



UNIVERSITY
OF TURKU

**LIFE SATISFACTION,
SENSE OF COHERENCE AND
SOCIAL SUPPORT OF FINNISH
BREAST CANCER SURVIVORS
– WITH SPECIAL REFERENCE
TO PERCEIVED SEXUALITY
AND REHABILITATION**

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The originality of this publication has been checked in accordance with the University of Turku quality assurance system using the Turnitin OriginalityCheck service.

ISBN 978-951-29-8016-1 (PRINT)
ISBN 978-951-29-8017-8 (PDF)
ISSN 0355-9483 (Print)
ISSN 2343-3213 (Online)
Painosalama Oy, Turku, Finland 2020

To my family

Faculty of Medicine
Public Health Science
MINNA SALAKARI: Life satisfaction, sense of coherence and social support of Finnish breast cancer survivors – with special reference to perceived sexuality and rehabilitation
Doctoral Dissertation, 143 pp.
Doctoral Programme in Clinical Research
February 2020

ABSTRACT

With continuing improvement in early detection and treatment of breast cancer, the number of breast cancer survivors is steadily increasing. As breast cancer is becoming more and more a chronic condition rather than a life-threatening illness, health care professionals must recognize and manage the long-term sequelae of the constellation of therapeutic modalities. The aim of the thesis was to evaluate the psychological and social factors affecting the overall life satisfaction and sense of coherence and to review the effects of rehabilitation of survivors of advanced cancer.

The thesis is composed of four sub-studies: Study I assessed the life satisfaction and sense of coherence of breast cancer survivors. Study II explored perceived social support during breast cancer trajectory, study III estimated the perceived importance of and satisfaction with sex life, and study IV was a systematic review of the effects of rehabilitation of patients with advanced cancer. The data of the studies I-III is drawn from the Finnish nationwide Health and Social Support (HeSSup) -study.

Women diagnosed with breast cancer are as satisfied with their lives as healthy controls, and they report significantly better life satisfaction and a stronger sense of coherence than women suffering from depression. There was a positive correlation between coherence and life satisfaction. The most important source of social support is spouse or partner. Breast cancer survivors felt dissatisfaction with their sex life and found it less important than those with hypertension, and healthy controls. Multidisciplinary rehabilitation can be seen to be an effective form of support for cancer even in the chronic stage of the disease.

The identification of factors affecting the improvement of the overall life satisfaction of breast cancer survivors is an important public health challenge. Moreover, the results underline the importance of social support, sexuality and rehabilitation during the trajectory of breast cancer survivors, and the awareness of this knowledge among healthcare professionals' should be enhanced.

KEYWORDS: breast cancer, life satisfaction, rehabilitation, sexuality, sense of coherence, social support, survival, quality of life

TURUN YLIOPISTO

Lääketieteellinen tiedekunta

Kansanterveystiede

MINNA SALAKARI: Life satisfaction, sense of coherence and social support of Finnish breast cancer survivors – with special reference to perceived sexuality and rehabilitation

Väitöskirja, 143 s.

Turun kliininen tohtorihjelma

Helmikuu 2020

TIIVISTELMÄ

Rintasyövistä selviytyneiden määrä on kasvussa syövän hoitojen kehittymisen myötä, mikä edellyttää olemassa olevien tukimuotojen kehittämistä syöpähoitopolun aikana. Tämän väitöskirjatyön tavoitteena oli arvioida rintasyöpään sairastuneiden naisten elämäntyytyväisyyttä ja siihen vaikuttavia terveyteen liittyviä ja sosiaalisia tekijöitä.

Tutkimustyö koostuu neljästä osatyöstä: ensimmäisen osatutkimuksen tarkoituksena oli arvioida rintasyöpää sairastaneiden naisten itse arvioitua elämäntyytyväisyyttä ja koherenssin tunnetta. Toinen osatutkimus tarkasteli rintasyöpään sairastuneiden sosiaalisen tuen saatavuutta ja lähteitä, kolmannessa osatutkimuksessa arvioitiin rintasyöpään sairastuneiden tyytyväisyyttä seksielämäänsä ja seksielämän tärkeyttä. Neljännessä osatutkimuksessa selvitettiin systemoidun kirjallisuuskatsauksen menetelmin kuntoutuksen vaikutuksia syöpää sairastavan tukimuotona. Kaikki kvantitatiiviset empiiriset osatyöt (I-III) toteutettiin vertailevan tutkimuksen menetelmin hyödyntäen kansallista Health and Social Support (HeSSup) -kohorttitutkimuksen aineistoa.

Rintasyöpään sairastuneet naiset ovat yhtä tyytyväisiä elämäänsä kuin terveet verrokkit: he arvioivat sekä elämäntyytyväisyytensä että koherenssin tunteensa merkittävästi vahvemmaksi kuin masennuksesta kärsivät naiset. Koherenssin tunteen ja elämäntyytyväisyyden välillä havaittiin positiivinen korrelaatio. Sosiaalisen tuen suhteen tärkeimmässä roolissa tuen tarjoajana oli puoliso tai kumppani. Rintasyövän sairastuneet kokivat tyytymättömyyttä seksielämäänsä, ja pitivät sitä vähemmän tärkeänä kuin verenpainetautia sairastavat ja terveet verrokkit. Merkittävää on, että monialaisen kuntoutuksen voidaan todeta olevan vaikuttava tukimuoto vielä kroonisessa vaiheessa sairautta.

Rintasyövistä selviytyneiden kokonaisvaltaisen elämänlaadun ylläpitämiseen vaikuttavien tekijöiden tunnistaminen on tärkeä kansanterveyshaaste. Tutkimustuloksia voidaan hyödyntää rintasyöpää sairastavien ja sairastaneiden sekä heidän läheistensä monipuolisten tukimuotojen kehittämisessä. Erityistä huomiota tulee kiinnittää sosiaaliseen tukeen, kuntoutukseen ja seksuaalisen hyvinvoinnin huomioimiseen syöpähoitopolun aikana.

AVAINSANAT: elämänlaatu, elämäntyytyväisyys, koherenssin tunne, kuntoutus, rintasyöpä, seksuaalisuus, selviytyminen, sosiaalinen tuki

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Abbreviations

AMSTAR	A MeaSurement Tool to Assess systematic Reviews
ANCOVA	Analysis of covariance
ANOVA	Analysis of variance
BC	Breast Cancer
FDP	Finnish Drug Purchase
FCR	Finnish Cancer Registry
HeSSup	Health and Social Support
HRQoL	Health-Related Quality of Life
LS	Life Satisfaction
QoL	Quality of Life
RCT	Randomized Controlled Trial
SOC	Sense of Coherence
SS	Social Support
WHO	World Health Organization

List of Original Publications

This thesis is based on the following publications referred to in the text by their Roman numerals I-IV.

- I Salakari M., Suominen S., Nurminen R., Sillanmaki L., Pylkkanen L., Rautava P., Koskenvuo M. Life satisfaction and sense of coherence of breast cancer survivors compared to women with mental depression, arterial hypertension and healthy controls. In: Li H, Nykänen P, Suomi R, Wickramasinghe N, Widén G, Zhan M, (eds). *Building Sustainable Health Ecosystems. Communications in Computer and Information Science*, vol. 636. Springer; 2016:253–265.
- II Salakari M., Pylkkänen L., Sillanmäki L., Nurminen R., Rautava P., Koskenvuo M., Suominen S. Social support and breast cancer: A comparative study of breast cancer survivors, women with mental depression, women with hypertension and healthy female controls. *Breast*. 2017;35:85–90.
- III Salakari M., Nurminen R., Sillanmäki L., Pylkkänen L., Suominen S. The importance of and satisfaction with sex life among breast cancer survivors in comparison with healthy female controls and women with mental depression or arterial hypertension. Results from the Finnish nationwide HeSSup cohort study. *Support Care Cancer*. 2019 Dec 14.
- IV Salakari M, Surakka T, Nurminen R, Pylkkänen L. Effects of rehabilitation among patients with advanced cancer: a systematic review. *Acta Oncol*. 2015;54(5):618–628.

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1 Introduction

Breast cancer (BC) is the second most common cancer in the world, following lung cancer and it is the most common cancer in women in 140 countries (IARC/GLOBOCAN, 2018). It is also the most common cancer in women in Finland, and although survival from the disease has significantly improved in recent years, it remains the most common cause of cancer death among Finnish women. (Finnish Cancer Registry 2016.) While developed countries have high BC incidence, they also have low BC mortality. Survival has improved, and this obliges us to consider more variable forms of supportive care.

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

The diagnosis of cancer evokes the feeling of stress, fear, sorrow, anger and uncertainty (Carlson & Bultz, 2003; Yusuf et al., 2012; Stark et al., 2014). The determinants of QoL in women with BC include psychosocial factors, such as coping style, as well as sociodemographic and medical factors (Mols et al., 2005). Sense of coherence (SOC), self-esteem, coping strategies, social support (SS) and emotional distress are associated with QoL among patients with BC. BC patients with a strong SOC experience fewer arduous events and better overall QoL. The associations between SOC and health status, life satisfaction (LS) and QoL are linear. (Gerasimčik-Pulko et al., 2009; Kenne Sarenmalm et al., 2011)

BC rehabilitation is a process that helps BC survivors to obtain and maintain the highest possible overall functioning within the limits created by cancer and its

treatments. Rehabilitation focuses on restoring or improving QoL and thus on independence and participation in life (Silver et al., 2007; Amatya et al.; Stubblefield, 2017; Wirtz & Baumann, 2018). Rehabilitation is also needed among cancer patients with advanced disease and in palliative care (Dittus et al. 2017, Haun et al. 2017).

The main purpose of the thesis was to evaluate the BC survivors' LS and SOC and psychological and social factors affecting those. The study focuses on SS, the importance and satisfaction of sex life, and the effects of cancer rehabilitation, particularly in advanced cancers, including BC. The importance of these factors has increased over the past few decades and potentially contributes to the overall risk of and survival from BC among Finnish women.

Consequently, cancer patients will require a considerable amount of health care resources in the future and cancer patients' treatment and rehabilitation should be developed.

2 Review of the Literature

2.1 Approach of the literature review

A review of the literature dealing with the QoL, LS and SOC of BC survivors and the psychological and social factors affecting them was carried out. This review first describes the background of BC and BC survivorship, as well as the concept of QoL, LS and SOC. Next, SS is reviewed and described including the social, cultural and societal factors influencing survivors' perceived QoL and SOC, and then finally, BC survivors' overall perceived sexuality is reviewed.

The literature review was conducted in the following databases: Cinahl, PubMed, PsycINFO, EBSCOhost and Medic databases, search engine Google Scholar and electronic journals from the field of medicine, nursing, psychological and social science focusing mainly on the period from 2003 to 2018. Reference lists from retrieved publications were used for further identification of relevant literature. Websites of the cancer registries were used to find information on the situation of BC worldwide. Searches were also performed in databases containing reports and policy documents from international organizations.

2.2 Breast cancer

BC is a malign transformation of the glandular tissue of the mammary gland. BC is about 100 times less common among men than among women. Male BC rates are generally less than 1 per 100,000 man-years (Ly et al., 2013).

BC is the most common cancer among women in the Western world, including Finland. It is also the leading cause of cancer-related deaths in the female population (Boyle & Levin, 2008; Jemal et al., 2011; Ferlay et al., 2015). Every year approximately 1.5 million new cases of BC are diagnosed worldwide resulting in approximately 450 000 deaths per year. Out of these cases, only 6.6% are diagnosed in premenopausal women with a median age at diagnosis of 40 years. In premenopausal women, BC seems to be more aggressive than in the post-menopausal period (Laudisio et al., 2018). According to the Finnish Cancer registry (FCR), 5161 new BCs were diagnosed in Finland in 2015, only 30 of which were in men (FCR, 2016). In 2017, the corresponding figures were 4960 and 28 (FCR 2019).

BC accounts for approximately 25% of all cancers among women worldwide, but only 14% of cancer-related deaths (Jemal et al., 2011). BC is uncommon in women under 40 years of age (Martinez-Ramos et al., 2012), and according to FCR, only 3% and 14% of BC patients are diagnosed under 40 and 50 years old, respectively (FCR, 2016).

The annual age-standardized incidence rates of BC per 100,000 women are shown in Figure 1.

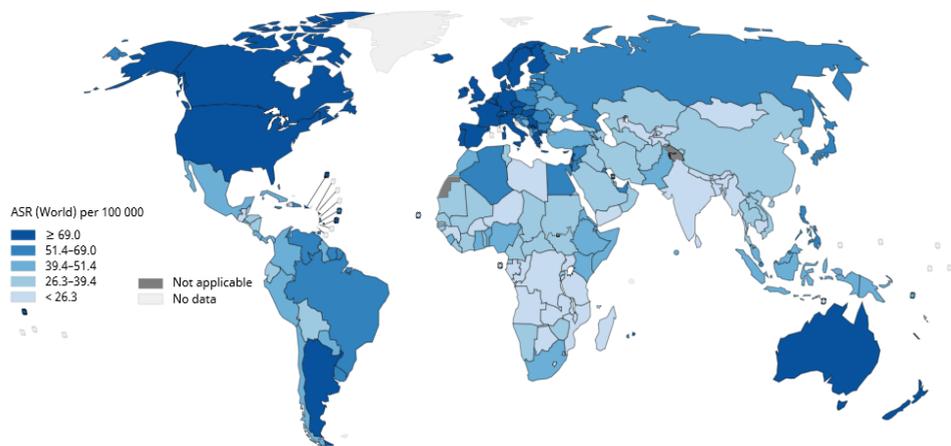


Figure 1. The annual age-standardized breast cancer incidence rates per 100,000 women in 2018 (IARC/GLOBOCAN, 2018).

Cancer diseases, along with cardiovascular diseases, are a leading cause of death in Finland and the Western world. The lifetime risk of developing BC for a woman in Finland is about 11%, and the lifetime risk of death from BC is only 2% (FCR, 2016). In Finland, about 60% of BCs are localized (not metastasized) at the time of diagnosis (FCR, 2016).

Figure 2. illustrates the time trends of BC incidence in Finland in 1955–2015. The initiation of the nationwide organized breast cancer screening in 1987 can be seen as a rise in the incidence curve.

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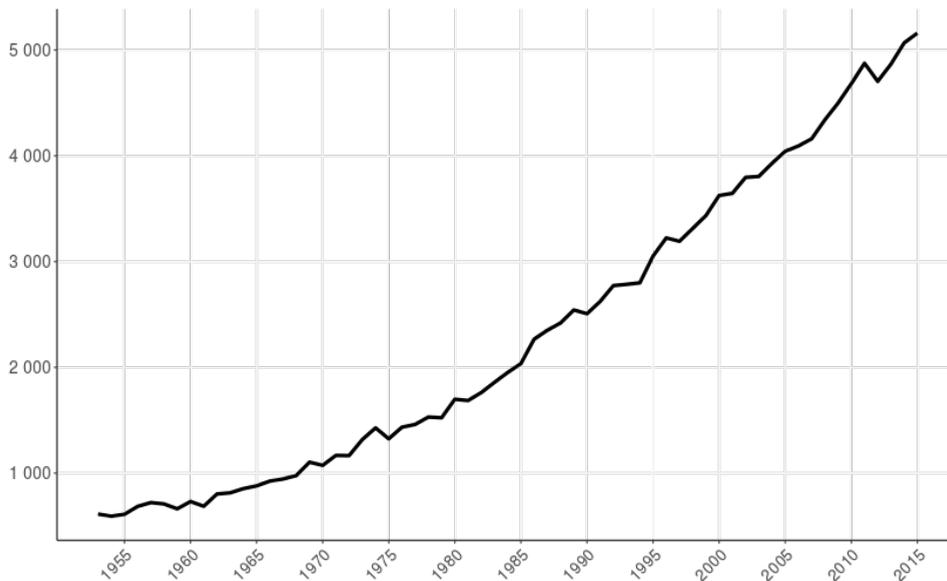


Figure 2. Time trends of breast cancer incidence in Finland in 1955–2015, total numbers (Finnish Cancer Registry Statistics, 2016).

The analysis of the WHO database of BC mortality trends in 30 European countries showed an almost 20% reduction in age-adjusted BC mortality in Europe from 1989 to 2006 (Autier et al., 2010). According to the FCR (2016), the relative survival figures in Finland at 1 and 5 years after diagnosis in 2007–2009 were 97.9 % and 90.5%, respectively. In 2016, over 99% of all breast cancer-associated deaths were reported in women over the age of 40, and 71% over the age of 60 (Siegel et al., 2017).

The main contributors to this observed BC mortality reduction are considered to be treatment, screening, and system efficiency (Autier et al., 2010). Some major life events regarding close personal relationships may play a role in BC-specific mortality, with certain negative life events increasing BC mortality and positive events decreasing it (Heikkinen et al., 2017). According to a French prospective cohort study, lifestyle characteristics and history of relapses vigorously predict the risk of death in BC cases (Lafourcade et al., 2018).

The exact causes of BC are not known (Hashemi et al., 2014), but there are several well known risk factors for breast cancer: sex, aging, estrogen, family history, gene mutations and unhealthy lifestyle (Hashemi et al., 2014; Majeed et al., 2014). According to Howell et al. (2014) lifestyle measures, exercise, and moderate

alcohol intake could reduce BC risk by about 30%. Aging is one of the most important risk factors of BC.

In Finland the standard types of treatments for patients with BC are surgery, radiation therapy, chemotherapy, hormonal therapy and targeted therapy. The treatment of BC has been based on a uniform set of national recommendations since 1992; the currently followed recommendations are published by the Finnish Breast Cancer Group (FBCG) and these recommendations are updated regularly (Finnish Breast Cancer Group (FBCG), 2019). Patients' treatment is individually tailored according to the type of cancer and the patients' general health and condition and other possible diseases and medications (FBCG, 2019). Patients are expected to actively participate in planning and making decisions about surgery and adjuvant treatments and therapies (FBCG, 2019; Brom et al., 2014).

