PSYCHOSOCIAL SUPPORT NEEDS AFTER A BREAST CANCER DIAGNOSIS

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To my family
Emma, Theo, and Magnus

Success is not final, failure is not fatal:
it is the courage to continue that counts.

Winston Churchill

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ABSTRACT

Background: With a growing number of women surviving breast cancer each year in combination with limited healthcare resources, clinics are increasingly pushed to optimize psychosocial support as life after a breast cancer diagnosis not only is a question of survival, but also a question of how well one survives. In light of this pressure, it becomes important to gain an understanding of women's own psychosocial support needs. Today, clinics remain unsure how to optimize psychosocial interventions. This may in part be caused by a knowledge gap of women's own preferences.

Aim: The aim of this study was to investigate the psychosocial support needs of breast cancer-diagnosed women during the year that follows diagnosis. We also wanted to identify variables associated with low psychological well-being as well as exploring the profile of those who accessed psychosocial services.

Methods: Through a population-based registry, we identified 511 women who had undergone surgery for breast cancer at the Sahlgrenska University Hospital, Gothenburg, Sweden. During a 14-month qualitative phase, we constructed a study-specific questionnaire comprising 126 questions. The questionnaire was based upon the themes emerging from in-depth interviews.

Results: We analyzed data from 313 eligible respondents. As presented in Paper I, we found that worrying about one's own children was significantly associated with low psychological well-being during the year that followed breast cancer surgery (relative risk 2.63; 95% CI 1.77-3.90; posterior probability value 98.9%). In Paper II, we found that of those who did not receive chemotherapy treatment, 70 out of 112 women (63%), reported a desire to receive support about the worry about their children and of those who received chemotherapy treatment, 20 out of 49 (41%), reported a need for support immediately following diagnosis before surgery. We identified having children at home ($P<0.0001$), worry about sex life ($P=0.0009$), fear of dying from breast cancer ($P=0.0055$), and worry about one's personal financial situation ($P=0.0413$) as the variables most closely related to worry about the children. In paper III, our results showed no statistically significant difference between the group receiving chemotherapy when compared with the group not receiving chemotherapy (fear of hair loss: age adjusted $P=0.5120$ and fear of nausea: age adjusted $P=0.7230$). Both groups reported a desire to receive psychosocial support immediately following diagnosis. In paper IV, we found that those who desired psychosocial intervention, but for some reason never received it, were characterized as younger women with children living at home who underwent chemotherapy and who reported low psychological well-being at some point during the year that followed diagnosis ($P<0.0001$). Also, the very same demographic and treatment-related profile was identified for those who did receive psychosocial treatment. Second, we found that with the exception of problems centering one's female body, a considerable proportion of those who desired intervention specifically reported a desire to receive it together with their partner.

Conclusions: Data show that there is an association between worrying about one's children and low psychological well-being. Additionally, women wish to talk about the worry about their children early in the treatment process. They also have a desire to receive basic information about treatment-related issues as early as possible, specifically including side-effects from chemotherapy. When exploring the profiles of the women who were 1) interested in, and 2) received psychosocial intervention, we found that mothers with children at home, who had undergone chemotherapy treatment and whose psychological well-being was affected during the year after diagnosis, were at an elevated risk.

Implications: We believe that if we want to better the situation for breast cancer survivors in a healthcare system where resources are scarce, we should immediately after diagnosis offer the mother structured psychosocial support with specific focus on her children and also offer her basic information concerning chemotherapy treatment. As such, we may help her activate and involve the resources in her social network and this needs to happen immediately after diagnosis in order to reduce the risk of a later, more complicated, unnecessarily prolonged rehabilitation process. Additionally, it is our recommendation that clinics allocate sufficient resources so that all younger women who are mothers of children living at home, who indicate that their psychological well-being is negatively affected, as a routine, are introduced to a mental health professional as early in the treatment trajectory as possible.

Keywords: Breast cancer, quality of life, psychosocial needs, parenting, children, psychological well-being, timing, chemotherapy, perception.

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SAMMANFATTNING PÅ SVENSKA

Idag saknas vetenskapligt grundad kunskap om de värderingar bröstcancerdiagnosticerade kvinnor gör av deras livskvalitet och deras behov av psykosociala insatser under året som följer diagnos. Bröstcancer, den vanligaste kvinnliga cancerformen, drabbar var tionde kvinna i Sverige någon gång under hennes livstid. Idag kan den medicinska tekniken behandla bröstcancersjukdomar med god framgång, men det är inte enbart en fråga om att överleva utan också en fråga om hur man mår som överlevande. Behandlingen kan orsaka biverkningar som kan påverka kvinnornas psykosociala hälsa under både kortare och längre tid. Livskvalitet är därför en fråga som får allt mer uppmärksamhet då antalet överlevande bröstcancerpatienter blir allt fler.

Denna studie hade som viktigt mål att ge dessa kvinnor en röst om deras upplevda livskvalitet och behov av insatser för att med den informationen bättre kunna bemöta deras psykosociala behandlingsbehov inom bröstcancervården.

Vi skapade en studiespecifik enkät för att kartlägga bröstcancerbehandlade kvinnors egna behov av psykosociala interventioner under året som följer diagnos. Enkäten utvecklades efter semi-strukturerade djupintervjuer med femton kvinnor som behandlats för bröstcancer ett år tidigare. Frågorna i enkäten validerades tillsammans med tio kvinnor. I studien inkluderade vi alla svensktalande, levande kvinnor som opererats för primär bröstcancer på Sahlgrenska Universitetssjukhuset i Göteborg mellan 1 augusti 2008 och 31 juli 2009.

Av de 434 kvinnor som inkluderades i studien svarade 313 (72%) på enkäten. Det *första delarbetet* handlade om lågt psykologiskt välbefinnande. Av de faktorer vi bedömde som möjligt associerade med lågt välbefinnande fann vi att oro för de egna barnen var den faktor med starkast samvariation. Vi fann även en trend där åldern på yngsta barnet var negativt korrelerad till mammans upplevda behov av psykosocial intervention. I det *andra delarbetet* fann vi att den största andelen av de bröstcanceropererade mödrarna hade behov av att få samtala om oron kring sina barn direkt efter diagnos, innan operation. De faktorer som identifierades som starkast samvarierande med oro för barnen var behandling med cellgifter, rädsla för

att dö av bröstcancer och oro över partnerrelationen. I det *tredje delarbetet* fann vi att kvinnorna ett år efter diagnos gjorde värderingen att de hade velat få basal information om cellgifter och eventuella bieffekter på en gång efter diagnos oavsett om de behandlades med kemoterapi eller inte. I det *fjärde* delarbetet sökte vi identifiera en demografisk och behandlingsrelaterad profil hos de kvinnor som hade samtalskontakt samt hos de som önskade att de haft samtalskontakt under året. Vi fann att de som antingen önskade att de haft samtal och de som faktiskt hade samtal delade samma demografiska profil: de var mödrar med barn som bodde hemma, de hade genomgått kemoterapibehandling och de hade upplevt nedsatt psykologiskt välbefinnande någon gång under året. Vi fann också att förutom de samtal som specifikt rörde kvinnans egna kropp, rapporterade en inte obetydande andel av kvinnorna att de önskade få samtalsbehandling tillsammans med sin partner.

Om den används, kan kunskapen som utfaller från den här avhandlingen bidra till att öka möjligheterna till en mer effektiv rehabilitering bland kvinnor som diagnosticerats med bröstcancer. Baserat på de lärdomar som tagits fram för att förhoppningsvis kunna förbättra för morgondagens kvinnor som får en bröstcancerdiagnos, föreslår vi att alla mödrar som diagnosticeras med bröstcancer genomgår bedömning av psykolog eller kurator i ett så tidigt skede efter diagnos som möjligt. Extra uppmärksamhet kan vid det tillfället ges till oron kring barnen för att hjälpa mamman aktivera sitt eget nätverk. Därutöver kan det vara behjälpligt att efterhöra huruvida kvinnan önskar samtala och få information om behandling med cellgifter i ett tidigt skede.

LIST OF PAPERS

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

I. **Stinesen-Kollberg K.M., Thorsteinsdottir T., Wilderäng U., and Steineck G.** "Worry about one's own children, psychological well-being, and interest in psychosocial interventions". *Psycho-Oncology* 2013; **22**(9): 2117-23.

II. **Stinesen-Kollberg K.M., Wilderäng U., Möller A., and Steineck G.** "Worrying about one's children after breast cancer diagnosis: desired timing for psychosocial intervention".
Submitted

III. **Stinesen-Kollberg K.M., Wilderäng U., Möller A., and Steineck G.** "Struggling for a sense of control in order to be prepared: consequences of chemotherapy-related fear among breast cancer patients".
Submitted

IV. **Stinesen-Kollberg K.M., Möller A., Steineck G., and Wilderäng U.** "The straw that broke the camel's back: exploring the attributes of women's psychosocial support needs after a breast cancer diagnosis".
Submitted.

CONTENTS

INTRODUCTION

Whereas I have always been a very curious person, my interest in research was primarily founded during my time as a student at University of California Los Angeles (UCLA) in the United States where I attended both college as well as graduate school after which I worked in the healthcare field for a total of almost eleven years. After graduation and continued clinical work in the United States and thereafter in Sweden, I knew that I one day would pursue an education in research.

I asked myself why I did things the way I did, how I knew that the interventions I applied to the women I treated were really helpful for them, and whether the problems presented to me in clinic were also the ones most highly prioritized for breast cancer-diagnosed women at group level. In short, I questioned how effective and well-directed "business as usual" was. In my search, I discovered that there is a substantial scientific knowledge gap in the psychosocial field that needed to be filled. This gap, in combination with my early interest in science from my education as well as an intense urge to help ameliorate the emotional pain and improve the lived experiences of women diagnosed with breast cancer, led me to pursue a doctoral degree.

As a doctoral student, I have learned that retrieving new knowledge, first and foremost, means playing a long game in a continuous process consisting of two sides. One quick, creative side that often suddenly sees things clearly, aching to write down the new knowledge on paper and spurring further questions with great enthusiasm. The other side continues to be in a state of confusion and disarray. True to form, it questions every step, every result and conclusion throughout the research process. During my doctoral studies, I have "befriended" this second side and learned that it is not only necessary in order for the research process to move forward, but also learned that it is a natural part of the process. These two sides feed off one another as they are both needed in the pursuit of getting as close to the truth as possible.

Before I began my doctoral studies, I was well aware of the cliché that we may not be able to find the truth to anything. During my doctoral studies I have not only confirmed this cliché to be accurate, but more valuably, I have gained a much deeper understanding of the complexities that lie behind this insight, in effect *why* we may never find the truth. This understanding will undoubtedly be valuable in future research endeavors when assessing how close to the truth my results lie. Nevertheless, even if we may be unable to find "the truth(s)", as researchers, we may never compromise in our aim for them.

This thesis presents my first contribution to the psychosocial research field in my aim toward improved experiences of the many women who have to endure the grim, life-changing reality of a breast cancer diagnosis.

2 BACKGROUND

It is not a coincidence that breast cancer receives so much attention as it is the most common invasive cancer among women worldwide, affecting 1.6 million new women each year [1]. Like in most Western countries, breast cancer statistics in Sweden consistently indicate a reason for public health concern as approximately 30 percent of all female cancer is a breast cancer [2]. During the year 2005-2009, the average annual number of deaths due to a breast cancer in Sweden was 14 out of 100 000 women [3]. Early detection through the use of mammography screening in combination with sophisticated treatment has substantially contributed to improvement in survival rates. The relative five- and ten-year survival rates in Sweden are today 89 percent and 79 percent respectively, which may be compared to 72 percent and 58 percent during the 1970s [4]. The sheer number of women diagnosed with breast cancer indicates that the disease has grown to become a public health concern mainstream society is unable to avoid. With a growing number of women who live with the aftermath of breast cancer for relatively long periods, it is clear that the need to understand its treatment effects and quality of life (QOL) issues becomes paramount [5]. Despite a massive amount of research on quality of life after a breast cancer diagnosis, the evidence-based knowledge gap of when, how, in what form, and what the women themselves desire to receive support about, leaves psychosocial support clinicians with very limited hands-on guidance for their everyday clinical practice.

