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# **PSYCHOSOCIAL SITUATION AND WORK AFTER BREAST CANCER SURGERY – women's experiences**

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## ABSTRACT

**Background:** Breast cancer is the most common cancer among women. Nowadays, most women survive the disease, and many working women continue in paid employment. Nevertheless, there is little scientific knowledge of working after breast cancer surgery and of how various stakeholders support women after a breast cancer diagnosis.

**Aim:** The aim of this thesis is to explore women's work situation after breast cancer surgery, with special focus on how women experience interactions with different stakeholders, and on women's reflections and actions with regard to work.

**Methods:** Four studies, based on information about women aged 26-63, living in Stockholm, who had had breast cancer surgery, were conducted. In studies I and II, data from four focus group interviews with 23 women, who had had breast cancer surgery three to thirteen months previously, were analyzed by means of qualitative content analysis and thematic analysis, respectively. For studies III and IV, questionnaire and treatment registry data on 605 women working at time of diagnosis were analyzed by means of descriptive statistics, and univariate and multivariable logistic regressions.

**Results:** Study I revealed that the women had encountered many different stakeholders regarding issues of paid employment. These encounters involved information exchange and adjustments, and reflected attitudes towards sickness absence and the women themselves. Examples concern the issues of job retention or sickness absence, e.g., of an inflexible interpretation of sickness absence regulations, and of a lack of information on the side-effects of treatment.

Study II focused on women's reflections and actions with regard to work. Several of the women had worked, at least to some extent, during the cancer trajectory. The following three action themes were identified: returning to work or not, asking for adjustments or not, and disclosing one's disease or not. Five themes with regard to reflections were found: health and function, the value of work, self-esteem and integrity, social circumstances, and relationships at work. Women who continued to work throughout the treatment period tended to refer to work as a normalizing factor, but others wanted to focus on rehabilitation and were on sick leave.

At the time of breast cancer were the vast majority of women working full-time and when answering the questionnaire were 61% sickness absent, whereof the majority on full-time. The results of Study III furthermore showed that women shortly after breast cancer surgery valued their paid work highly, and found it to be one of the most important aspects of life. Low job satisfaction and younger age were associated with being on sick leave.

Social support at work and adjustment of work was explored in Study IV. It was found that many women received social support from their colleagues and supervisors. Low perceived social support from supervisors and low work-adjustment opportunities were associated with being on sick leave, even after controlling for socio-demographic factors, work posture, axillary surgery, and planned adjuvant chemotherapy.

**Conclusion:** All stakeholders involved in women's circumstances after breast cancer surgery need to pay great attention to psychosocial factors, such as being flexible in providing support, solutions and information, and taking into account women's preferences and perceived competence. These are considerations of essential importance to the women, and may have a bearing on being sickness absent or returning to work.

# SAMMANFATTNING

**Bakgrund:** Bröstcancer är den vanligast förekommande cancer bland kvinnor i Sverige. Årligen får cirka 8000 kvinnor den diagnosen och av dessa är ungefär hälften i arbetsför ålder. Överlevnaden i bröstcancer är hög och många kvinnor fortsätter sitt aktiva arbetsliv efter diagnos och behandling. Arbetet är för många en mycket viktig del i livet och innebär inte bara försörjning, utan ger även ett socialt sammanhang och en känsla av tillfredsställelse. Forskning kring återgång i arbete efter bröstcancer har påvisat att flera medicinska faktorer påverkar längden på sjukskrivning, t.ex. sjukdomsstadium och typ av behandling. Några studier har även gjorts om psykosociala faktorer, såsom socialt stöd och anpassningsmöjligheter; den forskningen har främst gjorts längre tid efter diagnos och behandling.

**Syfte:** Syftet med denna avhandling är att undersöka den psykosociala situationen angående återgång i arbete efter bröstcancer. Frågeställningarna gäller vilka aktörer kvinnorna möter i frågor om arbete efter cancer, kvinnornas erfarenheter av aktörernas bemötande och stöd, samt hur kvinnorna själv resonerar kring arbete.

**Metod:** Fyra studier har genomförts med data från kvinnor i åldern 26-63 år, vilka behandlats för bröstcancer vid tre av sjukhusen i Stockholm (Karolinska universitetssjukhusets onkologkliniker vid Södersjukhuset och Radiumhemmet samt Sankt Görans sjukhus). Kvinnorna inkluderades konsekutivt vid det första onkologbesöket där beslut om vidare behandling fattas. I studie I och II genomfördes fyra fokusgruppsintervjuer med 23 av kvinnorna, som diagnosticerats med bröstcancer 3 till 13 månader tidigare och som yrkesarbetade när de fick sin diagnos. Data analyserades med hjälp av kvalitativ innehållsanalys respektive tematisk analys. I studie III och IV analyserades enkätdata och registerdata för 605 kvinnor. Kvinnorna hade opererats för en första bröstcancer, arbetade vid diagnosen, kunde läsa och skriva svenska, och hade besvarat enkäten inom 8 veckor. Data analyserades med deskriptiv statistik samt logistisk regression.

**Resultat:** Resultaten från studie I visade på att kvinnorna hade haft kontakt med ett flertal aktörer angående återgång i arbete. Enligt kvinnorna gällde dessa kontakter information och anpassningar och de mötte olika attityder gentemot återgång i arbete. Kvinnornas erfarenheter varierade, t.ex. hade vissa kvinnor fått information som underlättade planering av återgång i arbete, medan andra saknade detta. Vidare återfanns skillnader i hur anpassningar skett från handläggare vid Försäkringskassan i form av upplägning av deltidssjukskrivning, och även skillnader i vilka kvinnorna rådde fått och vilka attityder de mötts av kring att vara sjukskrivning eller inte.

I studie II analyserades hur kvinnorna själva reflekterat och agerat angående arbete efter bröstcancerdiagnosen. De hade vidtagit eller initierat anpassningar i olika former och tagit ställning till hur och när de skulle återgå i arbete samt om hur de berättade om sin sjukdom eller undvek detta. Kvinnornas resonemang gällde hälsa och funktion (t.ex. om man var för påverkad av behandlingsbiverkningar eller inte), hur man värderade arbetet, vilken vikt man lade på eget välbefinnande och integritet, sociala faktorer och relationerna med kollegor/chefer. Kvinnor som arbetat i någon utsträckning under behandlingen beskrev arbetet i huvudsak som en viktig faktor som normaliserade tillvaron, medan kvinnor som förblev sjukskrivna påtalade vikten av att återhämta sig själva.

Resultaten från studie III visade att 92 % av kvinnorna arbetade minst 75 % då de fick bröstcancerdiagnosen samt att 61 % var sjukskrivna vid besvarandet av enkäten; majoriteten på heltid. I stor utsträckning värderade kvinnorna sitt arbete mycket högt,

även tidigt efter operation. Två tredjedelar av kvinnorna skattade sitt arbete som en av de viktigaste aspekterna av sitt liv och en ännu större andel ansåg att deras arbete var givande och kände entusiasm och hängivenhet till sitt arbete. Endast hälften av kvinnorna var tillfredsställda med sin arbetssituation. Att vara mindre tillfredsställd med arbetssituationen var relaterat till att vara sjukskriven.

Enligt studie IV berättade 88 % respektive 90 % av kvinnorna om sin diagnos för chefer respektive kollegor. Majoriteten skattade också att de hade olika former av stöd från chefer och kollegor och flertalet hade möjlighet att anpassa sitt arbete om det blev för ansträngande. Det fanns samband mellan att inte uppleva stöd från chefen respektive att ha mindre möjlighet att anpassa arbetet och att vara sjukskriven. Denna association samband kvarstod även efter att ha kontrollerat för sociodemografiska, behandlingsrelaterade och arbetsrelaterade faktorer.

**Konklusion:** Alla aktörer involverade i kvinnornas situation efter bröstcancer behöver ta i beaktande psykosociala faktorer såsom tillgänglighet och flexibilitet gällande information, stöd och anpassningar av olika slag. Därtill är kvinnornas egna preferenser och upplevd förmåga centrala och behöver tas hänsyn till. Dessa aspekter synes ha samband med sjukskrivning eller återgång till arbete efter operation för bröstcancer.

## LIST OF PUBLICATIONS

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- II. Nilsson M, Olsson M, Wennman-Larsen A, Petersson L-M, Alexanderson K.  
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Psycho-Oncology 2012; DOI 10.1002/pon.3192
- III. Petersson L-M, Nilsson M, Alexanderson K, Olsson M, Wennman-Larsen A.  
How do women value work shortly after breast cancer surgery and are their valuations associated with being on sick leave?  
Journal of Occupation and Rehabilitation; DOI 10.1007/s10926-012-9402-0
- IV. Nilsson MI, Petersson L-M, Wennman-Larsen A, Olsson M, Vaez M, Alexanderson K.  
Adjustment and social support at workplace shortly after breast cancer and its association with sick leave.  
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# 1 BACKGROUND

In recent decades, more women have received a breast cancer diagnosis, but a higher percentage has survived the disease. This has increased interest in aspects of vocational rehabilitation and other aspects of work in research on cancer survival, but there are not many studies of the consequences of being sickness absent or at work among cancer patients, or even individuals without any such diagnosis (1). Some studies indicate that work is health-promoting (2), and that longer sick-leave spells are associated with poorer mental and/or physical health, and greater financial problems (1), which supports the argument that unnecessary sickness absence should be avoided.

The project, of which this thesis forms a part, has its origin in the need for greater knowledge of return to work after breast cancer (3). With my background as a medical social worker in cancer care, I found the psychosocial aspects of returning to work to be of great interest in planning the studies. Also, I found that some areas of possible importance were less explored. A bio-psychosocial starting point encompasses the entire individual and her situation, and bio-psychosocial aspects may include the content and quality of the encounters women have with various stakeholders after diagnosis, the supportive measures taken, and also the women's own stances regarding work or not to return to work. Knowledge of these aspects may provide a foundation for better health care, and equip others with the tools to intervene in health-promoting ways, even early in the cancer trajectory.

The context of this thesis in relation to other studies in the field of sickness absence research is presented below.

