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*Digital Comprehensive Summaries of Uppsala Dissertations
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Distress, Emotional reactivity and Fatigue following Breast Cancer

*A Theoretical Approach and a Randomised
Intervention Study*

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ACTA
UNIVERSITATIS
UPSALIENSIS
UPPSALA
2014

ISSN 1651-6206
ISBN 978-91-554-8982-3
urn:nbn:se:uu:diva-229042

Dissertation presented at Uppsala University to be publicly examined in Universitetshuset, Sal IX, Biskopsgatan 3, Uppsala, Wednesday, 10 September 2014 at 09:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish. Faculty examiner: Docent Karin Ahlberg (Institutionen för vårdvetenskap och hälsa, Sahlgrenska akademien vid Göteborgs universitet).

Abstract

Rissanen, R. 2014. Distress, Emotional reactivity and Fatigue following Breast Cancer. A Theoretical Approach and a Randomised Intervention Study. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 1012. 67 pp. Uppsala: Acta Universitatis Upsaliensis. ISBN 978-91-554-8982-3.

Aim: Overall aims were to evaluate a stress management intervention with a stepped care approach among women with breast cancer and to explore distress, emotional reactivity and fatigue, both using a theoretical approach and self-reported assessment.

Methods: A total of 821 women were approached, 372 women rejected participation, 23 women failed to return the questionnaire and one died, hence, 425 patients (52%) accepted participation. *Study I* evaluated the cognitive processing model with the aid of an untreated patient group, including 189 women according to the main study protocol. Sixty-six of these women were ineligible for the intervention, as they did not report clinical levels of distress. The remaining 123 women were eligible but they declined participation. *Study II* explored the validation of the ELSS and emotional reactivity among women with breast cancer. The population comprised of all 425 women (breast cancer sample) and 176 women randomly selected from the PAR register (random women sample). *Studies III and IV* evaluated the intervention and included all 425 women.

Main findings: *Study I:* avoidance does not mediate the relationship between intrusion and later psychological distress in an early stage breast cancer population. *Study II:* the ELSS has acceptable validity and reliability. The factor structure of the ELSS was similar in both samples and correlated well with the STAQ (gold standard). Younger age was the only variable associated with emotional reactivity at the start of curative treatment. *Studies III and IV:* a stepped care approach did not reduce the number of women who require a more extensive treatment at three-months post-diagnosis. Both intervention groups (group/individual) reduced their levels of distress, but there were no significant differences between them. Only about half of the women who were randomised in the second step of the intervention accepted participation.

Conclusions: The present thesis provides information regarding distress, emotional reactivity and fatigue among women with breast cancer. A majority of women with early stage breast cancer seem to process the trauma of a cancer diagnosis in a satisfactory way but may experience some emotional reactivity, and younger women may experience more emotional distress. The results also highlight the need for validated measures and carefully planned psychosocial interventions.

Keywords: Breast cancer, randomised intervention study, Group vs. individual therapy, Oncological rehabilitation, cognitive processing, validation

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ISSN 1651-6206

ISBN 978-91-554-8982-3

urn:nbn:se:uu:diva-229042 (<http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-229042>)

*Äidilleni joka on aina uskonut
minuun.*

*To my mother who always believed
in me.*

Front cover: illustration by Maria Guz Ravegård/Art On, 2014.

Back cover: photography by Patrik Lilja, 2014.

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Nordin, K., Rissanen, R., Ahlgren, J., Burell, G., Fjällskog, M. et al. Design of the study: How can health care help female breast cancer patients reduce their stress symptoms? A randomized intervention study with stepped-care. *BMC cancer*, 2012 12(1):167.
- II Rissanen, R., Arving, C., Ahlgren, J., Cernvall, M. and Nordin, K. Cognitive processing in women with breast cancer: a theoretical approach. *Psycooncology*, 2014. **23**(2): p. 222-228.
- III Rissanen, R., Arving, C., Ahlgren, J. and Nordin, K. Emotional reactivity among female breast cancer patients at the start of postoperative adjuvant treatment: An observational study and validation of the ELSS scale. Submitted to *Cancer Nursing*.
- IV Rissanen, R., Nordin, K., Ahlgren, J. and Arving, C. A stepped care stress management intervention on cancer-related traumatic stress symptoms among breast cancer patients – A randomized study of group vs individual setting. Submitted to *Psycho-Oncology*.
- V Rissanen, R., Arving, C., Ahlgren, J. and Nordin, K. Group vs. individual stress management intervention in breast cancer patients for fatigue and emotional reactivity: A randomized intervention study. *Acta Oncologica*, 2014. July 9. Doi: 10.3109/0284186X.2014.923935. [Epub ahead of print].

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Abbreviations

BC sample	Breast Cancer sample
CBT	Cognitive Behavioural Therapy
DSM-IV	Diagnostic and Statistical Manual for mental disorders, IV
ELSS	Everyday Life Stress Scale
ES	Effect Size
GSM	Group Stress Management
HADS	Hospital Anxiety and Depression Scale
IES	Impact of Event Scale
ISM	Individual Stress Management
MFI	Multidimensional Fatigue Inventory
NCCN	The National Comprehensive Cancer Network
NCU	The Nordic Cancer Union
NHG	Nottingham Histologic Grade
NHS	the British National Health Services
NOKC	the Norwegian Knowledge Centre for health and services
PTSD	Post-traumatic stress disorder
QoL	Quality of Life
RW sample	Random Women sample
SBU	The Swedish Council on Technology Assessment in Health Care
SD	Standard Deviation
SME	brief Stress Management Education intervention
SPSS	Statistical Package for the Social Sciences
STAQ	Simplified Type A Questionnaire
T1	Baseline assessment, all women
T2	Assessment 3-months post-inclusion, all women
T3	Assessment at the end of GSM/ISM intervention
T4	Assessment 12-months post-inclusion, all women

Introduction

Breast cancer diagnosis can have significant consequences for women affected. It is not just the diagnosis per se which has a negative impact on the quality of life of those affected, but also the time prior to treatment, the treatment itself and several years post-treatment, which are all factors that impact the patient's quality of life. This thesis deals with distress following breast cancer diagnosis and a stress management intervention for women diagnosed with breast cancer.

The way we view stress, which means hardship, originates from the prominent physicist-biologist Robert Hooke who was interested in the way man-made structures were designed to resist hardship and destruction. Hooke viewed stress as the area of the structure, which a load (weight) affected. During the 20th century, models of stress were greatly influenced by Hooke's definition of stress, i.e. the idea of stress as an external load or demand [1, 2]. This load can be on biological, social or psychological systems, which can be a cause of human distress and dysfunction. During the 1950s, researchers recognised that to understand stress and the way it affects people it was important to understand the role of individual differences in motivational and cognitive variables [2]. These differences exist both in physiological and psychological stress. Nowadays, we speak about the load as stress stimuli or a stressor, and the reaction to the stressor is called a stress response.

This thesis will only consider psychological stress, specifically, a term called distress in breast cancer survivors. The National Comprehensive Cancer Network (NCCN) Distress Management Panel has defined distress in cancer as 'a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis' [3]. A survivor is defined as 'one who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life' [4].

I recognise that there are several different approaches in research considering experiences of and survivorship of breast cancer and the extensive research done on coping within this field. My focus has been on breast can-

cer as a traumatic and threatening stressor that activates cognitive processes and the distress, which may follow a breast cancer diagnosis.

Epidemiology of Breast Cancer

In Sweden alone, approximately 27,600 women are diagnosed with cancer each year. Out of all the women diagnosed each year with cancer in Sweden, over 8,300 women are diagnosed with breast cancer [5], which is the most common cancer diagnosis for women. Currently there are more than 90,000 breast cancer survivors in Sweden [6]. Some of the established risk factors for breast cancer are nulliparity, high age at menarche and first birth and low age at menopause. During the past 20 years, the cancer incidence has increased 1.5 per cent annually, and the annual incidence for breast cancer has increased 1.4 per cent [7]. Although there has been an increase in the incidence during the past few decades, the mortality rate has remained largely unchanged during the same period [8]. The incidence rate increases with age [9], and continuous ageing of the population explains about half of the increase in the incidence [7]. Furthermore, the incidence is also greatly influenced by mammography screening [9]. Sweden introduced mammography screening in 1974, and in 1997 it became a nationwide programme for women aged 50-69 [8, 9]. The 5-year survival rate in Sweden is among the highest in Europe with an estimate of 88.5% [10]. The high survival rate in Sweden can partly be explained by the well implemented mammography screening programme and the centralisation of cancer treatments [8, 9, 11].

Treatment of breast cancer

Breast cancer can be divided into different stages, where stage 0 is non-invasive (*in situ*) cancer type and stage I-IV is defined as an invasive cancer [12]. In Sweden, treatment options follow national guidelines standardising the treatment of breast cancer and are based on cancer stage and other histological findings of the tumour [12]. Until the 1970s, radical mastectomy was the primary surgical treatment, and in the 1980s the evidence began to grow showing that less radical surgical options did not increase the morbidity or mortality and the surgical treatments were modified to include conservative surgery and local excision [13]. For a majority of women diagnosed with breast cancer, the treatment regime starts with surgery to remove the cancer either by removing a smaller part of the breast or the entire breast [12]. To secure that the cancer has not spread to the lymph nodes, a sentinel lymph node biopsy and/or axillary lymph node dissection is performed. Adjuvant treatment options, most often following the surgery, are chemotherapy, radiation and hormonal therapy. These treatment options can be given separately

or in any combination. The less invasive cancer tumours are primarily treated with surgery and neoadjuvant or adjuvant treatments, and palliative treatment is offered to patients with terminal breast cancer [11].

Both the surgical treatments and the adjuvant treatment options are associated with several side effects, side effects, which impact the quality of life for women who experience them [14, 15]. Side effects following surgery may include lymphedema and pain, which restricts the movement in the arm and shoulder [16]. The adjuvant treatments, especially chemotherapy is associated with toxicities, which are usually resolved when the treatment ends although some of these side effects may cause long-term morbidity. The side effects can include fatigue [17], pain [15, 16], lymphedema, nausea and diarrhoea [16]. Moreover, some women experience gynaecological symptoms such as vaginal dryness and premature menopause post-treatment [16].

Breast cancer as a traumatic stressor

Although breast cancer treatments have been modified to include the less radical and invasive treatment options, patients still report distress in relation to both the breast cancer diagnosis and treatments. According to the diagnostic and statistical manual for mental disorders, IV (DSM-IV) [18], life threatening events, such as cancer diagnosis has been recognised as a trigger for post-traumatic stress disorder (PTSD), a phobic and anxious reaction following a traumatic experience. A unique feature of PTSD is that specific triggers are linked to the phobic and anxious reactions. Unlike other PTSD triggers, cancer diagnosis is not a short-lived event. Instead, cancer experience consists of several events over a long period of time beginning with the diagnosis, followed by cancer treatments, sometimes months and years following diagnosis, which may act as potential triggers for trauma-related stressors.