2.1 BEING A CANCER PATIENT

2.1.1 *QUALITY OF LIFE (QOL)*

Quality of life can be studied as a multidimensional construct. It comprises broad concepts that affect global life satisfaction, including good health, adequate housing, employment, personal and family safety, education, and leisure pursuits. For matters related to healthcare, the concept of quality of life has been adapted to focus on those concepts that are most affected by health or illness, hence the term "health-related quality of life" [6]. Today, there is a fair consensus as to what dimensions health-related quality of life entail. These dimensions have been adapted to Breast Cancer Survivors

(Figure 1) [7] and further described in a model, developed by Ferrell and colleagues [8].

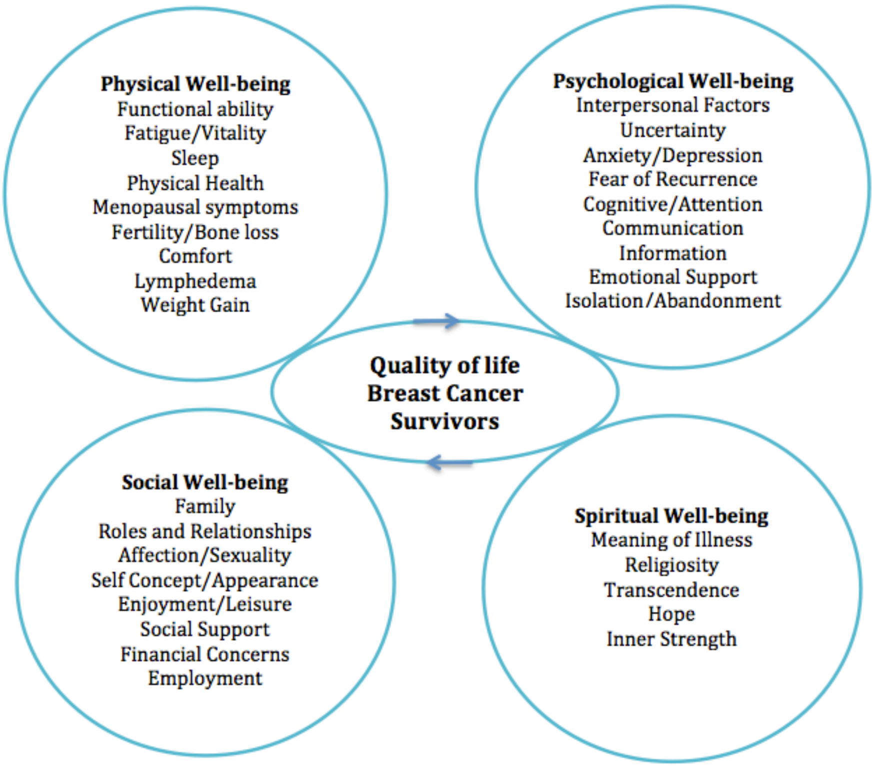

Figure 1. Quality Of Life Conceptual Model Applied to Cancer Survivors, City of Hope Beckman Research Institute (IOM 2006, page 68).

The first year that follows a breast cancer diagnosis is associated with profound challenges for the woman as well as her partner [9, 10] and her children [11, 12]. The challenges cut across physical [13, 14], psychological, social, sexual, and spiritual domains of life [15]. Immediately upon diagnosis, women's psychological distress may be understood in the context of complex decision-making regarding family and professional life as well as one's treatment options. This is an extremely stressful period for younger women in particular, as all demands of everyday life are the most intense while for example caring for a family with small children [16-18]. Intense treatment may result in an increased sense of vulnerability and a threat to one's self, uncertainty for the future, and existential concerns. Understandably, depression and anxiety have been repeatedly documented in this population [19, 20].

2.1.2 PSYCHOLOGICAL WELL-BEING

The question of psychological well-being used in paper I of this thesis aimed at capturing the psychological aspects of subjective well-being. Subjective well-being refers to how a person experiences her quality of life [21]. It includes moods and emotions such as positive and negative affect, as well as evaluations of a person's satisfaction with general and specific areas of one's life [22]. Diener and colleagues argued that subjective well-being may be considered "a general area of scientific interest rather than a single specific construct because the components of subjective well-being represent distinct constructs that need to be understood separately, despite being closely related to one another" [22]. Hence, an assessment of subjective well-being focuses on how a person evaluates her own life. It includes emotional experiences of pleasure versus pain in response to specific events and cognitive evaluations of what she considers a good life [23].

2.1.3 COPING

When encountering a challenging life event, many women experience stress. According to the suggestion by Lazarus, we may understand stress as a consequence of when "pressure exceeds one's perceived ability to cope" [24]. Folkman and colleagues distinguish between two types of coping: the trait-oriented approach, which views coping primarily as a property of a person, and the process-oriented approach, which takes the angle of coping as a response to psychological and "environmental demands of specific stressful encounters" [25]. In all situations, a woman has to evaluate whether an environmental encounter is relevant for her well-being, and if so, in what ways. This decision process is referred to as *cognitive appraisal*. As a part of this, in the process called *primary appraisal*, the woman has to assess, based on her values and goals, whether there is anything at stake for herself in this encounter, such as harm or benefit. In the final process, *secondary appraisal*, the woman has to determine how to deal with the encounter, such as altering the situation, accepting it, finding out more information about it, or stalling in a counterproductive way. Thus, coping is both process-oriented as it highlights what a person thinks and does in a stressful encounter and it is contextual as it is influenced by how one perceives the actual demands and resources for managing this encounter [25]. As healthcare professionals, it is imperative to understand breast cancer-diagnosed women's "good" and "bad" coping through the aforementioned lenses when for instance making complex treatment decisions. Regardless of coping style, however, a proportion of the women diagnosed with breast cancer experience symptoms of depression or anxiety at some point during the disease trajectory.

2.1.4 *DEPRESSION AND ANXIETY*

Depressive symptoms and reactions among breast cancer-diagnosed women have repeatedly been shown [26]. Likewise, although the prevalence of significant anxiety disorder has been less consistently documented, symptoms of anxiety have also been reported in studies with women diagnosed with breast cancer [27, 28]. The Hospital Anxiety and Depression Scale has been used in research to diagnose depression and anxiety [29]. In this thesis, however, I have not used it to identify clinical depression. Rather, it has primarily helped me capture depressive and anxious symptoms and reactions, and secondarily, it has provided me with the possibility to make comparisons with results from other studies.

2.1.5 *PSYCHOSOCIAL SUPPORT*

What is psychosocial support?

In the cancer care literature, the term *psychosocial* has been described as the person's inner world and her relationship with her environment [30, 31]. In this sense, *psychosocial* reflects a close link between psychological aspects of women's experiences and their wider social experience. The word "support", derived from Latin, means *to carry.* In the Merriam-Webster dictionary, *support* is defined as "to hold up or serve as a foundation for something". To that end, psychosocial support involves a range of care modalities and support influencing both the individual as well as the social environment in which she lives. Psychosocial support may be of emotional nature (communications of compassion, caring, and concern) or it may be of practical nature, involving matters like household chores (also referred to as tangible support) [32]. It may not only be provided to the woman herself but also to her next-of-kin such as her partner and her children [33, 34].

Psychosocial support may be provided by family and friends in one's social network and it may also be provided by individuals in a professional capacity, primarily a psychologist or a clinical social worker. Some level of psychosocial support comes with routine healthcare, such as the many brief moments nurses may just stop and listen to someone's concerns for a minute. However, whenever these resources are not available or sufficient, professional psychosocial support is needed. In this thesis, the concept of psychosocial support is referred to as the kind that is provided by professionals.

In the cancer care setting, a broad range of services may help women and their families manage the psychological, behavioral, and social aspects of a breast cancer diagnosis that can adversely impact their well-being [35]. For many women, a proportion of the stressors associated with diagnosis and treatment are often counteracted by a woman's own psychosocial resources (individual resilience, family, and friends). There is an array of developed services to address the variety of women's psychosocial support needs associated with a breast cancer diagnosis. These include, for example:

Supportive counseling: The goal of supportive counseling is to provide assistance with behavioral changes to minimize the impact of the disease as well as help with managing intrusion of the disease on one's family life, school, and work life. It may be delivered by any of the previously mentioned modes. Here, the clinician (often a clinical social worker) and the woman together identify and sort out the mechanisms involved that affect the woman's health status. The woman is provided with an opportunity to reflect upon her own life situation and its options such as those concerning treatment. The sessions may not only result in an insight to her life situation, but may also help her identify which factors in it that may be amenable to change. With an improved capacity to understand her life situation by placing it within a social context, supportive counseling may thus enhance adjustment to diagnosis and treatment [36].

Psychotherapy: Psychotherapy, which may also involve the woman's next-of-kin, are defined by "a wide range of techniques used by a designated professional that have as their common feature the attempt to influence the patient's behavior, emotions, thoughts, and attitudes through psychological techniques, most often verbal interchange, in the relationship between the psychotherapist and the patient" [37]. The term is often associated with psychoanalysis, yet various approaches may be included in this definition such as cognitive behavioral therapy, meaning-centered psychotherapy, and family therapy.

Information provision: Women going through breast cancer treatment report the need for a wide range of information at all stages of the disease trajectory. These include onset of the disease, progression, treatment and its side-effects, and how to access available psychosocial services. Based on clinical experience, they also need to find out about the normal course of their condition, prognosis, and available treatments in order to make the decisions that are consistent with their personal preferences.

Peer support programs: Peer support can be described as a relationship in which people with the same condition provide emotional support to each other and share knowledge about dealing effectively with that condition [38]. To experience someone else succeed helps to build one's own sense of self-efficacy, which is considered a predictor of how effectively individuals can motivate themselves and persevere despite adversity, as well as how much effort they will make in pursuing a course of action [39].

Psychosocial support in the oncology setting may be delivered in person, over a website, by telephone, by the use of a DVD, a CD, or a booklet, and may span across a wide array of topics from family-related problems to problems related to employment and personal financial concerns, all induced by the cancer experience [40]. Altogether, psychosocial support services were developed to enable women, their families, and healthcare providers to manage the psychosocial and behavioral aspects of the illness and its consequences and, as a result, enhance women's health status.

Why is psychosocial support important in the cancer setting?

Experiencing difficult events, such as receiving a breast cancer diagnosis, may significantly impact the social and emotional well-being of the woman, her family, and her friends [41]. Thus, intervening to minimize the emotional trauma through psychosocial support may increase the coping ability of the woman and, as a result, promote her enhanced psychological well-being. So far, with the exception of cognitive behavioral therapy, suggesting it may improve women's adjustment to diagnosis and treatment, results on the effectiveness of psychosocial support on quality of life measures specifically during the treatment phase have been mixed [26, 42, 43]. As such, even though there is some evidence that psychosocial support is helpful, until more solid evidence is available of its effectiveness, humanitarian and ethical values provide the basis and guide for the provision of professional psychosocial support. However, regardless of whether effects on any quality of life measures are detectable or not, psychosocial support and its availability may nevertheless hold a value for those women who desire it. Even though the challenges to improve psychosocial support for the women may seem daunting and at times overwhelming, we must never despair. Rather, in order to deliver quality care during and after treatment, we have to focus on what is important and what we are actually able to achieve [44].