2.3 Breast cancer survivors

Each year an increasing number of Finns are diagnosed with cancer. The Finnish Cancer Registry predicts the number of cancer cases to grow to 43,000 by 2030. The increase is mainly due to the aging of the population and the lengthening of life expectancy. According to the predictions, in Finland, approximately 140,000 cancer patients, whose illness has lasted less than five years, are alive in 2030 (FCR, 2016). Approximately 91% patients with BC are alive five years after diagnosis. (FCR 2019). Many cancer patients are aged when they get a cancer diagnosis, and with the development of cancer treatment, long-term survival rates after a diagnosis of BC are progressively rising (Finnish Cancer Registry, 2016; Bodai & Tusso, 2015).

A BC survivor is any person who has received a diagnosis of BC. The term "survivor" entered cancer discourse in 1985 when Dr. Fitzhugh Mullan described his cancer experience in a "Seasons of Survival" -article (Mullan, 1985; Kolata, 2004). Survivorship begins at diagnosis and continues through the balance of the patient's life. Survivorship starts with the acute, medical, stage in which diagnosis and treatment efforts dominate (Mullan 1985; Kaiser 2008).

Survivors of BC represent a unique and extremely complex group of patients. Women with BC achieve their maximum psychological and physical recovery one year after the establishment of the BC diagnosis (Arndt et al., 2006). Although a large proportion of women with BC survive, the survival or recovery phase is not harmless and includes many disadvantages. Previous studies have found that cancer survivors experience high levels of physical, emotional, and social problems relative to the general population regardless of ethnicity, race, and culture (Knobf, 2007; Lebel et al., 2008; Heppner et al., 2009; Silva et al., 2012). These problems can persist for some time after treatment has ended, sometimes for decades. Pain, fear,

and anxiety are the major issues confronting the patients as well as their families during this period (Mullan, 1985).

Van Leeuwen et al. (2018) identified 116 generic survivorship issues, which include, among other things, body image, cognitive functioning, health behaviors, negative and positive outlook, health distress, mental health, fatigue, sleep problems, physical functioning, pain, several physical symptoms, social functioning, and sexual problems. Patients rated most of the acute symptoms of cancer and its treatment as no longer relevant approximately one year after completion of treatment.

Cancer therapies have additional effects that may interfere with treatments directed toward the newly diagnosed BC. One year after the diagnosis may be a special period of arousal for patients (Hewitt et al., 2006), and risk for symptom burden induced by cancer and its treatment remains high during this period. The severity of symptoms is critical, as higher levels of symptom burden disproportionately impair function and QoL (Serlin et al., 1995; Given et al., 2008). Long-term survivors of adult-onset cancer are at increased risk especially for psychological distress (Hoffman et al., 2009). However, studies have found that cancer survivors' QoL typically returns to a level comparable to that of individuals with no history of cancer soon after treatment completion (Ahles et al., 2005).

Already studies conducted in the 1990s have shown that anxiety, depression, fears of disease recurrence, and concerns regarding passing the disease on to their offspring surface as persistent emotional and psychologic issues of cancer survivors. Cancer survivors have reported symptoms consistent with posttraumatic stress disorder, such as avoidance of cancer-related thoughts, re-experiencing negative experiences, and increased arousal. Sexual problems and issues of fertility are most prevalent among survivors of BC, and some survivors have reported cognitive dysfunction after treatment (Sneeuw, 1992; Polinsky, 1994).

Previous studies have also found cancer survivors to face a host of economic, financial, insurance, and employment issues after the completion of their treatment and the transition from a patient to a survivor. Reports of job discrimination and concerns about changing jobs due to fear of the loss of health insurance and medical care have been documented (Bordieri et al., 1990; Hoffman, 1997; Stewart, 2001; Short et al., 2005).

Baker et al. (2005) found that after surviving for one year past diagnosis, more than two thirds of cancer patients were concerned with their illness returning, and nearly 60% were fearful about their future. At one year post-diagnosis, in addition to the psychologic problems, approximately two-thirds of the survivors reported that they experienced physical problems including fatigue and loss of strength, and nearly half had sleep difficulties, and two-fifths of the respondents had problems with sexual dysfunction. Younger cancer patients (ages 18–54 years) reported more problems than older patients.

The extended survival stage refers to the time of remission or termination of major treatments, with the fear of recurrence as the major psychological issue. Also, there is a continuous period of physical limitations resulting from cancer and its treatment. During extended survival, diminished contact with healthcare providers (or oncology services) leaves patients and their families to deal with the problems alone. The greatest challenge the survivors face is that while still dealing with a high number of residual symptoms and limitations, and often adjustments from altered roles, they are expected to re-enter the active world and resume being “normal”. (Mullan, 1985; Simonelli et al., 2008)

The long-term stage of survival refers to the period when the probability of recurrence is minimal, and cancer can be considered permanently arrested. The long-term survivors’ general problems are employment and insurance-related problems, secondary cancer risk and reproductive health issues (Mullan 1985; Simonelli et al., 2008).

Research demonstrates that how BC patients cope has an impact on emotional distress (Heppner et al., 2009), depression (Silva et al., 2012), and long-term psychological adjustment (Stanton et al., 2000; Manne et al., 2004; Burgess et al., 2005; Knobf, 2007; Lebel et al., 2008; Donovan-Kicken & Caughlin, 2011; Astin et al., 2013). Furthermore, studies have shown how particular coping strategies, such as emotional expression (Stanton et al., 2000; Helgeson et al., 2004), positive re-appraisal (Manne et al., 2004; Silva et al., 2012) and SS (Spiegel et al., 1989; Dunkel-Schetter et al., 1992; Silva et al., 2012) are beneficial and necessary for overall well-being and comprehensive survival of BC patients.

2.4 Quality of life, sense of coherence and life satisfaction

2.4.1 Quality of life

The discussion around quality of life started in the 1960s (Haas, 1999; Axford, 2008), when it included objectively measurable issues of human life, such as the socio-economic situation, the level of education, housing and the living environment. The objective view of QoL by social scientists was then expanded by psychologists with subjective perspectives. Campbell and Rogers reported in 1972 that QoL is over 50% happiness and satisfaction (Haas, 1999). In social sciences, QoL is seen as part of well-being (Ferriss, 2004).

In a very broad sense, QoL, health and well-being are concepts close to each other. Well-being as a concept is an extensive and complex term of man's perceptions, and feelings of life, such as Dolan et al. (2008) have concluded. In the Nordic countries, welfare research was largely linked to social policy in the 1960s and 1970s. According to the welfare state project, the aim was to protect the essential

everyday resources of the population and to create equal opportunities and premises for the citizens (Allardt, 1976).

According to the WHO (1948), 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 about their goals.” In comparison to WHO’s definitions, the Wang-Baker Faces scale defines QoL as “life quality at a precise moment in time.” The close concepts of QoL are the standard of living, living conditions and well-being, but QoL is a more abstract construct. The QoL is close to mental well-being, it reflects the extent to which a person enjoys their lives and whether they are interpersonal, have time for hobbies and creativity, can do what they want, and use their talents meaningfully.

As well as wellbeing, QoL can be distinguished from both subjective and objective perspectives (Rapley, 2003; Bowling, 2005; Cummins, 2005). QoL is the general well-being of individuals and societies, outlining negative and positive features of life. It detects life satisfaction, including physical health, family, education, employment, wealth, safety, security, freedom, religious beliefs, finance and the environment. QoL has a wide range of contexts, including the fields of international development, healthcare, politics and employment (Patrick & Ericsson, 1993). It is the “feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated”. (Meeberg, 1993).

The QoL is not only health or another individual factor, but its determination is influenced by the cultural and social environment in which a person lives. Exterior material conditions and satisfaction with life in one's life reflect the QoL of a person. M. Powell Lawton (1991) utilized the WHO model of QoL (1948) in his model and developed it further by dividing the QoL into four dimensions, which are the same as the dimensions of functional capacity:

- 1) **The physical dimension of QoL** is related to the person's self-survival and ability to function. Capacity constraints do not determine the QoL, but how the remaining resources are used.
- 2) **The psychological dimension of QoL** is associated with mental capacity. Good mental ability to function is the management of emotions and activity. The balance of emotions and the feeling of life management are related to each other and determine the overall QoL.
- 3) **The social dimension of QoL** is explained through social ability, but it is related to physical and mental capacity. Social competence is inclusiveness and communality, and requires interaction with other people.
- 4) **The environmental dimension of QoL** is the importance of the environment. It is emphasized as the obstacles and conditions set by it determine to a great extent the individual's performance of daily activities.

Welfare is a part of the QoL. According to Finnish sociologist Erik Allardt (1976), welfare is more than material good: it is both the impersonal resource level of the individual and the QoL of human relationships. Thus, the QoL is divided into common relationships (loving), self-realization forms (being) and the standard of living (having). Allardt (1976) refers to Maslow's hierarchy of needs in which basic human needs are organized hierarchically and according to strengths. In order, priority is given to satisfying the basic physiological needs.

In conclusion, QoL can theoretically encompass a wide-ranging array of domains and components. These involve functional ability including role functioning, the degree and quality of social interaction, psychological well-being, somatic ambiances, happiness, life situations, life satisfaction and need for satisfaction (Brown et al., 2004). It also reflects significant life experiences, and the current phase of the life and the factors defining QoL – in this respect it further includes sex, socioeconomic status, age and generation. QoL is, therefore, a complex collection of interacting objective and subjective dimensions: comprises the individual's perspective, is assessed "through the eye of the experience" (Ziller et al., 1974). The concept and the indicator of QoL are presented in Figure 3.

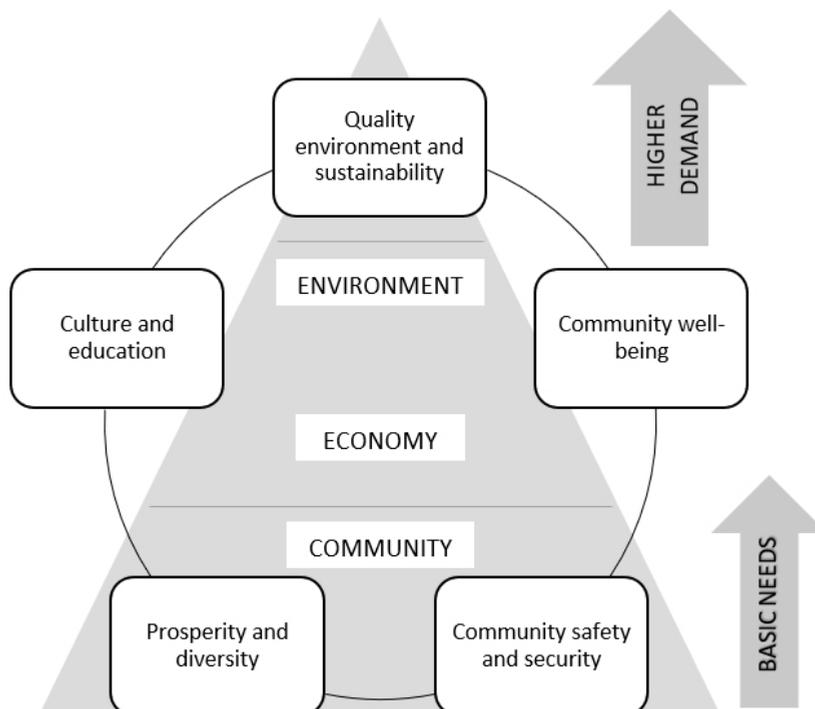


Figure 3. The concept and the indicators of the quality of life (adapted Doi, Kii and Nakanishi, 2008).

2.4.2 Health-related quality of life

Patrick & Erickson (1993) define health-related quality (HRQoL) of life as the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy. Wilson & Cleary (1995) describe a conceptual model of HRQoL that provides a theoretical approach to conceptualizing HRQoL as a multidimensional construct and integrates biological and psychological aspects of health outcomes. This model consists of five different levels: 1. physiological factors, 2. symptom status, 3. functional health, 4. general health perceptions and 5. overall QoL. It has been widely applied to different populations, including patients with cancer, arthritis, Parkinson's disease and HIV. It is indicated that symptom status, functional health, general health perceptions, and overall QoL are dimensions of HRQoL (Wilson & Cleary, 1995).

According to Bowling & Brazier (1995), the concept of HRQoL is based on a model of illness-health and dependency. They focused on the impact of illness-health status and disease on, and measurement of, physical and mental disability and impaired role functioning. The emphasis has been on dysfunctional status, how a person can achieve socially allocated roles free of health-related limitations.

In conclusion, HRQoL as a multidimensional construct has a lot of research that focuses on different dimensions. Wilson & Clary model is a model that integrates the biological and psychological aspects of health outcomes. Other researchers emphasize the absence of health and the ability of someone to perform activities of daily living (Bowling et al. 2003). The point is that all these views may seem different, but they tend to focus on the dimensions of HRQoL and provide us with useful findings (Patrick & Erickson, 1993; Bowling & Brazier, 1995; Wilson & Cleary, 1995).

2.4.3 Coping and sense of coherence

The sense of coherence (SOC) is a health-promoting resource within the salutogenic theory that reflects an individual's coping ability. According to Antonovsky (1987), salutogenesis focuses on "the origins of health," (from Latin salut = health, Greek genesis = origin), i.e., how people move toward health rather than what makes them fall ill. That is, in the health continuum, what makes people move toward "ease" rather than "disease." Embedded within this theory is the concept of sense of coherence (SOC) which is a stable disposition which generates coping resources and the sense of health preservation (Antonovsky, 1987). The concept in the salutogenic model explains the relationship between strain in life and health. The global SOC construct comprises of three elements:

1. Comprehensibility (a belief that events occur in an orderly, predictable manner, and a feeling that one can make sense of their life events as well as predict what may happen in the future),
2. Manageability (a belief that events are within one's control and that one has the resources (e.g., skills, support) needed to handle them), and
3. Meaningfulness (a belief that things in one's life are satisfying, interesting and worthy of caring).

SOC reflects a person's overall orientation to life. It guides the person in finding and applying resources to maintain health and manage stress. An individual who has a strong SOC will more likely perceive an arduous life event or situation in a positive manner and, consequently, select the suitable coping strategy to maintain well-being (Lindblad et al., 2018).

Research has indicated a strong relationship between SOC and various aspects of health (Suominen et al., 2001; Suominen et al., 2005) – people who develop a strong SOC also choose healthy behaviors and lifestyles (Kuuppelomäki & Utriainen, 2003; Savolainen et al., 2005; Von Ah et al., 2005; Bergh et al., 2006). Studies have also found that individuals with a strong SOC cope better if diagnosed with a chronic disease such as diabetes, cardiovascular disease, and cancer (Cohen & Kanter, 2004; Leksell et al., 2005; Eriksson & Lindström, 2007; Kouvonen et al., 2008). Surtees et al. (2007) found that a strong SOC was associated with a reduced rate of stroke incidence after adjustment for age, sex, social class, education, pre-existing myocardial infarction, diabetes, hypertension treatment, family history of stroke, cigarette smoking, systolic blood pressure, obesity, aggression, and depression.

A strong SOC is associated with higher chances of being adherent to positive life behaviours and overall life orientation, while a weak SOC was found to be indicative of higher morbidity and mortality (Super et al., 2014; Lindblad et al., 2018). Further, Leksell et al. (2005) reported that persons with a combination of a strong SOC and the ability to manage daily life perceived their health better, and experienced less burden of disease than individuals with weak SOC.

Interestingly, the relationship between SOC and cancer focuses mainly on psychological outcomes: strong SOC is associated with better QoL (Eriksson & Lindström, 2007; Bruscia et al., 2008), better adjustment to BC (Kulik & Kronfeld, 2005), higher levels of hope and psychological well-being, reduced distress (Gibson & Parker, 2002), and positive emotional perceptions, better perceived general health, and better mental well-being among cancer patients (Bowman, 1996). In a study examining the effect of SOC on cancer incidence, Poppius et al. (2006) interviewed Finnish male participants at 8 and 12 years after the first measurement of SOC. As a

result, participants with a weak SOC had a higher incidence of cancer compared to those who had a strong SOC.

Lindblad et al. (2018) found that over a median follow-up time of 10 years, BC patients with a stronger SOC had over 60 % lower risk of disease progression, 80 % lower risk of breast cancer mortality, and 80 % lower risk of all-cause mortality than the patients with a lower SOC. Women with a higher SOC and more positive illness appraisal show higher levels of QoL, and it can be stated that SOC and positive appraisal may have a protective role to reduce negative effects in the perceived QoL (Nesbitt & Heidrich, 2000). Rohani et al. (2015) findings suggest that a higher level of SOC may function as a protective mediator for HRQoL dimensions in the process of psychological adaptation to the cancer trajectory. Their results show that the ratings of some of the dimensions of HRQoL by BC patients are longitudinally mediated by the way how they view their life as comprehensible, manageable and meaningful, and thereby cope with life strain.

2.4.4 Life satisfaction

In different disciplines, life satisfaction (LS) has been studied from different perspectives. The ancient philosophers were pondering the issues of happiness. Aristotele considered happiness to be the ultimate goal of human life. Happiness meant "being happy", "living well" or "succeeding in life" (Saarinen, 1999; de Botton, 2003; Sihvola, 2006).

Social sciences were interested in exploring LS through the QoL (Campbell et al., 1976), and psychological research has focused on exploring the relationship between self-esteem and identity or personality traits and satisfaction (McGregor & Little, 1998). Instead, economics has investigated the relationship between economic considerations and perceived satisfaction (Easterlin, 2001). According to Blanchflower & Oswald (2004), the general rise in wealth does not make Western people more satisfied with their lives.

Health sciences have examined LS from the perspective of the physical and mental health (Davis et al., 2004). Population surveys in Finland have shown that dissatisfaction with life has increased the risk of overall mortality, suicides, accidental deaths and premature incapacity, and increased risk of alcohol use (Koivumaa-Honkanen et al., 2000, 2002, 2004, 2012). Thus, LS is a key part of subjective wellbeing and QoL (Fisher, 1992; Bowling, 1991; Vaillant 2003). Subjective well-being is an important element of good mental health. It is characterized by both LS and happiness (Vaillant, 2003). LS can be defined as an individual experience of one's own life. Everyone is an expert in the composition of his own well-being (Sharpe & Smith, 2005).

