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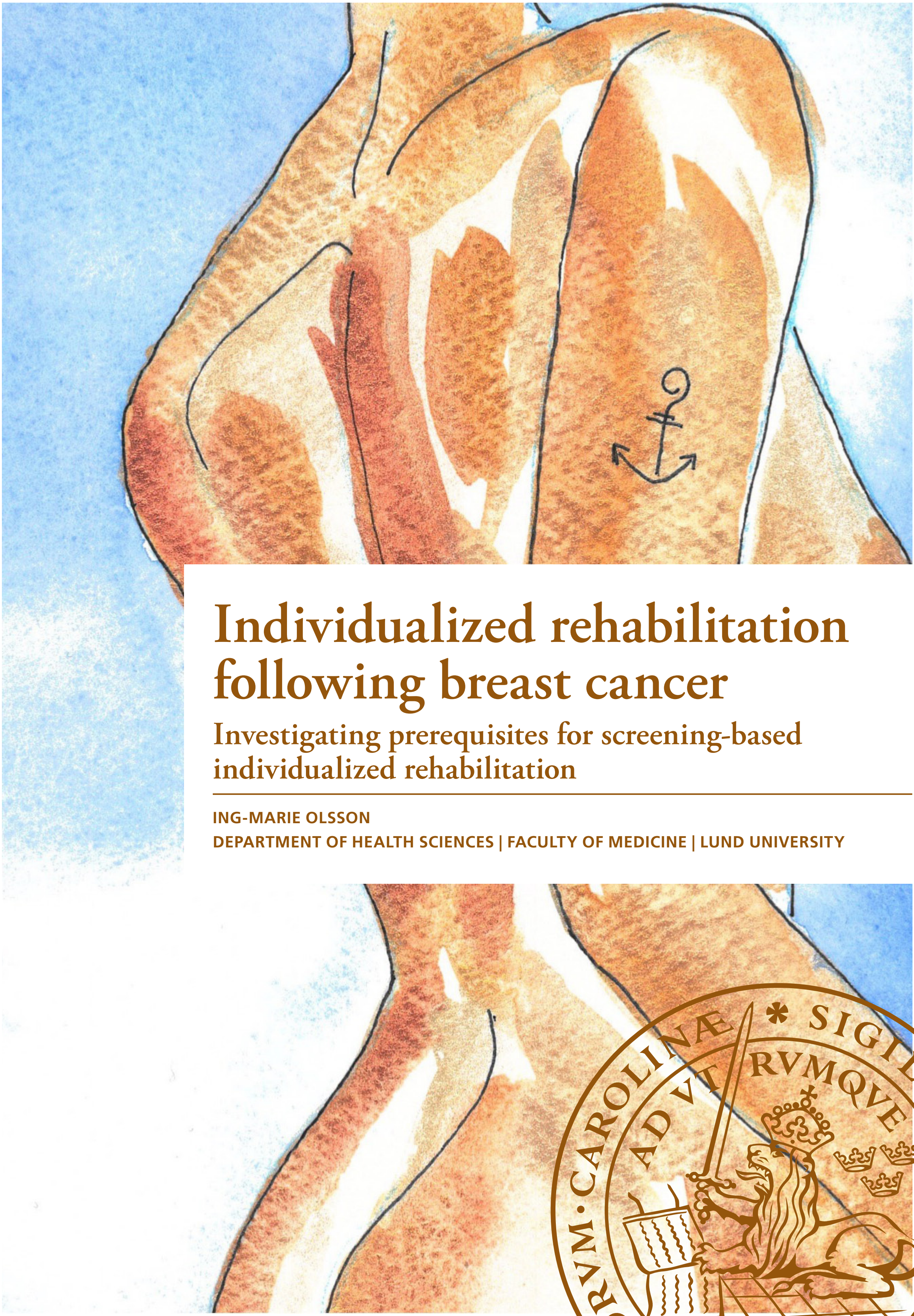

Individualized rehabilitation following breast cancer

Investigating prerequisites for screening-based individualized rehabilitation

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DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

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Investigating prerequisites for screening-based individualized rehabilitation

Ing-Marie Olsson

DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Medicine at Lund University to be publicly defended on the 21st of March at 13.00 in Belfrage Hall, Department of Health Science

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Title and subtitle: Individualized rehabilitation following breast cancer – Investigating prerequisites for screening-based individualized rehabilitation.

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Despite ongoing initiatives to implement national cancer rehabilitation guidelines, women with breast cancer (BC) report unmet rehabilitation needs. This thesis investigated prerequisites for screening-based individualized rehabilitation following primary BC diagnosis, treatment, and follow-up, using qualitative (I, IV) and quantitative (II, III) studies.

Study I conducted focus group interviews with healthcare professionals, exploring experiences of rehabilitation practices and barriers and facilitators for individualized rehabilitation. Inductive content analysis was applied. Facilitators included extensive competence and experience of working with BC patients, while barriers included lack of structures and knowledge.

Study II was a pilot study, examining the feasibility of the ReScreen randomized controlled trial (RCT) regarding recruitment, retention, distribution of distress, relevance of the intervention, and reported problems. The results showed that the procedures were feasible and the ReScreen intervention was relevant in this context, but the distress cut-off should be adjusted to identify extended rehabilitation needs.

Study III investigated associations between distress and demographics, clinical variables, health-related quality of life (HRQoL), and resilience using logistic regression. High distress was significantly associated with lower HRQoL, lower resilience, and several clinical and demographic variables including the modifiable variable exercise.

Study IV used focus group interviews with participants from the ReScreen RCT to comprehensively explore cancer rehabilitation experiences. Inductive and deductive content analyses were used. The inductive analysis showed great variation in experiences, emphasizing factors such as continuity, navigation, and individualized information. The deductive approach showed variation between randomization groups. Women in the intervention group mainly expressed experiences of being recognized and important, while some in the control group had felt abandoned by healthcare. The observation group mostly described fulfillment of their needs within the healthcare system.

Screening-based individualized rehabilitation requires structures that encompass factors that can affect distress, allowing optimization of support according to each person’s unique context and life situation. A comprehensive, proactive, and person-centered approach to rehabilitation could contribute to this.

Key words: Breast cancer, rehabilitation, distress, screening-based, individualized, person centred care

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MADE IN SWEDEN

To all women struggling with breast cancer
– you are my heroes.

Table of Contents

Abstract

Despite ongoing initiatives to implement national cancer rehabilitation guidelines, women with breast cancer (BC) report unmet rehabilitation needs. This thesis investigated prerequisites for screening-based individualized rehabilitation following primary BC diagnosis, treatment, and follow-up, using qualitative (I, IV) and quantitative (II, III) studies.

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Populärvetenskaplig sammanfattning

Bröstcancer drabbar ca 8700 personer per år i Sverige och är den vanligaste cancerformen hos kvinnor. Under senare år har utvecklingen inom området inneburit att sjukdomen upptäcks tidigare, och behandlingen har blivit effektivare. Idag överlever därmed de flesta som drabbas av bröstcancer. Detta innebär att många behöver rehabilitering och stöd för att möta potentiella långvariga och besvärliga biverkningar och konsekvenser från diagnos och behandling, såsom smärta, trötthet, sömnsvårigheter, oro, ångest, depression, förändrad kroppsuppfattning och försämrad livskvalitet. Sjukdomen drabbar kvinnor i alla åldrar och i olika livssituationer, och behovet av rehabiliteringsstöd varierat mycket. Riktlinjer för cancerrehabilitering rekommenderar personcentrerade arbetssätt. Det innebär att vården genom att identifiera behov, och möta dessa behov med individualiserade rehabiliteringsåtgärder, kan möjliggöra bäst rehabilitering för den enskilda individen. Implementeringen av dessa riktlinjer har dock visat sig vara utmanande. Många kvinnor rapporterar att de inte fått den rehabilitering som de behöver, vilket har påverkat deras återhämtning negativt. Detta innebär att rehabilitering fortfarande, trots riktlinjer som pekar på behovet av individualisering, ofta baseras på medicinska faktorer, snarare än det individuella behovet.

Tidigare studier indikerar att screening för distress, mätt med distresstermometern, kan identifiera kvinnor med behov av stöd vid bröstcancer. Distress beskrivs som en obehaglig, emotionell upplevelse av psykisk, social och/eller andlig natur, som kan hindra förmågan att hantera diagnosen samt de fysiska och psykiska symtom och problem som uppkommer till följd av cancerbehandlingen. Distresstermometern är ett självskattningsinstrument där patienten skattar sin distress på en skala mellan 0–10, där 0 motsvarar avsaknad av distress och 10 värsta tänkbara distress. Tidigare forskning har identifierat ett tröskelvärde på 7 som relevant för hög distress, och som skulle kunna innebära ett utökat behov av rehabilitering vid bröstcancer.

Denna avhandling är en del av ett större forskningsprojekt, ReScreen-studien, som genom olika faser har utvecklat och testat en intervention för screeningbaserad individualiserad rehabilitering vid bröstcancer. Med hjälp av screening av distress före start av behandling delades kvinnor med nydiagnostiserad bröstcancer upp i olika grupper beroende på hur de skattat sin distress. Alla fick ordinarie vård, vilket erbjuds till dem som drabbas av bröstcancer. Detta innebär kortfattat tillgång till en kontaktsjuksköterska och läkare som arbetar med bröstcancer. Det innebär också tillgång till fysioterapeut, och vid behov kurator. Ordinarie vård bygger på att kontakt med vården sker på patientens initiativ. De kvinnor som uppgav hög distress före start av behandling lottades till antingen en kontrollgrupp, eller en interventionsgrupp. De som uppgav låg distress utgjorde en observationsgrupp. Interventionsgruppen följdes av en forskningssjuksköterska i ett år efter behandlingsstart. Under den perioden fungerade forskningssjuksköterskan som en kontinuerlig vårdkontakt och ansvarade för proaktiv och systematisk utvärdering av behov för att säkerställa att potentiella nya problem eller förändrade rehabiliteringsbehov identifierades i tid.

Syftet med denna avhandling är att undersöka förutsättningarna för screeningbaserad individualiserad rehabilitering vid diagnos, behandling och uppföljning av bröstcancer. Detta görs genom fyra delstudier.

Delstudie I. Genom fem gruppintervjuer med 19 hälso- och sjukvårdspersonal (sjuksköterskor, undersköterskor, fysioterapeuter, kuratorer, läkare, psykolog och sexolog) undersöktes i denna studie erfarenheter av hinder och möjligheter till individualiserad rehabilitering för patienter diagnostiserade med bröstcancer. Resultatet visade att trots gedigen erfarenhet och kunskap så saknades strukturer för hur patienter med rehabiliteringsbehov ska identifieras och mötas på ett individuellt sätt. Resultatet visade också att rehabiliteringskompetensen varierade genom vårdkedjan, samt att samarbetet mellan olika rehabiliteringskompetenser inte fungerade optimalt.

Delstudie II. I denna studie testades genomförbarheten av ReScreen-studiens randomiserade kontrollerade studie (RCT) (85 kvinnor deltog) genom en pilottestning av de processer som planerades inom studien. Syftet var att undersöka rekrytering, retention (hur många som stannar kvar i studien under studietiden), fördelningen av distress, interventionens relevans och rapporterade problem. Screening av distress med distresstermometern användes för att hitta kvinnor med utökat behov av stöd. Resultaten visade att studien var relevant i det kliniska sammanhanget och att planerade procedurer var genomförbara. Utvärderingen av fördelningen av distress bland kvinnorna i pilotstudien visade att de rapporterade lägre distress jämfört med tidigare internationella studier. Detta ledde till en justering av tröskelvärdet för distress i huvudstudien för att möjliggöra utvärdering av distresstermometerns förmåga att identifiera kvinnor i behov av utökat rehabiliteringsstöd.

Delstudie III. I denna tvärsnittsstudie med syftet att undersöka nivån av distress hos kvinnor med nydiagnostiserad bröstcancer utvärderades sambandet mellan hög distress och demografiska och kliniska data, resiliens och hälsorelaterad livskvalitet. Preliminära resultat visar samband mellan hög distress och lägre livskvalitet och resiliens. Detta skulle kunna betyda att distresstermometern kan hitta dem med behov av mer rehabiliteringsstöd. Det fanns också samband mellan hög distress och flera faktorer för demografiska och kliniska variabler, så som lägre självskattad ekonomisk situation, lägre ålder, lägre träningsmängd per vecka och psykisk sjukdom i hälsohistorien.

Studie IV. Studien genomfördes med gruppintervjuer med kvinnor som hade deltagit i ReScreen-studiens RCT. Genom 9 intervjuer med totalt 30 kvinnor undersöktes kvinnornas erfarenheter av cancerrehabilitering efter deltagande i ReScreen-studien. Intervjuerna genomfördes uppdelade i grupper beroende på vilken grupp de tillhört i RCT-studien. Resultatet visade på en stor variation i upplevelser och behov där mötet med sjukvårdens organisation stämmer olika väl överens med den personliga processen. En del kvinnor beskriver en välfungerande process, andra beskriver avsaknad av individanpassad information, avsaknad av kontinuitet och tydliga kontaktvägar för rehabiliteringsstöd och vägledning. Kvinnor i interventionsgruppen uttryckte att ett proaktivt förhållningssätt och möjlighet att ställa frågor gav trygghet och möjliggjorde vägledning. De kände sig sedda och viktiga, medan kvinnor i kontrollgruppen beskrev känslor av att ha blivit övergivna av vården. Observationsgruppen uttryckte oftare att deras behov hade blivit tillgodosedda inom befintligt hälso- och sjukvårdssystem.

Sammanfattningsvis så visar avhandlingen på vikten av strukturer för identifiering av rehabiliteringsbehov genom hela vårdkedjan, liksom vikten av ett individualiserat bemötande och stöd. Avhandlingen visar också att redan tidigt i förloppet finns en skillnad i distressnivå som speglar sig bland annat i livskvalitet och olika demografiska och kliniska faktorer. Detta spelar roll för vad hälso-och sjukvårdspersonal behöver vara uppmärksamma på, och vilket stöd den enskilda kvinnan behöver.

List of Papers

Paper I

Olsson Möller U, Olsson IM, Sjövall K, Beck I, Rydén L, Malmström M. Barriers and facilitators for individualized rehabilitation during breast cancer treatment - a focus group study exploring health care professionals' experiences. BMC Health Serv Res. 2020 Mar 26;20(1):252. doi: 10.1186/s12913-020-05107-7. PMID: 32216786; PMCID: PMC7098158.

Paper II

Olsson IM, Malmström M, Rydén L, Olsson Möller U. Feasibility and Relevance of an Intervention with Systematic Screening as a Base for Individualized Rehabilitation in Breast Cancer Patients: A Pilot Trial of the ReScreen Randomized Controlled Trial. J Multidiscip Healthc. 2022 May 10;15:1057-1068. doi: 10.2147/JMDH.S355055. PMID: 35586080; PMCID: PMC9109980.

Paper III

Olsson IM, Olsson Möller U, Velickovic K, Rydén L, Bendahl P-O, Malmström M. Factors associated with distress among women newly diagnosed with breast cancer – a cross-sectional study based on baseline data from the ReScreen study. In manuscript.

Paper IV

Olsson IM, Dykes C, Rydén L, Olsson Möller U, Malmström M. Experiences of rehabilitation one year after breast cancer diagnosis – A focus group study from the ReScreen randomized controlled trial. Accepted for publication in PLOS One.

Author's contribution to the papers

Paper I

The author actively participated in the analysis and manuscript preparation and contributed to the discussions during the submission process.

Paper II

The author actively participated in data management and analysis, and was responsible for statistical analysis, manuscript preparation, and the submission process, supported by supervisors.

Paper III

The author was responsible for planning the study and processing the database. The author was also responsible for the statistical analysis and manuscript preparation, continuously supported by supervisors and statistician.

Paper IV

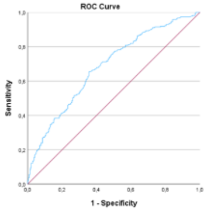
The author independently led the research process including data collection, supported by supervisors, and had a leading role in discussions of study design and analysis methods. The author was responsible for the analysis, manuscript preparation, and decision-making during the publication process.