Psychosocial support is not only important because it aims at improving women's well-being, but also because the women themselves tend to report psychosocial support needs [45, 46]. To this end, previous findings show that psychological and needs of everyday living domains were the most frequently reported unmet needs among cancer patients, followed by needs for health information and access to healthcare and support [47]. The definition of *need*, according to the Merriam-Webster dictionary, is "something that a person must have: something that is needed in order to live or succeed". However, some people might say that the understanding of what defines a *need* has commonly been misused as humans really are (in order to survive) essentially only in need of air to breathe and food and water to ingest, as opposed to most things considered "needed". With this as background, the modern understanding of need may have been broadened as it seems to range from basic survival needs that are common to all human beings, to cultural, intellectual, and social needs. As defined in this thesis, the "need" for psychosocial support regarding a variety of problems, refers to the subjective experience of reporting a *desire* for it. In this sense, it is expressed by the way women report that they *believe* they need psychosocial support. Hence, women's desires and wishes may in this thesis be understood as expressions of one's psychosocial support needs.

What disciplines provide psychosocial support and how widely used is it?

In order to help optimize psychosocial support the services are provided by healthcare professionals from a variety of disciplines, including nurses, clinical social workers, psychologists, and chaplains. In a study focusing on providers of psychosocial support, however, professionals from all disciplines agreed that in the oncology setting, clinical social workers were the primary providers of psychosocial services [48].

In Sweden, provision of psychosocial support to both the woman and her loved ones, including her partner as well as her children, has reached the legislative level. As mandated by law since July 1, 2009, healthcare-institutions are obligated to provide age appropriate information and support to family members as part of psychosocial support services (Socialtjänstlagen, 2009:5 10§).

Findings from one meta-analysis study suggest that uptake of conventional treatment is less than ideal [49]. Only about 30 percent of the patients with psychosocial complications appear to receive psychosocial support. Authors point out that the area of "how many with distress want help, how many are offered help, and how many comply with help" is an under-researched one and that, in addition, the quality of the psychosocial care provided is untested. Authors conclude that it is not only the uptake of psychosocial support that needs to improve but we also need to identify the main barriers to receiving it [49]. One barrier may be healthcare clinicians' reluctance to discuss the psychosocial impact of cancer. In one study with 2074 people, only 701 (33.8%), reported that a physician, nurse, or other healthcare professional had discussed with them "how cancer could affect their emotions or relationships with others" [50].

2.1.6 TREATMENT TRAJECTORY

Sahlgrenska University Hospital in Gothenburg, Sweden, hosts one of the larger breast cancer clinics in Scandinavia. Approximately 800 newly diagnosed breast cancer operations and an additional 300 recurrent breast cancer operations are performed at this hospital each year. In 2008, approximately 20 percent of the adjuvant breast cancer-diagnosed women were prescribed chemotherapy treatment and 80 percent were prescribed endocrine treatment.

Commonly, a breast tumour is discovered at routine screening (mammography). However, some women discover a palpable lump on their own and therefore seek diagnostic testing. If tests indicate a breast cancer, the woman is referred to the breast team for a doctor's appointment at which she commonly receives a diagnosis and two more appointments: a date for the surgery and a date for a surgical follow up appointment. Commonly, the time to wait for surgery may be between three and eight weeks long. At the Pathological Anatomical Diagnosis (PAD) follow-up appointment, about three or four weeks after the operation, the patient receives full information about the excised tumour. This includes for example the size of the cancer, the type, the stage, and an eventual spread to the lymph nodes. Hence, the time from diagnosis until the PAD follow-up may span between six and twelve weeks.

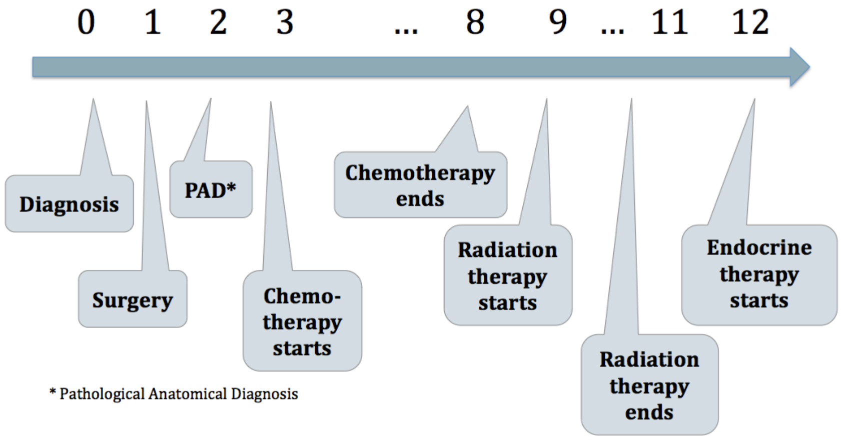

Figure 2. Timeline of breast cancer treatment during the first year after diagnosis.

The operation is merely the beginning of the modern breast cancer treatment (Figure 2). Chemotherapy, if prescribed, may in some cases be given before surgery. Commonly however, it is the treatment modality that follows the operation for the women whose tumor characteristics are classified as high risk. Chemotherapy varies greatly in length of time and combination from patient to patient. However, the most common regimens for adjuvant breast cancer are usually prescribed during the course of 18 weeks: six treatments with three-week intervals. Some women receive radiation treatment immediately following surgery. If however the woman is prescribed chemotherapy treatment, she receives the radiation after the chemotherapy. Radiation is given once per day during five days of the week for a total of either 16 or 25 days. For the women whose breast cancer is hormone sensitive, endocrine treatment follows radiation. It is commonly prescribed for at least five years unless there are extenuating circumstances present such as extremely difficult side effects.

At Sahlgrenska University Hospital today, a woman may be referred to the clinical social worker at the breast team during the first year after surgery. At the time of the data collection in 2008-2009, however, women had access to the clinical social worker of the breast team during the five years that followed surgery. One common need is crisis intervention triggered by the breast cancer diagnosis where the social worker works with the woman individually or with her whole family.

3 AIM

The overall aim of this thesis was to explore and describe aspects of women's psychosocial intervention needs in order to identify suitable areas for interventions that can support the enhancement of women's quality of life after a breast cancer diagnosis.

The specific aims were as follows:

- To identify the personal and healthcare-related factors associated with low psychological well-being.
- To investigate how women, when responding to a questionnaire one year after diagnosis, assessed their intervention needs concerning twelve psychosocial problems during the year that follows a breast cancer diagnosis.
- To explore the sociodemographic and treatment-related profile of those who accessed psychosocial services.

4 PATIENTS AND METHODS

4.1 METHODS

I was interested in learning more about the prevalence and distribution of breast cancer-diagnosed women's psychosocial support needs. I aimed at capturing the self-reported, as opposed to clinician-reported, description of the women's experiences.

According to the tradition at the Division of Clinical Cancer Epidemiology, I began my study with the voices from the women themselves through in-depth interviews, marking the start of the preparatory phase. Following the in-depth interviews, I developed a study-specific detailed questionnaire, which was validated in a face-to-face validation. The preparatory phase preceded the main study phase, which primarily consisted of collecting and managing data as well as analyses and interpretation of results.

4.2 PREPARATORY PHASE

The preparatory phase lasted approximately 14 months and laid the foundation of the study.

4.2.1 *DEVELOPMENT OF QUESTIONNAIRE*

In-depth interviews
I interviewed women who had received a diagnosis of breast cancer one year prior. Each interview lasted two hours. I conducted fifteen interviews, which were all tape-recorded and transcribed verbatim. The women were randomly selected for the interviews from the Swedish National Cancer Registry and informed about the study by postal mail. One week after the information letter had been sent to the women, the women were contacted by telephone, inviting them to participate. I did not know from the beginning how many interviews that would be needed for the study. After ten interviews, however, no new information emerged, indicating that I had reached a saturation of topics. The interviews were semi-structured with focus on psychosocial aspects of the treatment experience and the psychosocial support needs of the women. I asked open directive questions with focus on clarifying

psychological aspects and I used empathic statements as shown to help women disclose their concerns [51]. Themes that emerged from the in-depth interviews were *holding things together, children first, balancing life,* and *new perspectives*. All interviews were performed at the social work clinic, Sahlgrenska University Hospital, Gothenburg, Sweden.

Questionnaire

Based on the interviews, clinical experience, and existing literature, I constructed a questionnaire in accordance with the tradition at the Division of Clinical Cancer Epidemiology [52-56]. This one-concept-one-question questionnaire comprised 126 questions. Commonly, the items (questions) in a questionnaire are summarized to a global score, represented with a number. These types of psychometric scales were to an extent included in my questionnaire package as I used both the Hospital Anxiety and Depression Scale (HADS) and the Female Sexual Function Index (FSFI). After developing the questionnaire, I continued the preparatory phase with face-to-face validations.

Face-to-face validation

At this stage, I wanted to ensure that my questions were understood the way I had intended. Therefore, I invited another set of women who had received a diagnosis one year previously. Together with a total of twelve women in separate sessions, I went through the entire questionnaire and discussed how the women perceived each question, how they were phrased, and the response categories (anchors) to each question. Based on the feedback I received from these meetings, I revised the questions several times until representatives of the participants agreed that the questionnaire was comprehensive and easily understood. With the final version of the questionnaire, I proceeded to carry out the main study.

4.3 MAIN STUDY PHASE

In the main study, I invited the women to participate in the study by sending the questionnaires to them by postal mail.

4.3.1 PARTICIPANTS

All women who had been operated on for a breast cancer diagnosis at Sahlgrenska University Hospital from August 1st, 2008 through July 31st, 2009, were identified through the National Swedish Cancer Registry [57]. I determined that those women who met my exclusion criteria were not eligible to participate in the study. The exclusion criteria were 1) a benign tumor (DCIS), 2) a recurring breast cancer, 3) other cancer history, 4) blindness, 5) unable to read or write Swedish, 6) mental incapacity due to for example mental illness, dementia, stroke, mental retardation, or 7) deceased.

4.3.2 DATA COLLECTION

I began in August of 2008 and sent the questionnaires to all women who had undergone surgery during that specific month one year prior. On the first day of each month thereafter through July 2009, I mailed a letter along with the questionnaire to all women in the extracted cancer registry. The letter included information about the study and its purpose, the right of the woman to decline participation, and information how to contact the researchers who were responsible for the study. I also included contact information for available psychosocial support.

One week after mailing the questionnaire, my administrative research team followed up with a telephone call to those from whom we had not heard. The purposes were to find out if they had any questions about the study or if they needed any of the questions to be clarified. Some women had lost their questionnaire and requested a new copy. During this process, I identified those who met my pre-established exclusion criteria. Upon receipt of the questionnaires, I mailed out a Thank-you card to the participants to show my appreciation. The questionnaires were coded on the back and the code was linked to the identity information, which was only available to the primary researcher of the study.

4.3.3 DATA MANAGEMENT

I transferred all data manually from the questionnaires using the freeware data entry software EpiData 3.1 (www.epidata.dk). EpiData was programmed to only accept appropriate values for every question to minimize the risk for errors.

4.4 STATISTICAL ANALYSIS

Statistical analyses were performed using the statistical software SAS, version 9.3 (Statistical Analysis System, SAS Institute Inc., Cary, NC, USA) and R, version 2.13.2 (R Foundation for Statistical Computing, Vienna, Austria) using the *MICE* and *BMA* packages.

4.4.1 *FORWARD SELECTION*

When performing forward selection, variables are selected, one by one, until saturation and no new variables are added to the statistical model. First, I performed forward selection using the demographic variables. Then, I carried out forward selection using the variables comprising psychosocial problems. At last, I combined those variables that were identified as statistically significant ($P<0.05$) from both previous steps and performed forward selection again.