LS is the way in which people show their emotions and how they feel about their directions and options for the future. It is a measure of overall well-being assessed in terms of mood, satisfaction with relationships, achieved goals, self-concepts, and self-perceived ability to cope with one's daily life (Diener, 1984).

LS is believed to have antecedents in the work domain, family domain, and personality traits. Ruut Veenhoven (1994) has summarized LS “is the degree to which a person positively evaluates the overall quality of his/her life as a whole.” LS is one of the pointers of ‘apparent’ QoL along with other indicators of mental and physical health. It is referred as an assessment of the overall conditions of existence as derived from a comparison of one's aspiration to one's actual achievement (George & Bearon 1980). LS is assessed as the degree of the positive emotions experienced (Chang & Sanna, 2001).

According to Beutell (2006) it is believed that LS is related to better physical, and mental health, longevity, and other outcomes that are considered positive in nature. In addition, improved levels of LS might give rise to better health in the future (Chow, 2009).

2.5 Quality of life of breast cancer survivors

According to data from WHO, in the early 2000s, the increase in chronic diseases reached a high level, and it is estimated that, by 2020, 80% of the global burden of disease in developing countries will be due to chronic health problems. The majority of chronic diseases worsen the overall health of patients by limiting their capacity to live well, limit the functional status, productivity, and are a major contributor to health care costs (Megari, 2013).

In the medical and nursing fields, QoL has become a key concept for evaluating the quality and outcome of health care, especially in chronic diseases. The diagnosis of a chronic disease of an individual generally means the beginning of a decline in the QoL (Testa & Simonson, 1996; Megari, 2013). QoL differs among individuals, i.e. persons with the same health status may report a different QoL because they may have different values and expectations (Lavdaniti & Tsitsis, 2015).

BC patients' QoL has been addressed in several studies (Ferrell et al., 1996; Ferrell et al., 1997; Ferrell et al., 1998; Rustøen et al., 1999; Dow & Lafferty, 2000; King et al., 2000; Amichetti & Caffo, 2001; Arora et al., 2001; Sammarco, 2001; Sammarco, 2003; Sammarco & Konecny, 2008; Engel et al., 2003a; Schreier & Williams, 2004; Uzun et al., 2004; Avis et al., 2005; Rabin et al., 2008; Haas et al., 2010; Larsson et al., 2010). The diagnosis of BC and its treatments impact the patients' QoL at the psychological (Sammarco, 2001; Landmark & Wahl, 2002), physical (Lehto-Järnstedt, 2000; Arora et al., 2001; Landmark & Wahl, 2002) and social level (Landmark & Wahl, 2002; Engel et al., 2004). Reduced QoL impacts on

relationships, family and social function, and psychological and social needs, and can result in problems with coping (Miller & Triano, 2008).

Side effects of cancer treatments may leave BC patients with physical problems, psychological and sexual dysfunctions, body image disturbances and hormonal changes, all of which have a significant impact on the QoL (Klastersky & Lossignol, 2011; Rahou et al., 2016). Patients with BC suffer from anxiety (Schreier & Williams, 2004; Burgess et al., 2005; Stephens et al., 2008), depressive symptoms (Burgess et al., 2005; Rabin et al., 2008), uncertainty (Ferrell et al., 1996; Sammarco, 2001; Sammarco, 2003; Rabin et al., 2008; Sammarco, 2009; Farren, 2010), psychological fatigue and distress (Schover et al. 1995; Khan et al., 2010), in addition to mood and sleep disturbances (Shimozuma et al., 1999; Janz et al. 2007; Karakoyun-Celik et al., 2010).

Although BC and its treatments impact the overall functioning, it has been suggested that the QoL of women with BC is moderately high (Rustøen et al., 1999; Sammarco, 2001; Uzun et al., 2004). Individuals who survive female cancer have been reported to have either similar (Neyt & Albrecht, 2006; Awadalla et al., 2007) or higher (Awadalla et al., 2007) QoL than the general population especially in the family domain (Rustøen et al., 1999; Sammarco, 2001). The lowest QoL has been reported in the health and functioning (Rustøen et al., 1999) and in the psychological and spiritual domains (Sammarco, 2001; Xiaokun, 2002). On the other hand, some studies have shown that BC patients have a poorer QoL than patients with other cancer diagnoses (Rustøen et al. 1999, Engel et al. 2003), especially in the domains of psychological, sexual (Rustøen et al. 1999) and emotional functioning (Engel et al. 2003).

Changes in QoL are important indicators of the impact of the disease (Rustøen et al., 2000). Patients with BC commonly can adapt to their situation (Dow & Lafferty, 2000; Bloom et al., 2004; Engel et al., 2004). Significant longer-term enhancements have been reported in surgical symptoms and side effects, future outlook (Bloom et al., 2004; Montazeri et al. 2008), patient-physician communication, and invasiveness of treatment in women under age 50 (Bloom et al., 2004). Furthermore, several studies have found evidence of sexual dysfunction and menopausal symptoms (Rogers & Kristjanson, 2004).

According to studies performed several months after diagnosis, some patients treated for BC have difficulty adapting to being a cancer survivor (Andrykowski et al., 2000; Rustøen et al., 2000; Engel et al., 2004; Burgess et al. 2005; Loerzel et al., 2008; Montazeri et al. 2008; Gorman et al., 2010). Longitudinal studies have shown no improvement over time in sexual (Arora et al., 2001; Engel et al., 2004) or social functioning (Arora et al., 2001), body image (Engel et al., 2004; Montazeri et al. 2008), and lifestyle factors (Engel et al., 2004). Jarrett et al. (2013) stated in their literature review that a significant number of cancer survivors experience poor QoL.

Additionally, Burgess et al. (2005) reported that women with early stage of BC still suffered from depression and anxiety one year after diagnosis, some of them even for more than five years. Women at age 50 or under are at risk of impaired QoL up to several years after the BC diagnosis (Avis et al., 2005). Engel et al. (2004) have identified that most changes in QoL occur between the first and second year after surgical treatment.

Age was found to be a significant predictor of QoL in several sub-scales. (Kirschbaum et al., 2017) Wedding et al. (2008) reported that elderly patients with cancer tend to perceive their QoL as more important than gains in survival when compared with younger patients. Increasing age was negatively associated with sexual functioning, systemic therapy side effects and physical functioning, and positively associated with future perspective. Women treated for early stage were not disadvantaged by allocation to the open access supportive care model in terms of QoL experienced (Kirschbaum et al., 2017).

Systematic reviews have confirmed the association between physical activity and the improved QoL. Effective interventions include physical activity, cognitive behavioral therapy (CBT) and mindfulness-based stress reduction training. Personalized lifestyle interventions showed promise, as well as social and emotional support (Duncan et al., 2017). Low physical activity, little SS, and cigarette smoking were associated with the presence of distress. Lifestyle and support programs that develop and promote positive coping strategies have been shown to reduce distress symptoms in BC survivors (Syrowatka et al., 2017). Unmanaged distress has been shown to negatively impact all-cause and cancer-related morbidity and mortality, as well as QoL (Peuckmann et al., 2007). Moreover, female gender and aging were related to the decrease in the QoL and that the individuals who cohabited with a partner had a better QoL (Azevedo et al., 2013).

2.6 Social support during breast cancer trajectory

The concept of SS has been used in nursing and social sciences research since the initiation of it as an academic discipline in the 1970s (Norbeck, 1988). Perceived SS 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). SS is described as an exchange of resources between at least two individuals and assumed to be mutual (House, 1981; Cohen & Syme, 1985). The key elements in supportive transactions are affected, aid and affirmation (Kahn, 1979).

SS is given and received within a social network. The social network has been defined as the vehicle through which SS is provided (Kahn, 1979; Kahn & Antonucci, 1980). SS has been reported to protect individuals from the harmful effects of adverse life events (Cobb, 1976; Norbeck, 1988; Lehto-Järnstedt et al.,

2002; Lehto et al., 2005). It may also serve as a buffer against the negative consequences of illness (Cobb, 1976; Helgeson & Cohen, 1996). SS is helpful in dealing with anger and depression (Manuel et al., 2007), and it has a positive association with subjective experiences of good health (Norbeck, 1988), while lack of support has been suggested to predict mortality (House et al., 1988; Kroenke et al., 2006).

Perceived SS is positively associated with QoL in women with BC (Lehto-Järnstedt, 2000; Rustøen et al., 1999; Sammarco, 2001; Sammarco, 2003; Arving et al., 2006; Arora et al., 2007; Sammarco & Konecny, 2008; Sammarco, 2009; Kwan et al., 2010). SS has positive effects on BC patients' overall functioning and their QoL (Rehse & Pukrop, 2003; Badger et al., 2004; Arving et al., 2006). Also, it has found to be vital for coping with the disease and adjusting to the stress of it (Krishnasamy, 1996). According to Arora et al. (2007), emotional support two months and emotional and informational support five months after the BC diagnosis were positively associated with women's QoL outcomes. Further, SS is associated with a better quality of family life (Sammarco, 2001). It is an important resource of cancer patients' efforts to stay healthy (House et al., 1988; Rice & Halbert, 2017).

Sammarco (2003) found that SS correlates positively with health and functioning, psychological, spiritual and family subscales of QoL among women over 50 years. Patients receiving adjuvant treatments after BC surgery treatment are more likely to have caring SS compared to women not receiving adjuvant treatments (Bloom et al., 2001; Lehto-Järnstedt et al., 2002; Arora et al., 2007). Lehto-Järnstedt et al. (2002) reported that BC patients not receiving adjuvant treatment received less in the psychosocial sense than patients who underwent also adjuvant treatments. Bloom et al. (2001) described women undergoing chemotherapy or having positive lymph nodes to receive more emotional support, while women who reported having undergone mastectomy received more instrumental support such as financial or informational support. SS is also directly reflected in stress and health outcomes (Norbeck, 1988). However, SS from family, friends and health care providers decrease 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 be reduced (Arora et al., 2007).

Perceived SS can also include dimensions of social integration (House et al., 1988) and is related to various areas of health behavior (Rice & Halbert, 2017). Among BC survivors, inadequate SS is associated with a substantial increase in cancer-related mortality (Kroenke et al., 2006). Social isolation is a similar health risk factor as the more traditional ones like high blood pressure, obesity, and smoking (House et al., 1988). Adequate SS also improves sexual functioning (Yan et al., 2016; Salonen et al., 2014), and affects positively BC patients' physical, psychological and social functioning and their QoL (Arving et al., 2006; Winzelberg

et al., 2003; Goodwin et al., 2001; Tehrani et al., 2011; Kolokotroni et al., 2014). SS is identified to be associated with improved survival of BC patients (Kolokotroni et al., 2014).

Generally perceived emotional support and a vast, diverse social network, have been shown to strongly protect against depression among BC patients (Santini et al., 2015). In addition, social isolation is associated with reduced long-term survival following a diagnosis of various types of cancer, including BC. Most of the disease management takes place in the family environment, whether by the patient alone or with other family members (Ell, 1996; Matsuda et al., 2014).

BC patients' major sources of emotional support are usually their family: spouses, children, friends and siblings (Courstens et al., 1996; Sandgren et al., 2004, Arora et al., 2007). Also, the health care professionals (Davis et al., 2004; Arora et al., 2007) and volunteers (Davis et al., 2004) are mentioned as the sources of emotional support. Family environment as a source of SS plays a central role in BC patients' coping strategies and plays a significant role in increasing cancer patients' abilities to cope with the disease (Yoo et al., 2014). Spouses or partners are often identified as the major source of SS throughout the cancer trajectory. (Carlson et al., 2001; Hodginson et al., 2007; Kinsinger et al., 2011; Lim et al., 2014), and they are a significant source of symptom relief. Spousal support could lead to better management of the disease (Regan et al., 2012).

Song et al. (2016) found that SS received from a spouse or a partner was associated with better psychological well-being and long-term QoL. Marital status is strongly associated with improved health and longevity. Being married has also been shown to be positively associated with survival in patients with different types of cancer (Song et al., 2016; Hinyard et al., 2016). Marital status of being divorced and/or single and poor SS increase the risk of depression (Habtewold et al., 2016). Those without family SS receive this support more often from friends and health or social welfare professionals (Luttik et al., 2005). Van den Brink et al. (2017) concluded that if depressed persons experience difficulties in their social relationships, this impedes their recovery. It has also been found that when life strain of depressed persons increases the support available from the family decreases (Mitchell & Moos, 1984).

Various forms of SS are received from various sources. Lehto-Järnstedt (2000) found that patients reported the greatest amount of support from spouses, while physicians and nurses were nearly as essential providers of support. In the intervention study of Arora et al. (2007), women with BC received helpful informational support from health care providers three and five months after BC surgery, emotional support from family and friends, and decision-making support from health care providers. Maeda et al. (2008) concluded that family and friends might 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 seem to change markedly over time, whereas Courtens et al. (1996) concluded that the size of network and the amount of SS decreased to some extent.

According to Davis et al. (2004), women received the most frequent support from medical staff. However, Suominen et al. (1995) reported that BC patients usually received support from other people than health care professionals. It has been notified that size of the social network, number of support persons and quality and amount of SS are related to mortality (House et al., 1988; Kroenke et al., 2006). Socially isolated women are more affected by BC, and their role function, vitality and physical function is lower (Michael et al., 2002), and they have a significantly higher risk of mortality after the diagnosis of BC than socially integrated women (House et al., 1988, Kroenke et al. 2006).

Berterö & Wilmoth (2007) concluded BC affects women's individual, relational, and collective self, and therefore the relationship between mood disturbance and SS. Moreover, women with BC may avoid social contacts and thus be more liable to social isolation (Engel et al., 2004).

2.7 Perceived sexuality of breast cancer survivors

There is no general definition of sexuality. It is described as affection, partnership, sexual pleasure, personal charm, attraction, gender identity, and proximity. Sexuality is therefore much more than sex, intercourse and the continuation of the family. Sexuality is living as a man or woman in all life situations and age. At its best, sexuality and its expression give strength and enjoyment to life. Regular and satisfying sex life has a positive impact on both physical and mental health (Bucovik et al., 2005; Beckjord et al., 2007; Hautamäki-Lamminen et al., 2008).

Sexuality is one of the quality factors of living, and it has four dimensions:

1. Social and ethical dimensions are the values, ideals, religious attitudes and moral opinions of the patient.
2. Physical sexuality is part of the biological dimension.
3. Cultural dimension includes gender roles, beliefs and information on sexuality, the culture of marriage and socializing, and sexual acts affecting the community in the community.
4. Psychological dimensions include emotions and experiences, learned attitudes, the perception of oneself as a sexual being, learned sexual behavior and images of sexuality.

(Hautamäki-Lamminen et al., 2008)

Sexual health includes the ability to enjoy sexuality, the right to express sexuality and to implement it safely. Sexual health is tied to interpersonal relationships and is not conceptually identical to sexual and reproductive health that is linked to fertility, human physiology and anatomy, and use of services and illnesses (Edwards & Coleman, 2004).

Cancer and cancer treatments may have long-lasting adverse effects on sexuality. Other effects may be genital mutilation or loss of function, physical weakness, powerlessness, social isolation, decreased body image and self-esteem, and the loss of time and money required for treatment (Fobair & Spiegel, 2009; Gilbert et al., 2010; Kedde et al., 2013). Sexual survival is influenced by, for example, the severity of cancer and the estimated prognosis of the disease, cancer treatments, the time for the treatments, woman's age, the general perceived importance of sex life, the amount of information and false knowledge, and human ability to deal with emotions both alone and with others (Gilbert et al., 2010).

BC survivors experience poorer overall sexuality than the general female population (Boquiren et al., 2015). Sexuality and femininity can be critical issues for women recovering from BC. A decrease in BC mortality and improved screening and treatment has led to an increase of BC survivors, which in turn creates new challenges for health care (Bloom et al., 2004; Fobair et al., 2006). BC and its treatment is often linked to several physical and psychosocial changes. Also adverse to treatment-related effects can continue to influence sexuality for years (Speer et al., 2005; Montazeri et al., 2008; Fobair & Spiegel, 2009; Panjari et al., 2011).

Sexual dysfunction is highly prevalent among women diagnosed with BC (Kedde et al., 2013). BC patients experience sexual problems soon after treatment, and this continues in follow-up (Fobair & Spiegel, 2009; Hummel et al., 2017; Kedde et al., 2013). Several physical changes in a woman's sexuality following BC have been identified: lack of sexual desire and interest, body satisfaction, the frequency of intercourses, sexual satisfaction, arousal, orgasm, and pain associated with intercourse (Clayton, 2006). Women's adverse experiences also include fear of fertility loss, and feeling of being sexually unattractive (Gilbert et al., 2010). They also experience significantly poorer body image than do healthy women (Male et al., 2016), which have a negative impact on physical and psychological functioning of the BC survivors (Begovic-Juhant, 2012; Przedziecki et al., 2013) and also on the comfort of their relationships (Fobair et al., 2006). The quality of a relationship predicts sexuality after the BC diagnosis and treatment (Gilbert et al., 2010).

Sexual effects have been illustrated to be associated with cancer-related distress, mental depression, symptom severity, overall QoL (Meyerowitz, 1999; Reese, 2010; Zimmermann et al., 2014), and marital status and education (de Morain et al., 2016). Dorval et al. (1998) reported already 20 years ago BC survivors not differing from controls in general QoL domains except concerning sexuality, which was worse in

BC patients. However, despite new treatment modalities, impairment of sexuality still seems to be a significant problem related to BC. Depressive symptoms, age, and partnership satisfaction are critical factors for sexuality in follow up. Low partnership satisfaction undermines sexuality among BC survivors (Gilbert et al., 2010; Greendale, 2001; Oberguggenberger et al., 2017). Levels of sexual problems seem to exceed those of women with no previous or current BC in the same age range (Ganz et al., 2004).

