Changes in weight and body composition among women in adjuvant treatment for breast cancer

A multistage mixed methods study

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BY
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DISSERTATION SUBMITTED 2016

AALBORG UNIVERSITY
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CV

Birgith Pedersen graduated as a nurse in 1980. She has a clinical background in radiology, cardiology, intensive care and oncology. In 1987 she became a specialist in intensive care, but she soon switched to the field of oncology nursing. Working as an assistant ward sister in an oncology unit she completed her diploma in leadership in 1995. This stimulated her interest in developing an academic career, which was further deepened by her employment as a teacher at a nursing school during the period 1996-2002 and her acquisition of a Master of Science in Nursing from Aarhus University in 2001. As a developmental nurse at the Department of Oncology she has focussed on further developing the area of clinical nursing through research and development with a special view to increasing our understanding of living with side effects of cancer treatment. For a decade she has among other things been responsible for in-house course activities for trained nurses, the development of tools to support observations and documentation and organising network meetings. Focus has especially been on a) stimulating clinical nurses in evidence-based practice by organising journal clubs and projects days and providing support in connection with writing papers for nursing journals, and b) conducting research on how patients experience and cope with side effects from cancer treatment. Birgith has also participated in developing the curriculum for the bachelor's programme in nursing, in competency development (how to advance from novice to proficient nurse) and in describing possible career directions. In October 2012 she was enrolled as a PhD student at Aalborg University, where she has studied experiences with changes in weight and body composition among women during and after adjuvant treatment for breast cancer.

ENGLISH SUMMARY

The side effects of antineoplastic adjuvant treatment for breast cancer include changes in weight and body composition. These changes can influence women's general health and survival rate and may affect their perception of their body and their self. However, research findings on the factual changes are diverse and sometimes contrasting, and existing studies on the effects of weight changes on body and self perception among women during and after breast cancer treatment seem to be insufficiently explored. No studies have combined quantitative and qualitative data to expand the knowledge of the complex human phenomena and take into account the inseparable body-subject.

This study aims to increase our knowledge on how changes in weight and body composition influence women's experience of their body and self during and after adjuvant antineoplastic treatment for breast cancer to identify women with a special need for healthcare. The following research questions are scrutinised:

- What characterises changes in weight and body composition during 18 month from diagnosis, and how is the risk of weight changes associated with current antineoplastic treatment?

- What is the essential meaning of the phenomenon of changes in weight and body shape among women treated for breast cancer, and how do these changes influence the women's perception of body and self?

- How can an understanding of the women as unified body-subjects expand our knowledge of factual bodily changes and their influence on the women's perception of body and self?

Guided by existential phenomenology and a lifeworld perspective, this study applies a multi-stage mixed methods design consisting of two studies in three phases, which are integrated and illustrated in joint displays. *Study I* (Paper 3) utilises data collected among 95 women after surgery for breast cancer in stages I-III followed by endocrine treatment and/or chemotherapy. Baseline data are summarised by descriptive statistics. By means of bioelectric impedance analysis, data of weight and body composition were obtained 4 times during 18 months after breast cancer surgery. Estimated changes of repeated measurements and odds ratio were calculated using a linear mixed model and logistic regression. *Study II* (Paper 1 and 2) is a qualitative study consisting of two phases. To improve the data collection process for study II, an interview guide was been developed based on a focus group consisting of five women experiencing weight changes (phase one). Approximately 12 months after diagnosis 12 women from the initial sample were invited for

individual interviews (phase two). The interviews were analysed within the frame of existential phenomenology and reflective lifeworld research.
Study I showed modest average changes in weight, fat mass and waist. However, changes in body composition and an increased risk of developing changes were mainly observed over time among women treated with chemotherapy whereas women in endocrine therapy increased their waist circumference. Independent of treatment regimes, Study II showed that changes in weight and body composition influenced the women's perception of body and self. The essential meaning of the ambiguous transforming body was continuously associated with fear of recurrence and perceived as a demanding stranger. Occasionally the unified body-subject divided into subject and object. Even though some women managed to control the changes, showing great willpower, others had to realise that they were unable to do so and thus had to accept them.

Integrating the two studies and illustrating them in joint displays showed that even minor changes in weight combined with an extended waist circumference influenced the women's perception of body and self extensively (Paper 4). Weight gain triggered fear of recurrence, shame and self-blame and affected the women's view of themselves as a unified body-subject. Weight loss, on the other hand, supported a positive body perception, making the women feel capable of taking care of their body and self as autonomous agents.

In conclusion, changes analysed using statistical tools in a pooled sample neither explained nor corresponded to the perceived changes. All women are potentially in risk of changes in weight and body composition and deserve continuous attention from health professionals. Not paying attention to the women's experiences may prolong the illness and suffering and prevent the women from regaining the sense of a unifying body-subject. To support women in the transition to a new habitual body, health professionals must enter into a narrative work with the women. In addition, tailored interventions in the form of weight management, nutrition and physical activities must be offered to these women as prevention across sectors in the healthcare system.

DANSK RESUME

Vægtændringer hos kvinder i forbindelse med adjuvant behandling efter brystkræft er en kendt bivirkning, der kan påvirke langtidsoverlevelse og livskvalitet samt føre til livsstilssygdomme. På trods af disse konsekvenser er der i Danmark ikke forsket i, hvorledes vægtændringerne er fordelt på fedt og fedtfri masse – parametre, der kan belyse den sundhedsmæssige risiko. Kun sparsom forskning belyser, hvordan vægtændringerne påvirker kvindernes selv- og kropsopfattelse og ingen studier kombinerer kvantitative og kvalitative data for at belyse faktuelle ændringers påvirkning af opfattelse af krop og selv som et forenet subjekt - objekt.

Formålet med dette studie er at udvikle viden om kropslige forandringer i forbindelse med adjuvant antineoplastisk behandling for brystkræft og om hvorledes disse forandringer påvirker kvinderne opfattelse af krop og selv med henblik på at kunne identificere kvinder, der har brug for en særlig sundhedsfaglig indsats. Følgende forskningsspørgsmål er belyst:

- Hvad karakteriserer forandringer i vægt og kroppens sammensætning af fedt, fedtfri masse og kropsvæske gennem 18 måneder fra diagnosetidspunkt hos kvinder under og efter adjuvant antineoplastisk behandling for bryst kræft og hvordan er risikoen for ændringer relateret til denne behandling?

- Hvad kendetegner den essentielle mening af fænomenet 'ændringer i vægt og kropsfacon' blandt kvinder behandlet for brystkræft, og hvordan påvirker forandringerne kvindernes opfattelse af krop og selv?

- Hvordan kan en forståelse af kvinder som et forenet subjekt - objekt uddybe viden om betydningen af faktuelle kropslige forandringer for kvindernes opfattelse af sig selv og deres krop ved adjuvant behandling for brystkræft?

Med udgangspunkt i eksistentiel fænomenologi og et livsverdensperspektiv er der udført to studier i et 'multistage mixed methods design' bestående af tre faser. Resultaterne er integreret og illustreret i joint displays. *Studie I* (artikel 3) anvender data indsamlet blandt 95 kvinder opereret for brystkræft i stadie I-III med efterfølgende endokrin behandling og/eller kemoterapi. Baselinedata er sammenfattet ved hjælp af deskriptiv statistik. Gentagne målinger gennem 18 måneder er foretaget ved hjælp af bioelektrisk impedansanalyse. De gentagne målinger og odds ratioer er beregnet ved hjælp af en lineær mixed model og logistisk regression. *Studie II* (artikel 1 og 2) er et kvalitativt studie i to faser. Som udgangspunkt for dataindsamlingen er der udviklet en interviewguide på baggrund af en fokusgruppe bestående af kvinder, der har oplevet vægtforandringer efter

kræftbehandling (fase 1). Guiden er efterfølgende anvendt i individuelle interview med 12 kvinder fra studie I 12-18 måneder fra diagnosetidspunktet (fase 2). Interviewene er analyseret på baggrund af fænomenologisk refleksion og livsverdensanalyse.

Studie I viste, at de gennemsnitlige vægtforandringer er små, men at der sker forandringer i vægt, fedtmasse og livvidde over tid. Forandringen i disse parametre var primært relateret til kvinder behandlet med kemoterapi, mens kvinder i endokrin behandling alene øgede deres livvidde.

Studie II viste, at kvinder uagtet typen af behandling var optaget af kropslige forandringer. Den essentielle betydning af kroppens tvetydige forandringer var knyttet til frygt for tilbagefald relateret til vægtøgning, øget fedtmasse og forandret kropsfacon. Forandringerne fik betydning for kvindernes oplevelse af sig selv som et forenet subjekt. Kroppen forandrede sig under behandlingsforløbet og blev oplevet som et objekt, der var ude af kontrol eller skulle kontrolleres. Selvom det lykkedes nogle af kvinderne at kontrollere forandringerne med stor viljestyrke, måtte andre indse, at de kropslige forandringer var uden for deres kontrol, hvorfor accept heraf var den eneste løsning.

Integration og illustration af de to studier i joint displays viste, at de målte forandringer ikke var i samsvar med de oplevede forandringer (artikel 4). Selv mindre vægtændringer og forandringer i taljemål påvirkede kvindernes opfattelse af krop og selv betydeligt. Vægtøgning skabte frygt for tilbagefald, skam og skyld i modsætning til vægttab, der understøttede en positiv kropsfornemmelse og en følelse af at kunne tage ansvar for egen sundhed.

Det kan konkluderes, at målte kropslige forandringer ikke kan stå alene, men må komplementeres med kvindernes oplevelse heraf. Kvinder i adjuvant antineoplastisk behandling for brystkræft er potentielt i risiko for ændring i vægt og kroppens sammensætning af fedt, fedt fri masse og væske. Hvis ikke oplevelsen af disse forandringer tages alvorligt kan det forlænge og forstærke kvindernes lidelse. Med udgangspunkt i en narrativ tilgang og med skræddersyede interventioner på tværs af sektorer kan sundhedsprofessionelle støtte kvinderne i erkendelsen af en ny krops og selvopfattelse.

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I would like to acknowledge the contribution of my supervisors in supporting me during the study. Special thanks to Charlotte Delmar who helped me gather the treads in the overall writing process, and who is always available for a talk, and to Ursula Falkmer who supported my work with a prospective study in an everyday clinical setting challenged by continuous changes and unpredictability. Also thanks to Mette Grønkjær, who in particularly challenged me with constructive supervision and provided invaluable support and help when I wrote the first paper – which proved to be an unanticipated challenge. Mette Dahl Bendtsen, Ingvar Bosaeus, Andreas Carus, and Edith Mark also deserve thanks for their collaboration during the study and their willingness to share their scientific knowledge with me.

Clinical nurses at the outpatient clinic helped me prepare the study, and Bente Dalsgaard helped me collect data, thus allowing me time to participate in mandatory activities during the PhD study. A special thanks to my fellow PhD students Lone Jørgensen and Laurids Østergaard Poulsen for their willingness to discuss any subject during the study.

Most importantly, this PhD project would never have been realised without the support by the former head nurse at the Department of Oncology, Anne Winther, or the financial support from Aalborg University Hospital, Clinic for Surgery and Oncology and the Department of Oncology.

On a personal note, my family deserves a lot of credit for patiently accepting that everyday life was temporarily suspended. Last, but not least a special thanks to the women who participated in the study, and especially those who provided me with insight into their personal experiences during the focus group and the women that participated in the interview study.

PREFACE

In conducting a mixed methods study I acknowledge the challenges pointed out by researcher Janice Morse. Morse compares mixed methods research with serving two masters (1). She stresses the need to be a highly versatile researcher, adept in different research paradigms and being familiar with many different research methods. Accepting the challenges in this PhD project has enabled me to extend my knowledge of different methods and analytical strategies. Although Brinkman and Kvale (2) are mainly occupied with interviewing, borrowing their metaphor I have felt like a miner trying to reflect on the facts of a small part of the world – and like a traveller into unknown land, filled with choices.

A mixed methods study can contribute with understanding a complex phenomenon by using the best suited methods and analytical strategies to explore the attributes of the phenomenon, including considerations of the consistency between ontology, epistemology and method (3). One can also look at mixed methods as one method (4).

However, participating in courses on body and embodiment lead me to the world of phenomenology. Sharing my questions and arguments with a multidisciplinary phenomenology network made me consider the option of leaning on philosophical and epistemological assumptions from the position of existential phenomenology, as described by the French philosopher Maurice Merleau-Ponty. This position is not just in accordance with the healthcare perspective, but also significant from a nursing perspective.

Thus, by means of existential phenomenology and multiple methods the bodily changes in weight and body figure experienced by women with breast cancer during and after cancer treatment turned out to be a complex matter. Combining and integrating different forms of data inspired by mixed methods methodology contributed to a deeper understanding of the problem. The choices I have had to make during the research process have involved a series of scientific challenges, as this thesis uses a variety of mixed methods concepts to explain the study on the design level. On the data collection level multiple methods have been used to illuminate the bodily changes and their influence on the women from different perspectives. Finally, the use of different analytical tools has ensured that no stone was left unturned.

During the entire learning process, I developed awareness on different levels of what it can mean to exist in the world as an embodied human being. Conducting a scientific, comprehensive study and writing a thesis has been challenging. As a body-subject, I have been forced to sit down or stand up throughout the writing process. Thus, my body changed into a stiff body that impelled me to move, to go

outside or to just perform ordinary everyday tasks (displacement activities perhaps). Thinking, reading, and understanding the wholeness changed from a fluent process, which normally went unnoticed, to a fragmented, slow, always conscious process striving to understand and reveal coherent patterns that were meaningful to me and others.

The four papers and this thesis are the results of this effort. I invite you to join me on a travel into methodologies and philosophical thoughts to learn about the experience of changes in weight and body composition among women with breast cancer to get a glimpse of an unknown world, which, at the same time is familiar, because we are all embodied human beings.

