaisuuteen muuttui positiivisemmaksi verrattuna interventoryhmään ($p \leq .001$) ja tämä muutos parempaan oli myös suurempi kontrolliryhmässä ($p = .014$).

Taustamuuttujista ikä, koulutus, rinnanleikkaus- ja kainaloleikkaustapa olivat yhteydessä elämänlaatuun ja ennustivat huonoa elämänlaatua tutkimuksen molemmissa vaiheissa. Molemmissa vaiheissa kontrolliryhmä ja seurantavaiheessa liitännäishoidot ennustivat huonoa elämänlaatua. Elämänlaadun negatiivisia muutoksia ennustivat parhaiten koulutus, työtehtävät, alaikäiset lapset ja liitännäishoidot sekä verkostolta saatu tuki. Potilaat, jotka saivat enemmän emotionaalista tukea tukiverkostolta, oli suurempi todennäköisyys kokonaiselämänlaadun ja terveyden ja toimintakyvyn huononemiseen. Hoitajilta saadun konkreettisen tuen lisääntyessä todennäköisyys seksuaalisen toimintakyvyn parantumiseen kasvoi.

Tutkimuksessa käytetyt interventiot voidaan ottaa käyttöön osaksi rintasyöpäpotilaan hoitotyötä suhteellisen vähin resurssein. Lyhyelläkin tuella ja ohjauksella leikkauksen jälkeen ja hoitoprosessin kuluessa voidaan vaikuttaa rintasyöpäpotilaan elämänlaatuun. Leikkauksen jälkeinen ohjaus ja tuki tulee suunnitella osaksi rintasyöpäpotilaiden hoitotyötä ja se tulee toteuttaa tukeutuen tutkimusten antamaan näyttöön. Varhainen interventio lyhyen sairaalassaolon jälkeen edesauttaa parhaiten rintasyöpäpotilaiden selviytymistä ja hyvää fyysistä, psyykkistä ja sosiaalista elämänlaatua. Rintasyöpäpotilaat, joiden elämänlaatu on huono ja joiden elämänlaadun huonontuminen hoitoprosessin aikana voidaan tunnistaa, tarvitsevat eniten ohjausta ja tukea. Tämä tulee huomioida, kun suunnitellaan toiminnan kohdentamista ja toteutetaan tuki-interventioita rintasyöpäpotilaille.

Avainsanat: rintasyöpä, elämänlaatu, sosiaalinen tuki, ohjaus, interventio

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ABBREVIATIONS

ATAC	Arimidex, Tamoxifen, Alone or in Combination
CI	Confidence Interval
EBCTCG	Early Breast Cancer Trialists' Collaborative Group
EORTC	European Organization for Research and Treatment of Cancer
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30
EORTC QLQ-BR23	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Breast Cancer Module
FACT-G	Functional Assessment Cancer Therapy-General
FACT-B	Functional Assessment Cancer Therapy-Breast Cancer specific
FBCG	Finnish Breast Cancer Group
Gy	Gray is a unit of absorbed radiation dose of ionizing radiation
HRQOL	Health Related Quality of Life
Ki-67	Ki-67 protein is a cellular proliferation marker
MeSH	Medical Subject Headings
OR	Odds Ratio
QLI-CV	Quality of Life Index-Cancer Version
QOL	Quality of Life
SF-36	Medical Outcome Study Short Form Survey-36
TNM-classification	TNM is developed and maintained by the International Union against Cancer (UICC) to achieve consensus on one globally recognised standard for classifying the extent of spread of cancer. T describes the size of the tumour and whether it has invaded nearby tissue, N describes regional lymph nodes that are involved, M describes distant metastases
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life Assessment

LIST OF ORIGINAL PUBLICATIONS

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

- I Salonen P, Tarkka M-T, Kellokumpu-Lehtinen P-L, Åstedt-Kurki P, Luukkaala T & Kaunonen M (2009). Telephone intervention and quality of life in patients with breast cancer. *Cancer Nursing* 32, 177-190.
- II Salonen P, Tarkka M-T, Kellokumpu-Lehtinen P-L, Koivisto A-M, Åstedt-Kurki P & Kaunonen M (2011). Individual face-to-face intervention and quality of life in patients with breast cancer. *International Journal of Nursing Practice* 17, 396-410.
- III Salonen P, Kellokumpu-Lehtinen P-L, Tarkka M-T, Koivisto A-M & Kaunonen M (2010). Changes in quality of life in patients with breast cancer. *Journal of Clinical Nursing* 20, 255-266.
- IV Salonen P, Tarkka M-T, Kellokumpu-Lehtinen P, Koivisto A-M, Aalto P & Kaunonen M. Effect of social support on quality of life in early breast cancer patients: A longitudinal study. *Scandinavian Journal of Caring Science*. Submitted.

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1 INTRODUCTION

Breast cancer is the most common type of cancer among women in Finland. In 2009 a total of 4,474 new cases were reported, and the number is continuing to rise: currently one in ten Finnish women are expected to develop breast cancer in their lifetime. (Pukkala et al. 2011.) Most new cases are detected at age 50-59 years. By 2020, it is predicted that age-adjusted breast cancer mortality will fall by 24% from 2005-2007 (Finnish Cancer Registry 2011). According to the Finnish Cancer Registry (2011), 89% of breast cancer patients are still alive five years after the diagnosis. This high survival rate is attributed to effective treatment and the national mammography screening programme that started in 1987. Over a ten-year period starting in 2007, the target group for the screening programme will be progressively expanded from ages 50-59 up to age 69. This is expected to further decrease mortality, particularly at old age. (Pukkala et al. 2011.)

The diagnosis of breast cancer and its treatments have various adverse effects on quality of life (QOL), physical functioning and psychosocial well-being (Sammarco 2003, Badger et al. 2004a, Engel et al. 2004, Ganz et al. 2004, Avis et al. 2005, Boehmke & Dickerson 2005, Burgess et al. 2005, Janz et al. 2005, Badger et al. 2007, Janz et al. 2007, Montazeri et al. 2008a, Montazeri 2008b, Turgay et al. 2008, Karakoyun-Celik et al. 2010), and therefore women need support not just during the treatment process but for years beyond (Rustoen & Begnum 2000, Engel et al. 2003a, 2003b, Engel et al. 2004, Vivar & McQueen 2005, Hodgkinson et al. 2007). However, women's experiences of breast cancer, its treatments and side-effects (King et al. 2000, Rustoen & Begnum 2000, Arora et al. 2001), the importance of QOL items (Rustoen et al. 2000) and global QOL seem to change over time (Engel et al. 2004, Maeda et al. 2008).

Earlier research has highlighted the need for follow-up care after short periods of hospitalization as well as the importance of adequate support and

communication with breast cancer patients (Kerr et al. 2003, Kärki 2005, Beaver et al. 2006, Hodgkinson et al. 2007). Patients expect to receive more effective social support (Rustoen et al. 1999a, Wentzel et al. 1999, Rustoen & Begnum 2000, Engel et al. 2003a, Beaver et al. 2006, Hodgkinson et al. 2007), they want to be heard (Rustoen et al. 1999, Wentzel et al. 1999, Engel et al. 2003b, Beaver et al. 2006), and they are keen to express their feelings and to know that their needs and wishes will be addressed personally (Ferrel et al. 1997, 1998, Remmers et al. 2010). Numerous studies, reviews and meta-analyses indicate that breast cancer patients benefit from both group and individual therapeutic interventions (Sheard & Maguire 1999, Sandgren et al. 2000, Box et al. 2002a, 2002b, Samarel et al. 2002, Cox & Wilson 2003, Rehse & Pukrop 2003, Sandgren & McCaul 2003, Winzelberg et al. 2003, Badger et al. 2004b, 2005b, Kärki 2005, Coleman et al. 2005, Wilmoth et al. 2006, Allard et al. 2007, Arving et al. 2006, 2007) when the content and timing of those interventions is appropriate (Donnelly et al. 2000, Kärki 2005, Giese-Davis et al. 2006).

The theoretical framework for this study is based on Ferran's (1990) definition and conceptual model of QOL (also Ferrans & Powers 1985, Ferrans & Powers 1992, Ferrans 1996), and on Kahn's (1979) theory of social support. The QOL model was developed on the basis of an individualistic approach, working from the assumption that QOL depends on each individual's unique life experience (Ferrans 1990, 1996). According to Kahn (1979) the key elements in supportive transactions are affect, aid and affirmation. Social support is given and received within a social network structure (Kahn and Antonucci 1980). There is ample evidence that social support protects individuals from the pathological and harmful effects of many stressful life events (Cobb 1976, Norbeck 1988, Lehto-Järnstedt et al. 2002), and it may also serve as a buffer against the negative consequences of illness (Helgeson & Cohen 1996, Uchino 2006).

The purpose of this study is to describe the impact of two interventions and the role of social support in operated breast cancer patients. Its aim is to generate new knowledge about QOL and social support and so to help health care professionals achieve a deeper understanding of QOL and social support issues

and deliver follow-up services more effectively. The outcome measures are quality of life and social support.

The new knowledge emerging from the results of the present study may help health care professionals determine what kind of social support is needed most in the care of newly diagnosed breast cancer patients. Furthermore, the results will help create and implement systematic social support protocols and different follow-up options, including individual and group rehabilitation and support based on women's needs, concentrating more on the quality rather than the frequency of social support.

2 REVIEW OF THE LITERATURE

A review of the literature was conducted to identify what kind of interventions has been undertaken among breast cancer patients. A further aim was to gain a clearer picture of the support available to and the QOL of breast cancer patients. The literature was searched from the Cinahl, Medline, PubMed, British Nursing Index, PsycINFO, EBSCOhost and Medic databases, focusing mainly on the time period from 2000 to 2011. In all databases the search was limited to English-language abstracts and full texts. Medical Subject Headings (MeSH) terms were used as search terms, including "breast neoplasm", "quality of life", "social support", "education" and "intervention studies". Besides MeSH –terms, also "breast cancer" and "breast cancer treatments" were used as search terms. In addition the lists of references of the articles identified were manually searched. The texts selected for closer review were chosen on the basis of research questions and the quality of the research.

Several literature searches were conducted during the research process to review the latest results on interventions and QOL in patients with breast cancer. The latest search in January 2011 was limited to studies published in the English language and to the period from 2006 to 2011. The Cinahl search produced 929 citations and the Medline search 1042 citations using the search terms “quality of life” and “breast neoplasm”. When the search was restricted to “quality of life” and “breast neoplasm” and “support” (“social support” or “face-to-face support” or “telephone” or “telephone intervention” or “telephone support”) and “intervention studies” or “prospective studies”, the Cinahl search produced 30 citations and Medline 10 citations.

2.1 Treatments of breast cancer

In Finland the treatment of breast cancer has been based on a uniform set of national recommendations since 1992; the recommendations currently in force date from 2009 (Finnish Breast Cancer Group (FBCG) 2009). There are five types of standard treatment for patients with breast cancer: surgery, radiation therapy, chemotherapy, hormonal therapy and targeted therapy. However, each patient's treatment is individually tailored according to the type of cancer and the patient's general health and condition and other possible diseases and medications (FBCG 2009). Patients are expected to actively participate in planning and making decisions about surgery and adjuvant treatments and therapies (FBCG 2009, Dixon et al. 2010).

2.1.1 *Breast cancer surgery*

Whenever possible, preference should be given to *breast conserving surgery* (Goldhirsch et al. 2001, 2003, FBCG 2009). This requires that the primary tumour is no larger than 2 to 4 cm, depending on the size of the breast. In breast conserving surgery, which is called lumpectomy or sometimes partial mastectomy, only the tumour and some surrounding normal tissue is removed (FBCG 2009). Some lymph nodes under the axilla may also be removed (Goldhirsch et al. 2001, 2003, FBCG 2009). *Mastectomy*, then, involves the removal of the entire breast. Often some or all of the lymph nodes under the arm are removed. According to current treatment recommendations, mastectomy is required when the tumour is larger than 4 cm, when the cancer is inflammatory, and when there are several tumours distant from one another. Survival rates in breast conserving therapy combined with radiotherapy are the same as in total mastectomy. (FBCG 2009.)

Axillary dissection can be used for both diagnostic and therapeutic purposes. This usually involves the removal of some lymph nodes under the arm to see whether they contain cancer cells. (FBCG 2009.) One postoperative complication of the removal of axillary lymph nodes is morbidity of the upper extremity (Burak et al. 2002, Engel et al. 2003b, Gosselink et al 2003, Veronesi

et al. 2003, Wilke et al. 2006), including seroma (Pogson et al. 2003, Hashemi et al. 2004), lymphedema (Blanchard et al. 2003, Ozaslan & Kuru 2004, Rönkä et al. 2004, Kootstra et al. 2010), as well as sensory and functional disorders such as numbness and motion restrictions of the shoulder joint (Ververs et al. 2001, Kootstra et al. 2010). The findings suggest that type of surgery is a predicting factor for seroma formation in breast cancer patients (Blanchard et al. 2003, Hashemi et al. 2004), i.e. serious fluid collection under the skin flaps during mastectomy or in the axillary dead space after axillary dissection (Pogson et al. 2003).

Since the 1990s, sentinel node biopsy has been widely accepted as an alternative technique in breast cancer management (Krag et al. 1993). It causes less morbidity (Burak et al. 2002, Blanchard et al. 2003), less pain and allows for better arm function than axillary dissection (Veronesi et al. 2003). Sentinel node biopsy is the surgical removal of the sentinel lymph node (Rönkä et al. 2005), which is the first lymph node to receive lymphatic drainage from a tumour and to which the cancer is likely to spread from the tumour nodes. If the sentinel node is tumour-negative, the assumption is that there are no nodal metastases in the lymph node basin, for example in the axilla (Morton et al. 1992, Rutgers et al. 1998, Kim et al. 2006). It has been reported that nodal status and the number of lymph nodes involved are the most relevant factors for the estimation of the risk of breast cancer recurrence (Goldhirsch et al. 2001, FBCG 2009).

2.1.2 Adjuvant treatments of breast cancer

Radiation therapy is indicated after lumpectomy or partial mastectomy to kill any cancer cells missed during surgery or to prevent them from growing (Goldhirsch et al. 2001, 2003, Pierce 2005, FBCG 2009). Furthermore, the meta-analysis by the Early Breast Cancer Trialists' Group (EBCTG) (2000) reaffirms that mastectomy radiotherapy has the important benefit of reducing local and regional recurrence and breast cancer mortality (see also Goldhirsch et al. 2001, 2003, Pierce 2005, FBCG 2009). Mastectomy patients may also have to undergo radiation therapy if the number of positive lymph nodes exceeds

three or four (Truong et al. 2004, Pierce 2005, Jagsi et al. 2009), if their tumour size is larger than 5 cm (T3-T4) and/or if the tumour invades the skin or adjacent musculature (Truong et al. 2004, FBCG 2009). Radiotherapy treatment takes 5 to 6 weeks and the total dose is 50-60 Gy (Pierce 2005, FBCG 2009). Radiotherapy may cause both immediate and delayed tissue related complications, such as skin irritation (Porock et al. 1998, Sjövall et al. 2010) and lymphedema after axillary radiotherapy (Ozaslan & Kuru 2004, Ewertz & Jensen 2011). Potential delayed complications include pneumonitis, pulmonary fibrosis, and chronic cardiac toxicity (Pierce 2005).

Chemotherapy is used to reduce the risk of breast cancer recurrence by preventing the replication of cancer cells and their attack on other issues. Chemotherapy is almost always recommended if there is cancer in the lymph nodes, regardless of tumour size or menopausal status. Breast cancer tends to be more aggressive in premenopausal women, and therefore chemotherapy is often part of the treatment plan. In inflammatory breast cancer chemotherapy is given as a neoadjuvant treatment to improve the prognosis. (FBCG 2009.) Urruticoechea et al. (2005) reported in their earlier review that expression of Ki-67 is a sign of poor prognosis, and higher levels of Ki-67 had a good response to chemotherapy. A breast tumour that scores high for Ki-67 is composed of rapidly dividing and growing cells. The results of a Ki-67 test might help determine whether or not neoadjuvant therapy would be effective. Neoadjuvant chemotherapy is given before surgery to shrink the cancer (FBCG 2009). Chemotherapy is usually given in cycles, with rest periods in-between. Protocols typically consist of 4-6 cycles at 2-4 week intervals. Premenopausal women may undergo premature menopause when receiving adjuvant chemotherapy (Mar Fan et al. 2005, 2010). In the long term, it may cause sexual dysfunction and impair fertility (Rogers & Kristjanson 2002).

In hormone-receptor-positive breast cancers, *hormonal therapy* is used to block the action of cancer cells and to prevent them from growing. Hormonal drugs can block the effect of estrogen or reduce estrogen levels. This reduces the risk of cancer recurrence (EBCTCG 1998, ATAC (Arimidex, Tamoxifen, Alone or in Combination) Trialists' Group 2005), which is the primary goal of adjuvant hormonal therapy (Bria et al. 2010).

The most commonly used hormonal therapy is tamoxifen (Bottini et al. 2005), which reduces relapse and death in both pre- and postmenopausal women (FBCG 2009, EBCTCG 1998, ATAC Trialists' Group 2005). Tamoxifen antagonizes the effects of estrogen (EBCTCG (2005)). The side-effects of tamoxifen are similar to some of the symptoms of menopause, including sweating and hot flashes (FBCG 2009). Furthermore, tamoxifen has been associated with a higher incidence of endometrial cancers and abnormalities, venous thromboembolic events, cerebrovascular events, vaginal bleeding and discharge (Bria et al. 2010). The EBCTCG (2005) found in their meta-analysis that breast cancer recurrence and mortality decreased with five years of adjuvant tamoxifen. Bottini et al. (2005) reported that a combination of chemotherapy and tamoxifen is more effective than either therapy alone.

The hormonal drug options available for postmenopausal women include anastrozole, letrozole and exemestane, which are aromatase inhibitors. These drugs inhibit the conversion of peripheral androgens to estrogen and reduce plasma estrogen levels (Bria et al. 2010). Switching the previous standard of five years of adjuvant tamoxifen to exemestane and anastrozole after 2-3 years of treatment has been found to be more effective than continued tamoxifen in reducing breast cancer recurrence (FBCG 2009, Bria et al. 2010, Markopoulos 2010). According to the clinical trials of the ATAC Trialists Group (2005) at median 68 months follow-up, anastrozole should be preferred as initial treatment for postmenopausal women with localized hormone-receptor-positive breast cancer because it reduces the risk of cancer recurrence more effectively than tamoxifen. In 2009 an international panel of experts (Goldhirsch et al. 2009) indicated a preference for the up-front use of aromatase inhibitors, especially in patients with a greater risk of relapse. The most typical side-effects of aromatase inhibitors are muscle and joint aches and restricted joint mobility in the mornings (Guzick et al. 2008). Aromatase inhibitors have been shown to improve disease-free survival compared with tamoxifen (Eisen et al. 2008). However, clinical trials have demonstrated that aromatase inhibitors are associated with a higher incidence of arthralgias, myalgias, low-grade cholesterol elevations, bone loss and fractures (Bria et al. 2010). The findings indicate that some of the side-effects are significantly less common with the use of anastrozole than tamoxifen.

However, the risks of osteoporosis and fracture are higher with anastrozole than with tamoxifen (ATAC Trialist's Group 2005). Dixon et al. (2010) found no significant differences in the frequency or range of side-effects between anastrozole and letrozole. The most commonly reported side-effects are joint pain, hot flushes, rashes, lack of energy and night sweats (Dixon et al. 2010).

Targeted therapy is a type of treatment that targets specific characteristics of cancer cells, such as a protein that stimulates the rapid or abnormal growth of cancer cells. Targeted therapies are generally less likely than chemotherapy to harm normal, healthy cells. The most commonly used targeted therapy in breast cancer is trastuzumab for HER2-positive breast cancer patients (FBCG 2009). Trastuzumab targets human epidermal growth factor receptor 2 (HER2), and in this way reduces the risk of breast cancer recurrence and improves the survival of early HER2-positive breast cancer patients (Joensuu et al. 2009a, Joensuu et al. 2009b). Joensuu et al. (2009a) reported that women treated with trastuzumab tended to have better distant disease-free survival than women treated with chemotherapy only.

There are a number of overviews of randomized trials (EBCTCG 1998 & 2000), long-lasting clinical trials (ATAC Trialists' Group 2005, Joensuu et al. 2009a, 2009b), reviews (Truong et al. 2004, Bria et al. 2010) and publications from the International Conference of Adjuvant Therapy of Primary Breast Cancer (Goldhirsch et al. 2003) that have explored different breast cancer treatments and clinical guidelines for the treatment of breast cancer. Randomized clinical trials provide crucial evidence for the further development of medical treatments for breast cancer (Goldhirsch et al. 2001). Evidence-based data are important in planning and developing individually better tailored treatments. (FBCG 2009).

In Finland the treatment of breast cancer is very effective and survival rates are high (Finnish Cancer Registry 2009). However, although advances in prognostic factors, mammography screenings and surgical and especially adjuvant treatments have increased survival rates, breast cancer and its treatment still causes considerable physical and psychosocial problems for patients (Landmark & Wahl 2002, Schreier & Williams 2004, Karakoyun-Celik et al. 2010, Farren et al. 2010, Khan et al. 2010).

2.2 Patients' experiences of breast cancer diagnosis and treatments

Hoskins et al. (2001) have identified several key phases in the breast cancer experience, including diagnosis, post-surgery, adjuvant therapy, and ongoing recovery. The diagnosis of breast cancer and its treatments impact the patient's QOL at both the psychological (Sammarco 2001b, Landmark & Wahl 2002, Khan et al. 2010), physical (Lehto-Järnstedt 2000, Arora et al. 2001, Landmark & Wahl 2002) and social level (Landmark & Wahl 2002, Engel et al. 2004). Breast cancer patients often suffer from anxiety (Schreier & Williams 2004, Burgess et al. 2005, Stephens et al. 2008, Khan et al. 2010), depressive symptoms (Burgess et al. 2005, Rabin et al. 2008), uncertainty (Ferrel et al. 1996, Sammarco 2001a, Sammarco 2003, Rabin et al. 2008, Sammarco 2009, Farren 2010), psychological fatigue and distress (Schover et al. 1995, Khan et al. 2010), as well as mood and sleep disturbances (Shimozuma et al. 1999, Janz et al. 2007, Karakoyn-Celik et al. 2010).

In a recent study by Stephens et al. (2008), women reported that fear and anxiety were their major concerns in the immediate postoperative period, especially the fear of recurrence and metastasis, as well as anxiety regarding postoperative treatments and the future. The early stages of breast cancer in particular are a period of uncertainty about the future, and women experience a strong determination to live and fight for life (Landmark & Wahl 2002). Berterö & Wilmoth (2007) concluded from their meta-synthesis that breast cancer affects the woman's individual, relational, and collective self, and therefore the relationship between mood disturbance, social support, and symptoms may be more prominent than in other types of cancer. Moreover, women with breast cancer may avoid social contacts and therefore be more liable to social isolation (Engel et al. 2004).

The most commonly reported physical symptoms of breast cancer are pain (Ferrel et al. 1997, Lehto-Järnstedt 2000, Rietman et al. 2004, Avis et al. 2005, Steegers et al. 2008), decreased arm and shoulder mobility (Ferrel et al. 1997, Engel et al. 2003a, 2003b, Rietman et al. 2004) and lymphedema (Armer et al.

2005, Shih et al. 2009, Norman et al. 2009). Furthermore, women may suffer from decreased body image (Schover et al. 1995, Avis et al. 2005, Browall et al. 2008, Moreira & Canavarro 2010), menopausal symptoms (Lehto-Järnstedt 2000, Conde et al. 2005) and sexual problems (Schover et al. 1995, Arora et al. 2001, Conde et al. 2005, Pérez et al. 2010), which may have a negative influence on patients' QOL even several years after the diagnosis (King et al. 2000, Kerr et al. 2003, Armer et al. 2005, Avis et al. 2005, Hodginson et al. 2007, Shih et al. 2009, Norman et al. 2009). According to Hodginson et al. (2007), anxiety and fear of breast cancer recurrence continues to be a significant problem for many women even years after the diagnosis. However, Sammarco (2001b) reported that the way in which women experience breast cancer differs depending on their psychological life stage.

2.3 Quality of life

2.3.1 Quality of life in breast cancer patients

Breast cancer patients' QOL has been addressed in several descriptive and longitudinal studies (Ferrel et al. 1996, Ferrel et al. 1997, Ferrel et al. 1998, Rustoen et al. 1999a, Shimosuma et al. 1999, Broeckel et al. 2000, Dow & Lafferty 2000, King et al. 2000, Amichetti & Caffo 2001, Arora et al. 2001, Sammarco 2001a, 2001b, 2003, 2008, Engel et al. 2003a, Kerr et al. 2003, Schreier & Williams 2004, Uzun et al. 2004, Avis et al. 2005, Lu et al. 2007, Lee et al. 2008, Rabin et al. 2008, Turgay et al. 2008, Haas et al. 2010, Larsson et al. 2010). Although breast cancer and its treatments impact physical, psychological and social functioning in various ways, it has been suggested in several studies that the QOL of patients with breast cancer is in fact moderately high (Rustoen et al. 1999a, Sammarco 2001a, Uzun et al. 2004). Breast cancer patients have reported the highest QOL in the family domain (Rustoen et al. 1999a, Sammarco 2001a, Gupta et al. 2007), and the lowest QOL in the health and functioning (Rustoen et al. 1999a, Gupta et al. 2007) and in the psychological and spiritual domain (Sammarco 2001a, Xiaokun 2002). Overall, the findings of earlier

studies suggest that breast cancer patients have a poorer QOL than patients with other cancer diagnoses (Rustoen et al. 1999a, Engel et al. 2003c), especially in the domains of psychological, sexual (Rustoen et al. 1999a) and emotional functioning (Engel et al. 2003c).

Changes in QOL are important indicators of the impact of the cancer disease (Rustoen et al. 2000). It has been reported that patients with breast cancer generally have the capacity to adapt to their situation (Dow & Lafferty 2000, Bloom et al. 2004, Engel et al. 2004). Engel et al. (2004) found a significant improvement in patients' long-term emotional and social functioning. Fatigue, nausea, vomiting, future health concerns and pain decreased, while appetite and global QOL scores increased in three years (Engel et al. 2004). Furthermore, as reported by Rogers & Kristjanson (2002) in their review, several studies have found evidence of sexual dysfunction and menopausal symptoms. Significant longer-term improvements have been reported in surgical symptoms and side-effects, future outlook (Bloom et al. 2004, Montazeri et al. 2008b), patient-physician communication, and intrusiveness of treatment in women under age 50 (Bloom et al. 2004).

However, studies performed several months after diagnosis have shown that some patients treated for breast cancer have difficulty adapting to being a cancer survivor (Andrykowski et al. 2000, Rustoen et al. 2000, Engel et al. 2004, Burgess et al. 2005, Loerzel et al. 2008, Montazeri et al. 2008b, Gorman et al. 2010). Longitudinal studies have shown no improvement over time in sexual functioning (Arora et al. 2001, Engel et al. 2004, Montazeri et al. 2008b), social functioning (Arora et al. 2001), body image (Engel et al. 2004, Montazeri et al. 2008b), and lifestyle factors (Engel et al. 2004). Further, Burgess et al. (2005) reported in their five-year observational cohort study that women with early breast cancer still suffered from depression, anxiety or both one year after diagnosis, some of them for more than five years. Women at age 50 or under are at risk of impaired QOL up to several years after the breast cancer diagnosis (Avis et al. 2005). Engel et al. (2004) have suggested that most changes in QOL occur between the first and second year after breast cancer surgery (see also Maeda et al. 2008).