2.8 Breast cancer rehabilitation

2.8.1 Needs and goals of rehabilitation

BC survivors can experience multiple physical and functional disorders, pain and various psychological disadvantages as a result of their disease and its treatments (Stout et al., 2012; Amatya et al. 2017; Stubblefield, 2017). Common disorders include e.g. shoulder dysfunction, postmastectomy syndrome, chemotherapy-induced peripheral neuropathy, axillary cording and lymphedema (Stubblefield, 2017). The increasing incidence of cancer combined with extended survival in the Western world increases the need for rehabilitation (Hellbom et al., 2011).

BC rehabilitation is a process that helps BC survivors to obtain and maintain the highest possible physical, social, psychological, and vocational functioning within the limits created by cancer and its treatments. Rehabilitation focuses on restoring or improving QoL and thus on independence and participation in life (Silver et al., 2007; Amatya et al.; Stubblefield, 2017; Wirtz & Baumann, 2018). According to Gerber et al. (2005), cancer rehabilitation model presents opportunities for intervention during the disease continuum phases:

- Phase I:** staging/pre-treatment (patient education, functional preservation of a range of movement, mobility aids),
- Phase II:** primary treatment (effects of treatment, preserve function, symptom management),
- Phase III:** after treatment-rehabilitation (develop, implement daily routines to restore mobility and self-care, maintenance exercise programs, symptom management),
- Phase IV:** recurrence (education, adaptive equipment, exercise, symptom management),
- Phase V:** end of life (maintain independence, equipment, energy conservation).

“Rehabilitation, as defined by multiple organizations, covers a multidimensional view on chronic disease and its effect on the cancer patient's life. The rehabilitation systems in Denmark, Finland, Sweden, Germany and the Netherlands differ depending on the differing social security and health-care systems, but rehabilitation provided is largely based on a similar, multidimensional and multidisciplinary understanding of cancer rehabilitation” (Hellbom et al., 2011).

Rehabilitative activities in Finland started in the 1970s by the cancer societies. During the following decades, cancer rehabilitation became synonymous with five to seven-day multidisciplinary activity courses arranged by regional cancer societies or national patient organizations in rehabilitation centers across the country. In 2000, the Cancer Society of Finland extended this view into rehabilitative services to include all activities aiming to improve the overall well-being and QoL of cancer patients and their families. The Finnish model for cancer rehabilitation is based on seven principles:

1. The services cover the period from symptoms and diagnosis to post-treatment follow-up.
2. Different needs are met with specific services.
3. All patients do not need all the services or the same services.
4. Cancer patients have individual needs.
5. Effective rehabilitation is multidisciplinary teamwork.
6. Rehabilitation is an essential part of cancer treatment and recovery.
7. Need for rehabilitation should be considered for all cancer patients and survivors.

(Hellbom et al., 2011)

More recently, more targeted out-patient rehabilitation and psycho-social courses have been developed. These are financed by the National Social Insurance Institute or through funding from the National Slot Machine Association and the Cancer Society of Finland. In 2005 the National Social Insurance Institute published the first national guidelines for cancer rehabilitation in Finland.

At present the cancer both in-house and out-patient rehabilitation courses are organised by the National Social Insurance Institute and the Cancer Society of Finland. The Cancer Society of Finland, and its regional and patient organisations have organized cancer rehabilitation at their own facilities, and after competitive bidding in private professional rehabilitation centers (Hellbom et al., 2011).

2.8.2 Effects of breast cancer rehabilitation

Rehabilitation has been shown to have a significant impact on BC patients' and survivors' QoL, general health and survival. Specific, multidisciplinary rehabilitation interventions, such as physical therapy and psychosocial interventions, have shown to be beneficial in restoring and improving BC survivors' functional ability, participation and QoL (Duncan et al., 2017; Amatyia et al., 2018) and impaired physical, psychosocial and occupational outcomes of BC patients (D'Egidio et al., 2017). Different clinical trials have shown beneficial effects of physical training offered during and after BC treatment (Battaglini et al., 2014; Lahart et al., 2015; Leclert et al. 2017), and resistance training also seems to be safe for BC survivors (Dos Santos et al., 2018).

Leclert et al. (2017) identified the benefits of a well detailed multidisciplinary rehabilitation program, including physical re-conditioning and psycho-educational sessions, with essential improvements in functional capacity, body composition and the majority of functions and symptoms among women after BC treatments. Exercise-based interventions are effective in short term (less than 3–8 months) and in long term (Duncan et al., 2016). Regular exercise also has psychological benefits, including positive changes in levels of mood disorders (Khan et al., 2016), and cancer-related fatigue (Meneses-Echávez et al., 2015).

Rehabilitation is also needed among patients with advanced (metastatic or locally advanced), incurable disease and in palliative care. Dittus et al. (2017) reviewed that fatigue and QoL were identified to improve during and after rehabilitation, and Haun et al. (2017) stated that early palliative care interventions and rehabilitation might be beneficial on QoL and symptom intensity among cancer patients with advanced disease. Implementation of exercise interventions is safe and feasible also in advanced cancer clinical practice (Heywood et al. 2017).

WHO endorses a BC control program integrating prevention, early detection, diagnosis, treatment, and rehabilitation. Rehabilitation services should begin early to improve the recovery process and reduce disability (WHO, 2008). Despite the goals and efficacy of BC rehabilitation, there is noticeable underuse of these services. The reasons for this could be various but results from a lack of knowledge about BC rehabilitation on the part of patients, survivors and clinicians, limited access to rehabilitation services, and suboptimal adherence (Stubblefield, 2017).

3 Aims

The main purpose of the thesis was to evaluate the BC survivors' overall QoL, comprising of LS and SOC and the psychosocial and social factors affecting it.

The study had the following objectives:

1. To explore how BC survivors self-report their LS and SOC. (Study I)
2. To compare survivors' LS and SOC scores with the scores of groups of women suffering from mental depression and arterial hypertension and with corresponding scores of the healthy control group. (Study I)
3. To analyze the psychological and social factors which associate with survivors' overall QoL. (Studies II and III)
4. To analyze the importance of and satisfaction with sex life among BC survivors as compared to the same three groups mentioned above. (Study III)
5. To evaluate what is known about rehabilitation of patients with advanced, incurable cancer. (Study IV)

4 Materials and Methods

4.1 Health and Social Support -cohort study

HeSSup-study examines the factors predicting health, well-being, care, and need for rehabilitation. It is a follow-up study of 26,000 working-age Finnish people that began in 1998. The study is based on the fact, that in the Western countries the most common premature mortality and illness are caused by coronary heart and cerebrovascular disease, cancer, alcoholism, diabetes, depression and dementia. All these diseases are chronic, and biological, social and environmental factors, as well as lifestyles, play an important role in their etiology. Prevention, treatment and rehabilitation are ways of avoiding or alleviating illnesses and their disadvantages. Population surveys and follow-up data can be used to analyze a wide range of the factors related to behavioral health and rehabilitation needs, as well as the incidence of illness or disability.

One aim of the HeSSup-study is to find out how the health and risk factors of the survey and the register data for 1998-2011 predict the perceived and actual need for rehabilitation and its targeting. Another aim is also to complement previous research related to childhood and the family of the influence of psychosocial and socio-economic rehabilitation, health, and retirement, as well as to explore the role of regional factors.

The HeSSup follow-up study consists of randomly selected Finnish working age groups (20–24, 30–34, 40–44 and 50–54 years) selected in 1998 with a total of about 24,000 people authorized to collect tracking data. They participated in a survey in 1998, 2003 and 2011. The response rate of the initial survey was 40 %. The questionnaires in 1998, 2003 and 2011 were the same, except that in the 2011 survey, there were issues related to rehabilitation. The most important variables were:

1. Social support (childhood events and relationship with parents, the structure of a social network, exchange of social support, perceived social support, the relationship of a life partner).
2. Potential factors (training, job control, positive life events).
3. Personality factors (sense of coherence, expressed hostility, cynical anger, optimism, pessimism).

4. Load factors (at work, in family life, stress experienced, negative life events).
5. Health behavior (smoking, alcohol consumption, physical activity, eating habits, leisure activity, use of health services).
6. Health, workability and continuation of the work (depression, ability to work, use of medicines, symptoms of diseases, disorders detected by a doctor, perceived health, persistence in work).
7. Rehabilitation (the following topics were added to the 2011 questionnaire: the perceived need for rehabilitation, the actual rehabilitation and timing, as well as various forms of rehabilitation and date).

The health of the respondents is examined through National Health Insurance, morbidity, retirement, accident and death registry data maintained by the Social Insurance Institution, Federation of Accident Insurance Institutions and Statistics Finland. Depending on the research question, the study used logistic regression analyses, lifetime models, and structural equations that can take into account more than one measurement of at the same time.

4.2 Methodological approach

The data of the studies I-III is drawn from the HeSSup-study. The total number of all participants is 25 895, and female participants 15 267. The HeSSup survey data (female participants) of the year 2003 was used and, with the consent of the respondents, linked with national registry data of the FCR, the Finnish Drug Purchase (FDP) and Imbursement Registry of the Social Insurance Institution, and mortality statistics from Statistics Finland from the years 1998–2012.

The registry data contained information on diagnosis, time of diagnosis, histology, medical treatments, and cause of death of which diagnosis, time of diagnosis and cause of death were available for this study.

A comparative study was used as the research method in studies I–III (Figure 4.) A statistical, comparative study summarizes the similarities and differences between the selected cases. It allows simultaneous processing of numerous cases and comparable features or factors. Also, advanced statistical tools, e.g. multivariate methods, can be used in the analysis, and the significance of the results can be estimated using statistical criteria (Ragin, 1987).

The research method for the fourth study was a systematic literature review. Systematic review designed to provide a complete, exhaustive summary of current evidence which is relevant to the research question. A systematic review of the randomized controlled trials is the key to the practice of evidence-based medicine.

4.3 Study design and participants

4.3.1 Study design and participants in studies I–III

The respondents who had given permission for registry linkage, had a registered (verification by the FCR) diagnosis of BC in 1998-2002, and were alive at least one year after diagnosis, were included in the analyses. They had completed the 2003 survey and thus, formed the study group. No woman had to be excluded due to death. Also, those women with FCR based registered BC, who had also reported depression, were included. The youngest age group was omitted from the data. (Studies I and II) The patients with BC were followed-up for mortality until the end of 2012 when nine respondents with BC had died due to it. These respondents were removed from the study I. The registry data contained information on diagnosis, time of diagnosis, histology and cause of death were available for this study.

In addition to the previous criteria, in the third study, data related to perceived sexuality obtained from the 2012 survey were used in the analyses. If there was no information available, the person's survey was not taken into consideration. Individuals had been diagnosed with BC in 1998-2002, were included to the study. Women who had died between 2003 and 2005 were not removed from the data.

In study I and II, there were three groups to be compared with women with registry based BC: 1) the respondents, who reported having suffered from mental depression in the 2003 survey, had reported purchased of antidepressants and were alive in 2003-2005 (N=471); 2) the respondents, who reported having arterial hypertension in the 2003 survey, had purchased anti-hypertensive medication and were alive in 2003-2005 (N=841); and 3) all respondents of corresponding age, who had not reported any chronic disease, any cancer, depression or hypertension (N=6274) in the 2003 survey.

In study III, there were also three groups for comparison with the group with registry based BC: 1) respondents who reported having suffered from mental depression and showed registry based purchase of anti-depressive medication (N=612), 2) respondents who reported having arterial hypertension and showed registry based purchase of anti-hypertensive medication (N=873), and 3) all respondents of corresponding age who had not reported any chronic disease, any cancer, mental depression or arterial hypertension (N=9731). All participants had to have responded to the questions regarding satisfaction with and importance of sexual life. The youngest age group in each group was also accepted in the third study.

The control disease groups comprised of individuals suffering from a public health problem of high incidence and prevalence in Finland but otherwise due to the demographic background of the participants of the HeSSup study resembled the study group. Both depression and hypertension are diseases that require treatment,

usually medication, and may affect the patients' QoL as long-term, potentially threatening illnesses. The advantage of using several control groups provides a basis for valid generalization. The study design and participants are presented in Figure 4.

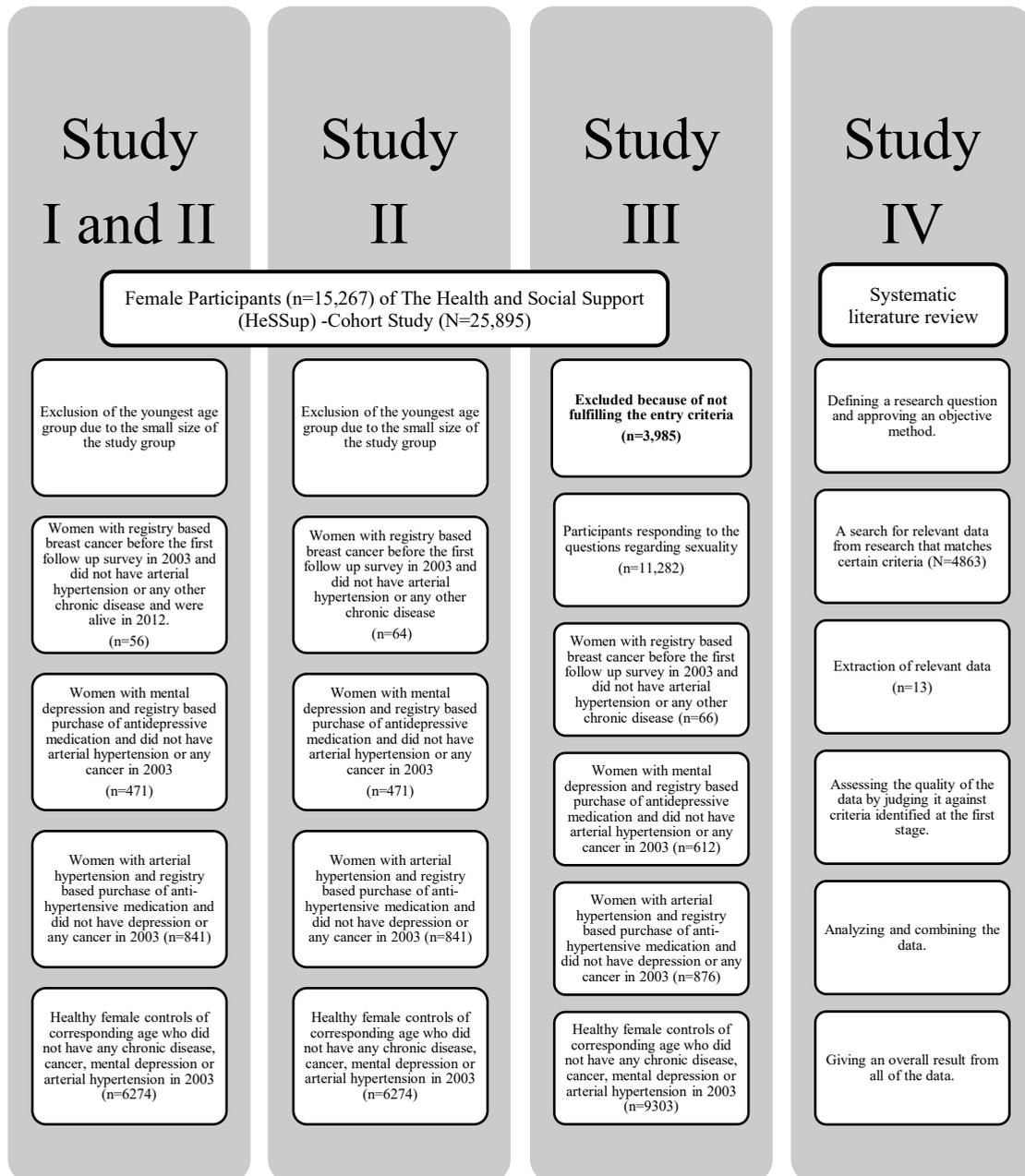


Figure 4. The study design and participants

4.3.2 Outcome variables in studies I–III

The data on the outcome variables in study I–III were derived from the 2003 HeSSup-survey. In addition, in the third study, variables measuring sexuality in the 2012 survey were used in the analyses. All instruments used in the study are established and translated earlier into Finnish. They have been used extensively in both national and international studies (Schover et al, 1995; Makar et al, 1997; Mortimer et al, 1999; Greendale et al, 2001; Thors et al, 2001; Jefferey et al. 2009; Dialla et al. 2015; Chu et al. 2016; Moonesar et al. 2016).

