



Aalborg Universitet

AALBORG UNIVERSITY  
DENMARK

## Distress among women taking part in surgical continuity of care for breast cancer - a mixed methods study

Jørgensen, Lone

DOI (link to publication from Publisher):  
[10.5278/vbn.phd.med.00013](https://doi.org/10.5278/vbn.phd.med.00013)

Publication date:  
2015

Document Version  
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):  
Jørgensen, L. (2015). *Distress among women taking part in surgical continuity of care for breast cancer - a mixed methods study*. Aalborg Universitetsforlag. <https://doi.org/10.5278/vbn.phd.med.00013>

### General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

### Take down policy

If you believe that this document breaches copyright please contact us at [vbn@aub.aau.dk](mailto:vbn@aub.aau.dk) providing details, and we will remove access to the work immediately and investigate your claim.

**DISTRESS AMONG WOMEN TAKING  
PART IN SURGICAL CONTINUITY  
OF CARE FOR BREAST CANCER**

- A MIXED METHODS STUDY

**BY  
LONE JØRGENSEN**

DISSERTATION SUBMITTED 2015



**AALBORG UNIVERSITY**  
DENMARK

# **DISTRESS AMONG WOMEN TAKING PART IN SURGICAL CONTINUITY OF CARE FOR BREAST CANCER**

- A MIXED METHODS STUDY

by

Lone Jørgensen



**AALBORG UNIVERSITY**  
DENMARK

Dissertation submitted 2015

Thesis submitted: March 11, 2015

PhD supervisor: Associate Prof. Birgitte Schanz Laursen,  
Aalborg University Hospital and Aalborg University

Assistant PhD supervisor: Senior researcher Mette Søggard DVM, PhD  
Department of Clinical Epidemiology,  
Aarhus University Hospital, Aarhus

Senior consultant, DMSc Jens Peter Garne  
Department of Breast Surgery,  
Aalborg University Hospital, Aalborg

PhD committee: Dr. Preben Ulrich Pedersen  
Aalborg University

Dr. Elisabeth Elder  
Westmead Breast Cancer Institute, Australia

Dr. Kirsten Rode  
Stavanger University Hospital, Norway

PhD Series: Faculty of Medicine, Aalborg University

ISSN: 2246-1302  
ISBN: 978-87-7112-255-8

Published by:  
Aalborg University Press  
Skjernvej 4A, 2nd floor  
DK – 9220 Aalborg Ø  
Phone: +45 99407140  
aauf@forlag.aau.dk  
forlag.aau.dk

© Copyright: Lone Jørgensen

Printed in Denmark by Rosendahls, 2015



## CV

Lone Jørgensen became a nurse in 1991. She has a nursing background in urology, medical gastroenterology, and breast surgery. Within the field of breast cancer, she has been a committee member of the Danish National Board of Health with regard to the revision of a breast cancer package in 2011, and with regard to follow-up among patients with breast cancer in 2013. In 2010 she was nominated for the International Visitor Leadership Programme on “U.S. – European Public Health Issues: Medical Infrastructure, Treatment and Outreach by the United States Department of State Bureau of Educational and Cultural Affairs. She completed a Diploma of Health at University College, Northern Jutland in 2008, and a Supplementary Programme in Nursing at Metropolian University Collage, Herlev in 2009. In 2011, she graduated as a Master of Science in Nursing at Aarhus University, and was enrolled as a PhD student at Aalborg University in March 2012. Using mixed methods, her research focuses on distress among women taking part in surgical continuity of care for breast cancer. Her thesis has resulted in three publications. She has developed three questionnaires specifically for women who take part in surgical continuity of care for breast cancer and tailored to specific time points. These questionnaires were used to investigate the prevalence of distress at time of diagnosis, changes in distress during surgical continuity of care, and factors associated with distress. In addition, she has explored the experience of distress based on individual interviews.

## ENGLISH SUMMARY

Breast cancer is the most common cancer among women worldwide. The initial treatment is removal of the tumour, and the surrounding tissue or removal of the whole breast. The axillary is examined to stage the spread of the cancer, and if metastases are detected an axillary clearance is performed. A breast cancer diagnosis may lead to distress caused by, for example, anxiety, depression, pain, sleep difficulties, fatigue and/or altered body image. Studies have shown that distress can affect the person's quality of life and increase admission rates to hospitals, and ultimately adds costs to health care systems. Therefore, the purpose was to investigate the prevalence of distress at the time of diagnosis and distress evolution in surgical continuity of care. In addition, the aim was to determine predictors of distress and to examine the experience of distress in more depth.

The study has a mixed methods design with a sequential and convergent component. Initially three questionnaires were developed specific to women taking part in surgical continuity of care for breast cancer and tailored to specific time points. The Distress Thermometer was included in each questionnaire to measure the distress level. The items in the questionnaires should indicate factors that are important for distress. 1.079 women from 11 departments of breast surgery in Denmark were included in the survey. At the same time, individual interviews with 12 women from five departments were conducted to examine the experience of distress in more depth

The results showed that approximately two-thirds of the women experienced moderate to severe distress at the time of diagnosis. Mean distress score decreased slightly during surgical continuity of care, but the experience of distress and changes in distress varied widely among individual women as did the sources of distress. Several predictors of distress were identified. Time since diagnosis was a significant predictor of distress, and especially younger women experienced a higher degree of distress at the time of diagnosis compared to older women. On the other hand, among older women the degree of distress decreased less during surgical continuity of care compared to younger women. Women who did not feel able to handle difficult situations before the diagnosis of breast cancer were more distressed, compared to women who felt better in handling such situations. However, this did not seem to affect distress over time. In addition, having children living at home was a predictor for distress just as not feeling sexual attractive. Distress varied in the different hospitals, however only one hospital remained a predictor with regard to reduced distress. These results were further nuanced by the findings in the interview study, which indicated that women were living in a time full of anxiety. In addition, their identities as women and mothers were changed. To get a feeling of support in a very distressing period of time, it was of great importance to be treated as a person in a caring humanistic way, which involved the perspective of the life world of each woman.

# DANSK RESUMÉ

Brystkræft er den hyppigste kræftform hos kvinder i verden. I Danmark får hver niende danske kvinde diagnosen. Den initiale behandling er fjernelse af knuden og det omkringliggende væv eller fjernelse af brystet. Dertil hører undersøgelse af lymfekirtler i armhulen for at afgøre, om kræftknuden har spredt sig. Ved spredning fjernes alle lymfekirtler i armhulen. Kvinder med brystkræft oplever belastning som følge af eksempelvis angst, depression, smerter, søvnløshed, træthed og/eller ændret body image. Belastningen kan påvirke livskvaliteten og kan medføre en øget indlæggelsesfrekvens på hospital og dermed øge sundhedsvæsenets omkostninger. Derfor var formålet at undersøge prævalensen af belastning på diagnosetidspunktet og udviklingen af denne i det kirurgiske forløb for brystkræft. Desuden var det at bestemme prædiktorer for belastning samt udforske kvinders oplevelse af belastning mere dybdegående.

Studiet har et mixed method design med en sekventiel og konvergerende komponent. Indledningsvis blev der udviklet tre spørgeskemaer specifikt til kvinder i det kirurgiske forløb og til specifikke tidspunkter i forløbet. I spørgeskemaerne var inkluderet et belastningstermometer til måling af belastningsgrad. I det efterfølgende survey var der inkluderet 1079 kvinder fra 11 afdelinger i Danmark. Samtidig med spørgeskemaundersøgelsen blev der udført individuelle interview med 12 kvinder fra fem afdelinger for at udforske kvinders oplevelse af belastning yderligere.

Undersøgelsen viste, at to tredjedele af kvinderne oplevede moderat til svær belastning på diagnosetidspunktet. Samlet faldt den gennemsnitlige belastning kun lidt i det kirurgiske patientforløb, men oplevelsen af belastning og ændringer i belastning varierede fra kvinde til kvinde ligesom årsagerne til belastningen varierede.

Adskillelige prædiktorer havde betydning for belastning. Tiden siden diagnosen var en signifikant prædiktor og især yngre kvinder oplevede større belastning på diagnosetidspunktet end ældre kvinder. Derimod faldt belastningen mindre hos ældre kvinder i det kirurgiske forløb. Ikke uventet oplevede kvinder, som i forvejen havde svært ved at håndtere vanskelige situationer, en øget belastning på diagnosetidspunktet, men dette så ikke ud til at påvirke belastningen over tid. Endvidere var det en prædiktor at have hjemmeboende børn ligesom det ikke at føle sig sexuel attraktiv påvirkede belastningen. Undersøgelsen viste variation i belastning på de forskellige hospitaler, men kun et hospital forblev statistisk signifikant med hensyn til reduceret belastning. Disse resultater blev yderligere nuanceret i interviewundersøgelsen, som supplerede at kvinderne levede i en tid fuld af angst samtidig med at deres identitet som kvinde og mor var ændret. For at opleve en følelse af støtte i det kirurgiske forløb var det af stor betydning at blive behandlet som en person på en omsorgsfuld og human måde, der involverede den enkelte kvindes livsverden perspektiv.





# ACKNOWLEDGEMENTS

This PhD thesis is based on a mixed methods study that was carried out during my employment at the Department of Plastic- and Breast Surgery at Aalborg University Hospital. A special thanks to Jens Peter Garne and Hanne Hartmann for encouraging and supporting this study in the first instance.

This work was possible thanks to a number of people. First and foremost, I wish to acknowledge all participants, who willingly took time to participate in the survey and shared their experiences of distress in the individual interviews. I also wish to thank the nursing staff at the participating departments for their commitment to distributing and collecting the questionnaires. Furthermore, I want to acknowledge the health professionals who contributed with input and comments on the questionnaires. Additionally, I want to thank my colleagues at the Department of Breast Surgery for participating in the focus group interview.

I am indebted to my supervisor Birgitte Schantz Laursen and, my assistant supervisors Mette Sjøgaard and Jens Peter Garne, who have continuously and positively supported me throughout the study. I am very thankful for our collaboration during this process.

I am grateful to my fellow students, especially Jane Andreasen, Mona Kyndi and Birgith Pedersen for many valued discussions.

Finally, my warmest and greatest thanks to my family, especially my husband Søren for his continuous and immeasurable support, and patience during this project.

This study was financed by the Department of Breast Surgery, Aalborg University Hospital, and financially supported by Region Nordjyllands Sundhedsvidenskabelige Forskningsfond, Afdelingen for Universitetshospitalsanliggender, Søster Marie Dalgaards Foundation, The Family Foundation of Obel, and Aalborg University, the Danish Nursing Council, and the Clinical Nursing Research Unit, Aalborg University Hospital

Lone Jørgensen, March 2015

## LIST OF PUBLICATIONS

1. Development of a questionnaire encompassing indicators of distress: A tool for use with women in surgical continuity of care for breast cancer.

Lone Jørgensen, Jens Peter Garne, Mette Sjøgaard  
and Birgitte Schantz Laursen

European Journal of Oncology Nursing (In press, 2014)

2. Prevalence and predictors of distress in women taking part in surgical continuity of care for breast cancer: A cohort study.

Lone Jørgensen, Jens Peter Garne, Birgitte Schantz Laursen, Kerry Sherman  
and Mette Sjøgaard

It has been submitted to European Journal of Oncology Nursing

3. The experience of distress in relation to surgical treatment and care for breast cancer: an interview study.

Lone Jørgensen, Jens Peter Garne, Mette Sjøgaard  
and Birgitte Schantz Laursen

It has been accepted for publication, subject to minor amendments, in the European Journal of Oncology Nursing.

# FIGURES AND TABLES

## FIGURES

Figure 1: Overview of the mixed methods design

Figure 2: Conceptual model for distress

Figure 3: Overview of the steps in the development of the distress questionnaires

Figure 4: An overview of the research process in study I

Figure 5: Illustration of womens distress evolution in surgical continuity of care

## TABLES

Table 1: An overview of publications on distress in connection with surgical continuity of care for breast cancer

Table 2: Characteristics of the participants in proportion to distress at the time of diagnosis

Table 3: Predictors of distress at different time points in surgical continuity of care

Table 4: Examples of structural analysis



# TABLES OF CONTENTS

<b>CHAPTER 1. INTRODUCTION</b> .....	15
1.1. Epidemiology of breast cancer .....	15
1.2. Consequences of breast cancer .....	15
1.3. A definition of distress .....	16
1.4. Surgical continuity of care for breast cancer .....	16
1.4.1. Entering surgical continuity of care .....	16
1.4.2. Cancer package for breast cancer.....	17
1.4.3. Accelerated continuity of care .....	17
1.5. Primary treatment for breast cancer .....	17
<b>CHAPTER 2. BACKGROUND</b> .....	19
2.1. Literature review .....	19
2.2. Summary of literature review .....	23
2.3. Applied measurement tools.....	23
2.3.1. Visual Analogue Scale (VAS).....	23
2.3.2. The Hospital Anxiety and Depression Scale (HADS) .....	24
2.3.3. Brief Symptom Inventory 18 (BSI-18) .....	24
2.3.4. The Distress Thermometer (DT) .....	24
2.3.5. The Profile of Mood States (POMS).....	24
2.3.6. Impact of Event Scale (IES-Intrusion).....	25
2.4. Measurement time points .....	25
2.5. Factors associated with distress .....	25
2.6. Recruitment sites .....	26
2.7. Rationale for this research.....	26
2.8. Purpose of this research .....	27
<b>CHAPTER 3. RESEARCH METHODOLOGY</b> .....	28
3.1. Mixed methods design .....	28
3.2. Pragmatism.....	29
<b>CHAPTER 4. STUDY I</b> .....	31
4.1. The construct and the underlying relationship.....	31
4.2. Data collection.....	32
4.3. Systematic literature review .....	32
4.4. Focus group interview.....	33
4.5. Questionnaire development .....	34
4.6. The Distress thermometer .....	35
4.7. Pilot test .....	35
4.8. Results.....	35

<b>CHAPTER 5. STUDY II</b> .....	37
5.1. Data collection.....	37
5.2. Statistical analyses.....	37
5.3. Results.....	38
5.3.1. Respondents.....	38
5.3.2. Prevalence of distress at time of diagnosis .....	38
5.3.3. Change of distress during surgical continuity of care.....	41
5.3.4. Predictors of distress.....	41
<b>CHAPTER 6. STUDY III</b> .....	45
6.1. Methodology .....	45
6.1.1. Interviews .....	45
6.2. Data collection.....	45
6.3. Transcription.....	46
6.4. Data analyses and interpretation.....	46
6.5. Findings .....	47
6.5.1. Naive reading .....	47
6.5.2. Structural analysis.....	47
6.5.3. Critical analysis and discussion .....	50
6.5.3.1 A time of anxiety.....	50
6.5.3.2 Loss of identities .....	52
6.5.3.3 To be treated as a person.....	53
6.5.3.4 To be part of a system .....	55
6.6. Ethical considerations .....	56
<b>CHAPTER 7. DISCUSSION</b> .....	57
7.1. Discussion of findings.....	57
7.1.1. Prevalence of distress .....	57
7.1.2. Change in distress .....	58
7.1.3. Factors associated with distress.....	59
7.2. Discussion of research process, design and methods .....	61
7.2.1. Studying own area .....	61
7.2.2. Mixed methods.....	62
7.2.3. Study I .....	63
7.2.4. Study II .....	66
7.2.5. Study III .....	67
<b>CHAPTER 8. CONCLUSION</b> .....	69
<b>CHAPTER 9. PERSPECTIVE</b> .....	70
<b>LITERATURE LIST</b> .....	71
<b>APPENDICES</b> .....	80







# CHAPTER 1. INTRODUCTION

A breast cancer diagnosis can have far-reaching consequences and may cause significant distress for women who suffer from this illness. The initial treatment of breast cancer is usually surgery. This thesis deals with distress in women taking part in surgical continuity of care for breast cancer.

## 1.1. EPIDEMIOLOGY OF BREAST CANCER

Worldwide, breast cancer is the second most common cancer and, by far the most frequent cancer affecting women with an estimated 1.67 million new cases in 2012. Since 2008 the incidence of breast cancer has increased by more than 20%, and mortality by 14 %, which makes it the most common cause of cancer death among women, with 522.000 deaths in 2012 (1).

In Denmark one in every nine women will be diagnosed with breast cancer during her life time, corresponding to 4.721 women in 2013 (2). In Denmark approximately 52.100 women are living with a history of treated breast cancer, and this number is expected to increase due to increasing life expectancy and improved surgical and medical therapies (3,4). In addition, the mammography screening programme has increased the possibility that breast cancer is diagnosed at an earlier stage and thus reduces the risk of dying from this illness (5). Early detection and treatment options are considered the most promising approaches to reducing breast cancer mortality and have increased the five-year age-standardised survival rate for breast cancer in Denmark from 84 % (95 % confidence interval [CI]: 83; 85) in 2007 - 2009 to 85 % (95% CI: 84; 87) in 2010 - 2012 (6).

## 1.2. CONSEQUENCES OF BREAST CANCER

The improvements in breast cancer detection and treatment may be associated with a prolonged period of living with the consequences of breast cancer. These consequences are manifold and vary within individuals. Some of the most cited are fear of dying (7), and recurrence (8,9), sleep difficulty (10), fatigue (11,12), pain (13), affected sexuality (14), cognitive functions (11,15), depression (16) and anxiety (17,18), altered body image (19), and lymphedema (20). These consequences may cause distress at some point during the cancer trajectory (21). Overall, distress has been linked to suffering, reduced quality of life, poor compliance with treatment, dissatisfaction with care, additional visits to emergency sites and increased hospitalisation (22). Apart from limiting the outcome of cancer therapy and affecting quality of life, distress may ultimately add costs to health care systems (23).

### **1.3. A DEFINITION OF DISTRESS**

The definition of distress is often implicit and rarely explicitly defined. The absence of a general definition has led to a divergence of conceptual and operational definitions (24). Often, anxiety and depression appear to be ranked alongside distress, because no universal definition exists. However, distress is recognized as a much broader concept than anxiety and depression. In this study distress refers to the experience affected by the consequences of a breast cancer diagnosis and surgical treatment. It is defined as “A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling as depression, anxiety, panic, social isolation and existential and spiritual crisis” (21). Rather than a single physical or emotional experience, distress can be multifactorial in etiology and may represent physical, social, and emotional components (25). This definition is widely cited and is based on consensus of a broad member panel from The National Comprehensive Cancer Network (NCCN), which comprises a variety of specialties from 19 cancer centers. Prevalence rates of distress in populations with breast cancer differ both between and within research studies depending on the applied definition of distress, measurement tools and time of measurement. Distress is recognized to likely differ at different key points during the cancer trajectory. These key points are the time of diagnosis, during initial treatment and following treatment, and times of changes in disease status (21,26).

### **1.4. SURGICAL CONTINUITY OF CARE FOR BREAST CANCER**

#### **1.4.1. ENTERING SURGICAL CONTINUITY OF CARE**

Surgical continuity of care is defined as the time period from diagnosis to the start of adjuvant treatment or follow-up. The Danish Healthcare System offers free tax-supported medical care. Overall, there are two different ways for a woman to enter continuity of care for breast cancer – either via the national mammography screening programme or via her general practitioner. Mammography screening is offered to asymptomatic women in the age group of 50-69 years and consists of a standardized breast x-ray examination at predetermined intervals. Screening by mammography has the potential to identify breast cancer at an earlier stage and thereby increases the likelihood for survival (27). If a woman discovers a lump or changes in her breast her general practitioner can refer her to a department of radiology for a mammogram and/or ultra sound. If there is suspicion of breast cancer the woman is referred to a surgical department of breast cancer and takes part in the cancer package for breast cancer.

### **1.4.2. CANCER PACKAGE FOR BREAST CANCER**

In 2007 an agreement between the Danish Government and The Danish Regions induced that all patients with cancer should enter into continuity of care without any unnecessary waiting time but with acute action and a clear message. A cancer package is part of such continuity of care, where the different steps are planned as content-defined time points based on pre-booked procedure. The intention of the cancer package is to make patients experience a well-planned, holistic and professional course without unnecessary waiting time in relation to diagnosing, initial treatment, adjuvant treatment, rehabilitation and palliative care (28).

### **1.4.3. ACCELERATED CONTINUITY OF CARE**

Limited financial resources in the health care system and better surgical treatment options have led to accelerated continuity of care for women with breast cancer. The length of hospital stays in surgical departments has been reduced to a great extent and replaced by treatment and care on an outpatient basis. In an English hospital, more than 80 % of patients undergoing non-reconstructive breast surgery were discharged safely within 23 hours (29). In a Danish hospital the mean length of stay decreased from 3.6 days before introduction of accelerated continuity of care to 1.2 days after implementation. The largest decrease was seen among patients having mastectomy where the length of stay was reduced from 5.0 to 1.6 days (30). The number of days that patients are hospitalised has increasingly become a criterion when assessing how well the health care system functions: departments with short stays are assessed as both good and productive, not just economically but also from a medical perspective (31-34).

## **1.5. PRIMARY TREATMENT FOR BREAST CANCER**

Surgery is an essential part of all current treatment to cure breast cancer. The primary treatment is mastectomy (removal of the breast) or lumpectomy (removal of the tumour and the surrounding tissue) depending on the tumour size, location, histological type, multi-centricity and options for postoperative radiation therapy (35). Lumpectomy can be performed if an acceptable cosmetic result and free margins can be achieved. If these preconditions are not met at the primary operation, a second operation is recommended. If it is not possible to achieve free margins a mastectomy is suggested. If a lumpectomy is possible and performed it is followed by radiotherapy to the rest of the breast to compare this surgical method with the method of mastectomy with regard to survival (36). If the tumour size, location of the tumour or other conditions suggests that a satisfactory cosmetic result cannot be achieved by a conventional lumpectomy, oncoplastic techniques such as volume displacement, volume reduction or volume replacement should be

considered. Oncoplastic surgery can be performed with the same oncological security as conventional lumpectomy and mastectomy (36).

The axillary needs to be examined to stage the spread of the cancer (36). If the axillary lymph nodes are without detectable metastases, a sentinel node<sup>1</sup> procedure is standard. When metastatic lymph node(s) are detected preoperatively an axillary clearance is recommended (36). If the metastases are not detected preoperatively an axillary clearance is recommended either during the primary operation or a second operation.

In summary, breast cancer diagnosis and treatment can have tremendous consequences, which may cause varying degrees of distress. Prevalence rates of distress differ depending on the applied definition of distress, various measurement tools, and timing of the measurement. Divergence in definitions has resulted in use of different measurement tools. Various measurement times are used during the cancer trajectory even though some key points are recognised. Increased levels of distress may lead to limited outcome of cancer therapy, impact the person's quality of life and ultimately adds costs to the health care system. Therefore, it is necessary to focus on distress in surgical continuity of care.

---

<sup>1</sup> The sentinel node is the first lymph node to receive lymphatic drainage from the tumour.

# CHAPTER 2. BACKGROUND

## 2.1. LITERATURE REVIEW

Existing knowledge on the topic “distress among women taking part in surgical continuity of care for breast cancer” was collected through repeated literature searches on a regular basis with support from a research librarian at the Medical Library at “Forskningens Hus”, Aalborg University Hospital. Primarily, the databases PubMed, Embase, Cinahl and PsycINFO were scrutinised for evidence based literature using key terms such as breast neoplasm(s), breast cancer, distress, depression, anxiety, quality of life, surgery, continuity of care and, stress. Furthermore, articles were examined for any additional references. Also, internet searches for reports, theses and books were conducted. The literature review revealed that the existence of distress overall in the trajectory of breast cancer has been widely documented in terms of for example anxiety and depression, fear of recurrence, fatigue, concern and survivorship. However, the literature is sparse with regard to distress specific in surgical continuity of care. Table 1 lists studies on distress among women taking part in surgical continuity of care for breast cancer with at least one measurement during that time point.

Table 1: An overview of publications on distress in connection with surgical continuity of care for breast cancer.