2.3.2 *Defining quality of life*

QOL is a critically important concept for health care (Ferrans & Powers 1992, Farquhar 1995, Ferrans 1996, Ferrans et al. 2005) that has been used as an outcome measure in a large number of intervention studies (Ashbury et al. 1998, Rustoen et al. 1998, Sheard & Maguire 1999, Sandgren et al. 2000, Samarel et al. 2002, Cox & Wilson 2003, Rehse & Pukrop 2003, Sandgren & McCaul 2003, Badger et al. 2004b, 2005b, Coleman et al. 2005, Wilmoth et al. 2006, Arving et al. 2006, Allard et al. 2007, Arving et al. 2007, Manos et al. 2009, Shafir et al. 2010). However, as Ferrans (1996) has pointed out, there is a growing need to clarify the concept of QOL. The lack of conceptual clarity may give rise to profound differences in research outcomes, in clinical practice, and in the allocation of health care resources (Ferrans 1996, Guyatt et al. 2007).

Farquhar (1995) had suggested three major types of QOL definitions: 1) global, 2) component and 3) focused definitions. Global definitions are all-encompassing, general, and they incorporate ideas of satisfaction/dissatisfaction and happiness/unhappiness. Component definitions, then, break QOL into component parts or dimensions, or identify certain characteristics that are deemed essential to any evaluation of QOL. Finally, focused definitions refer to only one or a small number of QOL components. However, there are also combination definitions of QOL that do not fit into this scheme. Combination definitions describe QOL as an abstract and complex term representing individual responses to physical, mental and social factors. (Farquhar 1995.)

QOL is dependent on the context and circumstances (Holmes & Dickerson 1987, Cella & Cherin 1988) and it means different things to different people (Hinds 1990, Farquhar 1995, Fayers & Machin 2000, Bowling 2003). QOL is recognized as a dynamic and multidimensional construct (Ferrans & Powers 1985, Cella & Cherin 1988, Ferrans 1990, Ferrans & Powers 1992, Ferrans 1996, Haas 1999) that has unique personal characteristics (Ferrans & Powers 1985, Ferrans 1990, Ferrans & Powers 1992, Ferrans 1996). QOL has received different definitions from different authors, who consider it to comprise different dimensions, including the psychological/mental (Holmes & Dickerson 1987, Ferrans 1990, Hinds 1990, WHOQOL Group 1995, Haas 1999, Pandey et al. 2002), social (Holmes & Dickerson 1987, Ferrans 1990, Hinds 1990, Haas 1999,

Pandey et al. 2002), economic (Ferrans 1990, Hinds 1990), health and functioning (Holmes & Dickerson 1987, Cella & Cherin 1988, Ferrans 1990, Ferrans 1996, Haas 1999, Pandey et al. 2002), and life satisfaction dimension (Holmes & Dickerson 1987, Ferrans & Powers 1985, Ferrans 1990). Furthermore, some include the spiritual (Ferrans & Powers 1985, Ferrans 1990, Ferrans & Powers 1992, Ferrans 1996, Ferrel et al. 1998, Haas 1999) and family dimension (Ferrans & Powers 1985, Ferrans 1990, Ferrans & Powers 1992, Ferrans 1996, Hinds 1990). The broad definition proposed by the WHOQOL Group (1995) also includes the cultural and environmental context in which the individual lives (see also Saxena & Orley 1997, Saxena & van Ommeren 2005). According to Ferrans et al. (2005), the concept of “health-related QOL” excludes aspects of QOL that are not related to health, such as cultural, political or societal attributes. The term HRQOL narrows the focus more specifically to the effects of health, illness and treatment on QOL. However the identification of “health-related” is itself a source of some conceptual confusion (Ferrans et al. 2005). The inherent contextuality of QOL makes the task of defining the concept highly problematic (Farquhar 1995). Indeed there is as yet no generally agreed definition of the concept of QOL (Joyce et al. 1999, Rustoen et al. 1999a, Carr et al. 2001).

The importance of QOL factors varies not only between individuals, but also within individuals over time (Bowling 2003). Ferrans (1996) suggests that individuals themselves are the only proper judges of their QOL because people differ in what they value (see also Ferrans & Powers 1985, Gupta et al. 2007). This is the main idea of the individualistic approach which recognizes that different people value different things (Ferrans 1996). In this study, QOL is used both as a subjective, global concept describing women’s satisfaction/dissatisfaction with various aspects of their lives, and as a narrower concept that focuses on therapy side-effects and level of functioning.

Given the different aims and purposes of assessing QOL, there are also many different generic and disease-specific measures (Montazeri et al. 2000, Montazeri 2008a). Despite the lack of consensus about QOL definitions, all the various concepts reflect issues that are important to well-being and therefore worth investigating and quantifying (Fayers & Machin 2000). Furthermore, it

has been shown that patients' QOL self-assessments often differ from the views of health care staff (Suominen et al. 1995), and therefore QOL should be measured from the patient's point of view, using questionnaires completed by patients (Fayers & Machin 2000).

Table 1 presents a list of existing definitions of QOL by year of publication.

Table 1. The descriptions of quality of life

Researchers and the year of publication	Definitions of QOL
Holmes & Dickerson 1987	QOL is recognized to be dynamic concept representing individual responses to the physical, mental, and social effects of illness which influence the extent to which personal satisfaction with life circumstances can be achieved, and which allows favourable comparison with others according to selected criteria.
Cella & Cherin 1988	QOL is a complex and multidimensional construct that, for patients with cancer, has been as the patient's appraisal of satisfaction with their current level of functioning as compared with what they perceive to be possible or ideal.
Ferrans 1990	QOL is a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to her. Ferran's conceptual model is composed of four QOL domains: health and functioning, socio-economic, psychological and spiritual, and family.
Hinds 1990	QOL is a complex concept, and it is viewed differently among various individuals. Quality of life is correlated to health, socio-economic, psychospiritual and family Determining QOL is subjective, unstable, and contextual.
Berterö & Ek 1993	QOL is individual for each person as is her experience of the value of the contents of her life. Different diseases and conditions should also give different QOL in relation to individual. Important dimensions of QOL are positive attitude to life, interpersonal relationships, autonomy, security, respect, information, and conversation.
Meeberg 1993	QOL is a feeling of overall satisfaction, as determined by the mentally alert individual whose life is being evaluated. Other people, preferably those from outside that person's living situation must also agree that the individual's conditions are not life threatening and are adequate meeting individual's basic needs.
WHOQOL 1995	QOL is defined as the individual's perception of their position in life in the context of the culture and value systems in which they live and relation to their goals, expectations, standards and concerns. It is a broad concept affected in a complex way a person's physical health, psychological state, level of independence, and their relationships to salient features of their environment.
Haas 1999	QOL is a multidimensional evaluation of an individual's current life circumstances in the context of the culture in which they live and the values they hold. QOL is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions. In some circumstances, objective indicators may supplement or, in the case individuals unable to subjectively perceive, serve as a proxy assessment of QOL.
Fayers & Machin 2000	QOL is often used with terms that have conceptually similar meanings, such as lifesatisfaction, well-being, functional status or happiness.
Pandey et al. 2002	HRQOL refers to the psychosocial, emotional and physical outcome of healthcare treatments as perceived by the patient.

2.3.3 Measuring quality of life

QOL assessment is gaining increasing importance in health care and medicine (O'Boyle & Waldron 1997, Rustoen & Schjolberg 2000, Osoba 2002). Rustoen & Schjolberg (2000) found in their study in Norway that nurses gave the highest research priority to QOL. Improving QOL has also become a major aim and outcome in the development of health care and treatment in patients with breast cancer (FBCG 2009). Dixon et al. (2010) reported that regular and standardized QOL assessment ensures that both the clinician and patient have enough information to make informed decisions about treatment intervention. However, Levine & Ganz (2002) urge researchers to measure QOL and translate these results into practice to improve individual patient care. In Finland, breast cancer treatment protocols are based primarily on medical outcomes, but also on their effects on QOL (FBCG 2009). Guyatt et al. (2007) have suggested that the measurement of QOL using valid and responsive instruments may help health care professionals choose the most effective treatments and interventions. Furthermore, QOL measurements can help health care managers choose more effective management strategies and save patients substantial cost and morbidity (Guyatt et al. 2007). The appropriate choice of QOL instrument is essential to ensuring that outcomes are valid and clinically useful (Cull 1997, Osoba 2002).

In medicine and health care, the measurement of QOL is guided by two principles, multidimensionality and subjectivity (Fayers & Machin 2000). QOL is measured either by generic instruments that provide a summary health profile, or disease-specific instruments that focus on specific side-effects and dysfunction (Montazeri 2008a). However, Cull (1997) reported that generic measures may fail to capture aspects of patient experiences that are of major clinical interest. Although QOL is inherently subjective, several studies using validated questionnaires have shown that QOL is indeed measurable and reproducible among breast cancer patients. Several valid and reliable instruments are available for the measurement of QOL in breast cancer patients.

The most commonly used QOL questionnaires are the European Organization for Cancer Research and Treatment of Cancer Core Quality of Life questionnaire (EORTC QLQ-C30) (Montazeri 2008a, 2008b, Lockett et al. 2011), and its breast cancer specific questionnaire EORTC QLQ-BR-23, which

was used in the present study, and explained in detail in Materials and Methods section. Other instruments widely used for the measurement of QOL in breast cancer patients include the Functional Assessment of Cancer Therapy (FACT-G) (Luckett et al. 2011) and especially its breast cancer module (FACT-B) (Arora et al. 2001, Avis et al. 2005, Montazeri 2008a). In Finland, the Medical Outcome Study Short Form Survey (SF-36) has been validated by Aalto et al. (1999). Furthermore, the Cancer Rehabilitation Evaluation System (CARES) and its short form (CARES-SF) have been used when measuring QOL in breast cancer patients (Rustoen et al. 1999, Shimozuma et al. 1999, Avis et al. 2005). EORTC QLQ-C30, FACT-G and CARES-SF are cancer-specific instruments, FACT-B is breast cancer specific and SF-36 is a generic instrument measuring QOL.

EORTC QLQ-C30 is a HRQOL questionnaire developed by the European Organization on Research and Treatment of Cancer (EORTC) Study Group (Aaronson et al. 1993, Sprangers et al. 1993, Fayers et al. 2001). The validity and reliability of the EORTC QLQ-C30 have been verified in several studies and reviews (Aaronson et al. 1993, Sprangers et al. 1996, Groenvold et al. 1997, Luckett et al. 2011), and the instrument is available in several languages (Cull 1997, Fayers et al. 2001). *CARES-SF* is a multidimensional instrument with well-documented validity, reliability and acceptability for breast cancer patients (Ganz et al. 1990, Schag et al. 1991). It has been used with older breast cancer survivors (Clough-Gorr et al. 2007) and with younger patients aged 40-49 at 5-10 years after breast cancer diagnosis (Casso et al. 2004). FACT-B focuses primarily on physical functioning and to a lesser extent on psychological functioning (Chen et al. 2010). *RAND SF-36* is a generic instrument used for assessing HRQOL (Ware & Sherbourne 1992), and it has been translated into Finnish by Aalto et al. (1999). The instrument has been designed for self-administration by persons aged 14 or over (Ware & Sherbourne 1992), and it has been used widely in exploring the impact of chronic illness on coping and adjustment (Hays & Morales 2001). In a recent study measuring QOL in breast cancer patients both pre- and post-operatively, Larsson et al. (2010) chose to use the SF-36 because it allows for comparisons with the normal population.

QOL measures are valuable when they measure aspects of QOL that are important to the patients, when they are valid and responsive, and when the results are meaningful to clinical practice, providing useful information about benefits, including treatment costs (Fallowfield 1993, Guyatt et al. 2007). It is expected that QOL measurements will gain even greater importance in the future as the number of women affected by breast cancer is continuing to rise (Finnish Cancer Registry 2009) and because most interventions are aimed at making patients feel better (Guyatt et al. 2007) by increasing their QOL. It is important that validated QOL instruments are used so that comparisons can be made between different studies assessing the effect of interventions (Fallowfield 1993, Fallowfield 1995).

Table 2 provides an overview of the QOL instruments most commonly used among breast cancer patients.

Table 2. Description of instruments most common used to measure quality of life in patients with breast cancer

Type of instrument	Instruments full name and abbreviations	Subscales/single items	Scoring range
Cancer specific	The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)	Physical (PF), role (RF), cognitive, (CF) emotional (EF) and social (SF) functioning, global QOL, (GQOL) pain (PA), fatigue (FA), nausea/vomiting (NV), dyspnea (DY), insomnia (SL), appetite loss (AP), constipation (CO), diarrhea (DI), and financial difficulties (FI)	0-100
Breast cancer specific	The European Organization for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life Questionnaire (EORTC QLQ-BR23)	Body image (BRBI), sexual functioning (BRSEF), sexual enjoyment (BRSEE), future perspective (BRFU), systematic therapy side-effects (BRST), breast symptoms (BRBS), arm symptoms (BRAS), and upset by hair loss (BRHL)	0-100
Cancer specific	The Quality of Life Index - Cancer Version (QLI-CV)	Health/functioning (HFSUB), socio-economic (SOCSUB), psychological/spiritual (PSBSUB) family subscales (FAMSUB), and global QLI score (QLI)	0-30
Cancer specific	Cancer Rehabilitation Evaluation System - Short Form (CARES-SF)	Physical, psychosocial, medical interaction, marital, and sexual scales	0-4
Breast cancer specific	Functional Assessment of Cancer Therapy questionnaire - breast cancer module (FACT-B)	Physical (PWB), functional (FWB), emotional (EWB) and social and family well-being (SWB), and breast cancer specific concerns (BCS)	0-4
General	Medical Outcomes Study Short Form Survey (SF-36)	Physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH) vitality (VT), social functioning (SF), role-emotional (RE), and mental health (MH)	0-100

2.4 Interventions in breast cancer patients

The most common type of social support and education intervention for breast cancer patients are support groups (Rustoen et al. 1998, Samarel et al. 1998, Sheard & Maguire 1999, Fukui et al. 2000, Helgeson et al. 1999, 2000, 2001, Rehse & Bukrop 2003, Okamura et al. 2003, Mutrie et al. 2007, Classen et al. 2008, Schou et al. 2008, Dolbeault et al. 2009, Capozzo et al. 2010). However, support and education may also be provided individually by telephone (Donnelly et al. 2000, Sandgren et al. 2000, Rawl et al. 2002, Samarel et al. 2002, Sandgren & McCaul 2003, Badger et al. 2004a, Badger et al. 2004b, Badger et al. 2005b, Coleman et al. 2005, Arving et al. 2006, Beaver et al. 2006, Giese-Davis et al. 2006, Sutton et al. 2006, Wilmoth et al. 2006, Allard et al. 2007, Arving et al. 2007, Badger et al. 2007, Budin et al. 2008, Beaver et al. 2009, Meneses et al. 2009, Sherman et al. 2010, Libigel et al. 2010, Marcus et al. 2010) or individually face-to-face (Ashbury et al. 1998, Box et al. 2002a, 2002b, Stanton et al. 2005, Arving et al. 2007, Beurskens et al. 2007, Maeda et al. 2008, Manos et al. 2008). Telephone interventions have also been used to improve breast health behaviours (Bowen & Powers 2010) and for women experiencing their first breast cancer recurrence (Gotay et al. 2007). However, there have been only few intervention studies exploring the QOL of couples (Donnelly et al. 2000, Badger et al. 2004b, Kalaitzi et al. 2007, Baucom et al. 2008, Scott & Kayser 2009, Kayser et al. 2010).

Most previous intervention studies have been longitudinal designs, involving two to four randomized groups (see Appendix 1). Sample sizes in randomized telephone intervention studies have ranged from 24 (Sandgren et al. 2000) to 191 (Beaver et al. 2009b) and in quasi-randomized or randomized face-to-face intervention studies from 14 (Maeda et al. 2008) to 192 (Ashbury et al. 1998). However, in a recent Finnish study by Penttinen et al. (2010), the total number of participants was 537. In the studies of Ashbury et al. (1998), Rawl et al. (2000), Samarel et al. (2002), Sandgren & McCaul (2003), Coleman et al. (2005), Stanton et al. (2005), Liu et al. (2006), Allard (2007), Arving et al. (2007), Badger et al. (2007), Beurskens et al. (2007), Mutrie et al. (2007), Budin et al. (2008), Classen et al. (2008), Baucom et al. (2009), Dolbeault et al. (2009),

Meneses et al. (2009), Marcus et al. (2010), and Sherman et al. (2010), the method of randomization or quasi-randomization was reported only shortly. Professional support and education has been provided by specialist nurses (Rawl et al. 2002, Sandgren & McCaul 2003, Badger et al. 2004b, Coleman et al. 2005, Arving et al. 2006, Wilmoth et al. 2006, Arving et al. 2007, Badger et al. 2007, Budin et al. 2008, Beaver et al. 2009, Meneses et al. 2009, Sherman et al. 2010), psychologists (Donnelly et al. 2000, Sandgren et al. 2000, Okamura et al. 2003, Arving et al. 2006, Arving et al. 2007, Manos et al. 2008), psychiatrists (Samarel et al. 2002, Okamura et al. 2003), psychotherapists (Capozzo et al. 2010), social workers (Samarel et al. 1998, Samarel et al. 2002, Okamura et al. 2003), physiotherapists (Box et al. 2002a, 2002b, Beurskens et al. 2007) or by physiologists (Libigel et al. 2010). The associations of peer support with QOL among breast cancer patients have also been reported (Ashbury et al. 1998, Dunn et al. 1999, Helgeson et al. 1999, 2000, 2001, Lieberman et al. 2003, Giese-Davis et al. 2006, Sutton et al. 2006, Hoey et al. 2008, Salzer et al. 2010, Shafir et al. 2010). Recently, breast cancer patients have received help adapting to their disease through web-based support groups (Lieberman et al. 2002, Winzelberg et al. 2003, Gustafson et al. 2008, Salzer et al. 2010) and from peers (Hoey et al. 2008, Salzer et al. 2010, Sharif et al. 2010). A recent systematic literature review by Ryhänen et al. (2010) found that the use of the internet or an interactive computer-based patient education programme had a positive association with patient's knowledge levels.

Individual and group interventions include providing support and counselling (Samarel et al. 2002, Badger et al. 2005a, Badger et al. 2005b, Arving et al. 2007, Badger et al. 2007, Manos et al. 2008, Budin et al. 2008, Dolbeault et al. 2009), teaching coping skills, managing symptoms, anxiety and stress (Sandgren et al. 2000, Samarel et al. 2002, Badger et al. 2005b, Allard 2007, Badger et al. 2008, Budin et al. 2008, Dolbeault et al. 2009), and discussing problems and topics that are meaningful to patients (Sandgren et al. 2000). Physiotherapy (Box et al. 2002a, 2002b, Kärki et al. 2005, Beurskens et al. 2007, Schou et al. 2008) and supervised exercise training (Penttinen et al. 2010) have also been provided.

Numerous studies, reviews and meta-analyses indicate that breast cancer patients benefit from a variety of interventions (Meyer & Mark 1995, Sheard &

Maguire 1999, Cox & Wilson 2003, Rehse & Pukrop 2003, Michalec 2005, Zabalegui et al. 2005, McNeely et al. 2006, Naaman et al. 2009, Sheppard 2009, Hoey et al. 2008, Scott & Kayser 2009). Patients themselves have reported positive experiences from their participation in support groups and individual interventions (Arving et al. 2006, Wilmoth et al. 2006), with no changes seen in these benefits over time (Arving et al. 2006). Beaver et al. (2010) reported that patients found telephone intervention a convenient method that provided much-needed continuity in breast cancer care. However, Badger et al. (2005a) suggested that women who reported no previous history of depression and who were in long-term marriages benefited most from interpersonal telephone counselling. Furthermore, the meta-analysis by Naaman et al. (2009) indicated that short interventions were associated with clinically moderate effects for patients with early breast cancer.

Several studies have underlined the importance of adequate communication and support to breast cancer patients' health care (Suominen et al. 1995, Brown et al. 2000, Öhlen et al. 2005, Li et al. 2011), even several years after the diagnosis (Vivar & McQueen 2005, Hodgkinson et al. 2007). However, the information received by patients during their illness has been described as inadequate (Suominen et al. 1995, Liu et al. 2006), unhelpful (Liu et al. 2006), the communication as unclear and unsatisfactory (Kerr et al. 2003), and education as insufficient and inconsistent for purposes of independent rehabilitation (Kärki 2005). In addition, Suominen et al. (1995) found that the opinions of breast cancer patients and health care professionals about the needs for support and support actually received differed widely. Furthermore, patients with different diagnoses have reported unmet information needs during hospitalization (Suhonen et al. 2005). There is no standard referral for follow-up support after breast cancer surgery and treatments (Kärki 2005), although education and support are an integral part of breast cancer treatment (Kärki et al. 2004b).

In this study the interventions were designed on the basis of Slujis's (1991) themes in order to ensure that they were relevant and structured (Appendix 2). The interventions complemented the care of breast cancer patients given at the hospitals and were the investigator's area of expertise. Despite the growing

interest in interventions for women with breast cancer, there is still lack of interventions, which actually focus on improving women's QOL. QOL was measured with two validated instruments that have also been tested with other cancer patient groups, such as patients with brain tumours and prostate cancer (Weitzner et al. 1996, Yarbo & Ferrans 1998, Wallace 2003).

Earlier intervention studies with breast cancer patients and their main findings are described in Appendix 1.

2.4.1 Telephone interventions in breast cancer patients

Several studies have shown that telephone support and education contribute to reduced stress (Sandgren et al. 2000, Badger et al. 2005, Allard 2007), less mood disturbance (Samarel et al. 2002, Sandgren & McCaul 2003), less loneliness (Samarel et al. 2002), effective symptom management (Badger et al. 2005b, Sherman et al. 2010), improved sexual functioning (Marcus et al. 2010) and improved QOL (Sandgren et al. 2000, Sandgren & McCaul 2003, Badger et al. 2005). Furthermore, it has been found that support via telephone decreases depression, fear and fatigue (Badger et al. 2005) as well as emotional distress, tension and confusion (Allard 2007). It helps women to express their feelings, deepens their awareness of themselves and improves women's attitudes towards their breast cancer (Wilmoth et al. 2006). However, some studies have shown only limited effects on psychological and physical functioning (Helgeson et al. 1999, Wilmoth et al. 2006, Classen et al. 2008), mood disturbance (Sandgren & McCaul 2003) and QOL (Schou et al. 2008).

Telephone interventions have been provided in the areas of psychotherapy (Donnelly et al. 2000), social support and education (Sandgren et al. 2000, Samarel et al. 2002, Sandgren & McCaul 2003, Badger et al. 2005a, 2005b, Coleman et al. 2005, Wilmoth et al. 2006), psychosocial and educational support (Badger et al. 2004a, Arving et al. 2006, Allard 2007, Arving et al. 2007, Badger et al. 2007, Budin et al. 2008, Meneses et al. 2008, Sherman et al. 2009), psychological support (Rawl et al. 2002, Badger et al. 2004b, Coleman et al. 2005, Beaver et al. 2006, Badger et al. 2007), cancer education (Badger et al. 2005b, Wilmoth et al. 2006, Badger et al. 2007), managing with anxiety (Budin

et al. 2008), stress (Sandgren et al. 2000) and depression (Arving et al. 2007). Furthermore, interventions have focused on managing treatment side-effects and symptoms (Samarel et al. 2002, Sandgren & McCaul 2003, Badger et al. 2004a, Allard 2007), fatigue (Sandgren & McCaul 2003, Badger et al. 2004a), and maintaining a healthy lifestyle (Sandgren & McCaul 2003). Beaver et al. (2009b) compared traditional hospital follow-up with a telephone follow-up programme by specialist nurses. In some studies the interventions have been more extensive, comprising teaching and facilitating coping strategies (Sandgren et al. 2000, Budin et al. 2008), encouragement to improving interpersonal communication (Samarel et al. 2002) and role transitions (Badger et al. 2004b, Badger et al. 2007), how to deal with the fear of recurrence, issues of self-image and sexuality (Samarel et al. 2002), and promoting the reintegration of a holistic concept of self (Budin et al. 2008).

Telephone interventions have been found to be important in providing vital support to vulnerable patients and in helping women adapt to breast cancer (Sandgren et al. 2000, Samarel et al. 2002, Wilmoth et al. 2006, Marcus et al. 2010). Telephone support is a viable option for those who are unable to attend support groups (Wilmoth et al. 2006). Sandgren et al. (2000) and Samarel et al. (2002) also argued for telephone support and education for women in rural areas who had limited access to cancer support services. In the intervention study by Arving et al. (2007), some intervention sessions were held by telephone because of long distances. Moreover, telephone support allows for greater privacy and anonymity (Badger et al. 2005a), and it is more appropriate for large groups of vulnerable patients (Cox & Wilson 2003). In addition, distressing symptoms such as fatigue and nausea from breast cancer treatments may prevent women from attending support groups and education meetings (Samarel et al. 2002). Beaver et al. (2010) reported in their qualitative study that women felt a telephone follow-up was more convenient and relaxed in their home settings as compared to the busy hospital setting, and some women furthermore felt more comfortable talking on the phone rather than face-to-face (see also Donnelly et al. 2000).

On the one hand, Beaver et al. (2009a) found in their randomized clinical trial of hospital follow-ups compared to telephone follow-up that the latter did

not lead to cost or salary savings, but it was found to reduce travel and productivity costs for patients and society. On the other hand, Grunfeld et al. (1999) concluded that average costs per patient were lower in a telephone than a hospital follow-up. In their meta-analysis Meyer & Mark (1995) argued for the more cost-effective delivery of support and education to cancer patients.

2.4.2 Face-to-face interventions in breast cancer patients

Face-to-face support for breast cancer patients has been provided both individually (Ashbury et al. 1998, Arving et al. 2007, Maeda et al. 2008, Manos et al. 2008) and primarily in groups (Rustoen et al. 1998, Samarel et al. 1998, Sheard & Maguire 1999, Fukui et al. 2000, Okamura et al. 2003, Rehse & Bukrop 2003, Liu et al. 2006, Dolbeault et al. 2009, Shafir et al. 2010). Face-to-face interventions may include psychosocial (Myer & Mark 1995, Rehse & Pukrop 2003, Arving et al. 2007, Dolbeault et al. 2009) and psychological (Sheard & Maguire 1999, Maeda et al. 2008) support as well as physiotherapy focusing on shoulder movement (Box et al. 2002a), minimizing lymphedema (Box et al. 2002b), and improving mobility and strength, as in a recent randomized controlled study by Beurskens et al. (2007). With the growing requirements of cost-effectiveness, the focus of cancer intervention studies has switched to examining the effects of group interventions on coping and QOL (Bottomley 1997).