Life satisfaction (LS) is an essential part of QoL. LS was assessed using a four-question scale modified from a questionnaire developed for measuring the QoL in Nordic QoL studies (Allardt, 1973). The participants were asked to rate four aspects of their life satisfaction: interest in life, happiness, ease of living and loneliness (Very interesting/Happy/Easy/Not at all = 1, Very boring/Unhappy/Hard/Lonely = 5). The LS sum score (range: 4–20) was further classified into the following categories: satisfied (4–6), intermediately satisfied (7–11) and unsatisfied (12–20). (Study I)

The sum scale of LS variable was reversed for statistical processing so that a higher score corresponded to better life satisfaction and vice versa. A sum was calculated under the condition that at least three items were responded to. A missing value was replaced by the mean of the remaining three. (Study I)

SOC was assessed using Antonovsky's 13-item scale (Antonovsky, 1987) which is derived from the original 29-item Orientation to Life Questionnaire. It covers the three main sub-components of SOC: comprehensibility (5 items), manageability (4 items), and meaningfulness (4 items). All items have a seven graded (Likert-type) response scale, and a sum was calculated (range 13–91) under the condition that at least 3 comprehensibility, 2 manageability and 2 meaningfulness items were filled in. Missing values were replaced with the mean of other items in each sub-component. (Study I)

Perceived SS was measured by a Sarason's 6-item shortened version of the original Social Support Questionnaire (SSQ) (Sarason et al., 1983). Each item solicits a two-part answer: 1) the scores for a number of sources of SS and 2) satisfaction with SS that is available. The response options were: spouse/partner, some other close relative, a close friend, close co-worker, a close neighbor, another close person, and no one. For each question, one or more response options/person could be chosen. (Study II)

The balance of perceived SS, i.e., whether BC patients currently received or provided more support from or to the persons mentioned above, was determined by the adapted and modified Antonucci's (1986) SS convoy model adapted for individuals moving with the person through time and with whom the person exchanges SS (Antonucci, 1986). If the respondent reported more receipt than provision of SS, this is from here on called receipt dominance, and if she again

reported more provision than receipt of SS, this is called provision overload. Respondents were also asked to report the gender of the supporter. (Study II)

The importance of and satisfaction with sex life were assessed using a seven-point Likert scale modified from a Sexual History Form questionnaire developed for measuring sexuality and sexual health in previous international studies (Schover et al., 1982). Two items from the Sexual History Form were selected and adapted and used in this study to provide an indicator of the importance of sex life and overall satisfaction with sex life. The format of the items was a conventional questionnaire with items presented as brief descriptive statements to which respondents rate their level of importance/satisfaction on a seven-point Likert scale. The scale interval anchors were Very important/Satisfied (1) – Not important at all/Very dissatisfied (7). (Study III)

4.3.3 Statistical Analyses in studies I–III

The age group of 20–24 years was omitted from the statistical analysis since there was only one respondent with BC (Studies I–II). The limit for statistical significance was set at $p = 0.05$. Fisher's exact test was used to determine relationships between the variables. Statistical analyses were performed with the SAS® software v.9.3 for Windows (SAS Institute Inc., USA). (Studies I–III)

Overall associations between the variables were measured with the Cochran-Mantel-Haenszel test. The following descriptive statistics were calculated: frequency, mean with 95 % confidence interval, range and median. The ANOVA with a pairwise comparison with Tukey-Kramer adjustment was used to determine differences between the study groups. Pearson's correlation test was used to compare the degrees of association between LS and SOC scale. (Study I)

The distributions for perceived SS (SSQ, Sarason et al., 1983) were highly skewed (range 0–6). The balance of SS formed three groups which were receipt dominance, an equal situation and provision overload. (Study II)

A logistic regression model was used to examine the associations between the study groups and the level of education and relationship status in study III. The ANOVA with a pairwise comparison with Dunnett's adjustment was used to determine differences between study groups. (Study III)

4.3.4 Study design and participants in study IV

The research method for the fourth study was a systematic literature review. The aim was to systematically evaluate what is known about the rehabilitation of patients with advanced or chronic cancer, what kind of rehabilitation is currently available for this patient group, what are the needs for rehabilitation among these patients, and to

identify where more research is needed in the future. The main stages (Fink, 2005) of the systematic review were:

1. Defining a research question and approving an objective method.
2. A search for relevant data from research that matches certain criteria.
3. Extraction of relevant data.
4. Assessing the quality of the data by judging it against criteria identified at the first stage.
5. Analyzing and combining the data.
6. Giving an overall result from all data.

(Fink, 2005)

The data were collected from the Medline/PubMed and Cochrane databases. The main focus was on the most recent literature and on studies published in 2009–2014 (until September 22, 2014). The following search terms were used: “advanced” AND “cancer” AND “rehabilitation” ; “chronic” AND “cancer” AND “rehabilitation” ; “palliative” AND “cancer” AND “rehabilitation” ; “supportive care” AND “advanced cancer” ; “advanced” AND “breast cancer” AND “rehabilitation”.

The terms “advanced AND cancer AND rehabilitation” and “chronic AND cancer AND rehabilitation” gave most of the hits. In this review, also the evolution of the number of studies published from 1990 to 2014 was examined. There were very few previous research reports before the year 2000. The inclusion and exclusion criteria for the selection of the articles are presented in Table 1.

Table 1. Inclusion and exclusion criteria for the selection of articles included in the review.

Inclusion	Exclusion
Studies on advanced cancer or palliative care and rehabilitation	Incomplete studies
Published 2009–2014	Non-English articles
Randomized controlled trials	Non-controlled or non-randomized studies
Studies on adult (18 years and over) cancer patients	Case reports of single patients or clinical practice presentation
Abstract and full text available	Treatment protocols and models

The search results yielded titles of articles. Articles whose titles did not fit the research topic or did not respond to the study questions were excluded. Only the articles which referred to advanced/chronic/palliative cancer and rehabilitation were included.

The titles and abstracts of all included studies were checked for relevance concerning the research topic. Randomized controlled trials, controlled clinical

trials, and systematic reviews were included at first. Two authors assessed the identified titles and abstracts independently and made proposals to include or exclude these articles. A third author evaluated these two independent proposals and made the final decision of inclusion or exclusion of the articles based on the inclusion and exclusion criteria (Table 1).

Each reviewer assessed the studies for relevance and methodological quality. The studies were rated according to AMSTAR (A Measurement Tool to Assess systematic Reviews). The total points are classified into three levels: 0–3 for low quality, 4–7 for intermediate quality and 8–11 for high quality. In this review, studies with quality scores from 7 to 10 were accepted.

All authors read the selected articles and came to consensus on the final selection of pertinent articles. A total of 4863 studies were initially identified by search terms in the Medline/Pubmed and Cochrane databases.

Medline/Pubmed: In total 4796 articles were found. Of these, 597 were included based on the first inclusion criteria, after reading of the titles there were 147 potentially suitable articles left, and after removal of duplicates, 75 articles remained for abstract review. Finally, 34 articles were left for full-text reading.

Cochrane: Thirty-nine articles were found. Of these, 19 were approved after a review of the inclusion criteria. Of these, four were duplicates. After abstract review, 14 articles were left for full test reading.

In total, 48 studies were selected for full-text reading, and finally, 13 RCT studies (1169 participants) were selected for this review. Also, 17 suitable good quality reviews were identified, and all of them are included in the systematic review.

4.4 Ethical considerations

The research was based and carried out by a multidisciplinary approach to ethics and research in the health sciences. The study design, methods, instruments, ethical considerations, funding, and the researcher's affiliations are accurately documented in the text.

Since the HeSSup study was not a medical study, the concurrent joint Ethics Committee of the University of Turku and the Turku University Central Hospital considered formal approval not necessary and stated that the study followed the ethical guidelines for good scientific practice. Because the register-based data were used (studies I-III), persons belonging to the study population were not contacted. The linking of different registers with the Personal Identity Code (PIC) was done by the HeSSup study leader. The researchers had no access to the PICs, nor had the researchers access to any other information that would have jeopardized the confidentiality of the data. The individuals could not be identified in the extensive

data. Permission to use the register-based data was obtained from each of the registrars.

In the HeSSup study permissions to collect the data were obtained. The ethical considerations related to data collection were focused on the ethical principles for research, confidentiality (related to questionnaires), privacy and voluntary participation in the study, in accordance with the guidelines laid down in the Declaration of Helsinki (2013). Permissions to use the instruments in HeSSup study were obtained from the copyright holders of the instruments by the leader of the research group, and the instruments were valid and reliable in previous international studies. Throughout the whole study process, the researcher and co-authors declared that they had no competing interests (Polit & Beck, 2008).

The systematic review required no special ethics permission. However, the review was carried out in accordance with acknowledged ethical principles. The publications for the study were searched for in the main and official databases used, publications were chosen with abstract and full text, and only peer-reviewed publications were selected and included in the review. Ethical considerations were seen as important to ensure the precision and fairness of the publications used in the systematic review analysis (Dickson et al., 2013).

5 Results

5.1 Results from study I

5.1.1 Baseline characteristics

The baseline characteristics of the study subjects are presented on Tables 2 and 3. When comparing the groups, the respondents' age distribution differed to some extent: women with BC were older than the women in the other groups. Only the share of the age group 40–44 years was of similar magnitude in the various groups. Most respondents had a vocational course/school or college education (Tables 2 and 3). The age and educational distributions were consistent in each group which enables the comparisons between different groups.

Table 2. Number and % of the row sum of the women studied by age.

Age	30–34 years		40–44 years		50–54 years		All	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Breast cancer	3	5.4	20	35.7	33	58.9	56	100
Mental depression	138	29.3	187	39.7	146	31.0	471	100
Arterial hypertension	70	8.3	215	25.6	556	66.1	841	100
Healthy controls	2330	37.1	2181	34.8	1763	28.1	6274	100
Total	2541	33.3	2603	34.0	2498	32.7	7642	100

Table 3. Number and % of the row sum of the women studied by education.

Level of education	No professional education		Vocational course or school / apprentice contract		College		University or higher		All	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Breast cancer	12	18.8	13	23.2	16	28.6	15	26.8	56	100
Mental depression	67	14.2	154	32.7	175	37.2	72	15.3	468	100
Arterial hypertension	158	18.8	289	34.4	308	36.6	79	9.4	834	100
Healthy controls	764	12.2	1886	30.1	2519	40.4	1057	24.0	6226	100
Total	1001	13.2	2344	30.9	3021	39.8	1226	16.1	7582	100

5.1.2 Life Satisfaction (LS)

When all age groups were combined, there were no significant differences in LS between patients with BC, patients with hypertension or healthy participants. (Table 4) Instead, women with mental depression had significantly worse LS compared to women in other groups. All results for LS remained unchanged when adjusted for age and level of education.

When analyzed according to age group, the result was particularly apparent among the oldest respondents. The statistically significant differences in comparison with women suffering from mental depression persisted except for the youngest age group. LS among women with BC, mental depression or arterial hypertension, and among healthy female controls is presented by age group and by age groups combined in Tables 4 and 5.

Table 4. Life satisfaction sum scores of women with registry-based breast cancer, self-reported and medicated mental depression and self-reported and medicated arterial hypertension and of healthy women controls by age groups. The values in the columns additionally to age and N stand for Range, Mean with 95% confidence interval (CI), and Median.

Group	Age	N	Range	Mean (95% CI)	Median
Breast cancer	30–34	3	13.0–14.0	13.7 (12.2-15.1)	14.0
	40–44	20	7.0–19.0	15.2 (13.8-16.5)	16.5
	50–54	33	7.0–20.0	15.8 (14.8-16.9)	17.0
Mental depression	30–34	138	5.0–20.0	13.8 (13.2-14.5)	15.0
	40–44	187	4.0–20.0	13.1 (12.5-13.7)	14.0
	50–54	146	6.0–20.0	13.8 (13.2-14.4)	15.0
Arterial hypertension	30–34	70	8.0–20.0	15.5 (14.8-16.2)	17.0
	40–44	215	5.0–20.0	15.0 (14.6-15.5)	17.0
	50–54	556	4.0–20.0	15.5 (15.2-15.8)	17.0
Healthy controls	30–34	2300	4.0–20.0	15.6 (15.4-15.7)	17.0
	40–44	2181	4.0–20.0	15.5 (15.4-15.6)	17.0
	50–54	1763	4.0–20.0	15.7 (15.6-15.9)	17.0

Table 5. Life satisfaction sum scores of women with registry-based breast cancer, self-reported and medicated mental depression and self-reported and medicated arterial hypertension and of healthy women controls by age groups combined. The values in the columns additionally to N stand for Range, Mean with 95% confidence interval (CI), Median and observed statistical significance.

Age groups combined	N	Range	Mean (95% CI)	Median	p*
Breast cancer	56	7.0–20.0	15.5 (14.7–16.3)	17.0	Ref.
Mental depression	471	4.0–20.0	13.5 (13.2–13.9)	15.0	.0001
Arterial hypertension	841	4.0–20.0	15.4 (15.2–15.6)	17.0	.9971
Healthy controls	6274	4.0–20.0	15.6 (15.5–15.7)	17.0	.9917

*Tukey-Kramer test for pairwise mean differences between BC and other groups.

5.1.3 Sense of Coherence (SOC)

Women with mental depression had the lowest SOC scores in each age group (Table 6). In the younger age groups, the differences in SOC between BC survivors and healthy controls were the greatest. The younger age groups had overall lower SOC scores than the older ones. The differences were, however, not statistically significant. The sense of coherence scores of women with BC, mental depression

and arterial hypertension and of healthy female controls by age groups combined are presented in Table 7.

Overall, the healthy controls had the highest SOC scores in all other age groups except age group 50-54 years. The individuals with BC in the age group 50-54 years had higher SOC scores than individuals of the same age in any other group. The individuals with arterial hypertension had lower SOC scores than individuals in BC group when the age groups were analyzed together. These differences were not statistically significant, except for the mental depression group.

There was a positive correlation ($r^2 = 0.36$, $p < 0.001$) between SOC and LS, i.e., the higher the SOC, the better the LS.

Table 6. The sense of coherence scores of women with registry-based breast cancer, self-reported and medicated mental depression and self-reported and medicated arterial hypertension and of healthy female controls by age groups. The values in the columns additionally to age and N stand for Range, Mean with 95% confidence interval (CI), and Median.

Group	Age	N	Range	Mean (95% CI)	Median
Breast cancer	30-34	3	60.0-62.0	61.0 (58.5-63.5)	61.0
	40-44	20	29.0-82.0	62.9 (56.8-69.0)	65.0
	50-54	33	44.0-86.0	69.7 (66.1-73.3)	69.0
Mental depression	30-34	138	24.0-86.0	58.3 (56.1-60.4)	59.0
	40-44	187	19.0-91.0	58.4 (56.6-60.2)	59.0
	50-54	146	32.0-86.0	60.2 (58.2-62.1)	61.0
Arterial hypertension	30-34	70	37.0-87.0	66.6 (62.8-68.5)	68.0
	40-44	215	25.0-90.0	65.6 (64.0-67.2)	68.0
	50-54	556	25.0-90.0	66.4 (65.5-67.3)	67.0
Healthy controls	30-34	2330	25.0-91.0	66.1 (65.7-66.6)	67.0
	40-44	2181	20.0-91.0	67.0 (66.6-67.5)	68.0
	50-54	1763	28.0-90.0	68.3 (67.8-68.8)	69.0

Table 7. The sense of coherence scores of women with registry-based breast cancer, self-reported and medicated mental depression and self-reported and medicated arterial hypertension and of healthy female controls by age groups combined. The values in the columns additionally to N stand for Range, Mean with 95% confidence interval (CI), and Median.

Age groups combined	N	Range	Mean (95% CI)	Median	p*
Breast cancer	56	29.0-86.0	66.8 (63.7-69.9)	67.7	Ref.**
Mental depression	471	19.0-91.0	58.9 (57.8-60.0)	59.0	<.0001
Arterial hypertension	841	25.0-90.0	66.1 (65.4-66.9)	67.0	.9705
Healthy controls	6274	20.0-91.0	67.1 (66.8-67.3)	67.3	.9982

*Tukey-Kramer test for pairwise mean differences between BC and other groups.

5.2 Results from study II

5.2.1 Baseline characteristics

The respondents' age distribution differed to some extent between the control groups and the BC group. Women with BC were older than the women in the other groups. (Table 8.) Most of the respondents were married (62.8 %), had vocational course/school or college education (70.8 %), lived with their spouse or partner (77.5 %), had children (84.3 %), and were employed or students (80.6 %).

The group with women suffering from mental depression differed statistically significantly from the other groups in marital status. They were less often married than women in any other group, 34% of the respondents in the mental depression group lived alone, while in the other groups 24% lived alone. The difference was statistically significant (Fisher's exact test, $p < 0.001$). There were no significant differences between the other two groups and the controls. Respondents' age is presented in Table 8 and marital status in Table 9.

Table 8. Number and percentage of the women studied by age.

Age	30–34 years		40–44 years		50–54 years		All	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Breast cancer	4	6.3	23	35.9	37	57.8	64	100
Mental depression	138	29.3	187	39.7	146	31.0	471	100
Arterial hypertension	70	8.3	215	25.6	556	66.1	841	100
Healthy controls	2330	37.1	2181	34.8	1763	28.1	6274	100

Table 9. Number and percentage of the women studied by marital status.

Marital status	Unmarried		Married		Cohabitation		Divorced or separation		Widow		All	
	%	N	%	N	%	N	%	N	%	N	%	100
Mental depression	69	14.7	239	50.9	63	13.4	84	17.9	15	3.2	470	100
Arterial hypertension	54	6.5	565	67.7	79	9.5	102	12.2	35	4.2	835	100
Healthy controls	586	9.4	3937	63.0	865	13.8	735	11.8	129	2.1	6252	100
Total	713	9.4	4786	62.8	1013	13.3	930	12.2	179	2.4	7621	100

5.2.2 Sources of social support

The research group determined the three groups of persons considered the closest. These were the partner/spouse, a close relative and a close friend/neighbor. When all age groups were combined, the main providers of SS of those who did not live alone were the spouse or the partner (94.3%), a close relative (12.0%) or a close friend (5.4%). The main providers of SS for women with BC, mental depression or arterial hypertension, and for healthy female controls are presented by age groups and as combined in Table 10.

Spousal support was seen as the most important form of SS in all study groups. A spouse or a partner was seen as the most important supporter in particular in the groups with BC and arterial hypertension. The group with women suffering from mental depression differed statistically significantly from the two other groups and the healthy controls in each domain ($p < 0.001$), and those of them who had a spouse or a partner reported spouse's/partner's support less often as the main provider of support ($p = 0.032$). There were no significant differences between the other two groups and the healthy controls.

Table 10. The main sources of perceived social support for women with registry based breast cancer, self-reported and medicated mental depression, self-reported and medicated arterial hypertension and healthy controls by age groups combined, according to Finnish nationwide HeSSup cohort study.

Group	Spouse / Partner ^a		Close Relative		Close friend		Total	
	N	%	N	%	N	%	N	%
Breast cancer	40	97.6	4	8.9	1	2.2	45	0.74
Mental depression	235	91.1	60	17.1	39	11.1	352	5.8
Arterial hypertension	511	96.8	47	7.8	21	3.5	603	9.9
Healthy controls	4031	94.1	624	12.2	267	5.2	5113	83.6
Total	4817	94.3	735	12.0	328	5.4	6113	100.0

^a In the column only women with a spouse or a partner are included

5.2.3 Balance of receiving and providing social support

The greatest share of all respondents (40.8%) reported receiving and providing SS equally or reported provision overload (34.6%), and 24.6% of all respondents reported receipt dominance (Table 11). When scrutinizing the groups separately, the group with arterial hypertension reported significantly less receipt dominance and

significantly more provision overload as compared to the other groups, $p=0.003$ (Cochran-Mantel-Haenszel -test for General Association).