Author, year and country	Aims	Methods	Results
Montgomery& Bovbjerg (2004) (USA)	To examine the contribution of pre-surgery response expectancies and distress to breast cancer surgical patients' postsurgery pain, nausea, fatigue, and general discomfort.	In one hospital 63 women scheduled for breast cancer surgery completed VAS (visual analogue scale) measures of acute distress and expectations of postsurgery pain, nausea, fatigue, and discomfort. Patients having mastectomy were excluded.	The mean presurgery distress score was 56.4. Presurgery distress added to postsurgery nausea, fatigue and discomfort and specific presurgery expectancies contributed to pain intensity, pain unpleasantness, and fatigue.
Hegel et al. (2006) (USA)	To assess clinically significant emotional distress, psychiatric	Distress was measured before surgery among 236 women. The Distress Thermometer (DT)	The mean distress score was 4.8 (SD 2.6) with 41% rating themselves > 5 on the DT. The most common cause was emotional distress (100%). This

	<p>syndromes and substance abuse among women with newly diagnosed breast cancer.</p>	<p>with a cut-off point of &gt; 5 and an accompanying problem list were used. The Patient Health Questionnaire measured depression, panic disorder, and generalized anxiety disorder. The Nine Symptom Depression Scale measured depression. A four item Primary Care Post Traumatic Stress Disorder (PTSD) Screen was used to measure PTSD and a history prior to cancer was measured according to two questions. Also, patients were asked about their tobacco and alcohol use.</p>	<p>included worry (89%, fear (82%), nervousness (78%), sadness (61%), and depression (50%). Emotional distress was also related to uncertainty about treatment (96%), physical symptoms (81%), practical life problems (63%), family problems (52%) and spiritual crises (9%). Depression was the most prevalent diagnosis related to psychiatric disorders (n=25) (11%).</p>
<p>McCorry et al. (2012) (Ireland)</p>	<p>To clarify the relationship between illness perceptions, coping and psychological distress (anxiety and depression) and to investigate whether illness perceptions and coping predict psychological distress</p>	<p>The Hospital Anxiety and Depression Scale (HADS) was used among 72 women for one-two weeks following a diagnosis of breast cancer and six month after. A score of <math>\geq 8</math> indicated problematic levels of distress. The Illness Perceptions Questionnaire-Revised was used to evaluate illness cognitions. The Cancer Coping Questionnaire was used to assess coping.</p>	<p>Shortly after diagnosis the mean HADS anxiety score was 8.67 (SD 4.84) and the mean HADS depression score was 4.01 (SD 4.21). The authors identified a particular pattern of illness cognition that was associated with lower levels of distress. The women reported lower levels of distress when they believed in an effective treatment, that the disease would not have serious consequences, and when they did not have particular strong opinions about the cause of the disease.</p>
<p>Andreu et al. (2012) (Spain)</p>	<p>To explore the prevalence and evolution of psychological distress among non-metastatic breast cancer patients. To explore whether demographic and</p>	<p>In an outpatient clinic The Brief Symptom Inventory 18 (BSI-18) was used to measure distress among 102 non-metastatic women at four points in times: preliminary diagnosis, between two-seven days after</p>	<p>The results indicated significant differences in distress from 25 % at the time of diagnosis to approximately 17 %. No relation between distress and demographic and medical factors was found. However, psychosocial aspects were identified as significant risk factors of distress.</p>

	<p>medical and personal characteristics were predictors of distress.</p>	<p>surgery, the final results based on pathology and during the third or fourth chemotherapy. A self-report form developed for the study was used to collect socio-demographic data.</p>	<p>Helplessness/hopelessness, anxious preoccupation, cognitive avoidance and fatalism were positively related to distress, whereas fighting spirit and perceived social support showed to have a protective role</p>
<p>Iwatani et al. (2013) (Japan)</p>	<p>To measure the proportion of women with psychological distress during breast cancer diagnosis and to identify predictors of distress related to the diagnostic process.</p>	<p>The HADS was used during pre-medical consultation, after radiological examination and after explaining pathological results in 222 women of which 35 had breast cancer. A cut-off score of <math>\geq 10</math> was applied. To identify predictors of distress the questionnaires: Functional Assessment of Cancer Therapy – Breast (FACT-B) and Functional Assessment of Chronic Illness Therapy – Spiritual subscale (FACIT-sp) were used.</p>	<p>11 women (31.4%) had a score <math>\leq 10</math> and 24 (68.6%) had a score <math>\geq 11</math>. The results indicated that breast cancer patients with large tumors were at higher risk of developing distress (HADS anxiety: odds ratio = 1.97 [CI 95% 1.27; 3.05] p-value = 0.003 and tumour stage: odds ratio = 3.31 [CI 95% 1.03;9.5] p-value = 0.04)</p>
<p>Costa-Reguena et al. (2012) (Spain)</p>	<p>To assess quality of life and psychological distress after diagnosis, during treatment and at the end of treatment and to detect the influence of psychological distress on quality of life at these time points</p>	<p>Psychological distress was assessed using the HADS with a cut-off score of <math>\geq 10</math>. In anxiety symptomatology, the cut-off score was 8, while a cut-off score <math>\geq 4</math> indicated depressive symptomatology. Distress was assessed: one week before surgery, in the middle of oncology treatment and 1 month after end of treatment. The Karnofsky Performance Scale measured physical disability and the</p>	<p>At the pretreatment point 51.6% (n=32) exceeded the clinically significant score of total HADS. They found that psychological distress had a negative impact on quality of life and accounted for 51.3 % of the variance in quality of life before treatment whereas scores during treatment, whereas scores during treatment were equal to <math>&gt; 10</math> for 47.4% (n = 27) of the women. The average score of depression did not reach a significant cut-off score. The level of the average score of anxiety at the pretreatment point was probably (51.6% n = 32).</p>

		Functional Assessment of Cancer Therapy-Breast (FACT-B) quality of life.	
<p>Agarwal et al (2013) (Germany)</p>	<p>To identify clinical and epidemiological factors that were associated with an increased likelihood of an elevated DT score</p>	<p>Distress was measured by the DT and an accompanying problem list of 229 women at the initial visit for breast cancer in one site. The women were divided into five groups depending on the time since diagnosis. The checklist included common emotional, family, physical, practical and spiritual concerns. A cut-off score of <math>\geq 4</math> indicated distress whereas a cut-off score <math>\geq 7</math> indicated extreme distress/depression. Information on patient characteristics, estrogen and progesterone status, stage of cancer and recurrence was obtained.</p>	<p>The odds of having a score <math>\geq 4</math> or <math>\geq 7</math> within the first 30 days of diagnosis were 1.00 for both of the scores. It was demonstrated that the likelihood of reporting an elevated DT score was highest within the first 30 days after receiving a diagnosis of breast cancer. The variables associated with a DT score <math>\geq 4</math> within the first 30 days of diagnosis were emotional concern (OR = 2.92, CI: 1.51; 5.65) and physical concern (OR = 2.40, CI: 1.40; 4.13). Also, the variables associated with a DT score of <math>\geq 7</math> within the first 30 days of diagnosis also included emotional concern (OR = 1.71, CI: 1.10; 2.64) and physical concern (OR = 1.51, CI: 1.07; 2.13). However, a multivariate model predicted that those patients whose score was registered at a later point during the 30 days period had decreased odds of reporting a score of <math>\geq 7</math> (OR = 0.89, CI: 1.01; 14.97)</p>
<p>Miller et al. (2014) (USA)</p>	<p>To compare body image of older and younger women facing breast cancer surgery. To compare pre surgical emotional distress among younger and older women respectively, and to examine whether age moderates the relationship between body image and presurgery emotional distress.</p>	<p>On the day of surgery (prior to surgery) 40 patients aged <math>&gt; 65</math> and 40 patients <math>&lt; 65</math> completed the FACT-B body image items, the SV-POMS, the IES-Intrusion scale and the VAS emotional upset item. Demographic data were assessed via a self-report questionnaire five days before surgery.</p>	<p>Women <math>\geq 65</math> had a general distress mean score of 29.08 (SD 27.31) and women <math>\leq 65</math> had a mean score of 53.48 (SD 48). The results indicated that the relationship between body image and pre-surgery emotional distress differed between the two age groups. Younger women with poor body image experienced heightened distress, while distress related to body image was no significant among older women.</p>



Mertz et al. (2012) (Denmark)	To determine the prevalence of distress and to investigate the related problems and characteristics of women with breast cancer who experienced psychological distress at the time of diagnosis	A Danish version of the DT and a problem list were applied among 343 women. The problem list consisted of 35 items with dichotomous responses (yes/no) addressing problems relating to practical, family, social, emotional, spiritual and physical domains. Also, items on socio-demographical data were completed. Cut-off scores of 3 and 7 were used.	The mean psychological distress score was 5.4 (SD 3.1) The results indicated that 77 % were distressed at the time of diagnosis with a cut-off score of 3 and 43 % when it was 7. The most frequent factors associated with distress were worry (77 %), nervousness (71%), sleep disturbance (50%), fatigue (49%), sadness (45%), fear (40%) and, memory or concentration problems (42%). Higher age was significantly associated with lower distress. The odds ratio was 0.96 per year (95% CI: 0.93; 0.98) using a cut-off point of 3 and 0.97 per year (95% CI: 0.95, 0.99) using a cut-off points at 7.
-------------------------------	---	---	---

## 2.2. SUMMARY OF LITERATURE REVIEW

As evidenced in the literature review, the prevalence of distress and the association of selected factors with distress in connection with surgical continuity of care for breast cancer have been measured. These studies have provided important knowledge, although they are not conclusive, which may be due to the use of different measurement tools and methods, cut-off points, measurement times, and inclusion or exclusion of specific characteristics of participants. The inconsistencies may also be a result of unclear or various definitions of distress. Different measurement tools yields results that are incomparable (37). Common for the scales identified through the literature review is that they are generic and not specific for measuring distress among women taking part in surgical continuity of care for breast cancer. Below follows short descriptions of a range of the most common scales found to measure distress.

## 2.3. APPLIED MEASUREMENT TOOLS

### 2.3.1. VISUAL ANALOGUE SCALE (VAS)

VAS measures a characteristic or attitude that can not be measured directly, but is believed to range across a continuum of values. VAS is a vertical or horizontal line of 100 mm in length (38). It was used as a response option to measure acute distress and expectations of postsurgery pain, nausea, fatigue, and discomfort (39) or as an emotional upset item (40).

### **2.3.2. THE HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)**

The HADS is a 14-item scale that has been well validated in several populations. Each item is rated on a 4-point scale from 0-3. The HADS assesses two specific psychological factors, which is depression and anxiety (41). Cut-off scores reported for the HADS vary (26). McCorry et al. (42) used  $\geq 8$ , whereas Costa-Requena et al. (43) and Iwatani et al. (44) both used  $\geq 10$ . Besides, Costa-Requena et al. (43) utilised cut-off scores specifically for anxiety ( $\geq 8$ ) and depression ( $\geq 4$ ).

### **2.3.3. BRIEF SYMPTOM INVENTORY 18 (BSI-18)**

The BSI-18 was developed from its longer parent instrument containing 53 items selected to reflect the 9 primarily symptom dimensions of the BCL-90-R, which was first developed. Originally, it was developed to assess the psychological symptom status of psychiatric and medical patients, as well as non-patients (45). The BSI-18 consists of 18 items that are rated on a 5-point Likert scale. It yields a global score (General Severity Index) and three subscale scores related to somatisation, depression and anxiety. Individuals with a *T*- score higher than 63 in general distress or at least in two of the subscales are considered cases of distress (46).

### **2.3.4. THE DISTRESS THERMOMETER (DT)**

The DT is a single item measurement tool that consists of a scale from 0 (no distress) to 10 (extreme distress) (47). The DT performs best in relation to distress (48) and has been validated in a Danish context (49). The DT is often used in combination with a problem list of 35 problems related to practical, family, emotional, spiritual and physical domains. However, the studies from the literature review showed inconsistencies with regard to the number of items used. Mertz et al. (50) used 35 items and Agarwal et al. (51) used 20 items in the existing categories, whereas Hegel et al. (52) included an additional category. The answers on the problem list are dichotomous with yes/no and do not explore the extent of distress. With regard to the DT, the literature review revealed that different cut-off scores were used, respectively  $>5$  (52),  $\geq 3$  and  $\geq 7$  (50), and  $\geq 4$  and  $\geq 7$  (51).

### **2.3.5. THE PROFILE OF MOOD STATES (POMS)**

The POMS assesses transient and fluctuation moods, and enduring states of affects. It consists of seven subscales: Anger-Hostility, Confusion-Bewilderment, Depression-Dejection, Fatigue-Inertia, Tension-Anxiety, Vigor-Activity and Friendliness. A short version consisting of 37 items was used to measure distress among breast cancer patients (40).

### **2.3.6. IMPACT OF EVENT SCALE (IES-INTRUSION)**

For more than 20 years this scale has been used to measure stress reactions after traumatic events. Originally, it was created for the study of bereaved persons, but was also widely used to explore the psychological impact of a variety of traumas (53). This seven item scale was used to measure surgery specific distress on a four-point Likert scale ranging from “not at all” to “often” (40).

### **2.4. MEASUREMENT TIME POINTS**

Distress has been measured at different time points during surgical continuity of care, which may, to some extent, explain the differences in prevalence of distress among the studies. Distress was primarily measured prior to surgery (39,40,42-44,46,50-52) or at several time points in addition to surgical continuity of care, but only one measurement time point was in surgical continuity of care (42-44). One study measured distress at three time points during surgical continuity of care. These time points were assumed to cover peaks in distress during surgical continuity of care (46). Questionnaires that are not developed to specifically address surgery-specific issues of breast cancer may not be sensitive enough to measure change as a result of a surgical intervention (54).

### **2.5. FACTORS ASSOCIATED WITH DISTRESS**

Most quantitative studies have examined predictors of distress in connection with surgical continuity of care. Research has indicated that presurgery distress had an impact on physical aspects such as postsurgery pain, nausea, fatigue and discomfort (39). Besides the physical aspects, frequent sources of distress were also related to emotional areas (50-52). In addition, one study has provided knowledge on the association of distress and body image, demonstrating that younger women with a poor body image reported higher levels of distress, whereas women, regardless of age, with good body image reported lower levels of distress (40). Furthermore, one study identified a group of respondents with a similar profile of illness perception that was more likely to report lower levels of distress (42). In one study demographic and medical factors were not found to be associated with distress although this study only included non-metastatic women treated with adjuvant chemotherapy (46). However, these results were contrary to the study of Iwatani et al. (44), who indicated that women with large tumours were at risk of developing distress. Costa-Requena et al. (43) investigated the effects of distress on quality of life and found that distress had a negative impact on quality of life. One qualitative study has contributed with important knowledge on distress as it illustrated that women experienced fear of anesthesia, further surgery, aesthetic outcome, and fear of dying. Furthermore, the women experienced distress if they felt they were a burden to the family (7).

## 2.6. RECRUITMENT SITES

Primarily, distress has been examined in one site related to surgical continuity of care for breast cancer. In one study it did not appear from where the participants had been recruited (40). However, there is a paucity of studies investigating distress from a broader perspective according to recruitment sites. Such studies enhance the generalisability, as distress may also be influenced by organisational factors.

## 2.7. RATIONALE FOR THIS RESEARCH

The rationale for focusing on distress in connection with surgical continuity of care is the fact that distress can have an unfavourable impact on quality of life, increase risk of admission to a psychiatric department, and increase risk of mortality (55-57). Although studies on distress are essential in order to minimise the individual consequences of a breast cancer diagnosis and its treatment, and to qualify surgical continuity of care, the literature on distress in connection with surgical continuity of care is sparse in a Danish context. Only one study in Denmark has investigated the prevalence of psychological distress and factors associated with distress at the time of diagnosis in one department of breast surgery (50). Even though this study has provided important information on distress, it has neither examined the evolution in distress during surgical continuity of care nor used a measurement tool specific to women with breast cancer. In addition, distress was measured in only one department of breast surgery in Denmark. Thus, there is a knowledge gap with regard to the prevalence of distress and changes in distress during the surgical continuity of care, and about which factors are associated with distress specific to women taking part in surgical continuity of care.

In relation to distress there is a prevalence of quantitative studies using questionnaires. Questionnaires allow for systematically obtaining meaningful samples of women in surgical continuity of care for breast cancer. The results from using measurement tools with a high measurement quality provide information that could be very important for further assessment or decision-making (58). This may be decisions regarding support, referral or medication. Because some of these decisions can be very important for the person involved and hopefully reduce distress, it is of special relevance that the measurement tool reflects the attributes that are believed (on theoretical and empirical grounds) to be essential for a correct decision or assessment. However, to our knowledge, no measurement tool exists that is able to identify specific factors associated with distress in connection with surgical continuity of care for breast cancer. It is therefore necessary to develop a measurement tool for measuring distress and factors associated with distress specific to women with breast cancer in surgical continuity of care.

Whereas quantitative studies are essential, such studies alone do not capture the complexities of distress in the phase of surgical continuity of care for breast cancer. Therefore, to understand this complexity it is important to examine women's world view and experiences using qualitative methods. The current research is therefore necessary in filling the present gap in knowledge about the experience of distress in a Danish population. From a research design point of view this argues for the use of a mixed methods design drawing on the strengths of both quantitative and qualitative methods.

## **2.8. PURPOSE OF THIS RESEARCH**

The purpose of this mixed methods study is to examine the prevalence and the evolution of distress among women taking part in surgical continuity of care for breast cancer in different sites of breast cancer surgery in Denmark. It is also to understand in more depth the experience of distress in the Danish population. The overall purpose is to create new knowledge about distress that can help health care professionals and other persons involved in surgical continuity of care for breast cancer to prevent or alleviate distress and to qualify breast cancer care in future surgical continuity of care. The thesis is based on the results of three studies.

The objectives of this PhD project are:

- To develop a questionnaire containing items pivotal for distress among women taking part in surgical continuity of care for breast cancer.
- To determine the prevalence of distress in different departments of breast surgery in Denmark.
- To examine the evolution of distress during surgical continuity of care for breast cancer in a Danish population.
- To identify predictors of distress in connection with surgical continuity of care for breast cancer.
- To better understand the experience of distress among women taking part in surgical continuity of care for breast cancer.

# CHAPTER 3. RESEARCH METHODOLOGY

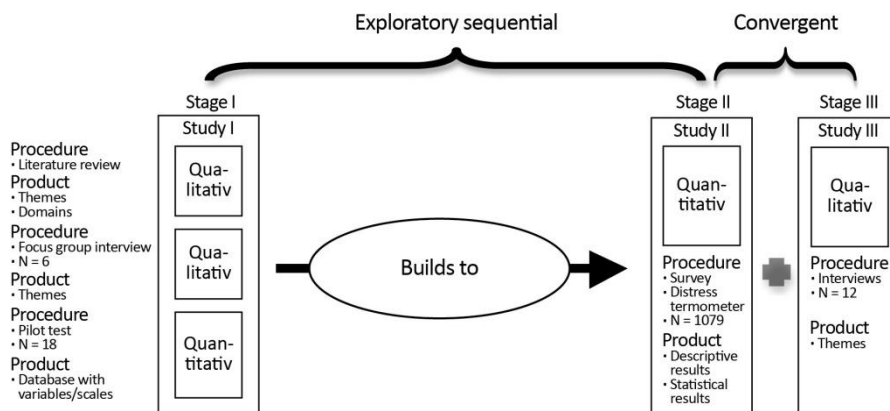
This section provides a description of the design used in this research. This is followed by a brief description of the central ideas of the philosophical assumptions underpinning this study.

## 3.1. MIXED METHODS DESIGN

Mixed methods is a research methodology by which the researcher gathers both quantitative and qualitative data, integrates the two sources of data by combining, merging, connecting or embedding them, and then draws interpretations based on the combined strength of both sets of data in order to understand research problems (59).

In this study, a multistage mixed methods design was applied to respond to the research objectives. This study consists of three stages and each stage can be a standalone study. Thus, one stage can comprise more phases (60), which is true for study I. The first phase was a literature review and the second a focus group interview which formed the basis for the third phase – a pilot study. The overall study uses a combination of exploratory sequential and convergent components (Figure 1). The aim of using an exploratory sequential component was to explore factors affecting distress among women taking part in surgical continuity of care for breast cancer in order to build a second subsequent quantitative stage – the survey. Convergently, the third stage consisted of an interview study. The quantitative and qualitative data of studies II and III were collected in parallel and the two forms of data were analysed separately and subsequently merged (60).

Figure 1: Overview of the mixed methods design



Integration of qualitative and quantitative data is important in mixed methods research. The integration can be implemented at the design, method, and interpretation and reporting level of research (60). The integration took place at the design level as study I informed study II and this study informed study III. Integration at the method level occurred as items for inclusion in the questionnaire were built upon findings from study I. In addition, integration at the method level occurred through connecting as the quantitative data from study II were linked with the data from study III through the sampling frame. The interview participants were purposefully selected from the participants who responded to the survey. Furthermore, integration occurred through merging, as the results from study II were merged with the findings from study III to enhance the understanding of distress among women taking part in surgical continuity of care for breast cancer. It was planned at the design level as the interview guide used in the interview study were based on questions similar to the items from the questionnaires in order to extend the responses from the survey. Integration at the interpretation and reporting level occurred through a staged process as the results of each study were reported in stages and analysed, and published separately. In this thesis the findings from studies II and III are integrated in the discussion.

The rationale behind the mixed methods design was that neither the quantitative nor the qualitative data alone were found to be sufficient to capture the breadth and the complexity of distress among women taking part in surgical continuity of care for breast cancer in different departments of breast surgery in Denmark. Quantitative research does not adequately provide in depth insight and understanding of distress from the perspective of individuals, and qualitative research does not investigate the breadth and magnitude of distress and its associated factors. The research thus consisted of a combination of qualitative and quantitative data collection in order to fulfil the purposes. The intention was to expand the understanding of distress by complementing the results from study II with the findings from study III. Furthermore, the findings from studies II and III were included in the questionnaire validation process. As such the mixed methods design also has a validation purpose (Appendix A).

### **3.2. PRAGMATISM**

The philosophical assumptions of this study are founded in pragmatism. The term pragmatism is derived from the Greek word 'pragma', meaning action, from which our words 'practice' and 'practical' come (61). The philosophy was first introduced by Charles Sanders Peirce (1839-1914) in the 1870s in USA as a reaction to 'the spirit of Cartesianism' (62) and later on extended by William James (1842-1910) and John Dewey (1859-1952) (61). They are among those who had the most influence on pragmatism in its many variations as a philosophy (63).

In pragmatism the emphasis is on the research problem, not the methods or the philosophical world view that underlies the methods. To provide knowledge and the best understanding of the research problem both qualitative and quantitative data may be used within a single study. This position breaks with alleged hierarchies between different methods and rather helps to make the case that different methods generate different outcomes (64). Choosing the methods that are best suited for answering the research questions is important to pragmatism and may help to build bridges between conflicting philosophies as this position rejects the traditional dualisms (65). Central to pragmatism is also the intended consequences of the research, which are oriented towards practice. It includes the sensations that are expected from the research and the reactions for which the researchers must be prepared (61).



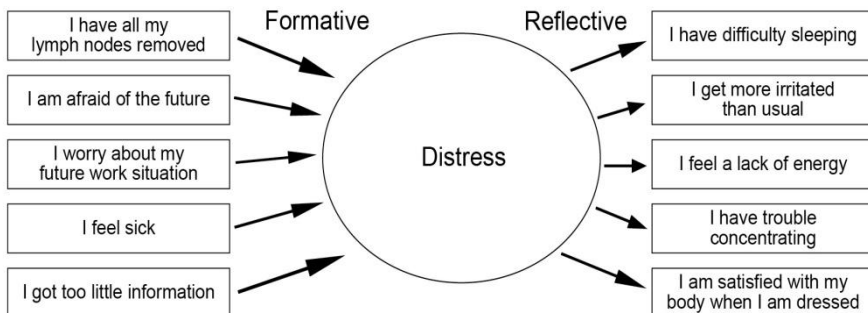
# CHAPTER 4. STUDY I

The following description of study I is based on the paper ‘Development of a questionnaire encompassing indicators of distress: a tool for use with women in surgical continuity of care for breast cancer’, which has been accepted for publication in the European Journal of Oncology Nursing (2014)

## 4.1. THE CONSTRUCT AND THE UNDERLYING RELATIONSHIP

Distress is a latent construct as it is not directly measurable or observable (66). It refers to an experience that is caused by different aspects experienced by women in connection with surgical continuity of care for breast cancer, and these are unique for each person. As distress involves different aspects, it is considered to be multidimensional (37). When working with a multidimensional construct the underlying relationship between the items and the construct has important consequences for the selection of items (37). Items can be either causal or effect indicators (66). There are two models for the underlying relationship: the reflective model and the formative model. In a reflective model the items reflects women’s underlying distress (effect indicators), whereas in a formative model the items form or cause the construct under study (causal indicators) (66). In a formative model each item contributes to a part of the construct and all items that cause considerable distress should be included. On the contrary, in a reflective model all items should correlate with each other and may be interchangeable. Complex constructs, such as distress, may combine reflective and formative models (37), as presented in Figure 2.

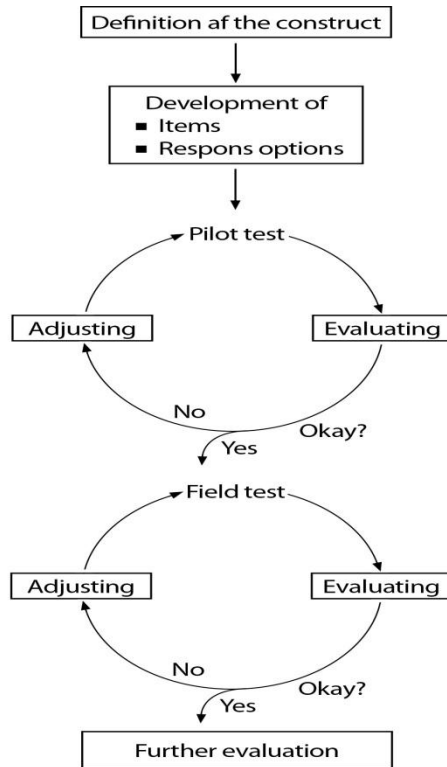
Figure 2: Conceptual model for distress. The examples on the left-hand side depict a formative model, whereas the examples on the right-hand side depict a reflective model.



## 4.2. DATA COLLECTION

Study I was conducted from March 2012 to March 2013 using mixed methods to develop a questionnaire encompassing items specific for women taking part in surgical continuity of care for breast cancer. This process was iterative and divided into several steps as shown in Figure 3.