Individual face-to-face interventions have been aimed at helping women recover (Ashbury et al. 1998) and adjust to the disease and its treatments (Manos et al. 2008a), understanding the influence of various stressors, and helping women find feasible ways of solving their problems (Maeda et al. 2008). Furthermore, interventions have included psychosocial support, such as relaxation and distraction, activity scheduling, and ways of improving communication (Arving et al. 2008). It has been found that peer-led programmes (Ashbury et al. 1998), individual psychosocial support (Arving et al. 2007, Manos et al. 2008) and psychological interventions (Maeda et al. 2008) are beneficial to breast cancer patients and have a positive effect on their QOL (Ashbury et al. 1998, Arving et al. 2007, Manos et al. 2008) and well-being

(Maeda et al. 2008). According to previous studies face-to-face interventions could be a realistic alternative in routine cancer care (Arving et al. 2007), although it has been stressed that there is still need for further trials with larger samples (Maeda et al. 2008).

2.5 Associations of background variables with quality of life in patients with breast cancer

Several studies have shown that QOL is associated with age (Rustoen et al. 1999a, Engel et al. 2003a, Ganz et al. 2003, Engel et al. 2004, King et al. 2000, Sammarco et al. 2009), educational level (King et al. 2000, Engel et al. 2003a, Uzun et al. 2004), employment status (Engel et al. 2003a), and type of surgery (Engel et al. 2004, Janz et al. 2005). Younger women with breast cancer experience significantly greater QOL disturbances than older women (Wentzel et al. 1999, King et al. 2000, Sammarco 2001a, Engel et al. 2004, Avis et al. 2005, Sammarco 2009). In addition, the problems they face are often very different from those faced by older women, such as concerns about premature menopause leading to fertility loss, and negative body image (King et al. 2000, Engel et al. 2003a, Ganz et al. 2003, Avis et al. 2005, Gorman et al. 2011) and about sexuality, career, job and financial security (Andrykowski et al. 2000, Sammarco 2001, Avis et al. 2005).

Sammarco (2009) reported that younger women had poorer socio-economic, psychological and spiritual QOL than older women. Younger women seem to be psychologically more affected by their cancer experience (Engel et al. 2003c, Wentzel et al. 1999) and to have poorer social (Engel et al. 2003a) and emotional functioning (Engel et al. 2004), more pain, severe arm dysfunction (King et al. 2000), more disrupted daily habits (Engel et al. 2003a), and more future health worries than older women (Engel et al. 2004). However, younger women seem to fare better than older women in physical functioning (Engel et al. 2003a, Wyatt et al. 2008). Furthermore, Rustoen et al. (2000) reported that family health was least important to the youngest age group and job/unemployment least important to the oldest group. Younger age and unmarried status were positively

related to poorer mental well-being and greater depressive symptoms (Broeckel et al. 2000). Employed women reported better QOL than unemployed or retired women (Uzun et al. 2004). Women with a high level of education and in employment had better QOL than women who were unemployed or retired (Uzun et al. 2004). Furthermore, it has been found that higher socio-economic status is associated with longer survival (Lehto et al. 2006).

Earlier studies have also reported associations between type of surgery and QOL in women with breast cancer. Women treated with breast conserving therapy have reported less QOL disturbance than women undergoing total mastectomy, especially in relation to body image scores and sexual functioning (King et al. 2000, Engel et al. 2004, Fobair et al. 2006). Mastectomy patients reported reduced sexual functioning and more difficulties with body image (Engel et al. 2004, King et al. 2000) than patients who underwent breast conserving surgery (Engel et al. 2003a). One month after surgery, women who had had mastectomy reported significantly lower body image and physical and functional well-being than women treated with lumpectomy. Women undergoing lumpectomy reported significantly lower emotional well-being and they worried more about the effects of stress on their illness (Arora et al. 2001). Furthermore, Xiaokun (2002) suggested that mastectomy patients receiving radiotherapy had the lowest satisfaction scores in the psychological and spiritual domain and the highest in the family domain.

The extent of axillary surgery significantly contributes to arm problems (Engel et al. 2003b). According to earlier studies sentinel node biopsy causes less postoperative morbidity than more extensive axillary treatment (Burak et al. 2002, Temple et al. 2002, Peintinger et al. 2003, Schjiven et al. 2003, Rönkä et al. 2004, 2005). Both breast oedema (Rönkä et al. 2004) and arm oedema (Engel et al. 2003b) seem to be related to the extent of axillary surgery. Breast symptoms were significantly less common after breast conserving therapy and sentinel node biopsy than after breast conserving therapy with axillary dissection (Rönkä et al. 2004). Rönkä et al. (2005) found that breast morbidity after axillary dissection had a significantly greater impact on work, leisure activities and daily life in general than sentinel node biopsy.

Studies focusing on adjuvant treatments have reported negative effects on body image, psychosocial well-being (Kayl & Meyers 2006), physical function (Arora et al. 2001, Watters et al. 2003), role function, social function and global health status during adjuvant chemotherapy (Watters et al. 2003). It has been found that chemotherapy is associated with nausea, vomiting, hair loss, cognitive dysfunction (Kayl & Meyers 2006), fatigue (Kayl & Meyers 2006, Haas 2010) and changes in sexual functioning (Kayl & Meyers 2006). Furthermore, chemotherapy affects body image, psychosocial distress and consequently reduces QOL ratings (Schover et al. 1995, McIlfatrick et al. 2007, Turgay et al. 2008). Physical function (Arora et al. 2001, Watters et al. 2005, Turgay et al. 2008), role function (Watters et al. 2003), social function, general health and well-being (Watters et al. 2003, Turgay et al. 2008) have also been found to decline during adjuvant chemotherapy. After chemotherapy, patients have reported decreased activity, fatigue (Byar et al. 2006), more sleep and sexual dysfunction, and decreased social participation and work performance than before chemotherapy (Turgay et al. 2008). Furthermore, patients receiving chemotherapy in a day hospital may experience more difficulties managing the side-effects of chemotherapy at home (McIlfatric et al. 2007).

Patients treated with a combination of chemotherapy and radiotherapy complain of lymphedema significantly more often than those treated with surgery, hormonal therapy, chemotherapy alone or radiotherapy alone (Schultz et al. 2005). It has been found that lymphoedema significantly reduces women's QOL (Ridner 2005). Radiotherapy alone also has an effect on QOL (Whelan et al. 2000). Compared to breast cancer patients receiving no further treatment, patients with radiotherapy reported significantly more physical symptoms, inconvenience and fatigue (Whelan et al. 2000). Women may suffer from fatigue even nine months after radiotherapy, which has been found to be associated with psychological distress (Smets et al. 1998). On the other hand, Haas (2010) reported that women undergoing chemotherapy had higher levels of fatigue than women receiving hormonal therapy. Furthermore, lymphedema, pneumonitis and pulmonary fibrosis and cardiac toxicity have been found to be associated with radiotherapy-associated complications (Pierce 2005). According to van den Hurk et al. (2010), the most distressing problem associated with chemotherapy was

alopecia, which remained six months after completing chemotherapy. Breast cancer treatments can also cause a financial burden to patients and lead to additional psychological stress, especially in women from a low socio-economic background (Khan et al. 2010).

2.6 Social support and its associations with quality of life

2.6.1 Social support in breast cancer patients

The concept of social support has been used in nursing research since it started in the 1970s (Norbeck 1988). Perceived social support is the awareness that leads to the belief that one is cared for, loved, esteemed and valued and that one belongs to a mutually obliging communication network (Cobb 1976). Social support is described as an exchange of resources between at least two individuals and assumed to be reciprocal (House 1981, Cohen & Syme 1985). The key elements in supportive transactions are affect, aid and affirmation. Affect refers to expressions of liking, admiration, respect, or love; aid refers to material elements of support such as money, information, time and entitlements; while affirmation includes expressions of agreement, or acknowledgement of the appropriateness or rightness of some act or statement by another person. (Kahn 1979.) According to Kahn & Antonucci (1980), social support is given and received within a social network structure. Social network has been defined as the vehicle through which social support is provided (Kahn 1979, Kahn & Antonucci 1980).

Social support has been reported to protect individuals from the pathological and harmful effects of many stressful life events (Cobb 1976, Norbeck 1988, Lehto-Järnstedt et al. 2002, Lehto et al. 2005), and it may also serve as a buffer against the negative consequences of illness (Cobb 1976, Helgeson & Cohen, 1996). It is helpful in dealing with anger and depression (Manuel et al. 2007), and it has been found to have a positive association with subjective experiences of good health (Norbeck 1988). Lack of support, on the other hand, has been suggested to predict mortality (House et al. 1988, Kroenke et al. 2006). However, Alqaissi & Dickerson (2010) reported that the meaning of social

support is influenced by culture, religion and also by clinical and personal characteristics.

Earlier studies have found that perceived social support is associated with QOL in women with breast cancer (Lehto-Järnstedt 2000, Rustoen et al. 1999a, Sammarco 2001a, Sammarco 2003, Arving et al. 2007, Arora et al. 2007, Sammarco & Konency 2008, Sammarco 2009, Kwan et al. 2010), and it has found to be vital for coping with breast cancer (Lungton 1997) and adjusting to the stress of the disease (Krishnasamy 1996). Support has positive effects on breast cancer patients' physical, psychological and social functioning and on their QOL (Rehse & Pukrop 2003, Badger et al. 2005, Arving et al. 2007). In a recent study by Arora et al. (2007), emotional support two months and emotional and informational support five months after the breast cancer diagnosis were associated with women's HRQOL and self-efficacy outcomes. Furthermore, social support has been found to be associated with a better quality of family life (Sammarco 2001a).

According to Sammarco (2003), social support correlates positively with health and functioning, psychological and spiritual and family QOL subscales among women over 50 years of age. Several studies have discovered that patients receiving adjuvant treatments after breast cancer surgery are more likely to have helpful social support compared to women not receiving adjuvant treatments (Bloom et al. 2001, Lehto-Järnstedt et al. 2002, Arora et al. 2007). According to Lehto-Järnstedt et al. (2002), patients received "less" in the psychosocial sense than patients who underwent adjuvant treatments. Bloom et al. (2001) reported that women undergoing chemotherapy or having positive lymph nodes received more emotional support, while women who reported having undergone mastectomy received more instrumental support.

Social support is also directly reflected in stress and health outcomes (Norbeck 1988). However, longitudinal studies have suggested that social support from family, friends and health care providers decreases over time (Arora et al. 2001, Arora et al. 2007). In a five-month follow-up both access to support and quality of support was found to diminish (Arora et al. 2007).

2.6.2 Major sources of social support

Breast cancer patients' major sources of emotional support are usually their family members (Courtens et al. 1996), spouses, children, friends, siblings (Sandgren et al. 2004, Arora et al. 2007), health care professionals (Davis et al. 2004, Arora et al. 2007), and volunteer breast cancer survivors (Davis et al. 2004). Lehto-Järnstedt (2000) found that patients reported the greatest amount of support from spouses, while physicians and nurses were nearly as important sources of support. In the intervention by Arora et al. (2007), women with breast cancer received helpful informational support three and five months after breast cancer surgery from health care providers, emotional support from family and friends, and decision-making support from health care providers and family members at three months and from health care providers at five months after surgery. Maeda et al. (2008) concluded in their recent study that family and friends may become less supportive once the patients got better and returned to normal social life. However, according to Kroenke et al. (2006) the social network did not appear to change markedly over time, while Courtens et al. (1996) concluded that size of network and the amount of social support decreased to some extent.

In Australia, Davis et al. (2004) reported that women received most frequent support from medical staff, including surgeons, the family doctor, and oncologist. However, Suominen et al. (1995) reported that breast cancer patients usually received support from other people than health care staff. Furthermore, in the study by Davis et al. (2004), women reported that volunteer breast cancer survivors were frequent sources of social support.

It has been reported that size of social network, number of support persons and quality and amount of social support are related to mortality (House 1988, Kroenke et al. 2006). Socially isolated women are more affected by breast cancer, and their role function, vitality and physical function is lower (Michael et al. 2002). They also have a significantly higher risk of mortality after the diagnosis of breast cancer than socially integrated women (House 1988, Kroenke et al. 2006).

2.6.3 Needs for social support

Numerous studies over the past few years have suggested that patients with breast cancer have a variety of support needs (Brown et al. 2000, Kerr et al. 2003, Hodgkinson et al. 2007, Schmid-Büchi et al. 2008), which persist after surgery and short hospitalization (Kärki et al. 2004b, Beaver et al. 2006) even for extended periods after the diagnosis (Vivar & McQueen 2005, Hodgkinson et al. 2007). During diagnosis and treatment, women need information about the stage of their disease, treatment options and side-effects, and during post-treatment about treatment and recovery (Rutten et al. 2005). Women with breast cancer have a long-standing needs for support and communication to help them deal with their life-threatening illness (Kerr et al. 2003, Beaver et al. 2006), and they also want information that is tailored to their personal needs (Brown et al. 2000).

The research evidence available suggests that women with breast cancer do not receive the support they need (Hodgkinson et al. 2007). According to Hodgkinson et al. (2007) women with breast cancer report the most unmet needs in managing their concerns about the recurrence of cancer and getting readily understandable information. If needs for support are not met in specific phases of the breast cancer experience, such as diagnosis, post-surgery, adjuvant therapy and ongoing recovery, they are likely to continue and compound the needs of subsequent phases (Hoskins et al. 1996). Rutten et al. (2005) concluded in their systematic review that the need of social support does not decrease over time, but its focus and content do change. According to Engel et al. (2003c), women reported insufficient support from family members, other patients, psychologists, nurses, priests and social workers.

Thewes et al. (2004) found that both younger and older women expressed a need for information about how to deal with physical problems, such as arm problems. Younger women reported greater needs for emotional support from health care professionals than older women (Thewes et al. 2004). According to earlier studies short-term breast cancer survivors' informational and emotional needs appear to differ according to age (Lindop & Cannon 2001, Thewes et al. 2004.) Wyatt et al. (2008) concluded that patients who may be in need of additional physical and psychological support are typically postsurgical breast

cancer patients who are younger, unmarried, receiving or in need of caregiver support, in the lowest income bracket, and who have a college education.

The literature review by Vivar & McQueen (2004) on the informational and emotional needs of long-term breast cancer survivors showed that women's needs are often unmet by oncology teams and that they have to find other sources of support. Furthermore, it was found that informational and emotional needs and type of support are age-related. Age has been found to be particularly important in relation to needs for support and the amount and type of social support (Norbeck 1981, Gaslloway et al. 1997, Lindop & Cannon 2001, Sammarco 2001a, Thewes et al. 2004, Gorman et al. 2011), with younger women reporting more needs for support than older women (Galloway et al. 1997).

Previous research has shown that there is an increased need for follow-up care after short periods of hospitalization, and it has highlighted the importance of adequate communication and support to breast cancer patients' health care (Kerr et al. 2003, Kärki et al. 2004a, 2004b). However, there is evidence that postoperative education is insufficient and inconsistent Kärki et al. (2004a). Furthermore, patients have described the information they receive as incomprehensible and incomplete (Kärki 2005). Patients expect to receive more effective social support and help (Beaver et al. 2006) and have the opportunity to speak with medical staff (Kerr et al. 2003). Women want to be heard (Engel et al. 2003a) and share their illness-related difficulties, and to have someone who will listen to and accept their emotions in order to feel safe and secure (Kerr et al. 2003). However, some cancer patients do not want to talk about their difficult feelings with nurses (Kvåle 2007) and have no need for psychosocial intervention (Moyer et al. 2009).

2.7 Summary of the literature

The QOL and perceived social support of women with breast cancer has been explored in several descriptive and longitudinal studies. Although breast cancer and its treatments have various effects on physical, psychological and social functioning, earlier studies have suggested that the QOL of breast cancer patients is moderately high. Some women adjust well, but a significant majority of women suffer from range ongoing difficulties that may have a negative impact on their QOL even for years after the diagnosis. Providing adequate social support to women is considered an important way of maintaining and promoting their coping and QOL.

In the present study QOL is understood as a subjective and holistic concept, acknowledging the fact that people have different values and that these have various impacts on QOL, and as a narrower concept that focuses on therapy side-effects and level of functioning. There is a lack of consensus about how to define QOL, and consequently there are almost as many definitions of QOL as there are instruments that are used to measure QOL. The lack of conceptual clarity about QOL may lead to profound differences in research outcomes, in clinical practice, and in the allocation of health care resources.

The research evidence available suggests that breast cancer patients benefit from both group and individual therapeutic and supportive interventions. Interventions seem to be an effective way of enhancing women's QOL, although the content and timing of these interventions vary and the results are not consistent. A review of the literature lends support to the conclusion that women with breast cancer have high needs for supportive care and services for up to ten years after their cancer treatments. A number of demographic factors are associated with women's QOL, most notably age, type of surgery and adjuvant treatments.

The social support that breast cancer patients receive from their social network and from health care professionals may help to buffer the negative consequences of the illness and its treatments. According to earlier intervention studies perceived social support is associated with QOL in women with breast

cancer. Patients expect to receive more effective social support and help, but the needs for social support are not met in patients with breast cancer.

Because of the increasing incidence of breast cancer and the unmet needs for social support, there is a growing need to investigate the impact of different types of interventions in the treatment of women with breast cancer. Assessments of the outcomes of social support and education provide crucial evidence for the development of systematic social support and education that is based on women's needs and expectations. The results of earlier studies underline the need to provide appropriate treatment through both telephone and face-to-face interventions and to further develop both outpatient and inpatient services.

In Finland there is broad recognition of the importance of QOL in patients with breast cancer, and consequently research in this field has been active (Nikander et al. 2007, Leidenius et al. 2010, Penttinen et al. 2010). Despite this increasing interest in QOL in Finnish nursing research, only limited attention has been paid to the type of short-term telephone and face-to-face interventions examined in the present study, even though the benefits of social support for patients with breast cancer are well documented.

Figure 1 describes the key concepts as used and understood in this study.

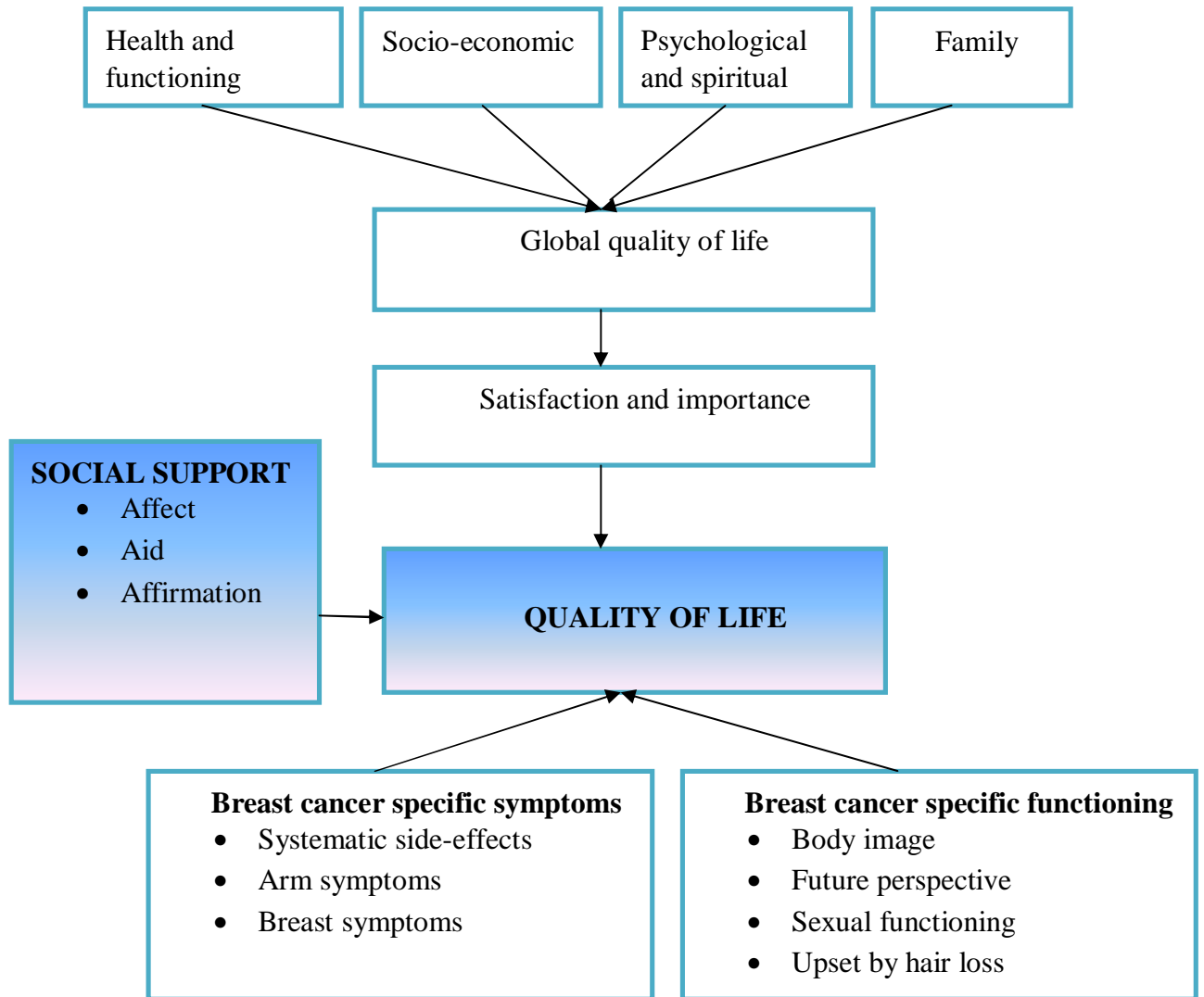


Figure 1. Concepts of this study

3 AIMS OF THE STUDY

The purpose of this study is to evaluate the effect of two individual interventions on QOL in breast cancer patients and the role of social support. The aim is to help health care professionals achieve a deeper understanding of QOL and social support issues and deliver follow-up services more effectively. The main outcome variable of this study is QOL; the secondary outcome variable is social support.

The following research questions were addressed:

- 1) What impact did a telephone intervention one week after breast cancer surgery have on the QOL of breast cancer patients? (Paper I)
- 2) What impact did a face-to-face intervention six months after breast cancer surgery have on the QOL of breast cancer patients? (Paper II)
- 3) How did QOL change in the intervention and control groups from one week to six months after breast cancer surgery? (Paper III),
- 4) What impact does social support have on the QOL of breast cancer patients? (Paper IV)
- 5) How are sociodemographic, medical and treatment factors associated with QOL in breast cancer patients? (Papers I, II)
- 6) What are the predictors of poor QOL in patients with breast cancer? (Papers I to IV)

4 MATERIALS AND METHODS

4.1 Study design, samples and data collection

4.1.1 Study design and samples

A quasi-experimental design with intervention and control groups was chosen in order to evaluate the impact of a telephone intervention one week after breast cancer surgery and a face-to-face intervention six months after breast cancer surgery on the QOL of women with breast cancer (Cook et al. 1979, Polit & Peck 2006). The choice of a longitudinal design and different samples was motivated by the interest to investigate changes in QOL and social support over six months. Patients were considered eligible for this study if: 1) they were female, 2) they were aged 18-75 years, 3) they were newly diagnosed and operated because of breast cancer, and 4) they had a good knowledge of Finnish and they could complete the questionnaires. This study was carried out between 2 August 2004 and 3 May 2007 in two hospitals in southern Finland. The instruments used were the Quality of Life Index-Cancer Version (QLI-CV) and the European Organisation for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life Questionnaire (EORTC QLQ-BR23).

Surgical nurses were recruited at both hospitals to identify 477 eligible breast cancer patients, of whom 359 agreed to participate and completed informed consent forms. The women in the intervention and in the control groups were quasi-randomized at the hospital after breast cancer surgery according to the pre-existing admission schedule. Women who got odd numbers were assigned to the intervention group, and women who got even numbers were assigned to the control group. Neither the oncology nurse nor the consenting women knew to which group each woman would be assigned.

4.1.2 Data collection

Phase I (Paper I)

The participants in the first phase of the study were the women who had taken part in the telephone intervention one week after breast cancer surgery and the control group. The data were collected on two surgical wards in two hospitals in southern Finland. The telephone intervention was conducted by physiotherapists who specialized in surgical physiotherapy. The physiotherapists were unable to reach 12 of the women in the intervention group even after three phone calls, and 10 women refused to participate. The sample in the first phase consisted of 120 women in the intervention group and 108 women in the control group. The questionnaires were handed to the women by nurses at the hospital, with instructions to complete the questionnaires at home within two weeks and then to mail them to the investigator. (Paper I.)

Phase II (Paper II)

The target population in the second phase consisted of the women who participated in the face-to-face intervention six months after breast cancer surgery and the control group, and who were admitted for treatment and/or follow-up to the Oncology Clinic in hospital. In the second phase the participants received a letter from an oncology nurse two weeks in advance in which they were invited to participate in a supportive face-to-face intervention. At the end of the intervention session, the physiotherapist handed the questionnaires to the women in the intervention group and asked them to fill in and return the questionnaires to the investigator within two weeks. The control group received their questionnaires by mail six months after breast cancer surgery. The study group thus consisted of 204 patients, 112 women in the intervention group and 92 women in the control group. The women who participated in the face-to-face intervention were not all the same as the women who took part in the telephone intervention. At phase II data on the surgical procedure, adjuvant therapy and other medical details were drawn from patient files at hospital in Finland. (Paper II.)

Phase III (Papers III and IV)

Only those intervention group patients who took part in both the telephone intervention and the face-to-face intervention were included in the study. From the control group, only those patients were included in the study who answered the questionnaires both one week and six months after surgery. The target population in these phases consisted of 85 women in the intervention group and 79 women in the control group. In these quasi-randomised longitudinal studies, the first point of measurement one week after surgery represented the baseline assessment and the second point of measurement six months after surgery represented the follow-up. Each breast cancer patient was thus assessed twice: one week and six months after breast cancer surgery. (Papers III and IV.) No significant differences were seen in any of the stages between the intervention and control groups in either sociodemographic or medical factors.

In phase I, one week after surgery, 120 women participated in the telephone intervention, and 85 of them also participated in the face-to-face intervention six months after surgery. The dropout rate was calculated from these women who took part in the telephone intervention in phase I but not in the face-to-face intervention in phase II. The response rate was 71%. Of the 120 women, 35 (29%) did not participate in the face-to-face intervention. Out of these 35 women in the intervention group, 34% were under 55 years of age. Most of the women did not have underage children (88%), were employed (65%) and had no vocational education (46%). At phase I, one week after surgery, 108 women participated in the control group, and 79 of them also took part in phase II, six months after surgery. Of these women, 29 in the control group did not take part in phase II; the response rate in the control group was 73%. Out of these 29 women, 59% were under 55 years of age, had no underage children (83%), were employed (79%) and had a vocational education (72%).

Differences in demographic variables between the women who participated in the phase I intervention (n=120) and control groups (n=108) and between the women who dropped out of the intervention group (n=35) and the control group (N=29) were tested with Pearson's chi-square test and Fisher's exact test. According to these analyses there were no statistically significant differences in women's age (p=.996), education (p=.384), employment status (p=.474) and

underage children ($p=.323$) between the women who participated in both the telephone intervention and face-to-face intervention ($n=84$) and the women who dropped out after the telephone intervention. Furthermore, no statistically significant differences were found in women's age ($p=.891$), education ($p=.431$), employment status ($p=.799$) and underage children ($p=.775$) between the women in the control group in phase I and those women who did not participate in phase II. (Polit & Beck 2008, 2010.)

The data collection process is described in Figure 2.