**Table 1.** Categorization of studies of sickness absence, adapted from the Swedish Council on Health Technology Assessment (4). The categories relevant to this thesis are indicated in bold.

Focus of the study	Scientific discipline	Perspective taken in the study	Structural level of the data included in the empirical analyses
<ul style="list-style-type: none"> <li>•Risk factors for sickness absence</li> <li>•<b>Factors that hinder or promote return to work</b></li> <li>•Consequences of being sickness absence</li> <li>•Sickness-certification practice</li> </ul>	Anthropology Economics History Law Management <b>Medicine</b> Philosophy Psychology Public health Sociology	Society Local society Insurance office <b>Health care</b> Employer Family Sickness absentee Patient/Client Individual	International National Community Workplace Family <b>Individual</b>

## 1.1 WOMEN, WORK AND SICKNESS ABSENCE

In Sweden in 2011, approximately 77% of women aged 20-64 years were in paid employment or self-employed (part- or full-time), and the employment rate of women in the ages 55-64 years was high (67%) in comparison with women of the same ages in the EU (38%) (5). Work is not only of financial benefit to an individual, but is also a source of self-esteem, provides activities, meaning and structure to the daily life, and gives a social context in which to interact with others (6). For people diagnosed with cancer, work can also provide a sense of normality and self-identity (7), and may be an essential element in recovering from the disruption caused by the disease (8).

### **1.1.1 Sickness absence and return to work in Sweden**

In Sweden, all individuals with income from work or on unemployment benefit are entitled to sickness benefit if unable to perform work due to disease or injury (9). The benefit is regulated in the National Insurance Act, and, with one exception, is administered by the Social Insurance Agency; employers usually reimburse sick pay during the first 14 days of a sick-leave spell after a one-day waiting period (10). The self-employed can opt for more waiting days, thus lowering their insurance payments. Waiving of the one-day waiting period is possible if a disease or treatment causes frequent sick-leave spells, although a special medical certificate is needed for this. Sickness benefit amounts to 80% of lost income up to a certain level, while sickness absence can be granted full- or part-time (25, 50, or 75% of ordinary working hours) (11). If disease or injury has led to permanent work incapacity, the individual can be granted a disability pension, part- or full-time. Disability pension amounts to about 65% of lost income up to a certain level (11). The retirement age is set at 65 years, but old-age retirement can be taken early. Regarding vocational rehabilitation, the Swedish Work Environment Act states that employers have duties to provide a good and sustainable work environment, and to aid employees with health problems, e.g., in making adjustments to various aspects of work (12).

## **1.2 BREAST CANCER**

Breast cancer is the most common cancer among women worldwide, with an annual incidence of approximately 1.4 million (13). The estimated number of deaths yearly in the world due to breast cancer is 450 000, and higher proportions die in developing countries, due to fewer screening opportunities and treatments (13, 14). In Sweden, about 8000 women are diagnosed with breast cancer each year, of whom half are of working age (15). There has been an increasing trend in breast cancer incidence from the end of the 20<sup>th</sup> century and the beginning of the 21<sup>st</sup> (16, 17). Globally, breast cancer incidence varies geographically, and there is a higher incidence in developed countries. Risk factors, such as greater age, fatty diet, high alcohol consumption, exposure to ionized radiation, and use of hormone replacement therapies (18) account for some of this geographic variation. Further, nulliparity and higher age at childbirth are known risk factors, which explain some of the higher incidence in women of higher socioeconomic status. For approximately 5-10% of women with breast cancer, there is a heritable cause of the disease (18).

The 5-year breast-cancer survival rate has risen in Sweden in recent decades and is currently 87% (15, 19), possibly due to early detection through e.g. screening programs (20) and more effective and precise treatment. In Sweden, nationwide mammography screening programs are in place, and the National Board of Health and Welfare recommends a biennial mammography scan for women between 40 and 74 years of age. In Stockholm County, mammography is provided, both by screening programs and by opportunistic screening.

### **1.2.1 Treatments**

The primary treatment for breast cancer is surgery. Mastectomy is a surgical procedure that involves removing the breast glandular tissue, whereas breast-conserving surgery involves removal of the section of the breast containing the tumor. Breast-conserving surgery is performed in just over 50% of breast cancer cases in Sweden (21). Breast reconstruction at the time of mastectomy is performed in approximately 20% of women in Stockholm County, but can also be performed as a late procedure, depending on the

type of post-surgical treatment (15). Approximately 9% of all women with breast cancer do not undergo surgery, mostly due to advanced tumor stage, severe comorbidity or patients' choice.

To find regional lymph node involvement and assess the risk for distant spread of the cancer, a procedure named sentinel node biopsy is employed (22). This is a less invasive technique for diagnosing the putative tumor bearing lymph node in breast cancer and it involves removal of the first lymph node (the sentinel lymph node) during surgery and examining it to see if contains tumor cells. If found to contain tumor cells, an axillary clearance (axillary lymph node dissection) is performed, which entails removing at least 8-10 lymph nodes in the axilla (armpit) (23). The technique is routinely used and avoids unnecessary axillary lymph node dissection (22).

Apart from surgical treatment cytotoxic (chemotherapy), endocrine (hormone therapy), antibody, and radiation therapy are part of the breast cancer treatment, often used in combination (24, 25). The post-surgical treatment depends on several factors, such as age, stage of the disease, menopausal status, grade of tumor, hormone receptor status, and HER2-gene, etc.

### **1.2.2 Sickness absence after breast cancer**

In 2007, the so-called Diagnosis-Specific Guidelines on Sickness Absence were implemented in Sweden nationwide (26, 27). Regarding breast cancer, these guidelines have been revised, with the latest revision on 21 December 2011. Since research on optimal duration of sickness absence is non-existent, the guidelines were constructed in collaboration with expert physicians in the field. The guidelines are designed to facilitate equality in the assessment of sickness benefit. For individuals diagnosed with breast cancer, the recommendations of the guidelines are as follows:

- Sick leave for up to 3 weeks is recommended after breast-conserving surgery with minor lymph node resection.
- Sick leave for up to 6 weeks is recommended after mastectomy and axillary clearance; partial sickness absence and work adjustment should be considered.
- Post-operative adjuvant chemotherapy treatment (lasting approximately 5 months) entails full-time sickness absence, although, for some women, partial work capacity can remain, which is why partial sickness absence is possible and work adjustments are warranted.
- During uncomplicated radiotherapy, sickness absence is often not necessary, but preventive sickness absence may be recommended if the treatment has an impact on work.
- During hormonal treatment, partial sickness absence may be an option.

### **1.2.3 Sequelae of the disease and/or treatment**

Being diagnosed with cancer disease is often described as a crisis where one's health and life are perceived as being under threat (28). There may be psychological sequelae, e.g., depression, anxiety (29), and sleep disturbance (30), partly due the stressful situation. Further, overall health-related quality of life some months after diagnosis has been reported to be lower than in the norm population (31). This finding though is at group level, and there are individual differences.

Breast-cancer treatments have evolved, such as the above-mentioned sentinel node biopsy technique, which means that fewer women have to undergo axillary clearance, which otherwise have negative health effects, e.g., arm morbidity. Other acute or later

side-effects can be related to the treatments given, which, for some women, entails more or less severe disability. Pain from the surgical wound, nausea due to chemotherapy, fatigue (30), cognitive problems (subjective and objective) (32, 33), hot flashes, arm morbidity (34-36) and lymphedema (37) are some of the reported side-effects. As stated in the national Diagnosis-Specific Guidelines on Sickness Absence regarding breast cancer, some women need full- or part-time sick leave due to the sequelae of treatment (26, 27). Despite the sickness benefits available in Sweden and some other Western countries, many women report financial difficulties due to lowered income while sickness absent. Stress over the economic and work situation has often been found in research (38), as too have feelings of shame due to changes in the body or hair loss (28, 39).

These side-effects may require medical attention, psychological treatment, and/or social interventions. Such supportive actions are often provided by health care personnel to a lesser or greater extent, but other people in the women's surroundings have also been assessed to be of great importance during when diagnosed with cancer (40).

### **1.3 WORKING AFTER CANCER**

Research on cancer focuses primarily on enhancing treatments to increase survival, and to decrease morbidity and sequelae. However, research on survivors, including their work situation, has evolved over time, starting with studies that included work as part of the assessment of the sequelae of treatment options in clinical trials (41). Nowadays, these studies have a standing in their own right (42), and several have been performed over the last decade, including ones that have concerned breast cancer survivors. Data from these studies have been included in some literature reviews, most of which cover studies of all cancer diagnoses (3, 43-47). The reviews have found that returning to work or taking sick leave after a cancer diagnosis is influenced by multiple factors. They fall into the following categories:

- Cancer survivor characteristics; greater age, a lower level of education, and being female have been found to be associated with a lower return to work or unemployment after cancer.
- Health and well-being, symptoms, extensive surgery, post-surgical treatments, such as chemotherapy, advanced tumor stage, comorbidities, physical and psychological symptoms, overall stress, and less continuity of care have all been shown to be associated with longer sickness absence, and less return to work or unemployment.
- Work demands and work environment, manual or non-sedentary work, union membership, employer discrimination, working environment, no work flexibility, and non-disclosure to colleagues are associated with barriers to return to work, but return-to-work meetings with the employer, training services, and job replacement services do facilitate return.

These factors are, related to several different outcomes – work-related, psychosocial, and economic. Contradictory findings have been reported regarding whether cancer survivors are less or more likely to return to work than cancer-free individuals. One recent review reported a mean proportion of 40% of people returning to work or continuing to work 6 months after diagnosis, a proportion that rose to 89% at 24 months; however, the overall proportion returning to work varies between 24% and 94% in studies of different cancer diagnoses (44). The importance of studying specific diagnoses has previously been pointed to in a systematic review of research on sickness

absence and return to work, since differences in, for example, treatment and functioning may influence the rate of return to work (48).

In studies of the factors associated with sickness absence or return to work after breast cancer, there have been many non-significant results. Studies of breast cancer and work have had different designs and lengths of follow-up, used different outcome measures, and different measures and definitions of independent variables, all of which render comparisons difficult.