The structure of the thesis is inspired by recommendations by the highly estimated scholar John W. Creswell (4,5). The thesis builds on articles. When writing empirical articles for mixed methods research it is recommended to write*: 'a quantitative article, a qualitative article, an overall mixed methods article. These articles could go out to different journals'* (4, p.92). Four papers are generated from this study: two qualitative, one quantitative and one mixed methods article, which were submitted for publication after completion of each analysis. Although the data collection for study I was initiated first, data collection and analysis for study II was completed before study I. Thus, the orders of the papers on the next page reflects when the papers were published or submitted for publication.

Birgith Pedersen

LIST OF PUBLICATIONS

Paper 1: Pedersen, Birgith; Delmar, Charlotte; Falkmer, Ursula; Grønkjær, Mette. Bridging the gap between interviewer and interviewee: developing an interview guide for individual interviews by means of a focus group. Scandinavian Journal of Caring Sciences, 2015, oi:10.1111/scs.12280.

Paper 2: Pedersen, Birgith; Grønkjær, Mette; Mark, Edith; Falkmer, Ursula; Delmar, Charlotte. 'The ambiguous transforming body' – A phenomenological study of the meaning of weight changes among women treated for breast cancer. International Journal of Nursing Studies, 2016; 55:15-25.

Paper 3: Pedersen, Birgith; Delmar, Charlotte; Dahl Bendtsen, Mette; Carus, Andreas; Bosaeus, Ingvar; Falkmer, Ursula; Grønkjær, Mette. Changes in weight and body composition among women with breast cancer during and after adjuvant treatment – A prospective follow-up study. Accepted for publication in the international journal for cancer care 'Cancer Nursing'.

Paper 4: Pedersen, Birgith; Grønkjær, Mette; Falkmer, Ursula; Delmar, Charlotte. Understanding the essential meaning of measured changes in weight and body composition among women during and after adjuvant treatment for breast cancer – A mixed methods study. Accepted for publication in the international journal for cancer care 'Cancer Nursing'.

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CHAPTER 1. INTRODUCTION

Being a nurse for several years in the field of oncology I have listened to my own and others' prejudices regarding weight gain among women in adjuvant treatment for breast cancer. Weight changes were considered an inevitable effect of normal ageing, a female issue only related to appearance and nothing to worry about in proportion to the risk of dying from cancer. However, turning my attention to what these women *actually* said, a new understanding emerged along with an incentive to conducting a research project with a view to increasing the knowledge, and understanding the issue, and giving a voice to the women concerned. The following quote illustrates a core issue of living with weight changes during and after treatment for breast cancer.

> *People might think: why do I moan about my two-three kilos when I am not too fat. But it concerns my self-perception and the fact that you cannot decide for yourself. You lose control when you start taking the pills. I am simply not able to make any impact on my weight. Suddenly, it is me gaining weight. I cannot stand it, but I do not talk about it. I feel like it is embarrassing, because I am certainly not too fat. But it means a lot to me and my body perception.* (Quote from a participant)

The changes gave rise to embarrassment, lack of comfort, silent suffering, and fear of losing control of one's weight. These serious feelings were suppressed, as the women did not expect others to understand the effect weight gain had on them. In addition, the changes were understood as a consequence of medication. So what do weight changes among women treated for breast cancer have to do with nursing and healthcare? This question will be considered in the following chapters.

CHAPTER 2. BODY WEIGHT, HEALTH, AND NURSING

This chapter deals with bodily changes as issues for nursing and healthcare. First, there is an elaboration on the body in nursing, followed by reflections on the relationships between breast cancer, weight changes and health.

2.1. BODILY CHANGES IN NURSING

Since Florence Nightingale, the founder of modern nursing, wrote her bedside observations and stressed the need for nurses to be able to observe the sick and make judgements based on adequate information, a central issue in nursing has been observation and prevention for the 'sake of saving life and increasing health and comfort' (6, p.125). Nightingale aimed to decrease risk and prevent disease and is referred to as an epidemiologist who opened up for nursing interventions on the organisational, population and individual level. Although Nightingale was concerned with giving patients the best conditions for nature to act (6, p.133), she also highlighted the urgency of taking the patients' experiences of illness seriously (6, pp. 95-104).

In addition to caring for patients' basic needs and creating nursing plans, her successors followed her example and turned the focus of nursing in the direction of care. Understanding the meaning of illness on everyday life became a central aspect of and a precondition for providing nursing care (7, p.28). In this endeavour the philosophy of science and nursing, including epistemological and ontological issues as natural ingredients in human- and care-oriented nursing, was brought to light (8,9). Favouring a focus on illness and care, it was stressed that the patient was not only a body to care for, but a person who might need assistance in finding meaning in the experience of illness and suffering (8,10, p.74).

In Denmark the Norwegian nurse and philosopher Kari Martinsen has influenced our understanding of care as a fundamental precondition in human lives and in nursing. From a caring perspective the aim is to strengthen the life courage of patients, to recognise the need of the suffering person and to act accordingly in the clinical encounter. Caring for the ill person requires that the body is recognised and clinical judgements made on the basis of structured professional knowledge and an open and sensitive approach that embraces the patients' subjective experiences of illness (11).

Although caring is a central value in nursing and a precondition for practicing good nursing, the Australian-American scientist Janice Morse stresses that comfort - or

well-being - is a central concept in nursing. Comfort is situated in a continuum that moves from serious discomfort that occupies the mind and influences everyday life where the body is no longer silent or taken for granted to a high level of relieving comfort (12,13). While nursing aims to provide comfort, recognise the need of others, save lives and increase health and life courage, it is pivotal to understand the experience of the injured body in serious illness conditions. To support the patient through caring practice the professional may apply knowledge that is based both on natural sciences and human and social sciences (14).

Building on these theorists this thesis takes a care-oriented nursing perspective. Consistent with a lifeworld perspective that acknowledges the individual's experience, it takes the individual's self-understanding, lived body and the meaning of suffering and well-being into account (13,15,16). A lifeworld perspective on weight changes associated with treatment for breast cancer involves focussing attention on the body as an essential unity for understanding how patients experience their illness (17-19). From an existential phenomenological point of view - as outlined by the French philosopher Maurice Merleau-Ponty - one does not possess the body as an object. Instead, the body is understood as an inseparable unity of body, mind, and soul as 'one's own body' or the body-subject in an attempt to overcome the dualistic understanding of a separate body and mind (20). Applying existential phenomenology as an overriding approach thus seems to be useful in exploring bodily changes related to weight changes among women with breast cancer. The next section will explain why weight changes associated with breast cancer is an important topic to explore.

2.2. BREAST CANCER – HEALTH AND SURVIVAL

Breast cancer is the main cancer disease among women in Denmark, and over the past decades the incidence has increased (21). By the end of 2013 the incidence was 4.897 and the prevalence 60.197 with a five-year survival rate of 85 % (22). One of the main reasons for this increase in the incidence of breast cancer is suggested to be exposure to estrogen from fat tissue, especially in postmenopausal women (23). Overweight and obesity are considered as an expanding problem in Denmark and worldwide (24), and this may lead to an increasing incidence of breast cancer. Although weight gains in general stagnated from 2010 to 2013, the proportion of overweight and obese women in the population remains 40-50 % from age of 35 and up (25); this number doubled during the period 1990-2000 (23).

In addition to the association between breast cancer and overweight, weight gain may increase the risk of all-cause mortality (26,27) and the development of lifestyle diseases such as cardiovascular diseases, diabetes, joint and muscle diseases, and respiratory diseases (24,28). To prevent breast cancer and increase long-term survival, women are advised to avoid weight gain in adult life, particularly after menopause (23,29,30). However, such recommendations may be seen as a 'double-

edged sword', as studies have demonstrated that weight changes and especially weight gain is considered a side effect of cancer treatment. Furthermore, due to long-term survival, there has been increasing focus on how these women are living with side effects after cancer treatment. Thus, an exploration of the extent and meaning of weight changes seems essential.

CHAPTER 3. BACKGROUND AND OVERVIEW OF LITERATURE

This chapter provides the background for the present study. A comprehensive literature review is conducted to identify knowledge gaps regarding factual changes in weight and body composition and how the changes influence breast cancer stricken women's perception of their body and self.

3.1. BACKGROUND

Weight changes in breast cancer women have been investigated for decades, due to the expected association between fat tissue and breast cancer development and the increased risk of both recurrence and early death (31-39). The duration of adjuvant chemotherapy is suggested to be a main contributor to weight gain (34,36,37,39,40). It is currently being discussed whether premenopausal status is a predictor for weight gain in association with treatment for breast cancer, though it has been observed that premenopausal women gain more weight than postmenopausal women (37,41). Reviewing studies, which applied imagining technology to determine changes in body composition over time, Sheean et al. (42) found that body weight did not increase consistently. Neither did weight gain depict changes in lean and adipose tissue, which are of concern for survival and health.

Adjuvant cancer treatment consists primarily of surgery, radiotherapy, chemotherapy, and endocrine treatment - alone or in combination (43). Acknowledging weight changes as a side effect of cancer treatment, there has been specific focus on the influence of endocrine treatment and chemotherapy. Kumar et al. (44) compared weight development in women allocated to radiotherapy or tamoxifen and found no difference. Studies by Ganz et al. and Goodwin et al. (32,40) confirmed these findings. They found it was the onset of menopause and treatment with chemotherapy that caused weight gain. Subsequently, a study demonstrated that premenopausal women were found to gain more weight than postmenopausal women in adjuvant chemotherapy in combination with tamoxifen (31). In line with this, it is documented that women in current adjuvant chemotherapy on average gain 2.0 kg during and after adjuvant treatment, although gaining as much as 10 kg is not uncommon (33).

As cancer treatment changes, a continuous evaluation of weight patterns following breast cancer diagnosis is needed. Recently, the effect of anastrozole (aromatase inhibitor) on weight change in postmenopausal women at high risk of developing breast cancer was compared with tamoxifen (estrogens receptor antagonist) or placebo (45). In this preventive setting, body weight increased by 0.9 kg at 12

months follow-up in women receiving tamoxifen as opposed to placebo. Weight gain associated with anastrozole versus placebo was 1.4 kg. None of the results were statistically significant but as no body composition data was included, it is unclear if the gain is related to increased fat mass. Comparing tamoxifen and anastrozole showed no statistically significant difference. However, severe weight gains > 5 kg were found in both groups.

In another study, Sedjo et al. (46) demonstrated that women receiving aromatase inhibitors as opposed to estrogen receptor antagonists during follow-up treatment were 46 % less likely to gain weight (ORadj = 0.54, 95 % CI 0.31 – 0.93). Still, the findings are inconclusive in that some studies have found premenopausal status to be a predictor (31,37,38), while others claim that women's menopausal status does not influence their weight gain (23,26,33). Menopause status in estrogen receptor-sensitive breast cancer predicts the choice of follow-up endocrine treatment, and significant factors influencing weight have been observed in connection with estrogen receptor antagonist treatment (38). This is in line with Sedjo et al. (46) who found that the risk of weight gain decreased among women given aromatase antagonists, which are normally given adjuvant to postmenopausal women. Also alcohol consumption (23,26) and decreased physical activity (37,38) may influence the weight.

In addition to these divergent findings, weight changes are depicted as distressing side effects in quality of life questionnaires (31,47-49). Quality of life can be affected by for example fatigue, weight gain and altered sexuality (50). However, distressing side effects are not discussed with the professionals, because the professionals seem to be more focussed on recovery than everyday life problems (51). Neglecting the individual's self-understanding of suffering and well-being may contrast fundamental values and preconditions for providing care in nursing (14-16). Thus, understanding and recognising the experience of suffering and illness, including side effects from cancer treatment, is essential. Loss of hair and breast may lead to a sense of losing parts of one's identity (52-54), and distressing symptoms in the years after active cancer treatment are reported to induce a feeling of losing one's pre-cancer being (55). Furthermore, a meta-analysis showed that breast cancer survivors experience changes in self-perception, which are not only related to breast cancer surgery and hair loss, but also to weight changes (56).

These studies demonstrate that body weight changes may fluctuate over time and be associated with treatment modality and menopause status. Despite the impact on the women's health, overall survival, and self-perception, some argue that the problem is overestimated, because treatment with current antineoplastic agents, e.g. anthracycline based chemotherapy, minimises the changes (57).

3.2. LITERATURE REVIEW

To investigate factual changes associated with contemporary anti-cancer medication and how weight changes may influence the women, a comprehensive literature search was conducted in collaboration with a librarian from Aalborg University Hospital. By means of PICO diagrams, the search was carried out in two phases. In order to find studies on bodily changes as well as the women's experiences of the changes, literature focusing on studies 1) reporting quantitative body changes and 2) reporting how the changes influence the women from a qualitatively point of view, were reviewed. Initially the searches were rather specific and provided very few hits. Subsequently the searches were broadened and repeated. The last search was conducted November 2015.

The quantitative literature search was conducted in the databases PubMed, CINAHL and Embase using MeSH terms, CINAHL terms and Emtree as well as free text (Appendix A). As the search in PubMed provided most of the selected papers, the search string from this database is shown. The search was broad not to exclude any important articles and the papers were selected as described in appendix A. The qualitative literature search was performed in the databases PubMed, CINAHL, and PsycINFO using MeSH terms, CINAHL terms and thesaurus as well as free text - with the PubMed search sting as displayed in appendix B. Subsequently, the search underwent a selection (Appendix B).

The literature review is described in the next sections. Given the adverse association between fat tissue and breast cancer development, the papers selected from the quantitative search provide an overview of changes in weight and body composition during and after treatment with current adjuvant treatment regimes for breast cancer. This is followed by papers selected from the qualitative search that are described and critically assessed for the purpose of getting acquainted with the contemporary research regarding the experience of weight changes. The overall aim of the literature review is to determine knowledge gaps for further investigations.

3.2.1. WEIGHT CHANGES – SIDE EFFECTS OF CANCER TREATMENT

This paragraph aims to provide an overview of changes in weight and body composition during and after treatment with current antineoplastic treatment regimes for breast cancer. The review focuses on breast cancer treatment with current chemotherapy and/or endocrine treatment and reports findings from 19 studies. Assessing studies published from 2004 and forward, one study was found which reported changes in weight associated with endocrine treatment as the main focus (58). However, the effect of endocrine treatment is also depicted in some studies reporting findings on chemotherapy.