Abbreviations

AIC	The Akaike information criterion
BC	Breast cancer
CG	Control group
CI	Confidence interval
CNCC	Contact nurse in cancer care
DST	Decision support tool
DT	Distress thermometer
EORTC	European Organization for Research and Treatment of Cancer
ESMO	European Society for Medical Oncology
HCP	Healthcare professional
HRQoL	Health related quality of life
IG	Intervention group
MDTM	Multidisciplinary team meetings
NCCN	National Comprehensive Cancer Network
NCRG	National cancer rehabilitation guidelines
OG	Observation group
OR	Odds ratio
PCC	Person centered care
QoL	Quality of life
RCT	Randomized controlled trial
SD	Standard deviation
WHO	World Health Organisation

Thesis at a glance

Table 1. Overview of studies included in the thesis

Study	Aims	Methods	Results
I 	To explore healthcare professionals experiences of current rehabilitation practice and describe current barriers and facilitators for individualized rehabilitation for patients following breast cancer treatment.	Five explorative qualitative focus group interviews were conducted with 19 health care professionals. The analysis was performed using conventional content analysis with an inductive approach.	Three categories and 8 sub-categories were identified. A varying attitude towards rehabilitation, incongruence in how to identify and meet rehabilitation needs, and suboptimal collaboration during cancer treatment appeared in the result.
II 7 ➡ 5	To examine recruitment, retention, distribution of distress, relevance of the intervention, and reported problems in a pilot trial of the ReScreen study.	A feasibility and pilot study involving 85 women with breast cancer was conducted. Analyses utilized descriptive statistics	Satisfactory inclusion and data collection rates, and few systematic errors indicated feasible procedures. The result indicated that the cut-off level needed to be reviewed before the main study.
III 	To investigate the level of distress in newly diagnosed breast cancer patients and the association with demographics, clinical data, resilience, and HRQoL.	A prospective, cross-sectional study involving 633 women with breast cancer was conducted. Univariable and multivariable regression models were used to investigate associations with high distress.	High distress was associated with lower HRQoL and resilience. In a prediction model, low exercise level, bad financial situation, symptom mode of detection, younger age, having few children, not being on beta blockers, and history of psychiatric disease were associated with high distress.
IV 	To explore the experiences of women with breast cancer after participating in a complex randomized controlled trial focusing on cancer rehabilitation from a comprehensive perspective.	Nine explorative focus group interviews were conducted with 30 women with breast cancer. The analysis was perfomed using conventional content analysis with both an inductive and a deductive approach.	Two categories and 4 sub-categories were identified, and an overall theme. Factors such as navigation, continuity, and individualized support were crucial during the rehabilitation process. Variations appeared between the groups.

Introduction of the thesis

Today, breast cancer (BC) is the most prevalent cancer among women worldwide (1). In Sweden, more than one in ten women are diagnosed with the disease at some point in their lives (2). Thanks to screening programs that enable early detection and improved multimodal treatments, the prognosis has dramatically improved in recent decades (3, 4). Consequently, a growing number of survivors are facing life after BC.

BC affects women of various ages and life stages, presenting them with a potentially deadly disease and a new reality affected by diagnosis and treatment. Studies indicate that many women recover and regain quality of life (QoL) levels comparable to the general population (5). However, both short-term and long-term consequences are frequently reported, impacting physical, psychological, social, and existential aspects of life. This highlights the need for individualized rehabilitation to be integrated early, and to continue throughout the cancer journey and into survivorship. Experiences and needs are highly individual, underscoring the necessity for rehabilitation support with an individualized approach.

Swedish law (6) mandates that the overall responsibility for cancer rehabilitation lies with the regional services. The fact that women with BC still report unmet rehabilitation needs, despite national guidelines, indicates the absence of structures to identify needs and structures for evidence-based rehabilitation. This gap potentially leads to prolonged recovery and suffering.

The four studies included in this thesis are part of the ReScreen study, a complex intervention study aiming to develop and evaluate a model for screening-based individualized rehabilitation following treatment for primary BC (7). The overall aim of this thesis was to investigate the prerequisites for screening-based individualized rehabilitation following primary BC diagnosis, treatment, and follow-up. Study I examined barriers and facilitators for individualized rehabilitation from the perspective of healthcare professionals (HCP). Study II evaluated the feasibility of the ReScreen randomized controlled trial (RCT), as well as the cut-off for distress to identify rehabilitation needs. Study III investigated the prevalence of distress and its associations with demographic factors, clinical factors, health related quality of life (HRQoL) and resilience. Finally, Study IV explored patients' experiences of rehabilitation after participation in the ReScreen study.

The primary focus within this thesis is the individual woman affected by BC, and her unique journey from diagnosis to follow-up, often marked by the consequences and side-effects of treatment. Before delving into the journey experienced by women with BC, key concepts that recur throughout this thesis will be described to establish a foundational framework.

Theoretical framework and concepts

Person-centered care

The World Health Organization (WHO) envisions a future in which all people have access to health services that are provided in a way that responds to their life course needs and preferences, and that are coordinated, safe, effective, timely, and of acceptable quality (8). This incorporates not only the narrow, personal perspective, but also the organizational perspective. The personal perspective in healthcare is of utmost importance, but it is also the responsibility of organizations to create person-centered cultures (9).

In Swedish healthcare, person-centered care (PCC) is expected to be the guide for the delivery of care and rehabilitation. This is supported by the Swedish Patient Act (10) which establishes that healthcare shall be designed and carried out in consultation with the patient; this means that the patient’s experiences, wishes, and needs must be respected. In Sweden, PCC has been defined as an ethic which guides the HCP’s practical actions both as a fellow human and as a professional, and includes a partnership between the patient/next of kin and the professionals within healthcare and rehabilitation (11). The concept of PCC is widely used, but is often described as complex, and there is no consensus in the literature regarding its definition (12).

The most fundamental aspect of PCC is the importance of understanding more about a person with a disease than solely how the body functions. This is crucial not only for making an accurate diagnosis, but also for creating conditions that promote long-term health, psychological wellbeing, and autonomy (13). This distinction is illuminated within the concepts of illness and disease, where disease refers to a condition affecting an organ, whereas illness is experienced by the person. Illness includes the patient’s subjective response to being unwell, which affects both the patient and those around them, influencing behaviors and relationships (14). The holistic view of a person encompasses physical and psychological aspects as well as the social and cultural context. This means that every individual should be seen as more than just a patient with a disease; it is essential to understand their entire life situation and their personal striving for well-being (15).

In this thesis, the framework for person-centered nursing developed by McCormack and McCance (2006) is used to address the components of PCC (16). The framework incorporates both the organizational and personal aspects, and consists of the four constructs described below (17). While the framework focuses on the nurse in relation to the patient and nursing, it is reasonable to assume that the constructs are equally relevant for all HCPs involved in the team supporting a person with BC in rehabilitation. The four constructs consist of prerequisites of the nurse (or, in this thesis, HCP in a broader sense), the care environment, the person-centered process, and the expected outcome (Figure 1).

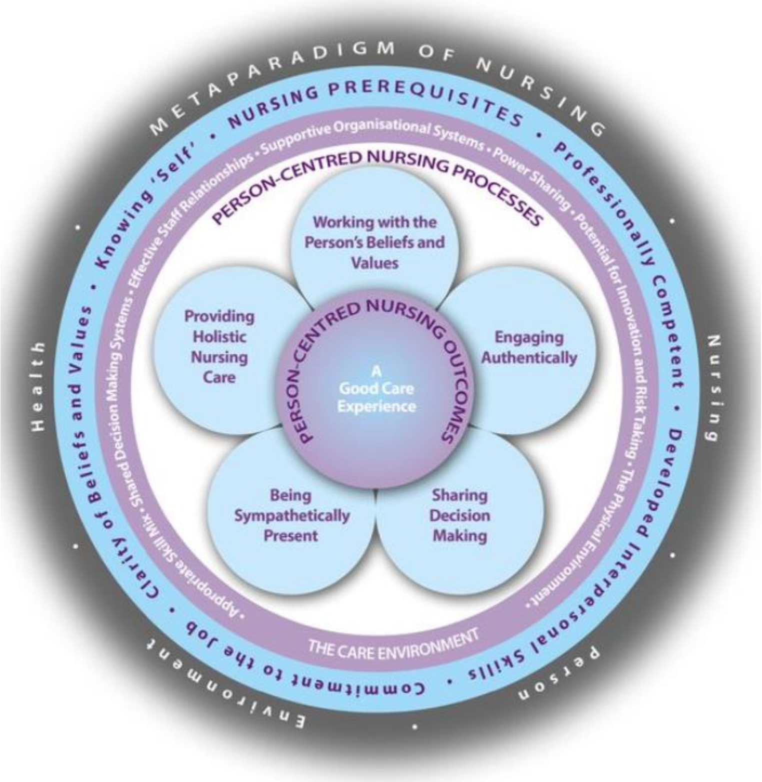


Figure 1. The four constructs of person-centered nursing. McCormack B, McCance T. The Person-Centred Nursing Framework. In: Dewing J, McCormack B, McCance, editors. Person-centred Nursing Research: Methodology, Methods and Outcomes. Cham: Springer Nature Switzerland AG; 2021 (17). Reproduced with permission from Springer Nature.

The central construct – a good care experience – is the key outcome of the framework, and should be evaluated from both the patient's and the HCP's perspective. The experience of good care reflects the quality of the three other constructs. Attributes of the HCPs, such as being professionally competent and having developed interprofessional skills, enable the patient to manage the care environment. This environment includes, for example, supportive organizational systems and an appropriate skill mix. These elements are prerequisites for delivering PCC through the person-centered process.

Within the PCC framework, the holistic view of a person is the basic ingredient. McCormack and McCance (2021) discuss five perspectives that are essential for how a person constructs life: being in relation, being in a social world, being with self, being in place, and being in time (17). Awareness of each person's individual being is crucial, as is the individual experience of life. Van Manen (2014) explains experiences as being related to basic existential aspects of life, represented by lived self-other, lived body, lived space, lived time, and lived things. These aspects provide a way to understand how a person experiences their living world and how they relate to themselves and others. For example, the body is not just a physical object, but also a tool to express feelings and identity (18). The woman with BC faces several challenges that potentially interfere with life in multiple areas, and so her personal constructs and experiences of life are crucial for how rehabilitation can be tailored to her unique experience and need.

A person's being and experience of life is fundamental, but the framework also highlights the importance of organizational structures to facilitate PCC. Research emphasizes the importance of establishing routines in daily clinical practice. While the framework of McCormack & McCance forms the theoretical base of PCC components in this thesis (17), the framework of Ekman et al. (2011) supports the daily practice and routine. The routine builds on a partnership between the HCP and the patient through the patient's narrative, shared decision-making, and documentation (19). This represents the person-centered process within McCormack and McCane's framework (17).

In the context of rehabilitation, Lepleige et al. (2007) concluded that PCC is important for successful rehabilitation. The person-centered approach is described as individualized, tailored, and including the flexibility and capacity to adjust when needs change, this means that interventions should be tailored for specific individuals and their evolving needs, instead of systematically adhering to rigid policies (20). This approach is the foundation of this thesis. Studies I–III investigated prerequisites for individualized rehabilitation with HCPs and within the organization, while Study IV explored the rehabilitation experience of women with BC.

Within this thesis, the woman with BC will mostly be referred to as a "person" or "woman with BC", but in some contexts the word "patient" will be used. The intention is always to express the greatest possible respect for the individual woman affected by BC.

Main concepts

Distress

Distress is a central concept in this thesis. It is highly prevalent among women with BC throughout the trajectory of diagnosis, treatment, and follow-up, research has suggested a pooled prevalence of 52% (21). The consequences of distress in women with BC such as non-adherence to treatment (22) and poorer social adjustment (23), highlight distress as an important factor to identify and intervene on.

The concept of distress has developed over the years. According to the Oxford English Dictionary, the meaning of the word is the sore pressure or strain of adversity, sickness, sorrow, trouble, or pain; anguish or affliction affecting the body, spirit, or community (24). Even though the word is widely used in the healthcare literature (25), the concept has not been clearly articulated, and there is a divergence between conceptual and operational definitions (25, 26). The term "distress" predominantly refers to psychological issues (27), and the literature often addresses emotional constructs such as anxiety and depression as attributes of distress (25, 26).

This thesis aligns with the definition of distress from the National Comprehensive Cancer Network (NCCN), defining distress as a multifactorial and unpleasant experience of a psychological, social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, related physical symptoms, and treatment. Distress extends along a continuum, ranging from common normal feelings of sadness, vulnerability, and fears to problems that can become disabling, such as depression, anxiety, social isolation, panic and existential and spiritual crisis (28). The NCCN chose "distress" as an umbrella term for emotional concerns among patients affected with cancer (27) because it was considered to be less embarrassing and stigmatizing as well as more acceptable and normal than words such as "psychiatric", "psychosocial", or "emotional" (28). Importantly, numerous factors contribute to the emotional constructs within the concept of distress, such as the emotional and social challenges of receiving a cancer diagnosis, physical symptoms, and decreased functional status interfering with daily living (29). Other aspects suggested to cause distress are the presence of stressors, demands and unmet needs, along with loss of control and ineffective coping (25).

Recent research investigating distress during BC treatment suggests that distress may serve as an indicator of needs that require rehabilitation interventions (30, 31). It is therefore important to explore optimal ways of measuring distress in order to identify women in need of rehabilitation. Research suggests screening for risk factors (21) and predictors of distress (32), such as certain sociodemographic characteristics, symptoms related to treatment, and living habits. The distress thermometer (DT) is a clinically relevant and easy to use instrument for measuring distress, developed by the NCCN (33), which has been shown to be valid in cancer contexts to identify distress (34-37). This instrument has a central role in the ReScreen RCT and will be described in the Methods section.

Quality of life and health related quality of life

QoL and HRQoL are also central concepts in this thesis. There is no consensus on the definitions of either concept, despite extensive efforts (38). According to the WHO, QoL is the individual’s perception of positions in life, in the context of culture and value systems in which they live, and in relation to their goals, standards, expectations, and concerns (39). Fayers and Machin (2016) state that QoL means different things to different people, and that the meaning depends on the area of application (40). In the context of health, the impact of a disease on QoL is referred to as HRQoL, and includes the physical, psychological, and social functioning of a person (41). HRQoL has been suggested to be the gap between our expectations of health and our experience of it (42).

There are numerous studies investigating the effect of BC diagnosis and treatment on HRQoL (43), as well as numerous instruments developed to measure HRQoL in cancer contexts. Two commonly-used and well-validated instruments were used in this thesis (Studies II and III), the QLQ-C30, which assesses functional health, symptom burden, and HRQoL in cancer contexts in general (41) and the QLQ-BR23, which assesses the same constructs in BC (44). These instruments will be described in the Methods section.

Background

In this section, the BC process will be presented in the order in which it is experienced by the affected woman. The medical perspective is described first, including the diagnostic procedure, the diagnosis, presentation of possible treatment recommendations, and follow-up (Figure 2). Nursing support from healthcare is then described, followed by the most important thing: the experiences of women with BC. Both medical aspects and the individual journey are essential to consider in cancer rehabilitation. This section also gives a description of the structures and challenges involved in providing rehabilitation based on individual needs, underscoring the importance of a person-centered approach.

Figure 2. The medical process.
Illustration: Katarina Jandér

Breast Cancer

Prevalence and prognosis

Among women worldwide, BC is both the most frequently diagnosed cancer and the leading cause of cancer deaths (1). In Sweden, BC is the second leading cause of cancer deaths among women, and 8700 women were diagnosed with the disease in 2021 (45). The incidence has increased in recent decades, but thanks to both improved diagnostic procedures and treatment, fortunately the prognosis has improved. In the 1980s, the 5-year relative survival rate was only 74%, compared to 93% today (45). The current 10-year relative survival rate is 88% (46).

Diagnosis, treatment, and follow-up – the medical perspective

Diagnostic procedure

The diagnostic procedure for BC starts either due to symptoms from the breast, – most commonly a lump, or fluid from the nipple, referred to as symptomatic (47)(chap 8) – or through the BC screening program. In Sweden mammography screening for BC is recommended every 18–24 months for women aged 40–74 (48), and approximately 60% of all BC cases in this age group are detected within the screening program (49). When there is a well-founded suspicion of BC, a standardized cancer patient pathway for BC treatment is begun, with the aim of providing well-organized, holistically-oriented, professional care without unnecessary waiting time (50).

Triple diagnostics are the gold standard when assessing a suspected BC: clinical examination, radiological assessments (mammography and ultrasound of breast and axilla), and biopsy (47)(chap 9). The results from the diagnostic investigations provide important information that supports the decision regarding the best treatment options for each patient (51-53) and allow treatment to be tailored to the properties of the tumour.

The results of the diagnostic modalities are discussed in a multidisciplinary team meeting (MDTM) that guides further diagnostic procedures and treatment recommendations. Participants in the MDTM should consist of a surgeon and an oncologist both specialized in BC, a breast radiologist, a pathologist, and a contact nurse in cancer care (CNCC). For primary BC, the aim of the multidisciplinary cooperation is to ensure optimal diagnostics and treatment to cure BC, and so an MDTM takes place both before and after surgery (47)(chap 11). Patient involvement in the MDTM is currently not practiced, and research has highlighted the significant challenges of incorporating the patient perspective during MDTMs (54). The patient’s preferences, individual prerequisites, and social situation can contribute and influence treatment decisions (51, 55). This underscores the responsibility of both the physician and the nurse to ensure that information about medical treatment options is understandable by the patient, and to consider the patient’s individual prerequisites and context in treatment decisions.

Treatment

Treatment of BC is complex and involves combinations of different modalities such as surgery, radiotherapy, and systemic anticancer treatments (55, 56).

Surgery of the breast

Surgery is an important part of BC treatment, and often the first step in the multi modal treatment process. Patient participation is of utmost importance when surgical treatment is planned, as the patient's wishes must be considered (47).