BC survivors and women suffering from mental depression reported slightly more SS receipt dominance than the healthy controls. However, this difference was not statistically significant.

Table 11. The balance of receiving and providing social support among the women studied.

Group	Receives support more than provides (receipt dominance)		Receives and provides support equally		Provides support more than receives (provision overload)		Total	
	N	%	N	%	N	%	N	%
Breast cancer	17	26.6	25	39.1	22	34.4	64	.84
Mental depression	125	26.9	182	39.2	157	33.8	464	6.2
Arterial hypertension	156	19.0	338	41.2	327	39.8	821	10.9
Healthy controls	1553	25.1	2527	40.9	2101	34.0	7530	82.1
Total	1851	24.6	3072	40.8	2607	34.6	7530	100

5.2.4 The effect of social support on the prognosis of breast cancer survivors

When the HeSSup data from the year 2003 was linked to registry-based data to enable follow-up for mortality until 2015, it was found that a total of 10 women in the BC group finally died from BC. When the perceived SS of these women ($n=10$) in their early recovery phase during the actual study period was compared to that of the rest ($n=54$), no statistically significant differences could be detected. The overall mortality of the BC group (20.3%) was significantly higher than in the groups of arterial hypertension (4.0%), mental depression (3.4%) and healthy controls (1.8%).

5.3 Results from study III

5.3.1 Baseline characteristics

Age distributions between groups were not identical, respondents with BC or arterial hypertension were older than respondents in other groups (Pearson's chi-squared test, $p < 0.001$). Most of respondents lived in couple relationship (74.2%) and had

vocational course/school or college education (69.6%). The group with women suffering from mental depression lived less often in a relationship than women in any other group ($p<0.001$).

5.3.2 Perceived sexuality

5.3.2.1 The importance of sex life

When all age groups were combined there were no significant differences in the mean values of perceived importance of sex life between study groups (BC: 3.76, Mental depression: 3.66, Arterial hypertension: 3.35, Healthy controls: 3.04 with Likert scale score 1–7), except between BC and healthy controls in the perceived importance of sex life. The BC group differed highly significantly from the group of healthy women (Dunnett $p<0.001$).

Only 7.7% of the respondents in the BC group considered sex life very important (Likert scale score 1), and 35.1% important (Likert scale score 2 or 3), while 12.1 % of healthy women considered it very important (Likert scale score 1) and 57.3 % important (Likert scale scores 2 or 3). Overall this difference was statistically highly significant ($p<0.001$).

Altogether 18.5% of respondents with BC did not consider sex life important (Likert scale score 6 or 7). In the group of healthy women, the corresponding result was 10.3 % and in the group with mental depression 23.6 % ($p=0.78$ when BC patients were compared to patients with mental depression; Table 12).

Table 12. The importance of sex life among women with registry based BC, self-reported and medicated mental depression or self-reported and medicated arterial hypertension, and among healthy female controls on a scale of 1 (Very important/Very satisfied) -7 (Not important at all/Very dissatisfied) age group combined, according to Finnish nationwide HeSSup cohort study.

Group	How important is sex life for you?							Total
	1	2	3	4	5	6	7	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Breast cancer	5 (7.7)	14 (21.2)	9 (13.9)	18 (27.7)	8 (12.3)	8 (12.3)	4 (6.2)	66 (0.6)
Mental depression	68 (11.2)	157 (25.7)	111 (18.2)	71 (11.6)	59 (9.8)	69 (11.3)	75 (12.3)	610 (5.6)
Arterial hypertension	100 (11.5)	220 (25.2)	207 (23.7)	144 (16.5)	79 (9.1)	68 (7.8)	55 (6.3)	873 (8.1)
Healthy controls	1121 (12.1)	3093 (33.3)	2225 (24.0)	1222 (13.2)	682 (7.4)	629 (6.9)	311 (3.4)	9283 (85.7)
Total	1294 (11.9)	3484 (32.2)	2552 (23.6)	1455 (13.4)	828 (7.6)	774 (7.1)	445 (4.1)	10832 (100.0)

Living single or education did not explain the differences between the groups. However, the effect of living single on the importance of sex life was different between the groups ($p=0.008$). Healthy women considered sex life more important than women in the other groups did. (Table 14)

5.3.2.2 Satisfaction with sex life

Perceived satisfaction with sex life among women with BC, mental depression or arterial hypertension, and among healthy female controls is presented in Table 2.

With age groups combined, there were significant differences in the mean (BC: 3.75, Mental depression: 3.67, Arterial hypertension: 3.26, Healthy controls: 3.17 with Likert scale score 1-7) between BC and healthy controls and between BC and arterial hypertension study groups in the perceived satisfaction with sex life. Women with BC were significantly less satisfied with their sex life than healthy women (Dunnett $p=0.01$) and women with arterial hypertension (Dunnett $p=0.04$), but there were no differences compared to women with mental depression (Dunnett $p=0.87$; Table 13).

For example, only 9.2 % of respondents in the BC group reported to be very satisfied (Likert scale score 1) and 33.9 % satisfied (Likert scale score 2 or 3) with their sex life, while in the healthy women group corresponding results were 15.9 % and 47.0 %. In the group of mental depression, 14.2 % of respondents were very satisfied and 36.9% satisfied with their sex life. (Table 13)

Table 13. Satisfaction with sex life among women with registry based BC, self-reported and medicated mental depression or self-reported and medicated arterial hypertension, and among healthy female controls on a scale of 1 (Very important/Very satisfied) -7 (Not important at all/Very dissatisfied) age group combined, according to Finnish nationwide HeSSup cohort study.

Group	Are you satisfied with your sex life?							Total
	1	2	3	4	5	6	7	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Breast cancer	6 (9.2)	12 (18.5)	10 (15.4)	16 (24.6)	10 (15.4)	7 (10.8)	4 (6.2)	65 (0.6)
Mental depression	86 (14.2)	128 (21.2)	95 (15.7)	94 (15.5)	6 (9.9)	74 (12.2)	68 (11.2)	605 (5.6)
Arterial hypertension	138 (15.9)	234 (26.9)	146 (16.8)	150 (17.2)	78 (9.0)	63 (7.2)	61 (7.0)	870 (8.1)
Healthy controls	1467 (15.9)	2729 (29.5)	1615 (17.5)	1331 (14.4)	878 (9.5)	731 (7.9)	493 (5.3)	9244 (85.7)
Total	1697 (15.7)	3103 (28.8)	1866 (17.3)	1591 (14.8)	1026 (9.5)	875 (8.1)	626 (5.8)	10784 (100.0)

When analyzed according to age group, the group with BC was statistically significantly more dissatisfied with their sex life than the respondents with arterial hypertension ($p=0.03$) and the healthy women ($p=0.03$, data not shown).

Living single or education did not explain the differences between the groups. According to the results, however, living alone had a different effect on satisfaction with sex life in the different groups ($p=0.02$). In the group of healthy controls, only those with a couple relationship considered sex life more satisfactory than the others. (Table 14)

Table 14. The association of relationship status on the importance of and perceived satisfaction with sex life in the different study groups and according to couple relationship status; age groups combined according to the Finnish nationwide HeSSup cohort study. Analysis of covariance (ANOVA) with pairwise comparison with Dunnett's adjustment.

	Importance of sex life						Satisfaction with sex life					
	Couple relationship			No Couple relationship			Couple relationship			No Couple relationship		
	N	Mean	95 % CI	N	Mean	95 % CI	N	Mean	95 % CI	N	Mean	95 % CI
Breast cancer	52	3.63	3.23–4.04	14	4.21	3.26–5.17	52	3.62	3.18–4.05	13	4.31	3.25–5.37
Mental depression	385	3.45	3.30–3.59	223	4.05	3.81–4.29	384	3.45	3.29–3.61	219	4.07	3.82–4.33
Arterial hypertension	670	3.20	3.09–3.31	197	3.88	3.62–4.13	671	3.14	3.02–3.26	193	3.69	3.42–3.97
Healthy controls	6909	2.96*	2.93–3.00	2346	3.27	3.19–3.34	6908	2.94**	2.90–2.98	2308	3.86	3.78–3.94
Total	8016			2780			8015			2733		

* The only significant difference between BC and other groups was found in the sub group of people living in couple relationship (BC vs. healthy controls, Dunnett-adjusted $p=0.02$).

** The only significant difference between BC and other groups was found in the subgroup of people living in couple relationship (BC vs. healthy controls, Dunnett-adjusted $p=0.005$).

5.4 Results from study IV

5.4.1 Characteristics of studies

Thirteen RCTs (1169 participants) were included in the analyses. Seven of the included RCT's were based on physical exercise intervention. Most studies included mixed diagnostic groups of patients with advanced cancer. Two studies were based on self-management rehabilitation of patients with advanced breast cancer. One study focused on the cost-effectiveness of rehabilitation and one on swallowing

rehabilitation of patients with neck and head cancer, one on cognitive-behavioral intervention, and one on psycho-education.

There were five studies from the USA and Canada, six from Europe (two including the Nordic countries), and two from Asia. The mean sample size of the intervention and control groups was 90 (range 24–231) patients. All patients were adults (>18 years). The studies were rated according to AMSTAR from 7 to 10 and had high (n= 10) or medium (n=3) methodological quality.

5.4.2 Physical exercise interventions

The physical exercise studies included patients with diverse diagnostic groups of advanced cancer: breast, prostate and hematological cancer.

Physical exercise had a valuable impact on the physical and psychological well-being, fatigue, and overall QoL. Patients experienced improved functional mobility and reduced anxiety, stress, and depression. Shortness of breath, constipation, and insomnia was alleviated. A combination of physical exercise and massage reduced pain and improved mood in patients with terminal cancer.

Physical rehabilitation increased muscle mass and muscle strength and improved overall physical function. Regular exercise reduced some of the complications associated with weakness and poor cardiopulmonary function. In addition, standardized resistive physiotherapy was feasible during radiation therapy. It is associated with preserved physical well-being in patients with advanced cancer.

Training improved cancer-related symptoms as well as the patients' physical activities of daily living. Men with advanced prostate cancer undergoing androgen deprivation therapy benefited from football training, and both resistance training and aerobic exercise training were feasible for patients with advanced gastrointestinal cancer undergoing chemotherapy.

Interventions for swallowing rehabilitation were feasible and could improve the functional outcomes of patients with advanced head and neck cancer. Further, a form of cognitive-behavioral intervention reduced the pain, fatigue, and sleep disturbances experienced by patients with different types of advanced cancers.

Overall, physical activity is effective in maintaining the QoL of patients with advanced cancer, and maintained the independent function for as long as possible. Home-based exercise improved mobility, reduced fatigue, and improved the sleep quality of patients with advanced cancer. Rehabilitation reduced the unmet needs of cancer survivors and was also cost-effective.

5.4.3 Self-management of BC patients and survivors

The self-management programs compared with usual care improved the QoL of BC survivors. These programs helped patients to manage the numerous medical, emotional, and role tasks on their own better than patients not attending these programs.

Self-management enabled people with advanced, incurable cancer to live their lives effectively. Educational information, cognitive restructuring, coping skills enhancement, and relaxation all resulted in significant improvement of overall QoL, health and functioning. The socioeconomic, psychological, and spiritual well-being of self-managing patients with advanced BC was better than of controls.

5.4.4 Rehabilitation in palliative care

Most of the rehabilitation studies in palliative and hospice care were based on physical therapy, typically massage and exercise training. Exercise programs improved cancer-related symptoms and cancer patients' physical activities of daily living. These programs enabled patients to cope better with their everyday life. Also home-based exercise programs appeared to improve mobility, reduce fatigue, and improve the sleep quality of patients with advanced cancer.

A psycho-educational intervention reduced the breathlessness, fatigue, and anxiety experienced by patients with advanced lung cancer. The input of a multidisciplinary team was beneficial concerning the psychological well-being and QoL of hospice patients and reduced the unmet need for supportive care of cancer patients significantly.

6 Discussion

6.1 Main findings

The results showed that women with BC in their recovery phase, at least one year after diagnosis, did not have impaired LS and SOC. Compared to the healthy female controls and the group of women with arterial hypertension there were no significant differences between women with BC and the other groups. (Study I)

However, women with depression reported significantly lower LS and SOC scores than the other groups. These results were particularly apparent when all the age groups were combined. The LS of women with BC in this study was relatively good. It seems that women may have a sense of relief after having survived at least a year after the diagnosis. (Study I)

Based on the results (Study I), after at least the one year initial recovery from BC, LS and SOC do not seem to be permanently affected at a group level since the women studied were rather satisfied with their lives and reported a good level of SOC. It appears that during the survival phase, after the acute crisis, LS might even improve. Women recovering from BC were in fact as satisfied with their life as the healthy controls. The SOC and LS also inter-correlated statistically significantly in accordance with the earlier findings (Gerasimčik-Pulko et al., 2009; Kenne Sarenmalm et al., 2013; Rohani et al., 2015).

Cancer, as a frightening disease at the time of diagnosis, may weaken LS, but coping with the disease improves it – serious illness and the survival becomes a part of survivors' own history. The conclusion is consistent with previous findings showing that successful coping with a serious disease leads to hope and gratitude, and growth and empowerment (Chopra & Kamal, 2012). Our results support Antonovsky's theoretical assumptions concerning SOC (Antonovsky, 1987). LS was linearly associated with SOC, i.e., the stronger the SOC, the better the LS. (Study I)

When studying social factors and social support affecting the QoL of BC, it could be noted that SS is a well-known determinant of wellbeing. The main providers of SS for all participants combined was a spouse or a partner, a close relative and friends. In all groups, particularly in the BC and arterial hypertension group, the spouse or the partner was seen as the most important supporter. This study confirms the spouse's or the partner's central role during the recovery phase of BC. The group

suffering from depression reported significantly less SS in each domain of appraisal. (Study II)

One additional interesting finding in this study was seen in the group suffering from mental depression as compared to the other groups in terms of SS from spouse/partner and the balance of SS. The mental depression group differed in an unfavorable direction from the other groups in each domain of appraisal. On the other hand, between women with BC and the other groups, except among the depressed individuals, there were no statistically significant differences in terms of closest people. (Study II)

Sexuality can be a critical issue for the QoL of women surviving from BC, which is often not paid adequate attention to. BC survivors experience poorer overall sexuality than the general female population (Boquiren et al., 2015). Based on the results of the research, there were no significant differences between women with BC, mental depression and arterial hypertension in the importance of sex life. (Study III)

BC survivors were significantly less satisfied with their sex life than respondents in the other study groups with the exception of women with mental depression. This is likely at least partially due to BC treatments and various post-treatment problems, as altered body image, fear of recurrence and death, and perceived sexual attractiveness. (Bloom et al., 2004; Fobair et al., 2006; Gilbert et al., 2010). Living in a relationship or not, does not explain the differences between the study groups. Instead of the status of relationship, the quality of it is the main factor affecting the perceived importance of and satisfaction with sex life. Low satisfaction may weaken overall sexuality among the BC survivors. (Study III)

As a result of a systematic review, also rehabilitation – especially physical exercise – is associated with a significant improvement in general well-being and QoL of cancer patients and survivors. Physical and psychosocial rehabilitation can improve symptom control, physical function, psychological well-being, and the QoL of the patient with advanced cancer. Physical rehabilitation is beneficial even in the palliative stage of cancer. It was concluded that rehabilitation is also needed among patients with advanced disease and in palliative care. Exercise has positive effects on several QoL domains. (Study IV)

6.2 Results in relation to previous studies

6.2.1 Quality of life, life satisfaction and sense of coherence of breast cancer survivors

Women with BC achieve their maximum psychological and physical recovery after one year of the diagnosis (Arndt et al., 2006). Numerous studies have found, that the

diagnosis of BC and its treatments have various adverse effects on QoL and overall well-being (Sammarco, 2003; Badger et al., 2004; Engel et al., 2004; Ganz et al., 2004; Avis et al., 2005; Burgess et al., 2005; Janz et al., 2005; Badger et al., 2007; Montazeri 2008; Montazeri et al., 2008; Karakoyun-Celik et al., 2010).

The study results showed that women with BC in their recovery phase, at least one year after diagnosis, did not seem to have impaired LS and SOC. Compared to the healthy female controls and the group of women with arterial hypertension, there were no significant differences between women with BC and the other groups. However, women with depression reported significantly lower LS and SOC scores than the other groups. These results were particularly apparent when all the age groups were combined.

The LS of women with BC was relatively good. It seems that women may have a sense of relief after having survived at least a year after the diagnosis. Ashing-Giwa et al. (1999) reported similar findings on improved health status and relatively good overall QoL in African-American and Caucasian BC groups. Also, Yost et al. (2005) and Hsu et al. (2013) have reported good LS among BC survivors.

These are interesting findings since the diagnosis of cancer evokes the feeling of stress, fear, sorrow, anger and uncertainty (Carlson & Bultz, 2003; Yusuf et al., 2013; Stark et al., 2014). The study findings may be due to the fact that the worst phase of the disease and crisis has passed, and the survivors may have received support services during their disease, which may have contributed to the process of surviving and the maintenance and improvement of LS. Further, BC treatment has evolved over the years, and at present, the survival of BC patients in Finland is excellent with 90 % 5-year- survival (Finnish Cancer Registry, 2016). This most likely has an impact on the SOC and LS of the patients.