Diagnosis may act as a trigger because of the uncertainty surrounding the breast cancer diagnosis, and the distress is often related to worries about the future and what it may hold [19-22]. The state of uncertainty per se may be more distressing than the actual cancer diagnosis [23]. Studies have shown that waiting for biopsy results and the diagnosis can be distressing, and about half of the cancer patients overestimate their personal risk for a negative outcome, which consequently elevated these participants' distress levels [21, 24]. The waiting period is often experienced as a type of limbo with panic attacks, insomnia and an inability to concentrate on work and reluctance to make plans for the future [25].

It is not only the time close to diagnosis, which might be experienced as stressful. A cancer diagnosis opposes a future threat by worries about the diagnosis and consequent treatment options [26-28]. The cancer treatment trajectory can be a long and burdensome ordeal, which might last from some

months to several years. Cancer treatments are highly invasive with negative consequences, such as hair loss, vomiting, nausea and fatigue, which affect the individual not only physically but also mentally [26].

Responses to breast cancer

Although many women experience distress after a breast cancer diagnosis, it cannot be concluded that the criteria for PTSD would be fulfilled by these women if a full assessment were to be undertaken. To be diagnosed with PTSD, certain criteria according to the DSM-IV must be fulfilled. The diagnostic criteria for PTSD include an exposure to a traumatic event, which meets specific stipulations and symptoms from each of four symptom clusters: intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity. The symptoms must have persisted for more than one month and must have functional significance. Lastly, the symptoms cannot be attributable to a substance or co-occurrence of a medical condition [18]. Approximately 5-13% of women with breast cancer fulfil all of the DSM-IV criteria for PTSD [29-31]. When patients do not meet the stringent criteria of PTSD, they may instead experience PTSD-like symptoms. There is evidence that many women experience PTSD-like symptoms (subjective and psychological distress) following a breast cancer diagnosis and that once women with breast cancer develop these symptoms they persist over a long period of time [31-36]. Studies have found that 60-80% of women with breast cancer who report high PTSD-like symptoms at the time of diagnosis report comparable high levels almost two years later [33, 37]. These findings support the notion that once women develop PTSD-like symptoms, they tend to continue experiencing distress, both subjective and psychological, over an extensive period of time [32].

Subjective distress

In this thesis, the term subjective distress comprises intrusions and avoidance. Intrusions can be defined as unbidden thoughts and images, troubled dreams, repetitive behaviour and waves of feelings [38]. Avoidance is represented by constricts of ideas, denial of the event (both the meaning and consequences of the event) and emotional numbing [38]. In the DSM-IV [18], intrusive thoughts and avoidance are included in the diagnostic criteria for PTSD. Notably, subjective distress has been recognised as a common trauma symptom among breast cancer survivors [27, 32, 39]. For example, Bleiker and colleagues [33] found that approximately half of the women diagnosed with breast cancer in their study reported elevated levels of intrusion two-months after surgery. They also found that about 60% of these women who initially reported elevated levels of intrusion also reported elevated levels

19-months later. These findings are confirmed by Lebel *et al.* [40] who found that women who report intrusion and avoidance at three-months post diagnosis also report elevated levels six years later, although the levels were somewhat elevated. Previous levels of subjective distress were the major predictor of distress at six years post diagnosis. Koopman and colleagues [32] noticed a significant reduction in the intrusion levels between baseline and 6-months later; however, they were not able to detect any significant reductions in the avoidance levels during the same period of time for women with breast cancer. However, it should be noted that avoidant behaviour may be difficult to define and measure in early breast cancer, as the disease and the treatment imposes a continuous confrontation of stressors related to the trauma [22].

A number of variables have been suggested to have an impact on the subjective distress experienced when diagnosed with breast cancer. For example, intrusive thoughts have been shown to be mediated by worry about what the surgeon may find [41], a finding that is supported by Mehnert and colleagues [28] who found that intrusive thoughts were related to being afraid of disease progression and severe medical treatments. Furthermore, Arving [37] reported that women who did not receive psychosocial support exhibited significantly higher levels of subjective distress compared to women who did receive psychosocial support.

Psychological distress

In this thesis, psychological distress is defined as anxiety and depression. Anxiety includes reactions such as tension, fear, worry, panic, restlessness and difficulties in relaxing [18, 42]. Depression is represented by loss of interest, low self-worth and feelings of guilt, low energy, depressed mood and poor concentration [18, 43]. Several studies have reported elevated levels of psychological distress, both anxiety and depression, for women with breast cancer. A Swedish study reported clinically significant levels of anxiety and depression with 18% and 6%, respectively, at the time of diagnosis for women with breast cancer [44]. Similar findings have been found by Höyer *et al.* who found that 14% of the women reported anxiety and 6% reported depression shortly after diagnosis [45]. Moreover, a review by Montgomery *et al.* [46] found that anxiety was present in varying degrees in every study population included in their review. These levels tend to stay elevated for a long period of time post diagnosis [27, 32, 34, 47]. Studies, which have measured anxiety and depression, have shown that at diagnosis and at a three-month assessment, 33% and 24%, respectively, of women with breast cancer report high levels of psychological distress. These levels do drop during the following years but still remain higher than the general population. Vahdaninia and colleagues [34] found that 18-months post diagnosis, 38% of the women included in the study experienced severe anxiety,

and 22% reported depression. These findings confirm the results of Burgess *et al.* [47] who found an annual prevalence of 25%-22% of anxiety, depression or both, during the second through fourth year post diagnosis. During the fifth year, the levels had dropped to 15%. These results provide further support for the notion that once women develop PTSD-like symptoms, they tend to continue experiencing distress, both subjective and psychological, over an extensive period of time [32].

Costanzo *et al.* [27] found that women who received adjuvant chemotherapy reported greater anxiety than women who only received radiation therapy. Furthermore, cancer progression has also been found to affect the psychological well-being of women diagnosed with breast cancer [35]. In addition, it has been suggested that patient-related variables such as age and social support are important and should be taken into account. Notably, a younger age has been positively related to both subjective and psychological distress [27, 29, 32, 35, 48]. Furthermore, results from several studies have indicated that social support may act as a buffer and reduce both subjective and psychological distress among breast cancer survivors [47, 49]. A finding of subjective and/or psychological distress at the time of diagnosis has been shown to be a good predictor of future distress [33, 47, 50].

Emotional reactivity

In all research dealing with distress it is also important to consider emotion, as these two fields are interdependent [1]. Both distress and emotions affect the psychological well-being, coping and somatic health [1]. In this thesis, emotions are considered in terms of emotional reactivity. Emotional reactivity can be defined as the tendency to react intensively to emotion-generating stimuli [51], which might be expressed by aggravation, anger, hostility and impatience [52, 53]. Emotional reactivity can be triggered by small unexpected stressors e.g. home- and work overload or network stressors such as arguments with a close friend or a spouse [1]. Even though these stressors are small and often not even remembered at the end of the day, they trigger emotional reactivity. These small unexpected stressors can mobilise a reaction to search for something or someone to blame because the situation may be seen as unfair. This, in turn, triggers emotional reactivity, for example, agitation and impatience. Women tend to experience more psychological stress than men and more minor levels of emotional distress on a daily basis [54].

There is some support that daily stressors magnify and mediate the effects of major life events and studies have shown that negative affect (negative emotions) in response to small daily stressors plays a significant role in later mental health outcomes [55]. Moreover, cancer survivors seem to be more vulnerable to small everyday stressors and perceive them as more disrupting than a cancer free comparison group [56]. Little is known about emotional

reactivity among women with breast cancer, and there are no valid instruments to measure emotional reactivity in this population. There is some support that emotional reactivity is associated with a higher mortality in breast cancer patients at 5-years post diagnosis [51], and about 50% of women with breast cancer who report irritability and frustration also report experiencing fatigue [57].

Fatigue

‘When healthy, I did not realize the energy required for activities of daily living, such as bathing, dressing, or sitting upright in a chair’ [58].

In this thesis fatigue is defined as a debilitating loss of energy and is a multi-dimensional symptom, which considers both psychological and physiological aspects [57, 59, 60]. Note that this definition is not exclusive to fatigue experienced following cancer, unlike the more stringent definition of cancer-related fatigue according to the NCCN [61]. Fatigue cannot be relieved by sleep or rest and causes alterations in the daily routines. Due to fatigue, it can be difficult to cope with daily activities such as bathing and getting dressed, keeping up with interpersonal relationships and participating in social activities [17, 57, 58] and therefore becomes a distressing symptom. From all the cancer treatment side effects, fatigue is reported to affect the patients’ daily lives the most compared to, for example, pain and nausea [57]. Breast cancer patients report significantly more fatigue than women not affected by cancer [17] and fatigue is one of the most anticipated adverse events in the cancer trajectory [16]. Some studies have reported that up to 90% of all cancer patients experience some degree of fatigue [57, 62, 63]. Up to one-third of patients with cancer report fatigue 5-10 years post diagnosis [14, 64, 65].

Although, several variables have been associated with higher levels of fatigue in cancer patient’s e.g. pain [66], medical and treatment variables [66-69], mental health [66-68, 70], previous trauma [71], and fatigue prior to treatment [65, 72], the mediating mechanisms of fatigue are not well understood [73]. In several studies, the primary variable correlating to fatigue has been depressed mood [66, 68, 74] and distress [75].

Some argue that treatment-related variables are only weakly correlated with fatigue [69] although the results from several studies indicate that the prevalence, intensity and disruptiveness of fatigue increases gradually after each cancer treatment cycle [14, 17, 63, 76], and patients undergoing chemotherapy report a peak of fatigue during the days following the treatment. The levels of fatigue than gradually lessen, but the levels never reached pre-treatment levels and with each treatment cycle the levels of fatigue increase in severity [77]. Similar patterns are reported by patients undergoing radia-

tion therapy, with highest levels of fatigue reported at the end of treatment [77].

Cancer rehabilitation

In May 2014, the first version of a national strategy for cancer rehabilitation in Sweden was released [78], a rehabilitation strategy that is vital considering the increasing number of cancer survivors. This national strategy includes an integrated patient-focused cancer rehabilitation, which begins at diagnosis and is present throughout the treatment trajectory. The Nordic Cancer Union (NCU) has defined cancer rehabilitation as ‘Cancer rehabilitation is a specific period of time during which the physical, psychological, social, and existential consequences of cancer and the treatment are prevented and reduced. The rehabilitation initiatives are to have clear objectives and effects, and provide each individual patient help and inspiration to have the best possible life. The individual rehabilitation plan is to be prepared in a close dialogue between the patient and the professionals’ [79]. This definition is the foundation for the national cancer rehabilitation strategy, which aims at preventing and reducing the physical, psychological, social and existential consequences following a cancer diagnosis and cancer treatments [78].

Breast cancer includes several different diagnoses and each breast cancer patient will face a unique set of problems and have individual rehabilitation needs due to the individual variations of both the cancer disease per se and the individual differences in both social and psychological variables [80]. The rehabilitation plan needs to consider psychological, social, behavioural and ethical aspects, which are of importance for the individual. All of these aspects are included in the term psychosocial oncology, which is an integrated part of cancer rehabilitation [78].