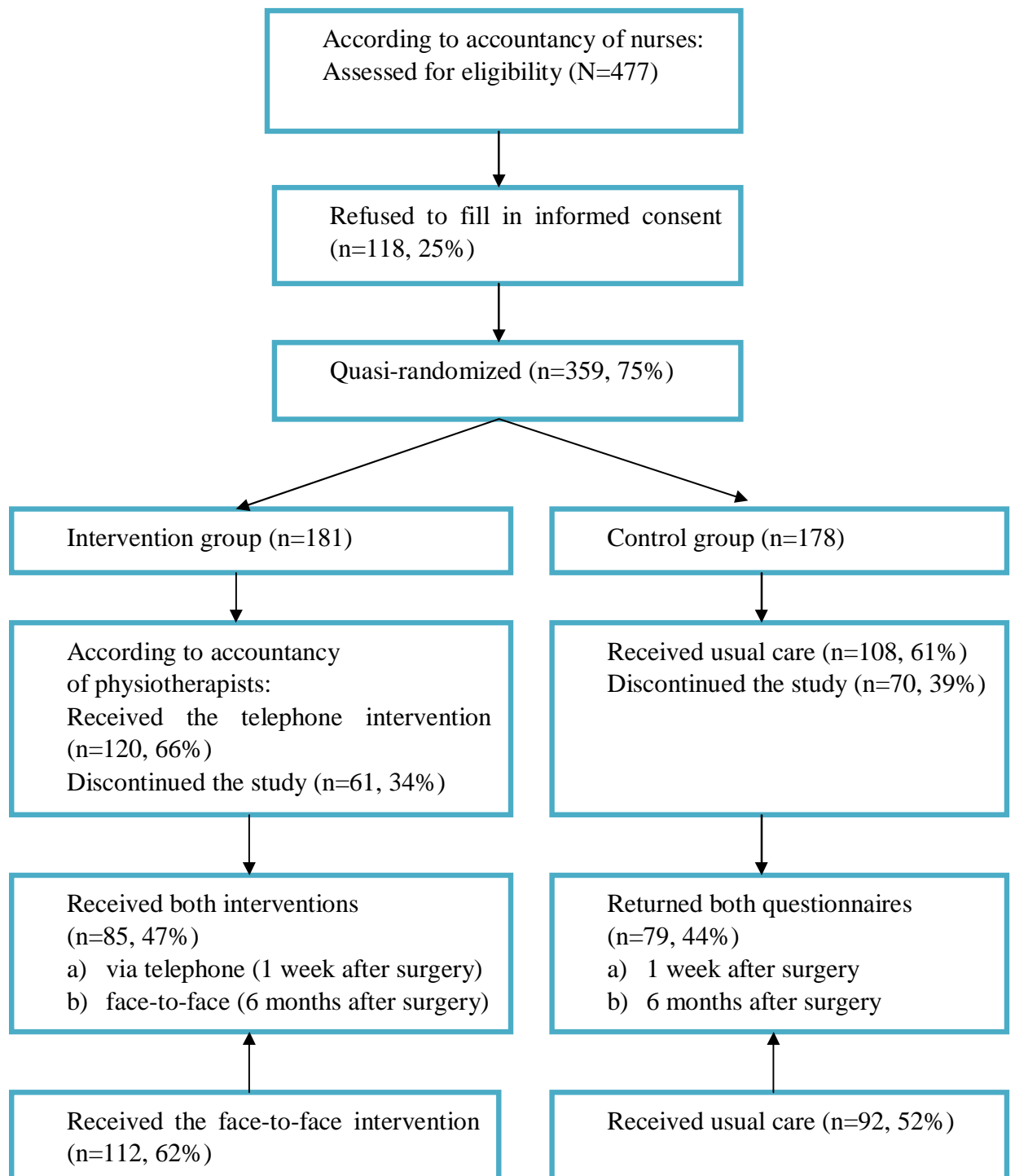


Figure 2. Design of data collection

4.2 Interventions

This study was focused on interventions aimed at improving the QOL of breast cancer patients by offering individual support and education. Both the individual telephone (Paper I) and the individual face-to-face intervention (Paper II) were based on Sluijs's (1991) themes of patient education in physical therapy and focused on providing support and information according to the individual needs of breast cancer patients. The themes were: 1) teaching and providing information about the illness, 2) giving instructions for home exercises, 3) giving advice and information, 4) giving general health education, 5) counselling on stress-related problems, 6) concentrating on the therapist-patient relationship, 7) focusing on a planned and systematic approach, and 8) exploring patients' demands and expectations. (Appendix 2.)

The aims of the interventions were to 1) offer concrete support and counselling in physical functioning and guidance about how to use the upper limb, 2) provide an opportunity for patients to talk about their feelings, 3) give patients a chance to ask questions about matters bothering them, and 4) provide information about rehabilitation and support groups in the area. Special importance was attached to each woman's individual needs and concerns. Both the intervention and control group received standard verbal and written education in the hospital about how to increase shoulder function and upper arm mobility and how to avoid upper limb oedema. The control group received standard postoperative education and support.

The interventions were planned by the investigator. The physiotherapists received training for support and education delivery from the investigator. The physiotherapist who counselled the patient at the hospital called the patient who was assigned to the intervention group one week after surgery. The physiotherapist phoned each patient a maximum of three times to contact them. The phone calls ranged in length from 3 to 25 minutes depending on the individual patient's needs. In the face-to-face intervention six months after breast cancer surgery, a physiotherapist (the investigator) provided individual support and education to the patients. The length of individual contacts was

limited to one hour. In addition, breast cancer patients received education and support from health care professionals during their adjuvant treatments.

The timing of the telephone intervention one week after breast cancer surgery was based on the short amount of time that patients today remain in hospital after surgery, i.e. for no more than some 24 hours. The immediate postoperative period can be a stressful and anxious time for women as they wait for the start of adjuvant treatments. As recommended in the study of Mertz & Williams (2010), special attention was given to psychological factors and to ensuring that women understood the information they were given at hospital about drain and wound management and postoperative pain management. Kärki et al. (2004b) reported that women suffered from late symptoms such as neck-shoulder pain and numbness six months after surgery, and several studies have found that decreased functioning may persist several years after surgery and treatments (Engel et al. 2003a, Engel et al. 2003b, Engel et al. 2004). The present face-to-face intervention six months after breast cancer surgery was developed to prevent common late symptoms such as arm oedema, muscle weakness, and reduced arm movement, and to support women after stressful adjuvant treatments such as radiotherapy and chemotherapy.

Appendix 2 describes Sluij's (1991) themes of patient education.

4.3 Instruments

Quality of Life Index – Cancer Version (QLI-CV)

The Ferrans and Powers Quality of Life Index–Cancer Version (QLI-CV) produces an overall QOL score and subscale scores for four specific domains, i.e. the 1) health and functioning, 2) social and economic, 3) psychological and spiritual, and 4) family domain. QLI-CV measures both satisfaction in these various domains and the relative importance of each domain to the individual. Importance ratings are used to weigh the satisfaction levels so that scores reflect the respondents' satisfaction with the aspects of life that they value most. Items that are rated as more important have a greater impact on scores than those of lesser importance. Each part of the instrument consists of 33 items, with possible

scores ranging from 0 to 30. Possible responses range in part one from 1 (very dissatisfied) to 6 (very satisfied) and likewise in part two from 1 (very unimportant) to 6 (very important). The Quality of Life Index (QLI) was developed by Ferrans and Powers to measure quality of life in terms of general life satisfaction (Ferrans & Powers, 1985). Quality of life is defined by Ferrans as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans & Powers 1985, Ferrans, 1990, Ferrans & Powers 1992, Ferrans 1996).

The reliability and validity of the QLI-CV have been demonstrated (Ferrans and Powers 1985, Ferrans 1990, Ferrans & Powers 1992) and in this study are reported in the Discussion. The Ferrans and Powers English-language version was translated into Finnish with the authors’ permission. The choice to use Ferrans’ and Power’s QLI-CV was based on the subjective nature of the concept and its holistic approach. This concept recognizes the fact that people have different values and that these values have different impacts on QOL.

The European Organisation for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life questionnaire (EORTC QLQ-BR23)

The EORTC QLQ-BR23 module consists of 23 items that are rated on a four-point scale from 1 (not at all) to 4 (very much). Items assess therapy side-effects, arm symptoms, breast symptoms, body image, and sexual functioning; individual items are included to assess sexual enjoyment, upset by hair loss, and future perspective. Scores range between 0 and 100. For scales evaluating function, a higher score represents a higher level of functioning. For scales evaluating symptoms, a higher score means more problems and a higher level of symptoms. The time frame for all scales of the questionnaire was the patient’s past week; however for items related to sexual activity a 4-week time frame was applied. This measurement tool is internationally well-known and has been validated and used with breast cancer patients (Aaronson et al. 1993, Sprangers et al. 1993, Sprangers et al. 1996, Yun et al. 2004). Permission to use the Finnish version of the QLQ-BR23 was obtained from the EORTC Quality of Life Group. The decision to use the disease-specific health-related QOL instrument (HRQOL) EORTC QLQ BR-23, in turn, was motivated by the research interest in disease symptoms and functioning, including body image, sexuality and future outlook.

Social Support from Social Network

The Social Support from Social Network and Social Support from Nurses scales were developed by Rantanen et al. (2004). These scales are based on Kahn's (1979) theory of social support, which makes a distinction between three aspects of social support, i.e. affect, aid and affirmation. The scale measuring social support received from the support network has six questions, two each to measure affect, aid and affirmation. Support received from the support network is assessed on a five-point scale, with 1 indicating limited social support and 5 indicating much social support. In this study the participants were asked to identify their most important sources of support within this network and to say how often they met them. The internal consistency of the instrument as assessed by correlation coefficients ranged from 0.39 to 0.77 at baseline and from 0.54 to 0.74 at follow-up.

Social Support from Nurses

The scale measuring social support received from nurses on the surgical and oncology wards included 15 questions, five for each of the three support dimensions. Responses were recorded on a five-point scale, with 1 indicating little social support and 5 very much social support. The component areas of the scale showed good internal consistency as measured by Cronbach's alpha, which ranged from .82 to .94 at baseline and from .78 to .92 at follow-up.

The questionnaires are reproduced in Appendix 3.

4.4 Data analyses

Descriptive statistics were used to characterize the sample's sociodemographic profile, medical and treatment characteristics. (Papers I to IV.) Patients' perceptions of telephone and face-to-face support and QOL were illustrated both by means of standard deviations and by medians with interquartile ranges. (Papers I and II.) Differences in sociodemographic, medical and treatment factors between the intervention and control groups were tested with Pearson's chi-square test and Fisher's exact test. Group differences in QOL were analysed

using the nonparametric Mann-Whitney U test because of skewed distributions. The associations of categorical background factors with QOL scores were analysed using the Mann-Whitney U test and Kruskal Wallis test. In these tests a p-value of less than .05 was considered significant. (Papers I and II.)

The QLQ-BR23 items were scored in accordance with the EORTC manual (Fayers et al. 2001). After scoring, all scale and single item scores were linearly transformed to a 0-100 scale. Group differences in QLQ-BR23 scores were interpreted for clinical relevance according to Osoba et al. (1998) on a 100-point scale (small 5-10, moderate 11-19, and large ≥ 20 points). Higher scores represent more symptoms (systematic side-effects, breast symptoms, arm symptoms) and higher functioning (body image, sexual functioning, future outlook). (Papers I to IV.)

To evaluate whether the change in QOL scores differed between the intervention and control group, change in score (calculated as follow-up score minus baseline score) was calculated for each participant, and the Mann-Whitney U test was used to test group differences in the magnitude of change. Because of multiple testing in these analyses, p-values were corrected with Bonferroni correction by dividing the p-value .05 by the number of comparisons made (three). The limit for statistical significance in these analyses was thus set at $p < .017$. (Paper III.)

To examine clinically significant changes in the QLI-CV and QLQ-BR23 subscales, the QOL changes were categorized. For QLI-CV subscales (Johnson et al. 1998) the following categorization was used: worse ≤ -2 , no change or better ≥ -1.9999 . In QLQ-BR23, the cutoff points in body image, sexual functioning and future outlook were: worse ≤ -10 , no change or better ≥ -9.9999 ; and in the subscales side-effects, breast symptoms and arm symptoms worse ≥ 10 and no change or better ≤ 9.9999 (Osoba et al. 1998). To see whether the QOL scores changed from baseline to follow-up, Wilcoxon's Signed Ranks test was applied separately to the intervention and control group. (Papers III and IV.)

Differences in perceived social support scores between the intervention and control group (separately for baseline and follow-up) were explored using the Mann-Whitney U test. To see whether the social support scores changed from baseline to follow-up, Wilcoxon's Signed Ranks test was applied separately for

the intervention and control group. Furthermore, to evaluate whether the changes in social support scores differed between the intervention and control group, change in score (calculated as follow-up score minus baseline score) was calculated for each participant, and the Mann-Whitney U test was used to test differences in the magnitude of changes between the groups. Because of multiple testing in these analyses, the $\leq .05$ level of statistical significance was corrected with Bonferroni correction by dividing the statistically significant p-value .05 by the number of comparisons made (five). The limit for statistical significance in these analyses was thus set at $p \leq .01$. (Paper IV.)

Logistic regression models with the enter method were used to identify the factors predicting the poorest quartile of QOL scores and predictors for negative changes in QOL (Munro 1997). For logistic regression analyses, the level of significance was set at $p \leq .05$. The results were reported as odds ratios (OR) with 95% confidence intervals (95% CI). (Papers I to IV.) Statistical analysis was carried out using SPSS for Windows 15.0.1.

4.5 Ethical considerations

Approval for the study was obtained from the ethics committee of the hospitals concerned. The study adhered to the standards of research ethics and good scientific practice in line with the Ethical Principles for Medical Research Involving Human Subjects, according to which the primary purpose of medical research involving human subjects is to understand the causes and effects of diseases and to improve preventive, diagnostic and therapeutic interventions (World Medical Association's Declaration of Helsinki 2004).

Ethical issues were given careful thought throughout the research process: the primary concern was with women's well-being and the validity of the study (ETENE 2001, World Medical Association's Declaration of Helsinki 2004). Women received adequate information regarding the research and were therefore in the position to consent voluntarily to participate in the research or to decline to take part (Polit & Beck 2006, 2008). The purpose of the support and education intervention was to help women feel better by giving them the

opportunity to talk about matters that bothered them. However, it was also recognized that the interventions might in themselves be a burden to these vulnerable women, who had a potentially life-threatening illness. The control group received standard postoperative education and support.

Questions of validity and research ethics were closely intertwined in this study (Polit & Hungler 1999). On the one hand, it was important to ensure that the women who gave their informed consent participated in both phases of the study. On the other hand, it was equally important to stress and guarantee that the women could withdraw from the study whenever they wanted to. It was therefore emphasized that participation in the study was entirely voluntary and that refusal to participate would not in any way affect the treatment that the women received. Based on this information that they received from a nurse and in a letter enclosed with the questionnaires, the women completed the informed consent forms. They were informed about the purpose of the study and explained how the research was organized. The covering letter attached to the questionnaires contained information about the purpose and process of the research, data collection procedures, time commitment, voluntary participation, right to withdraw, assurance of confidentiality, and details about the content of the research. It was also made clear that the women could always ask questions about any concerns they had. The face-to-face intervention six months after breast cancer surgery was provided by the investigator. Each woman was treated with respect and their privacy was protected. It was made clear to the women that any discussions would remain confidential and that all data would be collected anonymously.

The questionnaires were coded and they included no identifying information. The anonymity of the participants was also protected by the use of codes in data analysis. No outsiders have had any access to the questionnaires and data collected.

5 RESULTS

5.1 Participants of the study

Phase I (Paper I)

Out of the total of 477 women contacted, 359 (75%) agreed to participate in the study and completed the informed consent forms. The first phase intervention group consisted of the women who participated in the telephone intervention one week after breast cancer surgery (n=120) and the control group (n=108). The women in the intervention group ranged in age from 31 to 75 years (mean 57), and in the control group from 24 to 75 years (mean 56). Most women were aged 55 or over, had a vocational education, were employed, and had no underage children. Furthermore, most of the women in both groups were postmenopausal, and their estrogen and progesterone receptor status was mostly positive. The Pearson's chi-square test and Fisher's exact test showed no significant differences between the intervention and control groups in either sociodemographic (Table 3) or medical factors (Table 4).

Table 3. Sociodemographic background of the participants of the study in the intervention (n=120) and control groups (n=108)

Variable	Phase I				^a p
	Intervention group (n=120)		Control group (n=108)		
	n	%	n	%	
Age					.799
< 55 years old	48	40	45	42	
≥ 55 years old	72	60	63	58	
Education					.842
No vocational education	38	32	34	31	
Vocational education	61	51	58	54	
Academic education	21	17	16	15	
Employment status					.819
Employed	85	71	75	69	
Retired	35	29	33	31	
Underage children					.376
Yes	24	20	16	15	
No	93	77	91	84	
Unknown	3	3	1	1	

^a Differences between groups were tested by Pearson's chi-square test or Fisher's exact test. P-values $\leq .05$ were considered significant.

Table 4. Medical characteristics of the participants of the study in the intervention (n=120) and control groups (n=108)

Variable	Phase I				^a p
	Intervention group (n=120)		Control group (n=108)		
	n	%	n	%	
Menopausal status					.638
Premenopausal	31	26	25	23	
Postmenopausal	89	74	83	77	
The diameter of the tumor					.277
T1 (< 2 cm)	75	62	79	73	
T2 (2 - 5 cm)	35	29	22	20	
T3 (> 5 cm)	7	6	4	4	
T4	3	3	1	1	
Unknown	0	0	2	2	
Multifocal tumor					.586
Yes	20	17	21	19	
No	100	83	87	81	
Histological type					.557
Ductal carcinoma	100	84	84	78	
Lobular carcinoma	16	13	19	17	
Other	4	3	5	5	
Grade					.447
I	24	20	24	22	
II	52	43	52	48	
III	44	37	31	29	
Unknown	0	0	1	1	
Metastases					.403
None	75	63	74	69	
Regional	45	37	34	31	
Estrogen reseptors					.540
Positive	88	73	83	77	
Negative	32	27	25	23	
Progesterone reseptors					.977
Positive	78	65	70	65	
Negative	42	35	38	35	

^a Differences between groups were tested by Pearson's chi-square test or Fisher's exact test. P-values $\leq .05$ were considered significant.

Phase II (Paper II)

The six-month study group consisted of 204 patients, 112 women in the intervention group and 92 women in the control group. Half of the women in both groups had undergone either total mastectomy or breast conserving surgery. Furthermore, most of the women in both groups had undergone axillary dissection. Most of the women in both groups received adjuvant treatment in the form of chemotherapy, radiotherapy and hormonal therapy alone or in combination. In both groups the most common ongoing adjuvant therapy at six months was hormonal therapy. In the intervention group 25% and in the control group 28% had already completed all adjuvant treatments. The intervention and control groups were comparable in terms of all treatment parameters. (Table 5.)

Table 5. Treatments of breast cancer in the intervention (n=112) and control groups (n=92)

Variable	Phase II				
	Intervention group (n=112)		Control group (n=92)		
	n	%	n	%	
Type of surgery					.800
Breast conserving	54	48	46	50	
Total mastectomy	58	52	46	50	
Axillary treatment					.611
Axillary dissection	63	56	55	60	
Sentinel node biopsy	49	44	37	40	
Chemotherapy					.505
No	49	44	36	39	
Yes	63	56	56	61	
Radiotherapy					.900
No	35	31	28	30	
Yes	77	69	64	70	
Hormonal therapy					.850
No	33	29	26	28	
Yes	79	71	66	72	
Ongoing therapy at six months					.835
Chemotherapy	18	16	16	18	
Radiotherapy	4	4	4	4	
Chemo- and/or radiotherapy	2	2	0	0	
Hormonal therapy	42	37	32	35	
Radio- and hormonal therapy	18	16	14	15	
None	28	25	26	28	

^a Differences between groups were tested by Pearson's chi-square test or Fisher's exact test. P-values $\leq .05$ were considered significant.

Phase III (Papers III and IV)

Those breast cancer patients in the intervention group who took part both in the telephone intervention and in the face-to-face intervention and who answered both questionnaires were included in the study. As for the control group, only those patients were included who answered the questionnaires both one week and six months after surgery. The target populations in these phases consisted of 85 women in the intervention group and 79 women in the control group. The two groups did not differ significantly in terms of either sociodemographic

factors or breast cancer treatments. The mean age of the women in the intervention group was 57 years, ranging from 31 to 73 years. In the control group the mean age was 57, range 37 to 75 years. Most of the women in both groups were 55 or over, had a vocational education, were employed, and had no underage children. In both groups about half of the women had undergone either total mastectomy or breast conserving therapy. Furthermore, most of the women in both groups had undergone axillary dissection. The majority of women received adjuvant treatment in the form of chemotherapy, radiotherapy and hormonal therapy alone or in combination.

5.2 Support given by telephone

5.2.1 Perception of telephone support

Almost all women (98%) reported that it would be worthwhile to continue the telephone intervention. The vast majority (90%) of the women also thought that the timing of the support was appropriate; only 10% would have changed the timing. Most women (77%) agreed that the opportunity to talk had helped them. Overall, 74% thought that the support given via telephone had helped them quite much or very much, 23% thought it had been of little help. (Table 6.)

Table 6. Distributions of the participants perception of the support and education given via telephone one week after the breast cancer surgery (n=120)

Variable	Perception of the support via telephone			Total f (%)
	Did not help/ Uncertain f (%)	Helped a little f (%)	Helped quite/ very much f (%)	
Perception of the call	5 (4)	33 (29)	76 (67)	114 (100)
Topic of the telephone discussion	5 (4)	35 (31)	73 (65)	113 (100)
Possibility to talk about the matters bothering them	5 (5)	21 (18)	88 (77)	114 (100)
Counselling to obtain arm functioning	7 (6)	24 (21)	83 (73)	114 (100)
Possibility to talk about rehabilitation	13 (12)	25 (22)	74 (66)	112 (100)
Support given by physiotherapist	4 (3)	26 (23)	84 (74)	114 (100)

5.2.2 Impact of telephone intervention

One week after breast cancer surgery, measurements using QLQ-BR23 revealed statistically significant differences between the groups in body image ($p=.036$), future outlook ($p=.010$) and postoperative side-effects ($p=.004$). Women in the intervention group had a better body image, they worried less about the future and they had less postoperative side-effects than patients in the control group. Small clinically significant differences were found between the two groups in body image. Furthermore, there was a small clinically but not statistically significant difference between the groups in sexual functioning. A moderate clinical difference was found between the groups in future outlook and a small difference in postoperative side-effects. (Table 7.)

More information on group differences in QOL one week after breast cancer surgery is presented in paper I, Table 7.

Table 7. Significant differences between intervention and control groups in quality of life one week and six months after the breast cancer surgery

Scale	Phase I		Phase II	
	^a Statistical difference	^b Clinical difference	^a Statistical difference	^b Clinical difference
QLQ-BR23				
Body image	.036	Small (S)		
Sexual functioning		Small (S)		Small (S)
Future outlook	.010	Moderate (M)		
Systematic side-effects	.004	Small (S)		
Arm symptoms			.011	Small (S)
Upset by hair loss				Small (S)

^a Statistical difference between groups were tested by Mann-Whitney U test. P-values $\leq .05$ were considered significant.

^b Clinical difference according to mean scores: small (S) (5-10 points), moderate (M) (11-19 points), and large (L) (≥ 20 points).

5.3 Support given face-to-face

5.3.1 Perception of face-to-face support

Almost all participants in the intervention group (96%) were in favour of the continuation of the individual intervention at six months. Altogether 87% reported that the intervention was beneficial to them and 83% that the individual support and education given by the physiotherapist had helped them quite much or very much; 15% felt it had only been of little help and 2% that it hadn't helped at all or left women uncertain. Most of the participants (94%) felt that the best possible timing for support would be six months after breast cancer surgery. Overall, most participants (85%) agreed that the possibility to ask questions about issues bothering them had helped them quite much or very much, and 85% of the participants felt that the instructions about how to maintain their upper arm mobility had helped them a lot. (Table 8.)

Table 8. Distributions of the participants perception of the support and education given face-to-face six months after the breast cancer surgery (n=112)

Variable	Perception of the support given face-by-face			Total f (%)
	Did not help/ Uncertain f (%)	Helped a little f (%)	Helped quite/ very much f (%)	
Perception of the support	2 (2)	21 (19)	85 (79)	108 (100)
Topic of the face-to-face discussion	5 (5)	23 (21)	80 (74)	108 (100)
Possibility to talk about the matters bothering them	5 (5)	11 (10)	91 (85)	108 (100)
Counselling to obtain arm functioning	1 (1)	15 (14)	90 (85)	107 (100)
Possibility to talk about rehabilitation	5 (5)	21 (19)	83 (76)	109 (100)
Support given by physiotherapist	2 (2)	16 (15)	91 (83)	109 (100)

5.3.2 Impact of face-to-face intervention

Six months after breast cancer surgery a statistically significant difference was found between the groups in arm symptoms ($p=.011$). This difference was also clinically significant. In phase II women in the intervention group reported less arm symptoms than women in the control group. Furthermore, there was a small clinically but not statistically significant difference between the groups in sexual functioning and in being upset by hair loss. Women in the intervention group had better sexual functioning, but women in the control group were less upset by their hair loss than women in the intervention group. (Table 7.) (Paper II, Table 1.)

5.4 Quality of life in breast cancer patients

The breast cancer patients' QOL was moderately high and very similar in the intervention and control groups both one week and six months after surgery. In

both phases women in both groups reported the highest QOL in the family domain, and the lowest QOL in the health and functioning domain.

One week after surgery, the median global QLI score in the intervention group was 22.9 (mean 21.9; SD 4.0) and in the control group 21.7 (mean 21.6; SD 3.9). Six months after surgery, the median global QLI score was 22.9 (mean 22.0; SD 4.0) in the intervention group and 22.0 (mean 21.5; SD 4.1) in the control group. One week after surgery, the global QLI mean scores ranged from 7.5 to 28.4 in the intervention group, and from 6.9 to 29.2 in the control group. Six months after surgery QLI global scores ranged from 7.9 to 30.0 in the intervention group and from 10.3 to 29.8 in the control group. QLI-CV scores did not differ significantly between the intervention and control groups either one week or six months after surgery. (Paper I, Table 2 and Paper II.)

5.5 Six-month changes in quality of life

Six-month changes in QOL were evaluated separately for the intervention and control groups. In both groups statistically significant negative changes were found in body image and systematic therapy side-effects. Body image deteriorated in the intervention ($p \leq .001$) and in the control group ($p = .007$), and systematic therapy side-effects increased in the intervention group ($p \leq .001$) and in the control group ($p = .003$). Breast and arm symptoms decreased in both groups ($p \leq .001$) during six months. Future outlook improved significantly ($p \leq .001$) in the control group, but not in the intervention group. Clinically significant moderate changes were found in body image, in breast symptoms and in arm symptoms in the intervention group and in future outlook in the control group. Furthermore, there were minor but clinically significant changes in body image and in breast and arm symptoms in the control group; in future outlook in the intervention group; and in systematic side-effects in both groups. Significant difference of magnitude of changes between groups was found in future outlook in that the change was greater in the control group ($p = .014$). (Table 9.) (Paper III, Table 2.)