3.2.2. STUDY DESIGN AND DATA COLLECTION

The majority of the studies had a retrospective design (30,34,35,39,46,59-66) and examined breast cancer stages I-III (30,34,35,39,46,61,63,66). Most of the studies included between 100 and to 350 participants and one included more than 3000 women. Data was primarily extracted from records, and in several studies the methods used to estimate weight changes were not described (39,60,62-65) or did not specify the chemotherapy regimens (39,46,59-61). If the regimes were specified, the women received various regimes (30,34,35,64-67). Moreover, the descriptions of endocrine treatment differed. In most studies, endocrine treatment followed chemotherapy, but was given as a standalone treatment and reported separately in two studies (34,64). Cut-off points for assessing weight changes were either missing (30,66,67) or defined as absolute weight changes ranging from 1 to 5 kg (39,60,63,64), relative weight changes of ± 5 % (34,46,62), or as the difference between the first and last measurements (65). One study that applied a retro– and prospective design included approx. 6000 women, but had lost about 2000 women at the three-year follow-up (60).

Of six studies with a prospective design (36,57,58,67-69), three included women with breast cancer in stages I-III (67-69), two included women in stage I-II (36,57), and one did not describe the stages (58). The samples consisted of 20 to 272 women and follow-up time varied from completed chemotherapy (~ 4 to 6 months) and up to two years. Most studies ended measurement after one year (36,58,68,69). Chemotherapy regimens were specified in five studies (36,57,67-69). If cut-off points for assessing weight changes were described, they were defined as absolute weight changes of ± 2.5 kg (57) or relative changes of ± 5 % (69).

In general, the studies provide a picture of how the studies differ regarding heterogeneous sample sizes, treatment regimes and follow-up time including different cut-offs, which make them difficult to compare. Most studies measured short-term and up to one year (57,58,63,65,66,68). Other studies measured up to 24 months (30,62,67), and a few extended the weight measure time. Saquib et al. measured for three years (34), whereas Sedjo et al. and Heideman et al. provided follow-up for five years (46,64). However, Heideman et al. categorised their measure points widely with a mean follow-up of 3.5 years. The different time spans and measurement times make it difficult to get a clear picture of the context in which the studies took place.

3.2.3. RESULTS QUANTITATIVE LITERATURE REVIEW

In addition to the described differences, also the extent of the changes and the description of the changes differed, which prevented a common pattern. Although the studies investigated modern/third generation chemotherapy (57,65), they involved different chemotherapy regimens without specification. Some studies with

small sample sizes between 20 to 76 reported changes in body composition in addition to reporting weight changes (36,57,58,68).

In the following, an attempt will be made to discriminate findings related to anthracycline based chemotherapy (hereafter abbreviated ACCT) and the effect of endocrine treatment as these anticancer agents have been considered as adjuvant standard breast cancer treatment in Denmark recently (43). The findings will be reported in terms of changes in the short-term, after one year, after two years and after more than two years.

3.2.3.1. Short-term studies

Ingram et al. (57) investigated 76 premenopausal women for up to seven months. Of these, 39 received ACCT were measured until completed chemotherapy. With a cut-off of 2.5 kg, 55 % displayed stable weight, 34 % weight gain, and 10.5% weight loss, with the mean weight gain being 1 kg. Examining changes in body composition, they found that both fat mass and fat free mass increased during weight gain and decreased during weight loss. These findings showed that women receiving other regimes than ACCT were more exposed to changes. The opposite was shown in the study by Ricci et al. (66). An investigation of 172 women given ACCT, where 129 received AC-T[1], showed that women receiving ACCT and specifically AC-T regimes had the highest risk of weight gain one month after completed chemotherapy. The exposed women were younger (54.2 ± 11 years) than the women in the other regimes (59.3 ± 11.2 years), $p = 0.007$. In addition, their BMI increased from 27.4 kg/m2 at baseline to 28.3 kg/m2. These women were thus overweight in advance when assessed by the WHO BMI scale.

With a cut-off of ± 1 kg and after completed chemotherapy, Wang et al. found an even distribution in weight groups as approx. one third remained stable, one third gained weight, and one third lost weight in their study of 98 women, of whom 56 received ACCT. A different cut-off of 2.5 kg, as suggested in the study by Ingram et al., would probably have changed the distribution with more women in the stable group. However, the range of changes was –11 kg to +9 kg. Thus, some women are exposed to extensive weight changes in the short term. The authors conclude that age ≤40 years and weight ≥ 60 kg at diagnosis, numbers of chemotherapy ≥ 4 cycles, and antiemetic hormone dosage ≥ 200 mg increased risk of weight gain after chemotherapy (57,64). One kilo weight change in a 60 kg body weight corresponds to 1.6 % changes, while 2.5 kg correspond to approx. 4 %. This is more in line with the 5 % cut-off suggested by Saquib (34), which was found important for long-term survival in a study of Thivat et al. investigating 111 women, all treated with ACCT (35). In this study, 31 % presented a weight variation of more than 5 % from diagnosis to completed chemotherapy. In addition, the study demonstrated that the

[1] Doxorubicin, cyclophosphamide and paclitaxel

exposure to relative weight variations of 5 % had a negative impact on recurrence and survival assessed during a 20 years follow-up.

3.2.3.2. One year follow-up

Freedman et al (68) investigated 20 women in ACCT treatment baseline, for six and 12 months. They found no changes between baseline and six months (after completed chemotherapy), however, statistically the weight at one year was significantly increased ($p = 0.05$). The decrease in fat free mass was also statistically significant. As the sample was small, the findings must be assessed in association with the findings following completed chemotherapy in Ricci's (66) and Wang's (63) studies. Between baseline and one year, Gordon et al. (36) investigated 43 premenopausal women for body composition changes. Only 15 of these women received ACCT, and although they found increased fat mass especially in the trunk at 12 months, which may be clinically important for cardiovascular diseases, diabetes and breast cancer outcome, the data were unified and calculated in just one group. Thus, this analysis does not account specifically for changes in women given ACCT who only provided one third of the data for analysis. Nevertheless, interpreting the findings from the total group, the authors argue that premenopausal women at risk of premature menopause are more exposed to body changes.

Chaudhary et al.(65) reviewed 246 charts and found non-significantly mean weight gain of 0.39 % at one year compared to baseline. Premenopausal status was associated with significant weight gain. Out of this large sample only 40 received ACCT, and the findings from this group were not reported separately. However, pointing at premenopausal women at being at special risk of changes is in line with Gordon's and Wang's studies. Tredan et al. (69) measured in total 272 women, of whom 233 were given ACCT. Measurements took place at baseline, nine months and 15 months (~ one year), with a 5 % cut-off . At nine months, more than half the women (126) had gained weight, with the mean weight gain being 3.2 kg. 60 % of these women gained less the 5 %, 33 % between 5 -10 % and 7 % gained more than 10 %. At 15 months ~ one year, 60 % of the cohort had gained weight, with a mean increase of 3.9 kg. Forty-five percent gained less than 5 %, 32 percent between 5 and 10 %, and 14 percent gained more than 10 %. Nine patients dropped out corresponding to less than 10 %, which is a reasonable and accepted drop-out in a sample of this size. The findings demonstrated that 40 % of the weight gainers increased their weight by more than 5 % at nine months, increasing to 45 % of the women at 15 months. These relative weight changes depict a serious problem as Tivat et al. (35) found these relative weight changes essential for recurrence and survival.

Only one study examined the effect of endocrine treatment alone. Francini et al.(58) investigated 55 postmenopausal women randomised into an estrogens receptor antagonist group (27 women) and an aromatase inhibitor group (28 women)

baseline, six and 12 months. At 12 months the weight remained stable in the estrogen receptor antagonist group and fat mass and weight decreased in the aromatase inhibitor group. These findings do not correspond with the findings of Sestak et al. (45) that showed increasing body weight of 0.9 kg at 12 months follow up in women receiving estrogen receptor antagonist versus placebo. Weight gain associated with anastrozole versus placebo was 1.4 kg.

3.2.3.3. Two-year follow-up

Although Han et al. (30) investigated 260 breast cancer-stricken women, of whom 165 received ACCT, and described measurements at three, six, 12, and 24 months from baseline, the study suffers from a drop-out of approx. 30 %. Thus, the conclusion pointing at no weight changes during this follow-up has to be evaluated cautiously as we do not know whether these drop-outs were weight gainers. However, it is interesting that 23 women from the remaining group gained more than 5 %.

In line with Han et al. (30), Jeon et al. (62) conclude that there are no changes at two-year follow-up. However, investigating 108 women after completed ACCT (TAC) - equalling six months - showed a mean weight change of 3.64 kg, statistically significant with $p < 0.0001$). At 12 months, the mean weight slightly decreased to –0.19 kg. At 24 months the mean weight decreased to –0.2 kg, and 72 % displayed a stable weight calculated with a 5 % cut-off.

Also Liu et al. (67) who investigated 147 women, of whom 80 were given ACCT, found the highest weight changes after completed chemotherapy, assessed at eight months following baseline. After eight months, the mean gain was 2.5 kg, and at 24 months the mean weight was still 1.7 kg higher than baseline. Treatment with ACCT showed a slower and milder increase than in 67 women who were given other chemotherapeutic (CMF). Thus it seems that changes after completed chemotherapy demand further investigation, and although Han et al. (30) and Jeon et al. (62) demonstrate no changes at one year, this is contradictory to the findings of Liu et al. (67) and Tredan et al. (69).

3.2.3.4. Long-term follow-up – more than two years

Out of 2972 eligible women, data from 2859 participants aimed at examining the association between different chemotherapy regimes, estrogen receptor antagonist use, and weight gain. In this study, Saquib et al. (34) found that all types of chemotherapy were significantly associated with weight gain (OR = 1.65, 95% CI = 1.12, 2.43) as opposed to estrogen receptor inhibitors (OR = 1.03, 95 CI = 0.71, 1.51). In contrast to the study by Liu et al. (67), the regimes containing ACCT did not differ from other regimes. With a 5 % cut-off, 1031 women gained weight during chemotherapy. From this group, 868 women were followed for six years. The

weight gain occurred initially before the one-year measurement and for all women it they were unlikely to return to pre-cancer weight.

Heideman et al. (64) analysed data from 271 women, of whom 93 received ACCT. Out of the total group, only 68 women were given endocrine therapy, and 87 received combination therapy. The result from the ACCT group alone was not shown, but the study reported that 26 % of all women gained 5 kg or more during the first year following diagnosis. Women treated with chemotherapy gained a mean weight of 2.2 kg (SD ± 4.3) and women given combination therapy with chemotherapy and endocrine treatment gained a mean weight of 2.6 kg (SD ± 6.0; $p < 0.05$). The last group of women gained further weight after the first year and displayed the highest weight gain at five years. No significant changes in weight were found among women receiving endocrine treatment alone. Although the findings were analysed at diagnosis, after one year and after five years, the reliability of the findings must be discussed as time 'at diagnosis' included measurements one to three months following diagnosis, the one-year measurement included three to 15 months, and the five years measurement included 15 months to six years following diagnosis. These choices make variations over time unclear.

3.2.4. SUMMARY OF THE QUANTITATIVE LITERATURE REVIEW

Reviewing the quantitative literature demonstrated findings from most of the world as the studies were conducted in Asia, Europe, North and South America, and Australia. This indicates that weight changes as a side effect of cancer treatment are a worldwide issue for women with breast cancer. Although the studies report divergent findings and disagree concerning the amount and patterns of changes, it is demonstrated that some women suffer from severe changes that need further investigation.

Although several studies have investigated changes in weight involving different measure points, cut-offs, etc., only few studies have depicted changes in lean or adipose tissue relevant to the women's health. Research has mainly focussed on weight gain as a contributing factor for recurrence and decreased survival among women treated for breast cancer. However, weight variations > 5 % are found to be a prognostic factor for decreased survival in breast cancer (35). In addition, a relative weight loss of 2.4 % is also found to influence the survival rate among a mixed group of cancer patients, including women with breast cancer (70). In both studies, women with stage I-IV breast cancer participated. Stage IV breast cancer is characterised by distant metastases and thus a severe prognosis that may have influenced the findings.

The findings reveal several contradictions, and it seems that further investigations are needed at least for six to 12 months following diagnosis to examine whether the changes are overestimated as claimed by Ingram et al. (57). Besides, recognising

needs and providing comfort for women exposed to distressing side effects associated with cancer treatment demand further investigation of how this body change is experienced.

3.3. THE EXPERIENCES OF CHANGES IN WEIGHT AND BODY SHAPE

The literature search was conducted in three databases but only six studies appeared relevant for the topic under investigation. The literature review revealed that although weight changes may influence women's self-esteem and quality of life (56), their experiences of their altered bodies seem to be inadequately explored.

3.3.1. DESIGNS, DATA COLLECTION AND FINDINGS

The six studies used data from individual interviews (71-74) and focus groups (71,75,76). The sample size of individual interviews consisted of 11 (72), 12 (73), 15 (71), and 20 women (74). The women in the interview studies were mainly Caucasian, whereas the women in the focus group studies by Halbert et al. (75) and Weathers et al. (75) included African-American women. This group of women was claimed to be more exposed to overweight and obesity than Caucasian women. However, as the fat epidemic is spreading worldwide - from USA to Europe and now also appearing in Asian countries (77,78) - the breast cancer incidence is expected to be influenced in general (79) and to demand attention to weight changes among all ethnicities. The studies from the quantitative literature review covered four continents and disclosed a variation in weight changes over time. The studies in the qualitative review originate from USA and Canada. The experience of changes in weight and body composition has thus not been given the same attention as the factual changes. This may be essential for a caring practice that involves knowledge and understanding based on natural as well as human and social sciences (14).

Reviewing the quantitative literature, weight changes fluctuated over time and measurements were undertaken from months to years. The studies reviewed for the qualitative phase are conducted during different time spans after diagnosis and apply different analytical methods. Maley et al. (71) included women more than one year from diagnosis and analysed their interviews with constant comparative methods. In a transparent research process, they showed how the perception of body weight changes moved between vulnerability and control, stress and living well, uncertainty and confidence (71).