Figure 3: Overview of the steps in the development of the distress questionnaire

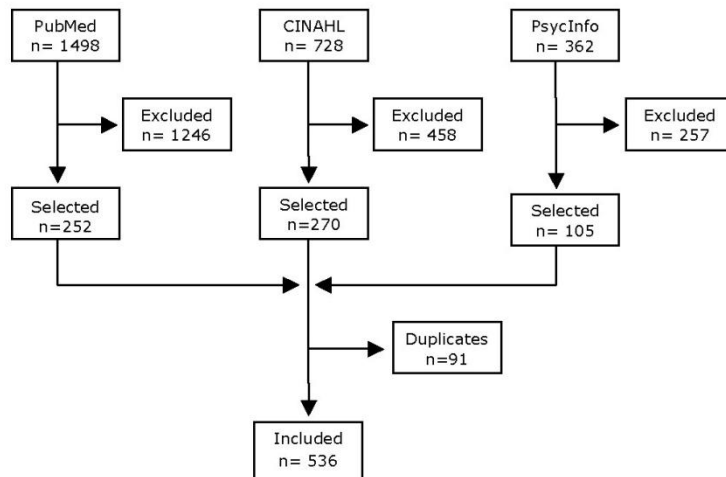


## 4.3. SYSTEMATIC LITERATURE REVIEW

The literature review aimed to identify all possible indicators of distress related to surgical continuity of care for breast cancer. In addition, it aimed to review existing questionnaires intended to measure distress to avoid developing a redundant questionnaire if a useful one already existed. The systematic literature review was conducted primarily through searches in the online databases PubMed, CINAHL

and PsycINFO. Figure 4 outlines the research process. Due to the large variation in the terminology of distress and the often unpredictable indexing, a research librarian at Aalborg University Hospital assisted with the searches to ensure a sensitive research. The criteria for inclusion were studies related to: women who had surgical treatment for breast cancer and articles concerning organizational factors. We assumed that organisational factors could have an impact on distress in connection with surgical continuity of care. Exclusions criteria were studies examining: men with breast cancer, genetic counseling and prophylactic treatment. All abstracts were read, and if a study contained information about distress or consequences of breast cancer, the article was read in its entire length. Key words related to indicators of distress were recorded. If a study used a questionnaire, its applicability was evaluated. The review of existing questionnaires also contributed with ideas about what a new questionnaire should or should not look like. Additionally, the existing questionnaires were assessed in order to collect well-articulated items.

Figure 4: An overview of the research process in study I.



#### 4.4. FOCUS GROUP INTERVIEW

A focus group interview with six specialised nurses from the Department of Breast Surgery at Aalborg University Hospital was performed to broaden the factors associated with distress identified through the literature review. Every nurse had

extensive knowledge of characteristic signs and consequences of breast cancer. A focus group interview capitalises on communication between participants in order to generate data and is an effective way of exploring experiences (67,68). To generate the best possible prerequisites for the group dynamic to work well, the women were informed about the informal nature of the focus group, that every contribution was equally important, and that there were no right or wrong responses to the themes discussed or emerging. Anonymity and confidentiality were outlined. The moderator encouraged the informants to talk to each other by asking questions, exchanging and commenting on experiences and points of views. In addition, the moderator endeavoured to include all participants in the discussions.

An interview guide was developed to guide and stimulate the group discussions and to ensure that the content of the discussions focused on issues central to the objective. Included in the interview guide were statements of patient experiences found in the literature review to facilitate the discussions (Appendix B). However, the aim was for the interview to be unstructured enough to such an extent that it would allow for the discovery of additional indicators of distress. The opening question was 'What do you think of when I say women with newly diagnosed breast cancer?' This was followed by a varied discussion of the nurses' experience related to distress in connection with surgical continuity of care for breast cancer.

The interview was audio-recorded onto a minidisc and subsequently transcribed using the transcription programme Express Scribe. The data analysis was based on the content analysis of Steinar Kvale, which consists of reading the interview in its entirety, determining meaning units and subsequently formulating themes (69).

#### **4.5. QUESTIONNAIRE DEVELOPMENT**

When designing the questionnaire, it had to be considered whether the women conceived the same aspects of distress as intended and if distress had the same meaning for each woman. A multi-item questionnaire often contains more specific items, which may make it easier for a person to understand these items and for the developers to evaluate whether the same construct is being measured (37). Development of the questionnaire was based on indicators of distress identified through the literature review and the focus group interview. In addition, the questionnaire was distributed to six departments of breast surgery in Denmark to make both doctors, nurses, a psychologist and a social worker contribute to the item selection and content validation. In order to create a uniform format the items were formulated as statements such as 'I am afraid of the future'. Items were mainly formulated on the basis of quotations from the qualitative articles and themes from the literature review and focus group interview. In addition, items from an American question bank were reviewed in order to use already well formulated items (70). A uniform response scale was created to make it easier for the participants to complete the questionnaire. The response options for most of

the questions were: to a great extent, to some extent, to a minor extent, and not at all. A small number of items had to be answered with yes or no.

#### **4.6. THE DISTRESS THERMOMETER**

Distress could potentially be assessed using a single-item questionnaire asking for example 'To what extent do you experience distress?' Nevertheless, different people would probably interpret the question differently. For example, some might understand the question to address physical aspects or only psychological aspects or even both (37). However, a global question measured on the Distress Thermometer (DT) was included in the present questionnaire as a summary measure which reflects the overall distress. We assumed that the global question represented the patients subjective averaging of the different dimensions of distress (71). The DT has been used in psycho-oncological research across the world and has been recommended as a tool for measuring distress (72).

#### **4.7. PILOT TEST**

The questionnaire was continuously evaluated and adjusted before it was pilot tested on 18 consecutive women scheduled for breast cancer surgery at Aalborg University Hospital in order to involve the target population during the process of item selection. The purpose was primarily to test the questionnaire's comprehensibility, relevance and completeness. The participants could choose to complete the questionnaire either at the hospital or at home. In order to examine whether the questionnaire could identify changes in distress and changes in indicators of distress during surgical continuity of care, the women were asked to complete the same questionnaire at the time of diagnosis (T1), at discharge (T2) and when they received their test results based on pathology (T3). To prevent recall bias, the women were asked to return each questionnaire immediately after completion in an enclosed envelope. A total of 38 questionnaires were completed. After the women had completed the questionnaires, debriefing was used as a strategic tool for gaining knowledge about comprehensibility, relevance, completeness, feasibility and time consumption to minimise response errors (73).

#### **4.8. RESULTS**

Several themes emerged from the literature review, focus group interview and the contributions from health professionals from other departments than Aalborg. These themes were categorized into seven subscales: emotional situation (24 statements), social condition (11 statements), sexuality (four statements), body image (six statements), physical situation (nine statements), religious situation (one statement) and organisational conditions (two statements). The pilot study and the subsequent debriefing revealed that for some women it did not make sense to

answer some of the questions more than once for example the questions on demographic data. A few women were also confused by the fact that some of the questions could not be answered until after surgery or after they had received the results based on pathology. Therefore, three questionnaires were developed, which were specifically targeted to the different time points during surgical continuity of care. However, they all had the same core of statements regarding the subscales, but differed on other items (Appendix C). Questionnaire I contained additional items regarding age, children, educational level, marital and employment status, type of surgery, adjuvant treatment, co-morbidity, previous or current treatment of anxiety and/or depression. To assess trait anxiety and to make a distinction between trait anxiety and state anxiety, questionnaire I also include four statements regarding how the participants generally felt, for example 'I easily handle difficult situations' with the response options: 'to a great extent, to some extent, to a minor extent and not at all'. Questionnaire II comprised more statements related to organisational factors, for example 'On the day of surgery I was admitted in the morning and discharged later on the same day or evening', which could be answered with yes or no. It also included one statement concerning the spread of cancer 'Because of cancer cells in the sentinel node, I had all lymph nodes removed'. These statements could only be answered after surgery. Beside the core statements, questionnaire III contained more questions related to organisational factors, body image and whether further surgery was recommended, for example 'I need another surgery in the armpit', which means that the cancer had spread.

The results from study I informed the data collection approach of study II. In addition, the questionnaires were initially field tested alongside study II.

## CHAPTER 5. STUDY II

The following description of study II is based on the paper 'Prevalence and predictors of distress in women taking part in surgical continuity of care for breast cancer: a cohort study'. It has been submitted to the European Journal of Oncology Nursing.

Surveys gain their inferential power from their ability to measure groups of persons that form a sample of large populations, but rarely achieve perfection on this dimension (74). This study allowed for the achievement of prevalence and changes in distress, and additionally identified indicators of distress under standardised conditions in a meaningful sample of women taking part in surgical continuity of care.

### 5.1. DATA COLLECTION

This study had a prospective longitudinal design and comprised 1079 consecutive women taking part in surgical continuity of care for breast cancer between April 2013 and May 2014 in 11 departments of breast surgery in Denmark. The inclusion criteria were women having surgery for breast cancer. The exclusion criteria were < 18 years of age, cancer in situ, relapse of breast cancer, language or cognitive difficulties. Eligible women were invited by a nurse to participate. Participants were asked to complete one questionnaire at the time of diagnosis (T1), another questionnaire at the time of discharge, either after hospitalisation or treatment on an outpatient basis (T2), and a third questionnaire just after receiving the test results based on pathology (T3).

At all participating hospitals 1.504 possible participants were registered. Out of them 249 were assessed unable to participate due to, for example too much distress, anxiety and depression, participation in other projects, and no surplus of resources. In 37 cases the nurses either did not have the time to explain the study and distribute the questionnaire or had forgotten to distribute the questionnaire. In total 139 women did not want to participate in the study.

### 5.2. STATISTICAL ANALYSES

Responses on each item in all three questionnaires were entered twice and compared in EpiData, a free programme for entry and data documentation. If an inconsistency was registered, the response was re-examined and re-entered. The statistical analyses were carried out using STATA version 13.1. Descriptive statistics were used to characterise the participants according to age, marital status, children

living at home, educational and employment status, surgery method and previous emotional status. Repeated measures ANOVA were conducted to describe the distribution of distress at the time of diagnosis (no or minor distress, moderate distress and severe distress). A mixed effect model with women as random effect was used to measure distress over time. A linear regression model and multiple linear regression models with a 95 % confidence interval (CI) were fitted to measure distress adjusted for age, educational level, children living at home and marital status. Predictors were identified using a full mixed effect regression model with women as random effect. In this analysis age was converted to a continuous variable. For all analyses the four variables: I often worry, I easily get nervous, I suffer from anxiety, and I easily handle difficult situations concerning prior emotional status were pooled into one variable, - prior emotional status. A higher value of this variable represents a better prior emotional status.

### **5.3. RESULTS**

#### **5.3.1. RESPONDENTS**

In total 1.079 women having surgery for breast cancer participated in the study. 757 (70 %) of these completed all three questionnaires, 110 (10 %) completed questionnaires I and II, and 54 (5 %) completed questionnaires I and III. However, 103 (9 %) women only completed questionnaire I, 18 (1.6 %) women only completed questionnaire II, and 21 (1.9 %) women only completed questionnaire III. The mean age was 60 years (standard deviation (SD) 10.75) and the age ranged from 38 to 89 years.

#### **5.3.2. PREVALENCE OF DISTRESS AT TIME OF DIAGNOSIS**

The mean distress score at the time of diagnosis was 5.5 (95 % CI: 5.4; 5.7). Table 2 displays characteristics according to distress of the 1.024 women who completed questionnaire I. At the time of diagnosis 249 (24.3 %) women reported no or minor distress, whereas 298 (29.1 %) demonstrated moderate distress and 407 (39.8 %) suffered from severe distress. Compared with women with no or minor distress, a larger proportion of women with moderate or severe distress were younger than 60 years (44.9 % and 54.8 %, respectively versus 30 %), married or living with a partner (75.5 % and 76.9 %, respectively versus 70.7 %), had children living at home (23.5 % and 31.2 %, respectively versus 12.9 %), had > 13 years of education (26.2 % and 30 %, respectively versus 22.9 %), and were often employed (45.0 % and 54.8 %, respectively versus 33.7 %). With regard to previous emotional status the proportion of women with moderate to severe distress reporting that they easily get nervous and/or suffer from anxiety was higher compared with women with no or low distress (Table 2). On the other hand, the proportion of women with no or



low distress reporting that they easily handle difficult situations were substantially higher among women with moderate or severe distress (37.8 % versus 23.8 % and 21.9 %, respectively). Distress varied little by type of surgery. Seventy women did not report distress on the DT. These women did not differ particularly from women who had completed the DT.

Table 2: Characteristics of the participants in proportion to distress

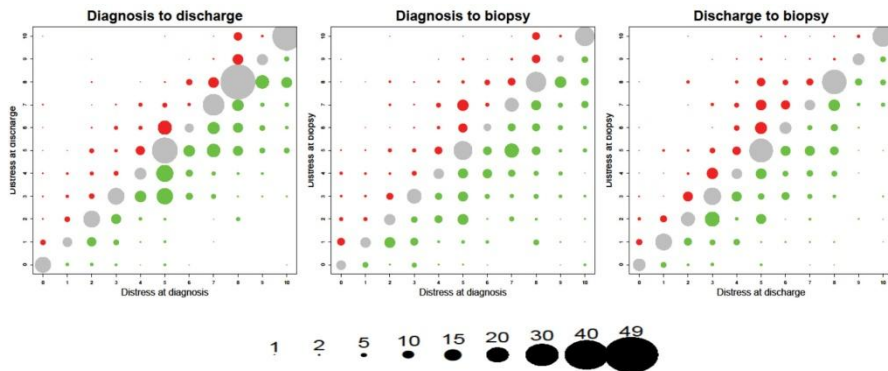
	N	Level of distress at diagnosis			Missing
		No distress (DT score 0-3)	Moderate distress (DT score 4-6)	Severe distress (DT score 7-10)	
Overall	1024	249 (24.3)	298 (29.1)	407 (39.8)	70 (6.8)
<b>Age group, years</b>					
<40	25	5 (2.0)	4 (1.3)	15 (3.7)	1 (1.4)
40-59	440	70 (28.1)	130 (43.6)	208 (51.1)	32 (45.7)
>59	546	171 (68.7)	162 (54.4)	181 (44.8)	32 (45.7)
Missing	13	3 (1.2)	2 (0.7)	3 (0.7)	5 (7.1)
<b>Marital status</b>					
Married/living together	771	176 (70.7)	225 (75.5)	313 (76.9)	57 (81.4)
Living alone	250	73 (29.3)	73 (24.5)	92 (22.6)	12 (17.1)
Missing	3	0 (0.0)	0 (0.0)	2 (0.5)	1 (1.4)
<b>Children living at home</b>					
Yes	246	32 (12.9)	70 (23.5)	127 (31.2)	17 (24.3)
No	706	194 (77.9)	209 (70.1)	257 (63.1)	46 (65.7)
Missing	72	23 (9.3)	19 (6.4)	23 (5.7)	7 (10.0)
<b>Educational level, years</b>					
7-10	457	132 (53.0)	125 (42.0)	170 (41.8)	30 (42.9)
11-13	266	55 (22.1)	85 (28.5)	112 (27.5)	14 (20.0)
>13	279	57 (22.9)	78 (26.2)	122 (30.0)	22 (31.4)
Missing	22	5 (2.0)	10 (3.4)	3 (0.7)	4 (5.7)
<b>Employment status</b>					
Employed/ off-sick	474	84 (33.7)	134 (45.0)	223 (54.8)	33 (47.1)
Unemployed	25	3 (1.2)	6 (2.0)	15 (3.7)	1 (1.4)
Retired	502	156 (62.7)	150 (50.3)	161 (39.6)	35 (50.0)
Missing	23	6 (2.41)	8 (2.7)	8 (2.0)	1 (1.4)
<b>Previous emotional status:</b>					
<b>- I often worry</b>					
To a great extent	69	3 (1.2)	12 (4.0)	48 (11.8)	6 (8.6)
To some extent	248	32 (12.9)	78 (26.2)	121 (29.7)	17 (24.3)
To a minor extent	458	115 (46.2)	143 (48.0)	170 (41.8)	30 (42.9)
Not at all	173	75 (30.1)	41 (13.8)	48 (11.8)	9 (12.9)
Missing	76	24 (9.64)	24 (8.1)	20 (4.9)	8 (11.4)
<b>- I easily get nervous</b>					
To a great extent	39	0 (0.0)	6 (2.0)	31 (7.6)	2 (2.9)
To some extent	168	21 (8.43)	58 (19.5)	78 (19.2)	11 (15.7)
To a minor extent	405	85 (34.1)	128 (43.0)	167 (41.0)	25 (35.7)
Not at all	332	119 (47.8)	79 (26.5)	110 (27.0)	24 (34.3)
Missing	80	24 (9.6)	27 (9.1)	21 (5.2)	8 (11.4)
<b>- I suffer from anxiety</b>					
To a great extent	13	0 (0.0)	2 (0.7)	10 (2.5)	1 (1.4)
To some extent	51	4 (1.6)	10 (3.4)	29 (7.1)	8 (11.4)
To a minor extent	174	27 (10.8)	61 (20.5)	78 (19.2)	8 (11.4)
Not at all	700	194 (77.9)	192 (64.4)	270 (66.3)	44 (62.9)
Missing	86	24 (9.64)	33 (11.1)	20 (4.9)	9 (12.9)
<b>- I feel easy handling difficult situations</b>					
To a great extent	273	94 (37.8)	71 (23.8)	89 (21.9)	19 (27.1)
To some extent	564	114 (45.8)	175 (58.7)	242 (59.5)	33 (47.1)
To a minor extent	119	25 (10.0)	32 (10.7)	53 (13.0)	9 (12.9)
Not at all	40	13 (5.2)	7 (2.4)	16 (3.9)	4 (5.7)
Missing	28	3 (1.2)	13 (4.4)	7 (1.7)	5 (7.1)
<b>Type of surgery</b>					
Lumpectomy + SN	686	169 (67.9)	210 (70.5)	260 (63.9)	47 (67.1)
Lumpectomy + axil.	60	18 (7.2)	13 (4.4)	25 (6.1)	4 (5.7)
Mastectomy + SN	174	39 (15.7)	48 (16.1)	77 (18.9)	10 (14.3)
Mastectomy + axil	69	14 (5.62)	22 (7.4)	29 (7.0)	4 (5.7)
Missing	35	9 (3.6)	5 (1.7)	16 (3.9)	5 (7.1)

### 5.3.3. CHANGE IN DISTRESS DURING SURGICAL CONTINUITY OF CARE

The distress score declined by 0.4 8-0.6; -0.39 points from T1 to T2 and by 0.70 (-0.9; -0.5) from T1 to T3 on the DT. The proportion of women with no or minor distress increased from 24.3 % at T1 to 28.4 % at T2 and 34.0 % at T3. The proportion of women with moderate distress increased from 29.1 % at T1 to 33.6 % at T2 and then decreased to 29.9 % at T3. The proportion of women with severe distress decreased from 39.8 % at T1 to 32.9 % at T2 and to 30.7 % at T3.

Figure 5 illustrates the course of distress of the individual women. Grey circles indicate women for whom the distress level did not change during surgical continuity of care; red circles represent women for whom distress increased over time; whereas green circles indicate women whose distress level decreased over time. The size of the circles represents the number of women. As appears, the changes in distress in surgical continuity of care varied widely among the individual women with the majority of women reporting no change in distress, whereas some women experienced increased distress over time, and some women experienced a decrease in distress.

Figure 5: Distress evolution of women taking part in surgical continuity of care



### 5.3.4. PREDICTORS OF DISTRESS

Table 3 displays predictors for distress at the time of diagnosis and predictors of change in distress during surgical continuity of care. The overall mean distress at the time of diagnosis was 5.5 (95 % CI: 5.37; 5.72) points, and 8.03 (95 % CI: 6.59; 9.46) points when adjusted for age, education level, children living at home and marital status. Time remained a significant predictor of distress from T1 to T3 in both the unadjusted and adjusted models.

DISTRESS AMONG WOMEN TAKING PART IN SURGICAL CONTINUITY OF CARE FOR BREAST CANCER

Table 3: Predictors of distress at different time points during surgical continuity of care.