4.4.2 *MULTIPLE IMPUTATIONS BY CHAINED EQUATIONS (MICE)*

A "completed" questionnaire is not always complete. Sometimes, questions are skipped or missed (missing values). If I were to apply complete case in analyses (as in forward selection), I would have to discard that participant. Therefore, I chose to impute the missing values using the computer software, R. The imputed values were randomly selected based on the response profile of the respondent. In order to minimize the risk that the wrong value was randomly imputed, the imputation was repeated 100 times, thus creating 100 new data sets with imputed values for each missing value. Finally, I performed an analysis on each of the 100 imputed data sets from which the mean value of these effect measures was yielded [58].

4.4.3 *BAYESIAN MODEL AVERAGING (BMA)*

The Bayesian Model Averaging procedure calculates the likelihood for each combination of variables, yielding Posterior probabilities as percentages. These are measures of how likely a certain variable is to be included in the final model. The procedure is restrictive in terms of inclusion of variables. Less than 50 percent indicates no association, 50-75 percent a weak association, 75-95 percent a positive association, 95-99 percent a strong association, and >99 percent indicates a very strong association.

4.5 ETHICAL CONSIDERATIONS

There are a number of ethical considerations needed to guide the research process. To the extent it is possible, we need to protect human subjects from any harm. For this study, asking women questions of very private nature, I recognized that there was a risk that the women would experience a threat against their personal integrity and thus feel distressed when perhaps being reminded of painful experiences. Central ethical principles of any study include the questions of autonomy, informed consent, confidentiality, and respect for integrity. Therefore, the women received written information with particular attention paid to the study aims, potential harms and benefits of participation, and the right to decline participation at any point without any reprisal, i.e. even after a completed questionnaire was returned. In the information letter, we also explained specifically who would have access to the women's personal identity.

I assessed that harm may be inflicted in two situations in this study. First, women may have experienced distress merely from receiving the questionnaire. Second, harm may have been inflicted in the process of responding to the questions. For ethical reasons, I was unable to identify those on the list who met my pre-established exclusion criteria before having received women's consent of participation. In general, however, a previous study (n=1068) measuring cancer survivors' perception of participating in follow-up studies of this type found that the vast majority of the survivors thought that participation was valuable for them [59]. My study was reviewed and approved by the Regional Ethics Committee of the Gothenburg and southern Bohuslän county region (Dnr: 335-09).

5 RESULTS

5.1 STUDY POPULATION

5.1.1 PARTICIPATION RATE

I analyzed 313 returned questionnaires (72%). Through the National Swedish Cancer Registry, I identified 511 women who had undergone surgery for breast cancer from August 1st, 2008 through July 31st, 2009 at Sahlgrenska University Hospital. Since I did not have access to their information until they had consented to participate in the study, I sent the questionnaires to all 511 women. To my knowledge, 434 of them were eligible to participate. Due to my pre-established exclusion criteria, 77 women were excluded due to:

- Ductal carcinoma in situ (DCIS) (n=5)
- Recurring breast cancer (n=6)
- Other cancer history (n=24)
- Language deficiency (n=14)
- Mental illness (n=5)
- Mental retardation (n=1)
- Stroke (n=1)
- Blindness (n=2)
- Dementia (n=5)
- Deceased (n=14)

A total of 121 women did not participate. I do not know how many of these women who met my pre-established exclusion criteria. Of these, 98 women declined participation upon telephone contact and I was unable to reach 23 of them. A significant proportion of the women who declined participation expressed that the year after diagnosis had been so difficult for them that they felt it would be too emotionally painful to respond to the questionnaire as they just wanted to "put things behind". This was the case for approximately 25 percent of the women I reached by telephone.

5.1.2 INTERNAL RESPONSE RATE

A total of 126 questions were included in the questionnaire. Background questions such as demography and treatment, Hospital Anxiety and

Depression Scale, and questions about how frequently someone had been worried about a particular problem were responded to by most women (Figure 3). Of the four sub-questions concerning different types of psychosocial problems, level of concern for the particular problem, desired timing, and the desired form of intervention were the questions with the lowest median internal response rates (91%), with ranges from 82-98 percent, 87-97 percent, and 86-97 percent respectively (Figure 3).

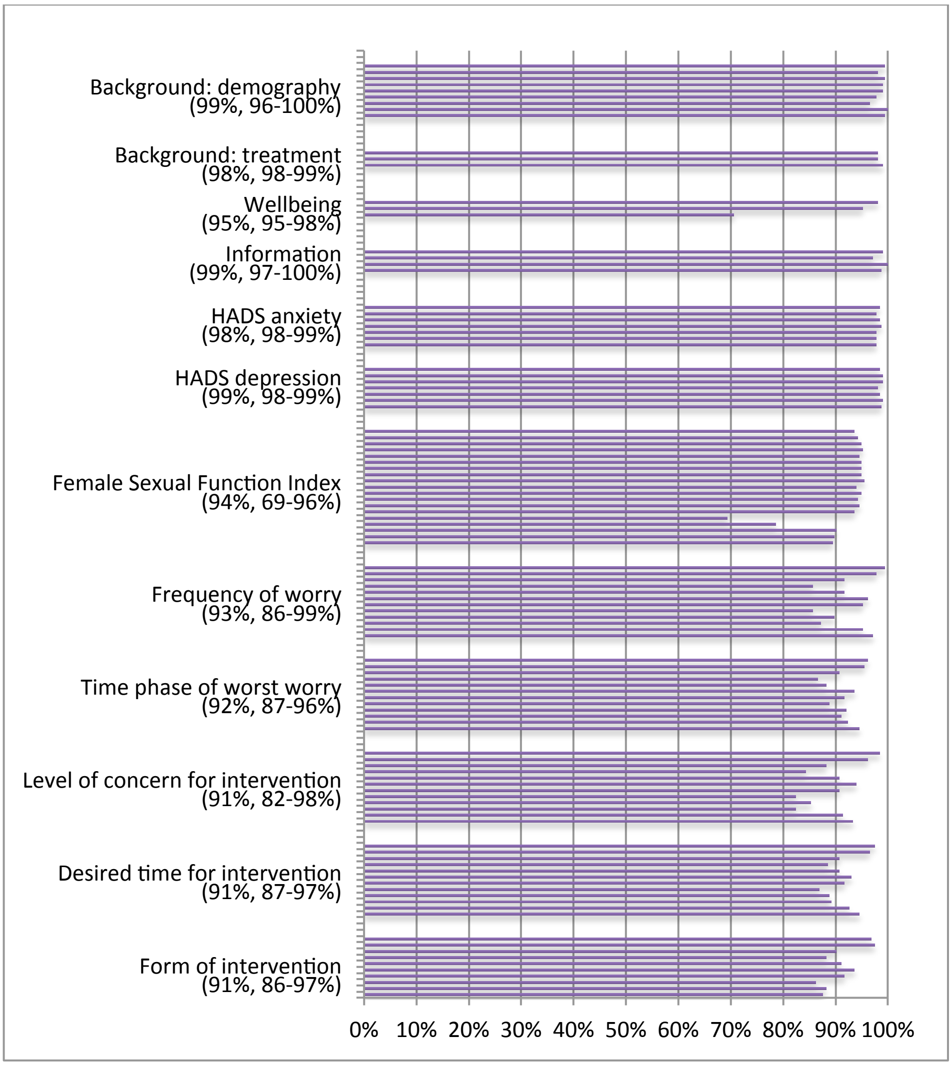

Figure 3. Median internal response rate % (median, range). Each bar represents one question.

5.1.3 CHARACTERISTICS

At the time of responding to the questionnaire, the mean age of the participants was 62 years (S.D. 12.7). The median age was 63. The youngest woman who participated was 26 years old and the oldest was 90. The mean age of the non-participants was 64 (S.D. 14.4).

Most participating women (n=226) had completed high school or more (72%). The greatest proportion of them were either employed (n=129; 41%) or retired (n=133; 43%). The majority was married or cohabitating (n=193; 62%) but a significant proportion lived alone (n=95; 30%).

Approximately half of the women had undergone mastectomy (n=155; 50%) and half a partial resection (n=152; 49%). The majority of the women had removed sentinel node only (n=175; 56%).

Eighty-four women (17%) had received chemotherapy, 193 (39%) had received radiotherapy, and 212 women (43%) had started or were planned to receive endocrine therapy.

In the papers, I divided the results for the Hospital Anxiety and Depression Scale (HADS) into three levels: 0-7 indicating no depression or anxiety, 8-10 indicating low levels, and 11-21 indicating moderate or high levels. The distribution of the HADS scores in the groups were as follows (Table 1):

Hospital Anxiety and Depression Scale	**no. (%)**
HAD-depression	
0-7 Normal	255 (83.3)
8-10 Mild	36 (11.8)
11-14 Moderate	9 (2.9)
15-21 Severe	6 (2.0)
Not stated	7 (2.3)
HAD-anxiety	
0-7 Normal	188 (63.7)
8-10 Mild	55 (18.6)
11-14 Moderate	36 (12.2)
15-21 Severe	16 (5.4)
Not stated	18 (6.1)

Table 1. Distribution of Hospital Anxiety and Depression Scale scores in the group.

The questionnaire also included the Female Sexual Function Index (FSFI). The drop-out rate for this part of the questionnaire deserves mention. Two hundred and four women (65%) responded to all FSFI questions. The rest, approximately 1/3 had skipped at least one FSFI question. The questions with the highest missing values were those stating or implying that the woman needed to have a partner in order to answer.

5.2.1 PAPER I. THE CHILDREN AND LOW PSYCHOLOGICAL WELL-BEING

In paper I, with a posterior probability value (PPV) of 98.8 percent, I found an association between worry about one's own children and low psychological well-being. The second variable associated with low psychological well-being was having received chemotherapy treatment (PPV 97.6%), and worry about one's partner relationship (PPV 94.2%). I also found that the relationship between age of the youngest child of the household and mother's concern to talk to a professional about her worry about her children appeared inversed, as the younger the youngest child of the household, the higher the age adjusted risk was that the mother reported a need for psychosocial intervention during the year that followed breast cancer surgery (RR 1.70 (1.25-2.30)) (Figure 3).

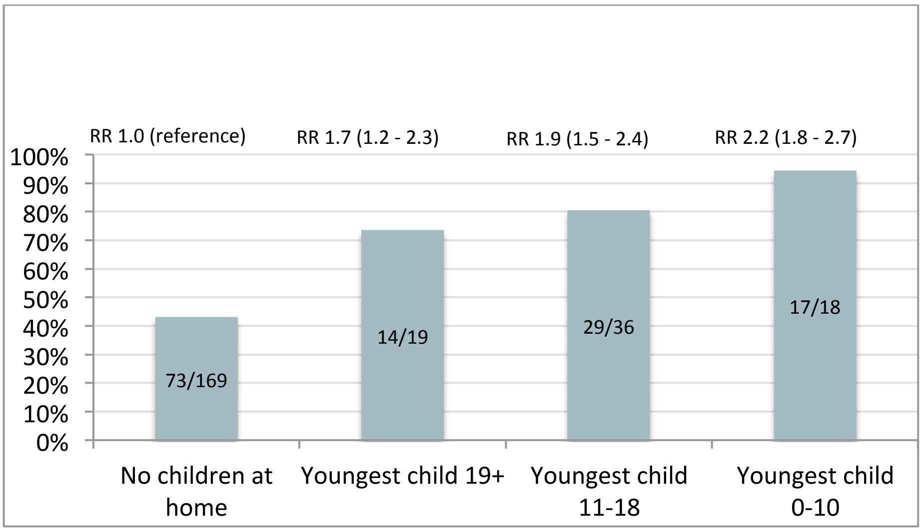

Figure 4. Mothers' concern to receive professional psychosocial support regarding their own children divided into age groups of children living at home and children not living at home. Percentages relate to the proportions of mothers who were concerned to receive professional psychosocial support.