There are two ways to perform breast surgery: mastectomy, which removes all breast tissue including breast skin and often the nipple-areola complex, and breast-conserving surgery, which removes only the tumour and a certain amount of healthy breast tissue around the tumor. Numerous studies have shown that there are no differences in survival when comparing breast-conserving surgery with radiotherapy and mastectomy (57, 58), and current international consensus guidelines recommend mastectomy to be performed only if breast-conserving surgery is not safe or feasible (59). If mastectomy is the best option, the patient should be objectively informed about mastectomy without and with reconstruction, including individual prerequisites for immediate or delayed reconstruction (47)(chap 13).

Resent research comparing the effects of breast-conserving surgery or mastectomy with or without reconstruction on, for example, HRQoL, body image, and self-esteem has produced results in favor of breast conserving surgery (60, 61).

Surgery of the axilla

If the tumor is invasive, the surgical procedure includes surgical staging of the axilla, which is important for the diagnostic procedure to guide the postoperative treatment and for prognostic information. Today, sentinel lymph node biopsy is the standard procedure for staging, where the first lymph nodes (mostly 1–4 nodes) draining the tumor are identified and extirpated (62). For the patient, this includes a preoperative procedure where a tracer is injected in the breast. Recent results from the randomized SENOMAC trial (63) have already been implemented into clinical practice in Sweden, leading to fewer full axillary lymph node dissections (including 10–30 lymph nodes) even for patients with metastatic sentinel lymph nodes. This de-escalation decreases the risk of morbidity after axillar surgery (64), though the risk of consequences from surgery in the axilla remains.

Adjuvant treatment

Radiation therapy

All patients undergoing breast-conserving surgery are recommended postoperative local radiation therapy. Node-negative patients receive radiotherapy localized to the breast only, while node-positive patients receive radiotherapy including both the breast and the regional lymph nodes, (locoregional radiotherapy). In patients undergoing mastectomy, radiation therapy is recommended for node-positive patients, whose tumors have certain properties, such as tumor size > 5 cm. Radiotherapy both reduces the risk of local recurrence, and improves survival (65).

Chemotherapy

In Sweden, approximately 40% of all patients with invasive BC receive some form of chemotherapy (66). Chemotherapy is recommended depending on the stage and biology of the tumor, and the patient's biology, preferences, and life situation (56). The treatments mostly involve a combination of different cytotoxic drugs that kill rapidly growing cells. This includes not only cancer cells, but also hair, skin, and gastrointestinal tract cells, leading to a number of troublesome side-effects, that can severely impact everyday life (47)(chap 15).

Sometimes preoperative chemotherapy is the primary treatment, either due to treatment-predictive factors of the tumor, or when aiming to enable breast-conserving surgery through downsizing of the tumor (47, 67)(chap 12).

Endocrine therapy

Hormone receptor positive BC represents approximately 80–90% of all BC (47)(chap 10). Treatment with endocrine therapy such as tamoxifen or aromatase inhibitors reduces both local recurrence and mortality rates (68), and should be given to all patients with estrogen-receptor positive BC (47). Tamoxifen is an anti-estrogen drug, that blocks the effect of estrogen on target organs (69) and is recommended to premenopausal women. Postmenopausal women are recommended aromatase inhibitors, which hinder estrogen syntheses (70). The treatment is recommended for 5–10 years depending on the stage of the tumour at diagnosis, and has a wide range of possible side-effects.

Follow-up

It is not always clear when the transition to follow-up care begins, as curative BC treatment can continue for an extended period. Follow-up examinations after a BC diagnosis aim to detect curable locoregional recurrences, but also to monitor side-effects and optimize compliance with additional treatments. Routine practice in Sweden includes a planned 1-year follow-up mammography combined with a visit to a BC unit. There are local differences in how the 1-year visit is carried out, and research is ongoing to compare the traditional visit to a physician with a nurse-led telephone follow-up. The 1-year follow-up can then be followed by regular cancer screenings (47)(chap 27).

Nursing – the caring perspective

Support from healthcare during cancer treatment

Research indicates that for patients with cancer, a sense of control and safety is paramount during their treatment. This encompasses feeling secure within themselves, in their relationships with family and friends, and within the healthcare system (71). In Sweden, an increasing number of cancer treatments are now administered in outpatient clinics or patients' homes rather than during hospital stays. While this approach may benefit patients, it also reduces opportunities for HCPs to provide information about treatment, expected outcomes, and side-effects (72) as it decreases the amount of time the person with cancer spends in places such as hospitals or outpatient clinics where they can meet HCPs with specialized knowledge of cancer. Consequently, patients bear greater responsibility both for coordinating their care, and for understanding and managing the side-effects and consequences of their cancer treatment (73).

As stated above, in BC care today, surgery is mostly performed in day surgery units, chemotherapy and radiotherapy are administered in outpatient clinics, and hormone therapy is an ongoing treatment in the patient's everyday life. Consequently, the person with BC mostly experiences living with the illness outside healthcare, and planned appointments with HCPs are few and often with a medical focus. Medical treatment and follow-up in general are based on the properties of the tumor, and there is often a vagueness or lack regarding a person-centered, individualized support approach that takes into account both the person's unique experience, and their context, history, family, and individual strengths and weaknesses (19). Limited time with the patient in today's specialized healthcare requires support structures that facilitate identification of treatment-related needs in a person-centered way, to enable the person to feel safe and in control during the BC process. In Sweden, the responsibility for identifying these needs predominantly lies with the CNCC.

The contact nurse in cancer care

One of the goals in the Swedish National Cancer Strategy (74) is that every patient with cancer should be assigned a dedicated HCP, such as a contact nurse, referred to as a contact nurse in cancer care (CNCC). The CNCC is suggested to be the main care contact and care provider with a holistic responsibility for patients and next of kin, ensuring patients’ involvement in their care. The assignment consists of factors related to high-quality information, availability, coordination, and support as well as assessment of needs, interventions, and follow-up. It is also stated that the CNCC shall enable individualized cancer information by considering individual prerequisites such as age, level of education, language, and religious and cultural features. The assignment is described in a national role description (75) but every care unit is required to clarify the assignment on a local level. The CNCC is supposed to meet the patient before start of cancer treatment in order to initiate a CNCC–patient relationship that continues during the treatment trajectory and follow-up.

In the context of BC, the CNCC meets the affected woman at the time of diagnosis. The CNCC provides information and support based on both the structures within the care units, and the needs expressed by the patient. The goal is to maintain continuity from diagnosis through follow-up. However, this continuity is not always achieved, due to structural issues within the units or the broader healthcare system. For instance, surgery might be performed in one unit while oncological treatment occurs in another. The extent to which a woman with BC needs support from a CNCC is individual, while the flexibility and availability of the CNCC are determined by structures on the local level.

During the past decade there has been a growing body of research in relation to CNCCs both nationally and internationally, even though the name and description of the role may differ in different contexts. A national report from 2016 illuminated the importance of the local organization in enabling fulfillment of the assignment (76). The same report showed that the role of the CNCC differed between cancer units, and that many patients did not have access to holistic rehabilitation support through a CNCC, leading to unequal care.

A recent international study concluded that the ambiguity of the role can result in confusion and underutilization of specialized skills (77), which emphasizes the importance of clarity, structures, and prerequisites to perform the role in the local setting. In a recent national study, inconsistencies were shown regarding both the CNCCs perception of their services and the organizational prerequisites to fulfill the assignment. The study also revealed an association between organizational prerequisites and moral stress (78) indicating a lack of opportunities to provide the patient with the support that the CNCC considered necessary. The patient’s experience of the role has also been investigated, showing that even though not all patients with cancer have access to a CNCC (79), access to a CNCC has increased overall. However, the above mentioned recent national study revealed that approximately one in three CNCCs had no contact with patients 3–6 months or 6–12 months after primary treatment (78).

In summary, organizational prerequisites to fulfill the assignment of the CNCC on the local level seem to differ, and the continuous support during treatment may not always be in accordance with the role description and patients' needs. This affects persons with BC who need support throughout the cancer process.

Receiving a breast cancer diagnosis – the person perspective

Women treated for BC often describe the journey as an emotional roller coaster that entails both physical and psychological side-effects, sometimes leading to changes in body image, identity, and social situation (Figure 3).

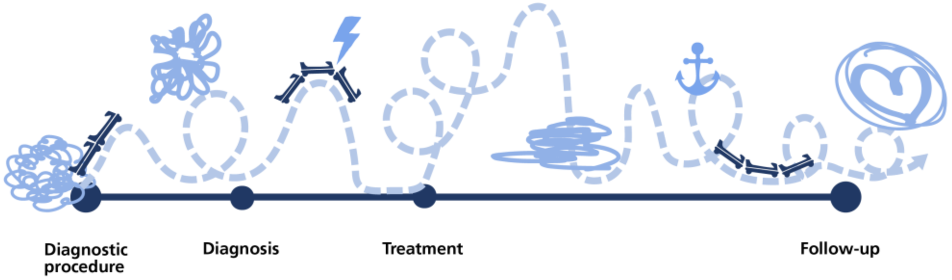


Figure 3. The experienced BC journey.
Illustration: Katarina Jandér

Awaiting and receiving the diagnosis

It is known that HRQoL among women newly diagnosed with BC is lower compared to the general population (80), and that the prevalence of distress and symptoms such as anxiety and depression is high (81, 82). According to the literature, even the first suspicion of a tumor in the breast heralds a life-changing situation, and after diagnosis there are feelings of chaos, loss of control, and threat to life, but also a will to live (83), along with uncertainty and fear regarding planned treatment (83, 84).

Concerns about the BC having already spread are common (85, 86), as are worries about family and financial situations (87). The need to manage the situation according to personal preferences highlights the importance of recognizing individual needs and strategies.

Experiencing side-effects from diagnosis and treatment

The initial feeling of shock and chaos after diagnosis are described as changing during the period of treatment, into something to live through (83). This is accompanied by acceptance of the situation (85). However, the multimodal treatment often leads to a complex mix of consequences and side-effects that can affect daily life in several ways.

The complexity of symptoms, their origins, and manifestations can be exemplified by the symptom of pain. Pain (88) and neuropathic pain (89) in BC are frequently discussed in large reviews, while qualitative research provides additional context and consequences. For instance, the feeling of swelling, tightness, and tenderness in the breast after surgery and radiotherapy can lead to uncertainty (90), while pain in the muscles or joints related to endocrine therapy (91, 92) can make it difficult to get out of bed in the morning (93). Upper limb morbidity resulting from surgery and/or radiotherapy often includes pain, and may produce limitations in arm function. This, in turn, leads to decreased QoL (94) and affects the ability to return to work (95).

Some symptoms and consequences are directly related to specific treatments. Lymphedema is a consequence of surgery and radiotherapy (96), while hair loss, mouth sores, and taste changes are common during chemotherapy (97). Chemotherapy can also cause poly neuropathy (98, 99) and cardiotoxicity (100), potentially leading to severe long-term severe consequences. Hot flashes (91, 92), vaginal dryness (91), and weight gain (101) are associated with endocrine therapy.

Other common consequences often arise because of various treatments, but are also due to individual reactions to the situation. Examples includes fatigue (86, 92, 97, 101, 102), sleep disturbance (97, 103, 104), loss of sexual interest (92, 97), and concentration problems (97, 101). These consequences often have a significant impact on daily life. Moreover, consequences such as anxiety, depression (105), fear of recurrence (106, 107), and cognitive impairments (108) add to the complexity of side-effects and consequences. This clearly shows that the women are affected physically, psychologically, existentially, and socially, and illustrates the complexity of symptoms and their effects on experiences and needs during BC rehabilitation.

Losses, changes, and the struggle to regain daily life

The feeling of different aspects of loss among women with BC is frequently described in the literature. Loss of control is mentioned, stemming from the uncertainty of treatment outcomes or how the treatment will affect them (86). Loss of identity (93), and femininity (85) are also commonly reported, often related to changes in body image due to surgery, treatment consequences, and side effects. Examples include hair loss (86, 90), mastectomy (85), scars, asymmetry in breast size causing insecurity about clothing choices (90), weight gain (90, 93), and dry mucous membranes affecting libido and sexual health (86, 90, 93).

The change in body image encompasses several limitations in daily life, including impaired social relationships, intimate relationships, and sexuality, which negatively affect women's emotional wellbeing (109). Younger women are also affected by loss of the potential to have children (110), which affects not only their identity and femininity but also their relationships (86, 90).

Despite this, research indicates that many women affected by BC regain HRQoL levels comparable to the general population (5). However, symptoms and experiences continue to impact their lives post-treatment, particularly when resuming important activities and life roles.

A common theme in qualitative research is the importance of regaining a sense of normalcy (111) and maintaining normal life (112), as well as the struggle to achieve this. Besides the difficulties discussed above, symptoms such as pain, fatigue, and impaired concentration can persist and affect daily life even years after treatment (113). Moreover, as endocrine therapy can continue for up to 5–10 years, so too can its side-effects (93). Persistent symptoms create a need for clear guidance and information on the available support and resources (111, 114). The absence of such support and guidance can lead to insecurity (90), resulting in uncertainty about recovery and affecting the ability to cope independently (93, 115) which hampers the ability to return to daily life. Unfortunately, studies have repeatedly found that women treated for BC experience a sense of being abandoned by healthcare at the end of primary treatment (90, 114, 116-118). This can clearly have a negative impact both on recovery and on the ability to regain some sort of normalcy.

Resources and prerequisites

The literature provides examples of how persons with BC handle the situation differently, as well as of strategies they use to cope. Most people's lives include the experience of both mildly and significantly stressful events, but reactions to these events differ; some people seem to experience highly stressful events as debilitating, others recover after a while, and some seem not to be strongly affected by even very challenging events. The ability to handle highly stressful events is reflected in the concept of resilience. Resilience is described as the capacity to positively adapt to stressful situations, such as a BC diagnosis (119). Some women with BC describe maintenance of a positive attitude and outlook on life, leading to acceptance, self-development, appreciation, and different priorities. Previous experiences of dealing with suffering or illness are described as beneficial in handling the situation of BC. In contrast, other women report feelings of pessimism and preparation for the worst (111). The choice to balance and adjust daily life to cope with symptoms such as fatigue, has been described (90), and descriptions of how to find strength again include the choice to take action for improving well-being. This often involves the resumption of daily life – returning to one’s work, exercise, and hobbies – as examples of participating in normal activities (83, 111).

An essential factor in coping with BC is the presence of a robust social network and social support (86, 118, 120). Family and friends are consistently identified as significant sources of support throughout the BC journey, along with support from other women who have experienced BC (90). Consequently, a lack of social support can make the journey more challenging, and the diagnosis and treatment may sometimes strain relationships with family and friends. Additionally, many women emphasize the importance of their family’s well-being (118), which can sometimes exacerbate the burden of the situation.

In summary, even though some women find strength and ways to cope with BC within their resources, individualized support and rehabilitation from health care remain important and essential for many women throughout the BC trajectory. Cancer rehabilitation specifically aims to address impairments caused by a cancer diagnosis and related treatment. This will be described in the following section.

Cancer rehabilitation

Definitions

The European Society for Medical Oncology (ESMO) considers patients to have a right to cancer rehabilitation as well as cancer treatment. Cancer rehabilitation is aimed at minimizing side-effects, optimizing QoL, and helping patients to regain normalcy in life (121). This thesis aligns with the Swedish national cancer rehabilitation guidelines (NCRG) which define cancer rehabilitation as interventions based on a person’s needs and conditions, that are intended to prevent functional impairments and ensure that the person maintains or regains the best possible functional capacity, activity capacity, QoL, and active participation in community life despite the consequences of cancer and cancer treatment (122)(chap 4). This definition is an updated version; before 2023, the definition included the aim of preventing and reducing the physical, psychological, social, and existential consequences of cancer and its treatment. The holistic approach, which is now well described in the context of cancer rehabilitation within the NCRG guidelines, enables a broad and comprehensive assessment of needs and planning of interventions (Figure 4).

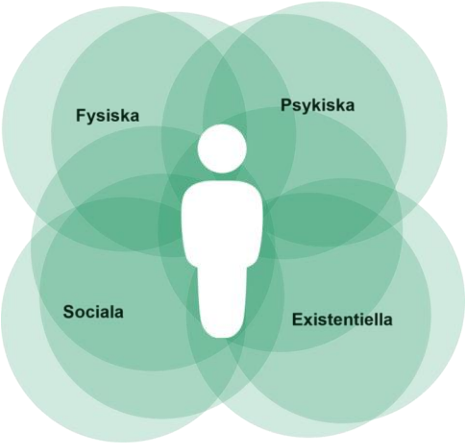


Figure 4. Needs and efforts based on physical, psychological, social, and existential areas of life according to the NCRG (122)(chap 5). In Swedish.

Cancer rehabilitation is closely integrated with preventive measures, medical measures, and nursing interventions, with a person-centered approach as a basis. The NCRG aims to complement diagnosis specific national cancer care guidelines, and contribute to a person-centered, equal, resource-efficient, and evidence-based cancer rehabilitation nationally. The first guidelines were published in 2014, followed by updated versions that have developed at focus on the person being offered rehabilitation measures based on their needs and situation, including the importance of follow-up (123).

The complex situation described by women with BC, including advanced treatments and related side-effects, demands a comprehensive and individualized approach for rehabilitation and support from healthcare. The holistic approach described above is of the utmost importance.