Distress Variable (Reference group and compared reference)	T1 (time of diagnosis)		T1 - T2 (from time of diagnosis to discharge)		T2 - T3 (from discharge to time of test results based on pathology)		T1 - T3 (from time of diagnosis to time of test results based on pathology)	
	Unadjusted Coef. (95%CI)	Adjusted* Coef. (95%CI)	Unadjusted Coef. (95%CI)	Adjusted* Coef. (95%CI)	Unadjusted Coef. (95%CI)	Adjusted* Coef. (95%CI)	Unadjusted Coef. (95%CI)	Adjusted* Coef. (95%CI)
Time	5.5 (5.37;5.72)	8.03 (6.59;9.46)	-0.41 (-0.57;-0.26)	-0.42 (-0.58;-0.26)			-0.70 (-0.85;-0.54)	0.72 (-0.88;0.55)
Age								
< 40 years (ref.)	6.83 (5.71;7.96)	5.74(4.43;7.05)	-1.00 (-1.87;-1.12)	-0.68 (-1.70;0.34)	-0.80 (-1.76; 0.16)	-0.23 (-1.36;0.90)	-1.8 (2.92;0.68)	-1.27 (-2.58;0.05)
40-59 years	-0.65 (-1.81;-0.51)	-0.34 (-1.52;0.84)	0.53 (-0.36;1.43)	0.40 (-0.51;1.32)	0.50 (-0.48;1.49)	0.39 (-0.62;1.39)	1.06 (-0.09;2.21)	0.91 (-0.26;2.09)
> 59	-1.82 (-2.97;-0.67)	-1.03 (-2.28;0.21)	0.57 (-0.33;1.45)	0.26 (-0.70;1.23)	0.50 (0.49;1.48)	0.16 (-0.91;1.23)	1.19 (0.04;2.33)	0.75 (-0.49;2.00)
Living alone (ref.)	5.2 (4.89; 5.62)	8.28 (6.62;9.98)	-0.59 (-0.87;-0.30)	-0.38 (-1.67;0.93)	-0.19 (-0.52;0.14)	0.49 (-1.99;1.01)	-0.75 (-1.14;-0.37)	-1.3 (-3.06;0.42)
Married or living with someone	0.40 (-0.02;0.82)	0.29 (-0.16;0.73)	0.18 (-0.15;0.50)	0.10 (-0.25;0.46)	-0.17 (-0.55;0.21)	-0.17 (-0.58;0.23)	0.08 (-0.36;0.81)	0.06 (-0.41;-0.54)
Children (ref.)	5.26 (5.04;5.47)	8.28 (6.62;9.94)	-0.42 (-0.59;-0.25)	-0.38 (-1.69;0.93)	-0.27 (-0.46;-0.08)	0.49 (-1.99;1.01)	-0.64 (-0.86;-0.43)	-1.32 (-3.06;0.42)
Children living at home	1.30 (0.88;1.72)	0.49 (-0.05;1.04)	-0.24 (-0.57;0.09)	-0.22 (-0.64;0.20)	-0.19 (-0.58;0.19)	-0.03 (-0.52;0.47)	-0.31 (-0.75;0.13)	-0.05 (-0.61;-0.51)
Hospital								
Ref.	5.11 (4.19;6.02)	7.96 (6.09;9.83)	0.27 (-0.44;0.98)	0.46 (-1.03;1.94)	0.58 (-0.28;1.45)	0.20 (-1.52;1.92)	0.77 (-0.21;1.75)	0.17 (-1.82;2.15)
1	0.67 (-0.54;1.89)	0.53 (-0.67;1.72)	-0.65 (-1.58;0.28)	-0.68 (-1.63;0.28)	-0.80 (-1.95;0.34)	-0.89 (-2.07;0.28)	-1.50 (-2.81;-1.9)	-1.63 (-2.97;0.28)
2	-0.11 (-1.36;1.15)	-0.17 (-1.43;1.10)	-0.73 (-1.75;0.29)	-0.76 (-1.82;0.31)	-0.65 (-1.85;0.53)	-0.69 (-1.93;0.55)	-1.27 (-2.58;0.05)	-1.31 (-2.67;0.04)
3	0.82 (-0.23;1.87)	0.79 (-0.25;1.84)	-0.51 (-1.32;0.29)	-0.64 (-1.47;0.10)	-1.29 (-2.26;-0.31)	-1.41 (-2.41;-0.41)	-1.67 (-2.78;-0.57)	-1.84 (-2.97;0.70)
4	0.80 (-0.25;1.85)	0.80 (-0.24;1.85)	-1.05 (-1.85;-0.24)	-1.14 (-1.97;-0.31)	-0.90 (-1.87;0.07)	-0.95 (-1.94;0.05)	-1.88 (-2.98;-0.78)	-1.98 (-3.10;0.85)
5	-0.12 (-1.14;0.89)	-0.39 (-1.40;0.61)	-1.10 (-1.88;-0.32)	-1.04 (-1.84;-0.23)	-0.50 (-1.44;0.45)	-0.48 (-1.45;0.49)	-1.51 (-2.58;-0.44)	-1.43 (-2.54;0.32)
6	-0.02 (-1.26;1.22)	-0.22 (-1.44;0.99)	-1.01 (-2.04;0.02)	-1.08 (-2.14;-0.01)	-0.16 (-1.36;1.04)	0.08 (-1.17;1.34)	-0.86 (-2.19;0.46)	-0.88 (-2.23;0.49)
7	0.48 (-0.59;1.55)	0.53 (-0.52;1.58)	-0.49 (-1.31;-0.34)	-0.49 (-1.34;0.35)	-1.49 (-2.48;0.49)	-1.48 (-2.50;-0.47)	-1.71 (-2.83;-0.59)	-1.69 (-2.83;0.55)
8	0.47 (-0.62;1.56)	0.42 (-0.66;1.50)	-0.20 (-1.03;0.64)	-0.26 (-1.12;0.61)	-1.20 (-2.21;-0.19)	-1.33 (-2.37;-0.30)	-1.20 (-2.35;-0.06)	-1.41 (-2.59;0.24)
9	0.67 (-0.36;1.70)	0.67 (0.35;1.68)	-0.69 (-1.48;0.10)	-0.73 (-1.55;0.08)	-0.97(-1.92;0.02)	-1.11 (-2.08;-0.13)	-1.47 (-2.55;-0.38)	-1.61 (-2.72;0.49)
10	0.84 (-0.33;2.02)	0.90 (-0.27;2.08)	-1.13 (-2.08;-0.18)	-1.16 (-2.13;-0.18)	-0.73 (-1.94;0.46)	-0.79 (-2.00;0.43)	-1.40 (-2.77;-0.03)	-1.59 (-2.98;0.19)
Surgery method								
Lump + SN (ref.)*	5.51 (5.29;5.73)	8.05 (6.37;9.74)	0.55 (0.72;-0.38)	-0.47 (-1.80;0.86)	0.35 (-0.54;-0.16)	-0.59 (-2.07;0.89)	-0.83 (-1.05;-0.61)	-1.61 (-3.36;0.14)
Lump + axil**	-0.19 (-0.97;0.59)	0.03 (-0.76;0.82)	0.30 (-0.27;0.88)	0.30 (-0.31;0.91)	0.33 (-0.36;1.01)	-0.36 (-0.35;1.07)	0.74 (-0.02;1.51)	0.77 (-0.03;1.56)
Mast + SN	0.24 (-0.25;0.73)	0.36 (-0.15;0.87)	0.35 (-0.03;0.73)	0.33 (-0.07;0.74)	-0.02 (-0.45;0.41)	-0.07 (-0.52;0.39)	0.34 (-0.16;0.83)	0.21 (-0.32;0.74)
Mast + axil	0.19 (-0.54;0.92)	0.09 (-0.65;0.85)	-1.19 (-0.75;0.37)	-0.13 (0.72;0.46)	0.37 (0.26;1.01)	-0.61 (-0.06;1.27)	0.17 (-0.58;0.93)	0.47 (0.32;1.27)
No medication with antidepressant or sedative med. (ref.)	5.41 (5.20;5.62)	8.01 (6.35;9.66)	-0.50 (-0.66;-0.34)	-0.44 (-1.75;0.88)	-0.38 (-0.56;-0.19)	-0.64 (-2.15;0.86)	-0.77 (-0.99;-0.56)	-1.48 (-3.23;0.27)
Medication with antidepressant or sedative med	0.59 (0.16;1.01)	0.72 (0.28;1.15)	0.11 (-0.20;0.43)	0.16 (-0.18;0.50)	0.21 (-0.17;0.58)	0.21 (-0.19;0.61)	0.26 (-0.17;0.68)	0.32 (-0.13;0.78)
Prior emotional status (ref.)	5.99 (5.62;6.36)	9.33 (7.63;11.03)	-0.48 (7.6;-0.20)	-0.50 (-1.85;0.86)	0.17 (0.49;0.16)	-0.25 (-1.78;1.30)	-0.61 (-0.99;-0.24)	-0.05 (-0.24;0.14)
Prior emotional status	0.25 (-0.44;-0.06)	-0.49 (-0.67;-0.27)	0.01 (-0.13;0.15)	0.05 (-0.11;0.21)	-0.09 (-0.26;0.07)	-0.11(-0.29;0.08)	-0.05 (-0.24;0.14)	0.03 (-0.24;0.19)
Sexual attractiveness								
To a high extent (ref.)	4.68 (4.22;5.15)	7.52 (5.69;9.36)	-0.15 (-0.52;0.21)	-0.15 (-1.67;1.38)	-0.40(-0.82;0.02)	-0.38(-2.12;1.36)	-0.61 (-1.09;-0.12)	-1.00 (-3.00;0.99)
To a certain extent	1.03 (0.47;1.59)	1.12 (0.55;1.68)	-0.40 (-0.85;0.04)	-0.41 (-0.88;0.05)	-0.64 (0.57;0.44)	-0.10 (-0.63;0.43)	-0.32 (-0.90;0.27)	0.38 (-0.99;0.22)
To a minor extent	1.45 (0.84;2.06)	1.53 (0.92;2.14)	-0.47 (-0.95;0.01)	-0.48 (-0.98;0.03)	0.08 (-4.62;6.64)	0.11 (-0.47;0.43)	-0.2 (-0.85;0.43)	-0.24 (-0.90;0.42)
Not at all	1.33 (0.68;1.98)	2.00 (1.32;2.68)	-0.07 (-0.59;0.45)	-0.19 (-0.76;0.37)	0.17 (-0.43;0.77)	0.12 (-0.53;0.78)	0.28 (-0.40;0.96)	0.01 (-0.73;0.76)
Physical attractiveness								
To a high extent (ref.)	5.07 (4.71;5.44)	7.70 (5.96;9.44)	-0.58 (-0.86;-0.30)	-0.35 (-1.77;1.07)	0.41 (0.74;-0.08)	-0.49 (-2.11;1.13)	-1 (-1.38;-0.62)	-1.26(-3.12;0.60)
To a certain extent	0.64 (0.18;1.09)	0.68 (0.22;1.14)	0.12(-0.23;0.47)	0.14(-0.23;0.51)	-0.02(-0.43;0.38)	0.05(-0.37;0.48)	0.26(-0.21;0.72)	0.32(-0.17;0.80)
To a minor extent	0.94 (0.40;1.49)	1.15 (0.60;1.71)	0.05(-0.37;0.47)	-0.08(-0.52;0.36)	0.26(-0.24;0.76)	0.31(-0.21;0.83)	0.40(-0.17;0.96)	0.29(-0.30;0.88)
Not at all	1.00 (0.07;1.92)	1.39 (0.47;2.30)	0.66(-0.04;1.36)	0.67(-0.05;1.39)	0.13(-0.67;0.93)	0.15(-0.67;0.96)	0.86(-0.05;1.77)	0.85(-0.07;1.78)
Femininity								
To a high extent (ref.)	5.14 (4.80;5.47)	7.82 (6.11;9.54)	-0.46(-0.72;-0.21)	-0.40(-1.80;1.00)	-0.44(-0.73;-0.15)	-0.55(-2.15;1.05)	-0.90(-1.24;-0.56)	-1.35(-3.18;0.47)
To a certain extent	0.65 (0.22;1.07)	0.81 (0.38;1.24)	-0.40(-0.37;-0.29)	-0.06(-0.40;0.28)	0.06(-0.32;0.44)	0.04(-0.36;0.43)	0.13(-0.30;0.57)	0.09(-0.36;0.54)
To a minor extent	0.68 (0.10;1.26)	0.99 (0.40;1.58)	0.03(-0.42;0.48)	0.04(-0.43;0.51)	0.38(-0.13;0.90)	0.27(-0.27;0.82)	0.49(0.09;0.88)	0.41(-0.20;1.03)
Not at all	1.12 (0.16;2.07)	1.71 (0.72;2.71)	-0.07(-0.81;-0.67)	-0.09(-0.8;0.69)	0.33(-0.55;-1.20)	0.23(-0.68;-1.14)	0.57(-0.41;1.54)	0.43(-0.59;1.45)

\* Adjusted for age, educational level, children living at home, and marital status. \*\*SN = sentinel node.

\*\*\*Axil = axillary clearance

The adjusted mean distress level for women < 40 years was 5.74 (95 % CI: 4.43; 7.05) points at T1. The distress level was 0.34 (95 % CI: -1.52; 0.84) points lower among women aged 40-59 years, and 1.03 (95 % CI: -2.28; 0.21) points lower among women above > 59 years. The distress level among women < 40 years decreased by 1.27 (95 % CI: -2.58; 0.05) points from T1 to T3 compared to an increase of 0.91 (95% CI -0.26; 2.09) points among women aged 40-59 years and 0.75 (95 % CI: -0.49; 2.0) among women > 59 years.

Women without children living at home had an adjusted mean distress level of 8.28 (95 % CI: 6.62; 9.94) points at T1, whereas the mean distress level was 0.49 (95 % CI: 0.88; 1.72) points higher for women with children living at home. Children living at home had no significant effect on the level of distress over time; however a decrease in the mean distress level tended to be greater among women without children living at home compared to those who had children at home.

Compared with the reference hospital (7.96 95 % CI: 6.09; 9.83) the adjusted mean distress level at T1 varied with -0.39 to 0.90 points at the other hospitals. The distress level tended to increase by 0.17 (95 % CI: -1.82; 2.15) points from T1 to T3 at the reference hospital, while it decreased by 0.88 points to 1.98 points at the other hospitals.

The adjusted mean distress level among women having lumpectomy and sentinel node biopsy was 8.05 (95 % CI: 6.37; 9.74) points at T1. For these women the mean distress level decreased by 1.61 (95 % CI: -3.36; 0.14) points from T1 to T3. In comparison, women having lumpectomy and axillary clearance had a slightly higher mean distress level at T1 (0.03 (95 % CI: -0.76; 0.82), whereas women with mastectomy tended to have a higher adjusted mean distress level at the time of diagnosis. Compared to women with lumpectomy and sentinel node biopsy, the mean distress level connected to other surgery methods increased over time (Table 3).

A higher emotional status prior to breast cancer diagnosis was associated with lower distress levels compared to women who reported a worse prior emotional status (adj. coef. -0.49 (95 % CI: -0.67; -0.27). However, prior emotional status did not seem to affect the level of distress over time (Table 3).

The adjusted mean distress level among women with no prior or current intake of antidepressant or sedative medicine was 8.01 (95 % CI: 6.35; 9.66) points, whereas it was 0.72 (95 % CI: 0.16; 1.01) points higher among women receiving these medications. From T1 to T3 a reduction of 1.48 (95 % CI: -3.23; 0.27) points were observed among women with no medications compared to an increase of 0.32 (95 % CI: -0.13; 0.78) points among women with prior or current intake of medication.

Women who reported feeling sexually and physically attractive or feminine at T1 had adjusted mean distress levels of respectively 7.52 (95 % CI: 5.69; 9.36), 7.70 (95 % CI: 5.96; 9.44), and 7.82 (95 % CI: 6.11; 9.54) points. In comparison, the mean distress level was 2.00 (95 % CI: 1.32; 2.68), 1.39 (95 % CI: 0.47; 2.30), and 1.71 (95 % CI: 0.72; 2.71) points higher, respectively, among women who did not feel sexually and physically attractive or feminine. Feeling sexually attractive and

physically attractive and feminine was associated with decreased levels of distress from T1 to T3 (Table 3).

In the full mixed effect model the mean distress level was 9.00 (95 % CI: 6.87; 11.13) points, and time since diagnosis remained significantly associated with distress (T1-T2: -0.60 95 % CI: -0.83; -0.38); T1-T3: -0.94 95 % CI: -1.16; -0.72). Age (-0.04 95 % CI: -0.07; -0.02), prior emotional status (-0.48 95 % CI: -0.68; -0.28), children living at home (0.59 95 % CI: 0.11; 1.07), and feeling sexually attractive to some extent (0.49 95 % CI: 0.11; 0.87), to a minor extent (0.8 95 % CI: 0.32; 1.30), or not at all (0.84 95 % CI: 0.23; 1.45) remained statistically significant. Furthermore, one hospital remained associated with reduced distress compared with the reference hospital (-1.46 95 % CI: -2.49; -0.44).

## CHAPTER 6. STUDY III

The following description of study III is based on the paper 'The experience of distress in relation to surgical treatment and care for breast cancer: an interview study', which has been accepted for publication, subject to minor amendments, in the European Journal of Oncology Nursing.

### 6.1. METHODOLOGY

A phenomenological-hermeneutic approach inspired by the French philosopher Paul Ricoeur was used to explain and understand women's experience of distress in relation to surgical continuity of care for breast cancer (75). Semi-structured interviews were applied to encourage the participants to talk about their experiences of distress and thus uncover the meaning content. According to Ricoeur a description is not sufficient to obtain a profound understanding of the life experience. The interview texts contain a surplus of meaning which necessitates an interpretation process. This process seeks to generate an understanding that exceeds the actual interviews (75,76). One of the most significant ideas in Ricoeur's thinking is that the phenomenological-hermeneutic approach is an argumentative discipline. He argues that a text never has only one interpretation, but that one interpretation can be more suitable than others. It depends of the argumentation that gives credibility and validity to the interpretation (76).

#### 6.1.1. INTERVIEWS

Research using interviews as a method is one of the most important approaches to understanding fellow human beings. Individual interviews are regarded as an active interaction between two persons and this interaction is crucial to the knowledge one achieves. A receptive, empathic and listening interviewer is able to provide knowledge about human experience, expressed in the words of the interviewee (77).

### 6.2. DATA COLLECTION

Data collection was conducted through individual interviews with 12 women aged 38 to 87 years who had recently undergone surgery for breast cancer in one of five breast surgery departments in Denmark. The interview participants were selected from the sample who responded to the survey in study II. In the written information to the participants in study II the women were asked to write their phone number on one of the questionnaires if they were willing to participate in the interview study. Some of those women who stated their phone number were

then asked for an interview. In order to capture a variation in the sample, a purposive sampling strategy was chosen covering the demographic and clinical characteristics of the women, such as age, children living at home, method of surgery, level of distress and different hospitals. The women were interviewed before the start of adjuvant treatment or follow-up, except for one woman, who had just started chemotherapy. The phenomenological perspective was expressed as the participants were asked to talk in a descriptive and clarified way about their experience of distress in relation to surgical continuity of care for breast cancer. The approach was open with the interviewer asking supplementary questions to elaborate the experience of distress. However, an interview guide was used to deepen the answers given by the woman in the survey and thus further explore the experience of distress (Appendix D). The interviews were conducted from May through November 2013 and the participants were given a choice regarding the location of the interview. 10 interviews took place in the participants' home, and two in the hospital. The duration of the interviews varied between 15 and 68 minutes. Brief notes primarily on the body language of the individual women and my initial reflections were made just after each interview.

### **6.3. TRANSCRIPTION**

The interviews were recorded on a mini disc and immediately downloaded and stored on my personal computer, which can only be unlocked by a personal code. The data were transcribed as soon as possible after each interview using the programme Express Scribe. The transcription procedure resulted in 162 A4 pages.

### **6.4. DATA ANALYSES AND INTERPRETATION**

The text comprised the data that were subject for analysis and interpretation. The analytic and interpretation process consisted of three levels: a naive reading, structural analysis, and critical analysis and discussion. The naive reading was a first reading of the interview texts aimed to achieve an immediate understanding of the meaning content. Next, the structural analysis described units of meaning (what is said) and identified and formulated units of significance (what is talked about) leading to development of themes and patterns (76). The final step, the critical analysis and discussion, was to make a comprehensive interpretation of the data taking into account the results of the structural analysis. The themes were discussed and related to the quotations from the interviews to the text as a whole incorporating theories and other research findings to obtain a deeper understanding of the experience of distress among these women. The text was analysed and interpreted independently by me and my supervisor and subsequently discussed to enhance trustworthiness and suitability of this interpretation.



## 6.5. FINDINGS

The findings are presented according to the levels of the process of analysis and interpretation. The presentation is a summation of the findings.

### 6.5.1. NAÏVE READING

What immediately appeared from the text was the women's experience of distress in a time characterised by anxiety: anxiety regarding potential spread of cancer, dying, recurrence, the unknown, possible loss of a breast, thoughts about chemotherapy, risk of additional operations and new tests, repeated waiting time for further operations and/or test results, discharge, the risk of developing lymphoedema, possible job loss and not being able to get help from professionals after discharge. The women also experienced distress regarding loss of roles and identities as women, mothers, and caregivers, and loss of control of their body. Moreover, they experienced distress when they were unable to handle their usual activities and if they felt they were a burden to their families.

The relationship with families and friends was of great importance to the experience of distress. The women identified those individuals who could help reduce their experience of distress, for example women who could tell good stories about surviving breast cancer. Another topic was the relationship with health professionals. It was important to the women that they were regarded as persons, and that the health professionals tried to get to know the person in relation to treatment and care for the cancer illness. It mattered that the health professionals had time to talk to the women, and it was essential that the health professionals showed humanity and were not just providing information about practical issues.

### 6.5.2. STRUCTURAL ANALYSIS

The process of deriving themes is exemplified in Table 4, and the critical analysis and discussion of the derived themes are presented separately below.

In the structural analysis two rectangular brackets [ ] mean that the researcher has added words to improve the understanding of the meaning. Points ..... indicate a break, and if a word has been written in upper case letter it means that the word is emphasized.

Table 4: Example of structural analysis

<b>Meaning units (What the women says)</b>	<b>Units of significance (What the women talks about)</b>	<b>Themes</b>
<p>I was really distressed, when we got the diagnosis. I think it is fear of dying; it really is fear of dying (9).</p> <p>I started to realise, what this was about, I think, what it implied, but I was frightened and uncertain and sad, and of course I was afraid of the future. Scared that I would not be here next summer. I didn't know how aggressive the cancer was and I didn't know if it was all over my body.... so I was very unsafe ... I didn't talk to anybody about this. It was a little frightening; it was not okay to say it out loud, because it was such a bad experience (2).</p> <p>I had surgery and was just discharged. It was too much ... maybe I was afraid of ... would I become weak or unwell..... I was scared of getting sick (1).</p> <p>I am worried whether I will still have my job when I come back [from treatment]. Will they fire me when I have been away for such a long time? This is one of my biggest worries. Do I have a job or do I also have to find the energy to find a .....new job. My social life revolves around my colleagues.....you get the diagnosis of breast cancer, which is life-threatening. Another thing is that you don't know if you have an income (2).</p>	<p>Fear of dying</p> <p>Fear of the time period after discharge</p> <p>Anxiety regarding loss of job</p>	<p>A time of anxiety</p>
<p>Will I be able to be a good mother to them ....I have got others to think of ...my husband and my siblings and especially my mother (1).</p> <p>Well, I was touchier. I just started yelling or raising my</p>	<p>Loss of the role as primary care giver for the children, husband, siblings and parents.</p>	<p>Loss of identities</p>

<p>voice. I felt I did this very quickly. I was sure I wasn't a very happy mother, because everything was very impacted (2).</p> <p>To find out that you are discharged as another person than you felt before. The world just keeps going and the neighbour does what he always does, but I come home as another person (2).</p> <p>I haven't had the energy to have sex or dared....to take off my clothes in front of my husband even though we know each other so well and he is so sweet to me (2).</p> <p>All my delicate underwear and things like that. I can throw it away, because I am never going to be sexy again (4).</p>	<p>Loss of being a happy mother</p> <p>Being discharged as another person than the one who entered the hospital</p> <p>Loss of femininity, attractiveness, sexuality</p>	
<p>I was very happy to see that it was the same nurse who had accompanied me to an earlier consultation, because I didn't need to spend much energy finding out who she was, what her name was and she didn't know how I reacted as I got the diagnosis. She did know and that mattered a lot to me (1).</p> <p>I think it matters a lot that you don't have to repeat everything, because it is a new person (12).</p> <p>Everyone that I have been in touch with in this department has given more than being a nurse on the human level and also been forward-looking. I was very happy about one particular nurse. She asked me a lot of questions, questions that I could feel I had, but that I was unable to articulate. I have never felt like a number. There has been very good support on the human and professional levels (2).</p>	<p>I know her and she knows me</p> <p>An individual person-centered human and professional communication and support</p>	<p>To be treated as a person</p>

<p>It was fantastic that everything went so fast, but it was as if I couldn't keep my head about me ..... I couldn't make head or tail of it all. I was very schocked (2)</p> <p>The waiting time was just awful..... I just froze; I waited almost four months. I was sad and completely froze in myself the way I was feeling. I couldn't pull myself together. I just sat there every day, just always looking in the letter box for a letter. It is the worst thing that I have ever experienced. It was this waiting time (5).</p> <p>The focus was on practical issues. You have breast cancer; you are going to have chemotherapy and surgery. Fine, this is important too, but they didn't ask about how I felt. I wasn't able to focus on practical issues, because of my emotional situation that was presence (1).</p>	<p>When everything is accelerated</p> <p>The repeated waiting times affect distress</p> <p>Practical information comes before the emotional situation.</p>	<p>To be part of the system</p>
---	--	---------------------------------

### 6.5.3. CRITICAL ANALYSIS AND DISCUSSION

The critical analysis and discussion are structured around the four themes that emerged from the structural analysis: 1) a time of anxiety, 2) loss of identities, 3) to be treated as a person, and 4) to be part of the system. The quotations (written in italic letters) are expressions of the interviewees. Two rectangular brackets [ ] refer to the interviewees.

#### 6.5.3.1. A TIME OF ANXIETY

Our findings suggest that anxiety was a very essential and overwhelming experience to the women during surgical continuity of care. One of the most frequent distressing issues was fear of recurrence, a negative emotional response to a potential life-threatening disease as exemplified in the following quotes: *You have to be convinced that the cancer is gone that is does not recur, but on the other hand, that I once got diagnosed with cancer... I wasn't supposed to. You can get it again even if you feel healthy* [4]. This quotation may be the result of doubt as to whether the cancer is truly gone or the possibility that it may recur. Fear of recurrence reduces the women's overall quality of life as well as their self-reported physical and mental health, causing considerable disruption in social functioning

and relationships (78). Mothers express greater fear of recurrence regardless of their age or that of their children (79). In the present study, this was exemplified by one woman, who started to cry when the interview focused on her children: *The minute I begin to speak about the children ... well, there is something.....*[6]. This quote combined with the mother's reaction indicated that this was a very sensitive topic that needed to be addressed in order to reduce her sense of anxiety and increase her well-being. It may relieve the women if they do not have to explain their feelings or to hide them.

Lower levels of anxiety were experienced among breast cancer patients who experienced better communication with their health care providers. In contrast, women who experienced medical mistrust showed a higher level of anxiety (80). This is in accordance with the findings of the present study, as illustrated by the following quote: *I didn't look at the dark side, but it is difficult not to continue doing this, because as they [the doctors] said the first time I got the tumor examine. You don't need to worry. There is nothing wrong. They kept saying that. OF COURSE there is nothing wrong. And now, after this first operation you try to convince yourself that they have removed all the cancer, but they didn't, so now I will need a second surgery, then it is....* [4]. The metaphor used in this quote indicates that the woman is trying not to mistrust the information and be positive, but that is not easy when she gets bad news with every test result she receives. Until the final histological result is known, it is uncertain whether further treatment is recommended. Women taking part in surgical continuity of care are afraid of further surgery (7), which may mean that this disease is more serious or that they will experience more bodily changes such as losing or disfigurement of a breast. Good communication skills and person-centered care are crucial to improving the women's interactions with health professionals, which may help to reduce mistrust and anxiety. Trustworthiness is primarily shown through the constant presence of health professionals and if contradictory information is avoided and the women are not constantly asked the same questions by different health professionals (7). For example, this can be achieved through the continuous contact with one contact person.

The women were anxious about losing their job: *I am worried whether I will have a job, when I have finished treatment. Will they fire me when I have been away for such a long time? This is one of my biggest worries. Do I have a job or do I also have to find the energy to find a..... new job. My social life revolves around my colleagues..... you get the diagnosis of breast cancer, which is life-threatening. Another thing is that you don't know if you have an income* [2]. Not only are these women experiencing anxiety regarding their job situation, but losing their job may also affect their social lives and/or income. Possible job loss is considered to impact on a woman's decision to work or not during treatment (81). This issue arose in the present study: *When I told my manager, that I was ill, she told me that she was expecting me to work.... not full time.... she didn't have to say it that way* [10].

Beforehand, the women experience fear of being a burden to their family due to the effects of the disease: *It was at discharge that I experienced a real letdown because how would I be able to manage everything at home, would I be a burden if I just could not do anything at home* [4]. The experience of being a burden to the family may increase if there is also a risk of job loss and thereby loss of income.

### 6.5.3.2. LOSS OF IDENTITIES

Another finding in this study was loss of identity. A diagnosis of breast cancer precipitates complex changes in a woman's identity: *To find out that you are discharged as another person than you felt before. The world just keeps going and the neighbour does what he always does, but I come home as another person* [2]. This also includes the change in identity as a mother: *That I am able to be a good mother to them....* [1]. This issue was very important to all mothers in this study and talking about it was very emotional to them. Often, women confronting breast cancer are unable to live up to their everyday role as a mother. They may get the feeling that they are letting their children down, because they do not respond or behave in the usual manner: *I hope I can be a happy mother as usual* [1]. As such, the impact of a breast cancer diagnosis and treatment can ostensibly lead to changes in identity. Women construct and reconstruct their identities as mothers in the context of living with breast cancer. For example, the objectification that is present in the healthcare systems, treating the women as patients and not as mothers suffering from breast cancer, may imply that their identity as a mother is no longer bound up with the mothering role, which can cause distress (82). This signifies that the impact of breast cancer on the mothering role should be an integral part of the support provided by health care professionals to ensure that mothers with breast cancer are recognised as mothers and not just as patients.