5.2.2 PAPER II. DESIRED TIMING OF INTERVENTION AND THE WORRY ABOUT ONE'S CHILDREN

In paper II, analyzing those women reporting they were mothers (n=280), I found that breast cancer-operated mothers in general desired psychosocial support immediately after diagnosis before surgery for the worry about their own children. However, when I stratified for whether they received chemotherapy treatment or not, there was a statistically significant difference between those who received chemotherapy and those who did not (age adjusted *P*=0.0115) (Figure 4).

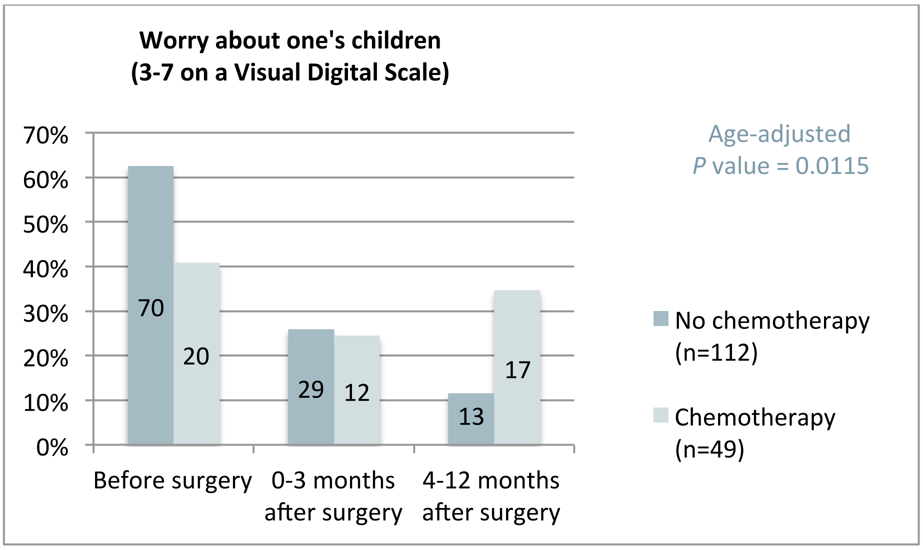

Figure 5. Mothers worried about their children stratified for chemotherapy treatment. Percentages relate to the proportions of women who were worried about their children.

Of those who did not receive chemotherapy treatment, 70 out of 112 women (63%) reported a desire to receive support for the worry about their children and of those who received chemotherapy treatment, 20 out of 49 (41%) reported a need for support immediately following diagnosis before surgery (Figure 4). Additionally, I identified worry about one's personal financial situation (PPV 99.7%), fear of dying from breast cancer (PPV 89.2%), and worry about one's sex life (PPV 80.3%) as variables associated with the worry about one's own children.

5.2.3 PAPER III. A SENSE OF CONTROL AND PREPAREDNESS AS WEAPON AGAINST FEAR

In paper III, I found that one year following diagnosis, women distinctly recalled an immediate desire to receive psychosocial support concerning chemotherapy-induced hair loss and nausea, regardless of receiving chemotherapy treatment or not.

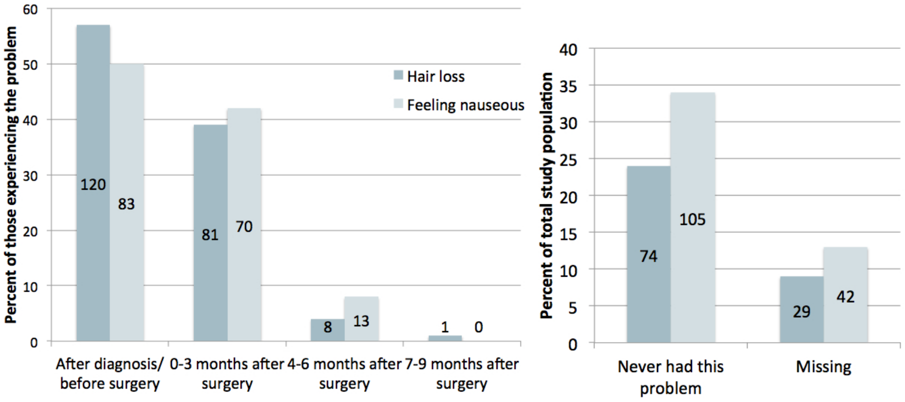

Figure 6. Time when worry about chemotherapy-induced hair loss and nausea was experienced as most troublesome.

One hundred and twenty women out of 210 (57%), reported that they had worried about hair loss already after diagnosis before surgery (Figure 5). In regard to chemotherapy-induced nausea, 83 out of 166 women (50%), reported an immediate worry. Seventy-four and 105 women respectively reported that they had never been worried about hair loss and nausea. In stratified analyses regarding how concerned the women were to receive psychosocial support about these specific problems, I did not find any statistically significant differences between the women who had received chemotherapy and those who had not received it (age adjusted P=0.5120). Forty-eight out of 80 women (60%) who did receive chemotherapy treatment reported feeling concerned about receiving psychosocial support immediately and 116 out of those 196 (59%) women who did not receive chemotherapy treatment reported feeling an immediate concern for intervention. There was also no statistically significant difference between the treatment groups in regard to the fear of chemotherapy-induced nausea (age adjusted P=0.7230). Concerning the worry about feeling nauseous, using the same cut-off, 43 out of 82 (52%) of those who had received chemotherapy felt concerned about receiving psychosocial support and 90 out of 182 (50%) of those who did not receive chemotherapy reported a concern for psychosocial support.

5.2.4 PAPER IV. EXPLORING THE ATTRIBUTES OF WOMEN WITH PSYCHOSOCIAL SUPPORT NEEDS

In paper IV, I compared the women who received psychosocial intervention with those who desired it but for some reason never accessed it. When comparing these groups, I found statistically significant differences for age, having undergone chemotherapy treatment, and reporting low psychological well-being at some point during the year ($P<0.0001$). Subgroup analysis showed that those who desired but never received intervention possessed the very same characteristics as those who received it. Younger women had an elevated RR of 1.35 (CI 1.12-1.62). Mothers with children at home were at a 33 percent elevated relative risk (CI 1.10-1.59). The risk for those who had undergone chemotherapy treatment were at an increased relative risk of 1.48 (CI 1.26-1.75). Finally, those reporting low psychological well-being were at higher risk of desiring intervention but not receiving it (RR 1.77, CI 1.50-2.09). Data also showed that except for problems concerning one's body, a substantial proportion of those who desired intervention reported a specific desire to receive it together with their partner.

6 DISCUSSION

6.1 VALIDITY

6.1.1 THE HIERARCHICAL STEP-MODEL

As researchers, we want all our work to represent reality as closely as possible. When aiming at methodologically sound research, the concept of validity becomes of central importance. No study is free from errors. Therefore, validity becomes a question of how close to the error-free study we have come. Errors in research may be either systematic or random. At the Division of Clinical Cancer Epidemiology, we apply epidemiological methods in study design and data interpretation as adapted to the cancer survivorship field according to the hierarchical step-model for causation of bias [60] (Figure 6). The model outlines the hypothesis-driven research process from beginning to end and highlights the sequential pitfalls that may give rise to different types of problems, all of which may reduce the validity of the study. Each step may cause deviation resulting in an error of the effect measure. Structured as such, it "demystifies" the concept of bias in research as it helps to classify and therefore also identify where in the research process the error arises. The understanding of where the problem arose does not only make it easier to figure out if the bias presents a problem for the effect measure, but it also helps determine how to handle it.

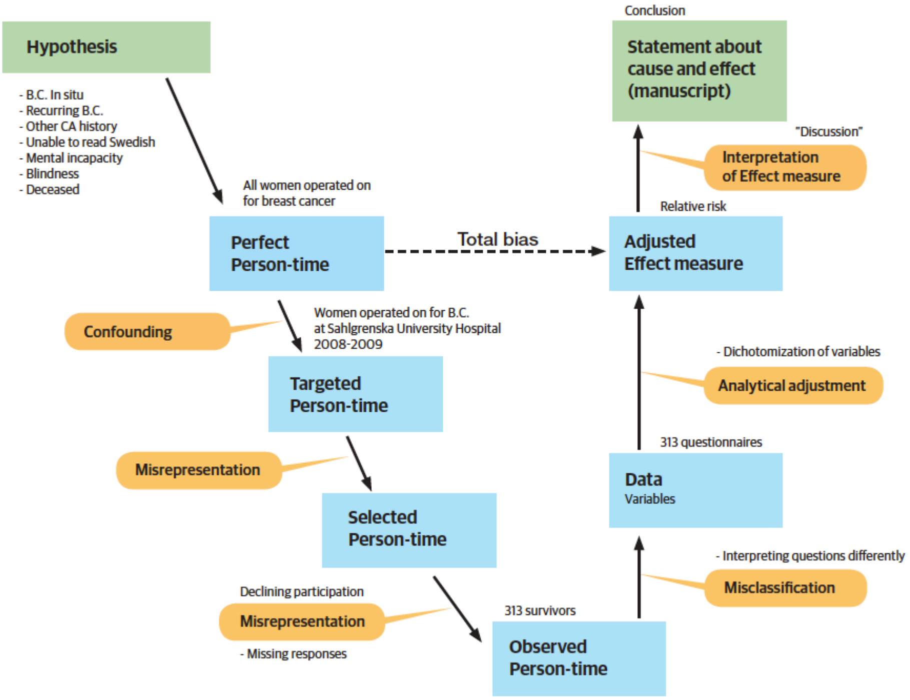

Figure 7. Different stages in a clinical study with corresponding biasing factors - A hierarchical step-model for causation of bias. "B.C" denotes breast cancer.

6.1.2 CONFOUNDING

In the transition from the perfect world to the real world, we inadvertently introduce confounding to our study. When designing a study, we imagine the perfect world (Perfect person-time). We clone this world and its planet and create a second, identical copy of it. Thereafter, we compare the two worlds with the only difference that one of them has been exposed to something like a new medicine, radiotherapy treatment, or a support group. Obviously, this perfect study in which both worlds are identical to one another with the only exception of the exposure is impossible to achieve. However, we strive to mimic this ideal situation as closely as possible. Therefore, in order to create a study from which the scientific conclusions correspond to reality as best as possible, we have to select the group of people we wish to study (Targeted person-time). By being forced to select a specific group of people to study instead of studying all individuals on the planet, we have moved from the Perfect person-time to the Targeted person-time.

When moving from this perfect world into the real world, we will end up deviating from the (unknown) true results in the ideal world as confounders are introduced to the study. We are able to establish that it is a confounder if it 1) is a true cause of the outcome, 2) is associated with the causal factor, and 3) is not part of the causal chain. When designing a study, we may minimize confounding by randomization, using placebo, using matching and restriction, and make certain that the two groups to be compared are studied during comparable time periods. After the data has been collected in a study, we may minimize the effects of confounding by stratifying the analyses and adjust for confounding factors in our statistical models. This requires, however, that we have indeed collected information about potentially confounding factors.

For this study there were several possibly confounding factors to consider. For instance, the literature consistently indicates that breast cancer-diagnosed women's support needs and quality of life are different depending on their age [61, 62]. In light of this, I chose, wherever possible (subgroup analyses in paper IV contained too few individuals for adjustment), to adjust for age as a categorical variable. With our population growing very active in their 60s, I selected the cut-off for young women to be set at 59 years and under. Other possibly confounding factors identified for this study were marital status, educational level, alcohol consumption, and exercise habits prior to diagnosis as these variables have previously been identified as confounders in the literature as related to breast cancer. With very limited control over how any possible confounders were distributed in the population, and my research design did not allow for randomization, which would distribute confounders evenly, I made careful attempts to identify possible confounders, collect information about them, and thereafter adjust for them in the analyses as appropriate.