Psychosocial interventions

The aim of psychosocial interventions is to change or influence malfunctioning behaviours, negative emotions and cognitions, individually or in combination, with the ultimate goal to decrease these. There are a large number of studies, which evaluate psychosocial interventions in cancer populations. Some of these interventions are tailored for specific cancer diagnosis [81] and populations [76, 82], whilst some studies have evaluated the interventions in heterogeneous cancer populations [83, 84]. The focus of these interventions ranges from physical exercise [77] to behavioural interventions [39, 85]. Studies that have evaluated the behavioural interventions include, but are not limited to, emotional support [86], mindfulness [87], empowerment [81], guided self-help [88] and patient education [89]. Studies testing behav-

avioural interventions have shown improvements regarding distress, both subjective and psychological [39, 90] and fatigue [91].

Mode of delivery

Psychosocial interventions can be delivered in several different ways. They can range from community-based interventions [92], interventions over the telephone [93], face-to-face interventions [39, 83] to interventions delivered over the Internet [94, 95]. Although several different types of treatments have been suggested to manage psychosocial morbidity, there is no consensus on the most effective treatment or mode of delivery for women with breast cancer [96-98].

The evaluations of majority of psychosocial interventions in breast cancer research include support provided either individually or in a group. Both advantages and disadvantages have been reported considering interventions delivered individually and in groups. These intervention studies have often compared the intervention group with a no-therapy control group or care as usual [88, 89]. In a review, Osborne and colleagues [89] concluded that individually-based interventions are more effective than interventions delivered in a group format, a finding which is supported by Tatrow and colleagues [90] who calculated, in their review, the effect size (ES) of cognitive behavioural therapy (CBT) based interventions for women with breast cancer delivered either in a group or individual format. The mean ES for individual format was significantly greater than the mean ES for the group format.

Although group interventions were not as effective as individual interventions, they offer several other benefits for the participants. For example, some of these benefits include improved information about the disease, increased empowerment and sense of control, improved self-esteem, facilitating positive relationships and valuing the group context and social support from others in the same situation, which could facilitate the therapeutic progression [99-101]. However, there are some potential difficulties with interventions that are delivered in a group format. Ussher and colleagues [102] investigated the reasons for prematurely leaving or not attending support groups. They found that some participants had difficulties to attend the support groups due to practical reasons, such as lack of time and work schedule. Moreover, participants reported to have moved on emotionally and support groups were also viewed as something for “other people” with more need for support.

Few studies have evaluated group versus individual interventions with each other in cancer populations; therefore, such studies have been called for [103].

Screening

Not all cancer survivors will experience psychosocial problems; thus, not all patients should be treated for these problems. One way of identifying individuals who experience psychosocial problems is by screening. With screening, it is possible to early identify individuals who are at risk or already experience psychosocial problems. Screening is most often performed by the aid of a test or an examination, such as physical examination or psychological evaluation. In 2003, the NCCN recommendations regarding clinical guidelines of distress management included screening. ‘All patients should be screened for distress during the initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status such as remission, recurrence, disease progression. Screening should identify the level and nature of the distress. Distress should be assessed and managed according to clinical practice guidelines’ [104].

The vast majority of screening tools for mental disorders are self-assessment questionnaires. The identification of “cases/clinical cases” i.e. those who experience problems according to the measure used, are in most cases done by the use of cut-offs. These cut-offs differentiate those who report elevated levels of symptoms and those who do not report high levels i.e. “non-cases”. Some instruments allow identification into three groups: clinical cases, doubtful cases and non-cases. The instrument used for the screening purposes needs to be able to correctly identify the cases (sensitivity) at the same time as it identifies the non-cases (specificity) that are not in the need for an intervention. Ideally, an instrument should have high specificity and high sensitivity. Although high sensitivity and specificity is not always possible to achieve, it is important that at least the sensitivity is high when screening for psychosocial problems. When the sensitivity is high and the specificity is low, there is an increased risk that individuals who are not in need of an intervention are falsely identified as cases. On the contrary, if the specificity is high and the sensitivity is low, there is a risk of missing and not identifying possible cases and therefore these individuals will not be offered an intervention and the help they might need. Screening does not have to be performed by only one instrument; thus, two or more measures can be combined to make sure that only true cases are identified. For example, Nordin and Glimelius [105] found that early identification of patients who are in need of psychosocial interventions are possible through screening for clinical levels of worry and depression in combination with intrusions.

Stepped care approach

As mentioned earlier, the cancer treatment side effects can be short lived but they can also last for a long period of time for cancer survivors. Since the level of psychosocial care offered could differ greatly among women with

breast cancer and because the resources in healthcare are limited, it is important that patients receive the time, expertise and the attention that each patient needs. One way of providing each patient the right level of care is by using stepped care models [106, 107]. Stepped care models require intervention in several steps, steps that are amended to the patient's needs of treatment. Patients are first offered the least intensive and invasive treatment. This low intensity level of the treatment is expected to generate effects without having great impact on the patient in terms of costs and inconvenience [108]. Thereafter, patients who require more extensive treatment are offered further treatment on a more intense level. A stepped care treatment requires that the initial step of the treatment be titrated against the patient's needs, followed by response monitoring and modification to the treatment as required. The evaluation of the guidelines by the British National Health Services (NHS) concluded that the recommended stepped care treatment is beneficial and should be further implemented in the clinical interventions [106]. Nonetheless, some researchers [109, 110] have called for more research to determine whether stepped care could be an efficient method of delivering e.g. cognitive-based stress management.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is an established treatment method for depression and anxiety [103]. CBT is a psychotherapeutic approach, which utilises both behavioural and cognitive principals in a manner, which considers the patient as someone who is seeking knowledge. The therapist acts both as a teacher and a guide and combines psycho-education with investigative techniques. The focal points in CBT are specific events, which have been experienced as problematic or distressing. By identifying these events, it becomes possible to identify the strategies the patient uses when reacting to the event, e.g. automatic negative thoughts, behaviours or schemas. Furthermore, in CBT it is important to address feelings and teach the patient how to handle them [111]. Hence, CBT is founded on three fundamental propositions: 1) cognitive activity affects behaviour, 2) cognitive activity may be monitored and altered and 3) desired behaviour change may be effected through cognitive change [112].

It is well established that CBT is effective for the management of distress [103], and CBT is recommended as the primary treatment for depression and anxiety by the Swedish National Board of Health and Welfare [113]. The Swedish Council on Technology Assessment in Health Care (SBU) [103] and the Norwegian Knowledge Centre for health and services (NOKC) [98] concluded in their systematic reviews that there is strong evidence that CBT in proximity to a cancer diagnosis is beneficial in preventing future distress disorders. These two reviews included systematic searches for controlled trials in the Cochrane Library, the Centre for Reviews and Dissemination

database, Medline, EmBase, Chinal, PsychINFO, AMED, PEDro, PsycLit and the Excerpta Mediline [98, 103].

CBT techniques have been empirically validated in cancer populations, [e.g. 114] but only a few studies have focused on specific cancer populations e.g. breast cancer. One review examined CBT interventions given to patients with breast cancer and concluded that interventions that used CBT techniques were beneficial for the treatment of distress [90]. Women with breast cancer who participated in CBT interventions had significantly less distress compared to those in control groups.

Theoretical Framework

Cognitive theory

In general, when one thinks about cognitions one usually means thoughts, but the term cognition includes more than thoughts, for example, reasoning, dreams, mental images, memories and fantasies [111]. Cognitions are complex processes rather than automatic responses; specifically it includes three processes: gathering of information from our environment, how one processes this information and how one uses and acts on this information. These three processes are included in cognitive theory, which can be defined as ‘A structured, goal-directed and present-oriented psychotherapy that utilizes cognitive and behavioral strategies to achieve symptom reduction by specifically targeting the faulty cognitive structures and processes that maintain psychiatric disorders’ [115].

In cognitive theory, it is argued that it is not the issues or problems we face per se, which make us regard them as problems, instead it is our way of interpreting these happenings that creates the problem [111, 115]. Each interpretation of a situation is dependent on the previous experiences of the individual, i.e. the information of our environment and how one has previously acted on the information. Each individual holds mental schemas of the world. These schemas allow individuals to interpret information of the world around them, including past experiences, assumptions and expectations of the future. One’s previous experiences are vital for the way one interprets, uses and acts on the information we get from our environment [111]. For example, a pool might be perceived as a relaxing place for the majority of people, but if one has had a near drowning experience seeing a pool and being in close proximity to one can induce high levels of fear and anxiety. This is because the previous experiences indicate that being close to a pool is dangerous due to risk of drowning.

Therapies based on cognitive theory have been empirically tested in several studies (see Clark *et al.* [115] for a summary). The results indicate that these therapies are effective in the treatment for depression and anxiety [115]. Moreover, in Sweden, CBT is recommended as a treatment for de-

pression and anxiety [113], a form of therapy that is based on the constructs of cognitive theory, modifying biased interpretations and dysfunctional automatic thoughts.

Cognitive processing theory

Similar to cognitive theory, the cognitive processing theory focuses on how individuals interpret information of the world around them, including past experiences, assumptions and expectations of the future [116]. Horowitz [116, 117] proposes that when an individual is exposed to a trauma, the exposure presents the individual with information, which is not compatible with the pre-existing schemas. As the new experience and information from the trauma is not compatible with the pre-existing schemas, they need to be revised in order to integrate the trauma experience into the existing schemas. The dose of incoming information is regulated by a control system, where intrusion and avoidance act as opposite actions of this system. Intrusion can be interpreted as an indication of the individual's ability to process the trauma cognitively, which indicates that the memory network has been activated, whereas avoidance is used to block or escape the psychological arousal, which is associated with traumatic memories. When high arousal is experienced, memories of the trauma might be blocked, by the use of avoidant strategies, in an attempt to escape the unpleasant feeling of the high arousal. In short term, these avoidant strategies can reduce immediate distress, but in the long run they hinder one from processing the trauma in a sufficient way as thoughts and memories are not confronted [118]. By regulating so that only small amounts of information are being processed, the individual is allowed to process the traumatic event and to revise the existing schemas so that they are compatible with the new experience.

A cancer diagnosis has been recognised as a trauma, which can trigger post-traumatic reactions [18], and the cognitive processing theory has been applied to women with breast cancer. The results have indicated that women with a late stage breast cancer and women with an early stage breast cancer process trauma in different ways. Late stage breast cancer patients seem to perceive a cancer diagnosis as a threat, which triggers both intrusions and avoidance according to the cognitive processing theory [119], whilst the model of cognitive processing was not significant for early stage breast cancer patients.

Aims

The overall aim of this thesis was to evaluate a stress management intervention with a stepped care approach in a breast cancer population, according to the study protocol presented in paper I. Moreover, we set out to explore distress, both psychological and subjective, emotional reactivity and fatigue among women with a newly diagnosed breast cancer, both by a theoretical approach and self-reported assessment.

Specific aims

Paper I

To present and describe the design of the intervention study, which is evaluated in papers III and IV.

Paper II (hereinafter called Study I)

To examine the longitudinal association between intrusion, avoidance and psychological distress and the mediating role of avoidance between intrusion and psychological distress.