The present study indicates that body image is closely related to identity, self-esteem, attractiveness, change in clothing and sexual functioning: *Before surgery I had thoughts about losing my breast that it wouldn't mean a lot to me, but OF COURSE it does. It isn't the same as it was before... now I only have one breast... now I'm not longer as fit as I used to be. When I look in the mirror, I don't have the same body as before* [1]. Dahl et al. (83) have suggested that poorer body image is associated with the loss of a breast, breast reconstruction, and change in clothing, poorer self-rated health, chronic fatigue and distress. A significantly greater proportion of the women who underwent reconstruction experienced a poorer body image. This may indicate that body image is a complex phenomenon, not only related to physical appearance, but also to psychological factors such as self-compassion (84). It is in accordance with our study that reconstruction is not necessarily associated with a better body image: *There are those people, who tell me, that it can be built up again. They are right, but it isn't the same... Your self-image has to be changed for the rest of your life. It just has changed forever [even if you get reconstruction]* [4]

The women felt anxious if they had to change their style of clothing due to scars or removal of a breast as they saw their style as being a part of their identity: *It is that particular type of clothing that I usually wear. If I had to change that, to cover everything [because of scars], it is not ME [4].* A change in clothing was also a factor in relation to sexuality: *All my delicate underwear and things like that. I can throw it away, because I am never going to be sexy again [4].* A critical factor for the shift in identity is the sexual relationship: *I don't think that I'm, let me say, attractive anymore...I haven't had the energy to have sex...or dared to take off my clothes in front of my husband, even though we know each other very well and he is my husband.....so sweet to me [2].* If the women had to have their breast removed, they felt like a part of them had been amputated, which also had an impact on their sense of femininity: *You have just been amputated, so you can't feel feminine at all [9].* The feeling of not being feminine and attractive also had consequences for their social life: *It was in my thoughts, FUCK if they take my breast and I have to wear a compression garment [because of lymphoedema] and I will lose my hair [because of chemotherapy], I couldn't bear it, and then I could just be buried. To walk outside and look like that. I couldn't relate to it [4].* This woman is using a strong metaphor to illustrate how much her body image means to her; she would rather be dead than have her identity changed in such an extensive way; however, she also describes how her body image would affect her social life. Such a change in identity and experience of an altered body image may have extensive consequences for women with breast cancer.

Body image, change of identity and sexuality are not typically discussed or addressed by health professionals. The lack of discussions of these topics may arise from cultural taboos, shame, and shyness, lack of suitable language or discomfort in discussing these issues. However, one important aspect of nursing care for women with breast cancer confronting changes in identity is to aid their understanding of living with this illness. It is through listening and dialogue that this can happen. Open dialogue about these concerns helps the women feel that they are being understood and that their feelings are being validated. It can be empowering to the women to realise that they are in a process of transition in life (19).

### 6.5.3.3. TO BE TREATED AS A PERSON

The findings of this study also indicated that being treated as a person affects on women taking part in surgical continuity of care for breast cancer: *Everyone that I have been in touch with in this department has given more than being a nurse on the human level and also been forward-looking. I was very happy about one particular nurse. She asked me a lot of questions, questions that I could feel I had, but that I was unable to articulate. I have never felt like a number. There have been very good support on the professional and human level [2].* This quotation points to the meaning of a caring humanistic process, helping this woman express her feelings of concern. In addition, it points to the attribute of the nurse's

interpersonal and communication skills as well as her professional competencies. Nurses can communicate effectively with the patients if they adopt a person-centered approach (85), bringing the patients perspective regarding cancer experiences and related challenges to the foreground. This means that the health professionals not only have to communicate about disease-oriented aspects but also to reorientate to a more life-oriented dimension (86), as one woman experienced and stated in this way: *We were talking about my thoughts – also regarding my daughter and things like that. And she was just there to talk to me for a while. I just felt they had time to talk to me, that it wasn't JUST about the disease, but also regarding concerns about other things* [4]. The ability to deliver person-centered care is heavily influenced by the context, which has the greatest potential to either limit or enhance the facilitation of this (87).

The findings from our study indicated that it was very important for the women to be treated as a person: *It is essential that you know who to talk to, that there are some persons who know you and know YOUR story... and who know what has happened to me* [8]. Verbal and non-verbal communication and use of the senses are effective tools to generate knowledge of the patients. This enables the health care provider to tailor a person-centered approach (for example the exact concerns related to the person in question) (88). Continuity in care was an important factor to some women: *I was very happy to see that it was the same nurse who had accompanied me to an earlier consultation, because I didn't need to spend much energy finding out who she was, what her name was and she didn't know how I reacted as I got the diagnosis. She did know and that mattered a lot to me* [1]. The perception is that the health professional knows you and knows your case history, but also that the communication can be based on former conversations and that future care and communications are informed by that.

Situational awareness can be seen as a part of person-centered care: *I shouldn't be in the hospital, because all other patients are admitted and discharged, but I didn't feel well and wanted to stay until Thursday. The doctor told me on Wednesday, when I crouched down in my bed. You don't look well; I think you need one more day in here. JUST that HE told me. That I didn't have to ASK for it* [4]. This signifies that situational awareness is very important in relation to person-centered care, but also that awareness of the patient's needs without him or her having to express them is very important.

Person-centered care is prominently positioned on the political agenda especially related to discussions about quality of care. Lost in many of these discussions are the different perspectives on what person-centered means. Thus, patients are known as persons in the context of their own world, which needs to be considered through good communication.



#### 6.5.3.4. TO BE PART OF A SYSTEM

Another finding in this study was related to being part of a system. According to the German philosopher Jürgen Habermas the modern society is divided into a system world and a life world, respectively. In his terminology the health care system is part of the system world (89). The system world is organised according to economy and administration and human action is formal and impersonal and does not presuppose understanding of the situations women are experiencing in connection with, for example, surgical continuity of care for breast cancer: *In the communication the focus was only on practical issues. You have breast cancer; you are going to have chemotherapy and surgery. Fine, that is important too, but they didn't ask about how I felt.....I wasn't able to focus on practical issues, because of my emotional situation that was present* [1]. This quotation from the present study reveals that the given health professional did not incorporate the perspective of the woman's life world, which is the world in which the woman lives. In this world human action is based on mutual understanding of the situation (89). According to Habermas (89), the tendency is that the system world dominates the life world, which is expressed in terms of accelerated continuity of care, nursing practice based on standards, accreditation and so on. A person-centered communication may be overlooked or even impossible in the system world: *It was fantastic that everything went so fast, but it was as if I couldn't keep my head about me .....I couldn't make head or tail of it all. I was ver shocked* [2]. This quotation indicates that accelerated continuity of care (for example, waiting for test results, surgery or adjuvant therapy) is a positive thing, but the metaphor used in this quotation also exemplifies that this woman did not really understand what was going on. Failure to reduce waiting times can cause a lot of distress: *The waiting time was awful.....I just froze; I waited almost four month. I was sad and completely froze in myself the way I was feeling. I couldn't pull myself together. I just sat there every day, just always looking in the letter box for a letter. It is the worst thing that I have ever experienced. It was this waiting time* [5]. A lot of distress was expressed here, and that influenced all aspects of this woman's life. She used the freezing metaphor to indicate that this was all she could do – sit and wait for a letter to inform her if she needed more investigations telling her that she might have breast cancer. In contrast, reduced waiting times and treating the women as persons, taking their life world into account, can lead to reduced levels of distress: *Friday I communicated with nurses and doctors and was prepared for surgery. It went very very well, there was little waiting time and all my questions were answered* [2].

If the system world colonises the life world, there may be a risk that nursing practice is based mainly on standards, which can cause distress: *I got so many papers, books, brochures, questionnaires and all that stuff..... groups for this and groups for that, I thought, oh my god this is really serious* [6], indicating that every woman, regardless of who she is, receives the same information no matter what. This quote also exemplifies that failure to give person-centered information may increase the person's level of distress. According to Remmers et al. (7), the patients

desire to be treated as individual persons and to feel that their personal needs and wishes are being addressed. Therefore, health care providers need to be sensitive and not just do what the standards tell them to do, as stated in this quotation: *They didn't tell you anything, when you had surgery. You were just discharged. You didn't know if they had taken all the lymph nodes or not. I asked if they had taken all my lymph nodes or not, but they just told me that everything went well. That isn't an answer. I asked to get a clear answer, but I didn't feel that I got an answer. Then I just went home to wait and wait - again* [11]. This woman clearly experienced being part of a system world which failed to take her life world into account, resulting in impersonal communication and consequently increased distress.

This finding points to how important it is for health care professionals to take an active part in strengthening the life world of the patients in order to thus achieve a more person-centered clinical practice, which may influence distress among women taking part in surgical continuity of care for breast cancer.

## 6.6 ETHICAL CONSIDERATIONS

The overall study was approved by the Data Protection Agency (journal number 2008-58-0028). This study was not reported to an ethic committee, as it is not subjected to approval by ethics committees in Denmark. The ethical guidelines for nursing research in the Nordic countries were followed throughout the study (90).

All participants were given information orally and in writing about the study and its purposes (Appendix E). All participants consented to their participation. Confidentiality and anonymity in the processing of the information collected in the research project was underlined and assured. Data materials were stored in a locked room and on my personal computer that only could be unlocked by a personal code.

The participants kindly and voluntarily agreed to participate in this project at a time point in their lives that may be considered particularly sensitive and vulnerable and the participants may be considered particularly exposed. They were given my e-mail address and telephone number, which they could use if they required further contact or information about the study. I had made agreements with all the participating departments in case a participant needed further support or counseling. All the participants were informed that they could withdraw from participation at any time with no consequences. It was considered whether the burden placed on the participants by the survey and the interview was reasonable.

# CHAPTER 7. DISCUSSION

In this section, the results of studies II and III are merged and discussed with reference to previously conducted research. The research process, design and methods of the studies, including strengths and limitations, are subsequently discussed followed by a conclusion and perspectives for surgical continuity of care for breast cancer, including implications for clinical practice.

## 7.1. DISCUSSION OF FINDINGS

This study has led to more key findings. One result concerns the level of distress among women taking part in surgical continuity of care for breast cancer in 11 sites of breast cancer surgery in Denmark. Another result concerns the evolution of distress, and a third points to predictors or factors associated with distress. These results are complemented with a more in-depth depiction and interpretation of women's experiences of distress in relation to surgical continuity of care for breast cancer.

### 7.1.1. PREVALENCE OF DISTRESS

The frame of reference based on equal measurement instrument and classifications of scores (0-3, 4-6 and 7-10 on the DT) allowed for comparison of results concerning prevalence in study II and the study of Agarwal et al. (51) at the time of diagnosis. The results, however, differed with regard to the prevalence. Study II did not support the results of Agarwal et al. (51) which showed that the majority of all participants reported either no or minor distress (42%) or moderate distress (42%), whereas only a smaller proportion of women reported severe distress (16%). Contrary to this result, study II indicated that 39.8 % of the women were severely distressed, 29.1 % were moderately distressed whereas 24.3 % were categorised as experiencing no or minor distress. Some of this divergence may stem from different measurement time point, even though this can only explain some of the inconsistency. The participants in study II were asked to complete questionnaire I, including the DT, just after receiving the diagnosis of breast cancer and bring it along to the next visit to the hospital, which was a maximum of 14 days later. Thus, a limitation of study II is that the exact number of days between diagnosis and administration of the DT is unknown. In the study by Agarwal et al. (51) the median interval from diagnosis to administration of the DT was 13 days for those reporting severe distress, 25 days for participants reporting moderate distress and 45 days for patients expressing minor or no distress. Therefore, the results of our study and the study of Agarwal et al. (51) are consistent in revealing that most women are severely distressed at the time of diagnosis.

The proportion of women in study II with DT scores  $\geq 7$  (39.8 %) supports the results of Mertz et al. (50), who demonstrated that 43 % had DT levels  $\geq 7$  at the time of diagnosis. They also calculated the proportion of distressed women using 3 as a cut-off score based on an investigation of the accuracy of a Danish version of the DT. They argued that a cut-off score of 2 versus 3 on the DT was optimal for ruling out distress with a sensitivity of 99 % and a specificity of 36 %, and that a cut-off score of 6 versus 7 was optimal for diagnosing distress with a sensitivity of 81 % and a specificity of 79 % (91). When using a cut-off score of 3 on the DT, 77 % of the women were identified as being distressed (50). However, a review regarding validation of the DT worldwide indicated that a cut-off score of 4 was determined to be indicative of clinically significant distress (72). Study II complemented the results of Mertz et al. (50) partly by the contributing knowledge from a more general perspective in the Danish population, partly by dividing distress into no or minor distress, moderate and severe distress, respectively. This classification intended to present a more varied picture of distress among women taking part in surgical continuity of care for breast cancer. These categorizations were assessed as important with regard to needed support and care in clinical practice, as this may differ depending on the category to which a woman belongs. If only one cut-off score, such as 3, is utilised, the level of distress may be very different for, for example, a score of 4 or a score of 9, even though they belong to the same category. The same is valid if the cut-off point is 7; there may be a big difference between a score of 1 and a score of 6 on the DT. Even though the level of distress did not differ much among studies using the DT Hegel et al. (52) reported a mean score of 4.8 (SD 2.6), Mertz et al. (50) showed a mean score of 5.4 (SD 3.1) and the mean score in study II was 5.5 (SD 2.9), a varied categorisation may make the experience of distress more clear. Generally, there is a lack of uniformity in cut-off scores even though scores usually range from 3-5. This is supported by Hegel et al. (52), who used the cut-off point  $> 5$  to indicate clinically meaningful distress levels. In that study the proportion of women who scored  $> 5$  was 96 (41 %).

### **7.1.2. CHANGE IN DISTRESS**

Only a few studies have examined the change in distress in connection with surgical continuity of care for breast cancer. The results of study II indicated the presence of distress, although small, during surgical continuity of care for breast cancer. By investigating how much distress evolves over time this study complemented the existing knowledge of changes in distress during surgical continuity of care, as studies investigating distress at its peaks through surgical continuity of care using the DT was not found. However, Andreu et al. (46) measured distress at similar time points during surgical continuity of care. On the one hand, the results of Andreu et al. (46) are not directly comparable with the results from study II, as two different measurement tools were used. On the other hand, it was stated that the mean distress level (15.97) was significantly higher at preliminary diagnosis than at

surgery. Thus, it is not clearly explicated whether the mean distress level was high, low, or moderate. That the level of distress is higher at the time of diagnosis is consistent with the results of study II. This may be due to the overwhelming experience of being diagnosed with a potentially life-threatening disease. At the time of diagnosis women are aware of the malignancy of the tumour, but they do not necessarily have knowledge of the aggressiveness or spread of the disease. Women who otherwise feel that they are in good health are suddenly forced to confront their own mortality. The fear of dying is overwhelming regardless of a good prognosis (7), which is in accordance with the findings in study III. They experience uncertainty and anticipation of severe consequences and the women go through a period of extreme anxiety. However, Andreu et al. (46) found no change in the mean distress level from the time of surgery (13.28) to the time of test results based on pathology (13.27) in comparison to a small reduction in distress in study II. One of the reasons for this difference may be the distribution of women having mastectomy versus the women having lumpectomy. In the study of Andreu et al. (46) the percentage of women having mastectomy was 66 % compared to 23.7 % in study II, and 34 % had lumpectomy compared to 72.9 % in study II. This may have affected the results, even though study II could not demonstrate that surgery method was a predictor of distress. Andreu et al. (46) also indicated that the level of distress differed between persons over the four assessments times in relation to how many times each person was considered clinically distressed. It was concluded that approximately five in ten women reported clinical distress at two or more times. In continuation of this result study II revealed that for most women the level of distress did not change during surgical continuity of care, for some the level of distress increased, and for others it decreased. This confirms that distress is experienced differently by different women and at different time points during surgical continuity of care for breast cancer. It also expands our understanding that distress is a personal matter that needs to be taken into consideration in connection with surgical continuity of care to qualify support and care.

### **7.1.3. FACTORS ASSOCIATED WITH DISTRESS**

As revealed in this research study several factors may affect distress in connection with surgical continuity of care for breast cancer. In study II time was found to be a significant predictor of distress at diagnosis and over time. Andreu et al. (46) also found that time was a significant predictor of distress from the time of diagnosis to surgery, but in that study the level of distress did not change in later stages as evidenced in study II.

The aspect of how women generally respond to and manage difficult situations are often not elucidated or taken into consideration in other studies. In study II prior emotional status was a significant predictor of distress, as those reporting that they normally felt good at handling difficult situations decreased in distress from time of

diagnosis to end of surgical continuity of care compared to those who did not report being good handling difficult situations. This effect supported the results of Iwatani et al. (44), who stated that trait anxiety was a significant predictor of distress after the diagnosis of breast cancer. However, trait anxiety was measured by HADS and it can be discussed whether this measurement tool elucidates trait anxiety. The results of study II confirms that trait anxiety or previous emotional status needs to be considered in the assessment of distress. In tune with this result, study II provided information that the level of distress decreased over time for women who did not have a prior or current intake of antidepressant or sedative medicine compared to women who previously or currently were treated with antidepressant or sedative medicine.

Distress seemed to be positively affected by age at the time of diagnosis, as older women were less distressed than younger women. These results support the results of Mertz et al. (50), who demonstrated a significant inverse association between distress and age; higher age was associated with lower levels of distress. This is also in accordance with the study of Miller et al. (40), who indicated that older women > 65 reported less emotional distress prior to surgery than women < 65. By investigating the distress evolution study II complemented that distress is positively affected by age at time of diagnosis, but its reduction from the time of diagnosis to the end of surgical continuity of care seemed to be negatively affected by it. Study III enhanced the understanding of distress with reference to age, as both younger and older women experienced distress. Distress seemed to be independent of age, but different factors associated with distress were present. One woman > 80 years old experienced distress because fatigue meant that she could not take part in her usual activities, while a younger women felt distressed due to concern about her children. In some cases women belonging to the older age group expressed distress both verbally and non-verbally while one woman in the age group < 40 did not express particular distress. Independent of age there may be inter-individual differences in how women experience and deal with distress in relation to breast cancer.

As seen in study II, having children living at home affected the level of distress at the time of diagnosis. Study III expanded the understanding of the effect of having children living at home. It pointed out that talking about children was a very sensitive topic that affected the level of distress, and this supports the findings of Landmark et al. (19) that women with newly diagnosed breast cancer have concerns about their children. Deshields et al. (92) indicated that women who are depressed have several children living at home. Study III supplemented this by indicating that women with breast cancer felt they were letting their children down if they were unable to fulfil their mothering role as usual. Their identity as mothers was at risk of changing, which could be very distressing. The findings of study III further pointed out that being viewed as a patient in the health care system and not as a mother suffering from breast cancer could imply that the

women's identity as mothers was no longer bound up to the mothering role, which could cause distress. It seemed very important to the women that they were treated as persons and not just as patients, or put in another way, that their life world was incorporated into the system world.

Study II indicated that the degree to which the women felt sexually attractive affected their level of distress. Women who did not at all or only to a minor extent feel sexually attractive at the time of diagnosis had a higher mean score on the DT compared to those feeling sexually attractive to a higher extent. Study III enhanced the understanding of the effect of sexual attractiveness on distress, as it could be difficult to still feel sexual attractive, regardless of the surgery method used. Women having lumpectomy also felt less sexual attractive. It was further illuminated that feeling sexually inattractive would affect a woman's sexual relationship with her husband as it was transcendent to taking off her clothes in front of him. This extends the understanding that an altered body image might be independent of surgery method indicating that body image is a complex phenomenon to consider in clinical practice. The experience of not being feminine also affected the level of distress at the time of diagnosis. Study II revealed that feeling feminine to a minor extent or not at all increased distress compared to women who felt feminine to a higher extent, even though this was not significant in the full analysis model. This result is supported and nuanced by the findings of study III which indicated that having a breast removed could lead to the feeling of being amputated and in consequence loss of femininity. These findings support the findings of Remmers et al. (7), who indicated that self-perception, sense of femininity and attractiveness were combined with insecurity and grief.

Study II revealed that the mean distress level and changes in the level of distress were affected by the hospital at which the women were treated. In one hospital, distress increased compared to other hospitals. However, the differences were not significant at the time of diagnosis, but rather from the time of diagnosis to the end of surgical continuity of care. Thus, in the final analysis one hospital remained associated with reduced distress indicating that organizational factors as for example a high level of person-centered support and care may affect distress.

## **7.2. DISCUSSION OF RESEARCH PROCESS, DESIGN AND METHODS**

### **7.2.1. STUDYING OWN AREA**

Being an experienced nurse in breast cancer care may have increased the risk that my pre-understanding has affected the findings of this study. In survey studies the researcher may be involved in the development of items and response options and in interview studies the researcher may be involved in the whole process of

generating data (93). It may increase the risk of reproducing common sense knowledge and avoid questions or elaborating on important information. On the other hand the questions may be more relevant and thorough because the researcher has considerable knowledge about the subject. Nevertheless, the researcher needs to be conscious of such pre-understanding (77). In this study my preunderstanding was discussed with my supervisor and assistant supervisors and colleagues, and dealt with in the construction of the questionnaire as health care professionals contributed with input and feedback. In the analytical part of the interview study the themes were derived independently by the supervisor and the researcher and subsequently discussed.

### **7.2.2. MIXED METHODS**

The main advantages of conducting mixed methods research was that using neither quantitative data nor qualitative data alone could provide a better understanding of distress in connection with surgical continuity of care for breast cancer. The use of mixed methods in study I intended to explore factors affecting distress and to make sure that the questionnaire actually fitted the women taking part in surgical continuity of care. Furthermore, the use of mixed methods research provided knowledge about distress from a broad perspective of the Danish population in study II and enhanced this understanding with a more in-depth perspective in study III. The joint discussion integrated these two perspectives to create a better understanding and more comprehensive view on distress among women taking part in surgical continuity of care for breast cancer.

Even though the mixed methods design has potential advantages it may be at the expense of the depth of the research, as the scope of a PhD project is limited. For example, it could have been beneficial to expand and elaborate on a more deeply operational definition of distress. Furthermore, it could have been rewarding to expand and elaborate on the effect of hospitals on distress. Another disadvantage that may affect the depth of the research is that the researcher is required to possess knowledge and skills of quantitative, qualitative and mixed methods research. Although there are advantages of mixed methods research, for example providing different insights from different perspectives and combining these to obtain a more comprehensive view of the research problem, there are also limitations which must continuously be considered.

Mixed methods research is not necessarily better research; rather it is an approach employed to address the purposes of the research, which may lead to the use of different methods. However, the data needs to be processed in relation to the different methods. Therefore, one point of discussion is the different epistemological stances that a mixed methods study may address. This issue has been widely discussed (59,63,64,94). Instead of discussing the incompatibility of



the different epistemological instances, it is important just to acknowledge that different methods generate different outcomes. This point of view is supported by Morgan (63) and Biesta (64) who ascertain the importance of focusing on the research problem and the relevant methods rather than on different epistemological stances. By default, this research has a pragmatic view and considers the epistemological stances to be complementary and compatible.

Given that no instrument was found for measuring distress among women taking part in surgical continuity of care for breast cancer it was relevant to conduct study I and study II in their individual sequences. However, a sequential design is time-consuming as the data of study I had to be collected and analysed before study II could be initiated. Reversely, the linear character of this design assisted in the time management as it was not possible to start study II before study I was completed. Having a part in the overall study that reflected the convergent design was time-saving. However, to be able to merge the data, which consisted of both numeric and text-based data, it was important to keep in mind the parallel construction of both studies. With the time frame and the parallel construction in mind, the priorities and choices made throughout the research were continuously considered and adjusted.

### **7.2.3. STUDY I**

The literature review revealed lack of consensus regarding the definition of distress, although distress exists as a readily understood concept. The absence of a universal definition has led to the use of generic and ad hoc designed instruments in order to measure distress. Many words that were synonymous with distress were used, for example psychological distress, psychosocial distress, emotional disturbance, strain, stress, concern, anxiety and depression, but these were not explicitly defined (95). Therefore, the development of a questionnaire that measures distress and factors affecting it was rather complex, especially due to the lack of consensus of distress and the broad definition.

When measuring a multidimensional construct the researcher must have knowledge of the underlying conceptual model, because it determines which measurement theory should be used in the validation process. Measurement theories are used to describe the statistical relationship between the items and the construct (37). In this study the underlying relationship was based on both a reflective and a formative model. However, there is no well-developed measurement theories for cases where the underlying relationship is formative and therefore the development is merely based on common sense (37). On the other hand, a number of criteria support the validation with regard to whether the questionnaires provide valid scores for women taking part in surgical continuity of care for breast cancer, which is a continuous process. Validity is defined as: the

degree to which an instrument truly measures the construct it purports to measure (96). Even though this seems to be a simple definition there is an ongoing discussion as to how validity should be assessed and how its results should be measured. Thus, validity can be difficult to judge with regard to such an unobservable construct as distress. According to Raykov & Marcoulides (58), there is no single approach to constructing questionnaires which is always applicable and yields a satisfactory measuring instrument. Nevertheless, there are three different types of validity which should be taken into consideration when developing a new instrument (37); content validity, criterion validity and construct validity.

Content validity refers to whether the content of an instrument is an adequate reflection of the construct to be measured (96). According to de Vet et al. (37), questionnaires based on a formative model imply that all items that contribute substantially to the construct should be included. To meet that criterion we used more methods in the development phase to identify items affecting distress. Quotes, themes and domains that were derived from the analysis of the different data sets were used in the development of scales and items.