### **1.3.1 Current research on return to work after breast cancer**

Research on women with breast cancer and return to work in comparison with other cancer diagnoses have shown that the women have a high rate of return to work (49), although it takes longer for them to return than individuals with urological, head/neck or gynecological cancers (50). Breast cancer is the most common cancer among women, and many suffer from lowered work capacity, which acts as a hindrance to work. This is why research in this area is of great importance. Some findings of recent research with a quantitative design on factors influencing return to work or sickness absence after a breast cancer diagnosis are summarized below. This summary is followed by a section on qualitative research on return to work after breast cancer and on research on interventions of return to work.

#### *1.3.1.1 Socio-demographic and individual factors*

Greater age is a significant risk factor for sickness absence in general (51), and the findings of research on return to work after breast cancer are consistent with this. Greater age is related both to less return to work and to longer periods before returning (52-54), but these results are not statistically significant in some studies, possibly due to small sample sizes (41, 55, 56). Researchers have found lower education to be associated with less return to work (53, 56, 57) but, again, the results are not statistically significantly in all studies (41, 52, 55).

Some studies have considered women's attachment of value to working life after breast cancer, and whether level of attachment is associated with being on sick leave. In a Canadian study, women were asked to rate how their valuation of work had changed over three years since a breast cancer diagnosis. The results showed that decreased perceived value of work was a predictor of not working (53), a finding that has been corroborated in a recent Swedish study (58). Both studies, however, asked the question on value of work in retrospect, although one of them used a comparison group (53).

Rural place of residence has been found to be a risk factor for sickness absence in general, and large regional differences in sick-leave duration following a breast cancer diagnosis has been found in Sweden (59). This study, however, was performed in 2003, before the National Guidelines on Sickness Absence Certification were implemented (27).

#### *1.3.1.2 Factors related to the disease, treatments and symptoms*

Elevated risks of prolonged time to return to work, of change in working time, and of sick leave have been found for treatment-related factors, especially in the cases of chemotherapy (54-58, 60) and combinations of therapies (61, 62). Further, there are some reports that hormonal treatment (53, 57) and radiotherapy (60) and axillary dissection (57) are risk factors for not working or taking a longer time to return to work. However, non-significant associations between the above-mentioned treatments and sickness absence or return to work have also been reported (52).

With regard to side-effects or symptoms, it has been shown that arm complaints (61, 63) and experiencing fatigue (64) are associated with later return to work. Comorbidities are risk factors for not returning to work (56, 65), as too is previous poor health (52).

#### *1.3.1.3 Work-related factors*

A job with high demands (55), strenuous work postures (52), blue-collar work, discrimination (52), and having a non-supportive supervisor (66) have all been found to be negatively associated with return to work. Conversely, being self-employed (67), work accommodation (52), flexible work schedules (56, 65), and supportive colleagues are positively associated with return to work (64).

#### *1.3.1.4 Qualitative studies*

Qualitative methods of data analysis have been used in several studies of working after breast cancer. They are used to gain more in-depth knowledge of women's experiences and motivations.

A recent meta-ethnographic investigation of qualitative studies on return to work after breast cancer has been performed, which includes ten studies undertaken from 1999 to the mid-2010s (68). Several work-related themes were found. Physical impairments caused by treatments were of importance, and sometimes acted as a hindrance to work after diagnosis. In particular, the women pointed to fatigue and cognitive problems after chemotherapy, including difficulties in concentrating, poor memory, and sometimes even speech difficulties, which required the slower pacing of work, etc. Changes in emotional functioning have also been reported, including less tolerance and altered temperament, possibly due to the psychological and physical strain imposed by diagnosis and treatments.

Encounters with and/or expectations from employers and colleagues can complicate return to work, where women have felt that their appearance has misled supervisors and colleagues into believing they have full work capacity. Accordingly, some women have not been taken seriously in relation to sought-after adjustments, and therefore have received less support. Nevertheless, this investigation also included studies from some European countries where women reported highly supportive work environments.

Another theme that emerged from the meta-ethnography was that the return-to-work process was deemed of great importance, and that being able to work was seen as a sign of normality by the women. Working was associated with positive feelings of structure and social interaction, although many women feared to disclose their diagnosis. Further, for some women, financial pressures forced them to return to work. One of the studies included, from the USA, found that several women had to reduce work to be able to fit in their treatments, and that they feared job loss as a result. Changes in perception of the importance of work were found among some women, probably due to re-assessments of values in life. A quite recent Swedish study (8), which was not included in the above-mentioned review, reported on a longitudinal qualitative study that explored women's ideas and reasons in relation to returning to work. The reasoning of some of the women concerning work fluctuated during different phases of the cancer trajectory.

#### *1.3.1.5 Interventions to promote return to work after breast cancer*

Although the authors reported on very few studies performed in the field, a recent review of interventions to promote return to work after sickness absence in multiple

target populations found that early intervention was associated with a positive outcome. (69). One systematic review of interventions designed to stimulate return to work or job retention after cancer has been undertaken, but it could not establish any evidence for best practice (70). Only four studies were identified, three of which were published between 1977 and 1983, and one in 2000. However, three of the studies did not have a comparison group, which is why conclusions about the effects of the interventions could not be drawn. To be able to design early interventions, there seems to be a need for greater awareness of the phases of the cancer trajectory, including the early phase following surgery.

## **1.4 THEORETICAL PERSPECTIVES AND CONCEPTS**

As discussed above, sickness absence and return to work are multifactorial phenomena, and several stakeholders may be involved in the processes. Some of the theories and concepts used for the design of studies and/or discussion of findings are described below.

### **1.4.1 The bio-psychosocial perspective**

The bio-psychosocial perspective is often termed holistic, and stresses interaction between medical factors and psychological/social factors e.g. in the return-to-work process. This approach integrates the previously dominant biomedical perspective with perspectives on the interaction between personal/psychological factors (e.g. cognitions and motivations) and the social contexts of individuals with health problems. The approach was proposed by Engel in 1977, who also considered these factors as part of systems interacting with each other (71). In this thesis, the perspective has enabled a focus on factors other than the biomedical, such as women's own experiences, reflections and actions, their work situation and also their interactions with various stakeholders.

### **1.4.2 Ecological systems theory**

In ecological systems theory, it is not only the individual's intra-personal life that is important, but also his or her ongoing transactions with the environment: a "progressive mutual accommodation throughout the life course between an active growing human being and his or her environment" (72). In this theory, goodness-of-fit is a central concept, meaning that there may be a match (or mismatch) between the individual's adaptive needs and resources or demands in the environment. Bronfenbrenner was one of the most influential researchers behind the ecological perspective, and he developed a theory of human development within the confines of his research on children's development. Also, the ecological perspective has, since its development, influenced social-work practice. Bronfenbrenner postulated that there are various sub-systems that interact within an overall ecological system. The systems are named microsystem, mesosystem, exosystem, and macrosystem (73). "The ecological perspective suggests that people connect with and act simultaneously within several systems" (72). The innermost circle is the individual with his or her own temperament, genetic predispositions, etc. The individual interacts in several microsystems, such as the family and the workplace. Mesosystems reflect the connectedness between microsystems, in which the individual interacts in. Examples of exosystems concern the employer or local government. Finally, the macrosystem consists of societal attitudes and values, and also cultural norms.

Ecological systems theory was used, although not explicitly referred to, in a Canadian study of stakeholder interactions and organizational structures in relation to return to work (74). In a recent review (75), the structure of Bronfenbrenner's theory was used as a backdrop for the organization of strategies to facilitate working when in having pain due to episodic illness (including after breast cancer surgery). This review found that most strategies and interventions were directed towards the micro level, i.e. the individual herself, by education, cognitive, physical or self-advocate strategies. Meso level found were mainly focusing on work environment, while macro level strategies included implementation of benefits and anti-discrimination laws. Finally, they concluded that few studies had been performed regarding paid work with episodic illness in breast cancer.

Further, an ecological case-management model has been developed (76) in research on return-to-work interventions after musculoskeletal disorders. The model has several similarities to the ecological systems theory, in that return to work is understood as a process within a context that takes into account the interplay between different levels in a system: macro (societal), meso (workplace, etc.), and micro (the individual) (76).

These theories and models have been used in interpretations and discussions of the findings of Study I, which is concerned with women's encounters with stakeholders and women's perceptions of them.

### **1.4.3 Action theory**

One action theory has been developed by Berglind (77, 78) in connection with unemployment and entering the work force, but has later been used in research on return to work. This specific theory of action takes its point of departure in motivation from the perspective of action, and postulates that motivation needs to be viewed within the social context of the individual. The individual's own perception of a situation is essential to how he or she chooses to act; that is, a woman's own perceived preferences (what she wants) interact with her perceived competences (what she think she is capable of) and her perceived outer opportunities (what she thinks she can get) (77). The theory was empirically tested in a study of individuals on long-term sick leave due to non-specific back and neck problems, and connections between individuals' own preferences, perceived competences and opportunities, and return to work were confirmed (77).

During discussions about Study II on women's reflections and actions, the above-mentioned theory enabled us to structure our findings.

### **1.4.4 Social support**

Social support is a concept that was introduced in the 1970s, but has its roots in e.g. sociological and psychological theories of social connectedness (79). The concept takes its starting point in the notion that social relationships are of great importance for health and well-being (80). Social support is theorized as having a main (direct) effect on health by promoting well-being, and/or a buffering effect, e.g. by alleviating or protecting against stress in difficult situations; this is the stress and coping perspective (81).

A distinction is made between received and perceived support, and their implications in relation to the buffering effect. It has been proposed that received support enhances coping performance which, in turn, enhances health; by contrast, perceived support (belief in its availability) leads the individual to appraise a stressful situation as less threatening (79, 82). In a meta-analytic review, Haber concluded that the constructs of



perceived and received support differ from each other, and suggested that perceived support is related to personality (83).

The concept of social support is complicated by how interactions take place, are evaluated, and the influences of reciprocity. Further, correct supportive actions need to be taken in a specific situation to achieve a buffering effect. Thus, there has been criticism of the measurement of social support, since few measures are elaborated enough to encompass the complexity of the construct (84).