The Swedish cancer rehabilitation process

The NCRG constitutes a valuable source of knowledge including physical, psychological, social, and existential interventions. According to the NCRG, cancer rehabilitation should be organized on three levels depending on the complexity of rehabilitation needs: basic, specialized, and advanced level of rehabilitation (122) (chap 5) (Figure 5).

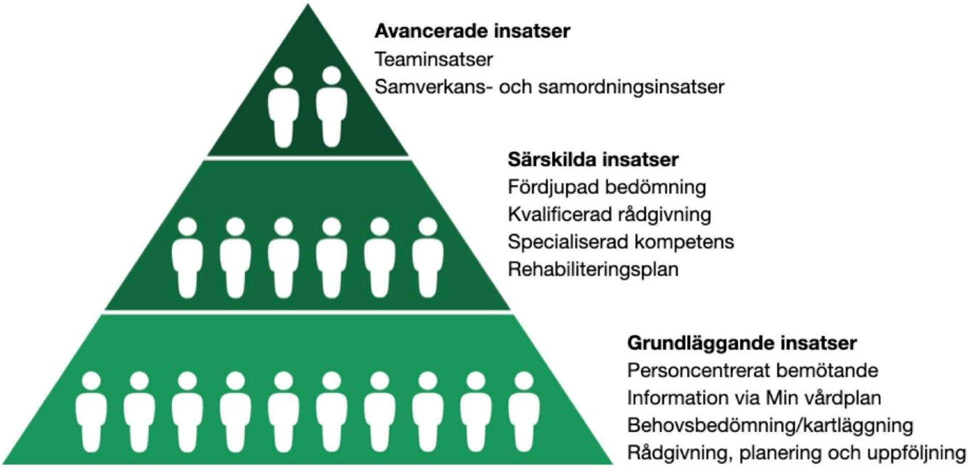


Figure 5. Interventions for cancer rehabilitation on the basic, specialized and advanced level according to the NCRG (122)(chap 5). In Swedish.

The basic level of rehabilitation

The NCRG recommend that all patients affected by cancer should be included in **the basic level** of rehabilitation when they receive the diagnosis. Here, the holistic perspective and the individual patient's prerequisites, resources, and needs are intended to be identified and guide support on the right level for rehabilitation. On this level, the intention behind giving basic advice on living habits and information about, for example, examinations, planned care and treatment, risks, side-effects, and rehabilitation is to help the patient to be involved and take responsibility for self-care and rehabilitation. Physician, CNCC, and patient can form a team, and next of kin can also be involved with the patient's permission. The foundation of this level should be the structured mapping of needs that decides the individual rehabilitation. Since rehabilitation needs change during the disease course, assessments of needs should be repeated continuously. The CNCC is important on this level, and should act as the continuous contact responsible for the structured mapping of needs. Within BC care, a physiotherapist and basic advice for physiotherapy after surgery are often included on this level.

The specialized level of rehabilitation

The patient will remain on the basic level unless identified as needing something more, at which point rehabilitation on **the specialized level** will be initiated. According to the NCRG, rehabilitation on this level should include in-depth assessments by HCPs with specialized competence within the identified area. A rehabilitation plan that contains a summary of assessments, the patient's goals, planned interventions, time plan, division of responsibilities, and follow-up should be decided between the patient and the HCP. A physiotherapist, social worker, and occupational therapist are often engaged for BC patients on this level. This can be organized differently at the local level but can constitute a specialized cancer rehabilitation unit.

The advanced level of rehabilitation

If the patient has complex needs, assessments and interventions sometimes demand rehabilitation on **the advanced level**. Specialized and multiprofessional teams cooperate and coordinate rehabilitation interventions on this level.

Knowledge of breast cancer and rehabilitation interventions

Research on rehabilitation during BC treatment predominantly focuses on exercise and physical activity. Physical activity is an important part of cancer rehabilitation, and regular exercise has been found to be safe and feasible both in improving several treatment-related symptoms and in lowering the risk of other chronic diseases (124-126). This illuminates the importance of integrating physical activity during BC treatment. For example, supervised exercise after surgery has been shown to improve muscle strength (127), reduce postoperative pain, increase the range of motion of the shoulder joint, reduce upper limb dysfunction, and reduce arm lymphedema (128). A review investigating exercise during chemotherapy showed positive impacts on fatigue, QoL, cognitive fatigue, physical and social functioning, constipation, and dyspnea (129). The effect of exercise during chemotherapy has also been studied in large, randomized studies in Sweden, showing beneficial effects on QoL up to one year after treatment (130), as well as long-term decreased levels of fatigue (127), and emotional symptoms (131) compared to usual care.

The findings regarding interventions focusing on psychological aspects for women with BC are less conclusive (132), but interventions targeting body image issues have been shown to be effective (133) and psychoeducation has been shown to decrease anxiety and increase QoL (134). Promising results for stress reduction and well-being have been found for interventions using strategies such as self-compassion (135) and mindfulness-based stress reduction (136). In a meta-analysis, psychological interventions aimed at fatigue showed promising results, but the effect varied depending on baseline levels of fatigue (137).

A systematic review of reviews evaluating current evidence on rehabilitation interventions following BC treatment showed that more than one intervention could have positive effects on a specific symptom, and that the effect depended on intervention type combined with when and how the intervention was provided (132). Individual prerequisites are crucial in deciding the best rehabilitation. With the person-centered rehabilitation approach taken in this thesis, rehabilitation is not limited or rigid, but flexible and inclusive of the person with BC’s opinions, experience, and preferences. There is no “one fits all” solution in cancer rehabilitation.

This was exemplified in a meta-synthesis investigating barriers and facilitators for participation in physical activity during BC treatment. Hindrances to participation were symptoms such as fatigue and pain, social factors such as responsibilities in everyday life, and information that was vague, inconsistent, or non-existent. Facilitating factors for participation included positive physical benefits, improvements in psychological well-being, increased self-esteem, and empowerment. Tailored information and a supportive environment were important, as well as the effect of the physical activity of feeling normal (138). This illuminates the importance of adapting information and rehabilitation depending on the affected person’s unique situation, and the need for a comprehensive approach. The challenge is to understand how rehabilitation should be structured on the local level, to enable evidence-based interventions provided in a person-centered way.

The gap between guidelines, research, and clinical practice

The Swedish report “Same but different everywhere – a mapping of access to rehabilitation for breast cancer patients” was published in 2021 (139), describing a reality where rehabilitation needs were strongly prevalent among women with BC, but these needs were often not identified and met. This is in line with earlier research in cancer patients showing that systematic needs assessment are challenging (140), often due to implementation struggles. The report also highlighted the significant variability in the availability of cancer rehabilitation across Sweden, encompassing the structures for assessments, planning, implementation, and follow-up.

This variability underscores the challenges in implementing the NCRG recommendations at local and clinical levels (123). One contributing factor could be the previously mentioned challenges faced by CNCCs when trying to perform their task in accordance with the role description, as they bear the primary responsibility for identifying rehabilitation needs at the basic level. Additional difficulties come from the patient’s journey through the healthcare system, which often includes moving from one clinic to another depending on treatment regime (139). Earlier research has shown the great challenge in these procedures (141), when differences in structures between organizations, including changing CNCC, interrupts the continuity of care and complicates the identification of rehabilitation needs.

Identification of needs may depend on the skills of the individual HCP, or the patient’s ability to ask for help (142). The patient ends up with the responsibility of asking for help, and even though personal liability is of the utmost importance in cancer rehabilitation (122), this cannot replace the professional responsibility of HCPs to offer high-quality care (139). The report from 2021 was followed by three other national reports (123, 143, 144), all unanimous in stating that cancer rehabilitation according to the NRCG is not fully implemented, and that cancer patients suffer from unidentified rehabilitation needs.

Rehabilitation and unmet needs

A recurrent theme in BC research is the occurrence of needs and unmet needs. From the holistic perspective on cancer rehabilitation, which encompasses physical, psychological, social, and existential aspects of life, unmet needs can be attributed to insufficient rehabilitation support. A systematic review by Fiszer et al. (2014) demonstrated that the needs and unmet needs of women with BC vary, and are influenced by individual characteristics such as younger age, treatment-related physical or psychological side-effects, marital status, time since diagnosis, stage of the disease, and level of distress (145). High levels of distress have been identified as the most influential risk factor for unmet needs (146), which suggests that distress could indicate a need for extended rehabilitation services.

A recent systematic review by Paltrinieri et al. (2024) further indicated that these needs change from the time of diagnosis onward (147). The authors suggested that their findings may reflect a gap in the provision of care, as evidenced by the number of unmet needs reported. One of the most prevalent unmet needs throughout the cancer trajectory, as described by Paltrinieri et al. (2024), is the need for information on self-help strategies to promote recovery. This highlights a critical lack of contact with healthcare services, which is crucial for managing the various challenges faced by women with BC. From diagnosis and treatment to follow-up care, consistent contact with HCPs is essential for facilitating rehabilitation and promoting independence.

In summary, the structures for rehabilitation within the NCRG, and the role description of the CNCC at both the national and the regional level have not been fully implemented, resulting in missed opportunities for rehabilitation and recovery. The prevalence of unmet needs reported in research underscores the importance of improving the identification of needs and acting in accordance with the individual situation. Implementation of structures on the local level to address individual rehabilitation needs is therefore of utmost importance.

Ontological and epistemological assumptions

The goal of integrating the person and their unique situation into rehabilitation interventions within the healthcare system underscores the importance of understanding the person's experiences. It also highlights the need to explore how healthcare structures relate to rehabilitation today, and how healthcare aligns with PCC principles. This influenced decisions about how knowledge in this matter could be gained, formed the basis of the ontological and epistemological assumptions on which this thesis rests, and decided the framework used in this thesis.

Ontology answers questions concerning the fundamental assumptions we make about the nature of the world (148). In this thesis, the reality is formed from the perspective of the person with BC, and depends on their unique beliefs, values and context. A person's lived life shapes how that person perceives the world (17), and when exploring the prerequisites for individualized rehabilitation, reality from both the patient's and the HCP's perspective is important. This thesis illuminates the viewpoints of both patients (Study IV) and HCPs (Study I), and the similarities and differences create a tension that is important to address in order to answer the aim of this thesis. This decides what we need to know to enable rehabilitation support in a person-centered way. In Study III, the subjective experience of reality was illuminated through questionnaires measuring aspects such as HRQoL, resilience, life situation, and distress. The data were treated with the greatest respect for individual experiences, despite being measured with predefined alternatives and analyzed on a group level.

Epistemology deals with questions about the knowledge we can retain about reality, and how the world is understood (148). A strength of this thesis is that new knowledge has been developed from different perspectives. The pilot and feasibility testing of the ReScreen intervention allowed knowledge to be gained of structures within the intervention, as well as of how the study could be operationalized in a robust way. A qualitative approach was used to explore experiences of rehabilitation from both the patient's and the HCP's viewpoint, as various perspectives are important in developing healthcare organizations in favor of PCC. Study III took a quantitative approach. The measurement of subjective experiences with questionnaires allowed investigation and interpretation of factors associated with the experience of receiving a BC diagnosis.

Rationale

Cancer rehabilitation aims to prevent functional impairments and to ensure that individuals with cancer maintain or regain optimal function, activity, and QoL despite the consequences of cancer and its treatment. Increasing survival rates for BC also mean an increasing need for rehabilitation and support, and research from the past two decades highlights the challenges faced by women throughout the cancer trajectory. While many women manage their condition with the help of their social context and standard care from HCPs, the challenge lies in identifying those who require extended support in a system where access to rehabilitation and promoting interventions is often limited, and where the responsibility often falls on the patient to communicate their needs.

Since the first national cancer rehabilitation guidelines were published in 2014, the importance of early identification of rehabilitation needs and the provision of holistic, individualized rehabilitation and follow-up has been stressed. Today, these two components are emphasized as the core of cancer rehabilitation. In the current NCRG, structures for early identification are provided and recommended at both national and regional levels, and validated instruments for identification of rehabilitation needs are suggested. According to the NCRG, at the local level, the individual situation and need for cancer rehabilitation should be assessed and evaluated together with the affected person, in accordance with the procedures established by each organization. However, the implementation of structures seems to differ between organizations, and recent reports indicate a gap between national guidelines and local practices and resources, leaving patients with suboptimal rehabilitation support. Implementing structures for the identification of needs by validated instruments and the provision of individualized rehabilitation at the local level is therefore of utmost importance to enable support for each individual woman.

This thesis is part of the ReScreen study, the overall aim of which was to develop an intervention based on early screening for distress as an indicator of extended rehabilitation needs, using a well-validated instrument: the distress thermometer. The thesis contributes to the development of knowledge by investigating the prerequisites for how structures such as those recommended within the NCRG can be applied on the local level. Its rationale is to provide a comprehensive understanding of the requirements for screening-based individualized rehabilitation according to the ReScreen intervention.

Aim

The overall aim of the thesis was to investigate the prerequisites for screening-based individualized rehabilitation following primary BC diagnosis, treatment, and follow-up.

The specific aims for each study:

I. To explore HCPs' experiences of current rehabilitation practice and describe current barriers and facilitators for individualized rehabilitation for patients following BC treatment.

II. To examine recruitment, retention, distribution of distress, relevance of the intervention, and reported problems in a pilot trial of the ReScreen study.

III. To investigate the level of distress in newly diagnosed BC patients and the association with demographics, clinical data, resilience, and HRQoL.

IV. To explore the experience of women with BC after participating in a complex RCT focusing on cancer rehabilitation from a comprehensive perspective.

Methods

Design

The overall aim of this thesis motivated the varying designs of Studies I–IV, as the intention was to gain a comprehensive understanding of different factors of importance for individualized rehabilitation. All four studies are part of the ReScreen RCT, a complex intervention study that is described in more detail below. In Studies I and IV, the qualitative design allowed the exploration of experiences of rehabilitation from the perspective of the HCP (Study I) and the patient (Study IV). Study II was a feasibility study piloting the ReScreen RCT. Study III used a cross-sectional design to investigate high and low distress in relation to demographics, clinical data, HRQoL, and resilience in newly diagnosed women with BC. An overview of the design, participants, data collection, and analysis in each of the four studies is presented in Table 2.

Table 2. Overview of design, participants, data collection, and data analysis in studies I-IV

	Study I	**Study II**	**Study III**	**Study IV**
Design	Qualitative/focus group interviews	Feasibility testing and pilot study	Quantitative/cross sectional study	Qualitative/focus group interviews
Participants	19 HCPs from surgical and oncological departments	85 women participating in the ReScreen feasibility study	633 women included in the ReScreen RCT	30 participants from the ReScreen RCT
Data collection	Focus group interviews	Self-reported questionnaires, medical records	Self reported questionnaires, medical records	Focus group interviews
Data analysis	Conventional content analysis, inductive approach	Descriptive statistics	Descriptive statistics, regression models	Conventional content analysis, inductive and deductive approach.

HCP= healthcare professional, RCT=randomized controlled trial,

Context

The ReScreen study

This section provides an introduction to the ReScreen study, in order to clarify the context from which the thesis originates. The overall aim of this complex intervention study was to develop and evaluate a model for screening-based individualized rehabilitation for women following primary BC treatment (7). It took inspiration from the Medical Research Council's framework for complex interventions (149), and included four phases: 1. development, 2. feasibility testing, 3. evaluation, and 4. implementation. This thesis includes work from the first three phases (Figure 6).

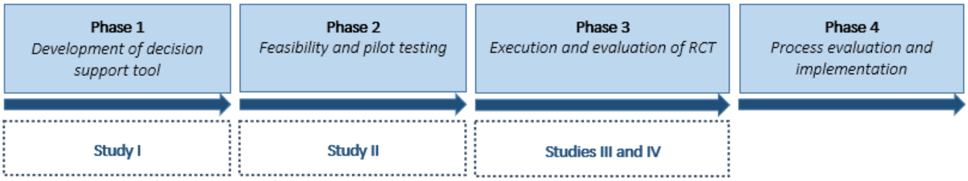


Figure 6. Overview of the ReScreen study.

Complex interventions

It is not always evident what makes an intervention complex. Craig et al. (2008) describe some characteristics that are important to consider for research strategies, such as the number of interacting components within the intervention, the number and difficulty of behaviors required by those receiving or delivering the intervention, and the number of organizational levels targeted by the intervention (149). Another aspect is the questions that are asked, such as how the intervention works, or how the intervention can be optimized (150). Within the ReScreen study, the complexity of real-world conditions results in numerous interacting components within the intervention. To comprehend these components, various study designs are necessary to address the overall aim (149, 151). This was an important foundation for the design of the studies included in this thesis.

The development of the ReScreen study

The design of the ReScreen study was inspired in part by a Danish study of individualized rehabilitation during BC treatment (152). During the development phase, a systematic review of systematic reviews was conducted in order to evaluate the current evidence on rehabilitation interventions in female patients following BC treatment (132). Additionally, a focus group study with HCPs was conducted to explore facilitators and barriers for individualized rehabilitation from the HCP's perspective (153) (Study I). The design of the ReScreen intervention for individualized rehabilitation, along with a clinically relevant decision support tool (DST), was developed on the basis of the results from these two studies, the NCRG, and meetings with stakeholders (patients, next of kin, interest organizations).