Halbert et al. (75) and Weathers et al. (76) illustrated how weight changes resulted in psychological stress and concerns about health. Weight changes appeared unexpected, and weight gain and weight loss could promote discomfort. Although weight loss could be perceived as an illness, it might induce a positive body perception, if the women had been heavy before the diagnosis. These qualitative

data were obtained from focus groups, and data were collected after completed cancer treatment less than five years and more than five years from diagnosis. The authors claimed a grounded theory approach with data analysed by constant comparative methods in one study (75), and the other study analysed data by a transactional model of stress and coping (76). However, the findings were described with brief textual quotes indicating a basic step in the analysis which does not seem to be performed on a theoretical level (75,76). It was unclear how 34 women participated in ten focus groups (75), and how 16 women were involved in focus groups to explore data from questionnaires (76). Given the delimited literature addressing the experiences of weight changes, these two studies may - despite their weaknesses - provide a sense of what may be at stake for these women.

In the studies by Brunet (72) and Thomas-MacLean (73), a transparent data analysis was described from a phenomenological point of view (72,73). According to Brunet et al., weight gain was perceived as a visible change that affected the overall self-worth and induced negative emotions about not being able to control weight. The interview referred to experiences from two to 31 years from diagnosis (72). In the study by Thomas Maclean et al., weight loss was interpreted as an illness whereas weight gain was associated with a feeling of undergoing a treatment without end. These findings were related to experiences from one to 24 years after completed treatment (73). One study used semi-structured interviews that contained questions about well-known side effects from cancer treatment. Weight changes appeared as unexpected and distressing, and changed weight distribution was a concern for the women. None of these experiences were unfolded as most of the data were transformed into numbers (74).

In general, the studies revealed that the women wanted to gain control over their health, which was deeply associated with both weight gain and weight loss (71,72,75). Related to disease and fear of possible death, the changes were associated with existential treats (72-75). The body weight changes were visible for the women themselves and others and had to be camouflaged by clothes (72,75). Besides appearing unexpectedly, the changes could be a constant reminder of the breast cancer diagnosis (76) and induce a feeling of never-ending treatment (73,75). In some cases, the changes were expressed as ‘rather die than look like this’ (75): p. 184). Although these changes seem to inflict women broadly, one study revealed that professionals did not take weight gain seriously in outpatient follow-up visits (71).

3.3.2. SUMMARY OF THE QUALITATIVE LITERATURE REVIEW

These findings demonstrate that the changes may be intertwined in a field of bodily changes and emotions that greatly influence the women. Although changes in body and weight were central elements in the studies, the participants were included from one to 31 years from diagnosis. As the influence of the changes may be relative and

dynamic during the cancer trajectory, findings from these studies can provide a sense of what may be at stake for these women during this varying time span.

However, it may be questioned whether these findings can provide specific and individualised support to the individual women during 12 months following diagnosis where weight changes seem to be increasing. Furthermore, the influence of changed body distribution was not explored. Valuable information about the women's experiences of changed body distribution may thus be missing.

Finally, losing one's pre-cancer being or parts of one's identity is reported in other studies associated with the consequences of cancer treatment such as loss of breast and hair (52-54), but is not specifically linked to changes in weight and body shape. Although Halbert et al. (75) reported an average weight gain of eight kilos among 47 % of 34 women, and Cappiello et al. (74) reported that half of the interviewed women (n = 20) experienced persistent weight gain, the literature review did not depict how the influence of changes of the women's perception of body and self could be associated with factual changes.

3.3.3. SUMMARISING THE LITERATURE

Changes in weight and body composition seem to be a complex multi-factorial phenomenon associated with bodily changes and long-term survival which influences quality of life, body perception, and self-esteem. The phenomenon of changes in weight and body composition is observable, measurable, felt, and sensed. Research on the factual changes caused by breast cancer treatment is diverse and sometimes contradictory. It seems that changes fluctuate over time and as a minimum have to be examined until one year following diagnosis. It is also argued that the problem of bodily changes may be overestimated. However, we cannot determine whether weight changes are over- or underestimated without taking the women's experiences of their altered body into account.

Current research on the experiences of weight changes on body perception is limited and reports experiences that cover a long time span. How these changes influence women's perception of body and self and the essential meaning of the bodily changes during and after initial cancer treatment short-term to approx. one year following treatment seems to be insufficiently explored and needs further investigation. Without understanding the essential meaning of the changes, health professionals risk ignoring a demanding discomfort that may influence the everyday life of women whose bodies have changed and are no longer silent and taken for granted.

Given the adverse effects of weight changes on breast cancer survival and the general health as well as the women's experiences, it is vital that health staff pays attention to how these serious consequences during and after adjuvant therapy are a

concern for the women as unified body-subjects. In addition to studies on factual changes in weight and body composition and the experiences of changes, the development of new knowledge of this complex topic requires further exploration.

Separate research on factual bodily changes or research about the experiences of bodily changes does not seem to provide a sufficient understanding of the relationship between the two perspectives. Neither does the research ensure a perspective that takes the unified body-subject into account. Thus, there is a risk of employing a dualistic understanding of a separate body and mind, which is inconsistent with fundamental assumptions in nursing. On the other hand, combining quantitative and qualitative methods and integrating findings may provide insight into the ways in which bodily changes influence the women's experiences in a more profound way.

3.4. PURPOSE AND RESEARCH QUESTIONS

The purpose of this study is to investigate the complexity of changes in weight and body composition among women during and after adjuvant antineoplastic treatment for breast cancer and to increase our knowledge on how changes in weight and body composition influence women's experience of their body and self as unified body-subjects. This leads to the following research questions:

- What characterises changes in weight and body composition during 18 month from diagnosis among women during and after adjuvant anitneoplastic treatment for breast cancer?
- How is the risk of weight changes associated with current adjuvant antineoplastic treatment?
- What is the essential meaning of the phenomenon of changes in weight and body shape among women treated for breast cancer?
- How do these changes influence the women's perception of body and self?
- How can an understanding of the women as unified body-subjects expand our knowledge of factual bodily changes and their influence on the women's perception of body and self?

The above mentioned research questions indicate the fundamental assumption that bodily changes cannot be understood without considering the individual's self-understanding and the meaning of suffering (13,15,16). This is consistent with a caring practice, where understanding the experience of an injured body in a state of

illness demands application of knowledge based on natural, human and social sciences (14).

As it is not the body as an object or the subject's experience, but rather the inseparable body-subject which must be taken into account, understanding complex human phenomena may demand complex research processes and explication of an overriding/underlying philosophy that acknowledges a unified body. In addition to clarifying research processes, the researchers are obliged to reflecting on and articulating these fundamental assumptions for their study (4).

This study demands a basic attitude that takes the unified body-subject into account. In addition, to overcome dualism when focussing on physical changes and the patient's experiences, the study must also be philosophically driven by a fundamental wish to understand the wholeness of bodily changes and the experience hereof. Framing this study with the philosophy of existential phenomenology acknowledges a unified body. This philosophy transcends dualism on the ontological and epistemological level and points towards a mixed methods research design that provides opportunity for this transcendence.

The next chapter elaborates on the philosophical perspective in existential phenomenology as an overriding framework and guidance for obtaining a phenomenological attitude.

CHAPTER 4. PHILOSOPHICAL PERSPECTIVE

In this study, fundamental assumptions on the ontological, epistemological, and methodological levels are unified by existential phenomenology as developed by Maurice Merleau-Ponty. In this chapter, the philosophical perspective is presented and link between the philosophy, the mixed methods methodology and fundamental assumption in nursing are provided, followed by a guidance for obtaining a phenomenological attitude.

4.1. EXISTENTIAL PHENOMENOLOGY AS AN OVERRIDING FRAMEWORK

Phenomenology is described as ontology and epistemology, an approach, and a method (80,81). It is also described as a scientific lifeworld approach that can serve as a methodological tool in revealing knowledge embedded in an intersubjective world that is unique to each human being and, at the same time, shared (15). From the perspective of Merleau-Ponty, the gap between the body as an object and the perceiving subject is changed into a unifying understanding of the lived body that aims at overcoming the dualistic mind-body notion (17,18). *Being* a body rather than *having* a body is consistent with a nursing philosophy focussing on the unified, inseparable body. Thus, existential phenomenology provides fundamental values and a manner of thinking that spans the philosophical and methodological levels.

To address patients' experience of health-related bodily changes within a frame of existential phenomenology, the human being is understood as essentially embodied, an inseparable body-subject (15,82,83). The body:

> […] is a physical thing, an object that can be weighed, measured and described using purely physical or naturalistic terms. But it is also the source of subjective feelings, perceptions and sensations; it is the seat of subjectivity, the place where consciousness occurs. As such the body is a subject-object, a unique being that can be experienced both from a first and a third person point of view (83, p.37).

The first person point of view may in this case be understood as the immediate experience of bodily perceptions and embodied activities as they appear in the consciousness. This is a first-hand experience that may provide an account of what it is to suffer from a particular illness. This perspective can for example be explored by means of qualitative methods. The third person point of view refers to the body

as an object that can be observed and examined in a detached manner. This perspective may be investigated by means of quantitative methods.

Focussing on physical and biomedical changes and paying attention to the patients' experiences and environment by application of multiple theories and methods is in accordance with the inclusion of different mental models (3,4,14). Bodily perceptions contain meanings and due to the inseparable body-subject, changes in body can lead to far-reaching changes in one's sense of self as everything exists through the body (83). Illness and suffering are thus experienced as a disruption of previously lived experiences, including bodily alienations, altered experiences of time and space, challenges to self-identity and integrity, etc. When perceiving patients as body- subjects, it is therefore not sufficient to examine the physical body and the subjective experience side by side, which leads us further into the realm of existential phenomenology.

The thoughts of Merleau-Ponty regarding the unified body-subject and how being in the world may appear for the perceiving subject are unfolded. This investigation provides the basis for understanding how existential phenomenology may direct values and tools for reflection throughout the study, focussing on the influence on body and self-perception caused by changes in weight and body composition. The following section provides an understanding of how Merleau-Ponty overcomes dualism by unifying idealism and realism and by combining Husserl's epistemology with Heidegger's ontology.

4.1.1. 'BEING-IN-THE-WORLD-AS-IT-APPEAR-FOR-US'

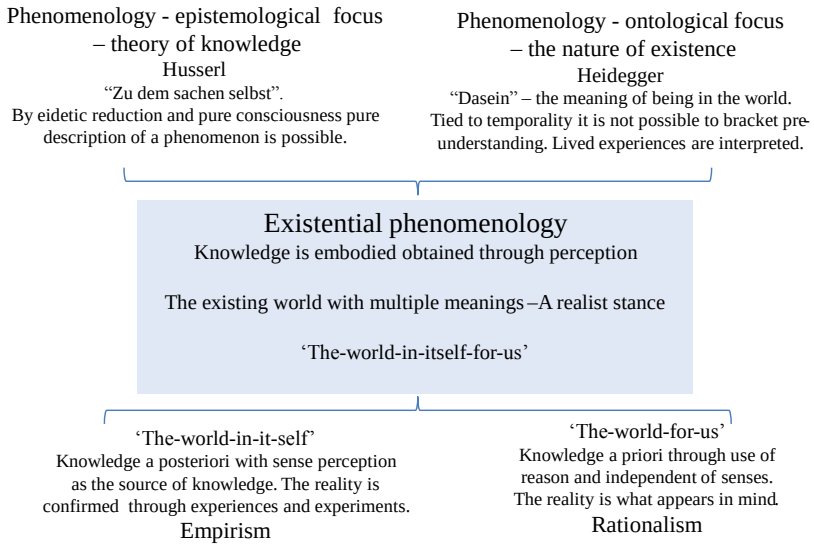
Building on the thoughts of Husserl and Heidegger, Merleau-Ponty strives to overcome the dualism between body and mind inherited from Descartes. Merleau-Ponty acknowledges that human beings exist as biological bodies (Körper), which, in some cases can be identified as objects. However, his concern is the lived body (Leib) and the human being as a historical person engaged and living in a shared world, a meaningful community with other persons.

Acknowledging that phenomenology is empirically driven, Merleau-Ponty argues that the world exists as a fact, representing real objects. However, the world exists for us, which means that the world consists of intersubjectively constructed meanings. Merleau-Ponty also acknowledges scientific knowledge, but discusses '*whether it is entitled to deny or rule as illusory all forms of inquiry that do not start out from measurements and comparisons'* (84, pp.34-35). Within this form of science important aspects of reality that are manifest within the perceived world risk being overlooked (84). To explore existential dimensions perceived by human beings in the lifeworld, Merleau-Ponty suggests phenomenology as a science that links realism and idealism. From this perspective it seems that Merleau-Ponty avoids

'either or' and highlight 'both and' in what is claimed to be a realist stance, a way of 'being-in-the-world'.

This realist stance draws both on empiricism, logical positivism and rationalism (84) as Merleau-Ponty stresses that things are not to be understood as existing solely in themselves, nor are they reduced to mere aspects of the subject's conceptual world (18). In other words, 'being-in-the-world' or being embodied means that all knowledge or ideas derive from experiencing 'the-world-in-itself'. This world becomes innate in the mind, 'the-world-for-us', and by combining ontology with epistemology, as a third option in existential phenomenology, 'the-world-in-itself-for-us' appears. The real world exists, but it exists for the individual human being in a perceiving act – i.e. it is subjective and constructed (Figure 1).

Figure 1. Existential phenomenology as a realist stance



Combining the ontological and epistemological levels in existential phenomenology, the women in this study are consequently considered as persons and human beings who experience physical changes and give meaning to these changes, psychologically, spiritually, and socially. Being a unity consisting of a biological, physical body and an animate organism with mental acts and processes, the perception of the body and world changes if the physical body changes.

In this study, it was taken for granted that knowledge is not purely objective, but always contains subjective elements. All knowledge in the world, even scientific

knowledge, is built upon the world as directly experienced from human beings' point of view. Knowledge is embodied when we perceive the world around us through our senses. Although knowledge derives from the empirical world, it is not identical with the real world. Rather, it is a map of a landscape and thus constructed by the researcher.