Some previous studies have also found, that individuals who survive female cancer have been reported to have either similar (Neyt & Albrecht, 2006; Awadalla et al., 2007) or higher (Awadalla et al., 2007) QoL than the general population especially in the family domain (Rustøen et al., 1999; Sammarco, 2001). The lowest QoL has been reported in the health and functioning (Rustøen et al., 1999) and in the psychological and spiritual domains (Sammarco, 2001; Xiaokun, 2002). BC patients with a strong SOC experience fewer demanding events and better overall QoL. The associations between SOC and health status, life satisfaction and QoL are linear (Gerasimčik-Pulko et al., 2009; Kenne Sarenmalm et al., 2011), also found in this study.

6.2.1.1 Association of depression and anxiety on quality of life, life satisfaction and sense of coherence

Mols et al. (2005) concluded, that the determinants of QoL in women with BC include psychosocial factors, such as coping style, as well as sociodemographic and medical factors. SOC, self-esteem, coping strategies, SS and emotional distress are associated with QoL among patients with BC (Gerasimčik-Pulko et al. 2009; Kenne Sarenmalm et al. 2011). Untreated mental depression clearly impairs the overall QoL. Earlier studies (de Souza et al., 2014; Love et al., 2014) have shown that patients with BC are particularly susceptible to depression, because of the disease and the symptoms, which cause a threat to their lives. Severe depression occurs in almost 25 % of all patients suffering from cancer.

Maass et al. (2015) evaluated the prevalence of depression and anxiety among BC survivors. Almost 40 % of women suffer from depressive symptoms, and over 27 % of anxiety. Symptoms of depression increase in the first year after diagnosis, while anxiety remains stable. Depression understandably also affects LS negatively and most of the loss of LS associated with chronic diseases may be attributed to mental disorders. The patient's perception of the severity of her disease is related to the complexity of the disease and to several areas of life that are affected by the symptoms (Saarni, 2008).

These observations explain some of the present study findings, e.g., that depression was associated with the poorest LS and SOC, even considering the use of antidepressants. Indeed, treatment of depression does improve LS, but depression is still associated with a poor overall QoL even when the patient is on medication (IsHak et al., 2011). Moreover, the sample included also those participants with BC, who also had self-reported depression in the 2003 survey. However, one has to keep in mind that LS improves with the number of post-diagnosis years (Cimprich et al., 2002) and women with BC in this study were younger than average BC patients, and thus highly selected.

Furthermore, individuals with the poorest prognosis were possibly not alive one year after the diagnosis or due to this or other reasons may not have participated in the second data collection of the HeSSup survey at all. This implies that for many individuals now included in the study the disease was considered treatable and even completely curable which probably has provided new hope and improved their LS and strengthened their SOC.

6.2.1.2 Life satisfaction and sense of coherence in the recovery phase of the disease

Based on the study results, it seems that in the survival phase, after the acute crisis, LS might improve. Cancer, as a frightening disease at the time of diagnosis, may

weaken LS, but coping with the disease even improves it – serious illness and survival become a part of survivors' own history. The conclusion is consistent with previous findings showing that coping with a serious disease leads to hope and gratitude, growth and empowerment (Chopra & Kamal, 2012). Coping raises patient's fighting spirit against the disease and improves current LS (Chopra & Kamal, 2012). The way of coping with fears and long-term effects might be predictors for long-term LS after cancer (Chopra & Kamal, 2012; Dahl et al., 2013).

Further, the results support Antonovsky's theoretical assumptions of SOC. (Schumacher et al., 2000) LS was linearly associated with SOC, i.e., the stronger the SOC, the better the LS. Zielińska-Więczkowska et al. (2012) have found that a strong SOC and high level of education have significant effects on LS. In this study, however, the educational background had no significant impact on the results.

In summary, it can be stated, that women recovering from BC were in fact as satisfied with their lives as the healthy controls. The SOC and LS also inter-correlated statistically significantly in accordance with earlier findings. However, factors affecting LS and SOC need to be examined and described more in detail in the future for designing and organizing optimal supportive health care and rehabilitation services for BC survivors.

Assessing and monitoring the QoL of individuals suffering from a chronic disease are important in the planning of intervention strategies, given that it provides relevant information on the patient, enabling the identification of his/her priorities and funding health programs towards the implementation of effective action and, therefore, offer a better QoL to users of healthcare services.

6.2.2 Breast cancer survivors and social support

6.2.2.1 Spousal support as a determinant in health and wellbeing of breast cancer survivors'

The results obtained from this nationwide prospective cohort study describe the availability of SS from different sources in BC survivors in comparison to individuals with mental depression, arterial hypertension and healthy controls. The study also determined the main providers of SS, and the respondents' perceived balance of receiving and providing SS. (Study II)

The results showed that spousal/partner support was experienced as the most important source of SS in all groups. Also, in the BC group, as compared with the group suffering from depression, a spouse or a partner was seen as the significantly most important supporter. Hence, the study hypothesis of the dominant spousal role in the provision of SS to particularly BC survivors as compared to other groups was not validated.

Social environment is a well-recognized determinant in health and wellbeing. Among BC patients, inadequate SS is associated with a substantial increase in cancer-related mortality (Pinquart & Duberstein, 2010). In addition, social isolation is associated with reduced long-term survival following a diagnosis of various types of cancer, including BC. Most of the disease management takes place in the family environment, whether by the patient alone or with other family members (Ell, 1996; Matsuda et al., 2013).

The results of the current study are consistent with previous studies: spouses or partners are often identified as the major source of SS throughout the cancer trajectory (Carlson et al., 2001; Hodginson et al., 2007; Kinsinger et al., 2011; Lim et al., 2014). Furthermore, spouses or partners are significant sources of symptom relief, and support could lead to better management of the disease (Regan et al., 2012). Song et al. (2016) found that SS received from a spouse or a partner was associated with better psychological well-being and long-term QoL.

One additional interesting finding in this study was seen in the group of mental depression as compared to the other groups in terms of SS from a spouse/partner and the balance of SS. The depressed differed into an unfavorable direction from the other groups in each domain of appraisal. On the other hand, between the BC group and the other groups, except the depressed one, there were no statistically significant differences in terms of the closest persons. This may be due to the fact that the numbers of women with mental depression lived significantly more often alone. However, the difference between the depressed and the other groups was not solely based on the fact that they lived more often single since the results remained unchanged when including only respondents with a spouse or a partner in the analysis.

Marital status is strongly associated with improved health and longevity. Being married has also been shown to be positively associated with survival in patients with different types of malignancy (Hinyard et al., 2016). Marital status (divorced and singles) and poor SS increase the risk of depression (Habtewold et al., 2016). Those with no family request and receive SS from friends and more often, for example, professionals (Luttik et al., 2005). Van den Brink et al. (2017) concluded that if depressed persons experience difficulties in their social relationships, this impedes their recovery. It has also been found that when stress increases in depressed persons, the support available from family decreases (Mitchell & Moos, 1984).

The SS from a spouse and a partner was particularly important in persons with BC and hypertension. Kroenke et al. (2006) found that the number of close friends and relatives as reported prior to BC diagnosis was associated with improved survival following the BC diagnosis even after adjusting for BC stage at diagnosis. As predicted, in the present study, SS received from friends was seen as being clearly at a lower level than the support received from a spouse or partner in the BC group.

Based on the existing literature, support from spouses or partners can help for successful adaptation to BC and it can improve the overall well-being (Bloom, 2000; Carver et al., 2006). BC survivors seem to cope better with the disease, if they are married, live with a family, have children and are employed (Ramadas et al., 2015; Hinyard et al., 2016). BC survivors also expect and need SS mostly from family members and significant others and less from friends (Faghani et al., 2015).

6.2.2.2 Social environment as a promoter of overall survival

The experience of a life-threatening illness, such as BC, requires a person to consider a range of emotional, social and existential demands. Diagnosis of BC often challenges a woman's identity, self-esteem, body image and also social relationships. Protective factors for distress include supportive social networks, such as family and professional resources. Research shows that SS provides actual benefits to BC survivors. Irrespective of whether it is informal support from family and friends or a more formal support from a group, SS can improve survivors' QoL (Kwan et al., 2010). Further, prospective cohort studies (Reynolds et al., 2000; Kroenke et al., 2006; Phillips et al., 2007; Epplein et al., 2011) suggest that survivors with more SS show better overall coping and survival.

Greater social network and emotional support close to BC diagnosis relieve women's suffering by strengthening coping skills, providing SS, and increasing opportunities to obtain cancer-related information. The dyadic relationship is critical in determining BC survivors' distress and needs, and may prove to be a good target for supportive interventions. Social relationship-based interventions represent a major opportunity to improve the QoL and also the survival of BC patients.

Several studies over the past years have suggested that patients with BC have a variety of support needs (Brown et al., 2000; Hodgkinson et al., 2007; Schmid-Büchi et al., 2008). Supportive needs persist after surgery and hospitalization even for prolonged periods after the diagnosis (Vivar & McQueen, 2005; Hodgkinson et al., 2007). Women need information about the stage of their disease, treatments and side-effects during post-treatment and recovery phase of the cancer disease (Rutten et al., 2005). BC patients and survivors have a continuing need of support and communication to help them deal with their illness (Kerr et al., 2003), and they also need personal tailored information (Brown et al., 2000). Rutten et al. (2005) concluded that the need for SS does not decrease over time, but its content changes.

Patients with BC expect to receive more effective SS (Beaver et al., 2006) and have the opportunity to speak with health care professionals (Kerr et al., 2003). Women want to be heard and share their illness-related difficulties and to have someone who will listen to their emotions in order to feel safe and secure (Engel et al., 2003b; Kerr et al., 2003). However, some cancer patients do not want to talk

about their feelings (Kvåle, 2007) and do not need psychosocial intervention (Moyer et al., 2009).

Finally, social environment is a well-recognized determinant in health and wellbeing. SS is one of the basic forms of social interaction and an indispensable part of human life. This study lends support to the spouse's or the partner's central role as a provider of SS during the recovery phase of BC. Even though the need for SS is increased in the BC recovery phase, women diagnosed with BC did not, however, report more receipt of SS as compared to healthy controls.

6.2.3 Breast cancer survivors' perceived sexuality: the importance of and satisfaction with sex life

6.2.3.1 Sexuality as a crucial determinant of breast cancer survival

There were no significant differences between women with BC, mental depression and arterial hypertension in the importance of sex life. However, women with BC differed in this respect significantly from healthy women. On the other hand, with regard to satisfaction with sex life, the group with BC differed significantly in a negative direction from the groups comprising of women with arterial hypertension and healthy women. Hence, the study hypothesis of the dissatisfaction with sex life was shown to be true.

Sexuality and femininity have been identified among the most crucial determinants for women surviving cancer (Graugaard et al., 2018; Obenguggenberger et al., 2017; Male et al., 2016; Dow & Sheldon, 2015; Bartula & Sherman, 2013; Kedde et al., 2013). In patients with BC, the most significant effect on their physical appearance, self-image and sex life is mastectomy (Nikbakhsh et al., 2014).

The negative impact of malignant disease on sexual functioning is well recognized among adults (Graugaard et al., 2018). Especially young cancer patients experience challenges in sexuality along with a lack of self-perceived attractiveness (Miaja et al., 2017). Sexual desire, the importance of sex life and satisfaction with it are reduced as generally in a person diagnosed with a life-threatening illness (Graugaard et al., 2018; Obenguggenberger et al., 2017; Male et al., 2016).

BC patients and survivors have several sexual problems and experience lack of sexual satisfaction soon after treatment and during the follow-up (Fobair & Spiegel 2009; Hummel et al., 2017; Kedde et al., 2013). Young women with BC have concerns regarding changes in sexuality, fertility and body image (Miaja et al., 2017). They also report years after treatment sexual health impairments that differ significantly from those of women without a history of BC (Obenguggenberger et al., 2017).

6.2.3.2 Perceived importance of and satisfaction with sex life among breast cancer survivors

BC survivors considered perceived sex life reasonably important, but were significantly less satisfied with their sex life than the healthy women. This is likely partially due to BC treatments and various post-treatment problems, as altered body image, fear of recurrence and death, and perceived sexual attractiveness, which weaken perceived satisfaction with sex life. According to previous studies, sexual satisfaction is associated with individual variables such as physical and psychological health status. A higher level of well-being is associated with increased sexual satisfaction (Dundon & Rellini, 2010; Sánchez-Fuentes et al., 2014). The experience of a life-threatening illness, such as BC, also causes uncertainty and fears and often challenges a woman's self-esteem, body image and overall sexuality and relationship (Clayton, 2006; Gilbert et al., 2010; Male et al., 2016).

One of the interesting findings was that BC survivors perceived their sex life less important than healthy women. Instead, the perceived importance of sex life of women with mental depression and hypertension was at the same level as among women with BC. Women with BC were also significantly less satisfied with their sex life than the group of healthy women or women with arterial hypertension, which is in line with previous studies. This may be because both BC and mental depression in contrast to arterial hypertension are subjectively experienced, long-term, life-threatening medical conditions.

Mental depression as a disease is associated with even 70% of increased risk of problems with sexuality. Interesting is, and also important to note, that problems with sexuality increase the risk of mental depression by even 200% (Atlantis et al., 2012; Clayton et al., 2014). Additionally, regardless of treatments, mental depression has a significant impact on overall sexuality and sexual functioning (Serretti & Chiesa, 2009) and sexual problems are a common side effect of many antidepressants (Clayton et al., 2007).

Living in a relationship or not, does not explain the differences between the study groups. Here remains the possibility, that instead of the status of relationships, the quality of it is the main factor affecting the perceived importance of and the satisfaction with sex life. Low satisfaction may weaken overall sexuality among the BC survivors. Together with partnership satisfaction, age and depressive symptoms have been earlier reported to be critical factors (Obenguggenberger et al., 2017; Gilbert et al., 2010; Greendale, 2001).

Living alone had a different effect on satisfaction with sex life in different groups. It can be stated, that living in a relationship enhances sexual satisfaction in the healthy women's group. In their review, Sánchez-Fuentes et al. (2014) recognized that sexual satisfaction is associated with individual variables such as intimate relationships and sexual response and factors related to family relationships.

Accordingly, Henderson et al. (2009) have found a relationship between SS, good relationships and high sexual satisfaction. Good dyadic adjustment (Dundon & Rellini, 2010), greater intimacy and communication (MacNeil & Byers, 2009) predict sexual satisfaction.

In the earlier study (Sánchez-Fuentes et al., 2014; Rosen & Bachmann, 2008; Arrington et al., 2004; Ventegodt, 1998), sexuality and satisfaction with sex life were seen as major factors of QoL. Based on the literature review, sexual satisfaction, relationships, body image and problems are related to QoL also among young BC patients. (Miaja et al., 2017) Dorval et al. (1998) reported BC survivors differed unfavourably from controls only in the sexuality domain of the QoL.

Ben Charif et al. (2015) found that only 42.6 % of young BC survivors reported being satisfied with the information provided about sexuality four years after diagnosis. A majority of these women had desired more information on sexuality than they received. There is also evidence that professionals are not adequately addressing the sexual information and support needs of people with cancer (Ussher et al., 2013). Problems in sexual life are common and difficult to diagnose due to patients' propensity to underreport sexual problems and its potential negative effect on QoL (Clayton et al., 2007).

Protective factors for distress include supportive social networks, such as partner and professional resources, which provide real benefit for BC survivors. Healthy overall sexuality supports QoL and the relationship between the spouses (Verschuren et al., 2010).

BC survivors and their partners experience sexual problems after BC treatments. Sexual problems again cause anxiety, loss of confidence, mental depression, lack of commitment, and deteriorates the relations. This suggests that not only the BC survivors but also their partners could benefit from sexual counseling (Graugaard et al., 2018; Hummel et al., 2017). As cancer treatments advance and patients live longer, it is relevant to treat the impacts of BC with evidence-based interventions (Ghizzani et al., 2018; Gudenkauf & Ehlers, 2018).

6.2.4 Rehabilitation of cancer patients with advanced cancer

6.2.4.1 Needs for multidisciplinary rehabilitation among patients with advanced cancer

The systematic review showed that there are few studies on the impact of rehabilitation on patients with advanced cancer. The available results suggested that physical and psychosocial rehabilitation can improve symptom control, physical function, psychological wellbeing, and the QoL of this patient group. Physical rehabilitation is beneficial even in the palliative stage of cancer. The improved

oncological treatment adds years to the life of patients with advanced cancer. It has also been shown that rehabilitation can add life to those years (Gupta et al., 2010).

For many people with advanced cancer, survival means living with a chronic and complex condition. Many patients end up with long-term disabilities requiring ongoing care and support. Since these impairments are often undetected or untreated, disability may ensue (Silver et al., 2013). The symptoms and impairments may be related to cancer itself but also to the treatments, as well, and the occurrence of treatment-related impairment among cancer survivors may increase in parallel with the number of treatments (Payne et al., 2012; Cavalheri et al., 2013).

As the incidence and prevalence of cancer increases, so does the number of patients living with cancer as a chronic condition. Patients also live longer with advanced cancer (i.e. locally advanced or metastatic incurable cancer) than in previous decades. (Cheville, 2001) Thus, the need for rehabilitation among patients with advanced cancer will increase. Since advanced cancer is rarely compatible with employment and since the condition may consume considerable health care resources, a major public health concern arises. Timely rehabilitation at appropriate volumes could save health care costs (Jones et al., 2013) ensure better functional capacity, maintain the QoL, and provide an opportunity for an independent life for the patient (Silver et al., 2013).

6.2.4.2 Effects of multidisciplinary rehabilitation on patients with advanced cancer

A large multicenter study showed that although the difference in the QoL (the primary endpoint of the study) was non-significant between groups receiving early palliative intervention vs standard cancer care, early palliative care for patients with advanced cancer was associated with benefit to some patients (Zimmerman et al., 2014). These interventions also include a rehabilitative attitude and maintenance of physical and psychosocial performance.