6.1.3 *MISREPRESENTATION*

Once we have identified the group of individuals we wish to include in our study (Targeted person-time), the task is to get as many of these individuals as possible to participate in our study in order for the results to be valid. The individuals who end up participating in the study are the subjects who generate the Observed person-time. In the hierarchical step-model, when moving from the Targeted person-time to the Observed person-time, there is a risk for *misrepresentation* to be introduced to the study. Misrepresentation is commonly the result of a high drop-out rate which may be due to a large number of individuals who decline participation or individuals who drop out due to attrition. Either way, it means that the study lacks information from its Targeted person-time. As a result, misrepresentation will inevitably affect the validity of the study as there are virtually no research tools available to handle it once it has occurred. A high drop-out rate can never be compensated for in the statistical analyses as lost information from the Targeted person-time is often nearly impossible to retrieve.

There are a few ways to avoid misrepresentation, however. We may plan a study very carefully prior to start, and if possible, conduct a pilot study of it in order to test logistics and for example identify any eventual recruitment difficulties and the run-in time needed. If the primary research tool is a questionnaire, the questions have to be very clear and carefully validated with a number of patients representative of the Targeted person-time, however not part of it. Moreover, in order to avoid misrepresentation, it is important to follow up the patients from whom we wish to collect information and this needs to be done closely in time after the questionnaire is mailed out. We live in a fast-paced society and a questionnaire is easily forgotten within a few days.

If there is a high drop-out rate of the study and we suspect that misrepresentation is a problem, we may calculate the best and worst case scenarios and what impact these would have had on the effect measure. For transparency purposes throughout the research process, it is important to declare and discuss the consequences of the misrepresentation when reporting the results of the study. Hence, it is of crucial importance to avoid a high drop-out rate because it is always a major threat to the validity of the study as there are no effective tools available to rectify it once the data collection is complete.

In order to avoid misrepresentation for this study, I took great care when planning it. First of all, I was very careful when considering how to phrase each question in order to maximize the chances of getting an answer. Second, I made every possible effort according to a predetermined time schedule to follow up those who had not returned their questionnaire in order to get their participation. Since my questionnaire package comprised questions focusing on one's sexual health and function, I was aware that careful planning and frequent follow-up would be of great importance as it in general poses a challenge to collect information regarding such private matters. Nevertheless, despite my intense activity to maximize the chances of measuring the whole targeted person-time, I achieved a 72 percent participation rate. Analysis of those who had not returned a completed questionnaire showed that a number of these had reported (either by phone or in writing on the questionnaire) that the treatment year had been extremely difficult for them and, as a result, they felt it would be too emotionally stressful to have to reflect upon the experiences again.

When assessing if misrepresentation was part of the total bias in my effect measures, this was valuable information for me as I got a sense of why some people chose not to participate. For example, if both depressed and non-depressed women were equally likely to decline participation in the study, this would not significantly alter the effect measures as it would bias the effect measures towards 1.0. On the other hand, if the group of non-participants contained a disproportionate number of women who were so depressed that they could not fill out the questionnaire, I would have underestimated the effect measures (relative risks) of a true positive association for my effect measures. My assessment was that it could have affected my results as I was, after all, trying to find out their psychosocial support needs and these may in turn be related to low psychological well-being.

6.1.4 MISCLASSIFICATION

Following the Observed person-time in the hierarchical step-model, the collected information results in a dataset. In this step, there may be misclassification introduced which is yet another threat to the validity of the study. The effect of the misclassification depends in part on the sensitivity and specificity of the research methods. We may never achieve neither 100 percent sensitivity, nor 100 percent specificity. Hence, all studies contain a certain amount of misclassification. Misclassification occurs because the responses, for various reasons, are classified in the wrong category. For instance, a scale that measures all participants to be one kilogram heavier than they in fact are or a question in a questionnaire that is so poorly designed that a substantial number of participants misunderstand the question and believe they are responding to something different when marking their answer. There are two types of misclassifications: non-differential misclassification and differential misclassification.

Non-differential misclassification of exposure of outcome is when the error is equally large between the two groups of comparison. The effect measure typically is unchanged or diluted, resulting in a deviation of the relative risks toward 1.0, which means that we would underestimate the effect measure. The above mentioned example of the wrongly calibrated scale and the poorly designed question are both examples of non-differential misclassification.

Differential misclassification of exposure of outcome occurs when the level of misclassification error differs between the two groups of comparison. If the badly calibrated scale is used throughout the study for only one of the comparison groups, we would end up with a differential misclassification bias in the effect measure. Differential misclassification may result in bias of the effect measure in either direction. As such, it is unpredictable and a serious threat to the validity of the study. Common sources of differential misclassification are recall bias and interview bias. We may avoid differential misclassification by planning the study carefully (for example when constructing the questionnaire), by using validated research tools and, whenever possible, by randomizing and blinding.

As I was neither able to use randomization, nor blinding for the present study, I put my efforts in creating a carefully constructed questionnaire which, to the extent it was validated, measured what I intended to measure. By using a design where the women filled out the questionnaire in the privacy of their own home, I may likely have minimized the risk for any type of interview bias, such as the I-want-to-please-the-doctor bias. One might argue that memory problems, as a potential type of misclassification, may have been a factor in my study, as I was asking women to recall their psychosocial support needs and experiences 12 months back. However, if memory-induced problems played an important part of my study, it would probably be a non-differential misclassification problem as it would likely be distributed evenly across the whole group of participating women.

As human beings, we actively construct meaning from our environment and continually adapt to changing circumstances. Essentially, we live our lives by creating narratives. However, the type of bias commonly referred to as "response shift bias" only occurs as a problem in the psychometric tradition in which items are summarized. Such would be a problem if I would have compared the women with a control group comprising healthy individuals. As the controls would not have experienced diagnosis and treatment of breast cancer, it would have been misguiding to compare these groups with psychometric scales built on equal weights of items (Figure 8). However, just like in any group, there was likely a variation of internal scales among the participating women. Some of them may have a very pessimistic outlook on life and others may, in general, be more positively oriented. Along the same lines, women may cope differently with challenging life events. These changes can be measured with the one-concept one question tradition we work in at the Division of Clinical Cancer Epidemiology (KCE). For example, we study self-assessed quality of life; if it changes when values change we can measure it while with a psychometric scale, we may not.

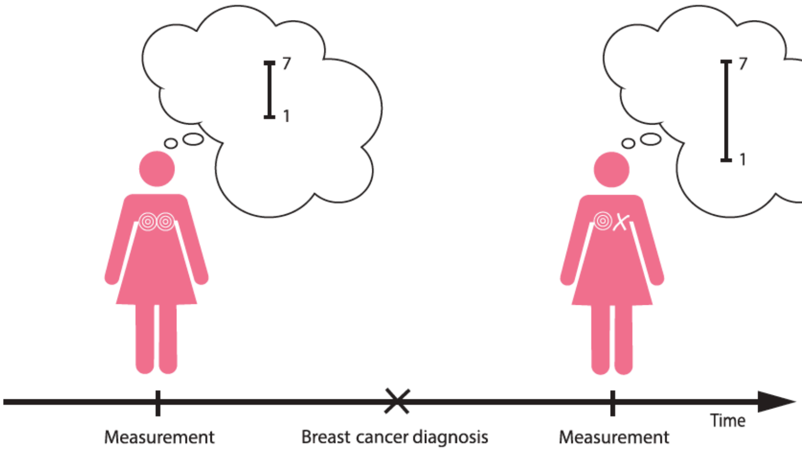

Figure 8. Response shift bias.

One might believe that changing values over time would affect my results in papers II and III where the desired intervention timing is in focus. Indeed, I was unable to exclude that the answers would have differed should I have measured the women at several points throughout the year. However, the continuous strive to construct one's life through the creation of a story suggests that the values reported by the women in my study were the ones that meant most to them emotionally. One may dispute if the woman's retrospective assessment of the care should guide us more than her reaction during the care. However, research has found that people tend to remember more easily the problems they felt emotionally most concerned about [63]. As such, my findings represent memory reconstructions of the events that follow during the year after a breast cancer diagnosis. In this sense, my observational data may nonetheless be valuable. For purposes of enhanced clinical practice, these are the painful memory reconstructions I as a clinician aim to minimize at any point throughout the disease trajectory. When designing a future prospective randomized intervention, it will however be important to keep the limitations of the observational results in mind. After all, observational results are important for identifying knowledge gaps that need attention and the purpose of randomized intervention studies are "for leading the way toward adoption of effective approaches to improving the quality of future care" [64].

6.1.5 *ANALYTICAL ADJUSTMENT*

Once we have data to work with, we may apply statistical analyses and end up with an adjusted effect measure. In this process, however, analytical adjustment problems may arise as a threat to the validity of the study. Analytical adjustment problems are introduced when the researcher analyzes the data incorrectly. It is for example important to apply appropriate types of statistical methods depending on whether the variables are continuous or ordinal and to not adjust for more variables than appropriate. Selecting the wrong reference category is yet another example of an analytical adjustment problem.

Through statistical regression models, we will never be able to determine causality. Statistics will merely determine an association between variables in the dataset. Hence, it is one's own clinical expertise, understanding of a phenomenon, and theoretical considerations that together help determine causality. This requires an understanding of possible patho-psychological mechanisms and insight to the limitations of the study design as well as the statistically adjusted effect measures.

In my study, the primary concern across all papers was to identify whether a variable was a confounder (for which we adjust) or an effect modifier (for which we stratify to study its influences). Clearly, it is very important to determine this in order to know how to use the variables in the analyses as well as when interpreting the results. With guidance from the hierarchical step-model and by building directed acyclic graphs, I was able to take a step back and ask myself if I was looking at effect modifying factors or a subgroup. Nonetheless, depending on the hypothesis, one variable may act as a confounder in one analysis and as an effect modifier in another.

6.2 GENERAL DISCUSSION

A research process is sprung from an idea about our reality, existing phenomena, and accompanying effects as a result of different exposures. Based on this idea, we formulate hypotheses, design data collections, carry out statistical analyses, and interpret the results of these analyses into scientific findings. After these interpretations, we have hopefully obtained new knowledge about our reality, gained new insight that lies closer to the truth of how reality works, and all this with an improved level of scientific evidence. For this study, I aimed at investigating a group of individuals diagnosed with breast cancer, a disease with life-threatening aspects. This may generate feelings of depression and anxiety, thoughts about death, and worry about a variety of psychosocial problems. Main themes resulting from my analyses were the worry about one's children, desire for early intervention regarding the children, and the desire for early intervention concerning chemotherapy-induced side-effects.

6.2.1 *THE WORRY ABOUT ONE'S CHILDREN*

Concern for one's own children turned out to be a central theme of this study. In paper I, I found that the worry about the children was the variable associated with low psychological well-being; in paper II, that the women desired to receive support about the children at a very early stage of the disease trajectory, and in paper IV, that having children living at home was part of the profile of those who either desired or received psychosocial intervention. This theme may not come as any surprise to anyone caring for these women as the notion that the worry about one's own children in the breast cancer-treatment context is supported in the qualitative literature [65, 66]. To my knowledge, however, this study is the first to confirm this association in quantitative analysis.

Today, the lack of evidence-based effective psychosocial support provided as a routine for concerns about one's own children leaves parents and other caregivers under an emotional turmoil with fears that may be unfounded. The question arises: When facing treatment for a possibly life-threatening disease like breast cancer, why is the welfare of one's children paramount to other concerns? We may understand part of the answer to this question through the intrinsic human urge to reproduce. As illustrated in research focused on infertility where for example the experience of childlessness resulting from the inability to reproduce may not only be perceived as a failed life plan (to become a parent), but also as an existential threat to one's own identity [67]. This lends belief to the finding that the psychological impact of infertility may be equivalent to that of a serious medical diagnosis such as cancer [68]. Hence, in light of the primitive need to ensure the survival of one's offspring, it seems plausible that a life-threatening encounter such as a cancer diagnosis may result in an instant worry of how one's child will fare. Also, this need is highlighted in the stories of firemen whose primary task in emergency situations did not turn out to be rescuing people out of houses on fire, but who rather had to use all their force to prevent parents from running into buildings fully in flames to save their children.