It has also been hypothesized that social support influences sickness absence and return to work. Studies have provided evidence that low social support is a risk factor for sickness absence and a slower return to work (85), and social support has been found to be associated with sickness absence in a large population-based cohort (86). Karlsson et al. (87) found social support to be associated with both higher frequency and longer duration of sickness absence, and concluded: “[T]he association between high emotional support and increased risk of sickness absence is not surprising if such absence is seen as the effect of an ‘illness behavior’ rather than illness itself. High level of confiding/emotional support may encourage empowerment, security, and perceptions of control, which legitimize taking leave from work when ill” (87, page 23). In studies of cancer survivors and work, it has been found that individuals with less social support changed labor-force status to a greater extent than did others who received more support (88), and less emotional support from colleagues was associated with longer time to return to work (64).

#### **1.4.5 Encounters regarding return to work**

In research on sickness absence, some studies have focused on encounters with health-care and other rehabilitation personnel. It has been postulated that the encounters with them have an impact on sickness absentees return to work (89). Negative encounters are hypothesized negatively to affect self-esteem by evoking shame in the individual, leaving him or her feeling wronged and disempowered, thereby weakening work capacity and the likelihood of return to work (90). The opposite is hypothesized in relation to positive encounters, which may evoke feelings of pride, energy, and so on. Some findings support the hypothesis that experiencing nonchalance, disrespect, or distrust, i.e., negative encounters, has a bearing on self-estimated ability to return to work (91).

The research on encounters with stakeholders influenced Study II at the planning stage, in that questions related to encounters were included in the questionnaire and interview guide.

#### **1.4.6 Work adjustment**

Work adjustment, accommodation, and adjustment latitude are somewhat similar concepts. They concern the possibilities of temporarily deciding what tasks are to be performed and when, and of making other adjustments needed because of lowered work capacity. These are hands-on changes performed in a straining situation. Several studies have hypothesized that lower adjustment is associated with more or longer sick-leave spells. This relates to the bio-psychosocial perspective and action theory, introduced above, in which external opportunities and social contexts are regarded as relevant to the taking of actions regarding work.

In a study on return to work after breast cancer, having no work accommodation was associated with not returning to work within 12 months (52). This finding, however, was

contradicted by Hoyer and colleagues, who found no such association after 16 months (58).

Since work adjustment had been previously found as an important factor, the concept was used in the questionnaire.

#### **1.4.7 Value of work**

It has been proposed that work is of great importance in people's lives, and not just for financial reasons. The intrinsic value of work has been described as: "The value an individual finds in performing the work, in and of itself, outside of its utilitarian function. Instrumentally, the value of work is found in its identity-defining characteristic; its basis for providing the necessities of life; its role in giving meaning and structure to the adulthood years; and serving as a channel for the individual's talents, abilities, and knowledge" (92, page 2). Several studies have studied involvement, satisfaction, meaning of work, and work engagement, finding that a lack of them is related to sickness absence and not returning to work (53, 58, 93, 94). This is described in a study of return to work after Guillain-Barré disease (95). Value of work is related to the quest for normality, which is often also described in relation to return to work after cancer (8, 96, 97). Few studies of return to work have aimed to quantify the effect of value of work and relate it to sickness absence, although Hoyer et al found that attaching less value to work was associated with not returning to work in women with breast cancer 16 months after diagnosis (58).

Conceptually, value of work concerns one's own preferences (action theory) or motivational factors (the bio-psychosocial perspective), and evolved in this thesis as an important psychosocial factor.

## **2 AIMS**

### **2.1 GENERAL AIM**

The general aim of this thesis is to explore women's work situation after breast cancer surgery, with special focus on how women experience interactions with different stakeholders, and on women's reflections and decisions regarding work.

### **2.2 SPECIFIC AIMS**

Specific aims were:

To gain knowledge about women's experiences of encounters with stakeholders regarding return to work during and following the breast cancer trajectory (Study I).

To elucidate how women with breast cancer reflect over and act upon work-related issues (Study II).

To investigate how working women in different age and educational groups, who recently have had breast cancer surgery, experience and value work (importance, satisfaction, dedication), and whether these experiences are associated with sick leave (Study III).

To investigate received and perceived social support from supervisors and colleagues, and the perceived opportunity for work adjustment, and their associations with sickness absence among women who recently have undergone breast cancer surgery (Study IV).

### 3 PARTICIPANTS AND METHODS

This thesis is based on the findings from four studies (I-IV) using data from focus group interviews (studies I and II) and questionnaires (studies III and IV) on women who have had breast cancer surgery (Table 2).

**Table 2.** Overview of the four studies included in this thesis.

	Study I	Study II	Study III	Study IV
Aim	To gain knowledge about women's experiences of encounters with stakeholders regarding return to work on and following the breast cancer trajectory.	To elucidate how women with breast cancer reflect and act on work-related issues.	To investigate how working women who have recently had breast cancer surgery experience and value work (importance, satisfaction, dedication) in different age and educational groups, and whether these experiences are associated with sick leave.	To investigate received and perceived social support from supervisors and colleagues, and perceived opportunities to adjust work, and their associations with sickness absence, among women who have recently had breast cancer surgery.
Study population	A sample of women, aged 20-63 years, who had had breast cancer surgery in Stockholm and had responded to a questionnaire in the breast-cancer project.	A sample of women, aged 20-63 years, who had had breast cancer surgery in Stockholm and had responded to a questionnaire in the breast-cancer project.	Women aged 20-63 years who had had breast cancer surgery at one of three hospitals in Stockholm during 2007-2009 (n=971)	Women aged 20-63 years who had had breast cancer surgery at one of three hospitals in Stockholm during 2007-2009 (n=971)
Year of data collection	2008	2008	2007-2009	2007-2009
Study group	Women (n=23) aged 37-62, who 3-13 months prior to interview had had breast cancer surgery. Groups were stratified on having received or not received post-operative chemotherapy, and were aged <55 vs. ≥55.	Women (n=23) aged 37-62, who 3-13 months prior to interview had had breast cancer surgery. Groups were stratified on having received or not received post-operative chemotherapy, and were aged <55 vs. ≥55.	Women aged 26-63 (n=605) who responded to the questionnaire within 8 weeks, and worked at diagnosis.	Women aged 26-63 (n=605) who responded to the questionnaire within 8 weeks, and worked at diagnosis.
Type of data	Focus group interviews	Focus group interviews	Questionnaire data	Questionnaire data, registry data on diagnosis, date of diagnosis, type of surgery, planned post-operative treatment,
Analyses	Qualitative content analysis	Thematic analysis	Descriptive statistics, multivariable logistic regression	Descriptive statistics, multivariable logistic regression
Main outcome	Categories of encounters with different stakeholders	Themes as types of reflections in relation to actions concerning return to work	Association of the value of work with being on sick leave	Associations of social support and adjustment at work with being on sick leave

### **3.1 THE PROJECT ON LIFE AND WORK SITUATION AFTER BREAST CANCER SURGERY**

This thesis is based on data from the project: “Life Situation and Return to Work after Breast Cancer Surgery – a Prospective Cohort Study”.

Included in the project were women who, between June 2007 and November 2009, received treatment for breast cancer at one of three hospital locations in Stockholm, Sweden: Karolinska University Hospital Oncological Department (with wards on 2 sites – Solna and Södersjukhuset) and Sankt Göran Hospital. Inclusion criteria for the project were being 20-63 years-old, living in Stockholm County, and being literate in Swedish. Exclusion criteria were known distant metastasis, pre-surgical chemotherapy, and/or a previous breast cancer diagnosis.

The women were included consecutively at their appointments for planning further treatment, usually four to eight weeks after surgery. At their appointment, they were informed of the project both orally and in writing, and were given a questionnaire and a prepaid return envelope. Information on voluntariness and confidentiality, and also the possibility of withdrawing from the study, was given. If the attending physician deemed it inappropriate, due, for example, to a mental disorder, the woman was not given the information, although her personal identification number was forwarded to the project team. Personal identification numbers were also forwarded for all the women to whom the questionnaire was administered. If the prepaid envelope was not returned to the project assistant within two weeks, two reminders were sent out.

In total, 971 women met the inclusion criteria for the project, of whom 48 (4.9%) were missed due to administrative failures. In total, 725 women (78.5%) completed and returned a comprehensive questionnaire, and thereby agreed to participate, with their informed consent. These women formed the study population from which some were invited to focus group interviews (studies I and II). It was also from this study population that women were included in studies III and IV, provided that they met the specific inclusion criteria for the particular study.

### **3.2 QUALITATIVE STUDIES (STUDY I AND STUDY II)**

#### **3.2.1 Participants**

Studies I and II were based on analyses of data from four focus group interviews. Invited to the focus group interviews were women who had responded to the above-mentioned questionnaire and had had surgery 3-13 months prior to the interview date. This time frame was chosen to ensure that each woman had had at least an opportunity to consider returning to work, but a longer time frame was applied to women who had had chemotherapy, since that type of treatment often entails longer sickness absence.

In order to facilitate discussions, the focus groups were made homogenous (98, 99) in two regards: type of cancer treatment (chemotherapy or not) since this has a major impact on return to work (52, 55, 61, 100), and age (being below or above the age of 55). Age has been shown to be associated with sickness absence in general (101), but the association is not so clear in the case of breast cancer patients (100). In terms of homogeneity, we assumed that work and life situation might be more equal within the same age group.

The women were invited by mail to a focus group discussion at a specific time. The letter gave information about the focus of the particular study and asked them to attend

on the set date. The date was determined in advance, and several women indicated this as a reason for not being able to attend. In total, 56 women were invited to participate in the focus group interviews, and 23 agreed to participate. The numbers of participants in the focus groups were:

- Group 1 – four women aged 55 to 61, all of whom had received chemotherapy;
- Group 2 – seven women aged 37 to 51, all chemotherapy recipients;
- Group 3 – seven women aged 57 to 62, none of whom had received chemotherapy;
- Group 4 - five women aged 42-54, all without chemotherapy.

Data on demographics, occupation, work situation, and type of treatment were obtained from the baseline questionnaires and from medical records. Classification of occupations was performed in accordance with Statistics Sweden's SSK96 (102), which corresponds to the International Classification ISCO-88 (103).