Depending on the context, phenomena may change, and thus the phenomenal 'world-in-itself-for-us' can never be exhaustively described. When all knowledge is based on the world as directly experienced from human beings' points of view, our senses can teach us to see the world by returning to the things themselves, '*zu den Sachen selbst'* (84, p.53). Revealing factual bodily changes from the women's point of view may thus be a question of 'the-world-in-itself-for-them'.

4.1.2. THE BODY IN THE WORLD

According to Merleau-Ponty, the real world is perceived through the body. Searching for this third way of 'being-in-the-world' in the attempt to overcome dualism, he introduces 'one's own body' (84). This refers to the lived body or the unified, inseparable body-subject that functions as an anchor in an already existing world, the natural setting of and field for thoughts and explicit perceptions (20). 'Being-in-the-world' - or embodiment - is thus a central concept that acknowledges human beings physical ties to the world. Human beings think, see, hear, feel and are conscious through their body's interaction with the world. Being an object and subject, nature and culture in an always dialectic relationship, the body-subject perceives the world through perception, language, emotion and movement in time and space, creating pre-reflective embodied knowledge (20).

It is important to note that humans not only see, hear, feel etc. They see the sunset; hear music and voices, love a beloved, etc. It is through our senses that we perceive the world, and it is the body that embraces and constitutes the world (84). Thus, all perceived phenomena and meanings are interconnected as flesh in a mutual relation with the world, culture and the environment. This interconnectedness which also includes the perception of bodily changes, serves as a horizon that is always implicitly present as shifting backgrounds for what stands out as figures or the significant element in a situation (20).

According to Merleau-Ponty the body comprises two distinct layers that always infiltrate each other. Normally the two layers adjust to each other effortlessly but in illness this effortless connection may be hindered. The one layer refers to the habitual body, which is a general and pre-reflexive existence, situated in taken-for-granted everyday living. The second layer is the present body that refers to a reflexive existence. The habitual body acts as a reference for the present body. With the present body in focus for the unified body-subject, the past, future and present

are tied together (20, pp.84, 287. Thus past and future exist for the present and as the present always exists as 'nows' the meaning of bodily changes are infinite.

Acknowledging that the human being exists as a biological body (Körper), the body may be identified as an object by others and by the perceiving subject. The perceiving subject is further more a historical person engaged and living in a shared world, a meaningful community with other persons. As it is the body-subject that perceives, if the biological body changes, so does that person's perception of body and world. Thus, the meaning of illness and suffering can never be understood without reference to the surroundings and the life project of the body-subject (20, pp.312-18, 346).

As existential phenomenology is claimed to be a science of phenomena (15), phenomenology as methodology and method also demands considerations.

4.2. PHENOMENOLOGY: A METHODOLOGY AND METHOD

Methodology is prior to method as methodology points towards the concrete methods that are to be used and implicitly contains the researcher's philosophical perspective, which is described in the former sections. Empirically driven, examining the life-world as a tacit ground for science, phenomenology is acknowledged as a methodology and a scientific life-world approach that can reveal knowledge embedded in an inter-subjective world, unique for every human being and at the same time shared (15).

Phenomenology is not restricted by a certain method. To reveal essences and explore meanings as they unfold for human beings, some conditions for obtaining scientific rigor have been described (15,80,85). Understanding the person's experience of the world and returning to the things themselves, the research methods are the methods of philosophy, accessible through a phenomenological method or attitude.

Going 'zu den Sachen selbst' without preconceived expectations and presuppositions, phenomenological investigations are looking for how the phenomenon is established or takes shapes and appears in typical structures or essentials and relationships (80). According to Merleau-Ponty, we shall consider things naively, try to forget what we find natural because of their familiarity (84, p.61), and *'look at ourselves in an un-familiar gaze'* (84, p.68). However, even though Merleau-Ponty wants to return to the prior knowledge, pure description is not possible because during the process an immediate interpretation takes place. To understand how this structure manifest requires a focus on the relationship between subject (researcher) and object (that which is being studied) a presentation of two essential concepts - phenomenological intentionality and reduction - are needed.

Intentionality refers to the directedness of consciousness towards objects or events, to something in an inseparable connection with the world. As people *are 'always in move […] in a coming-into-being of possibilities'* (17,p.286), the world is continuously transforming and thus infinite. What appears meaningful in this world emerges in an interaction between figure and background in the life-world context (15).

In this study, the intention is to put into words the essential meaning of factual changes in weight and body composition that may be tacit, pre-reflexive and embodied. Thus the researcher may be in a double position. On the one hand, the researcher endeavours to reveal what is essential for the women in a shift between figure and background from the women's perspectives. On the other hand, the researcher has to be aware of own intentionality, in the attempt to go 'zu den Sachen selbst' through phenomenological reflections.

Reduction is concerned with phenomenological reflection that aims to bring different perspectives into view (81). To perform phenomenological reduction, the researcher must recognise that she influences the situation with her pre-understanding and her research design. Instead of bracketing one's natural attitude, bridling is suggested as a means of attaining phenomenological reduction (15,16). Bridling means to be aware of our natural attitude and replace it by a phenomenological attitude by questioning a presumed reality in data gathering as well as in the analysis and interpretation of data.

In summary, phenomenology is a science that may explore existential dimensions perceived by human beings in the lifeworld, and for scientific reasons some requirements must be met. Scientific rigor and perpetual, critical self-reflection must be obtained during the research processes, irrespectively of whether the researcher is dealing with quantitative or qualitative data. This critical self-reflection is performed through a phenomenological attitude.

4.2.1. PHENOMENOLOGICAL ATTITUDE

Existential phenomenology as a science is performed through perpetual critical self-reflection and focuses on how the reality is presented to us through experience without taking anything for granted. Thus, the research process must take the natural attitude into account, the taken-for-granted assumptions. As researchers we should position ourselves in such a way as to allow things to reveal themselves to us as phenomena, *'that which shows itself in itself'* (15, p.32). To provide a direct description of experiences without psychological or causal explanation, researchers must be aware of their own dogmatic attitude towards reality as well as their constitutive contribution to the reality given (20, pp. xxiv, xxix).

The phenomenological reflections of this study demand that the researchers adopt a phenomenological attitude, bridling one's taken-for-granted assumptions (86). Thus, bridling is a means of scrutinising the researchers' involvement with the investigated phenomenon, not to suspend this involvement.

The first step is to recognise how researchers enter into the research situation with a specific pre-understanding and research design, and thus how they may influence the situation through data collection, analysis, and interpretation (2,15,87). Practicing a phenomenological attitude may thus imply a consideration of how one can position oneself and apply the multiple methods used in a trustworthy and transparent way. Being engaged as a researcher with data collection and being acquainted with the women behind the measurements and statements provided a unique opportunity to remain faithful and faithless throughout the process (88). However, to maintain such phenomenological attitude it is important to scrutinise one's pre-understanding.

4.2.2. PRE-UNDERSTANDING

The researcher's pre-understanding may prevent her from exploring what seems familiar or contributes to flavouring the data by making her look for supportive trends in datasets and interview statements. Therefore, I have conducted an investigation of my own pre-understanding. First, literature studies, discussions with colleagues in general, nurses at the outpatient clinic, breast cancer survivors, and friends became part of my pre-understanding. On the one hand, the literature and discussions confirmed that weight changes were perceived as a problem that was relevant to investigate. On the other hand, weight changes were considered as a minor problem related to a normal female perspective on the body, a wish to be attractive, and thus a matter of vanity. Another important issue was the contradiction between weight gain as a side effect of cancer treatment and lifestyle diseases caused by excess body fat. These serious implications and lack of understanding of the women's perspective urged me to commence the project.

Conducting a focus group (Paper 1) in preparation of the individual interviews revealed how the women struggled with changes in weight and body shape. Their thoughts, feelings, and opinions became part of my pre-understanding. This became obvious when I was interviewed by a clinical nurse consultant before conducting the individual interviews. This interview revealed that my driving force in researching the women's experiences was a feeling of solidarity, a wish to give the women a voice and acknowledge their concerns. Conducting the first individual interview, I was hit by a discouraging feeling, as it seemed to reveal nothing of importance. Reflecting on this I acknowledged that this could be a sign that I had fallen into the familiar trap: the taken-for-granted. My solidarity with the women and attempt not to downplay their feelings might prevent me from maintaining a phenomenological attitude. This insight emphasised the need for me to be more open, to wonder, and to be more conscious of applying a 'phenomenological method or attitude'. In the

following interviews, this remained a challenge, but I strove to stay more open and curious, and I consequently caught a glimpse of what might be at stake.

In this chapter, fundamental ideas which often serve as an orientation to the world when unarticulated and silent are explicated for research purposes. With existential phenomenology as an overriding philosophical perspective that prevails, the next section will provide the link to the mixed methods design used in this study, including descriptions of the further methodical steps.

4.2.3. THE LINK BETWEEN EXISTENTIAL PHENOMENOLOGY AND MIXED METHODS

Existential phenomenology is suggested to be an overriding philosophy for health care practice (19,82,83). Taking the stance of existential phenomenology also at the methodological level, including guidance by reflective life-world research, requires methods that follow the attempt to explore the unified body-subject. Thus, the methods must contribute to a deeper understanding of the women as unified body-subjects and expand our knowledge of the relationship between factual bodily changes and their influence on the women's perception of body and self. For this purpose, the attention is turned toward mixed methods in the next chapter, but first the link between mixed methods and the philosophical level will be provided.

In mixed methods literature, pragmatism is recommended as a philosophical stance for mixed methods studies because it allows the gathering of all types of data in order to best answer the research question (5). However, combining a framework that encompasses the human being as a unified body-subject with mixed methods may also be plausible by bringing in critical realism, which is another philosophical stance discussed in mixed methods literature.

In a former section it is shown how Merleau-Ponty combines Husserl's epistemology with Heidegger's ontology and thus idealism and realism in his 'third way', although pure realism and idealism/constructivism traditionally are said to be incompatible (Figure 1). This perspective is also prominent in critical realism. Integrating realist ontology with constructivist epistemology, critical realism is consequently claimed to be compatible with methodological characteristics of both qualitative and quantitative research (3,89,90). Thus, talking about alternative mental models in dialogue, Greene argues that critical realism can constitute a productive stance for mixed methods studies (89).

There seems to be some ontological and epistemological agreement between critical realism and phenomenology, which may suffice as the link to mixed methods methodology. Agreeing with existential phenomenology on the existence of a physical world independent of consciousness and the meaning of experiences

constructed by the individual, a critical realist perspective also advocates a moderate position between realism and idealism/constructivism (3,89,90).

Risjord (9) is a proponent of this moderate position for nursing enquiry and health professionals. In accordance with Merleau-Ponty, Risjord stresses that reality consists of meaningful objects and events, not multiple realities, because *'there is a difference between a person's health and his or her experience of health'* (9, p.205). What is multiple is not reality, but the significance of events and experiences for the human being (9). The exposition of existential phenomenology as an overriding frame for the study - by combining realism and idealism on the ontological and epistemological levels - thus gives rise to a perspective on the unified body-subject.

In this study, fundamental assumptions on the ontological, epistemological, and methodological levels are unified by existential phenomenology as developed by Merleau-Ponty. In this chapter, the philosophical perspective is presented and links between the philosophical perspective, mixed methods methodology, and fundamental assumption in nursing are provided. Finally, guidance for obtaining a phenomenological attitude is elaborated.

CHAPTER 5. MIXED METHODS

When complex research processes are required to capture the complexity of human phenomena, there has been an emerging focus on conducting mixed methods studies in health sciences and other professional domains (3,4,91,92). In this chapter 'mixed methods' for this study are described and applied to provide knowledge of changes in weight and body composition related to the unified body, essential for nursing practice.

5.1. MIXED METHODS

Mixed methods is still in a stage of development (93) and considered as an innovative process that draws on the strengths and overcomes the limitations of qualitative and quantitative research processes (4,91,94,95). By using a mixed methods design it is possible to integrate qualitative and quantitative research questions, methods, techniques and findings with a view to better understand a phenomenon and measure its magnitude, trends, causes and effects (89,93,95,96, p.56). Thus, it is not sufficient to use different forms of data, methods etc. To provide a comprehensive understanding of the phenomenon under study, the research process must involve some degree of integration (91,97).

There are various ways to represent integration in a study: in creating the design, in data collection, in data analysis, or in a discussion or conclusion section at the end of a study (4). The objective behind the integration of qualitative and quantitative methods is to reveal complementary aspects of the phenomenon in question and to elaborate, expand, and reveal nuances hereof (91,94). In addition to being a means of bridging different parts of a study, integration thus provides synergy and adds value to a mixed methods study. In our case, integrating throughout the study process aims to expand the understanding of weight changes among women during and after adjuvant treatment for breast cancer, contributing to a deeper understanding of the meaning of factual changes.

Independently of design, the study must basically satisfy three conditions: Qualitative and quantitative methods must be combined; the methods must be used rigorously; the study must involve integration of data collection and/or data analysis and/or results (4,91,95). Integration can take several forms such as merging, explaining, building, and embedding, depending on the type of design (4, p.7). To claim a mixed methods design, integration on different levels during the research process is thus essential. According to Fetters and Freshwater, the integration of qualitative and quantitative research procedure and data can be implemented at the design, methods, interpretation, and reporting levels of research (91, p.2135). Integration does not necessarily take place on all these levels.

Depending on the research question and clinical conditions for empirical studies, it is possible to use various combinations of sequential and convergent approaches and combine them in multistage mixed methods designs (91): p. 2137). In the following sections, the mixed methods design applied in this work will be elaborated in relation to feasibility in a clinical practice and time limits for a PhD project.