Based on the results, exercise programs have beneficial effects on fatigue and QoL in palliative care, and the rehabilitation programs affect positively the symptoms, physical functioning, functional capacities, muscle strength, emotional wellbeing, QoL, and even mortality and morbidity of cancer patients (Eva & Wee, 2010). For patients who are unable to undertake traditional forms of exercise, neuromuscular electrical stimulation may provide an alternative method of enhancing leg muscle strength (Maddocks et al., 2013). Exercise and rehabilitation are certainly very important approaches in hospice care and for palliation, but more controlled studies are needed to better assess the role of rehabilitation in palliative patient care (Eva & Wee, 2010, Nurminen et al., 2011).

Patients in palliative care benefit from physiotherapy and different types of art therapy. Music and voice therapy may be used as a form of rehabilitation in all stages of palliative care, because these forms of therapy may alleviate physical and psychological anxiety and pain (Dileo, 2011; Archie et al., 2013). The importance of early palliative care and rehabilitation for patients with advanced cancer has been recently emphasized (Chan et al., 2011; Zimmerman et al., 2014).

Spiritual and social needs can be met with focus group meetings. These meetings may be attended not only by patients and nursing staff but also, and importantly, by family members, spouses, and volunteer workers. At these meetings the persons convene for sharing thoughts of hope: hope for good care, hope for life continuing despite the cancer disease, hope for good hospice care (Kylmä et al., 2009).

Rehabilitation in palliative care units demonstrates that effective nurturing the idea of living instead of waiting for deterioration and death carries a strong rehabilitative effect. It is essential to empower patients, and the role of health care professionals is to support patients' self-care. The basic idea of rehabilitation is not to work for but to work with the patient (Johnston et al., 2009).

The number of elderly cancer survivors will increase as the population ages. Elderly patients with cancer usually have more severe impairments and comorbidities than younger patients (Gardner et al., 2014) and thus the rehabilitation needs of the elderly are different from those of younger patients (Balducci & Fossa, 2013). Prevention and management of pain, fatigue, deconditioning, functional impairment, cognitive decline, and peripheral neuropathy appear to be the most effective measures to prolong the active life expectancy of elderly patients with advanced cancer (Gupta et al., 2010).

Research stresses the need for rehabilitation also among patients with advanced disease, but at the same time rehabilitation is not used sufficiently (Silver et al., 2013). The reasons for its sub-optimal use may be a lack of information about the benefits of rehabilitation, a lack of referrals by oncologists, and a lack of resources.

Since patients with advanced cancer experience significant physical and psychological morbidity, minimizing disability and distress is very important (Chochinov, 2001). Patients also require ongoing care and support, which need to be well-coordinated, prevention focused, and involve ongoing surveillance while minimizing and managing co-morbidities and any long-term adverse effects of treatment (Phillips & Currow, 2010). Pain, fatigue, dyspnea, and anxiety are common symptoms among patients with advanced cancer. Healthcare providers need to be aware of these problems and be sensitive to assessing, preventing, and treating these symptoms which have a profound negative impact of the QoL of these patients (Loh et al., 2013).

Rehabilitation of cancer patients is intended to support the hopes of patients and their families and to maintain and improve the patients' QoL (Okamura, 2011).

Rehabilitation improves the physical, social, and psychological endurance of patients. This will help patients to cope with the limitations caused by cancer and its treatment. Rehabilitation helps patients to become more independent and less reliant on caregivers and to adjust to actual, perceived, and potential losses caused by advanced cancer. Rehabilitation can also reduce the number of hospitalizations (Silver et al., 2013).

Psychosocial rehabilitation can also improve patients' physical condition. Patients with untreated depression or anxiety are less likely to continue health-promoting habits and take their cancer medication because of fatigue or a lack of motivation. They may also withdraw from family and other social support systems, which means that they will not ask for the emotional and financial support they need to be able to cope with their cancer. This increases, in turn, stress and feelings of despair (Massie, 2004).

Physical exercise rehabilitation provides substantial physiological and psychological benefits for cancer patients (Spence et al., 2010), and exercise reduces anxiety, stress, and depression (Albrecht & Taylor, 2012). Lung cancer patients who exercise experience positive changes in exercise capacity, symptoms and some domains of health-related QoL (Chochinov, 2001; Granger et al., 2011). Versatile and multi-disciplinary physical rehabilitation clearly supports independent living, physical fitness, and overall well-being also among patients with advanced cancer (Oldervoll et al., 2011; Litterini et al., 2013; Stene et al., 2013), and it reduces some of the complications associated with immobility (Litterini et al., 2013). Based on these results it can be stated that exercise complemented with psychological support supports the survival of cancer patients.

It is important to realize that rehabilitation activities are not linked to any specific facility or hospital. Home-based exercise programs appear to improve mobility, reduce fatigue, and improve the sleep quality of patients with advanced cancer (Cheville et al., 2013). Rehabilitation could thus have an instrumental role in the management of patients with progressive, advanced cancer. This raises the question of whether rehabilitation activities should be instituted early in the course of the disease and continue throughout the whole cancer continuum.

For patients with advanced disease, it might be possible and feasible to implement a rehabilitation program where rehabilitation is initiated systematically while the patient is hospitalized. Hospital-based rehabilitation would benefit patients with obvious physical disadvantages and side effects of cancer or its treatment (e.g., van Der Molen et al., 2013). Hospital-based rehabilitation would also support the principle of continuity of the care. As the importance of rehabilitation is emphasized, the patient will be more eager to continue different forms of rehabilitation throughout the disease.

There is also undisputable evidence that psycho-educational rehabilitation boosts physical and mental well-being, and reduces fatigue and anxiety among lung cancer patients (Chan et al., 2011). Self-management programs improve the QoL of patients with advanced breast cancer. Self-management empowers patients with chronic cancer to live their lives effectively (Loh et al., 2013).

6.2.4.3 Summary of rehabilitation of patients with advanced cancer

The most useful components of rehabilitation of patients with advanced cancer are not known. The ultimate goal, nevertheless, is to provide comprehensive and effective multi-professional rehabilitation also for this patient group. In addition to the support provided by medical and nursing staff, effective and appropriate rehabilitation might include psychological and physical support and support by peers. Provision of detailed information tailored to the needs and receptive capacity of the patient is a natural part of rehabilitation, as well.

There were no adverse effects related to or caused by rehabilitation. All studies reported positive findings. There may, however, be reporting bias, i.e., only positive studies may have been published. On this basis, we can safely talk only about the benefits of rehabilitation – rather than the effects. The physical and psycho-educational rehabilitation and self-management programs do not have apparent adverse effects. Physical rehabilitation, in particular, produces several benefits for the patients.

Rehabilitation in palliative care units demonstrates that effective nurturing the idea of living instead of waiting for deterioration and death carries a strong rehabilitative effect. It is important to empower patients, and the role of health care professionals is to support patients' self-care. The basic idea of rehabilitation is not to work for but to work with the patient (Johnston et al., 2009).

6.3 Study limitations

The present study entity has several limitations. At the baseline HeSSup study, the study participation rate was moderate, only 40 %. Nevertheless, an analysis of non-respondents has shown that the sample is representative for the Finnish population. (Korkeila et al., 2001).

The number of women with BC in the HeSSup study sample is very low, and the group of women with BC in studies I-III represents a very special group, as the majority of BC patients in the general population are over 60 years. The results can not be generalized, because the group of BC survivors is small.

One additional limitation is that there is no information regarding the BC survivors' perceived sex life or satisfaction with their sex life prior to the diagnosis

and treatment. (Study III) Another limitation is the age of the material. However, it is known that the need for psychosocial factors and support are not time-dependent.

In Finland, practically all BC patients, in addition to medical treatment, undergo various supplementary interventions, such as rehabilitation. Unfortunately, no information about the interventions on the individual level is available in this study.

The current evidence on the effects of rehabilitation is based on small studies, usually with only a limited number of patients. The results of these small studies are probably suggestive at best, and no definitive conclusions can be drawn. (Study IV)

6.4 Strengths of the study

The design of the studies I-III is unique in that it compares LS and SOC, SS, and perceived sexuality of women in the recovery phase from BC with LS and SOC, SS, and perceived sexuality of two groups of women suffering from common long-term conditions, i.e. mental depression or arterial hypertension, and with LS and SOC of healthy female controls.

The strengths of the study are the wide source data of more than 15,000 women and careful follow-up of the individuals in the HeSSup-study.

The study included a low total number of BC survivors, but despite this, due to the study design, the BC group can be considered reliable and unbiased. The other strengths of the study include the use of reliable registry data, so the study results were not based only on self-reported data. According to contemporary legislation, The Finnish Cancer Registry collects data on all cancer cases in Finland systematically, hence, all BC cases in this study were confirmed. Moreover, all medications are registered by The Finnish Drug Purchase and Imbursement Registry of the Social Insurance Institution, so the allocation of patients within groups is reliable.

The instruments used in this study are well-known and reliable:

1. The 4-item life satisfaction scale is easily administered and well accepted.
2. The 13-item SOC questionnaire, equally easy to administer, has been applied in several population studies.
3. Perceived SS was measured by a Sarason's 6-item shortened version of the original Social Support Questionnaire (SSQ) (Sarason et al., 1983).
4. The balance of perceived SS i.e. was determined by the adapted and modified Antonucci's (1986) social support convoy model of the network of individuals moving with the person through time and with whom the person exchanges SS. (Antonucci, 1986)

5. The importance of and satisfaction with sex life were assessed using a seven-point Likert scale modified from a questionnaire developed for measuring the sexuality and sexual health in previous international studies (Schover et al., 1982).
6. The questions of sexuality based on the Sexual History Form (Schover et al., 1982) which is a structured, self-report questionnaire.

The study groups were mutually exclusive and the participants were entered into one study group only, except for the women with BC in which women suffering from mental depression were not excluded, whereas depressed individuals were excluded from hypertension and control groups. Due to small numbers of women diagnosed with BC, the exclusion of those BC patients with depression may have led to biased conclusions. However, in order to explore the potential influence of having included women with mental depression matching the study criteria into the group with BC, additional statistical analyses performed by excluding these individuals (N=11) yielded unchanged key results.

As the number of young BC survivors is generally low, it places this research data in a unique position (Studies I-III). The group of BC patients in this study represents a very special group, as the majority of BC patients in the general population, are over 60 years. Young BC patients may have special needs for variety and multi-professional support, sexual counseling and rehabilitation which has to be further investigated.

A systematic literature review (Study IV) was performed in accordance with carefully defined protocol steps (Fink, 2005). The quality of the studies included in the systematic literature review was evaluated according to the AMSTAR summary score. AMSTAR proved easy to be applied to systematic reviews of randomized studies. The fact that it has been validated, gives credibility to its use as a quality assessment tool. Although summary scores may mask inherent strengths and weaknesses of systematic reviews, these scores can also prove to be helpful in informing decision making.

7 Conclusions

Due to significant improvements in recent decades in BC screening protocols, diagnostic procedures, and treatment, BC mortality has decreased worldwide. However, BC and its treatment cause considerable harm to women in various life spheres including well-being. Psychological and social problems among adult cancer survivors include the need for variety support.

Numerous studies have found, that diagnosis of BC and its treatments have various adverse effects on QoL, physical functioning and psychosocial well-being. The results of this study showed that after at least one year after diagnosis from BC, LS and SOC do not seem to be permanently affected on a group level since the women studied were rather satisfied with their lives and reported a good level of SOC. Women recovering from BC were in fact as satisfied with their life as healthy controls. The SOC and LS also inter-correlated statistically significantly in accordance with earlier findings. However, factors affecting LS and SOC need to be examined and described more in detail in the future for achieving even improved supportive health care and rehabilitation services for BC survivors.

Social environment is a well-recognized determinant in health and well-being. SS is one of the basic forms of social interaction and an indispensable part of human life. Among BC survivors, inadequate SS is associated with a substantial increase in cancer-related mortality. Social isolation is a similar health risk factor as the more traditional ones like high blood pressure, obesity, and smoking. This study lends support to the spouse's or the partner's central role as provider of SS during the recovery phase of BC. Even though the need of SS is increased in the BC recovery phase, women diagnosed with BC did not, however, report more receipt of SS as compared to healthy controls.

BC patients and survivors have several sexual problems and experience a lack of sexual satisfaction soon after treatment and during the follow-up. Based on our results, BC survivors depreciate sex life and experience dissatisfaction with their sex life. Sexuality can be a critical issue for the QoL of women surviving from BC, which is often not paid adequate attention to. Health care professionals should regularly include sexual functioning in the evaluation of BC survivors.

Rehabilitation is needed for patients with advanced disease and in palliative care. Exercise improves physical performance and has positive effects on several other domains of QoL. Effective rehabilitation also improves overall QoL. More data and RCT's are needed on the efficacy and the safety of rehabilitation of patients with advanced cancer. The current evidence, although limited, gives an indication that rehabilitation can be recommended for patients with cancer as a chronic condition and for cancer patients in palliative care.

And finally, to improve and maintain the BC survivors' QoL, it is important to develop and provide support services, not only for BC survivors but also for their families and significant others, as their role in support of BC patients is crucial.

Based on the study results, it can be concluded that:

1. Younger BC survivors' LS remains relatively unchanged after the initial recovery phase of one year after the diagnosis.
2. Younger BC survivors are rather satisfied with their lives and reported a good level of SOC. Women with BC, in its recovery phase, are in fact as satisfied with their life as healthy controls.
3. The SOC and LS inter-correlate significantly.
4. The need of SS is increasing in the BC recovery phase. The spouse or the partner has a central role as a provider of SS during the recovery phase of BC.
5. Sexuality is a critical issue for the QoL of women surviving from BC. BC survivors depreciate sex life and experience dissatisfaction with their sex life.
6. The sexual functioning of younger women with BC may be affected, underscoring the importance of involving sexual counseling after BC treatment. There is a need to discuss concerns of sexuality with a health care professional.
7. Sexuality should be regarded as major health care determinant in BC survivorship care.
8. To improve and maintain the BC survivors' QoL, it is important to develop and provide support services, not only for BC survivors but also for their families and their significant others.

“Cancer survival has raised new needs, and caretakers have to understand the latent effects of the disease and its treatments” (Ghizzani et al., 2018).

8 Implications for Practice

Identification of factors that improve the overall QoL of BC survivors is an important public health challenge. To improve and maintain the BC survivors' QoL, it is important to develop and provide support services, not only for BC survivors but also for their families and significant others, as their role in support of BC patients is crucial.

Sexuality should be regarded as major health care determinant in BC survivorship care, as supported also by other authors. The sexual functioning of women is affected, underscoring the importance of involving sexual counseling after BC treatment. While BC treatment is being planned, all women should be informed about the possible side effects of treatment on sexuality, fertility, and body image. There is a need to discuss concerns of sexuality with a health care professional.

For patients living with advanced cancer, the rehabilitation goals are usually different from those of cured survivors. The main aim is to help the patient to live a good life irrespective of disabilities. The goal of rehabilitation may help a person to regain control over many aspects of his life and to remain as independent and productive as possible.

The goal of rehabilitation for the patients and survivors with advanced cancer is to minimize the adverse consequences of treatment and to support the psychosocial adaptation of the patient. Most interventions are intended for patients after their initial diagnosis and treatment. However, when long-term survival is uncertain or impossible, the right concept would be to focus on good living short-term. The role of relatives, friends, and caregivers is central.

The various forms of support and multi-professional and multiform rehabilitation must consequently be individualized and flexible. It is also important to evaluate the goals of patient education and rehabilitation frequently and to reset the targets accordingly. The challenge for the future is to design an effective and timely rehabilitation based on the individual BC patient's and survivor's needs. Assessment of the needs and appropriate tools to perform these assessments are needed.

Acknowledgements

This work is a part of the Health and Social Support (HeSSup) study. It was carried out at the Department of Medicine at the Turku Univeristy Hospital and the University of Turku during 1998-2012. I thank Professor Markku Koskenvuo and Professor Jussi Vahtera, the head of the Department of Public Health Sciences, for providing me the opportunity for the PhD and resident studies during these years.

I owe my sincere gratitude to my first supervisor, Professor Sakari Suominen, who guided me through this project. You introduced me the fascinating world of public health and the nobleness of scientific writing. I also thank my second supervisor docent Liisa Pylkkänen. You let me grow as a junior researcher, had faith in me and on my ideas. I greatly respect your vision in the field of oncology research. My warmest gratitude is also owed to my third supervisor PhD Raija Nurminen, whose professional help, support, and guidance have led me to where I am today. I am very grateful to my supervisors for professional, kind and patient support. I could not have done this without you.

I am also sincerely grateful for statistical help from Lauri Sillanmäki. He undoubtedly helped me make this thesis better one. Thank you, Jesse Fomin for the assistant literary work. Kati Noro and Aleksi Rajamäki, thank you for the proficient review of the language. It has absolutely been my pleasure to have the chance to work with you.

I am grateful for all my co-authors for their valuable contribution to the publications in this thesis. I express my gratitude to the follow up team of the thesis. Thank you, Docent Pirkko Routasalo, Docent Outi Hirvonen and Professor Päivi Rautava, who is thanked also for her contribution to the Study I-II. I warmly thank the reviewers, Professor Sirpa Wrede and Professor Inger Schou Bredal for their valuable time spent for the skillful revision and constructive criticism which greatly improved the quality of this thesis.

I thank all my colleagues and co-workers at Turku University of Applied Sciences and Southwest Cancer Association. I give a cheerful appreciation to all my dear friends for being friends, even though the busy years would have kept us apart, and for the enjoyable moments together. Cheers!

I am truly fortunate for having a family like I do. I thank my dear father in law, Professor Juhani Ruutinen revision of the thesis and for the wisdom and encouragement during the process. I thank my family – their encouragement, flexibility, love and support are never-ending. I thank my parents for the never-failing support, trust and love.

Finally, words are not enough to express my deep love and gratitude to my husband and best friend, Mikko. You never gave up on me and always support me with your great sense of humor and wisdom. Viljami, Elias and Anna, you beloved ones remind me every single day what really counts in this life. You four are the light of my days and the serenity of my nights. You four are my everything.

This thesis was financially supported by the Psychosocial Research grant from the Finnish Cancer Society in 2015, Turku University in 2018, and a research grant from Southwest Cancer Association in 2018.

Turku, March 2020

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