Paper III (hereinafter called Study II)

The first aim was to validate the everyday life stress scale (ELSS), which measures emotional reactivity, in a random sample of women. A second aim was to investigate emotional reactivity experienced by breast cancer patients at the start of post-operative curative treatment and to relate emotional reactivity to patient and treatment variables measured at start of curative treatment.

Paper IV (hereinafter called Study III)

To compare the effects of two different modes of delivery, a Group Stress Management (GSM) intervention to an intervention delivered as an Individual Stress Management (ISM) for patients diagnosed with breast cancer and with cancer-related traumatic stress symptoms. A secondary aim was to ex-

plore if the number of women who reported cancer-related traumatic stress symptoms would be reduced after receiving a brief Stress Management Education intervention (SME) in the first step of a stepped care model approach.

Paper V (hereinafter called study IV)

To evaluate if a CBT-based stress management intervention delivered either in a group setting (group stress management, GSM) or an individual setting (individual stress management, ISM) would improve fatigue and emotional reactivity among women with breast cancer.

Methods and materials

Population and sample

All studies are based on data collected for a research project aimed at evaluating the effectiveness of a stress management intervention using a stepped-care approach. Between May 2009 and August 2011, 901 women were referred to the department of oncology at Falun, Gävle and Uppsala hospital, Sweden, for adjuvant breast cancer treatment. According to the inclusion criteria, a consecutive series of 821 patients were approached and asked to participate based on the inclusion criteria: women over the age of 18, with stage I-III disease and about to receive curative treatment for breast cancer. All participants were planned to undergo chemotherapy, radiation therapy or hormonal therapy or any combination of these therapies. Exclusion criteria were: inability to understand or speak Swedish and/or patients who had ongoing psychiatric diagnoses (as determined by medical chart review). Out of the 821 patients approached, 372 patients rejected participation, 23 patients (5%) failed to return the questionnaire at baseline and one died prior to receiving the questionnaire. The total sample comprised of 425 patients (52%) accepted participation in the intervention study (evaluated in studies III and IV).

Study I

Participants were included between June 2009 and March 2011 (n=389). All participants were included according to the main study protocol described above. In this study, we set out to evaluate the cognitive processing model with the aid of an untreated patient group during the first year after the cancer diagnosis. Therefore, a total of 127 women were excluded from participation as they participated in the intervention part of the main study. Furthermore, 71 women failed to return the questionnaire and two died before receiving the questionnaire. Thus, 189 women were included in the present study. Sixty-six of these women were not eligible for the intervention in the main study, as they did not report clinical levels of distress. The remaining 123 women were eligible for the intervention but they declined participation mostly due to concerns about the intervention being too burdensome for them whilst undergoing treatment.

Study II

All 425 female patients who were included according to the main study protocol between May 2009 and August 2011 were included in this study (breast cancer sample). Moreover, the study sample included 176 women who were randomly selected from the PAR register (<http://www.par.se>). The PAR register contains all private persons over the age of 16 in Sweden who have a listed phone number. Inclusion criteria for the random sample were women over 18 years of age, living in the same catchment area as the women who participated in the intervention study (random women sample). Women who had experienced cancer during the past 5-years were excluded as we strived to include only women who had not been affected by a cancer diagnosis.

Studies III and IV

All 425 female patients who were included according to the main study protocol between May 2009 and August 2011 were included in these two studies.

Measures

An overview of the points of assessment and questionnaires used for the different studies included in the thesis is given in Table 1.

Table 1. *Points of assessment and questionnaires used for the different studies included in the thesis.*

Questionnaires	Inclusion	3 months post inclusion	After Step II intervention	12-months post inclusion
<i>Study I</i>				
IES	x	x		
HADS	x	x		x
<i>Study II</i>				
ELSS	x			
<i>Study III</i>				
IES	x	x	x	x
HADS	x	x	x	x
<i>Study IV</i>				
ELSS	x	x		x
MFI-20	x	x		x

Impact of Event Scale

The Impact of Event Scale (IES) consists of two subscales, which measure intrusions and avoidance. Intrusions are measured by 7-items and avoidance by 8-items. Participants are asked to indicate on a four-grade scale the frequency (not at all/rarely/sometimes/often) of which statements corresponded with their own experiences of breast cancer during the past week e.g. 'I had waves of strong feelings about it' and 'Any reminder brought back feelings about it'. The lowest grade of the scale is given a 0, the next 1, the third 3 and the fourth 5 and coded into two sets of sums. The maximum sum of intrusion is set at 35 and for avoidance the maximum sum set is 40. Scores above 9 are considered as clinical levels of both intrusion and avoidance [38]. Both subscales are graded in the same manner.

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) [42] was used to measure the current anxiety and depression levels and the severity of distress. The HADS is a validated [120] self-assessment instrument that consists of 14-items, which contain two subscales: anxiety (7-items) and depression (7-items). Each item is rated on a four-grade scale (0-3), with a maximum score of 21. Two cut-off scores have been recommended: 8–10 to indicate cases that warrant further psychiatric investigation, and ≥ 11 for clinical level of anxiety/depression, which was the cut-off score chosen for the present thesis.

Everyday Life Stress Scale

The Everyday Life Stress Scale (ELSS) [52, 53] was used to measure emotional reactivity. The ELSS measures subjective responses to stressors, principally other people's behaviour. The scale consists of two subscales, namely, time urgency/impatience and irritability/hostility. The scale comprises twenty short statements, on a 4-point scale (0-3), regarding emotional reactivity in everyday life situations e.g. 'I get irritated when others are fumbling or negligent', 'I get irritated with people who do things slowly' and 'I find myself hurrying even when I really have plenty of time'. Scores range between 0 and 60, whereby a higher score indicates more stressful reactions. A five-point increase or decrease is of major significance when using repeated measures.

Simplified Type A Questionnaire

The Simplified Type A Behaviour questionnaire (STAQ) [121] measures impatience, time pressure, hostility and anger and was used as gold standard in study II. Participants were asked to answer 10 short statements, e.g. 'I

easily get angry' and 'I never find enough time', by indicating on a three grade scale (0-2) if they agree to the statements or not: 'fully agree', 'partly agree' and 'do not agree at all'. The STAQ has been validated [121] and a higher total score indicates more Type A behaviour.

The Multidimensional Fatigue Inventory

Fatigue was assessed with the aid of the Multidimensional Fatigue Inventory (MFI-20). The MFI-20 includes five subscales: general fatigue, physical fatigue, mental fatigue, reduced activity and reduced motivation. Somatic symptoms of fatigue are not included in the scale in order to exclude symptoms of somatic illnesses, independent of fatigue [70]. The MFI consists of 20 statements for which the participant was asked to indicate the extent to which the statement applies to her on a five-point scale (agree/disagree). A total score is calculated for each subscale by adding up the scores for the five individual items. The score for each subscale can range from 4 to 20 and higher scores indicate a higher degree of fatigue. The Swedish version of MFI-20 has been validated and has demonstrated good psychometric properties [122-124].

Procedure

At the start of adjuvant treatment all eligible women were contacted by a research nurse and informed about the study. A week after receiving the initial information, patients were contacted by telephone and asked to participate in the intervention study (described in Paper I). If they agreed to participate, a written statement of consent and a questionnaire was sent out to them together with a prepaid return envelope (T1). Participants were initially informed about the different assessment points and were offered the first step of the intervention program, i.e. the 2-hour stress management education (SME). Three-months post-inclusion, all participants received a second questionnaire (T2). If participants reported over the cut-off on the Impact of Event Scale (IES) or the Hospital Anxiety and Depression Scale (HADS) at the second measurement, they were offered the second step of the intervention. Clinically significant levels on the IES are regarded as levels over 9 [38] and levels over 11 on the HADS [42]. These cut-offs have previously been validated and are considered suitable as a screening tool for clinical use [50]. Women who agreed to participate in the second step were randomised in blocks of two to a more intensive stress management in either a group (group stress management, GSM) or individual (individual stress management, ISM) setting. An additional questionnaire was sent at the end of step II (GSM or ISM) to the women who had participated in the more intensive intervention (T3) (data not presented in this thesis). At 12-months post-

inclusion, all participants received the last follow up questionnaire (T4). Flow chart of the study is presented in Figure 1.

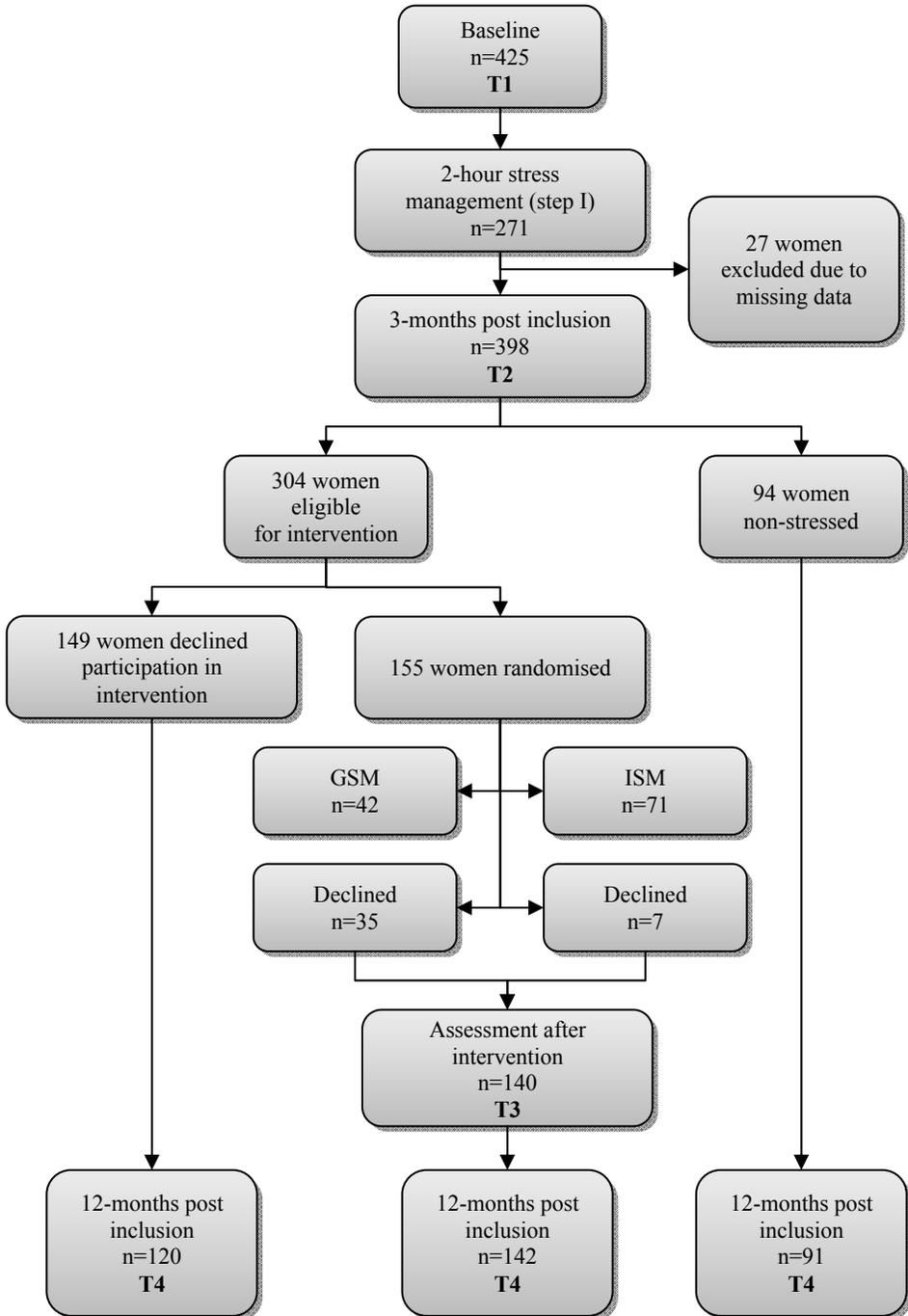


Figure 1. Flowchart of the patients throughout the study.