Previous studies suggest that when it comes to cancer, part of the explanation may also lie in the feelings of guilt evoked by the mere thought of leaving the children behind in the event of one's death [69, 70]. Connell and colleagues point out the concern for the youngest children who may not have the chance of ever having a sibling or who may have to be raised with one parent only. Feelings of guilt were also underlying the concerns for the older children as mothers expressed a fear that they would have to grow up more quickly and start sharing adult responsibilities prematurely [69]. Another study points out that parents imagine that a "good" parent would never abandon his or her dependent children [71]. Feelings of guilt were also a concern for the mothers in my study:

> *The fear of dying from her [the daughter] was great... the thought of abandoning her was unbearable for me. Who would take care of her like I do and make sure she would be ok?*
>
> *--Mother of a daughter, 2.5 years old*

Fear of recurrence among younger women has been part of grieving the future with the children which was yet another concern reflected in the comments in my study:

> *To not be a part of their lives as they grow up, go to college, see them get married, perhaps becoming parents themselves... I also want to share all those things with them... I want to be a part of all that... I don't want to... leave.*
>
> *--Mother of three children, 3, 5, and 8 years old*

Lebel and colleagues, focusing on the relationship between age and fear of recurrence in a study with different cancer types (n=3239), suggested that guilt for leaving the children and grieving the future with them is likely to be a part of the worry for them. Their study offers that it may be the general intrusiveness of the illness on daily living that may be one key to understanding the worry about one's children in women [72]. The authors further highlight the importance of perceived negative physical, social, and economic impact of the disease as predictor of fear of recurrence. In this study, mothers, regardless of their children's age, expressed greater fear of recurrence than women who were not mothers [72].

Another study found that continuing everyday life was an essential part of holding things together for the women [73] as the emotional concern may not be the only perceived burden for mothers just diagnosed with breast cancer. The burden of practical tasks, tending to fall on all women who are mothers with children at home, may further impact the need to feel prepared as the tasks associated with motherhood are often both numerous as well as demanding, requiring everyday presence. In a qualitative study, focusing on how practical support impacts the breast cancer experience, the majority of the women (n=33) found their role as primary caretaker of the children and the household as a major source of stress during breast cancer treatment [74]. Moreover, they expressed frustration about the inability to perform the tasks associated with caring for others and several of them expressed a wish to not burden their close family members. As such, maintaining the role of a mother at large refers to a sense of being *capable* to care for not only the children, but to also be able to tend to the everyday routines of the household. Since breast cancer treatment may be time-consuming and emotionally taxing, it is understandable that it is perceived as a threat to the capacity as a mother. Therefore, my results in paper II and III, that women desired support regarding the worry about their children and for the worry about chemotherapy-related hair loss and nausea at the earliest stage of the illness seem reasonable as the mere threat of neither *looking* the part of a capable mother due to chemotherapy-related hair loss, neither being able to *act* the part of a capable mother due to nausea, poses a clear and present threat from the day of diagnosis.

Hence, the answer to why the worry about one's children was related to low psychological well-being and why the desire to talk about this worry arose so early in the disease process seems to be found in, among other things, a sense of threat to one's self, a sense of guilt and in mourning the future with the children, as well as within the way cancer and its treatment intrudes in one's daily whereabouts and plans for the future. As such, my data and others' imply that mothers' own psychological well-being may essentially be even synonymous with the welfare of one's own children [75]. After all, "having children gives meaning to life" [67].

6.2.2 TIMING OF PSYCHOSOCIAL INTERVENTION

With the children as a main source of concern as associated with low psychological well-being in paper I, I chose to further study the desired *timing* of an intervention. In paper II, I stayed with the focus on the children and in paper III, I found that the women, in regard to the worry about chemotherapy-induced hair loss and nausea, desired intervention at a very early stage in the disease trajectory.

Based on existing literature and clinical experience, we know that the time phase around diagnosis and surgery is a highly stressful period [76-78]. In one study based on a sample of 200 women, authors found that emotional, social, and physical limitations were most challenging in the pre-treatment period and that quality of care could be improved by providing additional support services already during initial assessment [79]. Another study (n=236), found that approximately half of the sample had clinically significant distress levels or meeting criteria for a psychiatric syndrome [41]. Limited capacity to direct attention (cognitive impairment) has also been found in women before and during treatment for breast cancer [80]. Moreover, qualitative literature helps us further understand women's experiences during the pretreatment phase. Dickerson and colleagues emphasize that distress is a common finding among women at diagnosis and aim to understand the meaning of support for women during this period (n=18) [81]. Their findings highlight the need for the healthcare-team to make timely and accurate assessments in the pretreatment phase. The qualitative literature also helps us gain insight to the feelings of uncertainty while preparing for the worst, as well as what the wait before surgery entails for the women [82, 83]. These results in combination with my findings of women's desire for early intervention regarding one's children and chemotherapy-induced side-effects raise the question: does the timing of psychosocial intervention really matter?

The quantitative literature is very limited regarding the timing of psychosocial intervention once diagnosis has been determined. Despite existing evidence of the pretreatment period as extremely stressful, to my knowledge, only one publication has addressed the issue of appropriate timing for an intervention [84]. This study (n=67), tested whether women who had just received a breast cancer diagnosis benefited more from a psychosocial group intervention program when it was offered within four months after surgery compared to at least three months later [84]. Findings showed that women who started intervention early were less distressed at six months follow-up than women who were in the delayed intervention arm. In a multinational analysis, Jassem and colleagues investigated delays in diagnosis and treatment of breast cancer and found that several factors, mainly related to psychological and behavioral problems, correlated with delay in diagnosis and in treatment [85]. Another study, albeit small (n=84), comparing women with early breast cancer with those diagnosed with an advanced cancer, found that early psychosocial support was met with a high acceptance rate and improved quality of life [86]. Understandably so: early support may quell the worst emotional turmoil initially, thus increasing acceptance of services. As a result of increased acceptance, chances of actually being helped by psychosocial intervention may improve. Findings from one qualitative study highlight the need for assessment and offer of services beginning already in the pretreatment phase, in part to cope with the many unknown factors of the future and for support regarding the children [87]. Qualitative data from my own study point in the same direction:

> *I felt completely alone with my own fear of dying during those eight weeks between diagnosis and surgery. I wish someone from the clinic would have contacted me and offered support and answers to my many questions. A couple of times, I contacted the clinic myself because I had questions about what to tell my children, but I always got to talk to a new nurse each time. It was horrible. Those weeks were dreadful.*
>
> *--Mother of two children, 9 and 11 years old*

One should also understand that the early desire for intervention is sprung from a phase when women's contact with the healthcare team is at a minimum since most women receive their diagnosis and then return to the hospital for surgery weeks thereafter:

> *The absolutely most horrible phase, psychologically, was to first wait for the diagnosis, if it was a cancer. I would have needed professional help, it was like being in a haze. Thereafter, from the diagnosis until surgery was also extremely tough. 'What type of breast cancer is it? Will I need to have chemotherapy? Will I die? Has it spread?' How will I be able to take care of the children if I need chemotherapy?'*
>
> *--Mother of two children, 4 and 7 years old.*

In light of these narratives, it may seem understandable that someone would desire psychosocial support. Either way, indirect quantitative as well as direct qualitative evidence shows that when planning psychosocial support for women with breast cancer, the timing of the intervention is likely to be of importance.

6.2.3 EARLY SUPPORT REGARDING CHEMOTHERAPY

The desired timing of an intervention was in focus of both papers II and III, yet the topic of paper III primarily concerned chemotherapy-induced side-effects. Chemotherapy treatment stood out as a problematic aspect for the women in most of my analyses. In paper I, it was found to be associated with low psychological well-being (Posterior Probability Value 97.6%); in paper III, I found that there was no statistically significant difference whether one had received chemotherapy or not in regard to the desired early timing of an intervention, and in paper IV, I found that having undergone chemotherapy was one attribute possessed by those who received psychosocial intervention and also by those who desired but did not receive psychosocial intervention.

Available literature shows that chemotherapy is one of the most feared treatments associated with any cancer diagnosis [88, 89]. A small study (n=21 with a mean age 46 years), found that breast cancer-diagnosed women were not well prepared for the reality of alopecia and reported substantial physical, psychological, and social distress. Moreover, lack of information and limited social support in combination with negative images of cancer made it difficult for them to cope with the trauma, which resulted in poor quality of life [90]. This may be understandable given the extensive literature available, which suggests that chemotherapy treatment may indeed be one of the most challenging treatments both physically and psychosocially following a breast cancer diagnosis [91-93]. Even though some symptoms seem to level off during the first year after treatment [94, 95], this fact may not provide much comfort for those women who are just about to enter this long treatment type, neither will it help them while undergoing it unless provided with extra support for coping enhancement. Furthermore, studies showing how difficult it is to accurately assess the psychosocial needs of women undergoing chemotherapy highlight the complexity of the issues [96, 97] and show how difficult it may be for these women to receive well-directed support despite research findings indicating their desire for it [98, 99]. As a result, I was not surprised to also find chemotherapy-induced side-effects to be of concern for the women in my data even at the earliest stage (paper III). My results in paper III, however, raise the question: what does the early desire for support about chemotherapy treatment and its side-effects mean?

When facing the prospect of chemotherapy treatment, women appear to have a need to feel prepared:

> *I really would have needed more information about chemotherapy treatment. Everybody just told me I shouldn't get ahead of things and think about it before we knew whether I would receive it or not... that was so frustrating because I couldn't do anything to prepare myself. I had never felt so out of control before in my whole life.*
>
> *--Woman, 57 years old*

I know they couldn't give me any definitive answer about whether I would be getting chemo or not, but I wish they would have at least given me some information about it so that I would have been able to prepare myself and my family for it. I felt like everybody declined to give me information because they didn't want to 'worry' me when in reality, this just made me even more anxious!

--Mother of a daughter, 7 years old

Preparedness refers to actions that are taken as precautionary measures when facing an external threat [100]. It is an important part of achieving goals and when avoiding and mitigating negative outcomes. How prepared one feels concerning what to expect physically as well as emotionally may be a key to adjustment during the earliest stage of breast cancer treatment. In a publication from 1974, Lazarus points out that one underlying mechanism by which a feeling of preparedness may produce positive adjustment effects is the sense of control that stems from knowing what to expect and being able to predict what will happen in the future [101]. Research has also shown that people who were more informed and viewed themselves as better prepared to deal with a stressful event felt more in control and experienced less psychological distress [102]. By contrast, individuals facing a serious diagnosis who feel uncertain about how to manage their illness seem to be at increased risk for psychological distress [103]. Whereas preparedness has not been well studied in the early stage of cancer treatment, it has been in focus of research on the next-of-kin as related to advanced cancer [104, 105]. There is some evidence suggesting that preparedness may be positively related to quality of life and may be related to coping [106-108]. In one randomized controlled study (n=558), although focusing on the reentry phase, Stanton and colleagues demonstrated that a videotaped intervention designed to promote active coping behavior was more effective for women who felt less prepared for reentry. Moreover, they found that a two-session psycho-educational counseling intervention was only effective among participants with high perceived preparedness for reentry [107]. Authors suggest that better prepared women had a greater psychological readiness for the intervention.