The studies using qualitative methods found in the literature review were assumed to cover the perspective of the key respondents, namely the women taking part in surgical continuity of care. Still, it may be argued that an interview study with women taking part in surgical continuity of care would have further qualified the study by supplementing the findings from the literature review. Nevertheless, quotes and themes from study III were used in the validation process and indicated that the questionnaire to a great extent covered factors affecting distress based on the different methods, with the exception of waiting time. For some informants in study III waiting time induced severe distress during surgical continuity of care for breast cancer.

One of the methods used to supplement the content of the questionnaires was a focus group interview. The aim of the focus group interview with nurses was to assist in eliciting data based on their diversity of experiences to supplement the perspective on women taking part in surgical continuity of care. One ethical issue is the fact that all experiences in a focus group interview are shared with the moderator and the other participants, which may have influenced the discussions. In that respect the participants should at least be comfortable with each other and the moderator. This goal was attempted fulfilled by explicating the ground rules for participating in this focus group, reaffirming that there were no right or wrong answers and underlining the confidentiality of the study (68,97). On the one hand, hierarchical issues among the nurses may have influenced the discussions. On the other hand, the participants were believed to be comfortable as they seemed engaged in the discussions. Homogeneity is considered favourable with regard to group composition (67). This group may have been too homogenous as the

participants had been working together in the same department for at least two years. However, the group participants displayed different experiences and opinions.

It is recommended that the content validity is assessed by experts and by the researchers who will use the questionnaire, as the developers are often biased with regard to their own instrument (37). In an attempt to prevent this, the questionnaire was assessed by various health professionals from six departments of breast surgery in Denmark before it was further adjusted and pilot tested by the experts, which were representatives of the target population. The pilot test included 18 consecutive women taking part in surgical continuity of care for breast cancer. According to de Vet et al. (37) a small number of patients could be tested. In addition, the participants were debriefed. However, it could be argued that the debriefing was too superficial, because the participants were not asked about each item, which would have been preferable. The pilot test gave rise to further adjustments and, as described earlier, the development of three questionnaires instead of one. One of the main limitations of this study is that the questionnaires after further adjustment based on the pilot test should have been pilot tested again before the field test (37) and this research project.

Criterion validity is defined as the degree to which the scores of a measurement instrument adequately reflect a golden standard (96). However, this implies that a gold standard is available, which is rarely the case for instruments measuring patient-reported outcomes (37). It is argued that a global rating scale such as for example the DT can be a suitable criterion, or an acceptable gold standard might be the long version of a questionnaire for a shortened version of the questionnaire (37). In validation studies on distress the HADS is often used as a gold standard. However, the HADS only measures anxiety and depression even though distress is assessed to be a much broader construct than the former. With regard to the National Comprehensive Cancer Network's definition of distress no gold standard was found. In cases where a gold standard does exist it can be discussed why it is necessary to develop a new similar instrument.

Construct validity refers to the degree to which the scores of a measurement instrument are consistent with the hypotheses, for example with regard to internal relationship, relation to scores derived from other instruments or differences between relevant groups (96). As stated earlier the relationship between the construct and the items was based on both a reflective and a formative model, which means that the items do not necessarily have to be correlated. Usually factor analysis is used to measure construct validity; however this is not applicable for questionnaires based on formative models (37). Instead of seeking a high correlation structure and a high internal consistency, it was considered more important to group items which made good clinical sense (71).

#### 7.2.4. STUDY II

It can be discussed whether the new developed questionnaires provide valid scores and are able to present valid inferences. On the one hand, the questionnaires were used to answer research questions and, on the other hand they were used to draw inferences about the validity of the answers. This may question the interpretation of the results. Even though it is argued that there is no gold standard for measuring distress, other studies have indicated similar trends with regards to distress as pointed out in study I. This is even though they have not used a measurement specific to women taking part in surgical continuity of care for breast cancer. Prior to study II the questionnaires were to some extent content validated. However, this process is ongoing and the questionnaires need further adjustment following study II before they can be used in clinical practice. Another issue for discussion is whether the questionnaires are based on a formative model or a reflective model. The construct of distress and the items may reveal complex interrelationship, and therefore it can be difficult to determine whether some items are causal indicators or effect indicators (66). (Appendix F). For example it may be difficult to determine whether the item 'I feel sick precedes distress or vice versa.

The strength of study II was the large sample size recruited from different departments in Denmark. However, the response rate of approximately 70 % for women having completed a questionnaire at all three time points was low even though it was acceptable. Indeed, any level of nonresponse can, but need not, induce nonresponse bias in survey estimates. There are three major types of unit nonresponse; failure to deliver survey request, refusal to participate and inability to participate (74). Failure to deliver survey request may be caused by the following: business in the different departments, the survey did not make sense to the employees, they found the information to the possible participants to be too overwhelming, or the information about the study was insufficient. Refusal or inability to participate can to a great extent be related to for example the length of the questionnaires or the level of difficulty; the developers had attempted to take this into account, though. In addition, participants who have just been diagnosed with breast cancer are in a very vulnerable position, which may leave no surplus of resources to participate in the study. However, since the reasons for the lack of ability, capacity or resources to comply with the survey request are varied, statistics affected by non-response may be varied as well (74). Apart from unit nonresponse, the survey also displayed item non-response, which occurs when the response to a single item is missing (74). Item non-response was evident primarily with regard to sensitive items such as sexuality and body image. Contrary, many women did extend their responses by writing notes on the questionnaires. Some women did even tell their stories in the questionnaires. Non-response was also present with items related to organisational factors such as the duration of hospitalisation. The latter could be due to poorly formulated items.

The strength of the study is also its longitudinal design, as a questionnaire was distributed several times during surgical continuity of care. We demonstrated that there was a mean decrease in the level of distress during surgical continuity of care, and we indicated that some predictors affected distress over time. The maximum time period between measurement times was a couple of weeks, which may affect the change. According to de Vet et al. (37) the time period is not relevant, as long as it can be expected that during that time period at least a proportion of the women will improve or deteriorate with regard to distress. Study II was able to demonstrate small changes. However, a limitation of this study is that the exact time period from one of the three measurement time points to the time of administration of the appurtenant questionnaire is unknown. In addition, it may have induced some recall bias, as the women may have completed two different questionnaires within just a couple of days or even less.

The strength of study II is that it was performed in 11 departments of breast surgery in Denmark, which should somehow be representative of the breast cancer population in Denmark. However, the sample size from some of the departments was very small. In addition, the participants were between 38 and 89 years of age with a mean age of 60 years. The main group of participants was women > 59 years, which could indicate that younger women were less represented. On the contrary, the majority of women who get breast cancer are above the age of 59 years (27). In addition, the majority of participants had lumpectomy, which may lead to an underestimation of distress.

### **7.2.5. STUDY III**

The sampling strategy in study III was purposive. The 12 informants were asked to elaborate on their survey responses in order to get a deeper understanding of their experience of distress. The criteria for this strategy were heterogeneity regarding distress, possible changes in distress, age, surgery method and sites of treatment. This information had to be ascertained in advance. However, it was considered important that the interviews were made while the respondents underwent surgical continuity of care. It was assumed that having started adjuvant treatment could confuse their experiences of distress during surgical continuity of care with experiences of distress related to adjuvant treatment. The time period from answering the third questionnaire by the time of test results based on pathology and until the start of adjuvant treatment was only a couple of weeks. Nevertheless one informant had just started chemotherapy, which was first acknowledged in the interview situation. To consent participating the women were asked to write down their phone number on one of the questionnaires in study II. Even though the majority of the women provided their phone number, a limitation may be that the women experiencing severe distress did not want to participate. However, women who had reported different levels of distress on the DT were included. Qualitative

samples are usually small in size. Statements about for example prevalence are not of concern in qualitative research. This is in sharp contrast to survey samples which needs to be of an adequately size to draw precise statistical inferences (98).

The success of the interview depends, to a high degree, on the personal and professional qualifications of the interviewer. Contrary to quantitative survey research, qualitative research interviewers are research instruments (77,99). In study II the researcher did the interviews, and it can be discussed whether or how this has influenced the data generation, as the interviewer has been working with breast cancer patients for many years and, in addition, has a theoretical perspective on the topic. It can be argued that being knowledgeable about distress in relation to breast cancer may reduce the neutrality and objectivity of the research (77). However, an interview is never neutral as the interviewer always has a preunderstanding that influences the interview, and which enables him or her to ask the right questions (77). Nevertheless, it was considered important to enter the interview situation with an open mind partly to further explore the informants' answers from study II and partly to discover new aspects of distress in relation to surgical continuity of care for breast cancer based on the experiences of individuals. One of the tools used to ensure that the interviewer's preunderstanding did not control the interview situation to too large an extent was to avoid leading questions and instead pursue the expressions that seemed important to the individual interviewees (69). Often the interviewer did not have to ask the prepared questions to receive answers, but simply listen to the women. This is often the case if an interviewer utilises an interview guide that is based on knowledge about the topic (77).

In the analytical process the themes derived from the interview text were derived independently by the interviewer and the supervisor, respectively and subsequently discussed. This was meant to challenge the preunderstanding of the interviewer and to enhance the suitability of the analysis and interpretation. According to Ricoeur (100), one interpretation is just one of several probable interpretations. An interpretation depends on the argument that gives credibility and validity to the interpretation. By following the three steps (naïve reading, structural analysis, and critical analysis and discussion) in the process of interpretation, the interpretation will hopefully become transparent to the reader and thereby created credibility. The aim was not to judge different interpretations, but to identify the most appropriate interpretation based on the interviews and thereby get a deeper understanding of distress in relation to surgical continuity of care for breast cancer.

## CHAPTER 8. CONCLUSION

This research has made a contribution to the existing knowledge on distress among women taking part in surgical continuity of care for breast cancer in Denmark. It has provided quantitative descriptions of the distribution of distress and changes in the level of distress during surgical continuity of care as well as highlighted predictors of distress. In addition, the qualitative contribution has elaborated on distress and in a joint discussion enhanced the understanding of distress. Furthermore, this research has produced a questionnaire that can help identify women with distress and factors associated with distress for the individual women. Based on the objectives of this research it is concluded that:

- Three questionnaires have been developed encompassing comprehensive factors that are important for distress among women taking part in surgical continuity of care for breast cancer. They have been initially content validated. However, the questionnaires have to be further adjusted in response to the field test.
- More than two-thirds of the study population were distressed at the time of diagnosis of breast cancer. Approximately 40 % experienced severe distress whereas 30 % suffered from moderate distress, and 25 % reported no or low distress. In particular, younger women, women who were married and/or had children living at home, were employed and/or had a higher level of education were likely to experience distress.
- The overall mean distress level decreased slightly during surgical continuity of care. However, the changes in distress varied widely among the individual women. For most of the women, distress remained at the initial level during surgical continuity of care, whereas it worsened for a number of women and decreased for others.
- Predictors of distress were time since diagnosis, age, children living at home, prior emotional status, and feelings regarding sexual attractiveness and one hospital remained associated with reduced distress.
- Women taking part in surgical continuity of care experienced distress, as they were undergoing a period of extreme anxiety. In addition, their identities as women and mothers were changed. To get a feeling of support it was important for the women to be treated as persons in a caring humanistic way, which involved the perspective of the life world of each person.

## CHAPTER 9. PERSPECTIVE

Distress has been linked to suffering, reduced quality of life and hospital admission. However, individuals vary with regard to distress and the capacity to cope. Two women who report the same symptom may express different need of help. This discordance may be due to disease factors, socio-demographic factors, psychological and social variables or expectations based on previous health care experiences (101). Given that distress can be experienced by every person who suffers from breast cancer, identification of distress and factors associated with distress must be recommended in order to provide adequate support. Different and varied support is needed to target the complex and multifaceted distress in women with breast cancer. This may reduce the consequences of distress for each person and most likely contribute to a reduction in health care costs.

Overall, the length of hospital stays has decreased (31,102), reducing the available direct medical surveillance period. Our research points to a need for a more person-centered care in order to improve surgical continuity of care and thus reduce distress. The National Comprehensive Cancer Network has developed consensus-based guidelines for managing distress; here screening for distress is pivotal (103). Based on our findings, the Distress Thermometer is a simple, easily administrated and inexpensive tool that is able to identify women with varied levels of distress in a Danish population. It can contribute to the aim that no woman with distress goes unrecognised and untreated, and it may even prevent inequality in continuity of care. It seems important to monitor distress – not only in surgical continuity of care, but also during adjuvant treatment and at changes in disease status. Given that sources of distress are potentially varied, our questionnaires enable women to indicate the specific sources of distress at particular time points. The questionnaires can contribute to a more person-tailored and time-saving communication with regard to the specific sources of distress. However, the questionnaires must be adjusted and further validated before use in clinical practice. Further research is required to identify the most effective approaches to implementing distress screening and management of distress sources in clinical settings and to further evaluate the outcomes based on this. Our study indicated that one hospital remained associated with reduced distress. However, further research is required to explore the reasons for this. Our study is limited to the time frame of surgical continuity of care and it would be favourable to expand the time frame to include adjuvant treatment in order to follow the distress evolution during active treatment.



# LITERATURE LIST

(1) GLOBOCAN 2012: Estimated Cancer Incidence; Mortality and Prevalence Worldwide in 2012. . Accessed 2/23, 2015.

(2) Tal og analyse: Cancerregisteret 2013. . Accessed 2/23, 2015.

(3) Mols F, Vingerhoets AJ, Coebergh JW, van de Poll-Franse LV. Quality of life among long-term breast cancer survivors: a systematic review. *Eur J Cancer* 2005 Nov;41(17):2613-2619.

(4) Lietzen LW, Sorensen GV, Ording AG, Garne JP, Christiansen P, Norgaard M, et al. Survival of women with breast cancer in central and northern Denmark, 1998-2009. *Clin Epidemiol* 2011;3 Suppl 1:35-40.

(5) Kvalitetsindikatorrapport for Brystkræft 2013. Landsdækkende Klinisk Kvalitetsdatabase for Brystkræft.

(6) Kræftoverlevelse i Danmark 1998-2012. . Accessed 2/23, 2015.

(7) Remmers H, Holtgrawe M, Pinkert C. Stress and nursing care needs of women with breast cancer during primary treatment: a qualitative study. *Eur J Oncol Nurs* 2010 Feb;14(1):11-16.

(8) Oxlad M, Wade TD, Hallsworth L, Koczwara B. 'I'm living with a chronic illness, not . . . dying with cancer': a qualitative study of Australian women's self-identified concerns and needs following primary treatment for breast cancer. *Eur J Cancer Care (Engl)* 2008 Mar;17(2):157-166.

(9) Dunn LB, Langford DJ, Paul SM, Berman MB, Shumay DM, Kober K, et al. Trajectories of fear of recurrence in women with breast cancer. *Support Care Cancer* 2014 Dec 19.

(10) Colagiuri B, Christensen S, Jensen AB, Price MA, Butow PN, Zachariae R. Prevalence and predictors of sleep difficulty in a national cohort of women with primary breast cancer three to four months postsurgery. *J Pain Symptom Manage* 2011 Nov;42(5):710-720.

(11) Kjaer TK, Johansen C, Ibfelt E, Christensen J, Rottmann N, Hoybye MT, et al. Impact of symptom burden on health related quality of life of cancer survivors in a Danish cancer rehabilitation program: A longitudinal study. *Acta Oncol* 2011 Feb;50(2):223-232.

- (12) McGarry S, Ward C, Garrod R, Marsden J. An exploratory study into the unmet supportive needs of breast cancer patients. *Eur J Cancer Care (Engl)* 2013 Sep;22(5):673-683.
- (13) Denieffe S, Cowman S, Gooney M. Symptoms, clusters and quality of life prior to surgery for breast cancer. *J Clin Nurs* 2014 Sep;23(17-18):2491-2502.
- (14) Manganiello A, Hoga LA, Reberte LM, Miranda CM, Rocha CA. Sexuality and quality of life of breast cancer patients post mastectomy. *Eur J Oncol Nurs* 2011 Apr;15(2):167-172.
- (15) Debess J, Riis JO, Pedersen L, Ewertz M. Cognitive function and quality of life after surgery for early breast cancer in North Jutland, Denmark. *Acta Oncol* 2009;48(4):532-540.
- (16) Fann JR, Thomas-Rich AM, Katon WJ, Cowley D, Pepping M, McGregor BA, et al. Major depression after breast cancer: a review of epidemiology and treatment. *Gen Hosp Psychiatry* 2008 Mar-Apr;30(2):112-126.
- (17) Vahdaninia M, Omidvari S, Montazeri A. What do predict anxiety and depression in breast cancer patients? A follow-up study. *Soc Psychiatry Psychiatr Epidemiol* 2010 Mar;45(3):355-361.
- (18) Budden LM, Hayes BA, Buettner PG. Women's decision satisfaction and psychological distress following early breast cancer treatment: a treatment decision support role for nurses. *Int J Nurs Pract* 2014 Feb;20(1):8-16.
- (19) Landmark BT, Bohler A, Loberg K, Wahl AK. Women with newly diagnosed breast cancer and their perceptions of needs in a health-care context. *J Clin Nurs* 2008 Apr;17(7B):192-200.
- (20) Waldrop DP, O'Connor TL, Trabold N. "Waiting for the other shoe to drop:" distress and coping during and after treatment for breast cancer. *J Psychosoc Oncol* 2011;29(4):450-473.
- (21) Holland JC, Breitbart WS, Compas B, Dudley MM, Fulcher CD, Greiner CB, et al. Distress Management Clinical Practice Guidelines in Oncology. *JNCCN, Journal of the National Comprehensive Cancer Network* 2013;11(2):190-209.
- (22) Fitch MI. Screening for distress: a role for oncology nursing. *Current Opinion in Oncology* 2011;23(4):331-337.

- (23) Snowden A, White CA, Christie Z, Murray E, McGowan C, Scott R. The clinical utility of the distress thermometer: a review. *Br J Nurs* 2011 Feb 24-Mar 9;20(4):220-227.
- (24) Montgomery M, McCrone SH. Psychological distress associated with the diagnostic phase for suspected breast cancer: systematic review. *J Adv Nurs* 2010 Nov;66(11):2372-2390.
- (25) Vitek L, Rosenzweig MQ, Stollings S. Distress in patients with cancer: definition, assessment, and suggested interventions. *Clin J Oncol Nurs* 2007 Jun;11(3):413-418.
- (26) Ziegler L, Hill K, Neilly L, Bennett MI, Higginson IJ, Murray SA, et al. Identifying psychological distress at key stages of the cancer illness trajectory: a systematic review of validated self-report measures. *J Pain Symptom Manage* 2011 Mar;41(3):619-636.
- (27) Vejborg I, Mikkelsen E, Garne JP, Bak M, Lernevall A, Mogensen NB, et al. Mammography screening in Denmark. *Dan Med Bull* 2011 Jun;58(6):C4287.
- (28) Pakkeforløb for brystkræft 2012. 2012.
- (29) Hainsworth AJ, Lobo CR, Williams P, Case C, Surridge F, Sharma AK, et al. '23 h Model' for breast surgery: an early experience. *Breast* 2013 Oct;22(5):898-901.
- (30) Mertz BG, Kroman N, Williams H, Kehlet H. Fast-track surgery for breast cancer is possible. *Dan Med J* 2013 May;60(5):A4615.
- (31) Marla S, McMillan DC, Stallard S. Factors influencing postoperative length of hospital stay after breast cancer surgery. *Breast* 2013 Jun;22(3):289-294.
- (32) de Kok M, van der Weijden T, Kessels AG, Dirksen CD, Sixma HJ, van de Velde CJ, et al. Patients' opinions on quality of care before and after implementation of a short stay programme following breast cancer surgery. *Breast* 2010 Oct;19(5):404-409.
- (33) Holen M, Ahrenkiel A. 'After all, you should rather want to be at home': Responsibility as a means to patient involvement in the Danish health system. *Journal of Social Work Practice* 2011;25(3):297-310.
- (34) Ranieri E, Caprio G, Fobert MT, Civitelli L, Ceccarelli F, Barberi S, et al. One-day surgery in a series of 150 breast cancer patients: efficacy and cost-benefit analysis. *Chir Ital* 2004 May-Jun;56(3):415-418.

- (35) Kroman N, Christiansen P, Hussain ZB, Kehlet H. Breast cancer surgery in Denmark. *Ugeskr Laeger* 2010 Oct 11;172(41):2836-2839.
- (36) Danish Breast Cancer Cooperative Group. Retningslinjer: Kirurgisk behandling. 2013; . Accessed 03/03, 2015.
- (37) de Vet HC, Terwee CB, Mokkink LB, Knol DL. *Measurement in Medicine A practical Guide*. Cambridge: Cambridge University Press; 2011.
- (38) Wewers ME, Lowe NK. A critical review of visual analogue scales in the measurement of clinical phenomena. *Res Nurs Health* 1990 Aug;13(4):227-236.
- (39) Montgomery GH, Bovbjerg DH. Presurgery distress and specific response expectancies predict postsurgery outcomes in surgery patients confronting breast cancer. *Health Psychol* 2004 Jul;23(4):381-387.
- (40) Miller SJ, Schnur JB, Weinberger-Litman SL, Montgomery GH. The relationship between body image, age, and distress in women facing breast cancer surgery. *Palliat Support Care* 2014 Oct;12(5):363-367.
- (41) Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983 Jun;67(6):361-370.
- (42) McCorry NK, Dempster M, Quinn J, Hogg A, Newell J, Moore M, et al. Illness perception clusters at diagnosis predict psychological distress among women with breast cancer at 6 months post diagnosis. *Psychooncology* 2013 Mar;22(3):692-698.
- (43) Costa-Requena G, Rodriguez A, Fernandez-Ortega P. Longitudinal assessment of distress and quality of life in the early stages of breast cancer treatment. *Scand J Caring Sci* 2013 Mar;27(1):77-83.
- (44) Iwatani T, Matsuda A, Kawabata H, Miura D, Matsushima E. Predictive factors for psychological distress related to diagnosis of breast cancer. *Psychooncology* 2013 Mar;22(3):523-529.
- (45) Derogatis LR, Melisaratos N. The Brief Symptom Inventory: an introductory report. *Psychological Medicine* 1983;13:595-605.
- (46) Andreu Y, Galdon MJ, Dura E, Martinez P, Perez S, Murgui S. A longitudinal study of psychosocial distress in breast cancer: prevalence and risk factors. *Psychol Health* 2012;27(1):72-87.

#### LITERATURE LIST

- (47) Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher H, Holland J. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;82(10):1904-1908.
- (48) Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *Journal of Clinical Oncology* 2007;25(29):4670-4681.
- (49) Bidstrup PE, Mertz BG, Dalton SO, Deltour I, Kroman N, Kehlet H, et al. Accuracy of the Danish version of the 'distress thermometer'. *Psychooncology* 2012 Apr;21(4):436-443.
- (50) Mertz BG, Bistrup PE, Johansen C, Dalton SO, Deltour I, Kehlet H, et al. Psychological distress among women with newly diagnosed breast cancer. *Eur J Oncol Nurs* 2012 Sep;16(4):439-443.
- (51) Agarwal J, Powers K, Pappas L, Buchmann L, Anderson L, Gauchay L, et al. Correlates of elevated distress thermometer scores in breast cancer patients. *Support Care Cancer* 2013 Aug;21(8):2125-2136.
- (52) Hegel MT, Moore CP, Collins ED, Kearing S, Gillock KL, Riggs RL, et al. Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer. *Cancer* 2006 Dec 15;107(12):2924-2931.
- (53) Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *British Journal of Psychiatry* 2002;180:205-209.
- (54) Chen CM, Cano SJ, Klassen AF, King T, McCarthy C, Cordeiro PG, et al. Measuring quality of life in oncologic breast surgery: a systematic review of patient-reported outcome measures. *Breast J* 2010 Nov-Dec;16(6):587-597.
- (55) Hjerl K, Andersen EW, Keiding N, Mortensen PB, Jorgensen T. Increased incidence of affective disorders, anxiety disorders, and non-natural mortality in women after breast cancer diagnosis: a nation-wide cohort study in Denmark. *Acta Psychiatr Scand* 2002 Apr;105(4):258-264.
- (56) Weinberger T, Forrester A, Markov D, Chism K, Kunkel EJ. Women at a dangerous intersection: diagnosis and treatment of depression and related disorders in patients with breast cancer. *Psychiatr Clin North Am* 2010 Jun;33(2):409-422.
- (57) Bitsika V, Sharpley CF, Christie DRH. 'What made me unhappy': experiences of, and responses to, lifestyle changes in breast cancer patients. *British Journal of Guidance and Counselling* 2010;38(2):179-189.