Intervention

The intervention in this thesis focuses on three of the four aspects that are included in the NCU's [79] definition of cancer rehabilitation: the psychological, social and existential consequences of breast cancer (see figure 2). Each core component of the intervention is derived from these aspects, which are integrated and overlapping. Individuals may develop problems in one aspect without any problems in the other aspects whilst some individuals develop problems in one aspect, which is followed by problems in the other aspects. Furthermore, a stepped care approach was utilised. All participants were offered the first step of the intervention. The second step was offered to all study participants who reported levels over the cut off of 9 on the IES [38] and/or over 11 on the HADS [42] (n=304) at the three month assessment.

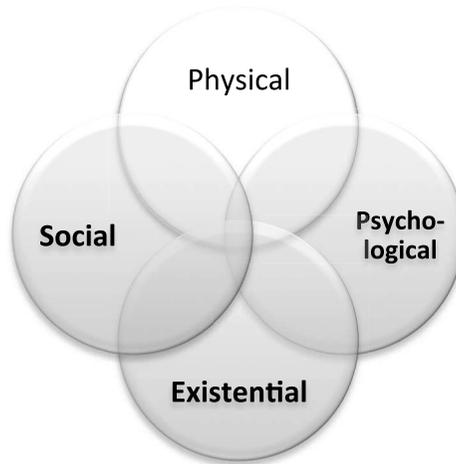


Figure 2. *Aspects of intervention indicated in grey.*

Step I

The first step of the intervention, the stress management education (SME), which was offered as a single session in a group format upon inclusion to all women, aimed at increasing the participant's knowledge about the cancer treatment trajectory and common stress reactions that might be experienced after a cancer diagnosis. It is not uncommon for cancer patients to experience the healthcare system as confusing, which can be a cause of distress and anxiety [78]. Therefore, the session started with a short presentation of breast cancer and the most common treatment options, such as surgery and adjuvant treatments options. Thereafter, a short introduction to stress and common stress responses were presented and discussed. Moreover, the SME aimed at giving the participant's tools to recognise their own stress reactions, which could be expressed by aggravations, hostility, intrusions and avoidant

behaviour. Reactions such as depression and anxiety were also discussed. These stress response and how the stress responses possibly could trigger emotions and thoughts as well as how to change these behaviours if they wanted were discussed. During the entire session, the women were encouraged to participate in discussions and to share their experiences of breast cancer. Participants also received written material and a CD with short relaxation exercises, which they were encouraged to practice at home.

Step II

The second step of the intervention contained two different intervention arms: the group setting (GSM) and the individual setting (ISM). Both intervention arms were intended to contain the same core components but in different settings. To achieve high fidelity, the intervention was monitored once a month by a psychologist trained in CBT, with extensive experience in CBT interventions for cancer patients.

Groups were arranged at each of the three hospital catchment areas. In Gävle and Falun, they were held at the hospital whilst in Uppsala they were arranged at the university. Each group were scheduled to meet once a week for 10 weeks and included up to 8 participants. Participants were not excluded if they did not attend all ten sessions.

The individual sessions were also held at all three locations. Each participant was offered 4-8, one-hour sessions. The first four sessions contained all the core components. Participants who, after these four sessions, still had problems that related to the core components covered in the initial assessment were offered additional sessions if they wanted; this decision was made in conjunction with the therapist and the patient.

Core components of the intervention given in Step II

Introduction to stress and stress responses:

This component addressed both physiological and psychological responses to stress. Information regarding physical symptoms, such as fatigue and what women who do experience fatigue can do to relieve the symptoms, e.g. exercise, were discussed. Moreover, differences between short- and long-term stress were highlighted, and participants were introduced to stress responses due to cancer diagnosis. Furthermore, a stress diary to monitor one's own stress reactions was introduced as a tool to identify emotion generating stimuli and everyday life situations where participants experienced stress. Furthermore, participants learnt how to utilise "the stop button" in these situations. In the stop button exercise, the participant takes a deep breath, holds the breath for a moment and then exhales. The purpose of the exercise is to both physically relax by the deep breath and exhale and to allow time to the participant for reflect before reacting.

Negative thoughts and stress behaviour:

According to the cognitive theory, each individual holds mental schemas of the world, which allows one to interpret information of the world around them, including, past experiences, assumptions and expectations of the future. These schemas are vital for the way we interpret the world around us [111, 115]. Therefore, this component focuses on automatic negative thoughts, especially, to become aware of and to identify one's negative thoughts and how to change these thoughts. Furthermore, typical characteristics for stress behaviour were discussed.

Irritability and anger including typical stress behaviours:

A cancer diagnosis can be the straw that breaks the camel's back and triggers intense emotional reactions, which may be expressed by aggravation, anger and hostility, reactions close to emotional reactivity. The main focal point of this session was to identify what anger is and situations and reactions connected to one's own anger reactions. Participants were asked to identify situations in which they had reacted with anger; thereafter, participants were engaged in a discussion about how they could have acted and reacted differently in that situation.

Quality of Life and expectations of life:

About 1 out of 5 cancer patients seek additional support after their cancer diagnosis. Female cancer patients are more prone to seeking additional support regarding worries about expectations of life after a cancer diagnosis [78]. Therefore, the focus of this component was on quality of life post-diagnosis. Participants were asked to reflect on and discuss their quality of life, and in specific what is important to them now, what to expect of life after the cancer trajectory, and how they could accomplish their goals.

Reactions to a cancer diagnosis:

A woman who is diagnosed with breast cancer is not alone in being affected by the cancer diagnosis. Most often, both family members and friends are also affected, and their presence or absence and reactions to the cancer diagnosis may have an impact on the well-being of the woman who is affected [78, 125]. Common psychological reactions in relation to a breast cancer diagnosis were addressed in this component. Participants were asked to discuss with whom and how they would like to share their thoughts and feelings about the cancer and who do they want/expect support from.

Sexuality:

Sexual health includes physical, emotional, mental and social well-being, aspects that can be affected when diagnosed with breast cancer. The sexual health of women with breast cancer may be affected by the surgery, i.e. removal of part of or the whole breast, which may affect the way in which one

views oneself. Moreover, the cancer treatments can also have an impact on the sexuality through bodily pain and dryness of the mucous membranes in the vagina [78]. It has been acknowledged that healthcare professionals seldom discuss the sexual health with their cancer patients [78]. Therefore, both physiological and psychological aspects of breast cancer treatments were discussed and emphasis was on how surgery of the breast and adjuvant treatments can/have affected one's identity and sexuality.

Recapturing

The last session recaptured the key points of the core components. Participants also got the opportunity to reflect on what aspects of the components have been useful and important to them.

Data analysis

Study I

To examine the longitudinal association between intrusion, avoidance and psychological distress, an ordinary least square regression-based analytical framework was used.

Study II

Means, standard deviations and minimum and maximum were calculated for continuous data. A principal component factor analysis with direct oblimin rotation was used to examine the factor structure of the ELSS. An exploratory factor analysis was performed, which generated four factors. Each of these factors had an eigenvalue greater than one but after a closer examination the factor structure was not logical. Therefore, to obtain the most optimal factor structure, the ELSS was forced into two factors. The analysis was interpreted in the following manner: the highest factor loading was identified for every item and the item was allocated to that factor. Only factor loadings over 0.30 were considered significant. The internal consistency of the ELSS was assessed by the calculation of Cronbach's alpha. Moreover, to assess the concurrent validity, Pearson's correlation coefficient was calculated for the ELSS and the STAQ.

To determine how much of the variance in emotional reactivity could be explained by age, income, having children under the age of 18, work, other health complaints, Nottingham Histologic Grade (NHG) and waiting period, a stepwise regression analysis was performed. The variables included in the analysis were selected based on their predictive value, as reported by previous studies [66-68, 126].

Studies III and IV

The effect of the SME (Step I) was evaluated by comparing the participants who attended the SME with non-attending participants. Women who participated in the SME were not randomised; instead, all women were offered Step I. Therefore, we wanted to minimise possible confounding bias. Prior to the analysis, a model [127] was proposed to identify covariates, which could increase or reduce the confounding bias, such as demographic variables. From the model, it was suggested that strata based on IES- and HADS-scores would minimise this bias. The first stratum contained participants who scored in the lowest 25%, next strata included participants who scored in the next 25% and so on, dividing participants into four different strata.

According to the power analysis, a total of 128 patients (64 patients per intervention arm) were required to detect significant differences between the two intervention arms in Step II (power 0.8, p .05, ES = 0.59). The power analysis was made based on IES and previous findings from Arving *et al*'s study [39].

Moreover, in order to detect significant differences between the two intervention arms, both intention to treat and per protocol analysis were used. The intention to treat analysis included all participants in the intervention arm, which they were randomised. The per protocol included participants who completed the intervention program. Mann-Whitney tests were used to address the main hypotheses of the difference in the main outcomes between the two interventions groups.

Ethical consideration

The studies included in this thesis were performed according to the Declaration of Helsinki [128] and Swedish law [129]. Ethical approval from the Regional ethical review board in Uppsala was received for all studies included in this thesis (dnr 2008/382, 2013/131). Written consent was required from all participants prior to inclusion. The intervention was delivered and supervised continuously by specially trained staff so that potentially harmful or toxic aspects of the interventions would be detected early on in the treatment and corrected immediately. No medical risks associated with study participation were anticipated.

All women who were approached for the intervention study were informed about assessment points and Step I (SME). All participants were informed that if they did not wish to answer a specific question in the questionnaire they were free to make a mark in the margin to indicate that they did not wish to fill in the answer. Women were also provided with contact information to all researchers involved in the study, and encouraged to contact us if they had any questions or enquiries regarding any issue in the

study. Several of the women did contact the research group with both study specific questions and questions in general regarding breast cancer. Women who mentioned more severe concerns were given contact details and encouraged to contact a counsellor who would be able to provide more advanced support than the scope of the study.