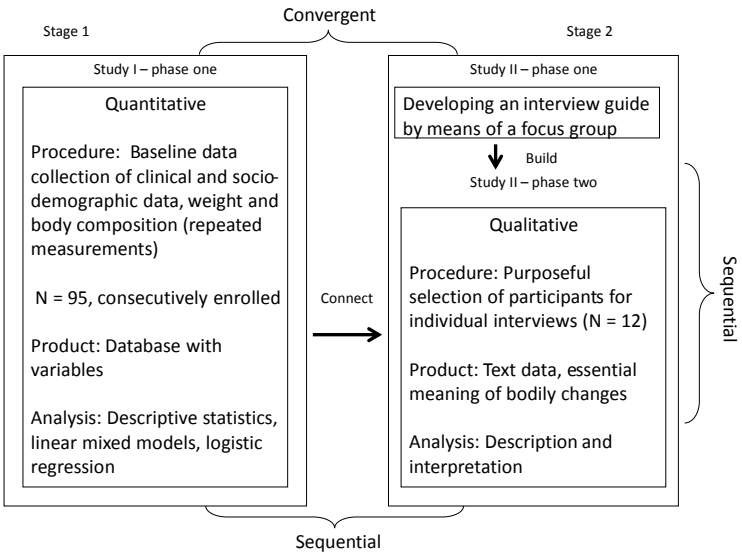
5.2. DESIGN AND INTEGRATION ON THE DESIGN LEVEL

Mixed methods designs consist of three basic designs: a convergent design where data collection takes place concurrently, an explanatory sequential design where the analysis of quantitative data collection informs the qualitative phase, and finally an exploratory, sequential design where analysis of qualitative data informs the quantitative phase (4,5,91). For example, in convergent designs, both datasets are analysed independently, and the results are merged for the purpose of comparing or validating. Explanatory sequential designs aim to explain, elaborate, and expand the understanding of a complex phenomenon and usually, findings from the quantitative phase are built into the qualitative phase (4,5). If applying one of these basic designs is insufficient, combinations of basic designs can be included in a multistage mixed methods framework defined as two or more phases in convergent design and three or more when sequential designs are involved.

Initially, an explanatory, sequential design was planned for this study. However, as the data collection for the quantitative phase took place longitudinally and required measurements over 18 months from inclusion, the design had to use a convergent design as well. Thus, the design was not wholly convergent or sequential, but aimed to provide depth and breadth, displaying a multistage design in two stages and a total of three phases (Figure 2). Following a convergent design, the quantitative data collection (Study I) proceeded alongside the development of a focus group-based interview guide in preparation of conducting individual interviews (Study II). Subsequently, the study followed a sequential design in which participants were selected for individual interviews on the basis of preliminary results from the quantitative component, and findings from the focus group were built into the thematic and dynamic dimensions of the individual interviews.

The convergent design thus consisted of three phases. One phase was associated with Study I, and two phases were associated with Study II as displayed in the two figures (Figures 2 and 3). In the three phases, a sequential component was applied. Application of three phases and the use of convergent and sequential design justify the multistage design. The models of the mixed methods design and processes show that integration takes place at the study design level.

Figure 2. Mixed methods study design

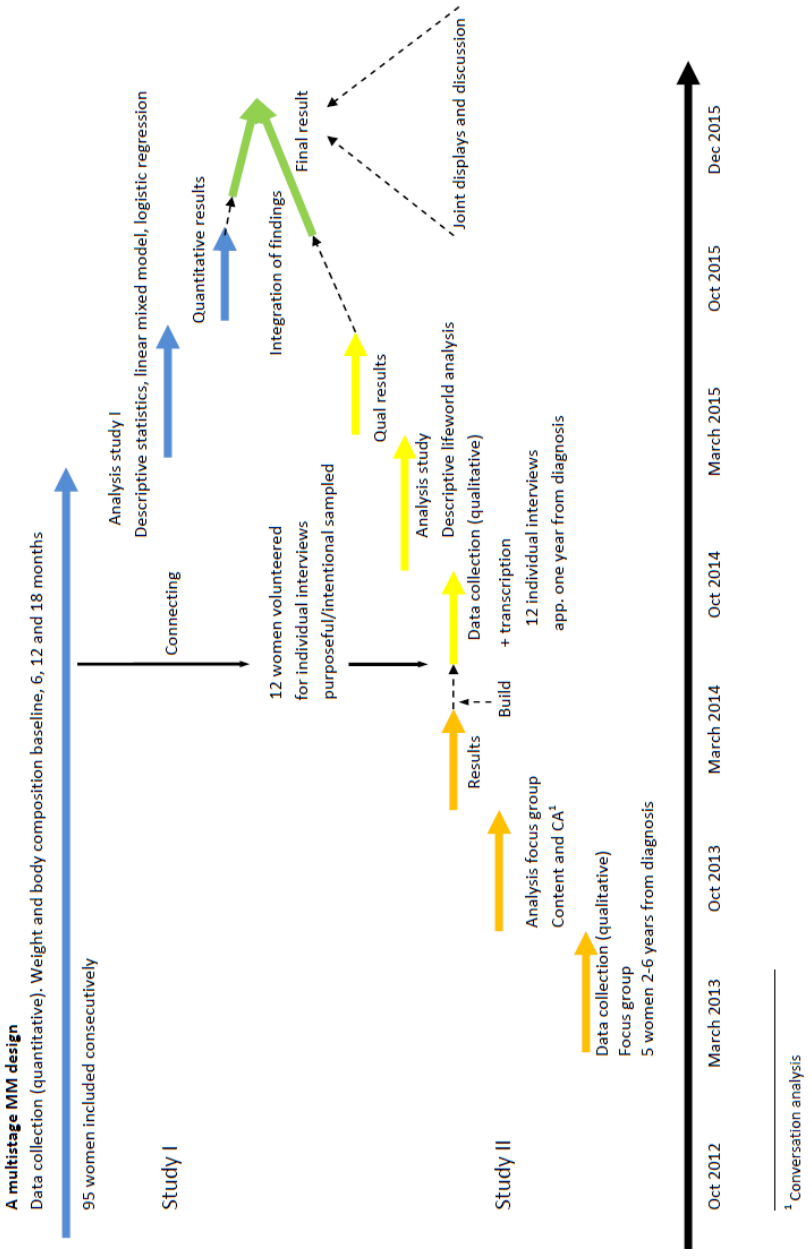


Creating a study design is thus a process in progression that evolves from simple to more complex figures (4). Figure 2 displays the results of the final project with the contents of each stage visualised except for the development of the interview guide that is explained in depth in the methods section (Chapter 6). Acknowledging that a timeline may provide additional understanding of the study course, a figure showing the study process was added (Figure 3). In this figure, the integration on different levels during the study is visualised and described by the concepts: connecting, building, merging, and joint display. In addition to integration on the study design level, Fetters, Curry and Creswell (91) consider integration on the methods level and finally on the interpretation and reporting levels. The integration in this study is further explained and discussed below.

5.3. INTEGRATION ON THE METHODS LEVEL

The integration on the method level follows the design and may take place by building, connecting and merging quantitative and qualitative data collection and the subsequent analysis (91). As the design in this study was partly convergent and partly explanatory sequential, data collection was integrated through connecting and building (Figure 3).

Figure 3. The study process



Connecting occurs when one type of data links with another through sampling. Building occurs when results from one data collection procedure informs the data collection approach of another procedure. Finally, merging occurs when the quantitative and qualitative databases are brought together for analysis (91).

According to the literature review, changes in weight and body composition were particularly reported after completed chemotherapy and at least 12 months following diagnosis. In the present study, we wanted to extend this limit to 18 months to follow the changes further on. To deal with the time limits of a PhD study we therefore decided to proceed with the qualitative component before the quantitative data analysis was complete and thus also applied a partly convergent design. Following a partly sequential design, a preliminary analysis of the quantitative data informed eligible women of the qualitative interview study (91,94). This ensured a purposeful sampling for the qualitative interview that displayed various experiences regarding their weight and thus also represented the quantitative cohort, which is further described in the methods chapter. Study II is thus connected with Study I (integrated) on the sample level (Figures 2 and 3).

In a convergent design, samples do not need to be linked to each other, as data collection and analysis are carried out in parallel (91). In parallel with the quantitative data collection, women who had experienced changes in weight and body shape were invited to a focus group session (Study II, Phase 1). The purpose of the focus group was to provide content and form for an interview guide. The results from the focus group informed data collection of the individual interviews. Thus results from the focus group (Study II, Phase 1) were built (integrated) into the interview study (Study II, Phase 2). As the study is a multistage mixed methods study, integration of findings appears later in the study process. This is explained in the next section.

5.4. INTEGRATION AT THE INTERPRETATION AND REPORTING LEVELS

Fetters, Curry and Creswell (91) introduce the stage approach to integration on the interpretation and reporting levels. The stage approach is used in multistage mixed methods. Using this approach, the results of each step are reported in stages as the data are analysed and published separately. The papers may briefly refer to each other. For convergent designs, a popular way to represent integration is in a discussion or conclusion section at the end of a study by arraying quantitative and qualitative findings in parallel (4). Another way of integration on this level is through joint displays. Using joint displays, data are integrated by bringing the data together in figures, tables, etc. to visualise new insight and generate new inferences.

Interpreting and reporting a multistage mixed methods study using a partly convergent, explanatory, sequential design bring these integration forms together. Initially, the results of each step are reported separately as the analysis was completed individually for each part of the study (Paper 1, Paper 2 and Paper 3). Paper 2 refers to Paper 1, but no connection is made in regard to Paper 3. However, Paper 4, the mixed methods paper, demonstrates how the phases of the whole study are integrated. In Paper 4, an integrative analysis/interpretation is structured around joint displays that give birth to new inferences. The assessment of how the quantitative and qualitative findings cohere can - according Fetters, Curry and Creswell (91) - lead to three outcomes. The integration can provide confirmation, expansion, or discordance. In the present study, expansion was sought as the aim was to elaborate, expand, and reveal nuances of complementary aspects of the phenomenon in question. Searching for expansion and complementarities through convergence and sequences provided breadth and depth. This is elaborated on in Paper 4.

In summary, integration has taken place on several levels during this multistage mixed methods study, which provides a strong structure for the relationship between the various parts of the study and is consistent with the perspective of a unified body-subject. Combining a convergent design with an explanatory, sequential design in a multistage mixed methods design provided integration at the design level. At the methods level, data were connected through sampling and results from a focus group built into individual interviews. At the interpretation and reporting levels, every phase was initially analysed and reported separately. Findings were subsequently integrated through a unifying analysis and interpretation that was reported in a mixed methods paper.

CHAPTER 6. METHODS

In this chapter, participants, data collections and analytical strategies applied in the two studies will be presented. In line with the phenomenological framework, the research questions are all explorative and point towards descriptions, which facilitate an open approach to gaining knowledge of bodily changes, including investigating subjective experiences. As the data must be analysed in their frame of logic (98), the studies are presented one by one. However, keeping quantitative data and qualitative data apart may be inconsistent with fundamental assumptions in nursing and existential phenomenology as the overall framework. To ensure a perspective on the unified body-subject, an integrative mixed methods interpretation is described in chapter 7.

6.1. STUDY I: THE QUANTITATIVE COMPONENT – CHANGES IN WEIGHT AND BODY COMPOSITION

Study I aimed to investigate characteristics of changes in weight and body composition during 18 months following diagnosis associated with current adjuvant antineoplastic treatment for breast cancer and to examine how the risk of weight changes are associated with this current treatment. The study is described in the paper 'Changes in weight and body composition among women with breast cancer during and after adjuvant treatment – A prospective follow-up study' (Paper 3).

Providing quantitative findings regarding bodily changes associated with weight, Study I takes a third person perspective and focuses on the biological body (Körper) (83,84). Although the analysis of data was performed with statistical models consistent with the features of data in this study, a phenomenological attitude was adopted not to take anything for granted. Becoming part of my pre-understanding, the diverse findings from the literature review stimulated curiosity that was put into play during the data collection process. Collecting the majority of the data, my familiarity with the data became extensive and created an immediate perception of the findings. This sharpened my critical assessment of the statistical analysis. Thus, the taken-for-granted was continuously scrutinised during the analysis, and the interpretation of quantitative data was made with an open mind to allow unexpected findings to be reveal.

6.1.1. PARTICIPANTS

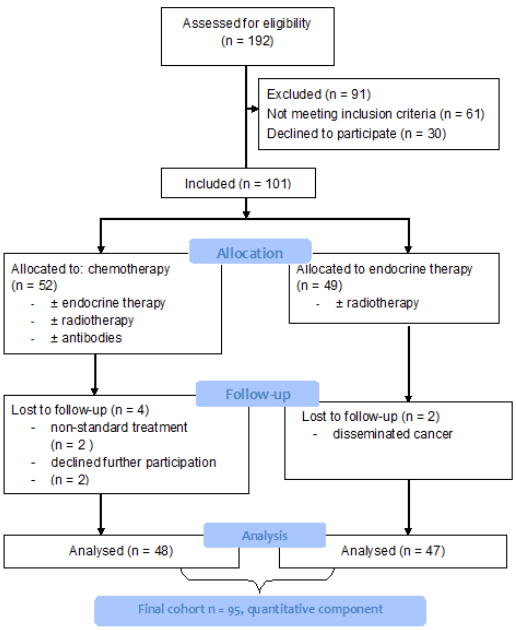
Participants in Study I were included consecutively when they attended the out-patient clinic for information of adjuvant treatment after surgery. Before that, the staff at the surgery clinic gave all eligible women written information along with brief verbal information after the initial surgery (Appendix C). Eligibility was

initially surgery and subsequently allocation to adjuvant treatment for stage I-III breast cancer, following the Danish Breast Cancer Group's recommendations for women at low or high risk of recurrence (43). In addition, the women should be able to read and speak Danish. Women with pacemakers or other electric devices implanted were not eligible. Furthermore, women suffering from psychiatric diseases in an unstable phase, cognitive impairment, severe co-morbidity, or other malign diseases, including disseminated breast cancer, were excluded. The clinical nurses at the out-patient clinic subsequently acted as gatekeepers and assessed the exclusion criteria in advance to minimise the inconvenience for these women.

When attending the oncology out-patient clinic, the women were already acquainted with the study, and the gatekeepers asked the women permission for the PhD student to present the project verbally. The women who accepted were subsequently informed about the study and the requirements for gaining valid data (See appendix C). Some wanted to be enrolled immediately. Others wanted time for further reflection and were enrolled afterwards. All measures were planned for a regularly scheduled clinic visit for minimal inconvenience for the participants.

A total of 192 women were screened. Of these, 61 women did not meet the inclusion criteria and 30 women who met the inclusion criteria refused to participate. Thus, 101 women were included, of which six women were lost to follow-up after the first measurement (Figure 4).