- (58) Raykov T, Marcoulides GA. Introduction to Psychometric Theory. New York: Routledge Taylor & Francis Group; 2011.
- (59) Creswell JW. A Concise Introduction to Mixed Methods Research. : SAGE Publications, Inc.; 2015.
- (60) Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res 2013 Dec;48(6 Pt 2):2134-2156.
- (61) Bacon M. Pragmatism An Introduction. : Polity Press; 2012.
- (62) Houser N, Klosel C editors. The Essential Peirce, Volume 1: Selected Philosophical Writings? (1867-1893). : Indiana University Press; 1992.
- (63) Morgan DL. Paradigm Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. Journal of Mixed Methods 2007;1(1):48-76.
- (64) Biesta G. Pragmatism and the philosophical foundations of mixed methods research. In: Tashakkori A, Teddlie C, editors. Mixed Methods in Social and Behavioral Research. 2.th ed.: SAGE Publications; 2010. p. 95-117.
- (65) Johnson RB, Onwuegbuzie AJ. Mixed Methods Research: A Research Paradigm Whose Time Has Come. Educational Research 2004;33(7):14-26.
- (66) Fayers PM, Hand DJ, Bjordal K, Groenvold M. Causal indicators in quality of life research. Qual Life Res 1997 Jul;6(5):393-406.
- (67) Kitzinger J. Introducing focus groups. British Medical Journal 1995:299-302.
- (68) Morgan DL. Focus Group as Qualitative Research. Research Methods: SAGE; 1997. p. 32-46.
- (69) Kvale S, Brinkmann S. Interviewanalyse med focus på mening. Interview Introduction til et håndværk. 2nd ed. København: Hans Reitzels Forlag; 2009. p. 223-242.
- (70) National Institute of Health USA.gov. Patient-Reported Outcomes Measurement Information System (PROMIS). . Accessed 03/04, 2015.
- (71) Fayers PM, Hand DJ. Factor analyses, causal indicators and quality of life. Quality of Life Research 1997;6(2):139-150.

#### LITERATURE LIST

(72) Donovan KA, Grassi L, McGinty HL, Jacobsen PB. Validation of the distress thermometer worldwide: state of the science. *Psychooncology* 2014 Mar;23(3):241-250.

(73) Fowler FJ. *Survey Research Methods*. 4th ed.: SAGE; 2009.

(74) Groves RM, Fowler FJ, Couper MP, Lepkowski JM, Singer E, Tourangeau R. *Nonresponse in Sample Surveys*. Survey Methodology New Jersey: Wiley-Interscience; 2004. p. 169-200.

(75) Hermansen M, Rendtorff JD editors. *En hermeneutisk brobygger*. Aarhus: Forlaget Klim; 2002.

(76) Ricoeur P. *Fortolkningsteori*. København: Vinten; 1979.

(77) Tanggaard L, Brinkmann S. *Interviewet: Samtalen som forskningsmetode. Kvalitative metoder*. En grundbog København: Hans Reitzels Forlag; 2010. p. 29-54.

(78) Tewari A, Chagpar AB. Worry about breast cancer recurrence: a population-based analysis. *Am Surg* 2014 Jul;80(7):640-645.

(79) Lebel S, Beattie S, Ares I, Bielajew C. Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychol* 2013 Jun;32(6):695-705.

(80) Sheppard VB, Harper FW, Davis K, Hirpa F, Makambi K. The importance of contextual factors and age in association with anxiety and depression in Black breast cancer patients. *Psychooncology* 2014 Feb;23(2):143-150.

(81) Tiedtke C, de Rijk A, Dierckx de Casterle B, Christiaens MR, Donceel P. Experiences and concerns about 'returning to work' for women breast cancer survivors: a literature review. *Psychooncology* 2010 Jul;19(7):677-683.

(82) Fisher C, O'Connor M. "Motherhood" in the context of living with breast cancer. *Cancer Nurs* 2012 Mar-Apr;35(2):157-163.

(83) Falk Dahl CA, Reinertsen KV, Nesvold IL, Fossa SD, Dahl AA. A study of body image in long-term breast cancer survivors. *Cancer* 2010 Aug 1;116(15):3549-3557.

(84) Przewdziecki A, Sherman KA, Baillie A, Taylor A, Foley E, Stalgis-Bilinski K. My changed body: breast cancer, body image, distress and self-compassion. *Psychooncology* 2013 Aug;22(8):1872-1879.

(85) McCabe C. Nurse-patient communication: an exploration of patients' experiences. *J Clin Nurs* 2004 Jan;13(1):41-49.

(86) Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model: sharing decision-making in chronic care. *Qual Health Res* 2008 May;18(5):670-685.

(87) McCormack B. Person-centredness in gerontological nursing: an overview of the literature. *J Clin Nurs* 2004 Mar;13(3a):31-38.

(88) Bundgaard K, Nielsen KB, Delmar C, Sorensen EE. What to know and how to get to know? A fieldwork study outlining the understanding of knowing the patient in facilities for short-term stay. *J Adv Nurs* 2012 Oct;68(10):2280-2288.

(89) Habermas J. The theory of communicative action Volume 2 Lifeworld and system: A critique of functionalist reason. . Accessed 03/04, 2015.

(90) Northern Nurses' Federation. Ethical guidelines for nursing research in the Nordic countries. 2003.

(91) Bidstrup PE, Mertz BG, Dalton SO, Deltour I, Kroman N, Kehlet H, et al. Accuracy of the Danish version of the 'distress thermometer'. *Psychooncology* 2012 Apr;21(4):436-443.

(92) Deshields T, Tibbs T, Fan M, Taylor M. Differences in patterns of depression after treatment for breast cancer. *Psychooncology* 2006;15(5):398-406.

(93) Schmidt L, Dyhr L. Det kvalitative forskningsinterview. In: Koch L, Vallgård S, editors. *Forskningsmetoder i folkesundhedsvidenskab* København: Munksgaard Danmark; 2003. p. 27-48.

(94) Brannen J. Mixing Methods: The Entry of Qualitative and Quantitative Approaches into the Research Process. *International Journal of Social Research Methodology* 2005;8(3):173-184.

(95) Schubart JR, Emerich M, Farnan M, Stanley Smith J, Kauffman GL, Kass RB. Screening for psychological distress in surgical breast cancer patients. *Ann Surg Oncol* 2014 Oct;21(10):3348-3353.

(96) Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol* 2010 Jul;63(7):737-745.

(97) Morrison-Beedy D, Cote-Arsenault D, Feinstein NF. Maximizing results with focus groups: moderator and analysis issues. *Appl Nurs Res* 2001 Feb;14(1):48-53.



#### LITERATURE LIST

(98) Richie J, Lewis J, Elam G. Designing and Selecting Samples. In: Richie J, Lewis J, editors. : SAGE; 2009. p. 77-107.

(99) Legard R, Keegan J, Ward K. In-depth Interviews. In: Ritchie J, Lewis J, editors. *Qualitative Research Practice A Guide for Social Science Students and Researchers*: SAGE; 2009. p. 138-170.

(100) Ricoeur P. The hermeneutical function of distanciation. *Philosophy Today* 1973;17(2):129-141.

(101) Fiszer C, Dolbeault S, Sultan S, Bredart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology* 2014 Apr;23(4):361-374.

(102) Marla S, Stallard S. Systematic review of day surgery for breast cancer. *Int J Surg* 2009 Aug;7(4):318-323.

(103) Holland JC, Andersen B, Breitbart WS, Compas B, Dudley MM, Fleishman S, et al. Distress Management Clinical Practice Guidelines in Oncology. *Journal of the National Comprehensive Cancer Network* 2010;8:448-485.

# APPENDICES

Appendix A: Content validation of distress questionnaire

Appendix B: Interview guide for focus group interview

Appendix C: The questionnaires

Appendix D: Interview guide for the individual interview

Appendix E: Patient information

Appendix F: Causal versus effect indicators

## APPENDIX A

Quotations from focus group interview	Quotations and domains from literature search	Corresponding survey items <sup>1</sup>	Quotations from survey	Quotations from interview
<p>"Fear of death.... can I be cured.... has the cancer spread?"</p> <p>"Then the "wagonload" toppled"</p> <p>"The problem is waiting time"</p>	<p>Sadness (Mertz et al., 2012)</p> <p>Hopelessness (Vitek et al., 2007)</p> <p>"That word cancer....a fear of death. Suddenly I was sick. I am afraid of the operations and what is going to happen in the future" (Saares et al., 2005)</p> <p>"I was really in the dark, I didn't know what to do and what to think" (Saares et al., 2005)</p>	<p>I feel sad (item 1)</p> <p>I am afraid of the future (item 5)</p> <p>I feel difficult thinking of other things than my disease (item 23)</p> <p>I experience hopelessness (item 24)</p>	<p>"The rug was pulled out under me" (ID 418)</p> <p>"Waiting time is distressing. I can't even blame the health professionals. They are doing all they can, I think. I think it is an important indicator of distress" (ID 359)</p> <p>"One moment every-thing is chaotic - the next moment I think everything will be all right" (ID 720)</p> <p>"I feel sickened" (ID 839)</p>	<p>"What are you going to go through.... life is over" (Informant 12)</p> <p>"It is fear of death" (Informant 9)</p> <p>"It was the uncertainty about my future (Informant 1)</p>
<p>"When am I fully recovered?"</p>	<p>Working conditions (Damkjær et al., 2011)</p>	<p>I worry about my future working conditions (item 32)</p>	<p>"I thought that I could start working, but I am in a position where my colleagues are dependent on me" (ID 545)</p>	<p>I am concerned about me job situation. Do I have a job to come back to. Do they dismiss me? That is distressing me. Do I have a job, when I have finished treatment?" (Informant 2)</p>
<p>"They have no surplus energy"</p>	<p>Practical problems (Mertz et al., 2012; Vitek et al., 2007)</p> <p>"At first I felt that I was spending all my energies supporting my husband and children" (Saares et al., 2005)</p>	<p>I worry about practical condition at home (item 34)</p>	<p>"I feel sad because of my transportation problems for treatment" (ID 523)</p> <p>"I feel my family is my biggest burden" (ID 749)</p>	<p>"How is it going to work at home? I can't just be sick, because then everything is going to be a mess at home. Oh no, here will not be cleaned" (Informant 4)</p>
<p>"They can't concentrate"</p> <p>"They don't remember what they are told"</p>	<p>Cognitive function (Debress et al., 2009)</p>	<p>I experience difficult concentrating (item 13)</p> <p>I have difficult remembering (item 14)</p>	<p>"Got too little information but there are things that I don't remember" (ID 14)</p> <p>"I came alone to the consultations but looking back I should have been followed by one, because I did not remember all the information" (ID 537)</p>	
<p>"It is as if they shut everything out of their minds"</p>		<p>I feel alone even if I am not alone (item 31)</p> <p>I avoid other people because of my appearance (item 44)</p>	<p>"I try to avoid different social situations, but I am not sure it is because of my appearance. I think it is because I am afraid of breaking down when other people are present" (ID 336)</p>	
<p>"They need the continuous dialogue whether it is the same health professionals or not"</p>	<p>Communication (Turner et al., 2005)</p> <p>Feeling well cared for (Arving et al., 2006)</p>	<p>I get emotional support from health professionals (item 26)</p> <p>I feel that the health professionals are talking with me about my situation (item 29)</p> <p>I get emotional support from family and/or friends (item 25)</p>	<p>"I didn't turn to them" [the health professionals] (ID 273)</p> <p>"There have not been many possibilities" [to talk with them] (ID 279)</p> <p>"I was at home and did not have any contact" (ID 278)</p> <p>"The experience of being taken care of imbued"</p>	<p>"The doctor was really really good" (Informant 10)</p> <p>"It is nice to think of that people are around me who worry about me" (Informant 10)</p> <p>"It means a lot to me, that I have got support from family and friend" (Informant 10)</p>

DISTRESS AMONG WOMEN TAKING PART IN SURGICAL CONTINUITY OF CARE FOR BREAST CANCER

			<p>continuity of care for breast cancer in [mention the name of the hospital], but at the other hospital you were left to your own device" (ID 726)</p> <p>"I do not wish emotional support" (ID 755)</p> <p>"I do not have any family or friends" (ID 879)</p>	
<p>"I had a young women and it was the worst we could tell her" [that she had to have her breast removed]</p> <p>"It means different to each individual"</p>	<p>Body image (Schou et al., 2005)</p> <p>"I'm lucky I have my breast because I don't know how I would feel if I lost one of my breasts (McGarry et al., 2013)</p>	<p>I was satisfied with my body before I got breast cancer (item 39)</p> <p>I am satisfied with my body when I am dressed (item 40)</p> <p>I am satisfied with my body when I am naked (item 41)</p> <p>I feel feminine (item 42)</p>	<p>"No interest in fulfilling these questions my age taking into account" [about body image] (ID 436)</p> <p>"Do not dare to look at myself very often" (ID 446)</p>	<p>"Before i got surgery i thought it would not mean anything to me to lose my breast. Of course it will" (Informant 1)</p> <p>"I was neither pretty nor feminine" (Informant 2)</p> <p>When you are amputated you can't feel feminine" (Informant 12)</p>
<p>"It is very difficult to summon strength to a second surgery"</p>		<p>I need a second surgery in my breast (item 64)</p> <p>I need another surgery in my armpit (item 65)</p> <p>Because spread of cancer cells were found in sentinel nodes, all the lymph nodes were removed (item 70)</p>	<p>"I don't know" [if cancer cells were found in the lymph nodes] (ID 291)</p> <p>"I have had surgery three times - last time my breast was removed" (ID 612)</p> <p>"I don't know if they have found spread of cancer cells during the surgery" (ID 360)</p>	<p>"It was first later that I found out that I might have a second surgery" (Informant 1)</p> <p>"When I got the message, that I needed another surgery, arggg" (Informant 4)</p>
<p>"They have no sense of belonging"</p>		<p>I have a contact doctor (item 55)</p> <p>I have a contact nurse (item 56)</p>	<p>"I did meet different people every time I had contact" (ID 279)</p> <p>"On the paper"(ID 667)</p> <p>"No, but I feel well informed and taken care of" (ID 572)</p>	<p>"I was glad that it was the same nurse as I had seen before, then I didn't have to tell everything again" (Informant 1)</p> <p>"I have met five or six nurses but this didn't matter, because they were all professionals" (Informant 10)</p>
<p>"When I tell them [the patients] that they are going to be discharges one or two days after surgery many of them express that this is too early"</p>		<p>I felt safe at discharge (item 66)</p>	<p>"I wasn't safe at discharge because it was short of information from a doctor. The doctor that had operated me had gone home and there were no other doctors" (ID 308).</p> <p>"I should have been hospitalized for one night" (ID 589)</p>	<p>"I just had surgery and had just been discharged, and I was afraid of getting sick when i got home.... anxious of feeling bad (Informant 1)</p> <p>"I have suddenly been discharged and there is no one to take care of me" (informant 2)</p>
	<p>Pain (Mertz et al., 2012; Törer et al., 2010)</p>	<p>I experience pain (item 49)</p>	<p>"I got pain killers for 10 -12 day after surgery" (ID 593)</p>	<p>"I was afraid not to take painkillers" (Informant 10)</p>
	<p>Sleep difficulties (Mertz et al., 2012; Colagiuri et al., 2011)</p>	<p>I feel difficult sleeping (item 48)</p> <p>I have difficulties fallen asleep right away (item 47)</p>		<p>"If I sleep well at night then I have more energy during the day" (Informant 7)</p>
	<p>Fatigue (Turner et al.,2005; Groenvold et al., 2007)</p>	<p>I feel tired (item 45)</p> <p>The tiredness means that I can't participate in normal activities (item 46)</p>	<p>"I feel totally exhausted" (ID 900)</p>	<p>"The diagnosis has caused at lot of fatigue" (Informant 12)</p>
	<p>Depression (Fann et al., 2008; Christensen</p>	<p>Have you ever or now been treated with</p>	<p>"Related to depression this [breast cancer]"</p>	

DISTRESS AMONG WOMEN TAKING PART IN SURGICAL CONTINUITY OF CARE FOR BREAST CANCER

	et al., 2009) Loss of interest (Peuckmann et al., 2009) Daily activities (Arving et al., 2006)	sedative or anti depression medicine (no item number) I have lost interest in daily activities (item 9)	is minor distressing" (ID 291) "I get sedative medicine now. I feel physical okay when I get the medicine. If I don` t get them I cry all the time" (ID 428)	
	The need of knowledge (Turner et al., 2005; Landmark et al., 2008) I was kept up to date all the time (Saares et al., 2005)	I get appropriate information (item 67) I get too much information(item 68) I get too little information (item 69)	"Overwhelming with all that information who have to deal with when you just got the diagnosis" (ID 359) "Can` t answer these questions because my brain deactivated" (ID 14)	"In this department you don` t get any pamphlets or anything else (Informant 11) "The health professionals were so geared in their answers" (Informant 8)
	"To appreciate, the act of love making again. Coz I` m finding that difficult.....I` ll be glad when things are back to normal again" (Oxlad et al., 2007)	I feel sexual attractive (item 36) I am satisfied with my sexual life (item 37)	"I have a husband that is sick of cancer" (ID306) "I do not have a sexual life anymore" (ID 551) "I don` t think of sex in the moment" (ID 692)	All my sexy under- wear and something like that - I can throw it away, because I am never feeling sexy again when I wear this" (informant 4)

<sup>1</sup>Response options were: 1=to a great extent, 2=to some extent, 3=to a minor extent and 4=not at all.  
A few questions could only be answered with yes or no.

<sup>2</sup>[ ] Words placed by the author

## APPENDIX B

Endnu en gang tak fordi I vil deltage. Målet for fokusgruppeinterview er ikke at opnå konsensus eller overensstemmelse mellem jer, men at få forskellighederne frem. Hensigten er, at det overordnet er jer der skal diskutere emnet indbyrdes ved at udfordre hinandens svar, inspirere og forløse formulering af synspunkter eller erfaring, men jeg vil guide og stimulere med spørgsmål ved behov samt sikre at vi holder os til emnet. Desuden er min rolle at få uddybet jeres forskellige erfaringer så emnets kompleksitet udforskes, ved behov præcisere det der bliver sagt og sikre at I alle får mulighed for at komme til orde.

Jeg stiller nu et indledende spørgsmål, som jeg vil bede jer om at drøfte indbyrdes

**Startspørgsmål:** Hvad kommer I umiddelbart til at tænke på, når jeg siger kvinder med nydiagnosticeret brystkræft?

**Citat:** *"På det tidspunkt havde jeg ikke fået svar på lungebilledet, så min bekymring var også, om der var spredning dertil"*

Hvad oplever I "fylder" hos/optager/belaster kvinderne, når de får diagnosen?

**Citat:** *"Følelsesmæssigt, menneskeligt er der jo ikke nogen støtte. At man får et behandlingstilbud og det har været godt, det har været fint, men der er jo ikke noget med at...jamen nu står du der og er ung og har små børn og er lige pludselig dødelig syg, jamen har du så ikke brug for nogen at snakke med, nej der er ikke noget tilbud på nogen måder. Der var heller ingen der spurgte til om jeg kunne få børnene passet. Ingen har snakket med mig om, hvordan jeg har det, det var sådan mere det fysiske det drejede sig om"*

Hvordan reagerer kvinderne, når de får diagnosen? Hvilke følelser kommer til udtryk?

Hvad oplever I "fylder" hos/optager/belaster kvinderne, når de informeres om det kirurgiske indgreb?

Hvordan reagerer de i forhold til det kirurgiske indgreb? Hvilke tanker udtrykker de?

Hvordan kommer en eventuel ændring af kvindernes bodimage/kropsopfattelse/feminitet/ seksualitet til udtryk?

**Citat:** *" Ingen har snakket med mig om, hvad det betyder at miste brystet. Der er ingen der har snakket direkte med mig om betydningen af at miste brystet, men det var måske også min egen skyld"*

Hvilken betydning har ventetiden mellem mammografi og forundersøgelsen for kvinderne? Hvordan beskriver kvinderne den tid?

Hvordan oplever de ventetiden fra diagnosetidspunktet til indlæggelsestidspunktet?  
Hvordan beskriver de tiden?

Hvordan oplever de ventetiden fra operationen til mikroskopisvaret?

Hvordan beskriver de ventetiden?

Hvordan påvirker/belaster det kvinderne, at de skal opereres igen, fordi der ikke var frie resektionsrande eller spredning til sentinel node?

Hvad oplever I eller kunne I forestille jer har betydning for kvinderne i forhold til organisatoriske faktorer? (eksempelvis i forhold til tid med personalet, indlæggelsestid, indlæggelsessted, ambulante forløb versus indlæggelsesforløb, kontinuitet, sygeplejefaglige kompetencer, fysiske rammer etc.)

**Citat:** *"Så ventede jeg en time og tre kvarter. Altså den ventetid, den giver bare følelsen af er vi glemt eller er det bare dårlig planlægning det her eller hvad er det for noget. Det kan simpelthen ikke passe, at man skal kaldes over og så sidde så lang tid på at komme ind og tale med en læge og sygeplejerske. Det er faktisk rimelig lang tid at sidde i en stol, når man er forholdsvis nyopereret"*

**Citat:** *"Det gør i hvert fald lige at man ser tiden an, går det her væk af sig selv, skal jeg nu tisse, så er det virkelig eller er det bare min fornemmelse. Det gør at man lige venter inden man forstyrrer personalet. Jeg ventede længe inden jeg kaldte, for jeg kunne godt mærke, at de har travlt"*

**Citat:** *"Jeg spurgte, hvad må jeg med den arm. Jeg skulle snakke med en fysioterapeut dagen efter, så det kunne jeg få at vide der. Jamen, hvad må jeg så indtil der. Føler ikke personalet er kompetente i forhold til det jeg er der for"*

**Citat:** *Der har ikke været nogen der har været min kontaktperson. Der har aldrig været en gennemgående person"*

**Citat:** *"Så kom receptionisten, som jo også er sygeplejerske og så til mit dræn til natten. Det var den kontakt jeg havde med personalet"*

**Citat:** *"De (sygeplejerskerne) var der ikke ret meget. Altså der var en aftenvagt, hvor jeg slet ikke så en sygeplejerske"*

#### **Afslutningsspørgsmål:**

Er der andet I gerne vil uddybe eller tilføje i forhold til emnet eller de drøftelser vi har haft?

Mange tak for jeres velvilje til at dele jeres erfaringer.

## APPENDIX C

# SPØRGESKEMA



Mammakirurgisk Klinik

AALBORG UNIVERSITETSHOSPITAL



## Spørgeskema til kvinder med nylig diagnosticeret brystkræft

Dato: \_\_\_\_\_ Evt. telefonnr.: \_\_\_\_\_

Navn: \_\_\_\_\_ Cpr. nr.: \_\_\_\_\_

**Jeg behandles for brystkræft i:** (sæt venligst kryds)

- |                                    |                                   |                                   |
|------------------------------------|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> Esbjerg   | <input type="checkbox"/> Randers  | <input type="checkbox"/> Aabenraa |
| <input type="checkbox"/> Holstebro | <input type="checkbox"/> Ringsted | <input type="checkbox"/> Aalborg  |
| <input type="checkbox"/> Hjørring  | <input type="checkbox"/> Vejle    | <input type="checkbox"/> Aarhus   |
| <input type="checkbox"/> Odense    | <input type="checkbox"/> Viborg   |                                   |

Mange kvinder oplever belastning i tiden, hvor de får konstateret brystkræft og i det kirurgiske pleje- og behandlingsforløb.

Særdeles belastet

10

9

8

7

6

5

4

3

2

1

0

Ikke belastet

Denne belastning kan blandt andet skyldes følelsesmæssige, fysiske og/eller sociale forhold.

*Sæt venligst kryds ved det tal mellem 0 - 10, som bedst beskriver hvor belastet du føler dig.*

Ved 0 føler du dig ikke belastet og ved 10 føler du dig særdeles belastet.

Udfyld herefter venligst spørgeskemaet, som du finder på de følgende sider.

Jeg er gift eller samboende Ja  Nej   
 Jeg er aleneboende Ja  Nej   
 Jeg har børn? Ja  Nej   
*Hvis ja*  
 Hjemmeboende børn   
 Alder på barnet/børnene: \_\_\_\_\_   
 Udeboende børn   
 Alder på barnet/børnene: \_\_\_\_\_   
  
 Jeg har gået i skole i: 7 - 10 år?  11 - 13 år?  mere end 13 år?   
  
 Jeg er i arbejde Ja  Nej   
 Jeg er i arbejde, men sygemeldt Ja  Nej   
 Jeg er arbejdssøgende/arbejdsløs Ja  Nej   
 Jeg er efterlønsmodtager Ja  Nej   
 Jeg er pensionist Ja  Nej   
  
 Jeg kender nogen, som har eller har haft brystkræft? Ja  Nej   
  
**Hvilken operation skal du gennemgå?**  
 Brystbevarende operation og fjernelse af enkelte lymfekirtler/skildvagslymfekirtler i armhulen Ja  Nej   
 Brystbevarende operation og fjernelse af alle lymfekirtler i armhulen Ja  Nej   
 Fjernelse af brystet og enkelte lymfekirtler/skildvagslymfekirtler i armhulen Ja  Nej   
 Fjernelse af brystet og alle lymfekirtler i armhulen Ja  Nej   
 Fjernelse af alle lymfekirtler i armhulen Ja  Nej   
 Genopbygning/rekonstruktion af brystet Ja  Nej   
 Har du fået kemoterapi inden operationen Ja  Nej   
 Har du fået anti hormonbehandling inden operationen Ja  Nej   
 Har du fået strålebehandling inden operationen Ja  Nej

Lider du af andre sygdomme (end brystkræft)?

Ja

Nej

Hvis ja

Hvilke(n): \_\_\_\_\_

\_\_\_\_\_

Hvilken medicin får du nu? \_\_\_\_\_

\_\_\_\_\_

Har du på noget tidspunkt i dit liv været i behandling med beroligende, angstdæmpende eller antidepressiv medicin?

Ja

Nej

Tænk på hvordan sygdommen/diagnosen har påvirket dig.