In the second phase, the feasibility of the ReScreen RCT was tested (154) (Study II). Feasibility testing is a crucial part in the development of a complex intervention, and should be designed to assess progression criteria such as recruitment, data collection, and retention to reduce uncertainty around these matters. It should also include evaluation of the optimal content and delivery of the intervention (151). The main goal of assessing feasibility is to avoid potentially disastrous consequences in the larger study that might affect the whole research effort (155). The results from Study II led to changing the selection of patients for randomization, which was crucial for the main ReScreen RCT. This phase also included evaluation of the DST, further details of this will be given in the Method and Result sections for study II.

The ReScreen RCT

The RCT started out as a single-center study conducted at the Department of Surgery, Skåne University Hospital, where approximately 720 women are diagnosed with and treated for BC annually. During the study, a second department was enrolled: the Department of Surgery at Helsingborg Hospital, where approximately 300 women are diagnosed and treated each year (156).

Women aged ≥18 who were diagnosed with primary BC and planned for surgery, and who were able to communicate in Swedish, were invited to the ReScreen RCT. Exclusion criteria were recurrent disease, pregnancy, inability to participate due to cognitive impairment, severe mental illness, or drug addiction. The participants were invited to the study by CNCCs working at the BC units, in slightly different ways due to differences in organizational structure between the two hospitals. Participants from the university hospital were included during a pre-planned visit to the BC unit, and completed a baseline questionnaire during the same visit. This appointment was conducted 1–2 weeks after receiving the diagnosis, and included information and practical details to prepare the patient for operation. Participants included at the county hospital were informed of and included in the ReScreen study by a CNCC during the visit when they were informed of the BC diagnosis. They received a baseline questionnaire with a pre-stamped envelope for completion at home.

The women who agreed to participate were included in a three-armed RCT, approximately 1–2 weeks before start of treatment. At inclusion, the participants were screened for distress using the DT described below. Participants identified as having high distress (≥5 on a scale of 0–10) were randomized to either an intervention group (IG) or a control group (CG). Participants scoring <5 were followed as an observational group (OG). A computerized random sequence was generated to ensure an allocation ratio of 1:1 for the IG versus CG. All three groups received usual care, and the IG was additionally offered the intervention described below.

For the RCT sample size evaluation was conducted with distress as the primary outcome. Assuming a standard deviation (SD) of 2.9 (of DT scores) at the follow-up visit in the two randomized groups, 266 patients (133 per group), were required for a two-sided two-sample t-test for 80% power to detect a 1.0 unit mean difference. Assuming that the OG accounted for 60% of the patients in the study, the sample size increased to 665.

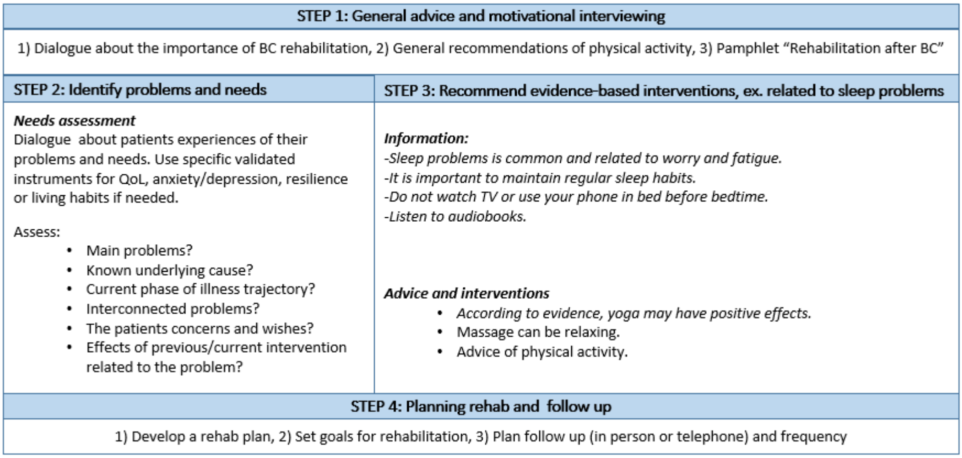
Usual care

Usual care in the study context referred to the basic level of rehabilitation, represented by access to a CNCC and a surgeon/oncologist working in the BC unit. The CNCC on the surgical BC unit served as the primary contact during both the pre-treatment and post-treatment period, unless chemotherapy was recommended as adjuvant treatment, in which case a CNCC from the oncological BC unit assumed responsibility for identifying needs and providing rehabilitation. Additional basic rehabilitation resources depended on treatment regime; for example, if full axillary lymph node dissection was performed, follow-up included structured contact with a physiotherapist. The CNCC was responsible for identifying additional rehabilitation needs, as well as making referrals to other HCPs if needed. Usual care was based on the patient’s initiative to contact, and there were some differences between the two hospitals, mostly represented by how the participant could get in contact with HCPs. Aside from planned appointments structured according to the medical process, the CNCC could be reached by phone for at least two hours per day.

The intervention and the decision support tool

In addition to usual care, the IG was involved in the rehabilitation process through the development of a rehabilitation plan decided between the patient and a dedicated research nurse, which constituted the basis for rehabilitation during the follow-up year. The plan was based on individual prerequisites and the DST that was developed in the first phase of the ReScreen study. The DST focused on health-related behaviors, and clinical and evidence-based knowledge of known problems related to BC and treatment: practical/relational problems, emotional/existential problems, and physical problems.

The DST was organized in four steps, and supported the dialogue between the patient and the nurse (Figure 7). The first step focused on general advice about rehabilitation and exercise. In the second step, the patients’ individual needs were identified, and in the third step these needs were matched to evidence-based interventions. The rehabilitation plan was formed in the fourth step, including explicit goals for the rehabilitation process. Follow-up and evaluation depended on the patients' individual needs, but took place as a minimum at 2 weeks after start of treatment and then once a month during the first 4 months. Follow-up lasted for 1 year, during which period the research nurse acted as a continuous healthcare contact responsible for proactive and systematic evaluation of needs to ensure that potential new problems or changed rehabilitation needs were identified. The research nurse monitored the women throughout the first year, even if the adjuvant treatment required transition from the surgical to oncological BC unit.



STEP 1: General advice and motivational interviewing

1) Dialogue about the importance of BC rehabilitation, 2) General recommendations of physical activity, 3) Pamphlet "Rehabilitation after BC"

STEP 2: Identify problems and needs	STEP 3: Recommend evidence-based interventions, ex. related to sleep problems
Needs assessment Dialogue about patients experiences of their problems and needs. Use specific validated instruments for QoL, anxiety/depression, resilience or living habits if needed. Assess: • Main problems? • Known underlying cause? • Current phase of illness trajectory? • Interconnected problems? • The patients concerns and wishes? • Effects of previous/current intervention related to the problem?	***Information:*** *-Sleep problems is common and related to worry and fatigue.* *-It is important to maintain regular sleep habits.* *-Do not watch TV or use your phone in bed before bedtime.* *-Listen to audiobooks.* ***Advice and interventions*** • *According to evidence, yoga may have positive effects.* • Massage can be relaxing. • Advice of physical activity.

STEP 4: Planning rehab and follow up

1) Develop a rehab plan, 2) Set goals for rehabilitation, 3) Plan follow up (in person or telephone) and frequency

Figure 7. Example of the DST focusing on sleep problems.

Participants and data collection

The studies presented in this thesis included a total of 737 participants: 19 HCPs and 718 women newly diagnosed with BC. The women with BC provided quantitative data for Studies II and III, and 30 of them also contributed qualitative data through interviews. The 19 HCPs provided interview data.

Participants and inclusion

Study 1

This explorative qualitative focus group study included HCPs working with BC at the Department of Surgery or the Department of Oncology at Skåne University

Hospital between November 2016 and March 2017. HCPs working with BC care or cancer rehabilitation in various parts of the cancer trajectory were considered eligible for inclusion in the study, and were purposefully invited through key persons. When applying purposeful sampling, participants are selected who will best contribute to the study (157). Variation in profession, workplace, and years of working with BC/rehabilitation was sought, in order to gain a comprehensive understanding of rehabilitation including perspectives from the different professions involved during the patient’s BC journey, and thus to gain rich and relevant information for the study aim (158, 159). A total of 19 HCPs were included.

Study II

This feasibility and pilot study was conducted at the Department of Surgery, Skåne University Hospital. Between November 2018 and April 2019, women with primary BC who fulfilled the ReScreen inclusion and exclusion criteria were consecutively invited to participate. Of 117 eligible women, 32 declined participation, leaving 85 participants to be included in the study.

Study III

This cross-sectional study was part of the main ReScreen RCT, which was conducted at two hospitals. Inclusion into the study lasted from May 2019 to November 2022. Participants were included on the basis of the ReScreen study inclusion and exclusion criteria. Because of the COVID-19 pandemic, inclusion was paused from December 2020 until August 2021. A total of 784 women were asked to participate, and 643 gave their consent. Of these, two withdrew their consent and eight were found not to fit the inclusion criteria, and so 633 participants were finally included in the study.

Study IV

In this qualitative focus group study, women who had completed their participation in the ReScreen RCT were eligible to participate. Inclusion lasted from April to November 2022. All eligible women during this period were purposefully invited to participate, with the aim of achieving variation regarding participation in the IG, CG, or OG. Time since start of treatment was limited to 24 months. Potential participants were approached by phone, and were asked if they wanted to participate in a group interview about rehabilitation. After an initial recruitment period during Spring 2022, six focus groups were conducted. Due to late cancellations, resulting in a low number of participants in some of the groups, further recruitment was initiated during Autumn 2022, and an additional three focus groups interviews were conducted to ensure richness of data. Of 109 eligible women, 95 were reached, 42 agreed to participate, and 30 women finally participated.

Data collection

Interviews – Studies I and IV

Five focus group interviews with 19 HCPs (3–5 participants in each group) were conducted in Study I. The participants in each group worked at the same unit and included different professions. Interviews were conducted face-to-face in a conference room at the hospital, and lasted 71–89 minutes.

Nine focus group interviews with 30 participants from the ReScreen RCT (2–6 participants in each group) were conducted in Study IV. The intended variation regarding participation in the IG/CG/OG was achieved, with 3 interviews being conducted among each group (total participants per group: N=12 from the IG, N=8 from the CG, N=10 from the OG). Interviews lasted 70–130 minutes, and were carried out face-to face in a separate room at the hospital.

In both Study I and Study IV, a semi-structured interview guide was used during the interviews to support the participants in focusing on the topic of the studies. Each interview started with an opening question:

Study I: “Could you please describe your role in the rehabilitation of patients following BC treatment?”

Study IV: “What are your thoughts about rehabilitation during the year after diagnosis?” In this study, the definition of cancer rehabilitation was given prior to commencing the interviews.

Two researchers were present during the interviews; one acted as a moderator, helping the participants to focus on the study aim, while the other took notes and asked probing questions (160). At the end of each interview, a summary of the content was presented to the participants to confirm and validate the interpretation, allowing for immediate member checking (161). In both studies, data collection was closed when no new information emerged. The interviews were recorded digitally.

Feasibility measurement and outcomes – Study II

The feasibility outcomes in Study II were recruitment rate, answer frequency, retention rate, and outcomes related to data management. This included procedures to identify potential systematic errors. Further outcomes were distribution of distress, adherence to intervention protocol, and frequency of reported problems.

ReScreen data collection and measurement – Studies II and III

The same procedures for data collection were performed in Studies II and III. Data collection time points are given in Table 3. Study III only included baseline data.

Follow-up questionnaires (T1–T5) were sent by post and returned in a pre-addressed, stamped envelope. Up to two reminders were sent.

Table 3. Overview of data collection time points for Studies II and III

Time points	0 Baseline[1]	T1 2 weeks[2]	T2 3 months[2]	T3 6 months[2]	T4 9 months[2]	T5 12 months[2]
Assessments						
Demographic data						
Height and weight	X			X		
Sick leave	X	X	X	X	X	X
Other[3]	X					
Clinical data	X	X	X			
Self-reported data						
DT	X	X	X	X	X	X
QLQ C-30, BR-23	X	X	X	X	X	X
CD-RISC	X	X	X	X	X	X
Living habits	X			X		X
Care satisfaction				X		X

[1] 1–2 weeks before start of treatment. [2] After start of treatment. [3] Age, marital status, number of children, born in Sweden (yes/no), living arrangements, financial situation, level of education. DT=Distress thermometer, CD-RISC=Connor-Davidson Resilience Scale.

The questionnaire included data on the following variables:

Sociodemographics

Demographic variables were collected via single items including information on date of birth, marital status, number of children, born in Sweden (yes/no), living arrangements, height and weight, being on sick leave, financial situation, and level of education.

Physical activity and health-related behavior

Items related to physical activity included questions about exercise and activity, while items related to health behaviors included questions on tobacco and alcohol consumption. The items were collected from the Swedish National Board of Health and Welfare.

Self-reported instruments for distress, HRQoL, and resilience

Distress, the primary outcome variable of the ReScreen RCT, was measured with the DT (33), a 11-point numeric scale on which the level of distress is indicated from none (0) to extreme distress (10). The DT includes a problem list comprising 39 common problems in cancer patients, divided into five categories: practical problems, family-related problems, emotional problems, spiritual or religious problems, and physical problems; all are responded to with “yes” or “no” (33).

Respondents are asked to answer on the basis of their experience during the past week. The DT has been validated in various cancer contexts (34-37), and has shown good potential in screening for distress-related practical, family, emotional, existential, and physical problems in patients with cancer (34, 35).

Resilience was evaluated using the Swedish version of the Connor-Davidson Resilience Scale (CD-RISC) (162). This instrument contains 25 items evaluated on a 5-point Likert scale from 0 (not true at all) to 4 (true nearly all the time). The 25 items correspond to 5 factors: 1. having high competence, standards, and tenacity (eight items), 2. reflects trusting one's instinct, perceiving strengthening effects of stress, and tolerance of negative affect (seven items), 3. having secure relationships and a positive attitude towards change (five items), 4. perceived control (three items), and 5. spirituality and religion (two items). A total score of 0-100 is calculated, with higher scores indicating higher resilience. CD-RISC has good psychometric properties (163) and has been validated in Swedish populations (164, 165).

HRQoL was evaluated using the Swedish versions of validated instruments from European Organization for Research and Treatment of Cancer (EORTC). The QLQ-C30 (41) is the core instrument, and is designed to assess the HRQoL in patients with cancer. Since its original publication in 1993, it has been translated into more than 120 languages, and it is now among the most widely used patient-reported outcome measures in both cancer research and clinical practice (166). A recent study investigating patients' experiences of their disease and symptoms was conducted to ensure that the concepts assessed by the QLQ-C30 questions are still important and relevant to patients today. The results showed that the questionnaire is appropriate and relevant for patients affected by various cancer types and stages of the disease (167).

The QLQ-C30 incorporates 30 items in 15 subscales. The two subscales on global QoL are scored on a 7-point Likert scale ranging from 1 (very poor) to 7 (excellent). The items in the remaining subscales, three on symptoms (fatigue, pain, and vomiting/nausea), five on functioning (role, physical, emotional, cognitive, and social), and six single-item scales (dyspnea, constipation, diarrhea, insomnia, financial difficulties, and loss of appetite), are scored on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much). In this thesis the scales were handled according to the manuals, meaning that the 4-point scales were linearly transformed to scores of 0-100 , with high scores on the global QoL and functioning scales representing better HRQoL and functioning, and high scores on the symptom subscales indicating more severe problems (168).

QLQ-BR23 (44) is a BC-specific module intended for use among patients varying in disease stages and treatment modalities. The module comprises four functional scales (body image, sexual functioning, sexual enjoyment, future perspective) and four symptom scales/items (systematic therapy side-effects, breast symptoms, arm symptoms, being upset by hair loss). The items are scored on 4-point Likert scales, and the scoring procedure is consistent with the functional and symptom scales of QLQ-C30 (168). A review conducted in 2015 determined the QLQ-BR23 to be reliable and valid for assessing HRQoL in patients with BC (169).

Clinical data collected from the medical journal included:

Clinical variables

Clinical and treatment-related data in terms of, for example, mode of detection, menstrual status, comorbidity, and being on psychotropic drugs or beta blockers were retrieved from patients' medical records. Several other clinical variables were included in the evaluation of the RCT, but were not relevant to the studies included in this thesis.

Data analysis

My preunderstanding

I first met women with BC as a nurse in the early years of the 21st century, when I was working on a surgical ward with multiple specialties. At that time, the women spent a few nights in hospital regardless of the method used for their operation. Usually they were placed together in a 4-bed room that was known as "the easy room". Mostly all we did as nurses was to administer painkillers, remove drainage, and help them decide on the size of their prosthesis. However, I soon learned that if I just sat down at their bedside and listened to their stories and feelings, life was not that easy. Several years later I started working in a BC unit, and eventually started my PhD in this project.

In almost every study I read, I can follow the common thread of experiences, which has a strong resonance from my clinical work as a CNCC on a BC unit. Throughout the process of conducting the studies, I needed to be aware of my preunderstanding, experience, knowledge, and opinions built upon meeting patients with BC as a CNCC, in order to avoid letting these affect the results.