Table 9. The significant six-month changes in quality of life in intervention (n=85) and control groups (n=79)

Scale	Group	n	Phase I		Phase II		P-value for the change between baseline and follow-up ^a	P-value for the difference of magnitude of changes between groups ^b
			Md	IQ	Md	IQ		
Body image								
	Intervention	83	75.0	50-100	66.7	25-83	≤.001 (M)	.739
	Control	78	75.0	40-92	66.7	42-77	.007 (S)	
Future perspective								
	Intervention	85	33.3	0-67	33.0	17-67	.041 (S)	.014
	Control	78	33.3	0-33	50.0	33-67	≤.001 (M)	
Systematic side-effects								
	Intervention	84	19.0	10-33	27.8	17-44	≤.001 (S)	.864
	Control	79	23.8	14-38	33.3	17-52	.003 (S)	
Breast symptoms								
	Intervention	83	25.0	17-42	16.7	8-25	≤.001 (M)	.211
	Control	75	33.3	17-42	16.7	8-33	≤.001 (S)	
Arm symptoms								
	Intervention	85	33.3	11-44	11.1	11-33	≤.001 (M)	.775
	Control	75	33.3	22-44	22.2	11-33	≤.001 (S)	

^aThe changes within intervention and control groups were tested by Wilcoxon Signed Ranks test. P-values <.017 were considered statistically significant (Bonferroni correction). Clinical difference according to mean scores: small (S) (5-10 points), moderate (M) (11-19 points), and large (L) (≥20 points).

^bThe difference in the magnitude of changes in groups were tested by Mann-Whitney U-test. P-values < .017 were considered statistically significant (Bonferroni correction).

5.6 Role of social support

5.6.1 Perceived social support

One week after breast cancer surgery the breast cancer patients' social network in both groups consisted mostly of two to four support persons. The mean number of support persons in the intervention group was 3.4 (min 1 – max 7)

and in the control group 3.2 (min 1 – max 7). Six months after surgery, the mean number of support persons in the intervention group was 3.2 (min 1 – max 7) and in the control group 3.4 (min 0 – max 8).

In phase I the two major sources of support in the intervention group were spouses (77%) and friends (74%), and in the control group children (79%) and spouses (71%). In the intervention group 11% and in the control group 13% of the women identified a health care professional as part of their social network at baseline. Six months after surgery the major sources of support in the intervention group were friends (75%), spouses (71%) and children (69%), and in the control group spouses (72%), children (68%) and friends (68%). In phase II 7% of the women in the intervention group and 14% in the control group reported having a health care professional as a member of their social network.

Most women (89%) in the intervention group interacted with their support persons on a weekly basis in both phases. In phase I 84% of the women in the control group interacted with their support person on a weekly basis, while in phase II 81% of the women in the control group had weekly contact with their support persons. In phase I women in the intervention group received significantly more support from their friends compared to the women in the control group ($p=.046$). (Paper IV, Table 1.)

Women in both groups reported the highest level of network support in the form of affect one week after surgery. Furthermore, women in the intervention group mostly received affect from their network six months after surgery. The control group received network support in the form of affect, aid and affirmation in equal amounts. Both one week and six months after breast cancer surgery the patients in both groups received most support from nurses in the form of affirmation. No statistically significant difference was seen between the groups in social support received from the network and from nurses either one week or six months after surgery. (Paper IV, Table 2.)

5.6.2 Changes in perceived social support

In the intervention group social support received from the network in the form of affect decreased significantly during the first six months after surgery

($p=.003$); the same was true in the control group ($p\leq.001$). Furthermore, the amount of social support received from the network in the form of aid decreased significantly in the intervention group ($p\leq.001$) and in the control group ($p=.002$). Affirmation from the network decreased significantly in the intervention group over the first six months after surgery ($p=.006$). There were no statistically significant changes over the six-month period in perceived social support from nurses. Furthermore, no statistically significant changes were found between the two groups in perceived social support or in the magnitude of change over time. The level of significance was set at $\leq.01$. (Paper IV, Table 2.)

5.7 Factors associated with quality of life

5.7.1 Factors associated with quality of life one week after breast cancer surgery

Several sociodemographic and medical factors as well as types of treatment were significantly associated ($p<.05$) with QOL one week after breast cancer surgery. Significantly higher associations ($p\leq.001$) were found between age and breast symptoms and age and arm symptoms, between employment status and sexual functioning, menopausal status and sexual functioning, between status of metastasis and arm symptoms, between type of surgery and body image and furthermore, between type of axillary treatment and body image and axillary treatment and arm symptoms.

Younger age was associated with increased breast and arm symptoms, and employment was found to be associated with sexual functioning so that employed women had better sexual functioning. As for medical factors, menopausal status and regional metastases were significantly associated with poor QOL. Premenopausal women had lower sexual functioning scores, and women with regional metastasis had more arm symptoms than women with no metastatic breast cancer. Both type of surgery and type of axillary treatment were significantly related to body image. Women with mastectomy had a

significantly poorer body image. Similarly, women with axillary dissection had a poorer body image and also more arm symptoms than women without axillary dissection. All significant ($p \leq 0.05$) associations are shown in Table 10. More information on the associations between demographic factors and QOL one week after breast cancer surgery is presented in paper I, Tables 3 and 4.

Table 10. Significantly associated variables with sum variables for QLI-CV and QLQ-BR23 one week after the breast cancer surgery

Variable	QLI-CV			QLQ-BR23				
	Global QOL	Health / functioning	Socio-economic	Family	Body image	Sexual functioning	Breast symptoms	Arm symptoms
	p-value							
Age	*		*		*		*	*
Education				*			*	*
Employment status			*			*	*	*
Underage children								*
Menopausal status					*	*		*
Tumour size							*	
Multifocal tumour	*	*	*		*			
Histologic type							*	
Metastases		*			*			*
Estrogen reseptors								*
Type of surgery	*			*	*			*
Axillary treatment	*	*			*			*

Associations were tested by Mann-Whitney U test and Kruskal Wallis test. P-values ≤ 0.05 were considered significant.

5.7.2 Factors associated with quality of life six months after the breast cancer surgery

Significant associations ($p < 0.05$) were found between sociodemographic factors, medical factors and adjuvant treatments and QOL six months after breast cancer surgery. Significantly higher associations ($p \leq 0.001$) were found between age and body image, type of surgery and body image and chemotherapy and body image. Furthermore, lymph node status, type of axillary treatment, chemotherapy and

ongoing therapy were significantly associated with side-effects. Women with a better body image were mostly aged 55 years or over. Women who had undergone breast conserving surgery and who received no chemotherapy as an adjuvant treatment had a better body image than women with mastectomy and/or who received chemotherapy. Furthermore, positive lymph node status, axillary dissection and chemotherapy were associated with increased systemic therapy side-effects. Women who at six months were receiving chemotherapy and/or radiotherapy had more side-effects than women receiving hormonal therapy, radiotherapy/hormonal therapy or who had already completed their adjuvant treatments. All significant ($p \leq .05$) associations are shown in Table 11. (Paper II, Tables 2 and 3.)

Table 11. Significantly associated variables with sum variables for QLI-CV and QLQ-BR23 six months after the breast cancer surgery

Variable	QLI-CV		QLQ-BR23				
	Family	Psycho-logical/spiritual	Body image	Future outlook	Side-effects	Breast symp-toms	Arm symp-toms
			p-value				
Age		*	*				
Education	*		*				
Employment status			*				
Lymph node status			*		*		*
Type of surgery			*				
Axillary treatment			*		*		*
Chemotherapy			*		*	*	*
Hormonal therapy		*	*	*	*		
Ongoing therapy			*		*		*

Associations were tested by Mann-Whitney U test and Kruskal Wallis test. P-values $\leq .05$ were considered significant.

5.8 Predictors of poor quality of life

5.8.1 Predictors of poor quality of life one week after breast cancer surgery

According to the enter method logistic regression model, the most important predictors ($p < .05$) of poor QOL one week after breast cancer surgery were being in the control group, age, education, employment status, histological type, receptor status, type of surgery, and type of axillary treatment. (Figure 3.) Age was found to be the most important factor explaining poor QOL. The lowest quartile of QLI-CV global scores, health and functioning, socio-economic and family domain scores was explained by being under age 55 years. At least 55 years of age explained the lowest quartile of breast symptoms. Women in the control group reported poorer body image, side-effects, and future outlook scores. Total mastectomy contributed to poorer body image, and sentinel node biopsy explained poor arm symptom scores. However, the lowest quartile of breast symptoms scores was explained breast conserving therapy (Paper I, Tables 5 and 6.)

5.8.2 Predictors of poor quality of life six months after breast cancer surgery

According to the enter method logistic regression model six months after breast cancer surgery, the most important predictors ($p < .05$) of poor QOL were being in the control group, age, education, type of surgery and type of axillary treatment, chemotherapy, and ongoing therapy. (Figure 3.) Women in the control group had a greater risk for poor sexual functioning and arm symptoms than women in the intervention group. Furthermore, age under 55 years explained the lowest quartile of body image. Education helped to explain poor future outlook in that women with a vocational education had a greater risk of poorer future outlook than women with an academic education. Both type of surgery and type of axillary treatment explained poorer body image in that women who had

undergone total mastectomy had a greater risk of poorer body image than women who had undergone breast conserving therapy, and women who had undergone sentinel node biopsy had a smaller risk of poor body image than women who had undergone axillary dissection. Women who had received chemotherapy as an adjuvant treatment had a lower risk of poorer socio-economic QOL than women who did not receive chemotherapy. Women with no ongoing therapy at six months had a lower risk of more arm symptoms than those receiving chemotherapy or radiotherapy. (Paper II, Tables 4 and 5.)

5.9 Factors predicting negative six-month changes in quality of life

Education, employment status, having underage children, chemotherapy, radiotherapy, and hormonal therapy predicted changes in QOL. (Figure 3.) Women with a vocational education were at lower risk of negative changes in arm symptoms than women with an academic education. Employed women had a lower risk of more negative changes in their global QLI score and in health and functioning, but a higher risk of negative changes in body image as compared to retired women. Women with no underage children had a lower risk of negative changes in family QOL than women with underage children. Chemotherapy and hormonal therapy predicted decreased body image in that women receiving no chemotherapy and no hormonal therapy had a lower risk of decreased body image than those who received chemotherapy or hormonal therapy as adjuvant treatment. Furthermore, women not receiving chemotherapy had a lower risk of poorer sexual functioning, poorer future outlook and increased side-effects than women who received chemotherapy. (Paper III, Tables 4 and 5.)

Higher scores in affect from network predicted decreased global QOL and health and functioning. Furthermore, increased scores in aid from nurses predicted increased sexual functioning. (Paper IV, Tables 3 and 4.)

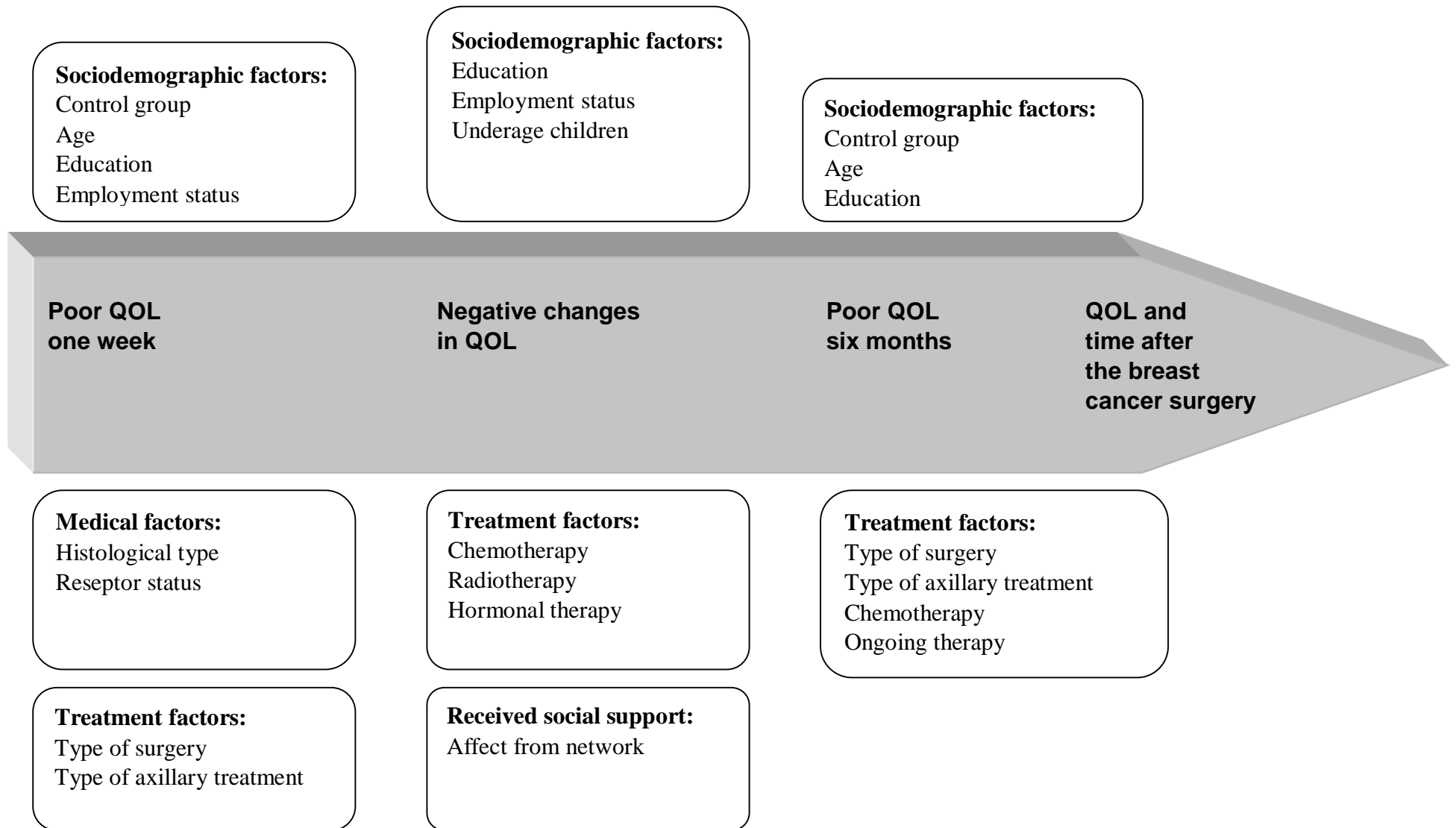


Figure 3. Predictors of poor quality of life

6 DISCUSSION

6.1 Validity and reliability of the study

Validity and reliability are here discussed in terms of the quality of the quantitative method, design, instruments, sampling and data analysis employed. Validity is a measure of truthfulness and accuracy in relation to the concept under study, while reliability refers to the quality of the measurement of consistency, stability and repeatability of the measures obtained (Burns & Grove 2005). The validity of this study is considered in terms of internal and external validity (Cook & Campbell 1979, Parahoo 2006). *Internal validity* refers to the extent to which it is possible to conclude that the independent variable is influencing the dependent variable and not attributed to extraneous variables (Polit & Beck 2006, 2010). Furthermore, threats to internal validity are considered in terms of selection bias and group comparability. These threats should be eliminated by study design and conduct (Moher et al. 2001, Borglin & Richards 2010). *External validity* is the generalizability of the study results to different settings with new subjects (Metsämuuronen 2006, Polit & Beck 2006). According to Borglin & Richards (2010), extended CONSORT criteria were associated with improved reporting in RCTs (Plint et al. 2006) and should be adopted when planning and reporting experimental research, both RCTs and non-randomized studies (Borglin & Richards 2010, Zwarenstein et al. 2008). Extended CONSORT statements describing four potential biases in research, i.e. selection, performance, attrition and detection (Borglin & Richards 2010), have been considered in the present study.

6.1.1 Validity of the research design

The choice of research design is particularly important in a quantitative study (Cook & Cambell 1979) to ensure that the evidence produced is valid and reliable (also Polit & Beck 2006). In this study the decision was made to use a quasi-experimental design because a full experimental design and randomization would not have been possible for ethical and practical reasons. Compared to true experimental randomization, a quasi-experimental design does not allow causal inferences to be drawn. However, a quasi-experimental design is considered the second best option after an experimental design (Polit & Beck 2006). Sometimes it may even be more practical and feasible (Fayers & Machin 2000). In this study, however, it was possible to draw causal inferences because of the use of a two-group study design, which was created through quasi-randomization and a longitudinal design. No blinding was used but at the time of consent, neither the nurse nor the consenting women knew to which group each woman would be assigned.

Within a quasi-experimental design it is not possible to control all possible sources of extraneous variations. This may have affected the research results. Other diagnoses, the amount of support received from other sources and women's coping strategies may have impacted their QOL, but these factors could not be accounted for in this study. The main difficulty, however, stems from controlling human beings (Fogg & Gross 2000) and the environment when studying humans in their natural settings (Polit & Beck 2006). In phase I it was not possible to structure the environment of the study. The women were in their own homes when they received support and education via telephone. In phase II, by contrast, the face-to-face intervention was provided by the same physiotherapists in the same environment.

Every effort was made to control extraneous variables by assuring the homogeneity of the sample and using inclusion and exclusion criteria. A longitudinal prospective study is of value when studying new interventions that require careful definition of the target groups and careful selection of variables (Bowling 2004). In a longitudinal research setting one major validity problem stems from attrition, which is discussed below.

6.1.2 Validity of the data and analyses

The most important strengths of the current study include the relatively large number of participants compared to recent longitudinal intervention studies (Badger et al. 2007, Maeda et al. 2008, Meneses et al. 2009) and the homogeneity of the intervention group and the control group with respect to sociodemographic, medical and treatment characteristics throughout the research process. The sample size was determined on the basis of earlier publications. Selection bias, which refers to the comparability of the groups (Borglin & Richards 2010) was avoided by the application of well-defined inclusion criteria. The longitudinal data and appropriate sample size provide a stronger foundation for explaining variations in QOL and for exploring the process of adjustment over time. However, in the investigation focusing on the quartile of women with poor QOL, the sample size was quite small and may have caused bias in the QOL results.

Another limitation with respect to data validity was the loss of participants during phase I and phase II. Dropout rates were calculated from the number of women who took part in the telephone intervention one week after surgery but who did not attend the face-to-face intervention six months after surgery. The response rate in the intervention group was a satisfactory 62%, which is supported by Badger & Werret (2005) who analysed recruitment and response rates in three peer reviewed nursing journals. Furthermore, Polit & Hungler (1999) say in their nursing textbook that a response rate of over 60% is sufficient for most purposes. In the control group the response rate was 52%, which has been suggested to be adequate for analyses and reporting (Babbie 2004, Groves et al. 2009). No sociodemographic differences were seen between the women who dropped out and the women who participated in the study, which increased the validity of the data (Borglin & Richards 2010). Furthermore, the attrition process was described in detail in diagram format for improved transparency (Moher et al. 2001, Borglin & Richards 2010) (Figure 2). The reasons for attrition before quasi-randomization and in part during the allocation of the patients to the intervention and control groups could not be established. No questions were asked about the reasons for refusal between the two

interventions, and therefore no information is available about the women who did not fill the informed consent forms. It is possible that the women who gave their informed consent and who participated in the study were in better physical and psychological health and considered support and education important to their recovery. It is also possible that the women who dropped out had more aggressive breast cancer and that the more serious side-effects from their surgery caused more problems in functioning. Consequently they may have lacked the strength and energy to participate in the study and the interventions. Furthermore, the women's decision on whether or not to participate may have been affected by the timing of the intervention. After their surgery and short hospitalization, women may be deeply upset and shocked about their illness and possible breast loss, and they may well be at their most vulnerable. Furthermore, high costs of travel to the oncology clinic may have persuaded women living furthest away not to take part in the face-to-face intervention six months after surgery.

Statistical analyses were carried out in close consultation with statisticians. The analyses were sensitive enough to produce significant group differences between the outcome variables. Statistical conclusion validity refers to the results and conclusions based on the data of the study (Polit & Beck 2006). In this research special attention was given to the choice of statistical methods employed and to interpreting the results and drawing conclusions from those interpretations.

6.1.3 Validity related to instruments

Validity refers to whether the instrument measures what it is intended to measure and whether it is useful for the intended purpose (Fayers & Machin 2000). To ensure that outcomes are valid and clinically useful, it is crucial that the appropriate QOL instrument is chosen (Cull 1997). In the present study, the primary outcome measure was QOL and the secondary outcome measure social support. The literature review clearly highlighted the difficulty of defining QOL; there are almost as many definitions as there are instruments for its measurement

(Farquhar 1995, Bowling 2003). In this study, detection bias was controlled (Borglin & Richards 2010) and validity ensured by using well-known, widely used and validated QOL instruments (Ferrans & Powers 1985, Ferrans 1990, Ferrans & Powers 1992, Aaronson et al. 1993, Sprangers et al. 1993, Sprangers et al. 1996). The internal consistency of the QLI-CV and QLQ-BR23 was estimated by Cronbach's alpha (Polit & Beck 2008). Several studies have reported satisfactory internal consistency for both QOL instruments (Ferrans 1990, Ferrans & Powers 1992, Aaronson et al 1993, Sprangers et al 1996, Rustoen et al. 1999a, 1999b, Sammarco 2001a, Schreier & Williams 2004, Yun et al. 2004). In the case of QLI-CV, internal consistency reliability reached high alpha values. For global QOL the figure was .95 and for the health and functioning domain .87, the psychological and spiritual domain .89, the family domain .75 and the socio-economic domain .71 (Sammarco 2009, Sammarco & Konecny 2010). In the Korean study by Yun et al. (2004), the Cronbach alpha values for all QLQ-BR23 subscales ranged from .72 to .92. In this study, the Cronbach's alpha values for QLI-CV subscales in phase I ranged from .75 to .93 and in phase II from .79 to .95. For QLQ-BR23 subscales, Cronbach's alphas ranged in phase I from .63 to .89 and in phase II from .73 to .92. (Table 12.) According to Nunnally & Bernstein (1994), the lowest acceptable Cronbach alpha value is .60, so on this basis the internal consistencies were satisfactory. Furthermore, the questionnaires were tested in a pilot study (n=35) and found feasible. The Ferrans & Powers English-language version was translated into Finnish using the back-translation technique with the authors' permission. This was the first time the QLI-CV was used in Finland.

Received social support was measured using the Social Support from Social Network and Social Support from Nurses scales developed Rantanen et al. (2004). These scales are based on Kahn's (1979) theory of social support, which makes a distinction between three aspects of social support: affect, aid and affirmation. The internal consistency of the social support from social network instrument, as assessed by correlation coefficients, ranged from .39 to .77 at baseline and from .54 to .74 at follow-up. The scale measuring social support received from nurses showed good internal consistency as measured by

Cronbach's alpha, ranging from .82 to .94 at baseline and from .78 to .92 at follow-up.

Table 12. Internal consistency of QLI-CV and QLQ-BR23 subscales

Scale	Items	Phase I		Phase II	
		n	Cronbach alfa	n	Cronbach alfa
QLI-CV					
Health and functioning	13	227	0.87	203	0.89
Socioeconomic	8	227	0.75	203	0.84
Psychological and spiritual	7	226	0.89	204	0.90
Family	5	221	0.80	197	0.79
QLI-CV global score	33	228	0.93	204	0.95
QLQ-BR23					
Body image	4	224	0.88	202	0.89
Sexual functioning	2	210	0.89	197	0.92
Future outlook	1	224		204	
Side-effects	7	227	0.63	203	0.74
Breast symptoms	4	220	0.69	201	0.75
Arm symptoms	3	221	0.79	202	0.73
Upset by hair loss	1	35		110	

6.1.4 Validity of the research process

The research protocol was carefully planned and standardized, which helped to control performance bias (Borglin & Richards 2010). The nurses who recruited the women for this study, were informed about the research process and how and when to record patient data. However, the ward in one of the hospitals where the breast cancer patients were operated changed twice during the process of data collection, as did the staff caring for the patients. Staff turnover presented a major challenge and underscored the importance of good communication and orientation. To minimize the risk of sampling bias, the study units were visited regularly in order to ensure close adherence to both the sampling and telephone intervention procedures.

In this study the telephone intervention for operated breast cancer patients was provided by physiotherapists specialized in working with surgical patients. In the absence of these two physiotherapists, the patients were contacted by their substitutes. To ensure the consistency of the intervention, all the physiotherapists received the same training, and the physiotherapist who counselled the patient during hospitalization would call the patient one week after surgery. Furthermore, the face-to-face intervention was provided by the investigator, which helped to ensure consistency.

Conn et al. (2001) argued that the effectiveness of interventions can be enhanced by careful consultation with both scientific and consumer experts. In the process of this research several literature searches were conducted to identify what kind of interventions has been undertaken among breast cancer patients. The researcher also worked closely with experts in this field to gain a deeper understanding and knowledge of the area (Blackwood 2006). In addition, the research team included an oncology specialist, which greatly enhanced the validity of the research process. However, the absence of an assessment of QOL at baseline, before any surgery, obviously compromised the ability of the study to gain a clear picture of the effect of the interventions on QOL.

External validity is related to the possibility of generalization and to the truth of the conclusions drawn from the research (Metsämuuronen 2006, Polit & Beck 2006). Even though the study was carried out in only two hospitals in Finland,

this did not undermine the external validity of the results because the treatment protocol for breast cancer patients is standardized in Finland. This means that these findings can be generalized to all Finnish-speaking breast cancer patients aged 18–75 in the south of Finland and, with caution, to the whole of Finland.

6.2 Interpretation of the results

This study has produced important new knowledge for clinical nursing practice and highlighted factors that should be taken into account when developing supportive interventions aimed at enhancing QOL in patients with early breast cancer. Several studies have explored QOL in women with breast cancer, but less attention has been given to the effects of individual, short-term telephone and face-to-face education and support delivered by physiotherapists. Identifying factors that predict poor QOL and negative changes in QOL is important because this is how we can identify the group of the women with breast cancer who should be given priority attention in support delivery. The present study produced new evidence about the positive effect of short-term one-time social support in patients with breast cancer. In addition, it identified factors predicting poor QOL and negative changes in QOL in breast cancer patients.

The following discusses the main results of this study by each of its subgoals.

6.2.1 Effects of interventions

One of the main aims of this study was to examine the effects of two interventions: support and education given via telephone one week after breast cancer surgery and face-to-face support and education six months after breast cancer surgery. The significance of the differences in QOL between the intervention and control group as measured by QLQ-BR23 were reported both from a statistical and clinical point of view.

The women who took part in this study considered both the supportive interventions beneficial to their QOL, which is consistent with the findings of an

earlier intervention by Wilmoth et al. (2006) where women themselves reported positive experiences of their participation. The women in Wilmoth's (2006) study felt that the opportunity to voice their feelings led to a deeper awareness of self, attitudes towards their illness and relationships with family members. Furthermore, the women in the present study reported that the timing of the interventions was appropriate, and they were also in favour of the continuation of the interventions.

The interventions in this study were found to have a positive effect on QOL in terms of body image, future outlook, and postoperative side-effects and sexual functioning in phase I; and in arm symptoms and sexual functioning in phase II. These results are supported by the findings of several previous studies using quasi-randomized (Ashbury et al. 1998) and randomized intervention designs, such as Badger et al. (2005b), Coleman et al. (2005), Wilmoth et al. (2006), Allard (2007), Arving et al. (2007), Badger et al. (2007), Beurskens et al. (2007), Budin et al. (2008), Maeda et al. (2008), Dolbeault et al. (2009), Manos et al. (2009), Marcus et al. (2010) and Shafir et al. (2010). These studies found that women who received social support reported better adjustment, QOL and coping with breast cancer.