### **3.2.2 Data collection**

An interview guide was developed in discussions with the multi-professional project group. It was based on previous research in the field of return to work after cancer including encounters with stakeholders (89, 90, 104). The guide included an introduction to the focus group, stressing, for example, voluntariness and confidentiality. Also, the overall subject area of the group interviews was again explained to the participants; it concerned work after breast cancer surgery, and also broad themes, such as encounters with others regarding work after cancer, and hindering and facilitating factors experienced.

The interviews took place at one of the hospitals in Stockholm, in a location separate from the treatment wards. The timing of the interviews was planned to allow as many as possible to participate; hence, the interviews were conducted during the evenings of November 2008.

All the interviews were audio-recorded and transcribed verbatim, and the author verified the transcripts by checking them against the original audio files. After the first focus group interview, the research group read the transcripts to determine whether there was a need to modify the guide or the interview procedure; no changes were deemed necessary.

### **3.2.3 Analysis (Study I)**

Although studies with a qualitative methodology have been performed previously on return to work after breast cancer, none has aimed at exploring encounters with the various stakeholders involved, or has explicitly explored women's reflections and actions in this situation. Accordingly, an inductive exploratory approach was adopted (105, 106). Data from the focus group interviews were analyzed inductively by means of qualitative content analysis (107). The process started with extensive reading of all the texts in full. All expressions concerning encounters with others associated with return to work, or reactions to these encounters, were identified as meaning units and extracted from the texts. The extracts were checked and discussed by all the co-authors until agreement on the texts to include was reached. All individuals that the women mentioned in their statements about return-to-work-related encounters, irrespective of context and setting, were categorized as belonging to groups of stakeholders, e.g. persons in social insurance, at work, or in health care. A tag identifying the role of the person who was encountered was attached to each statement to make it possible to

separate out information on the different stakeholders. Thereafter, the extracts/meaning units were condensed, and coded close to the text. The codes were then scrutinized, and a search for similarities and dissimilarities was performed. Categories were created, in which the codes were included. Further collation of codes was performed, and some categories were collapsed or included as sub-categories, thereby reducing the number of categories. It was not possible to arrive at a theme that encompassed all the categories. The first analysis was performed by the first and second authors, but the other co-authors participated in discussions of the categories and of other aspects throughout the process. The analysis was structured in QSR Nvivo, version 8.

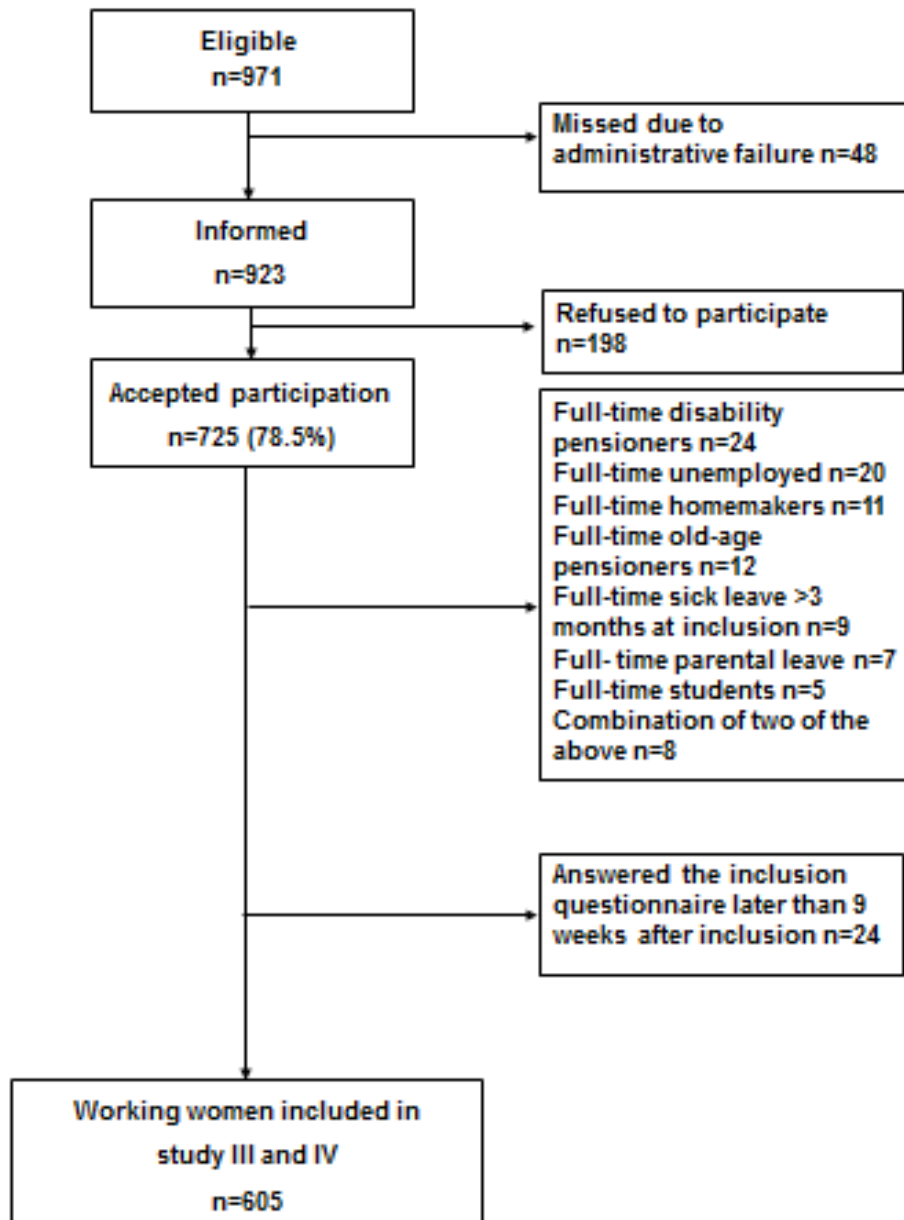
### **3.2.4 Analysis (Study II)**

The focus group data were also used in Study II, although, since this study had another objective, different excerpts were used. The analysis was inductive, based on thematic analysis as described by Braun and Clarke (106). First, the transcripts were read repeatedly once more. Statements concerning the women's actions regarding work and their associated reasoning were extracted and discussed by the co-authors until agreement was reached on which texts to include in the analysis. The initial coding and search for themes was performed by the first and second authors, but the themes were continuously discussed with the other co-authors. The themes were revised in relation to both the extracts and the entire data set, and a thematic map was developed. Further refinements and collations of definitions were performed, and finally names were given to the themes and sub-themes (106).

## **3.3 QUANTITATIVE STUDIES (STUDY III AND STUDY IV)**

### **3.3.1 Participants**

In total, 971 women fulfilled the inclusion criteria for the main project. Since studies III and IV concerned aspects of work, homemakers, old-age pensioners, students, and women on parental leave (n=96) were not included. Moreover, since the focus of the studies was on circumstances shortly after breast cancer surgery, the 24 women who did not respond to the questionnaire before eight weeks had passed were not included. This left a study group of 605 women.



**Figure 1.** Flowchart over inclusion in study III and IV.

### 3.3.2 Data collection

A comprehensive questionnaire was developed within the multi-professional and interdisciplinary research group. The questionnaire was pilot-tested at one hospital and amended somewhat thereafter.

Data on treatment and date of diagnosis were obtained from the Swedish National Quality Register for Breast Cancer, and were used with the permission of the Steering Board of the Swedish National Quality Register for Breast Cancer.

*Current sickness absence* was used as the dependent variable in both Study III and Study IV. It was measured by the question: “Are you currently on sick leave?” with the response options “no”, “yes, for the past week”, “yes, for the past month”, “yes, for the past three months”, “yes, for more than three months”. Extent or degree of sickness absence was specified in the response options “on full-time” or “on part-time”,



with the request to fill in percentage of full-time. The variable was dichotomized into “on sick leave” and “not on sick leave”.

### **3.3.2.1 Independent variables (Study III)**

*Importance of work* was measured by the question: “How important is your work to you?” with five response options ranging from “one of the least important things in my life” (=1) to “one of the most important things in my life” (=5). The responses were dichotomized into “least important” (1-3) and “most important” (4-5).

*Work satisfaction* was measured by four questions. One was modified from a previous project on work and sick leave concerning how rewarding a woman found her work, “Which of the following statements agrees best with how you feel about your work?” The response options were: “The most important thing about my job is the salary”, and “There’s something special about my job. Besides the salary, it gives me a feeling of personal satisfaction”.

One item was used from the LifeSatisfaction11 (LiSat11) instrument (108, 109) “My vocational situation is ...” with six response options ranging from “very dissatisfying” (=1) to “very satisfying” (=5). The responses were dichotomized into “dissatisfied” (1-4) and “satisfied” (5-6).

Two questions, developed by the research team, concerned wanting to change profession or employment, each with the response options “yes” and “no”.

An index on *dedication to work* was created using three items from the Utrecht Work Engagement Scale (UWES) (110)

1. “I feel that my work is meaningful”
2. “My work inspires me”
3. “I’m proud of the work I do”

The response options were “never” (=0), “about once a year” (=1), “a few times a month” (=2), “a few times a week” (=3), and “daily” (=4). The three responses were used to create an index (with values summed and divided by the number of items responded to, given a minimum number of 2 items). Dedication was dichotomized at the median into “lower” (0-3) and “very high” (4).

### **3.3.2.2 Independent variables (Study IV)**

*Perceived work adjustment* was measured by six questions from the Adjustment Latitude Scale (111, 112) and the National Working Life Cohort (113).

The following questions were taken from the Adjustment Latitude Scale:

1. “When the work you do becomes physically too strenuous, is it possible for you to slow the pace or perform your duties in some other way?”
2. “When the work you do becomes too psychologically strenuous, is it possible for you to influence your situation?”
3. “In what way can you adjust your work situation if you are not feeling well. Can you decide yourself which tasks to perform?”

Response options were: “always” (=3), “sometimes” (=2), “seldom/never” (=1), and “not applicable” (=0).

The following questions were taken from the National Working Life Cohort:

1. “Can you set your own work pace?”
2. “Can you to some extent decide when various tasks are to be done?”
3. Are you partly/sometimes allowed to participate in the planning/organization of your work?”