Research always requires some prior understanding; this provides an initial grasp of the phenomenon under investigation, allowing knowledge to develop (170). Ongoing discussion with my co-authors and fellow PhD students and researchers, who did not have my experience as a CNCC, was essential to balance my pre-understanding in the analytical process and to ensure that the results mirrored the participants' experiences rather than mine.

Studies I and IV

Conventional qualitative content analysis

Studies I and IV both had a qualitative design, but originated from two different samples. Study I aimed to explore HCPs' experiences of current rehabilitation practice, and to describe current barriers and facilitators for individualized rehabilitation for patients following BC treatment. Study IV aimed to explore the experience of women with BC after participating in a complex RCT focusing on cancer rehabilitation from a comprehensive perspective. Through the interviews, a deeper and comprehensive understanding of all the participants' experiences could be gained. Conventional qualitative content analysis was applied in both studies, following the process described by Graneheim and Lundman (2004) (171). Content analysis is appropriate in designs aiming to increase knowledge in areas where theory or research are currently limited (172).

The recorded interviews were transcribed verbatim, and validated by reading the text and listening to the recorded interviews simultaneously. Content analysis can take an inductive approach, which has no predefined themes or categories, or a deductive approach, which starts with a predefined theory, model category, or theme (173). Studies I and IV both started with an inductive approach, allowing categories to flow from the data (172). The researchers independently read and/or listened to the transcripts to achieve an overall understanding and sense of the whole. The texts were analyzed as a whole, and codes emerged thorough abstraction of condensed meaning units. Codes answering the aim of the studies were sorted into sub-categories and categories (171). In both Study I and Study IV, two authors had the main responsibility for the analysis while the other authors focused on ensuring the link between data and the analysis. This included a back-and-forth process between text, codes, sub-categories, and categories to validate the interpretation. Interpretations were discussed throughout the analytical process until consensus was reached between all authors.

The analysis continued in Study IV, using the results from the inductive analysis to reanalyze the data with a deductive approach. The two categories and four sub-categories included a great variety in experiences of rehabilitation and BC. To explore and increase the knowledge of possible variations between the IG, CG, and OG, the codes were sorted into categories and sub-categories for the three groups separately.

In both Study I and Study IV, the manifest content was interpreted in the sub-categories and categories. The analysis concluded in Study IV with the emergence of an overall theme (174).

Study II

Study II aimed to examine recruitment, retention, distribution of distress, relevance of the intervention, and reported problems in a pilot trial of the ReScreen RCT.

Descriptive statistics in terms of frequencies, means and standard deviations (SD) were used to evaluate the outcome data. Calculations were performed using version 25.0 of SPSS Statistics for Windows (IBM, Armonk, NY, USA).

Recruitment rate was evaluated by calculating the number and percentage of participants who agreed to participate in the study compared to all eligible patients. Reasons for non-participation were not structurally collected. *Answer frequency* was defined as the number and percentage of patients who returned the questionnaires at each follow-up point, both for the sample as a whole and divided into IG/CG/OG. The *retention rate* was defined as the number and percentage of patients remaining in the study at each follow-up point, and calculated both for the whole sample and for the IG, CG, and OG individually. To evaluate *data management outcomes*, all scanned questionnaires were manually verified and compared to the original data. The evaluation also involved manually comparing medical data in the electronic case report form with the medical journal; this was performed by two team members, one of whom had not been involved in the data management process.

The evaluation of the *distribution of distress* was an essential part of this study. In the feasibility study, the cut-off on the DT for deciding whether the participant had elevated distress was set to 7. This cut-off had been identified in earlier international studies as relevant to identify high distress among women newly diagnosed with BC (175, 176). The distribution of distress was assessed firstly by calculating the mean value in the total sample at each follow-up point, and secondly by calculating the number and percentages of participants scoring ≥7 at baseline, and then exploring alternative cut-offs (≥4, ≥5, ≥6, and ≥8).

Adherence to the intervention and study protocol was evaluated through a review of the study documentation of the IG. The review included number of contacts with the research nurse, whether each patient had an established rehabilitation plan, whether rehabilitation goals were stated and clearly documented, and whether the goals were followed up by the research nurse.

The *frequency of reported problems* was investigated in the total sample at each follow-up point using the problem list. The number of problems per patient was also investigated in the total sample. This enabled evaluation of the consistency of the DST with the most common patient-reported problems.

All participants were included in the analysis, except for the investigation of the frequency of reported problems, where only questionnaires with complete data on the problem list at baseline were included.

Study III

Study III aimed to investigate the level of distress in newly diagnosed BC patients and the association with demographics, clinical data, resilience, and HRQoL.

Statistical analysis

Version 29 of SPSS Statistics (IBM, Armonk, NY, USA) was used for the statistical analyses.

Descriptive statistics were used to investigate associations between demographics, clinical variables, resilience, and HRQoL and the primary outcome distress, which was dichotomized as low (≤4) versus high (≥5) distress.

The validated instruments used in this thesis for resilience and HRQoL were based on Likert scales, and before statistical testing these were lineally transformed to a 0–100 scale in accordance with instructions for the instruments (168). For CD-RISC, missing values were imputed using the mean of the other items if at least 75% (19 items) were completed, following the recommendations on the Connor-Davidson website (177). Missing items in QLQ-C30 and QLQ-BR23were imputed in accordance with the EORTC instructions (168).

To quantify associations between the outcome high/low distress and demographical and clinical variables, resilience, and HRQoL univariable logistic regression analyses were performed.

To identify predictors of high distress, a first model was fitted using backward selection (178). Only demographic and clinical variables were included in this model. A p-value threshold of 0.157 was applied for variable exclusion, corresponding to the minimization of the Akaike information criterion (AIC; a measure of fit adjusted for model complexity) (179). Model performance was assessed using the area under the receiver operating characteristic curve (180). Given the inclusion of the clinical variable mode of detection, the sample was restricted to individuals aged 40-74 years at diagnosis, aligning with the target population for mammography screening in Sweden. To avoid further restricting the sample, the variable being on sick leave was not included.

The following two models focused on exercise as the primary exposure of interest, given its modifiability by both the patient and the HCPs. In the second model, the effect of exercise on distress was adjusted for age, self-assessed financial situation, level of education, and psychiatric disease in health history. In the third model, the binary variable being on sick leave was included, and so the sample was restricted to <65 years of age, as this variable is only relevant prior to retirement.

P-values < 0.05 were considered statistically significant. Since no adjustment were made for multiple testing, caution is warranted when interpreting the results from each specific test.

Ethical considerations

The ReScreen study was approved by the Regional Ethical Review Board in Lund, Sweden (ref: 2015/505). Supplementary approval was obtained from the Regional Ethical Review Board (amendment 2018/924) and the Swedish Ethical Review Authority (amendments 2020-04664 and 2020-06752). All studies conformed to the Swedish research ethics legislation (181) and to the ethical principles defined by the Declaration of Helsinki (182, 183).

During the progress of the doctoral studies, continuous discussions were conducted to ensure the ethical principles of autonomy (the individual's right to make their own decisions), beneficence (the moral obligation to act for the benefit of others), non-maleficence (the moral obligation not to cause harm), and justice (fairness and equality among individuals) (184).

Autonomy. In Study I, HCPs were invited to participate by key persons, such as the unit manager. This could have implied a sense of pressure to participate, although all participants expressed that they were happy to participate and share their views. The interviews were conducted at the participants' workplaces, which could have influenced the power dynamics. Voluntary participation was emphasized. All participants received oral and written information about the study before signing their written informed consent (7). They were also assured that they had the right to decline participation or withdraw their consent at any time. The participants in Study IV, who had all previously participated in the ReScreen RCT, received further written and oral information and again gave their written informed consent prior to data collection in the focus group study.

Since the author of this thesis worked as a CNCC on the BC unit and conducted the interviews, there was a risk of interviewer and participants having previously met. It was decided that if any participant had met the author in the BC unit, another researcher would lead the interview. The invitation phone call was followed by an invitation letter, which provided several opportunities to decline participation. The participants were also aware that the interviews took place at the hospital. If that caused feelings of discomfort, they had the opportunity to abstain from participating. Initially, it was possible to choose between two hospital sites for the interview, and the interviews were held in a room separated from the clinical activities to avoid feelings of discomfort.

Beneficence. All studies included in this thesis had the aim of improving care for women with BC. Both HCPs and persons with BC participated in the studies. It is always important to consider individual participants' preferences regarding participation in research, especially for patients with cancer, as they are often vulnerable and dependent on healthcare. In all studies in this thesis, the participants were assured that participation was strictly voluntary, and that data would be handled confidentially.

For Study IV, participants from the ReScreen RCT were invited to the focus group study through a phone call from one of the researchers. Recruitment might have been challenging if the women did not want to be reminded of their journey, or if the phone call brought back negative experiences. Therefore, if they declined participation, the researcher did not ask for a reason but ended the call amicably. During the interviews, participants had the opportunity to articulate their experiences and share thoughts and feelings with others who had been through similar situations with BC.

To minimize the risk that the completion of questionnaires and participation in interviews could have been perceived as time-consuming, burdening the participants' everyday lives (157), two women who had experienced BC completed the questionnaires included in the RCT before the study. This was done to ensure the inclusion of only relevant instruments and to avoid unnecessary strain on the participants.

Non-maleficence. This principle was addressed by treating all data as confidential. All necessary permits were in place before inclusion of patients began. Participants were assured that they could not be identified in the presentation of the studies. Results were presented at group level, and quotations in Studies I and IV were anonymized. Upon inclusion in the studies, personal identification was pseudonymized. All data were stored in a locked, fireproof cabinet, and the code key was stored separately. Scanned data were handled on password-protected computers and databases, and medical data were registered in an electronic case report form.

During data collection, the participants could receive support for any questions, thoughts, or feelings that arose. The interviews were conducted within an atmosphere of permission to express feelings and thoughts, and it was clarified beforehand that what was said in the room would stay in the room.

Justice. Participation provided an opportunity for individuals to make their voices heard without anyone else setting their conditions. To ensure that all women with BC during the inclusion period had the same chance to participate, all eligible women during the inclusion periods were asked to participate in Studies II, III, and IV.

Results

The results of Studies I-IV show that the prerequisites for screening-based individualized rehabilitation require consistent structures for the identification of needs and communication throughout the different levels of cancer rehabilitation. In order to answer the overall aim of the thesis the results are presented below in the form of brief summaries focusing on the results of each study in turn, followed by a comprehensive approach presented under the subheadings *Prerequisites for early screening for rehabilitation needs,* and *Prerequisites for individualized rehabilitation.*

Summary of results

In **Study I**, HCPs' experiences of rehabilitation practices and barriers and facilitators for individualized rehabilitation were captured in eight sub-categories that formed three categories: varying attitudes towards rehabilitation, incongruence in how to identify and meet rehabilitation needs, and suboptimal collaboration during cancer treatment (Table 4).

Table 4. Overview of the categories and sub-categories in study I

Categories	Sub-Categories
Varying attitudes towards rehabilitation	Rehabilitation based on medical indicators Lack of consensus about approach towards rehabilitation Setting goals for rehabilitation
Incongruence in how to identify and meet rehabilitation needs	Identifying signs of vulnerability Screening for rehabilitation needs Actions triggered by signs of vulnerability
Suboptimal collaboration during cancer treatment	Interprofessional team collaboration Interdisciplinary collaboration

Despite the respondents' extensive knowledge and willingness to facilitate the BC journey for patients, several barriers to individualized rehabilitation were identified. These barriers were primarily related to the lack of structures for identifying rehabilitation needs, varying knowledge of and interest in rehabilitation, and the absence of organizational frameworks supporting individualized rehabilitation in clinical practice.

Study II explored the feasibility of the ReScreen RCT, and found satisfactory rates of both recruitment (73% enrolled patients included) and retention (here represented by answer frequency). The answer frequency was 92% overall, 98% in the IG, 64% in the CG, and 95% in the OG.

Only 18 participants (21.2%) scored ≥7 and were randomized to the IG (N=9) and CG (N=9).

To explore the relevance of the DST, reported problems on the DT problem list were investigated. The most frequently reported problems were related to the domains for emotional and physical problems, with concerns such as worry, fatigue, sleep, sadness, and memory/concentration, dominating across all timepoints.

Study III investigated the association between distress and demographic and clinical variables, resilience, and HRQoL. Of the 633 participants, 52% scored ≥5 on the DT and were randomized according to the study protocol.

The univariable logistic regression models for demographic and clinical factors showed significant associations between high distress and factors such as younger age, financial situation, amount of exercise per week, mode of detection, and psychiatric disease in health history. Moreover, there were strong associations between high distress and several subscales for HRQoL, such as lower summary scores, lower emotional functioning (QLQ-C30), and lower future perspective (QLQ-BR23). High distress was also strongly associated with lower resilience. In the multivariable logistic regression with backward selection, the following variables were retained in the model for distress: amount of exercise per week, self-assessed financial situation, mode of detection, age, use of beta blockers, number of children, and psychiatric disease in health history (Table 5). The corresponding area under curve was 0.684 (95% confidence interval [CI]: 0.638-0.729). In the models adjusting exercise per week for other variables, the association between high distress and exercise was stronger than in the univariable analysis (>90 vs <30, odds ratio [OR]: 0.50, 95% CI 0.33–0.77, compared to OR 0.58, 95% CI: 0.38–0.86).

Table 5. A multivariable prediction model for distress derived using logistic regression with backward elimination

Variables in the model	OR for high vs low distress (95% CI)	*P* -value
Exercise per week		
<30 min	ref	
30-90 min	0.83 (0.54-1.30)	0.424
>90 min	0.47 (0.30-0.78)	0.003
Self-assessed financial situation		
Good/very good	ref	
Neither good nor bad	1.55 (0.85-2.83)	0.150
Bad/very bad	3.89 (1.22-12.41)	0.022
Age at diagnosis, per year	0.98 (0.96-1.00)	0.034
Psychiatric disease in health history		
No	ref	
Yes	1.82 (0.91-3.62)	0.090
Mode of detection		
Symptomatic	ref	
Screening	0.63 (0.41-0.97)	0.036
On beta blockers		
No	ref	
Yes	0.63 (0.34-1.16)	0.137
Number of children		
0	ref	
1	1.70 (0.80-3.61)	0.172
2	1.08 (0.58-2.01)	0.811
3	0.58 (0.28-1.18)	0.131
>3	0.47 (0.15-1.43)	0.182
Constant	[1]6.71	

N=492, missing 43. Age at diagnosis 40–74 years. [1]The exponentiated intercept parameter.

Study IV explored experiences of cancer rehabilitation among women with BC. Interviews were conducted with women from all three randomization groups of the ReScreen RCT (IG/CG/OG), and analyzed with both inductive and deductive analysis in order to illuminate variation in experiences between individuals and between the three groups. The women’s experiences were captured in an overall theme: being an individual in a complex healthcare system. This was formed of two categories: *Feeling safe – a prerequisite for rehabilitation*, and *The individual needs as guidance for rehabilitation* (Table 6).

Table 6. Overview of theme, categories, and sub-categories

Theme: Being an individual in a complex healthcare system	
Categories	*Sub-categories*
Feeling safe – a prerequisite for rehabilitation	To be able to navigate and understand the healthcare system To be acknowledged and valued in the healthcare system
The individual needs as guidance for rehabilitation	To be able to adjust to and recover in daily life To receive support when needed

Prerequisites for early screening for rehabilitation needs.

One prerequisite for individualized rehabilitation is that the patients' needs are identified and addressed early in the process. This thesis therefore sheds light on early screening for rehabilitation needs from different perspectives. Study I was concerned with the perspective of the HCP, while Study II focused on the feasibility of conducting a study to evaluate the effect of screening-based individualized rehabilitation. Study III examined the association between distress and other variables. Finally, Study IV explored patients' experiences of their rehabilitation needs in the light of their reported baseline level of distress and the support they received during their recovery period.

A core component of the ReScreen project was to explore the use of the DT as a screening instrument for extended rehabilitation needs early in the BC trajectory. Based on previous research, Study II investigated the feasibility of using a cut-off score of ≥7. The results showed that only 21.2% of participants scored ≥7 on the DT, which is a considerably lower proportion than that reported in earlier research. This finding led to a change in cut-off from ≥7 to ≥5 in the main RCT, to allow identification of women with high distress and to enable investigation of the accurate cut-off in this population. In Study III, 52% of participants rated their distress as ≥5, and the distribution of distress levels was similar but not identical to that in Study II. Study III further showed significant associations between high distress and lower HRQoL for several domains and symptom scales of the EORTC QLQ-C30 and QLQ-BR23, and a strong association between high distress and lower resilience.

An exploration of the distribution of distress at baseline using alternative cut-offs is shown in Figure 8.