Venligst vurder hvordan nedenstående 4 udsagn var **før** du fik brystkræft

	I høj grad	I nogen grad	I mindre grad	Slet ikke
01. Jeg bekymrer mig ofte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. Jeg plejer let at blive nervøs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. Jeg lider af angst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. Jeg har let ved at håndtere vanskelige situationer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vurder venligst nedenstående udsagn ud fra hvordan du har det **i denne tid**

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Følelsesmæssig situation</b>				
01. Jeg føler mig ked af det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. Jeg føler mig trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. Jeg føler mig ensom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. Jeg føler mig rådvild	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. Jeg er bange for fremtiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
06. Jeg bekymrer mig over ting som sædvanligvis ikke bekymrer mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. Bekymringerne overvælder mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. Jeg er anspændt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. Jeg mangler interesse for mine daglige gøremål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Jeg har selvtilid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I høj grad	I nogen grad	I mindre grad	Slet ikke
11. Jeg har dårlig samvittighed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Jeg har skyldfølelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Jeg har svært ved at koncentrere mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Jeg har problemer med at huske	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Jeg føler mig rastløs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Jeg føler mig i godt humør	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Jeg føler mig i stand til at nyde livet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Jeg er tilfreds med min livskvalitet lige nu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Jeg glæder mig over de ting, jeg sædvanligvis glæder mig over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Jeg er mere irriteret end jeg plejer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Jeg føler mig rolig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Jeg føler vrede	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Jeg har svært ved at tænke på andet end min sygdom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Jeg føler håbløshed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Sociale forhold**

25. Jeg får følelsesmæssig støtte fra min familie og/eller venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Jeg får følelsesmæssig støtte fra personalet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Jeg oplever, at venner eller familie har svært ved at tale med mig om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Jeg oplever, at jeg har svært ved at tale med andre om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Jeg oplever, at personalet taler med mig om min situation med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Jeg undgår steder med flere mennesker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Jeg føler mig alene, selvom jeg ikke er alene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Jeg bekymrer mig om min fremtidige arbejdssituation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Jeg bekymrer mig om min økonomiske situation efter at jeg har fået brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Jeg bekymrer mig om praktiske forhold i hjemmet efter min operation for brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Jeg har taget kontakt til eksempelvis Kræftens Bekæmpelse, De Brystopererede, unge grupper, café for unge, psykolog og/eller andre	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Seksualitet</b>				
36. Jeg føler mig seksuel attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Jeg er tilfreds med mit seksuelle liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Svar på spørgsmålet, hvis du har været seksuel aktiv: Jeg har taget initiativ til samleje/seksuelt samvær	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
<b>Body image/kropsopfattelse</b>				
39. Jeg <u>var</u> tilfreds med mit udseende, før jeg fik brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Jeg er tilfreds med mit udseende, når jeg er påklædt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Jeg er tilfreds med mit udseende, når jeg er nøgen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Jeg føler mig feminin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Jeg føler mig (fysisk) attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Jeg undgår andre mennesker på grund af mit udseende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Fysisk situation</b>				
45. Jeg er træt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Trætheden påvirker mine sociale aktiviteter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Jeg falder let i søvn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Jeg har problemer med at sove om natten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Jeg har smerter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Jeg har problemer med at bevæge min arm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Jeg mangler energi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Jeg føler mig syg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Jeg har nedsat appetit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Religiøse forhold</b>				
54. Jeg har en religiøs og/eller åndelig tro, som hjælper mig i situationen med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Organisatoriske forhold</b>				
55. Jeg har en kontaktlæge	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
56. Jeg har en kontaktsygeplejerske	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
57. Jeg har fået en passende information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
58. Jeg har fået for meget information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
59. Jeg har fået for lidt information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		

Tusind tak for din besvarelse



**Kontaktperson**

Lone Jørgensen  
Aalborg Universitetshospital  
Mammakirurgisk Klinik  
Sdr. Skovvej 3  
9000 Aalborg  
Tlf. 99 32 22 76 eller mobil 30 13 81 35  
Mail [lojo@rn.dk](mailto:lojo@rn.dk)



REGION NORDJYLLAND

# SPØRGESKEMA



Mammakirurgisk Klinik



AALBORG UNIVERSITETSHOSPITAL

## Spørgeskema til kvinder med nylig diagnosticeret brystkræft

Dato: \_\_\_\_\_ Evt. telefonnr.: \_\_\_\_\_

Navn: \_\_\_\_\_ Cpr. nr.: \_\_\_\_\_

**Jeg behandles for brystkræft i:** (sæt venligst kryds)

- |                                    |                                   |                                   |
|------------------------------------|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> Esbjerg   | <input type="checkbox"/> Randers  | <input type="checkbox"/> Aabenraa |
| <input type="checkbox"/> Holstebro | <input type="checkbox"/> Ringsted | <input type="checkbox"/> Aalborg  |
| <input type="checkbox"/> Hjørring  | <input type="checkbox"/> Vejle    | <input type="checkbox"/> Aarhus   |
| <input type="checkbox"/> Odense    | <input type="checkbox"/> Viborg   |                                   |

Mange kvinder oplever belastning i tiden, hvor de får konstateret brystkræft og i det kirurgiske pleje- og behandlingsforløb.

<b>Særdeles belastet</b>		<p>Denne belastning kan blandt andet skyldes følelsesmæssige, fysiske og/eller sociale forhold.</p> <p><b>Sæt venligst kryds ved det tal mellem 0 - 10, som bedst beskriver hvor belastet du føler dig.</b></p> <p>Ved 0 føler du dig ikke belastet og ved 10 føler du dig særdeles belastet.</p>
<b>Ikke belastet</b>		

Udfyld herefter venligst spørgeskemaet, som du finder på de følgende sider.



Har du fået anden medicin siden du udfyldte det første spørgeskema,  
 eksempelvis sovemedicin og/eller beroligende medicin? \_\_\_\_\_

Vurder venligst nedenstående udsagn ud fra hvordan du har det **i denne tid**

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Følelsesmæssig situation</b>				
01. Jeg føler mig ked af det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. Jeg føler mig trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. Jeg føler mig ensom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. Jeg føler mig rådvild	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. Jeg er bange for fremtiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
06. Jeg bekymrer mig over ting som sædvanligvis ikke bekymrer mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. Bekymringerne overvælder mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. Jeg er anspændt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. Jeg mangler interesse for mine daglige gøremål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Jeg har selvtillid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Jeg har dårlig samvittighed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Jeg har skyldfølelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Jeg har svært ved at koncentrere mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Jeg har problemer med at huske	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Jeg føler mig rastløs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Jeg føler mig i godt humør	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Jeg føler mig i stand til at nyde livet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Jeg er tilfreds med min livskvalitet lige nu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Jeg glæder mig over de ting, jeg sædvanligvis glæder mig over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Jeg er mere irriteret end jeg plejer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Jeg føler mig rolig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Jeg føler vrede	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Jeg har svært ved at tænke på andet end min sygdom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Jeg føler håbløshed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Sociale forhold</b>				
25. Jeg får følelsesmæssig støtte fra min familie og/eller venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Jeg får følelsesmæssig støtte fra personalet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Jeg oplever, at venner eller familie har svært ved at tale med mig om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Jeg oplever, at jeg har svært ved at tale med andre om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Jeg oplever, at personalet taler med mig om min situation med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Jeg undgår steder med flere mennesker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Jeg føler mig alene, selvom jeg ikke er alene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Jeg bekymrer mig om min fremtidige arbejdssituation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Jeg bekymrer mig om min økonomiske situation efter at jeg har fået brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Jeg bekymrer mig om praktiske forhold i hjemmet efter min operation for brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Jeg har taget kontakt til eksempelvis Kræftens Bekæmpelse, De Brystopererede, unge grupper, café for unge, psykolog og/eller andre	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
<b>Seksualitet</b>				
36. Jeg føler mig seksuel attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Jeg er tilfreds med mit seksuelle liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Svar på spørgsmålet, hvis du har været seksuel aktiv: Jeg har taget initiativ til samleje/seksuelt samvær	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
<b>Body image/kropsopfattelse</b>				
39. Jeg <u>var</u> tilfreds med mit udseende, før jeg fik brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Jeg er tilfreds med mit udseende, når jeg er påklædt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Jeg er tilfreds med mit udseende, når jeg er nøgen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Jeg føler mig feminin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Jeg føler mig (fysisk) attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Jeg undgår andre mennesker på grund af mit udseende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Fysisk situation</b>				
45. Jeg er træt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Trætheden påvirker mine sociale aktiviteter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Jeg falder let i søvn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Jeg har problemer med at sove om natten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Jeg har smerter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Jeg har problemer med at bevæge min arm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Jeg mangler energi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Jeg føler mig syg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Jeg har nedsat appetit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Religiøse forhold</b>				
54. Jeg har en religiøs og/eller åndelig tro, som hjælper mig i situationen med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Organisatoriske forhold</b>				
55. Jeg har en kontaktlæge	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
56. Jeg har en kontaktsygeplejerske	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
57. Kontaktlægen har været til stede ved:				
Forundersøgelsen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
Operationen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
58. Kontaktsygeplejersken har været til stede ved:				
Forundersøgelsen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
Klargøringsbesøget	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
Operationsdagen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
1. dag efter operationen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
2. dag efter operationen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
3. dag efter operationen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
59. På operationsdagen mødte jeg om morgenen og kom hjem i løbet af dagen/aftenen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
60. Jeg var indlagt fra d. _____ til d. _____				
61. Indlæggelsestiden var for lang	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
62. Indlæggelsestiden var for kort	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
63. Indlæggelsestiden var passende	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
64. Jeg var indlagt på patienthotel	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
65. Jeg var indlagt på en hospitalsafdeling	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		



- |  | I høj<br>grad               | I nogen<br>grad              | I mindre<br>grad         | Slet<br>ikke             |
|--|-----------------------------|------------------------------|--------------------------|--------------------------|
| 66. Jeg følte mig tryk ved udskrivelsen/hjemsendelsen  | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 67. Jeg har fået en passende information   | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |
| 68. Jeg har fået for meget information   | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |
| 69. Jeg har fået for lidt information  | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |
| 70. På grund af fund af kræftceller i lymfekirterne/<br>skildvagtlymfekirterne under operationen fik jeg fjernet<br>alle lymfekirtler i armhulen | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |
| 71. Jeg er tilfreds med udseendet af mit ar  | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |

**Tusind tak for din besvarelse**





**Kontaktperson**

Lone Jørgensen  
Aalborg Universitetshospital  
Mammakirurgisk Klinik  
Sdr. Skovvej 3  
9000 Aalborg  
Tlf. 99 32 22 76 eller mobil 30 13 81 35  
Mail [lojo@rn.dk](mailto:lojo@rn.dk)



REGION NORDJYLLAND

# SPØRGESKEMA



Mammakirurgisk Klinik



AALBORG UNIVERSITETSHOSPITAL

## Spørgeskema til kvinder med nylig diagnosticeret brystkræft

Dato: \_\_\_\_\_ Evt. telefonnr.: \_\_\_\_\_

Navn: \_\_\_\_\_ Cpr. nr.: \_\_\_\_\_

**Jeg behandles for brystkræft i:** (sæt venligst kryds)

Esbjerg

Randers

Aabenraa

Holstebro

Ringsted

Aalborg

Hjørring

Vejle

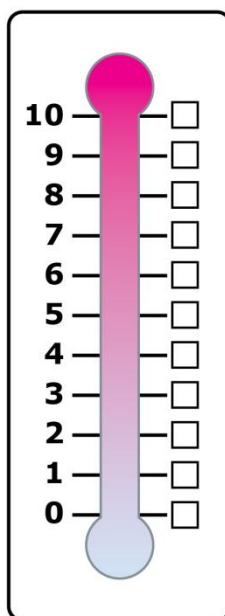
Aarhus

Odense

Viborg

Mange kvinder oplever belastning i tiden, hvor de får konstateret brystkræft og i det kirurgiske pleje- og behandlingsforløb.

Særdeles belastet



Ikke belastet

Denne belastning kan blandt andet skyldes følelsesmæssige, fysiske og/eller sociale forhold.

*Sæt venligst kryds ved det tal mellem 0 - 10, som bedst beskriver hvor belastet du føler dig.*

Ved 0 føler du dig ikke belastet og ved 10 føler du dig særdeles belastet.

Udfyld herefter venligst spørgeskemaet, som du finder på de følgende sider.

Har du fået anden medicin siden du udfyldte det første spørgeskema, eksempelvis sovemedicin og/eller beroligende medicin? \_\_\_\_\_

Vurder venligst nedenstående udsagn ud fra hvordan du har det **i denne tid**

	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Følelsesmæssig situation</b>				
01. Jeg føler mig ked af det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. Jeg føler mig trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. Jeg føler mig ensom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. Jeg føler mig rådvild	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. Jeg er bange for fremtiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
06. Jeg bekymrer mig over ting som sædvanligvis ikke bekymrer mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. Bekymringerne overvælder mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. Jeg er anspændt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. Jeg mangler interesse for mine daglige gøremål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Jeg har selvtillid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Jeg har dårlig samvittighed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Jeg har skyldfølelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Jeg har svært ved at koncentrere mig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Jeg har problemer med at huske	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Jeg føler mig rastløs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Jeg føler mig i godt humør	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Jeg føler mig i stand til at nyde livet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Jeg er tilfreds med min livskvalitet lige nu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Jeg glæder mig over de ting, jeg sædvanligvis glæder mig over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Jeg er mere irriteret end jeg plejer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Jeg føler mig rolig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Jeg føler vrede	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Jeg har svært ved at tænke på andet end min sygdom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Jeg føler håbløshed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Sociale forhold</b>				
25. Jeg får følelsesmæssig støtte fra min familie og/eller venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Jeg får følelsesmæssig støtte fra personalet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Jeg oplever, at venner eller familie har svært ved at tale med mig om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Jeg oplever, at jeg har svært ved at tale med andre om min sygdom/helbredstilstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Jeg oplever, at personalet taler med mig om min situation med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Jeg undgår steder med flere mennesker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Jeg føler mig alene, selvom jeg ikke er alene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Jeg bekymrer mig om min fremtidige arbejdssituation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Jeg bekymrer mig om min økonomiske situation efter at jeg har fået brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Jeg bekymrer mig om praktiske forhold i hjemmet efter min operation for brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Jeg har taget kontakt til eksempelvis Kræftens Bekæmpelse, De Brystopererede, unge grupper, café for unge, psykolog og/eller andre	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
<b>Seksualitet</b>				
36. Jeg føler mig seksuel attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Jeg er tilfreds med mit seksuelle liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Svar på spørgsmålet, hvis du har været seksuel aktiv: Jeg har taget initiativ til samleje/seksuelt samvær	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
<b>Body image/kropsopfattelse</b>				
39. Jeg <u>var</u> tilfreds med mit udseende, før jeg fik brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Jeg er tilfreds med mit udseende, når jeg er påklædt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Jeg er tilfreds med mit udseende, når jeg er nøgen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Jeg føler mig feminin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Jeg føler mig (fysisk) attraktiv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Jeg undgår andre mennesker på grund af mit udseende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	I høj grad	I nogen grad	I mindre grad	Slet ikke
<b>Fysisk situation</b>				
45. Jeg er træt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Trætheden påvirker mine sociale aktiviteter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Jeg falder let i søvn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Jeg har problemer med at sove om natten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Jeg har smerter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Jeg har problemer med at bevæge min arm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. Jeg mangler energi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Jeg føler mig syg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Jeg har nedsat appetit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Religiøse forhold</b>				
54. Jeg har en religiøs og/eller åndelig tro, som hjælper mig i situationen med brystkræft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Organisatoriske forhold</b>				
55. Jeg har en kontaktlæge	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
56. Jeg har en kontaktsygeplejerske	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
57. Kontaktlægen har været til stede ved mikroskopisvaret	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
58. Kontaktsygeplejersken har været til stede ved mikroskopisvaret	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
59. Jeg har fået en passende information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
60. Jeg har fået for meget information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
61. Jeg har fået for lidt information	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		

	I høj grad	I nogen grad	I mindre grad	Slet ikke
62. Jeg er tilfreds med udseendet af mit ar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Arret fra operationen påvirker mit seksuelle samvær	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Jeg skal opereres i brystet igen	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		
65. Jeg skal opereres i armhulen igen.	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>		

**Tusind tak for din besvarelse**





**Kontaktperson**

Lone Jørgensen  
Aalborg Universitetshospital  
Mammakirurgisk Klinik  
Sdr. Skovvej 3  
9000 Aalborg  
Tlf. 99 32 22 76 eller mobil 30 13 81 35  
Mail [lojo@rn.dk](mailto:lojo@rn.dk)



REGION NORDJYLLAND

## APPENDIX D

### Interview guide for individual interview

**Introduktion:** Endnu engang mange tak fordi du vil deltage i et interview, som handler om den belastning, du oplever i relation til at få konstateret brystkræft.

**Anonymitet:** Dit navn vil blive anonymiseret og det vil kun være mig, som får adgang til interviewet

**Båndoptagelse:** Interviewet vil blive optaget på bånd og efterfølgende skrevet ned. Det optagne interview vil efterfølgende blive slettet.

Områder i relation til belastning ved ny-diagnosticeret bryst-kræft - fundet ved litteraturgennemgang, fokusgruppe interview og debriefing af kvinder med nydiagnosticeret brystkræft.	Interview spørgsmål
Følelsesmæssig situation	<ul style="list-style-type: none"> <li>• Kan du fortælle om dengang du fik konstateret brystkræft (så detaljeret og systematisk som muligt).</li> <li>• Hvordan reagerede du?</li> <li>• Hvad tænkte du?</li> <li>• Hvad følte du?</li> <li>• Hvordan oplevede du, at diagnosen påvirker dit liv på nuværende tidspunkt?</li> <li>• Hvad belaster dig i din situation med brystkræft?</li> <li>• Hvad påvirker din belastning?</li> <li>• Hvad har betydning for at din belastning mindskes?</li> <li>• På hvilket tidspunkt i forløbet har du oplevet den største belastning?</li> </ul>
Sociale forhold	<ul style="list-style-type: none"> <li>• Hvordan har du oplevet støtte fra din familie/venner?</li> <li>• Hvordan har du oplevet støtte fra personalet?</li> </ul>

	<ul style="list-style-type: none"> <li>• Følte du dig rustet/tryk ved at komme hjem efter operationen?</li> </ul>
Fysisk situation	<ul style="list-style-type: none"> <li>• Kan du beskrive dit energiniveau?</li> <li>• Har du oplevet fysiske symptomer efter operationen?</li> <li>• Hvis ja, hvilke?</li> <li>• Oplever du smerter?</li> <li>• Oplever du træthed?</li> <li>• Har du problemer med at falde i søvn/sove om natten?</li> </ul>
Religiøse forhold	<ul style="list-style-type: none"> <li>• Har du en religiøs og/eller åndelig tro, som hjælper dig i situationen med brystkræft?</li> <li>• Hvis ja, hvordan?</li> </ul>
Body image/ kropsopfattelse	<ul style="list-style-type: none"> <li>• Hvordan har operationen påvirket din opfattelse af kroppen?</li> <li>• Har operationen påvirket din kvindelighed?</li> </ul>
Seksualitet	<ul style="list-style-type: none"> <li>• Hvilken betydning har diagnosen og operationen (kropsændringen/kropstabet) for dit (seksuelle) samvær med din partner?</li> </ul>
Organisatoriske forhold	<ul style="list-style-type: none"> <li>• Var du indlagt i forbindelse med operationen?</li> <li>• Hvor var du indlagt?</li> <li>• Hvordan oplevede du indlæggelsen?</li> <li>• Hvordan oplevede du forløbet fra du fik diagnosen og indtil nu?</li> <li>• Har det haft betydning at du har været indlagt? Hvis ja, hvilken?</li> <li>• Kunne du have ønsket dig et andet forløb?</li> <li>• Har du haft en kontaktperson i dit forløb?</li> <li>• Hvilken betydning har det haft?</li> <li>• Har du oplevet et sammenhængende forløb?</li> <li>• Hvordan har informationsniveauet været?</li> </ul>

# APPENDIX E

## Information om forskningsprojekt

Mammakirurgisk Klinik på Aalborg Universitetshospital undersøger, i samarbejde med andre afdelinger i Danmark, hvor mange og i hvilken grad kvinder med brystkræft oplever belastning på forskellige tidspunkter i deres pleje- og behandlingsforløb. Desuden vil vi undersøge hvilke faktorer, der påvirker belastningen. Vi forventer, at projektet kan bidrage med viden, der kan hjælpe til at forbedre patientforløbet for kvinder med brystkræft.

Vi vil derfor spørge, om du vil deltage i en spørgeskemaundersøgelse. Det vil tage ca. 5 - 30 minutter at udfylde spørgeskemaet. Du vil få udleveret et spørgeskema tre gange i løbet af dit behandlingsforløb for at undersøge om din oplevelse af belastning ændrer sig. Det er meget vigtigt for undersøgelsens pålidelighed, at du vurderer din aktuelle belastning samt udfylder alle spørgsmål i hvert spørgeskema, så vidt det er muligt. Har du behov for støtte til at udfylde spørgeskemaet, er du hjertelig velkommen til at ringe til mig på et af nedenstående numre, så kan vi udfylde spørgeskemaet sammen.

Når du har udfyldt et spørgeskema, skal du lægge det i den udleverede kuvert og enten aflevere kuverten til personalet eller lægge den i afdelingens interne postkasse (der behøves ikke frimærke). Der er frimærke på den tredje kuvert, som du kan aflevere enten på sygehuset eller i en almindelig postkasse. Så vil alle kuverter blive sendt direkte til undertegnede. Afdelingens personale vil **ikke** få kendskab til dine svar. Dine svar vil blive behandlet med største **fortrolighed**. Dit navn, cpr. nummer og telefonnummer vil ikke være tilgængeligt for andre end undertegnede.

For at uddybe spørgeskemaundersøgelsen vil der også blive lavet en interview-undersøgelse. Hvis du **også** kunne være **interesseret** i at deltage i interview-undersøgelsen skal du skrive dit telefonnummer på forsiden af et spørgeskema, så kontakter jeg dig med henblik på videre aftale. Interviewet vil foregå på sygehuset eller hjemme hos dig, alt efter hvad du foretrækker.

Din deltagelse er fuldstændig frivillig. Du kan når som helst og uden at give en grund trække dit tilsagn om deltagelse tilbage. Det vil på ingen måde få konsekvenser for din videre pleje og behandling.

Har du brug for yderligere information om forskningsprojektet eller din deltagelse, er du hjertelig velkommen til at kontakte mig.

***På forhånd tusind tak for din deltagelse.***

Med venlig hilsen

Lone Jørgensen

Sygeplejerske, ph.d. studerende

Mammakirurgisk Klinik, Aalborg Universitetshospital

Sdr. Skovvej 3

9000 Aalborg

Arbejdstelefon: 99 32 22 76 eller mobil 30 13 81 35

*OBS arbejdstelefon nummeret ændres pr. 3.12.2013 til 97 66 10 74*

E-mail: [lojo@rn.dk](mailto:lojo@rn.dk)

## APPENDIX F

	Causal indicator.	Effect indicator
Item 1	+	+
Item 2	+	+
Item 3	+	+
Item 4	+	
Item 5	+	
Item 6	+	
Item 8	+	+
Item 9		+
Item 10	(+)	+
Item 11	+	
Item 12	+	
Item 13		+
Item 14		+
Item 15	+	+
Item 16	+	
Item 17	+	+
Item 18	+	+
Item 19	+	+
Item 20	+	+
Item 21	+	+
Item 22	+	
Item 23	+	
Item 24	+	+
Item 25	+	
Item 26	+	
Item 27	+	
Item 28	+	
Item 29	+	
Item 30	+	
Item 31	+	+
Item 32	+	
Item 33	+	
Item 34	+	
Item 35		+
Item 36	+	
Item 37	+	+
Item 38		(+)
Item 39	(+)	
Item 40		+

DISTRESS AMONG WOMEN TAKING PART IN SURGICAL CONTINUITY OF CARE FOR BREAST CANCER

Item 41		+
Item 42		+
Item 43		+
Item 44	(+)	+
Item 45	+	+
Item 46	+	+
Item 47	+	+
Item 48	+	+
Item 49		+
Item 50		+
Item 51	+	+
Item 52	+	(+)
Item 53	+	+
Item 54		+
Item 55	+	
Item 56	(+)	
Item 57	(+)	
Item 58	+	+
Item 59	+	+



## SUMMARY

Breast cancer is the most common cancer among women worldwide. In Denmark, one in every 9 women will be diagnosed with breast cancer during her life. The initial treatment is removal of the tumour and the surrounding tissue, or removal of the breast. The axillary is examined to stage spread of cancer and if metastases are detected, an axillary clearance is performed. Consequences of breast cancer are manifold and vary within individuals, but the most cited are anxiety, depression, pain, sleep disturbance, fatigue, and/or altered body image. These consequences may cause distress at some point during breast cancer trajectory. Overall, distress has been linked to suffering, and lower quality of life, increased admission rates, and greater health care costs. This thesis uses mixed methods to investigate the prevalence of distress among women taking part in surgical continuity of care at time of diagnosis, and possible changes in distress during surgical continuity of care. In addition, it determines predictors of distress and explores the experience of distress in more depth.

ISSN: 2246-1302  
ISBN: 978-87-7112-255-8

AALBORG UNIVERSITY PRESS