Both of the interventions in this study showed a clinically significant effect on sexual functioning, and the telephone intervention had both a statistically and clinically significant effect on body image. It has been reported earlier that body image and sexual issues are a main source of concern especially for younger women with breast cancer (Moreira & Canavarro 2010, Pérez et al. 2010). Furthermore, type of surgery has a predictive effect on body image (Engel et al. 2004, Moreira & Canavarro 2010) and sexuality (Ganz 1997, Ganz et al. 1998, Ganz et al. 2004, Engel et al. 2004).

The results of the present study indicate that the provision of short-term support and education via telephone one week after surgery and via a face-to-face intervention six months after surgery may help women adapt better to their altered body image and achieve improved sexual functioning. The promising results of this study may also be due to improved relationships with spouses, as reported by Wilmoth et al. (2006), and to reduced levels of distress and depression (Marcus et al. 2010) as a result of telephone counselling. In a recent

study by Marcus et al. (2010), women in the telephone intervention group showed a significant improvement in sexual functioning at 12 and 18 months following 16 counselling sessions lasting 45 minutes each. Shafir et al. (2010) reported an improved body image, sexual functioning, sexual satisfaction and future outlook in an experimental group receiving peer-led education in four one-hour weekly sessions. However, Scott & Kayser (2009) discovered in their review that interventions with cancer patients that do not involve women's partners produced only weak effects on women's sexual adjustment. In this study, sexual matters that bothered women were discussed in face-to-face intervention whenever women felt they needed to talk to someone. One of the women's concerns was their decreased level of sexual activity, which has been reported to be more common among women with breast cancer than among women without breast cancer (Conde et al. 2005). According to Scott & Kayser (2009), interventions should aim to improve the recovery of sexual functioning and body image because these are the aspects of life that are most at risk of impairment among cancer patients.

In addition, the telephone intervention in this study helped to reduce women's future health concerns, as was suggested in the study of Shafir et al. (2010). In addition, the intervention helped women to manage better with the side-effects of breast cancer surgery. These results are consistent with previous findings that telephone support and education contribute to effective symptom management (Cox & Wilson 2003, Badger et al. 2005b, Allard et al. 2007) and to improved QOL (Sandgren et al. 2000, Sandgren & McCaul 2003, Badger et al. 2005b). Furthermore, Wilmoth and colleagues (2006) suggested that the opportunity to express one's feelings meant that the women in their intervention had a better attitude towards their breast cancer. However, in this study women in the control group were less upset by hair loss than women in the intervention group.

The face-to-face support and education intervention six months after breast cancer surgery had a significant effect on arm symptoms. This result is particularly important because decreased shoulder mobility and arm problems may have a negative impact on patients' QOL even several years after the diagnosis (Engel et al. 2003a, Engel et al. 2003b, Rietman et al. 2004, Janz et al.

2007, Chachaj et al. 2010), usually due to axillary dissection (Burak et al. 2002, Engel et al. 2003a, 2003b, Peintinger et al. 2003, Schijven et al. 2003, Rönkä et al. 2005) and lymphedema after breast cancer treatments (Chachaj et al. 2010).

Earlier results highlight the importance of intervention six months after breast cancer surgery in reducing arm symptoms and possibly in preventing later symptoms of breast cancer surgery and treatments (Kärki 2005). In the Finnish study by Kärki et al. (2004b), women suffered from late symptoms such as neck-shoulder pain and numbness six months after surgery, and another Finnish study reported that arm morbidity affected work, leisure activities and daily life (Rönkä et al. 2005). According to Engel et al. (2003a, 2003b), arm problems had the greatest influence on QOL in patients with breast cancer. Difficulties with arm movement and pain in the upper arm and operated breast have been found to be associated with lower QOL (Chachaj et al. 2010).

Based on these results it can be safely presumed that women have needs for support and education during their treatment and that these needs change over time and differ between women. Previous research has shown that there is an increased need for follow-up care after short periods of hospitalization, and it has also emphasized the importance of adequate communication and support for breast cancer patients' health care (Kerr et al. 2003, Kärki et al. 2005, Rutten et al. 2005, Beaver et al. 2006, Shcmid-Bücji et al. 2008, Halkett et al. 2009, Li et al. 2011). Wyatt et al. (2008) concluded that the postsurgical breast cancer patients who are most likely in need of additional physical and psychological supportive health services are those who are younger and unmarried, who receive or are in need of caregiver support, who are in the lowest income bracket, and who have a college education.

However, closer scrutiny of earlier intervention studies reveals many conflicting and contradictory results. Helgeson et al. (1999, 2000, 2001), Sandgren & McCaul (2003), and Wilmoth et al. (2006), for instance, reported that their interventions had not only positive results. Helgeson et al. (2001) found that a peer discussion based group intervention had no effect on psychological and physical functioning over a three-year period. Instead, peer discussions seemed to have a negative effect on vitality and affect (Helgeson et al. 1999). One possible explanation suggested by the authors was that the mere expression

of feelings was not enough to affect psychological or physical functioning (Sheard & Maguire 1999). Sandgren and McCaul (2003) found no evidence that their two brief education and emotional expression therapies had any effect on mood disturbance or QOL. It is possible that these inconsistencies are explained by differences in the instrument used, as well as by the different QOL definitions applied (see 2.3.2 and 2.3.3 above).

The results of the present study suggest that short-term and structured interventions based on individual needs may be an effective way of enhancing QOL in women with early breast cancer. Therefore it is suggested that this intervention model is worthwhile to apply in the standard care of breast cancer patients. In Finland patients with breast cancer stay at hospital for about 24 hours after surgery. Saares and Suominen (2005) found in their qualitative study that breast cancer patients tended to have a very positive experience of their short stay surgery, and most women were ready to go home on the very next day after the operation. Similar results have been reported in a Danish study on ultra-short hospital stays for patients with breast cancer (Mertz & Williams 2010). However, while the women were physically well enough to go home on the first day after the operation, psychologically they might have needed more time to adjust (Saares & Suominen 2005). Telephone support shortly after discharge may help women deal with this new situation at home and make them feel safer. Mertz and Williams (2010) observed that after early discharge, patient-centred communication, continuity of care, and telephone contact services were important in helping women to cope. The advantages of short telephone support include easy implementation and relatively low costs. It is important that these results are taken into account when planning interventions for recovering breast cancer patients.

6.2.2 Quality of life in breast cancer patients

One of the aims of this study was to describe the QOL of breast cancer patients and changes in their QOL. Measured by QLI-CV, QOL scores were relatively high in both phases and very similar in the intervention and control groups. The

highest QOL was reported in the family domain and the lowest QOL in the health and functioning domain in both phases. This supports the results of Rustoen et al. (1999a) and Sammarco (2001a). This is valuable information because family issues, including relationships with spouse or partner and children, are extremely important when the breast cancer diagnosis is made and when women undergo treatments (Oktay 1998). Family functioning and support from the family are crucially important in the process of adapting to the cancer survivor's role. Indeed it could be argued that strong family relationships are a major reason why women adjust to their disease so well.

In this study half of the women in phase II felt that the questions about sexual enjoyment and hair loss were not applicable, which is consistent with the earlier results of Lee et al. (2008). Therefore, these items were not included in logistic regression modelling. There was much interindividual variation in experiences of hair loss, which indeed has been suggested to be dependent on the individual and associated with age (Boehmke & Dickerson 2005). At worst, however, it can be very distressing and frightening (Frith et al. 2007). In the qualitative study of Frith et al. (2007), women were afraid that hair loss would make them visibly identifiable as a person-with-cancer.

The results of this study differed somewhat from the findings of earlier studies on changes in QOL. Engel et al. (2004) suggested that most body image scores did not improve significantly over years one to four, but in the long-term follow-up study of Hopwood et al. (2010) breast and body image concerns decreased during the five-year follow-up when assessing the late effects of radiotherapy. In the present study negative QOL changes were largely similar in both groups in that body image and therapy side-effects worsened during the six-month follow-up. These results are easy to understand in that recent breast surgery and ongoing adjuvant treatments may cause severe side-effects and altered body image (King et al. 2000, Engel et al. 2004, Moreira & Canavarro 2010). Awareness of changes happening in the body, including sexual problems, loss of femininity and attractiveness, may increase during the treatment process (Moreira & Canavarro 2010). However, as Oktay (1998) suggested, it is also possible that the psyche blocks information that is too threatening.

It has been found that side-effects are associated with type of surgery (King et al. 2000, Engel et al. 2003a, Engel et al. 2004, Kootstra et al. 2008, Rabin et al. 2008, Norman et al. 2009) and type of adjuvant treatment (Kayl & Meyers 2006, Browall et al. 2008, Rabin et al. 2008, Sjövall et al. 2010); the same discovery was made in this study, too. It has been found that the larger the operation (Engel et al. 2003b, Engel et al. 2003b, Fleissig et al. 2006, Rabin et al. 2008) and the greater the number of adjuvant treatments (Browall et al. 2008), the more side-effects women will have and the poorer their QOL will be.

After six months both groups showed an improvement in QOL, supporting the results of earlier longitudinal studies on arm symptoms and breast symptoms (Lee et al. 2008). During radiotherapy, breast symptoms first increased but by seven months returned to baseline level (Lee et al. 2008). However, symptoms may persist for a long time after treatments (King et al. 2000, Engel et al. 2003b, Engel et al. 2004). Up to five years after their diagnosis, 38% (n=990) of the women in the study of Engel et al. (2003a) experienced arm problems such as swelling and limited arm movement, which were found to be associated with poor QOL. It is possible that the supportive telephone and face-to-face intervention in this study slowed the decline in QOL in terms of arm and breast symptoms.

A follow-up lasting longer than six months might have yielded more time-related group differences in QOL. This is supported by the findings of Engel et al. (2004) and Maeda et al. (2008), who reported that most changes in QOL variables occurred between the first and second year after breast cancer surgery. However, the women studied by Arving et al. (2007) reported the greatest improvements in their QOL between baseline and six months. Unexpectedly, future outlook improved significantly in the control group, and significant differences were seen in the magnitude of changes in future outlook, with the greatest changes witnessed in the control group. One possible explanation for this result is that education given to the intervention group has increased women's knowledge and awareness of their current situation and therefore increasingly turned their focus to questions of health and functioning. Loerzel et al. (2008) reported that among women aged 65 to 83, QOL after six months

declined more sharply in the educational intervention group than in the control group.

The experience of breast cancer and its treatments is very individual (Landmark & Wahl 2002, Coyne & Borbasi 2009) and emotionally challenging (Scnhipper 2001). The previous literature suggests that recovery from breast cancer is a very dynamic process (King et al. 2000, Engel et al. 2003a, Engel et al. 2004, Arving et al. 2007, Lee et al. 2008), and in this study the process showed some differences between the intervention and control group. Earlier research has shown that most women do have the capacity to adapt to their situation (Courstens et al. 1996, Dow & Lafferty 2000, Bloom et al. 2004, Engel et al. 2004), but some have difficulties coping and accepting their situation (Andrykowski et al. 2000, Rustoen et al. 2000, Engel et al. 2004, Burgess et al. 2005, Montazeri et al. 2008a). The reason for the surprisingly minor positive changes seen in QOL over six months in both groups may lie in the relatively high baseline QOL levels.

6.2.3 Association of perceived support with quality of life

In keeping with the previous studies of Sandgren et al. (2004) and Arora et al. (2007), the major sources of social support in this study were spouses, friends and own children in both groups and in both phases. Lehto-Järnstedt (2000) identified spouses as the single most important source of support, followed by physicians and nurses. In this study most women interacted with their support persons on a weekly basis. Only a few women identified a health care professional as part of their social network in both phases of the study, which contrasts with the results of Arora et al. (2007). In addition, several studies have discovered that patients receiving adjuvant treatments receive helpful social support from health care staff as compared to women not receiving such treatments (Lehto-Järnstedt et al. 2002, Arora et al. 2007). Furthermore, Bloom et al. (2001) reported that women receiving chemotherapy as an adjuvant treatment received more emotional support and women with mastectomy received more instrumental support from different sources. In this study almost

all women received adjuvant treatments, but the results concerning support differed from those in earlier studies.

The results of the present study suggested that affect and aid received from the social network decreased in both groups over six months, which is consistent with the studies of Courtens et al. (1996) and Arora et al. (2007). Arora et al. (2007) reported that support provided by family, friends and health care providers decreased significantly over a 5-month follow-up, and that emotional support from the network decreased significantly over one year. In this study women with increased scores in affect from the social network were more likely to have a decreased global QLI score and health and functioning score. Furthermore, women with increased aid from nurses reported improved sexual functioning.

As has been reported earlier, it seems that supportive interventions do not always help women with breast cancer (Helgeson et al. 1999, 2000, 2001, Sandgren & McCaul 2003, Wilmoth et al. 2006). Furthermore, the results of this study are in keeping with the very early results of Courtens et al. (1996) in that cancer patients with more perceived instrumental support reported more dysfunctioning. However, the findings of this study differ from those from several earlier studies in the 1980s to 2000s (Norbeck 1988, Krishanamy 1996, Lungton 1997, Lehto-Järnstedt 2000, Rustoen et al. 1999a, Sammarco, 2001a, Sammarco 2003, Arora et al. 2007, Arving et al. 2007, Sammarco 2009), where support was found to have a positive effect on breast cancer patients' physical, psychological and social functioning and on their QOL (Rehse & Pukrop 2003, Badger et al. 2005a, 2005b, Arving et al. 2007). It is necessary to question the assumption that social support always and at all times helps women to adjust better. All women do not need support and do not feel it is helpful at a certain point of their recovery. Indeed, as Krishanamy (1996) points out in an early literature review of social support and cancer patients, it is also important to consider the negative effects of frequent social support. Supportive interventions should help women to avoid dependence and enhance their self-esteem and empowerment.

Nevertheless, Kroenke et al. (2006) reported that women who had no close relatives, friends or living children before the diagnosis of breast cancer had a

significantly greater risk of mortality after the diagnosis. However, longitudinal studies have suggested that social support from family, friends and health care providers tends to decrease over time (Arora et al. 2001, Arora et al. 2007). The study by Arora et al. (2007) showed that both access to support and the quality of support decreased over a five-month follow-up (Arora et al. 2007).

6.2.4 Factors associated with quality of life

Factors associated with QLI-CV and QLQ-BR23 sum variables were identified using the Mann Whitney U test and Kruskal Wallis test. Both one week and six months after breast cancer surgery sociodemographic factors such as age, education and employment status were associated with QOL. Furthermore, type of surgery and type of axillary surgery were associated with QOL in both phases. In phase I having underage children and in phase II lymph node status, chemotherapy and hormonal therapy were also associated with QOL.

In both phases younger women reported poorer body image than older women. Furthermore, in phase I younger women had poorer global QOL, socio-economic QOL, and significantly more breast and arm symptoms compared to older women. In phase II younger women had poorer psychological and spiritual QOL, which has also been found in the case of breast cancer survivors under 50 years who had completed treatments on average four and half years ago (Sammarco 2009). As has been reported earlier, younger age was found to be associated with poorer QOL overall (Rustoen et al. 1999a, Engel et al. 2003a, Engel et al. 2003c, Engel et al. 2004, King et al. 2000, Sammarco et al. 2009 Andrykowski et al. 2000, Sammarco 2001a, Avis et al. 2005). Younger women with breast cancer experience significantly greater QOL disturbances and face different problems than older women (Wentzel et al. 1999, King et al. 2000, Sammarco 2001a, Engel et al. 2004, Avis et al. 2005, Sammarco 2009). These results on the impact of age underscore the importance of paying special attention to younger women with early breast cancer.

Women who had undergone breast conserving therapy and sentinel node biopsy had a better body image than those who had undergone mastectomy and

axillary dissection. Moreover, women receiving chemotherapy and hormonal therapy had a poorer body image compared to women not receiving these adjuvant treatments. This result is consistent with earlier findings according to which mastectomy is associated with poor body image and sexual functioning (King et al. 2000, Arora et al. 2001, Xiaokun 2002, Engel et al. 2003a, Engel et al. 2004, Lehto et al. 2005), which may persist for many years after breast cancer surgery (King et al. 2000, Engel et al. 2004).

Moreira & Canavarro (2010) reported strong associations between mastectomy and higher body shame and lower satisfaction with appearance six months after the completion of adjuvant treatments. Pikler & Winterowd (2003) showed that women who felt better about their bodies had a strong belief in their ability to adjust and cope with the disease and their treatments (also Carver et al. 1998). Nevertheless, it seems that time from treatment does not explain problems with body image or the consequent problems with sexual functioning. There is strong earlier evidence that adjuvant treatments can have a negative impact on body image (Schover et al. 1995, Ganz et al. 2003, Janz et al. 2005, Kayl & Meyers 2006, McIlfatrick et al. 2007, Turgay et al. 2008). Given the increasing number of young women diagnosed with breast cancer (Finnish Cancer Registry 2011, Pukkala et al. 2011), it is important to address the question of how the negative impacts of type of surgery and adjuvant treatments can be reduced especially in younger women.

In this study the associations between education and family QOL differed in phase I and in phase II. In phase I women with a vocational education had poorer family QOL than women with no vocational education and academic education, and in phase II women with no vocational education had better family QOL than women with a vocational or academic education. Engel et al. (2003b) found that education was not a significant predictor of arm difficulties, but those still working were more likely to suffer from arm problems. This lends support to the result of the present study in that employed women were found to have more breast and arm symptoms than retired women. However, Uzun et al. (2004) suggested that employed women had better QOL than unemployed and retired women. Furthermore, in phase I employed women in this study had better sexual functioning, but poorer socio-economic QOL. Even if they are retired, older

women may experience less financial difficulties than younger women who have to take prolonged sick leave for their breast cancer treatments.

Several studies have reported on the associations between axillary treatment and adjuvant treatments and side-effects. One of the postoperative complications in the removal of axillary lymph nodes is morbidity of the upper extremity (Gosselink et al. 2003, Engel et al. 2003b, Wilke et al. 2006), including lymphedema (Ozaslan & Kuru 2004, Rönkä et al. 2004). As expected, the women in this study whose sentinel node status was positive and who had undergone axillary dissection had more systemic therapy side-effects than women who had negative sentinel node status and who had undergone sentinel node biopsy. In addition, the literature shows that adjuvant treatments, especially chemotherapy (Browall et al. 2008) but also radiotherapy (Lee et al. 2008), which surprisingly was not confirmed in this study, had a negative effect on women well-being's and QOL. In this study women with chemotherapy had more arm and breast symptoms. However, in earlier studies using different QOL instruments, women with chemotherapy reported broader symptoms, on the one hand increased levels of depression and decreased social functioning (Badger et al. 2004a, Browall et al. 2008), cognitive dysfunction, changes in sexual functioning (Kayl & Meyers 2006), and on the other hand nausea, vomiting and hair loss (Kayl & Meyers 2006), whereas women with radiotherapy reported more localized symptoms, such as arm and breast symptoms (Browall et al. 2008). Different results have been reported on the effects of radiotherapy on women's QOL (see Lee et al. 2008). Furthermore, the women in this study who received hormonal therapy had poorer future outlook and poorer psychological and spiritual QOL, and they had more side-effects than women not receiving hormonal therapy.

6.2.5 Predictors of poor quality of life

Although there is an extensive body of research exploring the associations of various background variables with QOL, very few studies have examined predictors of poor QOL in patients with breast cancer. In the present study,

logistic regression models were used to identify factors predicting the poorest quartile of QOL scores and factors predicting negative changes in QOL. The aim of the analyses of factors predicting negative changes in QOL was to identify those variables that predict the greatest risk for women to fall into the poorest QOL. This classification was justified by the importance of focusing on women who reported the poorest QOL.

In the present study the predictors of poor QOL in both phases were being in the control group, age, education, type of surgery and type of axillary treatment. In phase I employment status, histological type and receptor status and in phase II receiving chemotherapy and ongoing therapy were also identified as predictors of poor QOL. Variables that predicted negative six-month changes in QOL were education, employment status, having underage children, adjuvant treatments, and social support from network. Engel et al. (2003a) median dichotomized the EORTC QLQ-C30 scores for logistic regression analyses when they assessed the clinical and demographic predictors of QOL. Engel et al. (2003a) showed that significant predictors of arm problems were the extent of axillary surgery, age, employment, diabetes, cardiovascular disease and hospital treatment. Arm dysfunction, co-morbidity (Engel et al. 2003a, Engel et al. 2003b) and communication problems showed a strong and consistent association with poorer QOL (Engel et al. 2003a).

Another significant predictor of QOL over five years was age in that younger women had poorer social functioning and body image (Engel et al. 2003a). The same finding was made in the present study, but at two different time points. Social functioning may be altered in many different ways in younger women. Long periods on sick leave may lead to isolation and decreased social relationships and network support. In addition, in phase I being under age 55 explained the poorest quartile of health and functioning and family domain. As summarized earlier in sections 6.2.4 and 6.2.5, younger women should be given priority in the allocation of support.

There is strong evidence that younger age is a risk factor for poorer QOL (Wentzel et al. 1999, King et al. 2000, Sammarco 2001a, Engel et al. 2004, Avis et al. 2005, Sammarco 2009), as was seen in this study as well. Younger women seem to be psychologically more affected by their cancer experience (Engel et al.

2003c, Wentzel et al. 1999) and have poorer social (Engel et al. 2003a) and emotional functioning (Engel et al. 2004), more pain, severe arm dysfunction (King et al. 2000), more disrupted daily habits (Engel et al. 2003a), and more future health worries than older women (Engel et al. 2004).

Women in the control group had more postoperative side-effects, poorer body image and worse future outlook in phase I and poorer sexual functioning and more arm symptoms in phase II. This lends support to the effects of interventions reported earlier in sections 5.2.2 and 5.3.2: both of the interventions in this study had a clinically significant effect on sexual functioning and the face-to-face intervention had a statistically significant effect on arm symptoms.

Surgical and adjuvant treatments are also associated with poorer QOL (King et al. 2000, Burak et al. 2002, Temple et al. 2002, Xiaokun 2002, Peintinger et al. 2003, Schjiven et al. 2003, Rönkä et al. 2004, Engel et al. 2003b, Engel et al. 2004). This study confirmed the earlier finding that the more invasive the surgery and the more frequent the adjuvant treatments, the poorer the patient's QOL. In the present study, total mastectomy contributed to poorer body image in both phases; this is again consistent with earlier findings (King et al. 2000, Burak et al. 2002, Temple et al. 2002, Peintinger et al. 2003, Schjiven et al. 2003, Rönkä et al. 2004, Engel et al. 2003b, Engel et al. 2004). However, according to these same studies type of axillary treatment was also found to be associated with QOL. The results of this study were not consistent with earlier findings in that in phase I, breast conserving therapy explained the lowest quartile of breast symptoms scores and sentinel node biopsy explained the lowest quartile of arm symptoms. In phase II women who had undergone sentinel node biopsy had a smaller risk of poor body image than women who had undergone axillary dissection.

At six months, women who had received chemotherapy as an adjuvant treatment had a lower risk of poorer socio-economic QOL than women who did not receive chemotherapy. Those women who did not have ongoing therapy at six months had a lower risk of more arm symptoms than those receiving chemo- or radiotherapy. It has previously been reported that adjuvant treatments have negative effects on body image, psychosocial well-being (Kayl & Meyers 2006),

physical function (Arora et al. 2001, Watters et al. 2003), role function, social function and global health status during adjuvant chemotherapy (Watters et al. 2003). Patients treated with a combination of chemotherapy and radiotherapy complained of lymphedema significantly more often than those treated with surgery, hormone therapy, chemotherapy alone or radiotherapy alone (Schultz et al. 2005).

The analyses in this study of negative changes in QOL showed that gainful employment, having underage children and radiotherapy increased the risk of negative changes in QOL. Employed women had a lower risk of negative changes in body image than retired women, which may be explained by their larger number of contacts with other people. Women with underage children often worried more about their family and children, and therefore this result is not unexpected. Furthermore, in contrast to expectations, women who did not receive radiotherapy had a greater risk of decreased global, socio-economic and family QOL. However, this result is closely in line with the findings of Bloom et al. (2001), Lehto-Järnstedt et al. (2002) and Arora et al. (2007), who discovered that patients receiving no adjuvant treatments after breast cancer surgery received less helpful social support than women who did receive adjuvant treatments. Larger networks have been found to be related to a better availability of emotional support, which is a significant predictor of mental well-being and physical and emotional recovery (Bloom et al. 2001). However, chemotherapy and hormonal therapy seemed to have a negative effect on body image among the women in this study, as has been seen in several earlier studies (Arora et al. 2001, Watters et al. 2003, Kayl & Meyers 2006, McIlpatrick et al. 2007, Turgay et al. 2008). Furthermore, in contrast to previous studies, the women in this study who received more affect from their network were more likely to have decreased global QOL and health and functioning, whereas women with aid from nurses were more likely to have improved sexual functioning, as discussed in section 6.2.3 above.

6.3 Implications for nursing practice

The results of the present study are encouraging and have several implications for nursing practice. Firstly, the planning and implementation of interventions aimed at improving women's QOL depends essentially on the content of nursing education overall and on the support of management. Secondly, the study demonstrates that health care professionals need to be aware of the importance of patient's QOL and be able to assess their QOL. Thirdly, when implementing interventions health care professionals need to have the ability to take advantage of evidence-based knowledge aimed at improving women's QOL.

The results of this study underscore the need to consider the source, amount and timing of social support in newly diagnosed breast cancer patients. It is important that health care professionals are better aware of the problems faced by patients during the treatment process and develop supportive interventions to ensure that patients' needs are adequately met. Women should be offered systematic support and information about different follow-up options available, including rehabilitation and support groups.

Based on these results there is certainly good reason to recommend telephone support as a method of post-operative intervention. A telephone intervention is easy to implement, requires few resources and is a useful way of contacting large numbers of people. Telephone support given by a physiotherapist one week after a short hospital stay proved to be an effective way of increasing breast cancer patients' QOL after breast cancer surgery. Short-term face-to-face support and education should also be considered an alternative method of intervention in the treatment of patients with breast cancer who need more intensive support. Clinician support and education is an essential part of the care of breast cancer patients. In clinical practice it is essential that oncology nurses work closely with physiotherapists in recognizing and meeting the support and education needs of breast cancer patients and in planning follow-up protocols to help patients cope better. Physiotherapists play an important role in this process, provided that their expertise can be put to effective and appropriate use. Multiprofessional support and education is an essential part of the care of breast cancer patients. Both types

of intervention used in the present study are easy to apply in the treatment process. These interventions also help to ensure the continuity of care.

It is important to be aware of the importance of QOL to breast cancer patients and especially to consider the difficulties that younger women experience immediately after the operation. Interventions should aim to improve the recovery of sexual functioning and body image because these are the aspects of life that are most at risk of impairment in younger breast cancer patients. Problems with body image require special attention with a view to preventing difficulties in family functioning and in partner relationships. Interventions focused on reducing arm symptoms may possibly help to prevent later symptoms resulting from breast cancer surgery and treatments.