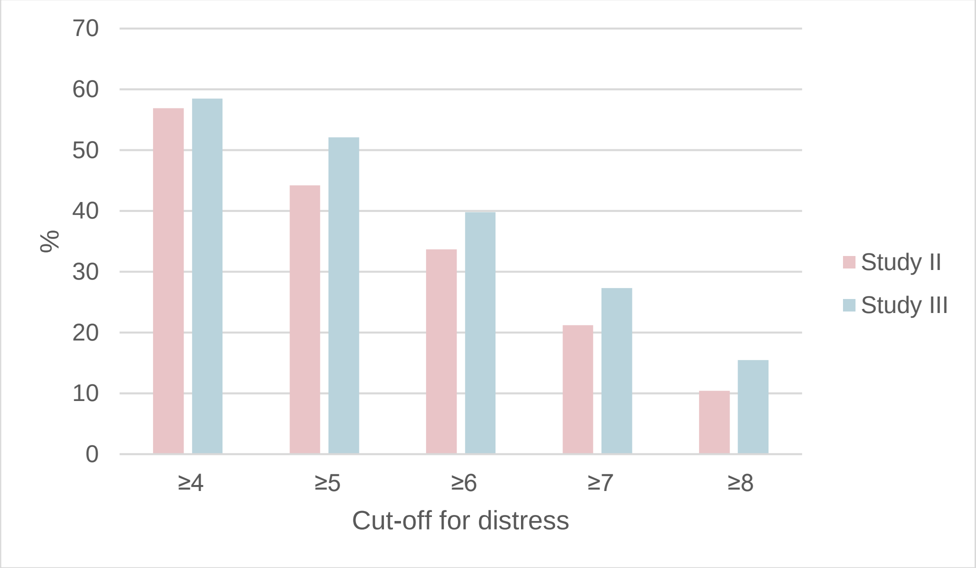


Figure 8. Exploring different cut-offs for distress at baseline, comparing results from Studies II and III.

Another perspective on early identification of needs was reflected by the overall theme in Study IV: Being an individual in a complex healthcare system. Experiences varied; some participants had having encountered a well-functioning healthcare system including both the medical and rehabilitation process, while others had not received support that met their individual needs. This emphasized the importance of identifying those in need of comprehensive individualized support to ensure timely rehabilitation. In Study I the lack of structures for systematic screening for needs, as well as different attitudes towards rehabilitation, were expressed as barriers to the patients' access to rehabilitation, even though early identification of needs was stated as important. On the basic level of rehabilitation, subjective assessments such as predictors (signs) of vulnerability were suggested as important for identifying needs, rather than instruments for routine screening. The suggested predictors varied, but could include factors such as age, social network, type of personality, or life situation. The result from Study III showing an association between high distress and demographic and clinical variables such as age, financial situation, and history of psychiatric disease suggests important factors to be aware of when assessing rehabilitation needs.

Participants in Study I who worked at the advanced level of rehabilitation often stated that patients were referred to them too late, and that systematic screening for needs could potentially improve this. Screening instruments were used at this level of rehabilitation, but not as a consistent routine. Overall, there were various opinions about the importance of adopting more structured screening procedures for rehabilitation needs; some HCPs saw this as an important and reliable way to identify needs, while others expressed concern that it would compromise the relationship between the HCP and the patient. The participants further stressed the importance of timing of support, since the system relied on the patient to contact healthcare when they needed support, and this could make early identification of needs difficult. The results of Study IV showed that if existing resources and structures for rehabilitation were aligned with individual needs, or if the women had the ability to communicate their need, this led to greater access to extended rehabilitation.

Prerequisites for individualized rehabilitation

When rehabilitation needs have been identified, the next step is to act upon them in a person-centered way to ensure individualized rehabilitation. The studies included in this thesis illuminate prerequisites for individualized rehabilitation from different perspectives. Studies I and IV explored the experiences of HCPs and patients, Study III investigated the complexity of factors associated with distress, and Study II examined the relevance of a DST by investigating the most frequently reported problems on the DT problem list.

The results of Study IV stress the importance of being valued and acknowledged as a person in the rehabilitation process, and of feeling safe. While facing a medical process that was often experienced as pre-determined and well planned, the rehabilitation process was sometimes experienced as unstructured and deprioritized. In order to feel secure and in control, the women considered it essential to be able to navigate the healthcare system, to receive relevant information, and to experience trust and continuity; and these things were experienced to varying degrees. The women with low distress at inclusion (OG) said that they had found the support they needed within the healthcare system, while the women with high distress at inclusion (IG/OG) often expressed extended needs.

Continuity was an important contributing factor to feeling acknowledged and known, and enabled individualized rehabilitation, but this also was experienced to varying degrees. In Study IV, women in the IG had the same nurse who followed them throughout the whole cancer process, independently of treatment regime, leading to a feeling that the nurse saw and knew them and their situation.

A woman from the CG described her feelings when this was not accomplished:

> *"...there was no continuity, so there were different doctors, different nurses, you know. And they had no idea who I was as a person. No, that's how I feel... [...] I think the feeling it might give, or gives… is that you're not... you know, you're not really included." (CG:1)*

The women also emphasized the need to know where to turn when problems or questions arose. Different roles and responsibilities of HCPs as well as structural gaps between specialties were expressed as confusing. If the women had limited knowledge of how to navigate these complexities, this could lead to uncertainty, lack of support, and increased needs.

In Study I, the HCPs discussed suboptimal collaboration both within and between specialties during cancer treatment, and described this as hindering a comprehensive rehabilitation process. HCPs who were experts in BC emphasized the importance of preparing the patients for potential problems by providing information in advance. In the absence of systematized approaches for providing rehabilitation, for example via a DST, patients received different support and advice depending on who the patient met, which indicates a lack of knowledge and consensus about timing and strategies for rehabilitation. Structures for team meetings on the basic level of rehabilitation, which could facilitate discussions of how to optimize rehabilitation for the individual person, were described as limited.

Study I also revealed a substantial hindrance to collaboration between levels of rehabilitation in terms of lack of knowledge of when, where, and how referral for higher levels of rehabilitation should be conducted. Overall, despite the extensive experience of the HCPs participating in this study, the lack of structures and routines for individualized rehabilitation led to medical indicators, such as treatment regime, becoming the driving factor for rehabilitation. This hindered cooperation across different levels of rehabilitation, and potentially hampered the individual woman's access to individualized rehabilitation.

The women in Study IV expressed a wish to return to their daily lives. Notably, the women in the OG highlighted their ability to achieve this within their own social networks and resources. In contrast, the women with high distress (IG/CG) experienced a journey that to a greater extent demanded individualized support based on their needs and individual situation. However, while women from the CG described gaps in the structures and unmet rehabilitation needs, those from the IG found the intervention and contact with the research nurse to be helpful in overcoming these barriers. For example, the proactive approach within the intervention enabled the women to receive navigation and advice customized to their unique situation throughout the follow-up year. A woman from the IG exemplified how basic exercise advice adjusted to her everyday life had helped her:

> *"Remove some of the 'musts', like, you don't have to, you can just... like you said, you could go out for a walk, just let it take time. [...] [The nurse] told me to try to be outside. Go out and walk the dog, do your... try to get going after these chemotherapy treatments. [...] But it actually helped. Up and out, even if I was a bit dizzy, it got much better when I was out walking, just walking. Out to my horses, taking care of them [...] It was good, it didn't get better by just lying on the couch." (IG:3)*

The participants in Study I emphasized the importance of preparing patients for potential problems and empowering them to call the nurses if needed. Even if the HCPs emphasized that a proactive approach to promote rehabilitation was fundamental, they also repeatedly described rehabilitation as being driven by the patient’s initiative. The experiences described in Study IV illuminate the potential consequences of this. Some women in the CG expressed a feeling of being left alone, and felt that they had to manage physical and psychological strains by themselves. Conversely, the proactive approach within the intervention, which included early identification of needs, provision of relevant information based on the situation, and support in navigating the healthcare system, supported the women in the IG and they expressed this proactive approach as a key component of their care. The women in the OG mostly expressed satisfaction with existing structures within the healthcare system.

Finally, the women in Study IV, regardless of group, expressed a need for follow-up beyond the period of active treatment. This need arose because the long-term side-effects and life adjustments to regain normalcy often required information and support to recognize the expected consequences and handle upcoming strain.

Discussion

Methodological considerations

In all research, the results must reflect the truth in order to contribute to and guide clinical practice (157). This thesis illuminates different perspectives on individualized rehabilitation, supported by both quantitative and qualitative methodologies, to enhance the understanding of prerequisites for screening-based individualized rehabilitation.

To understand the methodologies used, different approaches to discuss the results are required. For qualitative methodology in Studies I and IV, trustworthiness will be addressed by focusing on the well-established concepts of credibility, dependability, confirmability, and transferability (185). Studies II and III, both utilized a quantitative research design, and so the discussion will be guided by concepts such as validity and reliability (157, 186).

Trustworthiness

The degree of confidence that the researcher has in their qualitative data is assessed using the trustworthiness criteria of credibility, confirmability, dependability, and transferability. The central feature of trustworthiness is to confirm that the findings accurately reflect the experiences and viewpoints of the participants (157, 187).

Credibility

Credibility is concerned with confidence in the truth of the data and in the researchers' interpretations (157). This incorporates the relevance of the data collection, the analytical strategies, the study context, and the characteristics of the participants (185).

Focus group interviews for data collection are characterized by involving participants who possess certain traits and who are able to provide qualitative data through focused discussion that can then be used to understand the topic of interest (160). The group dynamic can lead to new insights that might not emerge in individual interviews, as experiences are mirrored against others. This was therefore considered to be a suitable data collection method in Studies I and IV.

One risk associated with focus groups is that dominant group members may influence the discussion topics, impeding some participants from having their voices heard and limiting the amount of truth generated from the interview. It is the researcher’s responsibility to ensure that all participants have the opportunity to speak during the interview. The decision to have two interviewers present in all interviews, one of whom had extensive experience with focus group interviews, ensured that all participants could contribute to the conversation and thereby increased the credibility.

Another criticism of focus group interviews is that they can be time-consuming and challenging to organize. In Study IV, last-minute cancellations meant that some interviews only included few participants. However, this might be expected when conducting research among people with health problems. In order to ensure credibility it was decided to conduct three additional interviews. Digital interviews might have reduced dropouts but would have entailed other risks, such as excluding individuals with limited knowledge of digital communication.

To further increase credibility, member checking (161) was conducted in both studies by having one interviewer summarize and present the identified issues to the participants for confirmation and clarification at the end of each interview.

Content analysis is a widely used method to analyze qualitative data, but has been questioned as being too standardized, leading to poorer quality than methods with a philosophical basis (188). Graneheim and Lundman (2004) discussed a number of concepts in qualitative content analysis to strengthen the validity and trustworthiness of the method (171), which were followed during the analyses in Studies I and IV. In a more recent article, Graneheim and Lundman (2020) divided the concepts into de-contextualization and re-contextualization, clarifying what really happens during the analysis. One risk during the de-contextualization is loss of context and meaning (174). In Study IV, two of the authors coded the text separately and agreed on the coding scheme, to ensure that important content remained during the analysis. A strength of both Study I and Study IV is the thorough description of the analytical process, and the fact that all authors were engaged in the analysis and agreed on the result.

The researchers involved in the studies came from different professions (research triangulation), each contributing unique perspectives and knowledge to the analysis (185).

The study context was relevant in relation to the aims of both studies. One limitation of Study I is that although a variety of professions and units participated, they were all part of the same university hospital. In Study I, key persons (unit managers) were involved in the recruitment process, potentially affecting the inclusion and exclusion of participants. In Study IV, the author of this thesis personally invited the participants, strengthening the trustworthiness of the recruitment process. Space triangulation (exploring the same phenomenon across multiple sites) and person triangulation (collecting data from different levels of people) (157) enhanced the credibility.

Participants were purposefully invited in both studies to achieve a variation in individual characteristics. Purposeful sampling is recommended when the intention is to recruit informants who are well-acquainted with the topic of interest (189). In Study I, various professions representing all three levels of the rehabilitation pyramid (basic, specialized, and advanced) were included in the interviews. This approach provided insights from a team perspective, although no conclusions can be drawn for individual professions. Study IV included participants from the different randomization groups (IG/CG/OG), of different ages, and with different-living situations, providing a broad range of experiences. Ensuring variation in the qualitative studies strengthened their credibility.

Dependability

Dependability refers to the stability of data over time (157, 185) and the possibility of the study being replicated with similar findings (185). The data in Study I were collected in 2016-2017 under the circumstances that characterized the organization at that time, while the data in Study IV were collected in 2022. To strengthen dependability, the procedures for data collection included a semi-structured interview guide to ensure that the interviews focused on the aim of the studies and that the different aspects were covered in all interviews. A thorough description of the context and the research process was provided in both studies to enhance dependability. Moreover, the involvement of co-authors during the process allowed for discussion related to changes over time. The content of the added interviews in Study IV did not differ from that of the initial interviews.

Confirmability

Confirmability refers to objectivity, and whether the result represents the experiences of the participants rather than being biased by the researchers' motivations or perspectives (157, 185, 187). Preunderstanding could be seen as a threat to confirmability, but has also been discussed as important and valuable in qualitative research (170). The preunderstanding of the authors was discussed repeatedly during the analysis in Studies I and IV. These discussions and the awareness among the researchers of the mix in experiences in BC care and rehabilitation ensured that the interpretation was grounded in the data (190). Both studies were strengthened by investigator triangulation, as at least two of the authors made decisions about the coding, analysis, and interpretation (157). Moreover, in both studies, quotations were used to exemplify the interpretation and support confirmability (157).

Transferability

Transferability refers to applicability, and whether the findings can be transferred to other settings (157, 185, 190). To enhance transferability of Studies I and IV, thorough descriptions of the context and the recruitment process were provided. The transferability was also increased by the consistency with results from other international studies, both within BC and for cancer diagnosis in general. A limitation is that only Swedish-speaking patients were invited in Study IV. In a multicultural society, knowledge of rehabilitation needs in all women diagnosed with BC is of the utmost importance to enable PCC. This demands further studies in this context to enable transferability of results across language and cultural boundaries.

Validity

Research aims to reach well-founded conclusions (186), and four concepts of validity are used to evaluate the methodology of a quantitative study: internal, external, construct, and statistical conclusion validity (157, 186). These concepts will guide the discussion of the validity of Studies II and III.

Internal validity

Internal validity refers to the extent to which an investigation makes alternative explanations of the results implausible. Within an investigation, the design is of utmost importance to ensure that the independent variable accounts for the results seen in the dependent variable (157, 186). The cross-sectional design of Study III precludes causal relationships between the dependent and independent variables. Still, a discussion of relevant threats to internal validity is important if factors outside a study are present that may affect the results.

A potential threat to the experience of distress at inclusion in Study III is *history*, which refers to any event occurring at the time of the study that may account for the results (186). Factors such as family crisis, change in jobs, or experience of illness other than BC could have contributed to the experienced level of distress on an individual level. The COVID-19 pandemic might have affected both self-reported distress and other self-reported data. This possibility is indicated by the fact that 44% reported distress levels of ≥5 in Study II (conducted before the pandemic) compared to 52% in Study III (conducted during the pandemic). However, future studies are needed to determine if the level of distress was indeed different during the pandemic. A strength is that Study II, that led to a change in cut-off for distress in this setting, was carried out before the COVID-19 pandemic.

Another potential threat is *instrumentation*, which refers to changes in the measuring instrument (186). The use of well-validated instruments for distress, HRQoL and resilience is therefore a strength of Studies II and III.

Attrition is an important concern in RCTs, and was therefore carefully explored in Study II. In this study, the CG did not complete participation to the same extent as the IG and OG. It is well known that attrition is a more common problem in control groups, possibly because they see no advantage in participating (157). A new power calculation was made based on these results, to ensure sufficient statistical power in the main RCT. This emphasizes the importance of feasibility testing to ensure internal validity in RCT studies.

External validity

External validity refers to whether the results can be generalized to other settings, populations, and circumstances (157, 186), and encompasses all dimensions of generality. Limitations in generality are referred to as threats to external validity.

Sample characteristics refer to whether the results can be generalized to other samples, including persons that might vary in age, ethnic background, gender, education, or any other characteristics (186). Studies II and III were both limited to Swedish-speaking persons. The setting for these studies is a multicultural society, and the exclusion of individuals not fluent in Swedish is a limitation. There is a need for future studies where language is not an exclusion criterion. Another limitation is that only women were included; however, since very few men are affected by BC, it would have been challenging to achieve statistically-significant conclusions when comparing results. A strength of the study is the multicenter design, as participants were included from both a university hospital and a county hospital.

Reactivity of assessment refers to the possibility of participants' responses being influenced by their knowing that they are being assessed (186). Most of the data in Study III were self-reported. Self-reported health data are valuable in research, but have limitations. Known risks include individuals giving socially desirable answers that are not completely true (social desirability), or intentionally trying to create a false-positive impression (fake good) (191). It is important to be aware of these possibilities.

Construct validity

This term refers to the extent to which the measure assesses the area of interest (186), how well the measure captures what it is intended to measure, and its usefulness in explaining the results (157). The design of the ReScreen study was based on screening for distress with the DT. The term "distress" has no direct equivalent in Swedish, and the instrument has been validated in Swedish cancer contexts using the English word "distress". Understanding this term was crucial for the study design.

To ensure understanding of the term "distress", before the start of the feasibility study approximately 50 patients were asked to complete the DT and reflect on its usefulness and their understanding of the concept. Neither in this pre-test nor during the inclusion in Study II was the understanding of the term identified as an issue. This aligns with previous research findings in a Swedish context, showing that the concept and definition of distress are well understood (34). Additionally, the findings from Study III, with associations between high distress and lower HRQoL, lower resilience, and poorer self-reported financial situation, indicate that the participants comprehended the meaning of “distress”. The DT has been further validated in numerous countries and contexts (37).