The response options were: “always” (=3), “usually” (=2), “seldom” (=1), and “never” (=0). The latter two response options (seldom and never) were collapsed into “seldom/never” (=1) to correspond to the response options on the Adjustment Latitude Scale.

A mean index score was calculated if a minimum of three questions were answered, where a lower score indicated less work adjustment. The index ranged between 1 and 3, and its distribution was dichotomized (median value: 2.00, mean 1.95, SD 0.48) into “high” (>2) and “low” (≤2).

*Received social support* from supervisor and colleagues was measured on the basis of responses on the Structural Functional Social Support Scale (114-116). Support from supervisors included the items:

1. “... maintains contact during the disease”
2. “... shows sympathy and understanding”
3. “... gives advice on how to handle working life”
4. “... takes the disease into consideration when planning work tasks”

Support from colleagues included the first two items listed above. The items were ranked on 3-point Likert scales; “do not agree” (=1), “agree somewhat” (=2), and “agree” (=3).

The index mean and median were calculated on the basis of at least two items responded to, with lower values indicating less social support (88, 117). A binary variable for cancer-related support from supervisor was created by dichotomizing at the median into: “highly supportive” >2.5 to 3, and “less supportive” 1 to ≤2.5 (mean 2.39, SD 0.48).

*Perceived social support at work* was measured by two single items from the National Working Life Cohort (113): “Are you able to get support and encouragement from colleagues when you feel that things aren’t going well at work?” and “Are you able to get support and encouragement from your immediate boss/supervisor when you feel that things aren’t going well at work?”. The response options were “always” (=3), “usually” (=2), “seldom” (=1), and “never” (=0). The items were dichotomized at the median into “highly supportive” (>2), and “less supportive” (≤2).

### 3.3.2.3 Covariates (studies III & IV)

*Age* was dichotomized at the median into “younger” and “older” (<52 and ≥52 years). *Education* was classified into three groups: “elementary school or equivalent” (≤9 years), “grammar/secondary school” (10-12 years), and “college/university” (>13 years). The variable was dichotomized into “low” (elementary or grammar/junior secondary school) and “high” (college/university) education.

### 3.3.2.4 Covariates (Study IV)

#### *Treatment-related data*

*Final axillary surgery* was coded into “sentinel node” and “axillary clearance”.

*Planned post-operative chemotherapy* was coded “yes” and “no”.

*Number of days* from diagnosis to responding to the questionnaire was calculated and dichotomized at the median (77 days).

#### *Work-related data*

*Work situation at diagnosis* was measured by the question “What was your working situation at diagnosis?” The response options were: “working”, “on sick leave for more than three months”, “on disability pension”, “unemployed”, “student”, “on parental leave”, “on old age pension”, and “homemaker”. More than one response could be chosen, and a request was made to specify the percentage of full-time work. Percentage of full-time work was used rather than hours worked per week, since in many jobs (e.g., shift work) full-time employment is less than 40 hours/week.

*Disclosure of disease* in the workplace was measured by the item “Have you told people at work about your cancer?” with the response alternatives: “no” and “yes”, for my boss and for my colleagues.

*Number of years at current employer* was dichotomized into “≤1 year” and “>1 year”.

*Strenuous work posture* was self-reported using three questions: “Do you have to work with your arms above your shoulders or below your knees?”, “Do you have to work in a bent or twisted position, or in any other inappropriate posture?”, and “Does your job require heavy lifting?”. The response options were: “rarely/never” (=1), “not very often” (=2), “sometimes” (=3), “fairly often” (=4), and “very often/always” (=5). An index “work posture” was created using a summed average, for which a minimum of two items had to be responded to (Cronbach’s  $\alpha=91$ ; inter-item correlation 0.77-0.80). The index was dichotomized on the basis of the response options into  $<3.0$  “no strenuous work posture”, and  $\geq 3.0$  “strenuous work posture” (36).

### 3.3.3 Analyses (studies III and IV)

Descriptive statistics (percentages, means, medians) were calculated using conventional methods. The significance level was set at  $p<0.05$ , and all tests were two-tailed.

Pearson chi-square tests were used to distinguish differences between groups, and ANOVA was used to compare the mean ages of participants and non-participants.

Univariate or multivariable logistic regression was employed to estimate crude and adjusted odds ratios (ORs) with 95% confidence intervals (CIs) for the associations between the independent variables, covariates, and sickness absence.

In Study III, all the variables were analyzed using univariate, age-adjusted logistic regression. Included in the final regression model were the variables that had been found, independently, to be significantly associated statistically with sick leave.

In Study IV a factor analysis was performed of the independent variables, which strengthened the variable items used and the structure of the index. The principal component analysis was conducted on 12 items using oblique rotation (direct oblimin). In the univariate and multivariable logistic analyses of variables related to received and

perceived support from supervisor, a dummy variable was created with women without a supervisor as a category, thereby allowing them to be included in the analysis, despite the category not being interpreted in the results.

In the multivariable logistic regression (Study IV) three models were employed, adjusting for: 1) age; 2) age, socio-demographic and work-related covariates; 3) age, socio-demographic, work- and treatment-related covariates. The variables included in the multivariable models were those that had been found to be statistically significant in the univariate analyses.

Data management and statistical analyses were performed using IBM SPSS Statistics 20.

### **3.4 ETHICS**

The project was approved by the Regional Ethical Review Board in Stockholm, Sweden.

## **4 RESULTS**

### **4.1 MAIN FINDINGS**

Women who had had breast cancer surgery encountered several different types of stakeholders in the return-to-work process. These encounters concerned different types of adjustments and information, and various attitudes were conveyed. Their own preferences, their perceptions of their own competence, and their perceived outer opportunities all interacted in their decisions regarding (return to) work. Most of the women valued work very highly, and work played an important role in normalizing their lives. Low perceived social support from supervisor, poor adjustment opportunities at work, and low vocational satisfaction were associated with being on sick leave during the period immediately following breast cancer surgery.

#### **4.1.1 Study I – encounters with different stakeholders**

The women stated that many stakeholders, in four different arenas, were involved in the return-to-work process: employer, colleagues, and clients; health care personnel; officials from the Social Insurance Agency; and family and friends.

The encounters with stakeholders concerned three categories: adjustment, information and attitudes. The adjustment category contained, in various sub-categories, changes made in the workplace, adjustments to the application of social insurance benefits, the planning and timing of health care and sickness certification (or a lack of it). In some instances lack of adjustments not only affected the women, but also other stakeholders, e.g. rigid applications of part-time sick leave. Information was found to vary in content and quality, if indeed it was provided, e.g., information of side effects in medical consultations or information on social benefits. There was an expressed need for information on side-effects and the timing of treatments in order better to plan return to work, and to enhance ability to ask for work adjustments. Some attitudes were perceived as directed at the woman herself, e.g., those that showed disrespect for her and her work situation. There were furthermore other attitudes that were perceived as being concerned with whether adjustments should be made to meet the woman's needs at work, or whether she should be sickness absent or not. The latter attitudes were, in some cases, perceived as disrespectful, discouraging return to work when the woman wanted to return, or forcing her to return when she did not.

The women indicated that stakeholders are involved, and play an important role, in their return to work. They could provide adequate information, facilitate flexible arrangements regarding sick leave, work and/or treatment in line with the women's needs, and also encounter the women with a more neutral attitude towards work or sick leave. Lack of adjustments, less than optimal information, a disrespectful attitude towards the woman, and not taking the woman's preference for sickness absence or work into account were found in the encounters to which the women referred negatively.

#### **4.1.2 Study II – women's own reflections and actions**

All but one of the women was working full-time when diagnosed with breast cancer. At time of interview, 14 of the 24 women worked full-time. Five women worked part-time, of these had four had taken part-time leave of absence or vacation, while a fifth had been working part-time prior to diagnosis. Further, three of the women combined work and partial sick leave, and one was unemployed. Two women had changed job

and employer during the treatment period, and had chosen not to disclose their disease to their new employer. The unemployed woman had been dismissed after the breast cancer diagnosis, shortly before her probationary employment ended. During the cancer trajectory there had been individual patterns of sick leave; some women had worked except for days of surgery and treatment, whereas others had had partial or full time sick leave throughout. There was a considerable variety of types of occupations among the participants in the focus group interviews, although none of the women were in service/retail, industrial, or unskilled jobs.

Five themes concerning reflections on work were identified and named: “Health and functioning”, “Self-esteem/integrity”, “Value of work”, “Relationships at work”, and “Social circumstances”. These reflections were, in certain combinations, related to actions taken regarding work and sickness absence. Three different action themes were identified: “To work or to be absent”, “To adjust work according to one’s own needs or not”, and “To disclose or to conceal one’s cancer”. As mentioned above, several had women worked during their treatment to some extent, especially those who were self-employed. These themes came up in all the four focus group interviews.

When discussing the findings, the framework of action theory proved to be useful, in that own preferences, perceptions of one’s own competences, and external opportunities could be detected in the themes of reflection, which then interacted in relation to the actions taken.

Many of the women valued work as a normalizing factor. Working by choice during treatment had economic and psychological benefits, whereas being forced to work against one’s own preferences had physical and emotional disadvantages.

Further, it was found that it is essential to address the specific issue of disclosure in the workplace, since this may be distressing for some women.

#### **4.1.3 Study III – value of work**

Of the women investigated (n=605), 92% worked at least 75% of full-time at inclusion in the study; at time of responding to the questionnaire, 61% were on sick leave, of whom 80% were on sick leave full-time. A majority (77%) of the women on sick leave had been absent from work for one month or more and 18% for one week, while 5% did not state their length of absence. Of the women on sick leave, 98% were absent due to the breast cancer diagnosis.

Two-thirds of the women reported work to be one of the most important aspects of their lives, and 86% stated that there was something special about their job that gave them personal satisfaction (rewarding work). A vast majority of the women (84.5-91%) were dedicated to their work (finding work meaningful, inspiring, and something to be proud of). Half of the women were satisfied with their vocational situation (job satisfaction), although 14% wanted to change profession, and 18% to change employment.