Figure 4. Consort diagram – inclusion process Study I



The eligible, but not included women were older than the included women and differed with regard to menopause status and cancer stage (Appendix D). The final sample of 95 women represented 75 % of the eligible women. All 95 women completed the study, and only five (1.3 %) data collections out of 380 scheduled appointments were missed.

6.1.2. INSTRUMENTS AND DATA COLLECTION

The study examined changes in weight and body composition through longitudinally, repeated measurements. Patient characteristics, selected lifestyle, and comorbidity factors were collected at baseline. Body composition data were collected repeatedly for 18 months. Clinical variables included menopause status, type of surgery, tumour stage, receptor status, histology, and adjuvant medication. Lifestyle included smoking and alcohol consumption, and comorbidity variables that might influence changes in weight and body composition were cardiovascular, muscular-skeletal, lung, and neurological diseases. These data were stored in EpiData prior to being subjected to analysis. Body composition data included age, weight, height, fat mass, fat free mass, total body water, and waist measurements.

Data on changes in weight and body composition such as body fat mass, fat free mass, and total body water were measured by means of an bioelectrical impedance analysis on a Tanita BC-418 Segmental Body Composition Analyzer (selected standard body type) (99,100). The device was calibrated regularly, and a comparison with BioScan 920-II using supine measurements (wrist-ankle measurements) showed no significant difference in comparable variables (Appendix E). The data were obtained when the women attended the oncology outpatient clinic for treatment or follow-up with a time schedule of 6 months ± 2 months, four times in total. The data were stored in a Tanita database and transferred to Excel prior to being subjected to statistical analysis.

Since relative weight changes are clinically more relevant than weight changes measured as a number of kilograms (34), a clinical cut-off with relative weight changes of ± 2.4 % was chosen (70). This limit takes diurnal variations into account (70) and is chosen as a reasonable way of assessing weight loss, stable weight, and weight gain.

6.1.3. ANALYSIS

For the sake of the analysis and to minimise subgroups, the variables were transferred into categorical variables in the final analysis. For comorbidity factors, the categories were ‘yes’ and ‘no’. Smoking and alcohol were displayed in two groups as current or non-smoker and alcohol consumption as less than seven units per week or more than seven units per week. Clinical characteristics were chosen to

give an overview of the distribution of disease-related factors, leaving out medication doses as these followed existing recommendations.

Baseline demographic and clinical characteristics were summarised using descriptive statistics, including mean, standard deviations and number of patients in the total sample and in subgroups. Fisher's exact test was used to determine the distribution in the two subgroups except for age distribution that was estimated by t^2-test (Chi^2). Linear mixed models using time as a fixed effect and person as a random effect were applied to estimate patterns of changes in weight and body composition over time. The outcome measures for these models were weight, fat mass, fat free mass, total body water, and waist circumference, respectively. The flexibility of linear mixed models allows for handling of repeated measurements and missing observations within subjects (101).

Associations between patient characteristics and weight changes from baseline to 18 months were examined through logistic regression. Stratified into three weight categories – weight loss below 2.4 %, weight gain above 2.4 %, and stable weight between ± 2.4 % - descriptive statistics provided an overview of the distribution of weight and waist circumference. Odds ratios (OR) were estimated for weight gain versus stable weight and for weight loss versus stable weight with respect to the characteristics of interest. Thus, the calculated odds ratios quantify the relation between patient characteristics and weight loss or weight gain, respectively. Statistical analyses were performed using the statistical package Stata 13.1 (StataCorp, Texas, USA). All P values reported in the analyses are two-sided values with a significance level of 0.05.

6.2. STUDY II: THE QUALITATIVE COMPONENT – THE ESSENTIAL MEANING OF CHANGES IN WEIGHT AND BODY COMPOSITION

Study II aimed to explore the essential meaning of the phenomenon of changes in weight and body shape among women treated for breast cancer and how the changes influence the women's perception of body and self? The study is described in two papers. Paper 1: 'Bridging the gap between interviewer and interviewee: developing an interview guide for individual interviews by means of a focus group'. Paper 2: 'The ambiguous transforming body – A phenomenological study of the meaning of weight changes among women treated for breast cancer'.

Paper 1 demonstrates findings that followed the partly convergent design as data was collected alongside the quantitative data collection in Study I with no connections between the two samples. Inviting women experiencing changes in weight and body shape aimed to contribute in developing an interview guide and thus to prepare the next step: the individual interviews. Developing the interview guide contributed to theory development regarding the use of focus groups as a basis

for subsequent, individual interviews. To provide the reader with an understanding of the whole study process, findings from the focus group are described in this method chapter.

Paper 2 illustrates how individual interviews aimed to explore the essential meaning of the phenomenon of changes in weight and body shape from the perspective of women belonging to the same cohort as Study I. Thus, a partly explanatory, sequential design was followed and the two studies (Studies I and II) became connected at sample level. The findings from this part are described in the findings section as they present the main findings of the qualitative part of the study.

The focus group and the individual interviews in Study II take a first person perspective and focus on the lived body (Leib) (83,84). Being part of a mixed methods study, this qualitative component provided important knowledge of the experiences of bodily changes and their influence on the women's perception of their body and self. In terms of lifeworld descriptions, this study thus provides an essential contribution to the final integration.

6.3. DEVELOPING AN INTERVIEW GUIDE (PAPER 1)

Studying people's experiences and collecting qualitative data requires a basic familiarity with the topic and a language that bridges the gap between the researcher and the study participants (2). The findings on the women's experiences were limited as described in the literature review. Although the papers contained quotes and thus gave insight into the women's language, the findings were mainly described in unifying concepts or themes.

A focus group may provide a platform for sharing and comparing experiences and opinions among the participants (102-106). Furthermore, discussions and interactions in a focus group may reveal important issues and provide insight into the interviewees' language (107). Thus, a focus group was conducted to extend knowledge of the topic, the 'what', but also to further extend my familiarity with the 'how'. The focus group aimed to provide the thematic and dynamic dimensions of the subsequent interview guide and support a natural conversation in an everyday language during the interview (2).

6.3.1. PARTICIPANTS, SETTING, AND DATA COLLECTION

We anticipated that one group was sufficient to cover the core elements as the aim of the focus group was not primarily to generate research data, but to use the data and analysis process in the development of an interview guide. Purposeful selection of women aimed to ensure a balance between homogeneity and variation, allowing for contrasting opinions (104,108). A team leader at a rehabilitation centre gave potential participants from a group of women with breast cancer written information

of the mixed methods project and the aim of the focus group (Appendix F). The women were expected to have experienced changes in weight (gain or loss) and/or changes in their body shape. Seven women with perceived changes were interested in sharing their experiences.

The team leader provided the women's telephone numbers to the researcher who subsequently contacted the women and gave them verbal information. All seven women consented to participate. As two of the women cancelled the appointment a few days before the scheduled day, the focus group was carried out with five participants, during spring 2013. These women demonstrated homogeneity and variation in age, treatment and body changes (Table 1).

Table 1. Participants, focus group

Participant pseudonym	Age	Treatment and year initiated	Weight changes	Comments
Bea	62	Mastectomy, endocrine treatment 2006	Gain 5-6 kg	Changed body composition to male figure. Feeling lack of control
Joan	63	Lumpectomy, chemotherapy, radiotherapy, endocrine treatment 2008	Gain 4-5 kg	No changes in body composition but overall weight gain Feeling lack of control
Eliza	62	Lumpectomy, chemotherapy, radio therapy, endocrine treatment 2008	Gain 5 kg	Weight gain on waist Feeling lack of control
Anne	51	Lumpectomy, chemotherapy, radio therapy, endocrine treatment 2010	Gain 2-3 kg	Weight gain on waist and hips Feeling lack of control
Christy	50	Mastectomy, chemotherapy 2008	Loss 4 kg	Controlling weight loss

The focus group took place at the hospital in a meeting room that was convenient for the purpose. The women were situated around a square table to signal that everybody's contribution was equally important (102). The interview lasted one hour and 11 minutes and was recorded using a digital recorder. The women had in

advance received four questions to consider and were asked to think about further topics concerning weight and body changes (Appendix F). During the focus group, the women were encouraged to share their experiences regarding changes in weight and body composition, and the meeting was moderated with only a small degree of control to ensure equal participation (102).

6.3.2. DATA ANALYSIS

The focus group data were scrutinised through content and conversation analysis. The content analysis was inspired by Graneheim and Lundman who developed a model of analysis that is widely used in nursing contexts. Using this model provides concrete analytical strategies, demonstrated in examples, and combines how manifest and latent content may reveal and be described in an analysis (109). In addition to defining concept analysis as a means of organising the content in themes and concepts displaying the manifest content, the authors claim that both manifest and latent content involves interpretation. However, searching the latent content, the underlying meaning of the text leads a step further into interpretation on a deeper and more abstract level (109).

Initially, the text data were structured and organised in subthemes and main themes and analysed for manifest and latent content. The themes served as a preliminary framework for structuring the conversation analysis. The conversation analysis was inspired by an understanding that language cannot be extracted from the linguistic and non-linguistic context in which it appears. Production of talk is thus not defined by a single participant, but co-constructed in the relationships among participants (110). Analysing 'talk-in-action', using tools such as turn-taking, sequences, and repair, revealed how the talking was organised in sequences with preferred and non-preferred adjacency pairs, and how the participants dealt with problems that arose in the conversation, producing repair (110, pp.208, 333 – 334).

Analysing the focus group with both content analysis and conversation analysis thus provided insight into the 'what' and the 'how'. Although I proceeded with content and conversation analyses, the phenomenological attitude was intentional to allow the women's experiences and stories to come forward in the discussion and stay close to their statements in the analysis. Discussions with co-authors and a conscious effort not to make hasty conclusions contributed to challenging and bridling the taken-for-granted.

6.3.3. THE THEMATIC AND DYNAMIC DIMENSIONS OF THE INTERVIEW GUIDE

Studying the text data through content analysis revealed four main themes as presented in Paper 1: a) experiencing the body with weight changes, b) being out of or in control, c) being afraid of recurrence, and d) helping nature. These themes

provided the thematic dimension of the interview guide. Subsequently, the conversation analysis showed examples of the dynamic dimension in an everyday language. Thus, focussing on what the participants said and how they said it, three dynamic areas were revealed as significant: a) using words, images and metaphors – a shield and self-protection, b) exploring multiple meanings, c) maintaining everyday language.

6.3.3.1. Using words, images and metaphors – a shield and self-protection

The women expressed their body as 'being significantly changed', literally, in images and metaphors, using terms such as 'male distribution' and 'large beer belly'. Struggling with weight changes and being survivors of breast cancer, the women also used the words 'being here' for being alive. When one woman concluded that it 'is better to be fat and alive', this open reference to the potential of death triggered the group and made everyone speak at the same time. Metaphorical and symbolic language makes strong emotions more bearable and is a creative means of expressing personal meanings and feelings and to make sense of experiences (111). The reaction caused by changing the gentle 'being here' into the confronting 'staying alive' may thus rely on a disturbance of the shield of self-protection offered by metaphors.

6.3.3.2. Exploring multiple meanings

The meaning of weight changes appeared to be multiple and related to general prejudice concerning potential alcohol addiction and advice from other people which was inconsistent with the women's body perception. As a matter of different opinions and a question of autonomous and competent choices, without being harmful to oneself, the term *control* appeared central. Lack of control and autonomy were found to be intertwined with responsibility and guilt (112) and may promote uncertainty about cancer recurrence (71) as well as influence one's self-perception and ability to cope with an altered body (113). In addition to these former findings, lack of control was associated with strong feelings of embarrassment and silent suffering, as the women did not expect other people to understand how much losing control of one's weight could influence one's self-perception.

6.3.3.3. Maintaining everyday language

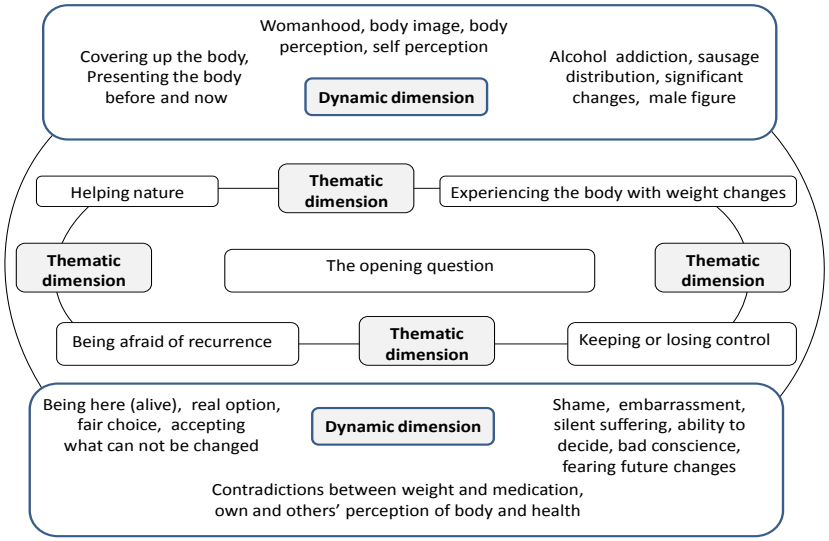
The women's everyday language was filled with images and metaphors. They helped nature with haircuts, looked into friendly mirrors pretending to be slim and used makeup to cope on days when they felt grey. Presenting themselves by helping nature through different means helped them feel comfortable and come closer to a body image that corresponded with their self-image (114). This form of self-presentation can also be seen as an investment in feeling satisfied, happy or well (47,114), or as protection against painful or difficult topics like cancer and death

(115). These images and metaphors were occasionally combined with humour, which may contribute to increased comfort levels and reduced anxiety and discomfort (116,117). Use of humour and laughter may thus contain key information on sensitive topics.

6.3.4. FOCUS GROUP – A BASIS FOR INDIVIDUAL INTERVIEWS

Assigned to facilitate the women in telling their stories and produce a narrative in collaboration, Dahlberg et al. talk about interviews as open dialogue (15). The crucial point is *what* and *in which way* the interviewee expresses her experience of a certain phenomenon, and how the dialogue supports further reflections on the topic. Furthermore, it is essential to balance between being unstructured and structured as the researcher is obliged to keep focus in the interview on why questions and comments during the interview should be led by the phenomenon (15). First, the focus group provided content for the dynamic and thematic dimension of the interview guide and pointed at topics that might be relevant to explore without preventing the interviewee in revealing new aspects of the phenomenon (Figure 5).