A strength of Study III was its use of well-validated instruments for distress, HRQoL, and resilience. Steiner and colleagues (2015) have stated that a study can only show the validity of an instrument in a certain context, among a certain group of people (191). The QLQ-C30 and QLQ-BR23 have been validated in several contexts, in cancer and in BC (41, 44, 167, 169). CD-RISC has good psychometric properties, and has been found to be suitable for use in research and clinical settings in Sweden (165).

Statistical conclusion validity

Statistical conclusion validity refers to whether the conclusions drawn from statistical analyses are reasonable, accurate, and reliable, based on adequate sampling procedures, appropriate statistical tests, and measurement procedures. A major strength of Study III was that the data were monitored by an external auditor. Another strength, concerning missing data, was that standard instructions from the EORTC were used when imputing data for the QLQ-C30 and QLQ-BR23 (168), and recommendations from the Connor Davidson website were used when imputing data for the CD-RISC (177).

Type I and II errors are critical threats that need to be addressed. A type I error occurs when a significant group difference is found but no actual group difference exists (186). This risk is associated with the p-value threshold, which was set to 0.05 in Study III. With this threshold, the risk of a false positive claim for a single test is 5% (180).

No p-values were adjusted for multiple testing in Study III. Conducting multiple tests increases the risk of a type I error (157). A Bonferroni correction can mitigate this risk, corresponding to a more conservative p-value threshold. However, the downside is that it tends to increase the risk of a type II error (157), where no statistically significant group difference is found even though an actual group difference exists (186). Since no adjustment for multiple testing was performed, the results of each test should be interpreted with caution.

Backward selection, or elimination, was used in order to develop a prediction model for high distress. Variable selection ultimately provides a balance between fit and simplicity (178). Backward elimination assesses the joint predictive ability of variables. The process starts with all variables being included in the model. Next, the variable with the highest p-value is removed and the model is refitted. This variable removal and refitting is then repeated until all variables pass a predefined p-value based criterion (179). One disadvantage is that once a variable is eliminated from the model, it is not re-entered. A variable dropped at an early stage of this process could have been significant in the final model (178). Backward selection with a p-value threshold for variable removal of 0.157 corresponds to minimization of the AIC, which takes into account both model fit and model complexity in order to minimize the risk of overfitting in prediction modeling (179).

The final prediction model for distress reached an AUC of 0.684, which has the following interpretation: if one patient with and one without distress are randomly drawn from the underlying population, then the model will assign a higher predicted probability of distress for the patient with distress with 68.4% probability.

Reliability

Reliability is concerned with consistency and the absence of variation when measuring an attribute for an individual (157). The HRQoL instruments used in this thesis were developed by the EORTC and have been psychometrically tested, showing good or moderate results for validity and reliability (41, 44). The core instrument (QLQ-C30) combined with the diagnosis-specific module (QLQ-BR23) allowed measuring both general and specific HRQoL. The EORTC instruments are commonly used within cancer and BC contexts, which enables comparison of results with other studies. When measuring resilience, the instrument developed by Connor and Davidson (2003) was used, which is a widely used scale to measure resilience. The instrument has shown good validity and reliability (162). The DT is extensively used worldwide (37), and has shown good validity and reliability in Swedish cancer contexts (34, 35).

One important aspect to consider regarding reliability is the internal consistency of the instrument, which refers to the extent to which items in an instrument are reliably measuring the critical attribute. Greater internal consistency is obtained when a set of items are highly intercorrelated (157). Internal consistency is often assessed using Cronbach’s alpha. Coefficients above 0.7 are generally regarded as acceptable, although values are often recommended to be above 0.8 (good), or even 0.9 (excellent) (40). In previous research investigating the reliability of the instruments used in this thesis, Cronbach’s alpha was 0.7 or higher for most of the scales within the instruments.

General discussion of results

The overall aim of this thesis was to investigate the prerequisites for screening-based individualized rehabilitation following primary BC diagnosis, treatment, and follow-up. The results highlight the importance of organizational structures for identifying needs, as well as knowledge and collaboration within and between different parts of the cancer trajectory to ensure prerequisites for individualized rehabilitation. The results also clearly show associations between high distress and several demographic and clinical variables, as well as lower HRQoL and resilience, all together indicating a great need for individualized rehabilitation. Cancer rehabilitation is a prioritized area in Swedish cancer care (47, 74, 122), with initiatives aiming to strengthen and improve access to rehabilitation for individuals with cancer. The results from this thesis have the potential to contribute to accomplishing this.

Screening for rehabilitation needs

When Study I took place, early screening for rehabilitation needs was not fully implemented in clinical practice, and the study identified both organizational and individual barriers among HCPs. Lack of structures was evident, and screening for needs with validated instruments was not applied routinely. Instead, HCPs often relied on their own ability to identify signs of vulnerability as an indicator of extended needs. Today there is an ongoing strategy on the national and regional levels to implement the NCRG, which includes screening for rehabilitation needs with validated instruments. However, in line with the findings from Studies I and IV, there still appear to be challenges in implementing these routines at the local level.

This issue has also been observed internationally, where the implementation of rehabilitation strategies articulated by policy bodies remains challenging (192). Previous research has shown several barriers to using screening tools, including both organizational issues such as insufficient implementation of structured needs assessments (193), and individual factors such as HCPs questioning the added value of these tools (140, 194). In Study I, screening was described as an improved and reliable way to identify needs, but also as a risk since a more structured approach might compromise the patient–HCP relationship. This result contrasts with earlier findings that validated screening instruments improve the relationship between the patient and the HCP (193). The lack of congruence in identifying rehabilitation needs may explain why rehabilitation often focuses on medical and treatment-related perspectives, as the structures for such actions are already well established within the medical process. While these structures are important, they need to be complemented to increase patients’ access to rehabilitation. Moreover, systematic screening for needs should be emphasized as a prerequisite for identifying individual rehabilitation requirements.

The DT is used worldwide, which provides robustness to the screening part of the ReScreen intervention. However, despite international studies indicating relevant cut-offs for distress to identify patients with extended needs, there is a lack of corresponding knowledge in the Swedish context. The decision to use the DT for screening in the ReScreen RCT was based on earlier promising results when using the DT in rehabilitation interventions for women with BC (152). The association between high distress and lower HRQoL in Study III indicates that screening for distress was relevant to identify persons with extended rehabilitation needs also in this context. The finding aligns with earlier research that concluded the DT to be effective in discriminating between high and low HRQoL (34, 195). This is crucial, since if a more vulnerable group of women can be identified early, resources can be allocated to those most in need of support and extended rehabilitation.

One particularly interesting result of this thesis is the variation in rehabilitation experience between the three groups (IG, CG, OG) in Study IV. The women with low distress before start of treatment (OG) expressed satisfaction and trust in the healthcare system (usual care) to a greater extent than the women with high distress. This finding may indicate that distress level before the start of treatment can be used to identify people in need of extended rehabilitation support. However, further investigation is warranted.

Individualized rehabilitation

Besides screening for rehabilitation needs, other factors are important to ensure individualized rehabilitation. Systematic screening for distress concerns the early identification of individuals who may require additional support, and needs to be followed by conversations with the patient to jointly develop a rehabilitation plan tailored to the patient’s needs and preferences. Feeling normal and being able to return to everyday life, repeatedly raised as important in Study IV, are core aspects of the goal of cancer rehabilitation (121, 122), and are frequently mentioned in research exploring the experience of women with BC. Although many women regain levels of QoL comparable to general populations, long-term issues such as hot flashes, sexual problems, pain, fatigue, cognitive difficulties, and sleep disturbance continue to affect many women years after BC treatment. Ongoing screening and support for such issues are essential for the return to normalcy (5, 196). This knowledge puts a focus on individualized rehabilitation that requires a comprehensive and holistic approach, and includes strains related to diagnosis and treatment, individual reactions, and what normal life represents for the individual woman.

According to Ekman and colleges (2011), a partnership with the patient is initiated through the narrative, which includes the personal account of the illness, related symptoms, and how these affect life in relation to the personal context (19). Shifting the focus from medical aspects to the individual needs and resources enables the person to share beliefs and values that need to be part of the individualized rehabilitation process. In Study IV the women's stories indicated individual prerequisites for recovery during the cancer trajectory, often influenced by factors such as social network and the individual attitudes and recourses in the cancer process. Research has repeatedly shown the need for an individualized rehabilitation approach that considers personal experiences and prerequisites (111, 197) to optimize rehabilitation. The opportunity for patients to share their narrative facilitates this process.

In Study III, several demographic and clinical variables were associated with distress, emphasizing the need to address factors potentially affecting the level of distress before start of treatment. The person's narrative, complemented with well-designed validated instruments, enables identification of these factors, and even though the majority are not modifiable by HCPs, it is important to recognize them to provide individualized support. This is an essential part of PCC, and means that HCPs must be attentive and flexible to the person's prerequisites when developing a rehabilitation plan.

The finding that a lower level of exercise before start of treatment was associated with high distress is important in this context. The well-known favorable effects of physical activity during and after BC treatment motivate the inclusion of exercise as an integral part of rehabilitation. However, evidence shows that it is challenging to maintain a physically active lifestyle during and after BC treatment (198). The importance of encouraging physical activity becomes even more evident and challenging if the initial level of exercise is low. Understanding individuals' experiences of facilitators and barriers to physical activity becomes crucial, especially since physical activity is often viewed as a means to return to or maintain normalcy (112, 198).

McCormack and McCance (2021) have underscored the need for competent HCPs who can navigate the contextual elements within the care environment, ensuring that the person's needs remain the focal point of all caring processes (17). The holistic and comprehensive assignment of the CNCC incorporates ingredients such as high-quality information, availability, and care coordination (75), all of which are factors that the women in Study IV expressed as important to facilitate their rehabilitation journey. They also emphasized the importance of feeling safe, which was closely related to the feeling of being recognized and known, as well as receiving relevant and individualized information. Continuity and pro-activity were factors expressed as facilitating, but the experience of having received them varied greatly. This might have been due to the fact that patients were expected to contact healthcare when problems arose, meaning that rehabilitation was driven by the patient’s initiative and not by healthcare.

Research has repeatedly emphasized that women with BC desire timely and individualized information during the cancer trajectory (90, 199, 200), as well as information about rehabilitation and available rehabilitation resources (201, 202). They seek assistance in navigating a fragmented healthcare system (71, 203), and desire continuity with the healthcare providers they encounter (71, 118, 141). These important areas are often reported in research as unmet needs of women with BC (147, 204), and the comprehensive and holistic approach that is demanded for support and rehabilitation seems to be challenging (204). The known challenge in implementing the role of the CNCC on the local level in Sweden (78) is possibly mirrored in the results of both Study I and Study IV. Even though the competence among HCPs was high, as were the intentions to provide individualized rehabilitation, the lack of structures hampered the patients’ access to rehabilitation. The components of the CNCC role description were incorporated into the structure of the ReScreen intervention. The results of Study IV clearly show that the IG appreciated receiving continuity, navigation, and individualized information. Furthermore, the findings indicate that this approach facilitated rehabilitation for the women in the IG.

One potential barrier in screening for needs, identified in previous research, is the HCPs’ ability to respond to the result of the screening (193, 205). This further highlights the importance of structures, not only to enable identification of needs, but also to provide HCPs with evidence-based tools showing how these needs can be met with effective rehabilitation actions. A key challenge identified in both Study I and Study IV was the suboptimal collaboration both within and between units during cancer treatment, which hindered a comprehensive rehabilitation process, including referral to specialized and advanced levels for rehabilitation. While HCPs were experts in breast cancer treatment and its expected side effects, emphasizing the importance of preparing patients for potential problems, the absence of structured rehabilitation pathways led to inconsistent support and advice.

Previous research has highlighted the difficulties in implementing cancer rehabilitation models that emphasize the importance of interdisciplinary teams. Barriers such as provider awareness, resource availability, and infrastructure needs have been identified (206). Another significant barrier is that the CNCC often changes during the cancer trajectory, because different specialties and CNCCs handle different treatment modalities (141). This affects continuity, one of the core aspects emphasized by the women in Study IV. Knowledge about whom to contact and how to do so is essential for the patient, and so common structures and recommendations for rehabilitation within and between specialties are crucial. A well-defined rehabilitation process is essential, encompassing both the expertise in rehabilitation itself and the organizational support for rehabilitation. This ensures that needs are accurately identified and addressed at the appropriate level of rehabilitation required.

The DST within the ReScreen intervention was developed on the basis of known problems in the context of BC, aiming to provide HCPs with a tool to facilitate rehabilitation actions based on best knowledge and evidence. In Study IV the research nurse followed the women in the IG throughout the follow-up year, independent of treatment regimen, and used the DST in the rehabilitation plan. The results indicate that this structure facilitated the patient's rehabilitation process.

In summary, establishing structures for screening is an essential prerequisite for individualized rehabilitation. It is also crucial to provide frameworks for HCPs to manage the screening results and address the underlying cause of distress, including effective support and rehabilitation on the level of rehabilitation that best support the individual's needs. The results from this thesis add important knowledge regarding how this can be accomplished, but further studies are needed to evaluate how the ReScreen intervention can contribute to and facilitate individuals access to the rehabilitation they need.

Strengths and limitations

Table 7. Summary of strength and limitations of the four studies

	Strengths	Limitations
Study I	• Focus group interviews conducted by experienced researchers. • Immediate member checking. • Participants varied in both profession and levels of rehabilitation.	• Only participants from hospital-based cancer rehabilitation, lacking perspectives from primary healthcare. • Only one physician and one psychologist participated
Study II	• Large number of participants for a feasibility and pilot study (N=85).	• Exclusion of women with relapse and those unable to communicate in Swedish.
Study III	• Comprehensive investigation allowed comparison of several predictors of distress. • Assessment time point close to diagnosis, a critical period known to be stressful. • Prospective design. • Large sample size (N=633). • Cut-off for distress based on feasibility study in the same context. • Procedures standardized according to published protocol. • Validated instruments. • Multicenter study.	• Cross-sectional design prevented exploration of causal relationships. • HRQoL, distress, resilience, living habits, and medication based on self-reported data. • Exclusion of women with relapse and those unable to communicate in Swedish.
Study IV	• Inductive and deductive design. • One experienced researcher present at each interview. • Immediate member checking. • Participants from all three groups (intervention, control, and observation).	• Only 30 of 96 invited persons participated. • Some focus groups smaller than recommended.

Conclusions

This thesis provides significant insights, new data, and a deeper understanding of the prerequisites for screening-based individualized rehabilitation in the initial phase of receiving a BC diagnosis. It emphasizes the importance of implementing structures that incorporate validated screening instruments and a person-centered approach for recovery and rehabilitation. A lack of such structures increases the risk of the BC trajectory becoming predominantly medically and treatment-driven, which can complicate and hinder rehabilitation tailored to individual needs. The following conclusions can be drawn from the studies:

- Lack of structures for rehabilitation, including referral for specialized or advanced rehabilitation, underscores the urgent need to implement such structures.
- Inconsistency in identifying and supporting women with extended needs may result in rehabilitation being dependent on the capacity and knowledge of individual HCPs rather than tailored to women's individual needs.
- The DT is a clinically useful tool for early identification of women with extended rehabilitation needs, and high distress is associated with lower HRQoL.
- It is crucial for HCPs to focus on modifiable lifestyle factors associated with high distress, such as exercise, at an early stage.
- Navigation, continuity, and individualized support are important throughout the rehabilitation process. When the needs of women receiving a BC diagnosis do not align with the resources offered by the healthcare system, a comprehensive, proactive, and person-centered approach to rehabilitation is essential.
- The feasibility study provided crucial knowledge that enhanced the conditions for conducting the ReScreen study in a stable and robust manner.

Future perspectives

Based on findings from the studies included in this thesis, future research should focus on:

- The effect of screening-based individualized rehabilitation on distress, HRQoL, resilience, healthcare consumption, sick leave, patient satisfaction with care, and health economic effects.
- Implementation of the NCRG in terms of screening for extended needs and the use of a DST. This should include exploring HCPs' experiences of using screening instruments as well as DSTs, and investigating the organizational structures needed to facilitate implementation. It is also important to continue exploring patient experiences of cancer rehabilitation.
- Interventions based on screening for rehabilitation needs and comprehensive individualized rehabilitation in various cancer contexts.
- Longitudinal studies to investigate how distress changes over time, and relationships between distress and demographic and clinical factors, to enable optimized support.
- Investigating the team perspective in cancer rehabilitation, and how needs can be identified to jointly support the patient throughout the cancer process.
- Exploring the experience of migrated women, who are often excluded from studies due to language barriers, to enable rehabilitation tailored to their needs and context.

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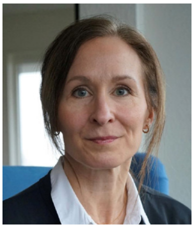

Ing-Marie Olsson is currently working as a contact nurse in cancer care at the Department of Surgery, Skåne University Hospital. In this thesis, the prerequisites for screening-based individualized rehabilitation following breast cancer diagnosis, treatment, and follow-up were investigated.

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