Moreover, women were not informed about the more intense intervention, Step II, when they were included to the study. When the study was designed, a discussion was held regarding the ethics of not telling the women about Step II and the possible risks of revealing the intention of Step II prior to the screening. Although the risk that participants would report more distress than they actually experience just so that they can partake in the intervention was small, we still wanted to control for this by not revealing Step II and screening for distress prior to informing the women about Step II. It is possible that this decision has impacted the inclusion and results of Step II.

The sample of random women who were included in study II was informed about the purpose of the study as well as the voluntary nature and confidentiality of the study. All women who were contacted for the study had the opportunity to fill in and send in a part of the cover letter, which stated that they did not want to participate and did not want to receive a reminder. Returning the completed questionnaire was considered as giving informed consent to the study.

Results

Study I

Main findings

The study evaluated the longitudinal association between intrusion, avoidance and psychological distress and the mediating role of avoidance. Furthermore, an estimation of the total effect and the direct effect of intrusion on psychological distress was obtained, as well as the indirect effect of intrusion on psychological distress through avoidance. The results indicate that avoidance did not mediate the relationship between intrusion at T1 and later psychological distress. (See Figure 3 for model and coefficient for each path).

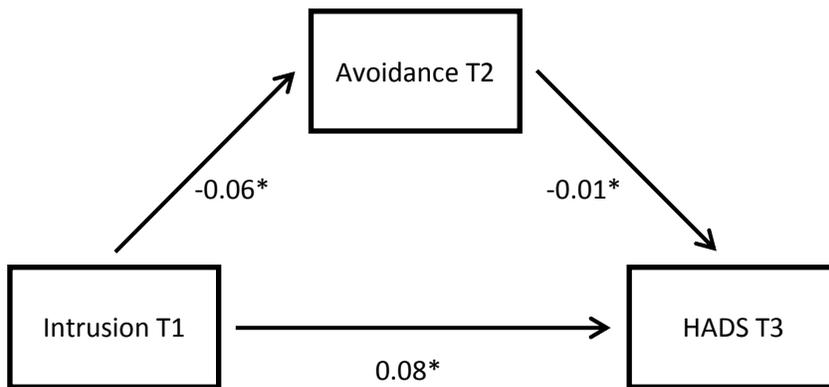


Fig. 3. Regression coefficients for observed model longitudinal association between intrusion, avoidance and psychological distress and the mediating role of avoidance. * p -values $> .05$.

Study II

Main findings

The most optimal factor structure was obtained by forcing the ELSS into a two factor solution. The items loaded onto the same factors in the two samples, except for one item, which differed (item 13). The two factors provided a logical explanation of 49% in the RW (random women) sample and 45% in

the BC (breast cancer) sample. The internal consistency was high in both the BC and RW sample (Cronbach's alpha = 0.91, and 0.92, respectively). Moreover, there was a positive significant correlation between the ELSS and the Simplified Type A Questionnaire (STAQ) (gold standard) in the RW population ($r = .819$, $N = 171$, $p = .00$).

To determine which, if any, variables were associated with emotional reactivity in the BC sample at the time of inclusion, a stepwise multiple regression analysis was conducted. The results indicated that the only variable associated with emotional reactivity was younger age ($F(1, 304) = 20.70$, $p < .00$), which accounted for approximately 6% of the variance in emotional reactivity (Adjusted $R^2 = 0.061$).

Studies III and IV

Main findings

In the project, a total of 62 SME (stress management education, Step I) sessions were offered between August 2009 and October 2011. In general, strata with the highest median scores at T1 improved significantly (T2), independent of participation in SME. Thus, no significant differences were found between women who participated in the SME and non-participants of the SME, with all participants showing the same pattern, regression towards the mean over time.

Of the 425 participants included in the study, 304 participants (72%) reported elevated levels of distress at three-months post-inclusion and were invited to participate in the intervention (GSM and ISM in Step II). A total of 149 participants (49%) declined participation; thus, 77 participants were randomised to the group setting and 78 participants to the individual setting. When examining if and how the participants differed from the non-participants of the intervention, some statistically significant differences were found. The ISM group reported more other health complaints $\chi^2(2, N = 302) = 6.260$, $p = .044$, and participants in the GSM group underwent more chemotherapy $\chi^2(2, N = 301) = 7.050$, $p = .029$. Moreover, those who declined the participation in the intervention reported significantly less anxiety ($F(2, 300) = 6.623$, $p = .02$) and depression ($F(2, 300) = 5.269$, $p = .006$), and significantly less reduced activity ($F(2, 301) = 5.466$, $p = .005$) at T2 than those who participated in the intervention.

Both studies III and IV evaluate the intervention in the same manner, although the two studies include different outcome variables. Study III evaluates the intervention in relation to intrusion, avoidance, anxiety and depression. Study IV investigates the possible benefits of the intervention on emotional reactivity and fatigue. Although study III found significant improvements over time for those women who participated in the intervention, on

outcome variables measured by IES and HADS, there were no significant differences between the two intervention arms on any of the outcome variables in either study III or IV.

Discussion

Discussion of key findings

This thesis explores subjective- and psychological distress, emotional reactivity and fatigue among women with breast cancer who are about to start adjuvant treatment.

Study I

In study I, we evaluated the cognitive processing model proposed by Creamer *et al.* [118]. The results suggest that avoidance does not mediate the relationship between intrusion and later psychological distress in an early stage breast cancer population. It is plausible that women who were included in the study did not experience the cancer diagnosis as a sufficient trauma to trigger the cognitive process, according to the model. A possible explanation for this could be that a majority of the women in the study region (approximately 80–90%) were aware of their breast cancer diagnosis at the time of surgery [130]. Moreover, the 5-year survivor rate in the Nordic countries has increased during the past few decades [8], and the survival rate in Sweden is among the highest in the world [10]. The increase in survival hopefully impacts the stigma associated with a cancer diagnosis and the possible perceived threat of a premature death a cancer diagnosis may symbolise. The appraisal of the threatening event is essential in the development of PTSD and PTSD-like symptoms. This is because events (or stimuli), which have previously been perceived as safe, have become associated with danger. This association with danger results in high cognitive arousal [131]. If the memories associated with the trauma are not perceived as threatening or frightening, they will not result in cognitive arousal; hence, the cognitive processes will not be activated. This notion is supported by Manne *et al.* [119] who found support for the proposed model in the late stage cancer group but not in the early stage cancer group, which is in agreement with the results of the present study.

Study II

In the second study, we set out to do a first validation of the ELSS and to explore emotional reactivity among women with breast cancer. Emotional

reactivity is not well understood or explored among women with breast cancer and the ELSS has previously not been used in this population. The results showed that the ELSS has acceptable validity and reliability. The factor structure of the ELSS was similar in both the RW and BC samples, except for one item, and correlated well with the STAQ (which was used as gold standard).

Furthermore, women in the present study report lower levels of emotional reactivity compared to patients in previous studies evaluated with the ELSS [53, 132-134]. These results should be interpreted with caution since the ELSS has previously not been used in a cancer population. Although the results of the present study indicate that women with breast cancer do not report high levels of emotional reactivity, previous studies indicate that patients with cancer do find small unexpected everyday stressors, which trigger emotional reactivity, as more disrupting than a cancer free comparison group, especially arguments or disagreements [56]. Emotional reactivity in cancer patients has also been associated with higher mortality in breast cancer patients, five years post-diagnosis [51].

Moreover, when examining variables associated with emotional reactivity at the start of curative treatment, younger age was the only variable associated with emotional reactivity; other variables included were not significant. This finding is not surprising considering that several studies have reported that younger women tend to report lower quality of life (QoL) and more symptoms after a cancer diagnosis [135-138]. Avis *et al.* [135] found that younger women report more relationship problems than older women. Considering these findings and the findings of Costanzo *et al.* [56] who reported that cancer survivors are more sensitive to arguments and disagreements, it is not surprising that younger age was associated with emotional reactivity in the present study. Although these findings are in line with previous studies, more research is needed, as emotional reactivity is not well understood in cancer patients.

Studies III and IV

In studies III and IV, we evaluated a stress management intervention, delivered either in a group setting or an individual setting. Moreover, in study III we evaluated the stepped care approach of the intervention. In accordance with the stepped care approach, the aim of the SME was to reduce the number of women who reported elevated levels of distress at T2, thus requiring a more extensive treatment. The results of this study do not support the assumption that using a stepped care approach reduces the number of breast cancer patients who require a more extensive treatment at three-months post-diagnosis. These results should be interpreted with care, as it is plausible that the intervention in SME is not sufficient enough to decrease distress levels. The SME consisted of a 2-hour session addressing information about breast

cancer treatments and common stress reactions following a breast cancer diagnosis. With the development of the Internet and other medias during the past few decades, medical information has become more easily accessible by patients and the general population. The information seeking pattern among cancer patients is changing [139], as a new generation of women are getting diagnosed. We are at a time where a transition from a generation that is made up of immigrants in the world of Internet and information seeking is being replaced by a generation that is native to the world of information as it is today. Today's patients are more prone to seek information on their own [139] and are an active part in the choice of treatments [140]. Breast cancer is the most common cancer type researched on the Internet [139], and over 368,000 Google searches are performed each month on the topic [141]. Nguyen *et al.* [140] found that women with breast cancer who searched information on the Internet also searched information on treatment options, and about half of these women sought information on symptom management. Considering the results of the present study, we suggest that information-based interventions and patient education interventions need to be reformed to address this new age of information. Information about the disease and treatment options might not provide participants with new information, as this information is freely available on the Internet; therefore, the interventions showed no effects in the evaluations. If these types of interventions are to be used and implemented, they need to be revised. It is possible that interventions which contain just information are not sufficient enough and other components need to be included if effects of the intervention are to be expected.

The primary aim of studies III and IV was to evaluate the mode of delivery of the intervention. Although the results of study III indicated that both intervention groups reduced their levels of distress (subjective and psychological), there were no significant differences between the two intervention arms. One interesting and surprising finding was that only about half of the women who were randomised in to the second step of the intervention (GSM and ISM) accepted participation. The dropout was largest in the group intervention where only 54% of the randomised participants attended the group intervention compared to 91% of the participants who were randomised to the individual intervention. A majority of the women who rejected participation in the second step stated that they did not feel distressed and therefore did not have a need for a stress management intervention. However, these women did report clinically significant levels of distress at T2 (screening). Only 2% of the non-participants stated that they already had sufficient support. Similar result has been reported by Thalén-Lindström *et al.* [85]. In their study, only 43% of the participants who were offered a referral for psychosocial support accepted, which was lower than anticipated. The reasons for not accepting a referral were similar to the ones stated in our study; no need for support and too long a distance to travel. These findings are in line

with the findings of Moyer *et al.*'s review [142], which indicates that patients with cancer do not utilise psychosocial resources naturalistically. One of the studies referred to in the review is a study conducted by Hellbom *et al.* [143]. This particular study is interesting since it is conducted in the same catchment area as the present study and reported that 25% of the participants who rejected participation in the project stated that they did not have a need for psychosocial interventions. Although it is important to note that one out of four did not feel the need for psychosocial interventions, Hellbom's study differed from the present study and Thalén-Lindström's study [85] in a vital way. Participants in the present study and the study by Thalén-Lindström were screened for distress, contrary to the participants in Hellbom's study; hence, it was expected that more women would express a need for psychosocial interventions.