This study provided valuable information about QOL changes in newly diagnosed breast cancer patients over time. Nurses and other health care professionals involved in the care of breast cancer patients should pay more attention to the individual experiences and needs of women, and target support accordingly, because QOL is very much an individual perception. Health care professionals in breast cancer teams should focus on the factors that most undermine QOL and therefore should be given closest attention when supporting breast cancer patients. They should make the best possible use of these results in focusing their support and developing support services for newly diagnosed breast cancer patients. Above all, health care professionals should be trained themselves to understand and assess QOL and use this knowledge systematically in improving the care of breast cancer patients. As mentioned above, this is the matter of both education and management.

6.4 Implications for further research

Further research is needed to examine the effect of different kinds of interventions at different time points on QOL in women with early breast cancer and to assess longer-term changes in their QOL using longitudinal designs. Future research will enable health care professionals to provide more patient-

centred supportive care and identify the type of support that women need and from whom they want support. This study produced useful information on the effect of different kinds of interventions at different time points. However, it is also necessary to examine the cost-effectiveness of different types of interventions and to compare telephone interventions with other support methods. Considerations of cost-effectiveness should include not only health care productivity, but also outcomes from women's point of view. It is also important to consider alternative approaches to the delivery of interventions, taking into account not only cost considerations but also the complexity of maintaining different types of follow-up protocols. More evidence is needed to achieve consensus about optimal intervention methods.

Repeated measurements over long periods of time might be able to show statistically significant time effects in QOL. There is a continuing need for longitudinal research to evaluate longer-term changes in breast cancer patients' social support and its relationship to QOL. Moreover, more extensive and longer-term experimental studies are needed.

The present study generated important knowledge about factors predicting poor QOL and negative changes in QOL. There is a lack of research exploring which factors predict poor QOL and negative changes in QOL, and more evidence is needed in this area. Providing support and education for this group of women should be recognized as an absolute priority in the evidence-based efforts of health care professionals because of the increasing number of new breast cancer cases and the short period of hospitalization after surgery.

7 CONCLUSIONS

The main conclusions of this series of studies are summarized as follows:

1. The positive effects of the telephone intervention one week after breast cancer surgery and the face-to-face intervention six months after breast cancer surgery indicate that the supportive intervention model developed in this study can help to increase QOL in operated breast cancer patients. It is important that breast cancer patients' QOL is supported and enhanced by the use of individually tailored methods at different time points in their treatment process.
2. Women with breast cancer had a moderate QOL both one week and six months after breast cancer surgery, regardless of the type of surgery and adjuvant treatments. Patients in the intervention and control groups showed an improvement in some aspects of their QOL over the six-month follow-up. Despite these positive changes in QOL over time, there are certain areas such as body image, treatment side-effects, arm symptoms and family functioning which require special attention with a view to preventing future problems in physical health, psychosocial functioning and family relationships.
3. Family members were the major source of social support in the intervention and control groups at both phases of the study. Decreased affect and aid from the network may increase the need for support from other sources during the adjuvant treatment process, which challenges health care professionals to recognize these vulnerable women and to get involved whenever necessary.

4. The results of this study on factors predicting poor QOL and negative changes in QOL provide important information for training purposes and for clinical practice as well as for drawing up evidence-based guidelines for long-term support protocols with breast cancer patients. They also provide important clues for the further development of breast cancer support programmes. Younger women who have undergone mastectomy and axillary dissection and who receive adjuvant treatments should be given special consideration. This applies most particularly to problems with body image and sexual function in younger women with breast cancer. Even though increased affect over six months led to a short-term decrease in QOL, it could have longer term benefits.

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Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Interventions including telephone support				
Donnelly et al. 2000 USA	Non-randomized, single-arm study with pre-test and post-test design. Women's group (n=14), partners group (n=10). Statistical tests were not performed.	Mental Health Inventory, Impact of Event Scale (IES), Perceived Self Efficacy Scale, Social Support Survey (MOS), Services Assessment Questionnaire, Technical Quality, Communication, Interpersonal Care & Outcomes subscales, Consumer Satisfaction Survey, Orientation-Memory-Consentration Test, EORTC QLQ-C30.	Psychotherapeutic telephone sessions close to the time the first chemotherapy ending 4 weeks after patients was discharged from the chemotherapy trial. Weekly sessions, mean number 16 for patients and 11 for partners provided by psychologist.	Participants rated their satisfaction between "good" and "excellent". Intervention reduced emotional isolation, increased psychological and practical support, enhanced coping skills, especially in communicating with medical staff.
Sandgren et al. 2000 USA	Randomly assigned: 1) therapy group (n=24) and 2) control group (n=29).	Coping Response Indices-Revised Scale, Profile of Mood States (POMS), Medical Outcome Scale (MOS).	10 telephone calls administered once a week for 4 weeks and then every other week for 6 more sessions conducted by clinical psychology.	Women in both groups reported reduced stress and improved QOL over time. Women in therapy group reported a high degree of comfort with the telephone therapy. Therapy group reported better physical functioning, less anxiety, and less confusion, though the improvements were only moderate.
Rawl et al. 2002 USA	Randomized controlled trial of 109 with breast, lung and colon cancer patients receiving chemotherapy and their caregivers assigned to the intervention group (n=55) and to the control group (n=54).	Medical Outcomes Study 36 Short Form (SF-36), Centers of Epidemiological Studies Depression-20 scale (CESD-20), State-Trait Anxiety Inventory (STAI).	Intervention consisted 9 visits, 4 telephone interventions and 5 in-person clinic visits within 18 weeks provided by nurse specialists.	Women in the intervention group had less depression and anxiety, greater improvement in the role-emotional and mental health between baseline and the midway point compared to the control group.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

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Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Samarel et al. 2002 USA	Three group, three-phase randomized clinical trial: 1) experimental group (n=55), 2) control group I (n=68), 3) control group II (n=60).	Visual Analogue Scale-Worry (VAS-W), Existential Well-Being Scale (EWBS), Profile of Mood States (POMS), UCLA Loneliness Scale-Version 3 (UCLA-3), Relationship Change Scale (RSC).	Intervention group received 13-months of combined individual telephone and in-person group support and education. Control group I received only 13-months telephone support. Control II received one-time mailed educational information. Support was provided by oncology clinicians and social worker.	Women in experimental group and in control group I reported less mood disturbance at the end of three phases, and loneliness at the end phases II and III than control group II. Women in the experimental group had higher quality relationships with a significant other at the end of phase II than had control group II.
Sandgren & McCaul 2003 USA	Randomly assigned to the interventions: 1) health education (n=78), 2) emotional expression (n=89), and 3) standard care (n=55).	Perceived Stress Scale, Cancer Behaviour Inventory, Functional Assessment of Cancer Therapy-Breast instrument (FACT-B), Profile of Mood States (POMS).	5 weekly 30 minute phone calls with a 6th follow-up call made 3 months later. Support was provided by nurses.	Women reported improvements in QOL, in functional, emotional, and physical well-being but no treatment effects were found. Health education group reported greater perceived control than did standard care group.
Badger et al. 2004b USA	Repeated measures experimental design: women (n=48) and their partners (n=48) were assigned to the 1) telephone inter-personal (TIP-C) group and 2) control group. Subjects of the case study (married couple) received the TIP-C.	No quantitative instrument were used.	Woman received 6 weeks counseling, and her partner 3 weeks counselling provided by master's-prepared clinical nurse specialists in psychiatric mental health nursing with additional oncology expertise.	The couple reported positive changes in psychological distress and the nature of their relationship and in relationship with their children.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Badger et al. 2004b USA	Non-randomized study: women with either no depression burden, (n=123) or high depression burden (n=46). Data was drawn from earlier intervention study.	16-item side-effects checklist developed for this study.	The five 6-six week intervention were: a) self-help course, b) uncertainty management (telephone contact by a nurse case manager, c) an independent study self-help course, d) combined a) and b), and combined b) and c).	Women with high depression burden in the intervention group demonstrated improved psychological adjustment from baseline to 3 months. Women with high depression burden in the control group evidenced a decrease in psychological adjustment. At baseline, all women with high depression burden evidenced lower overall QOL. Regardless level of depression burden women in the intervention group reported improved QOL, whereas women in the control group evidenced sharp decrease in QOL.
Badger et al. 2005 USA	Repeated measures experimental design: intervention group (n=24), usual care group (n=24).	Center for Epidemiologic Studies-Depression Scale (CES-D), Positive and Negative Affect Schedule (PANAS), Multidimensional Fatigue Inventory (MFI), Index of Clinical Stress (ICS).	6 weekly supportive telephone calls provided by professionals (see Badger et al. 2004a)	The telephone interpersonal counseling intervention had an effect on symptom management and QOL. Intervention group experienced decrease in depression fatigue, stress and an increase in positive affect.
Coleman et al. 2005 USA	Randomly assigned: 1) experimental group (n=54) and 2) control group (n=52).	Profile of Mood States (POMS), Visual Analogue Scale-Worry (VAS-W), Relationship Change Scale (RCS), University of California, Los Angeles, Loneliness Scale-Version 3 (UCLA-3), Symptom Experience Scale (SES).	13 months of telephone social support and education delivered by oncology nurses.	Both groups showed significant improvements over time in mood, symptom management and relationships with significant others. No statistically significant group differences was found between groups.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

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Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Arving et al. 2006 Sweden	Randomized study with 3 groups: 1) n=60 2) n=60 3) n=59.	The Patient Satisfaction Questionnaire, The Hospital Anxiety and Depression Scale (HADS), The Impact of Event Scale (IES).	1) Individual psychosocial support by a specially trained oncology nurse, 2) individual psychological support by a psychologist, 3) standard care. A number of sessions were held by telephone (n=90) and has the same content as sessions held face-to-face.	All patients in both groups were satisfied with the sessions. Perceived benefits were higher in the group where support was provided by oncology nurse in areas "Worry about the disease", "Worry about test and treatment", "In receiving and handling information about the disease and treatment" and "Contact with hospital". The perceived benefits did not change over time.
Giese-Davis et al. 2006 USA	Observational study: 1) newly diagnosed women (Sojourners) (n=25) and 2) peer counselors (Navigators) (n=29).	Center for Epidemiologic Studies-Depression Scale (CES-D), Posttraumatic Stress Disorder Checklist-Civilian Version (PCL-C), Functional Analysis of Cancer Therapy (FACT-B), Brief Cancer Behaviour Inventory (CBI), Cancer Rehabilitation Evaluation System (CARES), Breast Cancer Resources Questionnaire (BCRQ), The Courtauld Emotional Scale (CECS), Weinberger Adjustment Inventory (WAI), Stanford Emotional Self-Efficacy Scale-Cancer (SESES-C).	Contacts mostly by phone for 3 to 6 months, 1 to 4 times a week with peer counselors.	Women rated feeling understood most highly as a helpful aspect of the intervention. Trauma symptoms decreased, emotional well-being and cancer self-efficacy for coping with treatment and side-effects increased.
Sutton et al. 2006 USA	Matched-pairs, baseline postintervention design: 62 women and 31 dyads.	The Sociodemographic Questionnaire (SDQ), The Meaningful Observations Journal (MOJ) developed for this study.	Contacts by telephone (80,4%), and face-to-face (19,6%). Mutually supportive, self-directed dyads twice a week for 8 weeks.	Only little changes was found in QOL and only little difference between two groups. Fear of recurrence was expressed by newly diagnosed women and also survivors.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

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Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Beaver et al. 2006 USA	Non-randomised controlled trial: 1) intervention group (n=67), 2) control group (n=68).	With semi-structured interviews.	Telephone intervention aimed to meet the information needs of women at two time points: 1) 2 months and 2) 8-12 months postdiagnosis administered by specialist breast care nurse.	Women in the intervention group were more likely to have had their information needs met than women in the control group.
Wilmoth et al. 2006 USA	Study sample was from original study of Coleman et al. (2005): 1) experimental group of the study (n=35), 2) control group (n=42).	With a standardized interview schedule.	13 months of telephone social support and education delivered by oncology nurses.	Women in the intervention group reported improvement in their attitudes towards living with breast cancer and they perceived better relationships with their significant others compared to the control group.
Allard 2007 Canada	Repeated measures prospective, randomized clinical trial: 1) intervention group (n=61), 2) control group (n=56).	Symptom Impact Profile (SIP), Profile of Mood States (POMS).	Attentional Focus and Symptom Management Intervention (AFSMI) during 2 phone sessions, at 3-4 days and 10-11 days after the surgery by principal investigator.	Intervention had an effect on the home management dimensions of functioning, on overall emotional distress, and on the confusion dimension of emotional distress in that women in the intervention group coped better than women in the control group. Intervention was also effective reducing the level of tension.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Arving et al. 2007 Sweden	Prospective study, randomized into 1 of 3 alternatives: Support given by 1) a specially trained oncology nurse (n=60), 2) a psychologist (n=60) or standard care (n=59).	EORTC QLQ-C30, EORTC QLQ-BR23, Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale (IES), State-Trait Anxiety Inventory-State (STAI-S).	Some sessions were held by telephone because of long traveling distances focusing on psychosocial support by specially trained oncology nurses and psychologists.	All three groups showed significant improvements with time on several subscales. Women in the groups 1) and 2) improved clinically significantly from "High levels of distress" to "Lower levels of distress".
Badger et al. 2007 USA	Randomly assigned in 1 of 3 different 6-weeks programs 165 women and their partners: 1) telephone interpersonal counseling (n=38) 2) exercise group (n=23), 3) attention control (n=35)	Center for Epidemiological Studies-Depression Scale (CES-D), An 8-item composite index of anxiety which included items from the Positive and Negative Affect Schedule, from the SF-12 and from the Index of Clinical Stress.	Interpersonal counseling intervention based on interpersonal communication techniques. Participants received 6-week counseling by weekly telephone call from a psychiatric nurse counselor with oncology expertise.	Both interventions were effective in reducing anxiety over time. Depressive symptoms decreased over time in all groups. Similar to women, partners anxiety and depression decreased in intervention groups but not in attention control group.
Budin et al. 2008 USA	Randomized controlled design with 249 patient-partner dyads: 1) control group (n=59) 2) standardized psychoeducation (n=66) 3) telephone counseling (n=66), 4) standardized psychoeducation and telephone counseling (n=58).	Psychosocial Adjustment to Illness Scale (PAIS), Profile of Adaptation to Life Clinical Scale (PAL-C), Self-rated Health Subscale (SRHS), Breast Cancer Treatment Response Inventory (BCTRI).	Telephone intervention consisted of 4 sessions for each patients and her partner provided by nurse.	Changes over time in psychological well-being were significant only for women in the telephone intervention group. There were a significant improvement from post-surgery to adjuvant therapy period, and significant decrease from adjuvant therapy to the ongoing recovery. Women who received both psychoeducation and telephone counseling reported less side-effect severity at ongoing recovery compared to postsurgery.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Beaver et al. 2009b USA	Randomized equivalence trial: 1) hospital follow-up (n=183), 2) telephone follow-up (n=191).	State-trait Anxiety Inventory (STAI) and General Health Questionnaire (GHO-12).	Participants in the telephone follow-up group received telephone appointments from breast cancer nurses at intervals consistent with hospital follow-up policy. The telephone follow-up was designed to meet the information needs of patients.	Telephone follow-up had positive benefits. Women reported greater satisfaction with the information received and reported appointments as more helpful meeting their needs.
Meneses et al. 2009 USA	Randomized study: 1) experimental group (n=27), 2) wait-control arm (n=26).	Fita Scale, Breast Cancer Treatment and Sociodemographic Data Tool, and Quality of Life-Breast Cancer Survivors Tool (QOL-BC).	BCEI Psychoeducational Support Intervention consist of 3 education and support sessions delivered face-to-face by a nurse and 5 follow-up sessions (ie 3 telephone and 2 face-to-face. Wait-control group received 3 face-to-face and 3 telephone sessions, but not BCEI.	Women in the intervention group had significantly better overall QOL compared to the wait-control group. Significant improvement in mean psychological QOL score was found in the experimental arm over time compared to the wait-control arm.
Sherman et al. 2010 USA	Randomized controlled design 249 patients assigned to 1) usual care group, 2) psycho-educational videos group, 3) telephone counseling group, 4) group that received all 3 mentioned above. Sample size reduced from 61 per group to roughly 40 per group.	Profile of Adaptation to Life Clinical Scale (PAL-C), Self-Report Health Scale (SRHS), Psychosocial Adjustment to Illness Scale (PAIS), Breast Cancer Treatment Response Inventory (BCTRI).	Phase-specific videos provided health relevant information, information for skill development and psychosocial support. Telephone intervention consisted of four phase-specific telephone-counseling sessions given by a nurse.	Overall health, psychological well-being and adjustment improved from postsurgery through ongoing recovery in all groups. In control group the emotional adjustment was poorer than in intervention groups. In telephone counseling group psychological well-being increased from baseline to adjuvant therapy, but decreased from adjuvant therapy to recovery phase. Side-effects distress increased only in the usual care group.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Libigel et al. 2010 USA	Single-arm pilot study (n=41).	EORTC QLQ-C30, Appearance Orientation Scale from the Multidimensional Body-Self Relations Questionnaire, Bruce Modified Ramp Protocol Teatmill Test, and also Maximum, Qxygen Consumption (Vo ₂ max) was calculated.	12-week, moderaty-intensity aerobic exercise intervention during adjuvant chemotherapy and/or radiotherapy. All exercise counseling was delivered via telephone with weekly calls from exercise physiologist.	Physical activity and cardiorespiratory fitness increased over the 12-week intervention. Participants did not experience significant changes in weight or percentage body fat. QOL improved significantly, and there was a trend toward improvement in fatigue.
Marcus et al. 2010 USA	Randomized two-group design with a sample of 304 patients: 1) control group (n=152) 2) intervention group (n=152).	Impact of Event Scale (IES), Center of Epidemiologic Studies Depression Scale (CES-D), Sexual Dysfunction Scale, Behavioral Scale, Evaluative Scale, and a composite measure to assess personal growth.	One-year 16 session telephone coueseling which lasted on average 45 min each. Nine sessions at two-week intervals, and 10-16 at one-month intervals provided by four master-level psychosocial oncology. Additional print materials were included.	Sexual functioning improved in the intervention group at both 12 and 18 months. Personal growth improved in both groups, but improvement was greater in the intervention group.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Face-to-face and Internet based interventions				
Ashbury et al. 1998 Canada	Quasi-experimental design: 1) participants (n= 175) and 2) comparison subjects (n=192).	The Functional Living Index - Cancer (FLIC), The Functional Assessment of Cancer Therapy), Scale (FACT), The Duke-UNC Functional Social Support.	Reach to Recovery program, which provided one-on-one support delivered by breast cancer survivors.	Program had an positive influence on QOL on QOL. Participants were satisfied with the program.
Rustoen et al. 1998 Norway	Experimental design: 1) experimental group (n=32, 12 with breast cancer diagnosis), 2) coping group (n=23), 7 with breast cancer), 3) control group (n=41, 22 with breast cancer).	The Nowotny Hope Scale (NHS), Ferrans and Powers Quality of Life Index (QLI), Cancer Rehabilitation, Evaluation Systems, short form (CARES-SF).	Experimental group intervention was designed to increase hope. The second group received the "Learning to Live with Cancer" program. Intervention included 2-hour meetings within a period of 8 weeks and 8 times provided by oncology nurses.	2 weeks after the intervention global QOL increased in the hope group and decreased in the control group. In the coping group QOL did not change or improved slightly 6 months after the intervention there were no significant changes in hope and global QOL in any groups.
Samarel et al. 1998 USA	Women's own reports (n=70) who participated in group of social support and education.	A structured interview schedule developed by the investigators.	Social support and education group with coaching by significant other or social support and education without coaching for 8 weeks (once a week for 2 hours) led by nurse and social worker team.	No differences were found between group with coaching and without coaching. 73% of the women reported improvement in attitude towards breast cancer, and all women regarded participation in the groups as positive.
Helgeson et al. 1999 USA	Randomly assigned: 1) to the control group (n=77), 2) education group (n=79), 3) peer discussion group (n=74), and 4) combination group (n=82).	Medical Outcomes Study, short form (MOS SF-36), Positive and Negative Affect Scale (PONS), Impact of Event Scale (IES), Rosenberg Self-Esteem Scale, Cancer Rehabilitation Evaluation System.	Education in the 8 sessions; peer discussion once a week for 8 weeks with 3 additional monthly meetings; combined intervention began with education and ended with peer discussion, where 3 additional meetings were held.	Immediately after the intervention and 6 months vitality, social and physical functioning, role limitations due to physical health and general health increased in education groups. No benefits were found of participation in peer discussion groups.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Fukui et al. 2000 Japan	Randomized controlled trial: 1) intervention group (n=25), 2) control group (n=25).	Profile Mood States(POMS), Mental Adjustment to Cancer (MAC) scale, Hospital Anxiety and Depression (HADS).	Structured, 6-weeks psychosocial intervention consisting health education, coping skills training, stress management and psychologic support.	Women in the intervention group had higher scores in the vigor score at 6 weeks and 6 months. Total mood disturbance was significantly lower in the intervention group both at 6 weeks and at 6 months than in the control group. At 6 weeks fighting spirit was significantly higher in the intervention group compared to the control group.
Helgeson et al. 2000 USA	Randomly assigned: 1) control groups (n=77), 2) education groups (n=79), 3) peer discussion groups (n=74), and 4) combination groups (n=82).	Medical Outcomes Study, short form (MOS SF-36), Rosenverg Self-Esteem Scale, Cancer Rehabilitation Evaluation System (CARES), three items used with chronically ill patients: future course of illness, day-to-day illness symptoms and emotions related to illness, and 15-item support scale developed by authors for this study.	Education and peer-discussion groups met weekly for 8 weeks. Interventions were provided by pairs of oncology nurses and oncology social workers. The peer-discussion intervention focused on the discussion about feelings and experiences and facilitated by oncology nurse and social workers.	Women who lacked emotional support from their partners or who reported more negative interactions with their partner did not benefit from peer-discussion group support. Women who reported low oncologist informational support benefited from either intervention compared to the control group.
Helgeson et al. 2001 USA	Randomly assigned: 1) control group (n=77), 2) education group (n=79), 3) peer discussion group (n=74), and 4) combination group (n=82). Three year follow-up study.	Medical Outcomes Study, short form (MOS SF-36).	Education and peer-discussion groups met weekly for 8 weeks. Interventions were provided by pairs of oncology nurses and oncology social workers.	Education group sustained greater vitality and social functioning over time compared to the control group. Education group improved in bodily pain and sustained greater improvements in physical functioning compared to the control group. In mental functioning the education group fared better than the peer discussion group.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

11 (16)

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Box et al. 2002a Australia	Randomly assigned: (n=65) to the elective physiotherapy intervention group or to the control group.	Myrin Goniometer to measure active shoulder movements, and 12-item functional outcome measure modified from previous studies.	Physiotherapy Management Care Plan (PMCP). Control group received exercise instruction booklet.	Functional recovery was greater among in the intervention group at 1 month. Women in the intervention group showed greater recovery of abduction at 3 months that was maintained to 2 years postoperatively.
Box et al. 2002b Australia	See above Box et al. (2002a).	Arm circumferences (CIRC), arm volyme (VOL), multi-frequency bioimpedance (MFBIA).	Physiotherapy intervention including principles for lymphoedema risk minimisation and management of this condition.	At 24 months, 30% of the women in the control group had secondary lymphoedema compared to 11% of the intervention group. The incidence of the secondary lymphoedema within 2 years postoperatively was 18,5% among women in the interventing group and 40% among women in the control group.
Lieberman et al. 2003 USA	Women who accepted authors invitation (n=32) were devided in 4 groups, each 8 participants.	Center for Epidemiologic Studies-Depression Scale (CES-D), Posttraumatic Inventory (PTGI), Pain: Self ratings, intensity, interference, and reactions, Courtauld Emotional Control Scale (CECS), Weinberger Adjustment Inventory (WAI), Mini-Mental Adjustment to Cancer Scale (short form) (MAC).	Internet-delivered electronic support group (ESG) 16 sessions once a week facilitated by a trained Wellness Community facilitator (TWS).	Approximately 67% found the experience helpful. Depression and reactions of pain reduced. Women demonstrated a trend toward increased new possibilities and spirituality. Women appeared to increase in emotional suppression.
Okamura . et al. 2003 Japan	Explanatory analysis of the study of Fukui et al. (2000) for 41 women.	Visual Analogue Scale (VAS), Profile of Mood States (POMS), and Total Mood Disturbance (TMD).	Group of 6-10 patient met weekly for 6 weeks led by therapist, a psychiatrist and either a clinical psychologist or a social worker.	At both 6 weeks and 6 months satisfaction with information about breast cancer and coping with cancer were associated with lower total mood disturbance scores.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

12 (16)

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Winzelberg et al. 2003 USA	Randomly assigned: 1) intervention (n=36) 2) control (n=36) groups.	Center for Epidemiological Studies-Depression Scale (CES-D), PTSD checklist-civilian version, State-trait Anxiety Inventory-State Scale (STAI), 14-item self-report measure of global perceived stress (PSS).	Web-based 12-week social support group moderated by mental health professional. Moderator encouraged members to support one another.	Intervention reduced womens' depression perceived stress, and cancer-related trauma. Women benefited the intervention in variety ways. Women used the group e.g. for providing and receiving social support and confronting difficult problems and fears.
Stanton et al. 2005 USA	Randomly assigned: 1) standard print material group (n=136), 2) videotape intervention (n=139), and 3) psychoeducational counseling (n=143).	Short Form-36 (SF-36), Revised Impact Event Scale (IES-R), Center for Epidemiologic Studies-Depression Scale (CES-D), audiotaped counseling sessions.	One individually conducted in-person session and one telephone session with trained cancer educators.	Peer-modelling videotape intervention produced an increase in vitality relative to the standard print material intervention at 6 months. Psychoeducational counseling was effective in decreaseing distress at 6 months relative to standard print material group only among women with greater perceived preparedness for re-entry.
Liu et al. 2006 China	A longitudinal quasi-experimental study: 1) experimental group (n=31), and 2) control group (n=30).	Social Support Questionnaire (SSQ), Uncertainty Scale (US).	Continuing supportive care provided with psychological support and health education and the patient's misunderstanding of the disease by trained registered nurse for 3 months.	Intervention improved social support and disease uncertainty. Higher levels of social support were associated with lower levels of perceived uncertainty 1 month after surgery and 3 months after diagnosis.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

13 (16)

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Beurskens et al. 2007 Netherlands	Randomly assigned 1) to the intervention group (n=15), and 2) to the control group (n=15).	Vas score, Disabilities of the Arm Shoulder and Hand (DASH), Water displacement, grip strength (Kg) using hand-held dynamometer, Sickness Impact Profile -short version (SIP).	Intervention group received physiotherapy, which started 2 weeks following surgery. Control group received leaflet flyer with advice and exercises for the arm/shoulder for the first weeks following surgery.	Intervention improved shoulder function and QOL and reduced shoulder pain in patients with axillary dissection after 3 and 6 months after the surgery.
Kalaitzi et al. 2007 Greece	A cohort of 40 women who underwent mastectomy were randomized: 1) intervention group (n=20), and 2) control group (n=20, remaining 20 women).	State Trait Anxiety Inventory (STAI), Epidemiological Studies-Depression Scale (CES-D).	Intervention provided to women and their partners consist 6 psychotherapeutic brief couples and sex therapy sessions (CBPI).	Women in the intervention group showed improvement in depression, anxiety, body image, satisfaction with relationship, presumed attractiveness to their partner, orgasm frequency, and communication their desire.
Mutrie et al. 2007 United Kingdom	Pragmatic randomized controlled prospective study: 1) exercise group (n=99), 2) control group (n=102).	Functional Assessment of Cancer Therapy - General (FACT-G), Beck Depression Inventory, Body mass index, a 12 minute walk test, shoulder mobility.	Intervention was supervised group exercise programme for 12 weeks provided by specially trained exercise specialist 14 sessions together. After the exercise, group discussion was conducted. Women were helped to construct an individual exercise programme at the end of the intervention.	Intervention group showed benefits in physical and psychological functioning 12 weeks after the intervention and these were maintained to 6 months follow-up, with exception of self reported minutes of physical activity. In QOL intervention showed benefits only at the 6-month follow-up.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

14 (16)

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Classen et al. 2008 USA	Randomly assigned: 1) support group (n=177), 2) treatment group (n=177) and 3) educational control condition (n=176).	Profile of Mood States Questionnaire (POMS), The Hospital Anxiety and Depression Scale (HADS), Mini-Mental Adjustment to Cancer Scale (MAC), Courtauld Emotional Control Scale, Impact of Event Scale (IES), Stanford Self-Efficacy Scale for Serious Illness, CARES Medical Interaction Subscale, Family Relations Index, Sleep and Pain Measure, Yale Social Support Index.	Intervention group received supportive-expressive group therapy for 12 weeks, once a week. In addition to the intervention women got education materials.	No effect was found on distress for brief intervention. Primary breast cancer patients and women with highly distress did not benefit from intervention.
Maeda et al. 2008 Japan	Controlled clinical trial assigned to either the experimental group or the control group according to the order of their surgery: 1) experimental group (n=14), 2) control group (n=14).	Self-esteem scale, Emotional support Scale, Mental Adjustment to Cancer Scale (MACS), Hospital Anxiety and Depression Scale (HADS).	Psychological intervention including 3 sessions: at 3 to 4 days after surgery and at 1 and 3 months after discharge.	Experimental group showed improvement in self-repression, in self-esteem, in anxiety, in depression, and in fighting spirit. Helplessness/hopelessness, anxious preoccupation and fatalism improved in the experimental group, whereas control group improved only in fatalism and only at 6 months.
Schou et al. 2008 Norway	Quasi-experimental design with 1) participants (n=94), and 2) non-participants n=71).	Hospital Anxiety and Depression Scale (HADS), EORTC QLQ-C30, Life Orientation Test-Revised (LOT-R).	Psychosocial intervention with 3 weekly group sessions at the hospital, 1 to 4 weeks after surgery provided by nurses, surgeon, physiotherapist and a Breast Cancer Society member.	Participation in support group did not have any significant effect on women's QOL. However, prevalence of anxiety for the non-participants at 12 months was significantly lower among participants than among non-participants.