A higher proportion of younger than older women wanted to change their profession and/or employment. Further, a higher proportion of older than younger women found their work meaningful and had vocational satisfaction. Differences were found between the educational groups, where women with a high education found their job important to a greater extent than women with a low education; the higher educated also found their work rewarding, were dedicated to work, and were satisfied with their vocational situation to a greater extent than the lower educated.

Lower age (OR 1.44; 95% CI 1.02-2.03) and dissatisfaction with vocational situation (OR 2.38; 95% CI 1.66-3.41) were associated with being on sick leave shortly after breast cancer surgery.

#### **4.1.4 Study IV – adjustment and social support at work**

A large majority of the women had disclosed their diagnosis to their supervisor (87.6%) and colleagues (89.6%); only five had not disclosed their diagnosis at all in the workplace. A quarter of the women in the study reported having a strenuous work posture.

A fifth of the women could never or seldom adjust work when it became physically straining and a quarter when it became a psychologically straining. Even more of the women could never or seldom set their own pace of work, decide when to perform their tasks, or choose what tasks to do.

A majority of women had received support from their supervisor, and had colleagues who stayed in contact and showed sympathy, while only a third had received support in the form of advice about work life. Perceived support from supervisors was reported by 77%, while the proportion perceiving colleagues as supportive was 86%.

Lower levels of work adjustment (OR 2.14; 95% CI 1.45-3.18) and lower perceived social support from supervisors (OR 1.80; 95% CI 1.16-2.78) were associated with being sickness absent shortly after breast cancer surgery. The estimates were not attenuated by controlling for the significant covariates, i.e., age, country of birth, strenuous work posture, and axillary clearance or planned post-operative adjuvant chemotherapy.

## 5 DISCUSSION

The aim of this thesis is to explore women's work situation after breast cancer surgery, with a special focus on how women experience interactions with different stakeholders, and on women's reflections over and decisions concerning work. A large proportion of the women investigated (49%) worked shortly after breast cancer surgery (studies III and IV). Individual patterns of work and sick leave were found (Study II); some of the women worked to some extent throughout the cancer trajectory, whereas others remained on sick leave. Work was valued highly; that is, work was of great importance in many of the women's lives, and they showed a high dedication to work (Study III). Further, work was referred as a normalizing factor, which reflected a preference to work rather than be on sick leave (Study II). Having less vocational satisfaction was associated with sickness absence (Study III). Women took an active role in the return to work process, and their decisions were influenced by the interplay between own preferences of valuing work or wanting to focus on recuperation, perceived health and functioning, and the social context of their work (Study II).

There was an expressed need for information on side-effects and the timing of treatments, so as better to plan return to work, and to enhance ability to ask for work adjustments (Study I). Having such adjustment opportunities at work is an important factor in being able to continue to work or to return to work (Study I). Having limited adjustment opportunities was associated with being sickness absent, an association that remained after controlling for well-known risk factors for being absent (Study IV).

A majority of the women reported having received social support from their employer and colleagues at work. Having such support, especially from supervisors, is essential, and is also associated with not being on sick leave shortly after breast cancer surgery (Study IV). The suggestions of people in healthcare and at work, and of friends and family, about taking sick leave were found sometimes to be in conflict with the women's own preference to be at work or not, and they were then regarded as less supportive (Study I).

Women with breast cancer encounter many different stakeholders, and the availability and flexibility of the stakeholders, and also receipt of information, work accommodation, and social support seem to be pivotal in relation to working after breast cancer.

### 5.1 DISCUSSION OF RESULTS

Two overarching themes in the results of the different studies appear throughout the statements and ratings. These are the value of work and the need for flexibility, which are discussed below.

#### 5.1.1 Value of work

Value of work is a concept that concerns not only the economic benefit of working but also the idea that work has a value in its own right, by giving personal satisfaction, by being a source of self-esteem and a way of structuring the day, and by providing a social context. After falling ill, return to work is often one of the goals of recovery, since it can normalize an otherwise new or unfamiliar situation. In this thesis, the value of work is conceptualized as multifaceted, encompassing satisfaction with one's own work, the importance of work in one's life, and degree of being engaged in work.



Several studies have found motives for people on sick leave to return to work; they include a longing for normality and a need for social contact (8, 118, 119). Further, during the cancer trajectory there are different ways of relating to work, as described, for example, in the idea of “transition in work approach” (8), or as dialectic relations between experiences “disruption”, “episode” and “meaningful period” (120), which means that the value attached to work fluctuates during the stages of cancer rehabilitation. Individuals who are unable to return to work after cancer have been found to create new patterns of activities to give meaning to life, where a “biographical reconstruction of identity is created over time” (119). This is a transition that can be compared to taking retirement (121). Still, there may be a striving to remain in the workforce, despite recognizing the gloomy outlook that emanates from the thought of being less attractive as an employee (118). In Study III, the women rated the value of work highly; work was seen as one of the most important aspects of life, even at such a short time after breast cancer surgery. This finding contradicts the finding of a previous study that perceived importance of work is reduced at the initial return-to-work stage (122). Further, in Study II, work and return to work were seen as an action theme in their own right, albeit closely related to, and not necessarily in opposition to the theme of self-esteem/integrity.

The women in Study II took an active role in the decision on return to work. Their own preference in relation to work or staying on sick leave is significant, although it interacts with perceived competences and perceived opportunities. Health and functioning have been reported, in both qualitative and quantitative studies, to make up one of the most influential factors in return to work after cancer (55, 56, 60, 64). A diagnosis in itself is not sufficient to obtain certified sick leave, since the disease or its treatment sequelae must also lead to a decrease in work capacity relative to work demands. The interaction shown in Study II is exemplified by the preferences expressed with regard to regaining normality through work if possible (and asking for adjustments) or focusing on recuperation. It has been previously suggested, for example, that individuals’ own preferences, in interaction with perceived competences and opportunities (e.g., collaboration between stakeholders), are critical factors in returning to work after stroke rehabilitation (123).

Interactions with co-workers and supervisors form the worker role and there are certain expectations on the part of others concerning what this role entails, as has been pointed out in theories of return to work (124). When a disruption takes place, e.g., being diagnosed and treated for breast cancer, not only are the routines and roles of the working person subject to challenge, but other people’s expectations may change; for example, there may be an expectation that the woman will act in another way due to the disruption caused by her disease or treatment. As found in Study I, there are differences in how individuals interpret encounters as positive or negative, possibly in accordance with whether or not the attitudes conveyed are in line with the woman’s own preferences. It was found in a recent Dutch study that others’ attitudes could be a barrier to return to work, in that women had to “fight the stigma that work was not important to them during or after treatment, that they were not able to resume work, or that their work productivity was lower in comparison to healthy subjects” (122). Further, previous research on individuals who were sickness absent due to musculoskeletal diagnoses, and their encounters with social insurance offices and health care personnel, has found that negative encounters can, via lowered self-esteem, lead to a delayed return to work (90, 104). Study I reveals that several women expressed that a positive attitude of stakeholders towards sickness absence made them feel discouraged in their own striving to return to work, while others felt it was appropriate, since it was in harmony with their own preference. Thus, it seems important that stakeholders have a

neutral attitude towards being sickness absent or working after breast cancer. Further, if, for example, work is deemed by stakeholders to be counter-productive from a rehabilitation standpoint, it seems relevant to have a more reflective discussion on the pros and cons of working or being absent, while maintaining an empathetic stance that includes understanding of the woman's needs and preferences.

The only aspects of value of work that were associated with being sickness absent were when not experiencing vocational satisfaction and wanting to change profession (study III). These findings may, on the one hand, imply that sick leave due to breast cancer can provide an opportunity to reflect on goals in life, which might entail re-assessment of one's current occupation, reflection over a lack of satisfaction in the current job, and/or changes in life values and priorities in work life (8, 58, 97, 120, 122, 125, 126). On the other hand, not having vocational satisfaction may also be due to being in a state of biographical disruption, despite work remaining to be of great importance in one's life; hence, sickness absence may lower vocational satisfaction. Thus, more research is needed to assess changes in perceived value of work over time, taking into account possible confounders, such as different post-operative treatments, and consideration of whether or not the associations of value of work with being on sickness absent change over time.

### **5.1.2 Need for flexibility**

Flexibility in this thesis is used as a concept to reflect the openness, availability, adaptability, and responsiveness of stakeholders that permit adjustments or changes to be made in relation to the women. It entails being able to recognize an individual's needs, having opportunities to make changes or adjustments, and taking the actions required to make such needed adjustments. These adjustments may not only be related to the work situation, but also to other areas (as discussed below).

This overarching theme of flexibility can be found in part in many studies of return to work, although it is not labeled as such; rather, communication, co-operation and support for work adjustments are highlighted as important aspects (74, 127, 128). These aspects were also regarded as important in the studies in this thesis, but what also seem important are the direction and number of interventions, in terms, for example, of information or accommodation, and the extent to which they are related to the needs and preferences of the individual, i.e., the degree of flexibility in decisions made on intervention.

In this thesis, the concept of flexibility first arose when discussing the results of Study I, where women talked more positively about encounters with stakeholders who were attentive to, and made adjustments according to, the women's preferences and needs, e.g., in the accommodation of work. The same was also found in Study IV, where low adjustment opportunities (inflexibility in the work situation) were associated with being on sick leave shortly after breast cancer. On the one hand, this corroborates the results of an earlier study of return to work after breast cancer, which found employer accommodation to be related to return (52), but, on the other hand, it contradicts the findings of another earlier study (58). These, last mentioned, studies were performed, on average, at 18 and 16 months post-diagnosis, respectively, and the subjects were asked about work accommodations in retrospect. Further, they used different outcome measures. Accordingly, as stated in a systematic review of the literature on working after cancer, the evidence is inconclusive on this issue, and more research is needed (129). A different aspect of adjustment is found in the reflections of some women on disclosure, in which they expressed the fear that they would be given less interesting or

challenging tasks because they had had cancer (study II). Thus, there is a need to be receptive in discussions of work adjustments.

In Study I, some women stated they had lacked information, especially on the risk of diminished cognitive functioning; however, the remedy is not merely to provide more information to all. Flexibility in tailoring individualized information must be taken into account, acknowledging the importance of the kind of person receiving the information (130). For example: What type of job does she do? What are her preferences, e.g., in relation to work? To include, apart from one's professional judgement on treatment and information needed, also asking about and being receptive to what the woman expresses as needed, and what the preference of the woman actually is with regard to information relating to work capacity is a prerequisite for good health care, i.e. being professional in encountering individuals.