Although women in the present study stated that they did not feel the need for psychosocial support, it is possible that individuals were intimidated by the intervention, as participation in the intervention would most likely involve confrontation and re-experiencing of fears and anxieties associated with the cancer diagnosis. For individuals with PTSD or PTSD-like symptoms, the re-experiencing of the trauma, e.g. through discussions, is distressing and anxiety evoking. In a study by Andrykowski *et al.* [36], participants who reported distress indicated that they did not want treatment since the treatment would require re-experiencing their breast cancer.

It is important to consider how to successfully recruit participants to psychosocial interventions. One aspect, which should be considered when planning an intervention, is the mode of delivery. Our experiences from the study indicate that preference can be a key factor for the clinics when recruiting patients to interventions. Participants who are offered (or randomised in studies) interventions that they do not find attractive are more prone not to participate or more likely to terminate participation prematurely [102]. These findings are supported by Edgar *et al.* [144], who experienced problems in including patients to the group intervention of their study. Participants in Edgar's study stated that they preferred to choose whether or not to participate in a group.

Moreover, interventions differ in the amount of involvement and active participation required of the patient. Psychosocial interventions vary in how much active participation they require. Patients vary in the degree they are willing to engage in interventions and some are unwilling to participate in interventions, which require active participation [144]. The intervention in the present study required that participants be active both during and between the intervention sessions. The intervention was derived from CBT and utilised techniques from CBT; it was problem focused and action oriented, i.e. the therapist helps the participant in solving their problems by assisting in selecting the strategies to address these problems. Moreover, the participants were asked to work on home assessments between the sessions. When

planning interventions in both study and clinical settings, it is important to consider these two aspects, preference and active participation, as these aspects can hinder the inclusion of participants to the intervention.

Methodological considerations

One of the strengths of study I was the homogeneous study sample. When Manne *et al.* [119] evaluated the cognitive processing theory in a cancer population, the study included a heterogeneous study sample. By including a homogeneous study sample of women newly diagnosed with breast cancer in the present study, we were able to control for the possible impact of cancer reoccurrence and cancer site on cognitive processing. It is plausible that a specific cancer types is experienced as more threatening depending on the prognosis. Moreover, in the study we controlled for avoidance at T1 and distress at T1 and T2. These variables are often experienced simultaneously; therefore, it is plausible that a longitudinal relationship between these variables can be explained by a longitudinal pattern of psychological disturbance characterised by constant high levels of intrusion, avoidance and distress.

Participants in study I were originally recruited for the main intervention study. We wanted to evaluate the cognitive processing model in a sample of women who had not received any psychosocial interventions. Therefore, we excluded all women who had participated in the second step of the main intervention study (Studies III and IV). Hence, we only included women who did not report clinical levels of intrusion, avoidance or distress at T2 and those who reported clinical levels on these variables but who declined participation in the interventions. Although inclusion of participants to the study opposes a risk for bias, it is believed that the study sample is representative of the group we set out to study. The reason to believe this is two-fold: participants who reported clinically high levels of intrusion included in the study did not significantly differ in the main study variables (intrusion, avoidance and distress) when compared to the women who reported clinically high levels on these variables and who participated in the intervention. Furthermore, the levels reported on these variables in the present study corresponded to the levels reported by Manne *et al.* [119] in their study.

To our knowledge, study II is the first cross-sectional study that explores emotional reactivity in women with breast cancer. We set out to do a first validation of the ELSS and to explore which, if any variables would be associated with emotional reactivity in this population. Although the study is just a first step of the validation of a new measure, the study has some strength. A random sample of women from the same catchment areas and with similar demographic backgrounds as the breast cancer sample was included as a comparison group. Moreover, we used a validated questionnaire as gold standard.

One of the major strengths of studies III and IV was that the intervention was well planned and controlled for. The intervention was manual-based, and both intervention arms contained the same core components although the mode of delivery differed. All nurses involved in the intervention were well trained in the techniques and the components of the intervention prior to the start of the study. The training comprised of training over several days, which was held by staff who were experienced in the method and components used in the intervention. Monthly supervision was also provided to the nurses who delivered the intervention. The aim of the supervision was to provide mentorship in general and to provide specific support on how to handle situations, which could have arisen in both the group and individual sessions. To ensure that the intervention delivered did not differ between the three study locations, the intervention was monitored by audio recording. The aim of the monitoring was to ensure that the sessions contained the same core components. When the nurse had finished her first group, i.e. all ten sessions for one group, sessions 1 and 4 of the next group were audio recorded and analysed to ensure high fidelity. The individual sessions were monitored during the second session with two different participants. An experienced psychologist trained in CBT and with extensive experience in CBT interventions for cancer patients was responsible for the monitoring.

Considering that there were no significant differences over time or between the two intervention groups, it is possible that a rigid manual-based intervention is not suitable for women with breast cancer. Today there are several standardised treatment regimens considering, for example, depression and anxiety disorders [103, 145]. The experiences from the research group do not support the notion that a standardised treatment regimen is suitable for women with breast cancer. In short, CBT is governed by principles and not by rules. Therapists practicing CBT have an arsenal of different techniques but are required to be flexible and adherent to the needs of each individual patient and adjust the techniques to the individual and the problem. This requires the therapist to be knowledgeable and comfortable in both behavioural and cognitive principles and the techniques that can be used both to reinforce and to extinguish behaviours [111]. It is possible that since the intervention in the present study was manual-based, the therapeutic progression was hindered by the manual, since the core of CBT is each patient's unique problems and requirements which direct the therapy [111]. The general principals of cognitive theory support this notion. In cognitive theory, it is argued that it is not the issues or problems we face per se, which make us regard them as problems, but rather our way of interpreting these happenings, which create the problem experienced [111, 115]. Therefore, the therapist needs to be attentive to the individual problems and interpretations of experiences each individual patient experiences.

Moreover, since the nurses delivering the intervention were encouraged to deliver the intervention according to the manual, it might have hindered

them to use other techniques, which might have been more appropriate for the individual patient and problem, hence hindering the therapeutic progression. Arving *et al.* [39] found that a psychosocial intervention did have effects on the psychological well-being of women with a newly diagnosed breast cancer. The intervention was similar to the one used in the present studies, although it differed in that it was not manual-based and the nurses were able to adjust the intervention to the individual patient and their individual problems that needed to be addressed.

One limitation of the intervention study (studies III and IV) is the lack of a control group. As in any study, we had to carefully make decisions on the study design, decisions which both included pros and cons, hence we decided to not include a control group due to three major reasons. Firstly, the aim of the two studies was not to evaluate the intervention per se, but rather to evaluate the mode of delivery by comparing the two intervention arms (GSM and ISM) as stated in the study protocol; hence, we are not able to draw any other conclusions except for that there are no differences between the two intervention arms considering the outcome variables. Secondly, it has been well documented that CBT in proximity to a cancer diagnosis reduces the risk of PTSD and has a positive effect on QoL and psychological well-being, and both the Swedish Council on Technology Assessment in Health Care (SBU) and the Norwegian Knowledge Centre for the health services (NOKC) concluded in their reviews that CBT is beneficial in preventing future distress disorders ([103, 146, 98]. Thirdly, by including a control group the number of participating women in the study would increase significantly to gain sufficient power in the statistical analysis. In hindsight, although we are not able to draw further conclusions from the results, the decision not to include a control group was more beneficial to the study than expected, as we struggled with the recruitment of women to the intervention.

Conclusions

The present thesis provides information regarding the subjective- and psychological distress, emotional reactivity and fatigue among women with breast cancer. The evaluation of the cognitive processing model supports the notion that a majority of women with early stage breast cancer process the trauma of a cancer diagnosis in a satisfactory way. The cognitive processing model is not sufficient in explaining the variations in distress experienced by women who are diagnosed with an early-stage breast cancer. However, we still have not answered the question of cognitive processing in women with breast cancer, but the combined results from the present study and Manne *et al.*'s study [119] indicate that early- and late-stage cancer patients require different types of support, as the cognitive processing seems to differ between these two groups.

Moreover, the results from study II indicate that women with breast cancer may experience some emotional reactivity and younger women may experience more emotional distress. Emotional reactivity can be monitored with the ELSS, which showed acceptable validity and reliability. The evaluation of the ELSS was a first step in the validation of the instrument; however more research is needed, as the aspect of emotional reactivity among women with breast cancer is not well understood.

The results from studies III and IV indicate that Step I of the intervention did not significantly reduce distress levels between inclusion and 3-months post-inclusion. Furthermore, mode of delivery of the stress management intervention did not have significant benefits in either intervention arm, but there are clinical implications that should be considered. During the study, it was problematic to include women to the intervention, especially to the group setting. This suggests that it is important to consider the preference of the participants when planning interventions.

Clinical implications and future research

In clinical practice, knowledge regarding the psychological problems women with breast cancer experience is a vital step in providing the right type of care to each individual. This can be obtained by screening for psychological problems, which is included in the NCCN recommendations regarding clinical guidelines for distress management [104] and the national cancer rehabil-

itation strategy [78]. The patient should be provided with feedback and information regarding the available resources provided by healthcare professional. In future studies, it is important to consider how and when patients are screened for distress. Which measures catch the issues that the patient needs and wants help with? It is plausible that the instruments, which are traditionally used to screen patients, are not sufficient enough and may not actually identify the issues that are important for the patient. Patients might wish to get help with other issues than the ones, which are clinically identified as important, for example, existential concerns/worries.

The results from the studies included in this thesis highlight the need for psychosocial interventions, which are carefully planned. If psychosocial support is to be provided to women with breast cancer, it is important to consider the mode of delivery of the intervention. The results indicate that women are not willing to participate in group interventions, even though they might deliver several benefits both to the participants and the healthcare providers. At a first glance, group interventions might be attractive to the healthcare providers, as these are commonly considered as being more cost effective than individual interventions, but it is important to consider the cost effectiveness of interventions that are not attractive or attended by the patients.

Future studies should focus on the hesitation, and resistance to participate in psychosocial intervention. An interesting feature of research would be to investigate which aspects influence the decision to take part in an intervention, especially when patients report elevated levels of distress. Why do patients not consider themselves as someone who would be in need of a psychosocial intervention, that are the barriers and which factors would promote participation in these interventions?

Svensk sammanfattning (Swedish summary)

Bakgrund

Bröstcancer är den vanligaste cancerformen som drabbar kvinnor i Sverige och varje år insjuknar över 8,300 kvinnor i bröstcancer. Med förbättrad diagnostik och behandling är det idag möjligt att bota majoriteten av de kvinnor som drabbas, vilket leder till ett ökat krav på cancerrehabilitering med fokus både på den fysiska samt den psykologiska återhämtningen.

Hälften av de kvinnor som i Sverige diagnostiseras med bröstcancer är under 65 år, dvs. i arbetsför ålder. Att balansera arbetslivet med familj samt hantera en bröstcancerdiagnos kan vara ”tuva som får lasset att stjälpas”. Tidigare forskning har visat att en livshotande sjukdom såsom bröstcancer kan ge upphov till posttraumatiska reaktioner. Dessa reaktioner innefattar bland annat påträngande tankar, undvikande beteenden, depression och fatigue. Idag finns dock relativt lite forskning gjort kring speciella stressorer, till exempel vardagslivets stress, bland kvinnliga patienter som diagnostiserats med en bröstcancer.