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Baucom et al. 2009 USA	Randomly assigned: 1) couple-based relationship enhancement (RE), (n=8) and 2) treatment as usual (TAU), (n=6).	Quality of Marriage Index (QMI), Derogatis Inventory of Sexual Functioning (DISF-SR), Brief Symptom Inventory-18 (BSI-18), Posttraumatic Growth Inventory (PGI), Functional Assessment of Cancer Therapy (FACT-B), Self-Image Scale (SIS), Brief Fatigue Inventory (BFI), Brief Pain Inventory (BPI), Rotterdam Symptom Checklist (RSC).	A couple-based intervention 6 bi-weekly provided by advanced doctoral students in clinical psychology.	Women in the RE group showed in most domains improved individual functioning and well-being, relative gains in posttraumatic growth, and improved in areas focal to cancer. Also men reported improved individual functioning compared to the men in TAU. Women and men in RE reported greater improvements in relationship functioning than couples in TAU after the treatment and 12 months.
Dolbeault et al. 2009 France	Randomly assigned: 1) treatment group (n=102) and 2) control group (n=101).	State-Trait Anxiety Inventory (STAI), Profile of Mood States (POMS), Mental Adjustment to Cancer Scale (MAC), EORTC QLQ-C30, EORTC QLQ-BR23.	Psycho-educational group intervention including 8 weekly 2 h sessions provided either psychologist or psychiatrists.	Intervention had positive effect on anxiety, anger, depression and fatigue. Significant improvements in vigor, in interpersonal relationships, in emotional and role functioning, in health status and fatigue level was found in the intervention group.
Manos et al. 2009 Spain	Women who agreed to take part, constituted the intervention group and those who did not constituted the control group (N=188).	(EORTC QLQ-C30) and Mental Adjustment to Cancer Scale (MAC).	Psychosocial intervention programme combined educational and cognitive-behavioural interventions and offering social support 14 weekly sessions.	Intervention improved QOL, women's fighting spirit and hopefulness/optimism and decreased depression and psychological distress. Women in the intervention group had less sexual problems and socio-economic problems compared to the women in the control group.

Appendix 1. Characteristics of the intervention studies in breast cancer patients

16 (16)

Researcher and year of publication	Design and sample	Instruments	The intervention	Main results
Capozzo et al. 2010 Italy	Non-randomized study: (n=29).	Mini Mental Adjustment (Mini-MAC).	Structured psychoeducational intervention with 6 weekly group sessions performed by psychotherapist and healthcare team: cancer surgeon, an oncologist, a radiotherapist or a physiotherapist.	Intervention was found to be effective in reduction in anxious preoccupation.
Kayser et al. 2010 USA	Randomized controlled design 1) intervention group consisted of 24 couples and 1) control group of 23 couples.	Functional Assessment of Cancer Therapy-Breast (FACT-B) and Quality of Life Questionnaire for Spouses (QL-SP).	Couple-based intervention called Partners in Coping Programme (PICP). Control group were provided standard social work services.	No statistical significant differences was found in QOL between groups. Women in the intervention group who were in shorter marriages and received chemotherapy made the greatest gains in their QOL.
Penttinen et al. 2010 Finland	Randomized trial (N=537).	EORTC QLQ-C30, FACIT-Fatigue scale, Beck's depression scale (RBDI), Women's Health Questionnaire (WHQ), 2 km walking test.	Supervised exercise training shortly after adjuvant treatment for 1 year.	Physical activity was the only factor improving QOL. Depression, fatigue, increasing BMI, comorbidity and vasomotor symptoms impaired QOL.
Sharif et al. 2010 Iran	Randomly assigned: 1) intervention (n=49) and 2) control group (n=50). Intervention group were divided into 5 sub-groups.	EORTC QLQ-C30, EORTC QLQ-BR23.	Peer-led education 4 sessions on weekly basis for 1 month.	Body image, sexual functioning, sexual satisfaction and future perspective increased in the intervention group from pre to post and follow-up. Breast symptoms and upset by hair loss decreased in the intervention group. Fatigue, pain, insomnia and loss of appetite declined in the intervention group.

THE CHECKLIST TO ASSESS PATIENT EDUCATION IN PHYSICAL THERAPY PRACTISE (according to Sluijs 1991, 24)

1. Teaching and informing about the illness

- about diagnosis and complaints
- about the cause of the illness
- about the prognosis
- illustrative material to clarify information
- miscellaneous or remaining topics

2. Giving instructions on home exercises

- explaining home exercises
- frequency of each exercise
- number of sessions per day
- the build-up of the exercise programme
- the build-up of each exercise
- exercise leaflet
- instructions written by the therapist
- integrating exercises to daily activities
- motivating the patient to comply
- monitoring the patient's compliance
- resolving compliance problems
- miscellaneous or remaining topics

3. Giving advice and information

- on taking rest
- on correct posture and movement
- on work, sports or hobbies
- on daily activities
- on self care and domestic medicines
- on adaptations
- on aids and appliances
- on health services
- on family physicians or specialists
- motivating the patient to comply
- monitoring the patient's compliance
- resolving compliance problems
- miscellaneous or remaining topics

4. General health education

- on sports and exercise
- on weight control or nutrition
- on smoking of alcohol or drug intake
- on painkillers or medicine
- on health and illness in general

Appendix 2. Themes of patient's education and information by Sluijs (1991)

- motivating the patient to comply
- monitoring the patient's compliance
- resolving compliance problems
- miscellaneous or remaining topics

5. Counselling on stress-related problems and giving care and support

- explaining mind-body relation
- exploring stress-related problems
- supportive care with handicaps
- supportive care with personal distress

6. Therapist-patient relationship

- reinforcing the patient's performance
- showing concern for pain
- showing interest in the patient
- showing involvement in treatment
- facilitating patient participation

7. Planned and systematic approach

- explaining treatment session
- explaining follow-up treatments
- explaining duration of the treatment
- communicating findings from history taking
- communicating findings of the physical examinations
- communicating findings of the therapy
- explaining aim of physical examination
- explaining aim of massage
- explaining aim of a physical agent
- explaining possible side-effects of treatment
- evaluating the course of treatment

8. Patient's demands and perceptions

- exploring demands and expectations
- exploring ideas and perceptions
- exploring self-care activities
- checking the patient's understanding

TAMPEREEN YLIOPISTO
Hoitotieteen laitos

SAATEKIRJE

Phase I

Arvoisa potilas,

Teemme Tampereen yliopistollisessa sairaalassa sekä Tampereen kaupungin sosiaali- ja terveystoimen Hatanpään sairaalassa tutkimusta, jolla selvitetään rintasyöpäpotilaiden ja heidän läheistensä elämänlaatua.

Tutkimus tapahtuu keräämällä 400:lta rintasyöpäpotilaalta ja heidän läheisiltään kyselylomakkeiden avulla tietoja **kolmessa eri vaiheessa**:

Ensimmäisessä vaiheessa kyselylomakkeet annetaan potilaalle ja hänen nimeämälleen läheiselle ensimmäisen sairaalajakson päättyessä. Toiset kyselylomakkeet lähetetään potilaalle ja hänen läheiselleen puoli vuotta ensimmäisestä sairaalajaksosta. Kolmannet kyselylomakkeet lähetetään potilaalle ja hänen läheiselleen vuoden päästä sairastumisesta.

Mikäli olette tulleet valituksi koeryhmään ensimmäisen ja toisen vaiheen kyselylomakkeet sisältävät myös kysymyksiä koskien fysioterapeutin antamaa ohjausta.

Pyydämme Teitä ystävällisesti vastaamaan oheisiin kyselylomakkeisiin. Saadut tiedot tullaan käsittelemään luottamuksellisesti salassapitovelvollisuuden mukaisesti. Tutkimuksen tulokset ovat tilastollisia lukuja, joista ei yksittäisiä vastaajia voida tunnistaa. Tutkimukseen osallistuminen on täysin vapaaehtoista ja osallistumisesta voi luopua milloin tahansa syytä ilmoittamatta.

Tutkimuksen onnistumisen kannalta olisi kuitenkin tärkeää, että tutkimukseen tulevat vastaisivat kaikkiin kolmeen kyselyyn. Kieltäytyminen tutkimuksesta tai lomakkeiden vastaamatta jättäminen ei vaikuta millään tavoin hoitoon. Toivomme lämpimästi, että osallistutte tähän tutkimukseen ja sen avulla potilaiden ja heidän läheistensä hoidon kehittämiseen.

Olkaa hyvä ja palauttakaa lomake postitse vastauskuoressa **kahden viikon kuluessa**. Postimaksu on maksettu puolestanne.

Lisätietoja halutessanne voitte ottaa yhteyttä Päivi Saloseen.

Päivi Salonen
Terveystieteen
jatko-opiskelija
Tampereen yliopisto
Hoitotieteen laitos
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Tiina Salminen
ylihoitaja
TAYS

KYSELYLOMAKE RINTASYÖPÄPOTILAALLE KOODI _____

Olkaa hyvä ja ympyröikää oikea vaihtoehto tai kirjoittakaa vastauksenne sille varattuun tilaan.

1. Minkä ikäinen olette tällä hetkellä? _____ vuotta

2. Mikä on koulutuksenne? Ympyröikää korkein koulutuksenne.

1. kansa-, kansalais- tai peruskoulu
2. keskikoulu
3. lukio
4. ammattikoulu
5. opistotasoinen koulutus
6. yliopisto
7. muu, mikä _____

3. Minkä tyyppisessä työssä/tehtävissä olette?

1. työntekijä (esim. leipomo- tai tehdastyö)
2. alempi toimihenkilö (esim. myyjä, toimistovirkailija)
3. ylempi toimihenkilö (esim. opettaja, insinööri)
4. yrittäjä
5. maatalousyrittäjä
6. eläkkeellä
7. muu, mikä _____

4. Onko Teillä alaikäisiä lapsia?

1. kyllä
2. ei

5. Seuraavassa on lueteltu joukko henkilöitä. Ketkä heistä ovat tärkeimmät tukijanne, jotka antavat Teille tukea?

1. avo- tai aviopuoliso
2. omat vanhemmat
3. lapsi
4. ystävä
5. naapuri
6. työtoveri
7. terveydenhuoltoalan henkilö
8. kotipalvelun työntekijä
9. seurakunnan työntekijä
10. toinen rintasyöpää sairastava henkilö
11. muu, kuka _____
12. ei kukaan

Appendix 3. The questionnaires

6. Kuinka usein olette yhteydessä edellä kuvaamistanne kaikista tärkeimpään henkilöön?

1. päivittäin
2. viikoittain
3. kuukausittain
4. muutaman kerran vuodessa

7. Kuinka paljon olette saaneet tukea Teille tärkeiltä henkilöiltä tässä elämäntilanteessa?

	vähän	melko vähän	kohtalaisesti	melko paljon	paljon
a) mahdollisuuteen ilmaista omia tunteitanne	1	2	3	4	5
b) huolenpidon tunteen luomiseen	1	2	3	4	5
c) kotitöiden tekemiseen	1	2	3	4	5
d) rauhoittumiseen ("akkujen lataamiseen")	1	2	3	4	5
e) taloudellisista asioista päättämiseen	1	2	3	4	5
f) ajankäytöstä päättämiseen	1	2	3	4	5

TUKEA KOSKEVAT KYSYMYKSET

Missä määrin seuraavat asiat ovat toteutuneet rintasyöpäne hoidossa? Olkaa hyvä ja ympyröikää se vastausvaihtoehto, joka parhaiten vastaa saamaanne hoitoa.

	vähän	melko vähän	kohtalaisesti	melko paljon	paljon
1. Olen saanut tietoa sairaudesta	1	2	3	4	5
2. Olen saanut tietoa eri hoitomahdollisuuksista	1	2	3	4	5
3. Olen saanut tietoa, joka auttaa minua hoitamaan itseäni kotona	1	2	3	4	5
4. Olen saanut tietoa, mistä hakea apua pulmatilanteissa	1	2	3	4	5
5. Olen saanut kannustusta arkielämän tilanteiden ratkaisuihin	1	2	3	4	5
6. Hoitajat auttoivat minua ymmärtämään omia sairauteen liittyviä tunteitani	1	2	3	4	5
7. Sairaalassa hoitajat olivat kiinnostuneita tunteistani	1	2	3	4	5
8. Hoitajat loivat minuun uskoa toipumisesta	1	2	3	4	5
9. Sairaalassa hoitajilla oli aikaa kuunnella minua	1	2	3	4	5
10. Koin, että hoitajat arvostivat minua ja pitivät tärkeänä	1	2	3	4	5
11. Tiedän, mitä kuntoutuspalveluja minun on mahdollisuus saada	1	2	3	4	5
12. Tiedän, että minun on mahdollisuus saada apua seksuaalielämän ongelmiin liittyvissä asioissa	1	2	3	4	5
13. Minulle on järjestetty tarvitsemaani apua kotiin	1	2	3	4	5
14. Minulle on annettu kotiohjeita kirjallisena	1	2	3	4	5
15. Tiedän, mistä saan apua ja neuvoja, kun tarvitsen niitä	1	2	3	4	5

Appendix 3. The questionnaires

ELÄMÄNLAATUKYSELY (EORTC QLQ-BR23)

Koitteko **kuluneella viikolla** mitään seuraavista:

	ei lainkaan	vähän	melko paljon	hyvin paljon
1. Tuntuiko suunne kuivalta?	1	2	3	4
2. Maistuivatko ruoka ja juoma erilaisilta kuin ennen?	1	2	3	4
3. Vuotivatko silmäanne tai olivatko ne kipeät tai ärtyneet?	1	2	3	4
4. Oliko teillä hiustenlähtöä?	1	2	3	4

Vastatkaa tähän kohtaan vain, jos teillä on ollut hiustenlähtöä

5. Tuntuiko hiustenlähtö teistä pahalta?	1	2	3	4
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Koitteko **kuluneella viikolla** mitään seuraavista:

6. Tunsitteko olevanne sairas tai huonovointinen?	1	2	3	4
7. Oliko teillä kuumia aaltoja?	1	2	3	4
8. Oliko teillä päänsärkyä?	1	2	3	4
9. Onko sairautenne tai saamanne hoito tehnyt teidät mielestänne vähemmän viehättäväksi?	1	2	3	4
10. Onko sairautenne tai saamanne hoito vaikuttanut naisellisuuteenne?	1	2	3	4
11. Oliko teistä vaikea katsoa itseänne alasti?	1	2	3	4
12. Oletteko tyytymätön vartaloonne?	1	2	3	4
13. Olitteko huolissanne tulevasta terveydentilastanne?	1	2	3	4

Neljän viimeisen viikon aikana:

14. Missä määrin olitte kiinnostunut sukupuoli-elämästä?	1	2	3	4
15. Olitteko seksuaalisesti aktiivinen? (yhdynnässä tai muulla tavoin)	1	2	3	4

Vastatkaa alla olevaan kohtaan vain, jos vastasitte myönteisesti yllä oleviin kysymyksiin

16. Missä määrin nautitte sukupuolielämästänne?	1	2	3	4
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Appendix 3. The questionnaires

Koittako **kuluneella viikolla** mitään seuraavista:

	ei lainkaan	vähän	melko paljon	hyvin paljon
17. Oliko teillä kipuja käsivarressa tai olkapäässä?	1	2	3	4
18. Oliko käsivartenne tai kätenne turvonnut?	1	2	3	4
19. Tuntuiko teistä vaikealta nostaa käsivarttanne tai liikuttaa sitä sivulle?	1	2	3	4
20. Oliko teillä kipuja hoidetun rinnan alueella?	1	2	3	4
21. Oliko hoidetun rinnan alueella turvotusta?	1	2	3	4
22. Oliko hoidetun rinnan alue yliherkkä kosketukselle?	1	2	3	4
23. Oliko hoidetun rinnan alueella iho-ongelmia (esim. kutinaa, ihon kuivuutta, hilseilyä)?	1	2	3	4

ELÄMÄNLAATUKYSELY (QLI)

Olkaa hyvä ja valitkaa seuraavista vaihtoehdoista se, joka parhaiten kuvaa, miten tyytyväinen olette kyseiseen elämäalueeseen tällä hetkellä. Ympyröikää valitsemanne vastausvaihtoehto. Kysymyksiin ei ole oikeaa tai väärää vastausta.

	Erittäin tyytymätön	Kohtalaisen tyytymätön	Vähän tyytymätön	Vähän tyytyväinen	Kohtalaisen tyytyväinen	Erittäin tyytyväinen
KUINKA TYYTYVÄINEN OLETTE						
1. Terveysteenne?	1	2	3	4	5	6
2. Terveystenhoitoon?	1	2	3	4	5	6
3. Kipujenne määrään?	1	2	3	4	5	6
4. Voimavaroihinne päivittäisissä toiminnoissa?	1	2	3	4	5	6
5. Kykyynne huolehtia itsestänne ilman apua?	1	2	3	4	5	6
6. Oman elämänne hallinnan tasoon?	1	2	3	4	5	6
7. Mahdollisuuksiinne elää niin pitkään kuin haluaisitte?	1	2	3	4	5	6
8. Perheenne terveyteen?	1	2	3	4	5	6
9. Lapsiinne?	1	2	3	4	5	6
10. Perheenne onnellisuuteen?	1	2	3	4	5	6
11. Seksuaalielämäänne?	1	2	3	4	5	6
12. Puolisoonne tai kumppaniinne?	1	2	3	4	5	6
13. Ystäviinne?	1	2	3	4	5	6
14. Perheeltänne saamaanne henkiseen tukeen?	1	2	3	4	5	6
15. Muilta kuin perheeltänne saamaanne henkiseen tukeen?	1	2	3	4	5	6
16. Kykyynne ottaa vastuuta perheestänne?	1	2	3	4	5	6

Appendix 3. The questionnaires

KUINKA TYYTYVÄINEN OLETTE	Erittäin tyytymätön	Kohtalaisen tyytymätön	Vähän tyytymätön	Vähän tyytyväinen	Kohtalaisen tyytyväinen	Erittäin tyytyväinen
17. Tarpeellisuudestanne muille?	1	2	3	4	5	6
18. Huolten määrään elämässänne?	1	2	3	4	5	6
19. Asuinympäristöönnne?	1	2	3	4	5	6
20. Kotiinne tai asuinpaikkaanne?	1	2	3	4	5	6
21. Työhönne (jos olette työsuhhteessa)?	1	2	3	4	5	6
22. Työstä poissaoloihin?	1	2	3	4	5	6
23. Koulutukseenne?	1	2	3	4	5	6
24. Mahdollisuuteenne huolehtia taloudellisista asioistanne?	1	2	3	4	5	6
25. Vapaa-ajanviettotapoihinne?	1	2	3	4	5	6
26. Mahdollisuuksiinne onnelliseen tulevaisuuteen?	1	2	3	4	5	6
27. Mielenrauhaanne?	1	2	3	4	5	6
28. Uskoonne Jumalaan?	1	2	3	4	5	6
29. Henkilökohtaisten päämäärienne saavuttamiseen?	1	2	3	4	5	6
30. Yleisesti onnellisuuteenne?	1	2	3	4	5	6
31. Elämäänne yleensä?	1	2	3	4	5	6
32. Ulkonäköönne?	1	2	3	4	5	6
33. Itseenne yleensä ottaen?	1	2	3	4	5	6

Appendix 3. The questionnaires

Olkaa hyvä ja valitkaa seuraavista vaihtoehdoista se, joka parhaiten kuvaa, miten tärkeä kyseinen elämäalue on Teille tällä hetkellä. Ympyröikää valitsemanne vaihtoehto. Kysymyksiin ei ole oikeaa tai väärää vastausta.

MITEN TÄRKEÄNÄ PIDÄTTE	Ei lainkaan tärkeänä	Hyvin vähän tärkeänä	Vähän tärkeänä	Jonkin verran tärkeänä	Kohtalaisen tärkeänä	Erittäin tärkeänä
1. Terveyttänne?	1	2	3	4	5	6
2. Terveydenhoitoanne?	1	2	3	4	5	6
3. Että Teillä ei ole kipuja?	1	2	3	4	5	6
4. Että Teillä on riittävästi voimia päivittäisiin asioihin?	1	2	3	4	5	6
5. Selviytymisestäänne päivittäisistä asioista ilman apua?	1	2	3	4	5	6
6. Että pystytte säätelemään elämäännne?	1	2	3	4	5	6
7. Että saatte elää niin pitkään kuin haluatte?	1	2	3	4	5	6
8. Perheenne terveyttä?	1	2	3	4	5	6
9. Lapsianne?	1	2	3	4	5	6
10. Perheenne onnellisuutta?	1	2	3	4	5	6
11. Seksuaalielämäännne?	1	2	3	4	5	6
12. Puolisoanne tai kumppanianne?	1	2	3	4	5	6
13. Ystäviänne?	1	2	3	4	5	6
14. Perheeltänne saamaanne henkistä tukea?	1	2	3	4	5	6
15. Muilta kuin perheeltänne saamaanne henkistä tukea?	1	2	3	4	5	6
16. Että kykenette ottamaan vastuuta perheestänne?	1	2	3	4	5	6

Appendix 3. The questionnaires

MITEN TÄRKEÄNÄ PIDÄTTE	Ei lainkaan tärkeänä	Hyvin vähän tärkeänä	Vähän tärkeänä	Jonkin verran tärkeänä	Kohtalaisen tärkeänä	Erittäin tärkeänä
17. Että olette tarpeellinen muille?	1	2	3	4	5	6
18. Ettei ole huolia?	1	2	3	4	5	6
19. Asuinympäristöänne?	1	2	3	4	5	6
20. Kotianne tai asuinpaikkaanne?	1	2	3	4	5	6
21. Työtänne (jos olette työsuhhteessa)?	1	2	3	4	5	6
22. Että Teille olisi työtä (jos olette työtön)?	1	2	3	4	5	6
23. Koulutustanne?	1	2	3	4	5	6
24. Että kykenette huolehtimaan taloudellisista asioistanne?	1	2	3	4	5	6
25. Vapaa-aikaanne?	1	2	3	4	5	6
26. Onnellista tulevaisuutta?	1	2	3	4	5	6
27. Mielenrauhaa?	1	2	3	4	5	6
28. Uskoa Jumalaan?	1	2	3	4	5	6
29. Että saavutate henkilökohtaiset päämääränne?	1	2	3	4	5	6
30. Yleisesti onnellisuutta?	1	2	3	4	5	6
31. Että olette tyytyväinen elämään?	1	2	3	4	5	6
32. Ulkonäköänne?	1	2	3	4	5	6
33. Olla oma itsenne?	1	2	3	4	5	6

KIITÄN LÄMPIMÄSTI VASTAUKSISTANNE!

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KYSELY FYSIOTERAPEUTIN ANTAMASTA PUHELINOHJAUKSESTA VIIKKO LEIKKAUKSEN JÄLKEEN

Olkaa hyvä ja vastatkaa alla oleviin kysymyksiin.

Teitä hoitanut fysioterapeutti soitti Teille noin viikon päästä sairaalahoidostanne. Kertoisitteko kokemuksianne siitä, miltä tämä puhelu tuntui. Ympyröikää oikea vaihtoehto.

1. Fysioterapeutin puhelu leikkauksessa olleelle rintasyöpäpotilaalle on kokeilu. Kannattaako mielestänne tällaista kokeilua jatkaa?

1. Kyllä 2. Ei

2. Koitteko fysioterapeutin soiton

1. Erittäin hyödyttömäksi
2. Melko hyödyttömäksi
3. Ei hyödyttömäksi eikä hyödylliseksi
4. Melko hyödylliseksi
5. Erittäin hyödylliseksi

3. Oliko viikko leikkauksesta sopiva ajankohta puhelulle?

1. Kyllä 2. Ei

4. Mikä ajankohta fysioterapeutin puhelinsoitolle leikkauksen jälkeen olisi mielestänne sopivin?

Ympyröikää seuraavien väittämien vaihtoehtoista mielestänne parhaiten sopivin.

	ei auttanut	jätti/ jättivät epä- varmaksi	auttoi vähän	auttoi melko paljon	auttoi hyvin paljon
1. Mielestäni fysioterapeutin soitto	1	2	3	4	5
2. Puhelinkeskustelussa esille tulleet aiheet	1	2	3	4	5
3. Mahdollisuus kysyä mieltä askarruttavista asioista	1	2	3	4	5
4. Ohjeet yläraajan toimintakyvyn ylläpitämisestä	1	2	3	4	5
5. Mahdollisuus keskustella kuntoutumisesta yleensä	1	2	3	4	5
6. Fysioterapeutin antama ohjaus ja tuki	1	2	3	4	5