When using ecological systems theory as a frame, it became clear that the women's statements in Study I showed the effects of interactions between different mesosystems involving the women, but also of interactions between mesosystems in which the woman participates, but not actively, i.e., at an exolevel. This was evident when the social insurance officers, in their interpretations of the sickness certification rules, maintained a rigid position on, for example, the division of part-time work, which had repercussions for other stakeholders, including those in the workplace. Another example was when hospitals were unable to accommodate appointments for radiotherapy, or were unable to provide information on the timing of treatments, which interfered with the woman's work and her possibilities of planning for it. In ecological systems theory, this is referred to as "maladaptive goodness-of-fit", which involves a mismatch between the person and the environment (72). Such interaction has been recognized in a previous study, in which various stakeholders reported on perceived facilitators of and barriers to return to work. It was found that barriers included delays in information, decisions and goals, and less than effective communication between stakeholders, while facilitators included trust, effective communication, co-operation and trust between stakeholders (74, 131). Such findings have also been presented in studies of return to work after cancer, where cooperation, communication and support from and between stakeholders have been found to be of importance, both at the initial phase, and later at the post-return to work or sustainability phase (132). The results of this thesis indicate that it is also important to take into account how interactions between stakeholders at an exolevel may affect women with breast cancer.

In the present studies, a large majority of women stated that they had received social support from co-workers and their supervisor even at this early time point. A cancer diagnosis may evoke feelings of sympathy and support, which may be more easily accessed at this time. But previous research has pointed to possible deterioration in support from family, friends and health care personnel over time (40). Further, colleagues are sometimes left with a responsibility to accommodate the work (133, 134), which may be associated with weakening support. In relation to flexibility in the provision of social support, there have been contradictory research findings concerning the associations of receiving social support being sickness absent and/or a prolonged time to return to work. In a large prospective case-control study of the risk of becoming sickness absent no association was found between lack of social support and sick leave (135), but some studies have reported a negative association between lack of support and sick leave among men (86). Also, one study has found a positive association between perceived emotional support and sickness absence (87).

According to Study IV, perceived lack of social support from supervisors is associated with being on sick leave. Moreover, the positive attitude of stakeholders to sickness

absence experienced by the women was regarded by most of them as a way of showing consideration and support (studies I and II). However, as discussed previously, not all the women regarded the positive stance of stakeholders to sickness absence as encouraging and supportive, but rather as overprotective and discouraging. This has been recognized previously in the reporting of negative beliefs that women with breast cancer are frail and to be pitied, and that women have to fight against preconceived views that work is unimportant in their situation (122). Further, with regard to co-workers' responsibility as main support regarding adjustment mentioned above, negative attitudes from colleagues towards the woman's return to work can arise (133). This raises the issue of whether support is always productive and adequate; rather, it can be non-supportive in the return-to-work process, which shows the complexity of the social-support construct (84, 136). Accordingly, results in the thesis point to differences in how individuals experience encounters with stakeholders, where attentiveness seems to be important e.g. since some women prefer one stance, while other women prefer another stance, e.g., on sickness absence. Thus, openness, professionalism and flexibility in encountering the individual woman and her needs seem to be of great importance.

## **5.2 METHODOLOGICAL CONSIDERATIONS**

In this thesis, different types of data, as well as qualitative and quantitative data analyses were employed. The methods jointly provide a comprehensive way of exploring the work situation of women after breast cancer surgery.

One strength of this thesis lies in its use of purposeful sampling of informants (in studies I and II), where only women of working age who were actually working prior to diagnosis were included. Also, the homogenous composition of each focus group facilitated discussion and created an environment of support and recognition, which encouraged the women to share their experiences (98, 137). Further, to achieve such an environment, a trained and experienced group moderator was appointed. She and the assistant moderator were both trained medical social workers, experienced in working with individuals with diseases and their possible consequences. The goal was reached, since the environment was acknowledged by the informants as open, supportive and permissive, which created an atmosphere that made it possible for conflicting experiences to be reported.

Qualitative content analysis and thematic analysis have been proposed as good methods when performing inductive exploratory studies. They furthermore offer systematic procedures in analytic steps (105, 106), which is why they were chosen. The entire analytic process was carefully discussed in the multi-professional research group in seminars (138). The discussions made it easier for the extracts to be concordant with the specific aim of each study, and for there to be congruence in how to judge similarities and differences between categories and themes (107). The members of the research team were from different professions and had experience in qualitative as well as quantitative research, which was an additional strength in that it allowed any preconceptions to be challenged.

Strengths of studies III and IV were the use of a large sample of consecutively included women and a high response rate (78.5%). The women were included in the analyses only if they had responded to the questionnaire within 8 weeks of their inclusion in the studies, which entails less recall bias. In addition the internal drop-out rates were low.

Since women with metastatic breast cancer undergo more advanced anti-tumoral treatment, we did not include them, thus eliminating possible confounding by severity

of disease. Further, women not currently working at all were excluded, since they did not have a current job to which the variables could be related. Other known confounders were taken into account in the multivariable analyses. Adjusting for time since diagnosis, axillary surgery and planned chemotherapy was possible through the use of data from the National Register for Breast Cancer, with a coverage of nearly 100% (15), which minimizes the risk of misclassification.

Some variables in the analyses were dichotomized at the median, in order not to lose statistical power. Further, the variable “number of years at current employer” was dichotomized into  $\leq 1$  year and  $> 1$  year. This boundary was decided upon since women with short occupational tenure are new to the job, may have temporary employment or be in a less secure position, may hypothetically receive less work adjustment, and also may be more reluctant to take sick leave (139).

For studies I and II, 59 women were invited to the focus group interviews, of whom 23 chose to participate. A quarter of the participants had a lower level of education, and none of them worked in service/retail, industry, or had occupations without specific educational requirements. This may be seen as a limitation, in that that the full diversity of experiences may not have been captured. It would not have altered the findings, but it may have hindered the introduction of additional categories and themes. Women diagnosed with breast cancer have a higher educational level than the norm population (140), so the sample, with a relatively high educational level (for studies III and IV), probably reflects the source population. Further, the educational level in Stockholm County is much higher than the average in Sweden (141). A lack of access to information on education among the non-participants and the women missed due to administrative error are limitations of the studies.

Sickness absence to any extent was chosen as the outcome in studies III and IV. It can be viewed as a limitation that sub-analyses were not performed in relation to part-time sickness absence, although, because a vast majority of the women were on sick leave full-time, sub-analyses of part-time sickness absence would have had fewer women in each group, leading to less statistical power for the detection of any associations.

In Study IV, planned chemotherapy was adjusted for in the analyses. This was deemed appropriate as data on the actual treatments given were not available. No study has yet been performed to test the reliability of the data on planned chemotherapy, as reported to the National Register for Breast Cancer, against the treatments given, although chemotherapy is often planned for specific groups and changes in treatment are likely to be small at group level.

Several measurements of value of work, perceived work adjustment and social support were used, covering different (but similar) dimensions of the concepts. Such a design may introduce multicollinearity, which can confound associations with the outcome. Possible multicollinearity was therefore examined and found to be at an acceptable level (142). A factor analysis was performed, and its results were used to structure the indexes, for which Cronbach’s alphas were acceptable (143). Questions from previously validated instruments were used as much as possible. In some instances, only parts of instruments were used in the questionnaire in order to reduce its length. This was done to minimize external and internal drop-out. Further validations may need to be performed of the indexes created in these studies; thus, comparisons with other studies should be made with caution.

To the items in Study III there were some missing responses, which were equally distributed between the women on and not on sick leave. In Study IV, missing data ranged between 2% and 10%. Highly educated women were overrepresented in

choosing the “not applicable” response option to the item on the opportunity for work adjustment in the case of physical straining work, indicating the possibility that they worked in occupations with no physical strain.

The cross-sectional design of the studies prevents conclusions on causality from being drawn regarding the associations found with sick leave. This is, however, one of the first exploratory studies of the associations between psychosocial factors and sickness absence early after breast cancer.

## 6 CONCLUSIONS

A large proportion of women worked early after breast cancer surgery, valued work highly, and found work to be of great importance in their lives. Women take an active role in return to work, and their decisions are influenced by the interactions between their own preferences with regard to valuing work or wanting to focus on recuperation, their perceived health and functioning, social circumstances, and also the social context of their work.

Women with breast cancer encounter many stakeholders, and flexibility on their part regarding issues of availability of information, accommodation e.g. of work and social support, seems to be pivotal in relation to working after breast cancer in accordance with the women's preferences.

Many women expressed the need for information on side-effects and the timing of treatments so as better to be able to plan their return to work, and to enhance their ability to ask for work adjustments. Having such adjustment opportunities at work is often of importance for being able to continue to work or return to work.

Social support, especially from supervisors, is essential, and low support is associated with being on sick leave shortly after breast cancer. Suggestions from people in health care and at work, and also from friends or family, about whether to be sickness absent or not conflicted with some women's own preference to be at work or stay on sick leave, which was regarded as negative support by some of the women. Accordingly, preconceptions and attitudes regarding women's sickness absence or not should be questioned and minimized, since they may conflict with the women's own preferences and negatively influence their return to work. Information on this issue needs to be spread to the stakeholders who encounter women with breast cancer.

Almost all women disclose their diagnosis to their employer, although they are concerned that such disclosure may have consequences for their future work life.

## 7 FUTURE RESEARCH

In these studies, women who recently had had breast cancer surgery were found to value their work highly. Few studies have been done in this area, which is why more knowledge is needed on how to support women in the return-to-work process. Knowledge of possible changes in psychosocial factors on the cancer trajectory is also of importance, which is why prospective longitudinal studies should be conducted.

There have been few interventions regarding return to work after cancer so far. Future interventions should be designed and evaluated, with account taken of interactions with the stakeholders involved in the process and their contributions to supportive actions.

Attention should be paid to issues of possible discriminatory actions in future studies, since women are worried about the effects of disclosure.



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