Internationellt finns det tämligen säker evidens för att interventioner som använder sig av metoder hämtade från kognitiv beteende terapi (KBT) kan förbättra livskvalitet och minska de psykiska påfrestningar en bröstcancerdiagnos kan innebära. Enligt SBU finns starkt stöd för att KBT insatt en till tre månader efter traumat kan minska uppkomsten av posttraumatiska stressyndrom. Dock är det vetenskapliga underlaget för att jämföra olika behandlingsmetoder otillräckliga.

Syfte

Syftet med avhandlingen var att utvärdera en stresshanteringsintervention som syftade till att förbättra det psykosociala välbefinnandet hos kvinnor med en nydiagnostiserad bröstcancer. Vidare syftade avhandlingen till att studera påträngande tankar, undvikande beteende, oro/ångest, reaktioner på vardagslivets stress samt fatigue under det första året efter en bröstcancerdiagnos.

Metod

De fyra delarbetena i denna avhandling utgår ifrån en interventionsstudie där behandlingen ”trappas upp” stegvis utifrån behov. I det första steget erbjuds en lågintensiv behandling (2-timmars stresshanteringsutbildning samt information om bröstcancer och behandlingar) till alla deltagare. Den mer intensiva behandlingen, steg två, innebär en randomisering mellan två olika behandlingsalternativ (stresshantering i grupp eller individuellt). Deltagarna till studien inkluderades från onkologklinikerna i Gävle, Falun och Uppsala mellan maj 2009 och augusti 2011. Alla tillfrågade deltagare planerade att genomgå tilläggsbehandling i form av cytostatika, strålbehandling och/eller hormonell behandling efter operation. Totalt tillfrågades 821 kvinnor att delta i studien, varav 425 (52 %) valde att delta genom att besvara baslinjemätningen. Exklusionskriterier var pågående psykiatrisk sjukdom och patienter som inte talade och/eller förstod det svenska språket. I frågeformuläret ingick instrument som mäter påträngande tankar och undvikande beteende (Impact of events scale, IES; delarbete I, III), oro och ångest (Hospital Anxiety and Depression Scale, HADS; delarbete I, III), fatigues (Multidimensional Fatigue Inventory, MFI-20; delarbete IV) samt vardagslivets stress (The Everyday Life Stress Scale, ELSS; delarbete II, IV).

Delarbete I syftade till att utvärdera en kognitiv modell hos kvinnor som inte fått psykologisk hjälp efter sin cancerdiagnos. Studien inkluderade 189 kvinnor som deltog i interventionsstudien, men som exkluderats från steg 2 interventionen (n=66) då de ej uppgav kliniska nivåer av stress 3 månader efter diagnos eller de kvinnor (n=123) som tackat nej till deltagande i den, trots att de rapporterat kliniska nivåer av stress.

Delarbete II syftade till att validera ett nytt instrument som mäter vardagslivets stress. Instrumentet har inte tidigare använts i en cancerpopulation och en första validering av instrumentet var önskat. Populationen i delarbete II bestod av alla 425 kvinnor som inkluderats i interventionsstudien (bröstcancerpopulationen) samt en slumpmässigt utvald population av kvinnor från Mellansverige (slumpmässig population) (n = 176).

Delarbete III och IV utvärderade interventionen och inkluderade alla 425 kvinnor som tackat ja till interventionsstudien.

Resultat

Delarbete I: Resultaten från delarbete I gav inte stöd till den kognitiva modellen som utvärderats. Undvikande beteende medierade inte relationen mellan påträngande tankar och oro/depression vid ett senare skede hos kvinnor med bröstcancer som behandlas med tilläggsbehandling.

Delarbete II: Utvärderingen av mätinstrumentet ELSS påvisade god validitet och reliabilitet. Faktorstrukturen hos de båda populationerna var snarlik

och ELSS korrelerade väl med STAQ (gold standard). Den enda variabeln som var associerade med vardagslivets stress vid diagnos var yngre ålder.

Delarbete III och IV: Det första steget i interventionen, lågintensiv stresshantering, reducerade inte antalet kvinnor som uppgav kliniskt förhöjda nivåer av påträngande tankar, undvikande beteende, oro/ångest eller depression vid 3 månader efter diagnos. Utvärderingen av interventionens andra steg, grupp jämfört med individuell stresshantering, påvisade inga signifikanta skillnader mellan dessa två alternativ, dock ökade det psykologiska välbefinnande hos både alternativen. Ett överraskande fynd var det låga antal kvinnor som ville delta i interventionen trots att de rapporterade höga nivåer av påträngande tankar, undvikande beteende, oro/ångest eller depression. Framför allt tackade många kvinnor nej till interventionen efter att de randomiserats till interventionen i grupp.

Slutsats

Studiens resultat visade att majoriteten kvinnor med en nydiagnostiserad bröstcancer upplever kliniskt förhöjda nivåer av påträngande tankar, undvikande beteende, oro/ångest, depression, vardagslivets stress och/eller fatigue vid 3 månader efter diagnos. Resultaten tyder på att de flesta kvinnor i studien kan kognitivt hantera cancertraumat på ett tillfredställande sätt, enligt den kognitiva modellen som utvärderats. Utvärderingen av interventionen tyder inte på att det finns några signifikanta fördelar med att ge en stresshanteringsutbildning i grupp jämfört med individuellt. Dock är det viktigt att ta hänsyn till att ungefär hälften av kvinnorna som blev randomiserade till gruppinterventionen tackade nej till den efter att de fått reda på randomiseringen trots att de rapporterade höga nivåer av påträngande tankar, undvikande beteende, oro/ångest eller depression 3 månader efter diagnos.

Acknowledgements

I wish to express my sincere gratitude and appreciation to all of you who have supported me during my doctoral studies and contributed to make this thesis possible.

First and foremost, I would like to thank *all the women* who participated in the study, thank you for taking time and sharing your experiences and information with me.

I would like to gratefully acknowledge the funding of the study by the *Swedish Cancer Society, the Swedish Research Council and the Regional Research Council for the Uppsala-Örebro Region.*

I am grateful to the surgical and *oncological clinics at Gävle Hospital, Falu Hospital and Uppsala University Hospital* for welcoming the study. A special thank you to all the staff that made the project possible: *Carina Andersson, Susanne Hellerstedt-Börjesson, Kerstin Candell, Lilian Enochsson-Eisen, Sandra Enlund, Helene Halvarsson, Annelie Lagerquist, Inger Malmesjö, Pia Stenberg, Marie-Louise Fjällskog, Marie Elmebring Lindström and Annika Lundquist. Gunilla Burell*, thank you for helping us develop the intervention and for all the small talk about the research during these years and your knowledge, which contributed to the research project. You have given me great input, which has inspired me in my work. *Marie Elmebring Lindström*, thank you for your friendship and all the laughs.

The production of this thesis would not have been possible without my supervisors. Therefore I would like to thank *Karin Nordin, Cecilia Arving and Johan Ahlgren* for the support and guidance during these years. I am grateful you let me try my wings and ideas (which resulted in study I). I would especially like to thank my main supervisor, *Karin Nordin*, for your never-ending support, wisdom and positive attitude. You always believed it was possible. *Cecilia Arving*, you always encouraged me to find my voice in research, which I think I have finally done. And lastly, thank you *Johan Ahlgren*, for your wisdom, excellent clinical and scientific knowledge and positive feedback.

I would like to thank all the present and former Ph.D. students at the Department of Public Health and Caring Sciences for making my time at Uppsala University memorable. *Stina Isaksson*, thank you for sharing not just the office during these years but also your laughs and knowledge with me. How would I ever have made it past the application without you? *Susanne Mattsson* and *Susanne Hellerstedt-Börjesson*, welcome to the office. You have both inspired me, both as persons and as researchers. *Mona Pettersson* and *Annika Ternér*, thank you for all the conversations especially during the past year. A special thank you to Martin Cernvall for sharing your statistical knowledge. Thank you *Maja Bodin*, *Ingrid Demmelmaier*, *Jennifer Drevin*, *Johan Glad*, *Maria Andér Gottvall*, *Maria Grandahl*, *Marie Høyer Lundh*, *Charlotta Ingvoldstad*, *Elenor Kaminsky*, *Marie Kirsebom*, *Afsaneh Roshanai*, *Jenny Stern* and *Josefin Westerberg Jacobson*. I would also like to thank all of the other Ph.D. students at the department for all of your contributions both to the sciences and the laughs during formal and informal conversations during seminars and breaks.

Thank you to all the present and former colleagues at the Department of Public Health and Caring Sciences. Firstly, I would like to acknowledge the fantastic work of *Annika Lundquist*. What would I have done without you? You are a star! Thank you *Marianne Carlsson* for sharing your scientific wisdom. Special thanks to *Carina Ahlstedt* who made it possible at the end! *Helena Lindstedt*, *Ulrika Pöder*, *Öie Umb-Carlsson* and *Christine Leo Swenne* thank you for all the advice and support in teaching. *Catarina Dahlqvist*, *Håkan Jansson* and *Sören Jonasson*, thank you for both administrative and technical support during these years.

I am grateful to all the present and former members of the *Uppsala Psychosocial Oncology network* and the *Cancer Rehabilitation network* for sharing your scientific knowledge, which always enriched the discussions.

Thank you *Henrik Renlund* and *Lars Berglund* at the Uppsala Clinical Research Unit, for help with the statistical analyses.

I am ever so grateful to my former supervisor during my masters, *Gabriel Oxenstierna*, you showed me the world of research. You always welcomed me with open arms and believed in me. Keep up the good work!

Brooke Donnelly, my former course mate and close friend, you amaze me with your wisdom. Thank you for always believing in me and supporting me. You have always made me feel as part of your family.

My dear friend *Jessica Martens*, thank you for being such a fantastic person and friend.

Syjuntan, what would a girl do without a syjunta? Thank you for your friendship and support, *Ann Hallner, Gabriella Jansson, Lena Krohn, Laura Piri* and *Jennie Tång*.

Maria Ravegård and *Karin Åberg Martinsaari*, thank you for all the miles and miles we have spent together, both going fast on fantastic roads and slow in the forest. A special thank you to *Maria Ravegård* for the beautiful graphical design you made for the front cover.

Thank you to my family in-law, *familjen Lilja*, both on *Pilvägen* and *Lillsjöbacken*, for welcoming me into your families and for all the laughs and great dinners. Thank you *Patrik Lilja*, for taking the photo for the back cover.

Thank you to my family, *my brother and my mother*, for your love and support. A special thank you to my mother who always believed in me and supported me no matter what. *Kiitos mamma!*

Last but not least, to my love, *Fredrik Lilja*. You always loved me more than I deserved. You are an amazing person who I love and admire. You are my rhythm and blues. Thank you for being my friend and my companion in life.

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