Based on my results from papers II and III, that women desired psychosocial intervention early regarding the worry about their children as well as regarding any eventual chemotherapy-induced side-effects, I find it plausible that the answer to the question about what the early need for intervention means, lies in the *desire to be prepared*. The question then arises: would better preparation through early intervention really make any difference? As data from this study fall short in answering this question and since this is an understudied area, we will have to look to future studies to tell us.

In conclusion, available literature in combination with my results show a paucity of information regarding how we may be able to help women psychosocially who are diagnosed with breast cancer at the earliest stage. If we wish to improve the situation for breast cancer-diagnosed women, not only do we need to measure any eventual quality of life-related effects of early large-scale interventions in the shorter term, but we may also need to explore if more psychosocial support earlier entails less desire for it later.

6.2.4 FROM SEXUALITY TO CHILDREN

I began this doctoral project with the hypothesis that the primary concern among breast cancer-diagnosed women would be their sexual health. In the earliest phase of my analyses, however, the finding that the worry about one's own children was the variable associated with low psychological well-being, laid the basis for a changed focus of this thesis. The response rate of the most intimate questions in the Female Sexual Function Index (FSFI) was low. Out of all questions in the FSFI, the response rate to question number 16 "Over the past four weeks, how satisfied have you been with your overall sexual life"? was the lowest with 246 out of 313 women (79%). About one third of the women (n=109) had skipped at least one FSFI question (65% response rate). One may speculate about why women to a higher extent had skipped some questions of the FSFI. Perhaps they did so because they erroneously thought that all questions referred to a context with a partner. Maybe instructions should have been explained more clearly in the questionnaire. The lesson to be learned here is that if the aim is to specifically find new knowledge about women's sexual health, it may be helpful to more closely follow the data collection guidelines from previous studies of my research group focusing on sensitive matters [109, 110] even if resources, as in my case, were extremely limited. In previous data collections at KCE, eligible participants were contacted by telephone prior to receiving the questionnaire, were thus perhaps more prepared for those types of questions, and as a result, were more inclined to respond to questions concerning even the most sensitive matters. Based on the literature and clinical experience, I nevertheless believe that sexual health is of concern for these women [111-115]. In this thesis, however, I ended up not focusing on it.

6.2.5 NO NEED FOR SUPPORT

In paper IV, findings did not only yield that a proportion of the women specifically desired to include one's partner in an intervention, but also that a substantial proportion did not desire any intervention at all (see Figure 2 in paper IV). This is in line with others' findings suggesting that most women diagnosed with a breast cancer go through the treatment without professional support [116].

6.2.6 PSYCHOSOCIAL SUPPORT REGISTRY

The Swedish National Cancer Registry concerning all cancer types was established in 1958. The purpose of this registry was to map prevalence and changes across time, to create a platform for clinical and epidemiological research as well as provide an opportunity to make international comparisons. For the very same reasons, the need to include psychosocial support measures as part of a registry became clear during the course of working with this thesis. Nowhere may psychosocial clinicians and researchers access data to evaluate, follow up, and quantify needs, access, and changes of psychosocial resources today. Through this registry, professionals would for example one day be able to quantify how much healthcare spending is saved in the longer run if women with a breast cancer diagnosis receive effective psychosocial support immediately. Healthcare systems are complex. As the need to assess changes in quality of life in the oncology setting is dire, the claim that psychosocial effects cannot be measured no longer holds up. If recorded, not only would we be able to accurately assess the current status and quality of psychosocial support provided to women diagnosed with a breast cancer, we would also be able to measure any changes and eventual improvements to its provision.

7 CONCLUSION

Hopefully the new knowledge derived from my thesis will provide meaningful contributions to the growing scientific literature that centers psychosocial issues after breast cancer diagnosis and, in turn, help improve clinical practice within the healthcare system. If applied, it may help clinicians plan for interventions that more specifically target the most common concerns of these women at the right time phase.

I show that whereas a significant proportion of women diagnosed with breast cancer did not report any need for psychosocial intervention, there was a proportion of women who were psychosocially vulnerable and who had a need for support primarily concerning the worry about their children immediately following diagnosis. The papers presented in this thesis showed that:

Out of twelve different psychosocial possibly modifiable variables, there was a strong association between worry about one's own children and low psychological well-being. Additionally, mothers with the youngest children at home were at statistically significantly higher risk of needing psychosocial support in regard to their children.

The most preferred time for psychosocial intervention in regard to worrying about the children during the year that follows breast cancer diagnosis was the time immediately after diagnosis before surgery. The three factors associated with worry about one's own children were worry about one's sex life, fear of dying from breast cancer, and worry about one's personal financial situation.

One year after breast cancer diagnosis, survivors distinctly recalled an immediate desire to receive psychosocial support and basic information about chemotherapy-induced hair loss and nausea, regardless of receiving chemotherapy treatment or not.

Women who received as well as those who desired psychosocial intervention, but for some reason never received it, possessed either one or more of the following four attributes: 59 years of age or younger, children living at home, treated with chemotherapy, and low psychological well-being at some point during the year that followed diagnosis. Also, the very same demographic- and treatment-related attributes were identified for those who did receive psychosocial treatment. Additionally, I found that with the exception of problems centering one's female body, a considerable proportion of those who desired intervention specifically reported a desire to receive it together with their partner.

8 FUTURE PERSPECTIVES

"Forewarned, forearmed; to be prepared is half the victory" as expressed by Miguel de Cervantes, author of the novel Don Quixote. When it comes to psychosocial support needs after breast cancer treatment, mine and others' data indicate that women express a need for an immediate intervention right after diagnosis in order to get prepared for what may lie ahead.

The healthcare system is increasingly depending on each individual to take care of herself as follow-up routines in breast cancer care are changing. Resources for psycho-oncological support in Sweden are no exceptions as they continue to decrease in a healthcare system that is constantly pushed to meet patients' care needs. In light of this, we may need to alter our understanding of how to best provide psychosocial support for women diagnosed with breast cancer. From all the women calling the clinic requesting psychosocial intervention, we know that the need for psychosocial support is dire. From my data, we have indications that a sizeable proportion of the women desire a prolonged psychosocial intervention throughout the treatment. Previously, this has indeed been feasible for most of them. With the help from a strong evidence-base from research in the future, however, we may likely have to, to a larger extent than today, focus on developing time and cost-effective group oriented techniques that essentially help the women help themselves. Essentially, we need to become better at providing them with an early emotional foundation they can stand more firmly on throughout the disease trajectory and for the future. Our job will be to help them maximize their chances at successful rehabilitation. In order to achieve this, however, we will need to find ways to work smarter in a system where the level of psychosocial support provision will have to become routine and should not be left to each clinic. I believe that we may be able to accomplish that by focusing on getting them better prepared for what lies ahead when first diagnosed as well as when finishing the medical/surgical treatment. In other words, we need to investigate if a proactive healthcare team is helpful for the women in the long run. Also, we will need to be able to track psychosocial services better than we can today in order to evaluate the quality of psychosocial support provided to the women.

Drawing upon the results from this study, the next step is to continue the quest for answers of what may actually help these women fare better psychosocially by conducting prospective randomized intervention studies. Important research questions for these studies are, for example:

- Worrying about one's own children was associated with psychological morbidity. This raises the question: To what extent are we able to improve overall quality of life by early information and support centering the worry about one's children?
- Given that we found a desire for intervention at the earliest phase of the disease trajectory, three research questions have arisen: a) are we able to reduce psychological and symptom distress of women before surgery and there through improve their quality of life on specific measures in comparison with controls who receive usual psychosocial support? b) If so, is the outcome measure different if the psychosocial support is provided early or later? And c) if so, are these benefits detectable in the longer term?
- During the very emotionally challenging phase after diagnosis until immediately after surgery, to what extent are we able to reduce psychological distress and there through enhance emotional adjustment by increasing women's preparedness for threatening procedures such as surgery and eventual chemotherapy treatment? In other words: how much of women's distress are we able to "inform away"?
- What psychosocial symptoms are healthcare providers most easily able to lessen for women with breast cancer?
- From a qualitative perspective, the questionnaires for this study contain a large amount of qualitative data in the many sections devoted to open-ended answers. Further analysis of these data would enrich and deepen the understanding of the women's lived experiences.
- As resources will remain scarce, we have to develop a solid registry system from which we, in the future, are able to extract data that can be used to help clinics evaluate the quality of psychosocial support provided to cancer patients. It would not only act as a valuable tool for further clinical research but would also help make predictions about future needs of psychosocial support.

In conclusion, if we wish to better the situation for breast cancer-diagnosed women, our future psychosocial research priority is to find ways to support them by providing immediate, effective support. One major component of this is to help those who are mothering young children to talk about their concerns about their children in a structured way. Another major component is to, at an early stage, provide basic information about chemotherapy-related side-effects. Any eventual effects of this type of intervention have to be investigated through randomized controlled trials. The intervention may provide the tools necessary to increase the preparedness for what may lie ahead in order to maximize women's chances of a successful rehabilitation. The third recommendation in the future is to construct a psychosocial registry to be used to make predictions and prioritizations in the future.

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If I have seen further it is by standing on the shoulders of giants

Isaac Newton

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APPENDIX

Below, I present some of the questions as they were printed in the questionnaire (translated into English):

Please circle the response that best corresponds to your experience. Please observe: no circles between the numbers.

2.2) When at its worst, how low has your psychological well-being been during the past 12 months?

1---------2---------3---------4---------5---------6---------7

Worst imaginable Actually fairly well

2.10) How many people in your social network did you have in whom you could confide about your concerns related to breast cancer?

☐ No one available

☐ Yes, 1 person

☐ Yes, 2-3 people

☐ Yes, 4-5 people

☐ Yes, 6 people of more

[The questionnaire comprised questions about twelve common psychosocial problem domains with sub-questions to each problem. The first question (a) concerned the *frequency* by which the women had experienced a problem. The words on the dotted lines were replaced with those on the list below to address all twelve psychosocial problem domains. Question (b) focused on the time phase the problem was experienced as most troublesome, question (c) how important it was for the woman to receive professional psychosocial support, question (d) concerned during which time phase psychosocial support was desired, and (e), if so, in what form professional psychosocial support was desired.]

2.13 a) During the past year, have you ever ...?

1----------2----------3----------4----------5----------6----------7

Never All the time

13a ... felt grief and a sense of loss due to the loss of your breast?
14a ... experienced a fear of dying as a result of breast cancer?
15a ... felt worried about losing your hair due to chemotherapy?
16a ... felt worried about feeling nauseous due to chemotherapy?
17a ... felt worried about your sex life?
18a ... felt concerned about a changed body image?
19a ... felt worried about an eventual reconstructive surgery?
20a ... felt worried about your partner relationship?
21a ... felt worried about meeting a new partner?
22a ... felt worried about your own children?
23a ... felt worried about your relationship to friends?
24a ... felt worried about your personal financial situation?

2.13 b) During which phase was this problem most troublesome for you?
(Please choose one alternative.)

☐ I never had a problem with this

☐ Before surgery

☐ 0-3 months after surgery

☐ 4-6 months after surgery

☐ 7-9 months after surgery

☐ 10-12 months after surgery

2.13 c) How important was it for you to receive professional psychosocial support concerning this problem?

1----------2----------3----------4----------5----------6----------7

Not important at all Very important

2.13 d) During which phase did you desire to receive professional psychosocial support about this problem? (Please choose one alternative.)

☐ I never had a problem with this

☐ Before surgery

☐ 0-3 months after surgery

☐ 4-6 months after surgery

☐ 7-9 months after surgery

☐ 10-12 months after surgery

2.13 e) In which form did you desire to receive professional psychosocial support concerning this problem? (You may choose more than one alternative.)

☐ I never had a problem with this

☐ Individual counseling

☐ Counseling together with partner

☐ In a peer support group with other women

☐ Don't know

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