Figure 5. An open interview frame



Second, to follow the overriding philosophical perspective and let the women's perspective come forward in the subsequent interviews, explorative questions were formulated in line with Dahlberg, Dahlberg and Nyström's open lifeworld approach (15, pp.184 - 187). Inspired by the interview guide, the women were encouraged to

reflect on their experiences and provide lived examples. Thus, this open lifeworld approach enabled an emphasis on the individual's experiences and endeavoured to come close to the patient's lifeworld acknowledging the patient as the main expert on herself. An extract from the interview guide is shown in Table 2.

To grasp the essential meaning of changes in weight and body shape among women treated for breast cancer, the aim of subsequent individual interviews was to reveal lifeworld experiences of the informant. Although interviews are considered collaborative narratives, it is important to minimise the interviewer's impact on the informants' expressions and responses.

Providing inspiration for the thematic and dynamic dimensions of the individual interviews (2), the analysis increased my familiarity with the topic and became part of my pre-understanding. Being a part of my pre-understanding, the attention to the use of images, metaphors, and humour made me aware of protective elements in the language (102). Furthermore, listening to how the women spoke about their experiences sharpened the awareness on my own and the women's vocabulary and supported an open approach in the following interviews. Focus group findings thus became integrated (built) into the individual interviews as an extended understanding of the topic that enabled a broader perspective from the interviewer.

Table 2. Extract from interview guide

The thematic dimension Exploring the experience of changes in weight, body shape and body perception.
Opening question 'Please tell me about the weight changes you have experienced during and after your cancer treatment, and how the weight changes have influenced your body perception'
Suggestions for questions to be asked in the dynamic dimension
How did you experience the changes of your body? Tell me when you first recognised the changes. What happened? What thoughts/feelings occurred when you recognised the changes? How were the weight changes (gain/loss) distributed? How did it influence your image of yourself? How did it influence your perception of yourself? What do the changes mean to you? Did the changes influence your sense of womanhood/your perception of yourself as a woman? Under which circumstances do you experiences this influence? How did you recognise the influence? What did you feel/think? What induced these feelings/thoughts?

6.4. THE EXPERIENCE AND INFLUENCE OF WEIGHT CHANGES ON BODY AND SELF

Seeing the body as an essential unity for understanding, lived experience is central in the philosophy of existential phenomenology. In accordance with the philosophical perspective, revealing the women's embodied experiences is guided by means of an inductive, descriptive research method – 'reflective lifeworld research' as described by Dahlberg, Dahlberg and Nyström (15). Using this method, the qualitative data are analysed in their frame of logic (98) to answer the qualitative research questions. Thus, the perspective of phenomenology is more explicit and recurring at the method level in this part of the study.

Embodied knowledge is pre-reflective, created through inter-relatedness with the world, culture, environment - a horizon always implicitly present as shifting backgrounds for what stands out as figures or the significant in a situation (20). Factual changes in body and shape may provide changed, embodied knowledge. Verbally expressed, this embodied knowledge cannot be extracted from the linguistic and non-linguistic context in which it appears. Thus, the meaning of the changed body is closely tied to the actual context that provides a fundamental understanding of how changes of phenomena may influence and disturb the women's relationship with the world. Connecting Studies I and II at sample level contributes to this contextualisation. Lessons drawn from the focus group analysis enhanced attention on verbal expressions. The individual interviews conducted in Study II are consequently associated with Study I, Phase 1, and Study II, Phase 1, in the mixed methods design.

6.4.1. PARTICIPANTS, SETTING, AND DATA COLLECTION

In Study II, 12 women were purposefully sampled for interviews from the Study I cohort. As variation is more important than numbers (15), women were included if they displayed changes in weight and shape or felt essentially changed. In addition to including a homogenous sample of women treated for breast cancer approx. one year from diagnosis, heterogeneous variations were sought by means of different ages, treatment modalities, and body changes (Table 3).

Mean age was 57 years (range 35 to 83), which reflects the total cohort with a mean, measured baseline of 58 years (range 28 to 82). Treatment modalities covered a wide range that reflected the cohort except for surgery (mastectomy) which was over-represented in the interview study compared to the cohort. Finally, the women represented stable weight, weight gain, and weight loss.

Regardless of the importance of variation, 15 ± 10 participants are recommended in interview studies (2), whereas sample size in phenomenological studies is typically fewer than 10 (4,118). The inclusion of 12 women who had experienced the

phenomenon under study and was able to articulate their experiences provided rich data with a wealth of variations on the investigated topic. As these rich data enabled patterns that structured the essential meaning of the phenomenon to reveal, the sample size was deemed sufficient.

Table 3. Participants in individual interviews

Partici-pant (P)	Age	Menopausal status	Treatment	Changes weight/waist
P1	70	Postmenopausal	Mastectomy, endocrine treatment	+ 0.6 kg/ + 10.5 cm
P2	64	Postmenopausal	Mastectomy, radiation, endocrine therapy	+ 1.7 kg/ + 5 cm
P3	50	Premenopausal	Lumpectomy, chemo- and endocrine therapy, radiation	-5.7 kg/ -3.5 cm
P4	65	Postmenopausal	Mastectomy, endocrine therapy, radiation	+ 1.1 kg/ + 6 cm
P5	54	Postmenopausal	Mastectomy, chemo- and endocrine therapy, radiation	+ 4.4 kg/ + 9 cm
P6	39	Pre-menopausal	Lumpectomy, chemo- and endocrine therapy	+ 5.4 kg/ + 7 cm
P7	55	Postmenopausal	Mastectomy, chemo- and endocrine therapy	-9.4 kg/ -5.5 cm
P8	35	Premenopausal	Lumpectomy, chemotherapy, radiation	+ 2.6 kg/ + 2 cm
P9	83	Postmenopausal	Mastectomy, endocrine therapy, radiation	-0.8 kg/ 0 cm
P10	46	Premenopausal	Mastectomy, chemo- and endocrine therapy, radiation	+10.4 kg/ + 4 cm
P11	61	Postmenopausal	Lumpectomy, chemo- and endocrine therapy, radiation	+ 1.7 kg/ + 8.5 cm
P12	55	Premenopausal	Lumpectomy, endocrine therapy, radiation	+ 1.3 kg/ + 5.5 cm

Approx. one year after baseline - in connection with their outpatient visit - the women were asked to participate and provide written information about Study II (Appendix G). Three days later they were phoned for their decision and further appointments. During the inclusion process, three women declined participation.

Reasons were not sought. Of the 12 women, three were interviewed during outpatient visits, and nine were interviewed in their own homes. All interviews took place in a relaxed atmosphere and lasted from 20 – 65 minutes.

To obtain descriptions from the participants in their own words, the researcher needs to explore the topic of interest, posing broad and non-leading questions to provide opportunities for interesting and pertinent data to appear. Starting with an opening question (1,15), the women were encouraged to describe their experiences with follow-up questions from the interview guide developed in Phase 1, Study II (Table 2). The aims of the individual interviews were not to confirm the statements from the focus group interview, but to extend and clarify the meaning of weight changes. Thus, to allow new questions to be formed during the interview, as recommended by Dahlberg et al. (15), the guide was used as an inspiration. This ensured focus on the topic and at the same time allowed the women to speak freely, to reveal unexpected topics and experiences to be pursued.

6.4.2. DATA ANALYSIS

The aim of exploring changes in weight and body composition as they appear by means of phenomenological reflection demands that researchers step into a phenomenological attitude where one's taken-for-granted assumptions are bridled (86). This phenomenological attitude was performed through several steps.

After verbatim transcription and several readings, the interviews were coded and organised in meanings units. In order to understand the meaning of every unit, the units were moved around and those that seemed to belong together were collected in clusters. These clustered meanings were related to each other and formed patterns that described the essence of the phenomenon, the structure of the meaning and finally, the essential meaning of the phenomenon (15, pp.241-256).

Patterns of meanings are made up by differences and similarities, and when switching back and forth between figure and background by asking questions to the text – it reveals what is said, how is it said, and what is the contents and special meaning (15,86). Describing the meaning implies 'laying out', i.e. discovering explicit and implicit, visible and invisible meanings by using the visible as a point of departure (15). Thus, 'laying out' focuses on the meaning of what is already there, inherent in the phenomena. Laying out the detailed descriptions of bodily changes and questioning visible as well as invisible threads combined with self-reflection helped bridle my pre-understandings.

As mentioned earlier, bridling is a reflective stance that helps us 'slacken' the firm intentional threads that tie us to the world and helps us to restrain our pre-understanding in the form of personal beliefs and theories in order not to understand too quickly, too carelessly, too slovenly (86). Thus, bridling is a means of

scrutinising involvement with the investigated phenomenon. To distinguish the particular phenomenon from one's pre-understanding and to avoid some of the pitfalls in conducting interviews and analysis (2,81,86), I was interviewed by a clinical nurse specialist to let presumptions come out into the open.

In addition, inter-subjective discussions in the research group helped me 'keep wondering' and prevented the analysis from closing prematurely. During the analysis, six interviews were read and discussed with senior researchers and to remain open-minded, the findings were continuously discussed by means of questions, such as: I think the meaning is … can I be sure? How can I be sure? Are there other ways of understanding this?

6.5. ETHICAL CONSIDERATIONS

The study was registered at and approved by the Danish Data Protection Agency (No. 2008-58-0028) and complies with existing rules on data storage, ethical guidelines for nursing research (119) and the Danish Health Act (120). The project was discussed with the local scientific ethics committee, which found formal ethical registration and approval unnecessary. Participation was voluntary, and the women initially signed an informed consent form after receiving information orally and in writing about the study (119). Anonymity and confidentiality were ensured by safe-keeping data and anonymising names.

The ethical requirement in patient-based research urges the researcher to reflect on the transformative power of the encounter, when patients are confronted with and asked to put their experiences of suffering and vulnerability into words (121). Bodily changes may be considered a potentially sensitive topic, displayed in repeated measurements, and the interview may be the first time the interviewees were given an opportunity to express their experiences with these changes (15). With this in mind I met the women with sensitivity and awareness. If the women became emotionally affected, whether during measurements or the interview, room and space were provided for these feelings. If such feelings emerged during the interview, the participant was offered a break, and I only returned to the sensitive topic with the participant's permission. To distract the women from the emotional impact of the specific topic, I closed the encounter with small talk, acknowledging the women's contribution to the study as suggested by Brinkman and Kvale (2), and Legrand (121).

CHAPTER 7. FINDINGS

In this chapter, the main findings of Studies I and II regarding the quantitative and qualitative research questions are reported separately, consistently with the multistage mixed methods design. To answer the mixed methods questions, an integrative mixed methods interpretation is carried out. This unifying analysis and interpretation meet the requirements for mixed methods integration and aim to push the findings to a higher level, displaying meta-inferences.

7.1. MAIN FINDINGS OF STUDY I (PAPER 3)

The main findings of Study I describe the characteristics of changes in weight and body composition during 18 months following diagnosis which are associated with current adjuvant antineoplastic treatment and examine the association between risk of changes and the current treatment.

7.1.1. PATIENT CHARACTERISTICS

The samples were included consecutively, and the 95 women were randomly evenly distributed into two groups: a) an endocrine treatment group (EG), and b) a chemotherapy ± endocrine treatment group (CG). The distribution into the two groups showed that the women in the CG statistically were significantly younger and premenopausal with less comorbidity than the women in the EG (Table 4). Especially in the EG, comorbidity factors like hypertension (n EG = 22) and osteoarthritis (n EG = 13) were prominent (Figure 6).

Figure 6. Comorbidity factors in the two groups

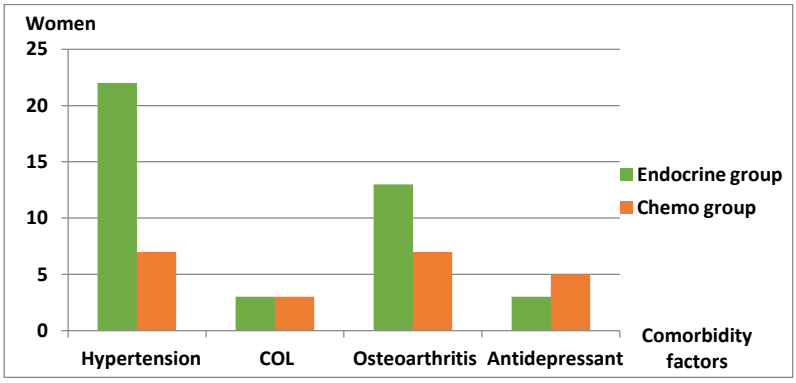


Table 4. Baseline characteristics in the total cohort and the treatment groups

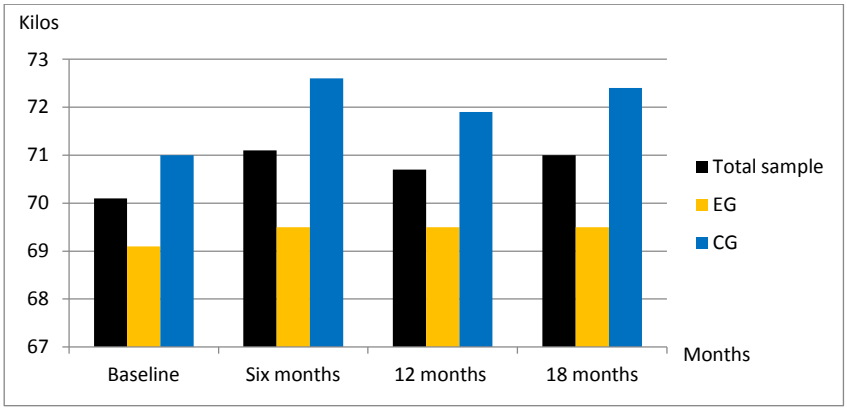
Variables	**Total N = 95**	**Endocrine N = 47**	**Chemo ± endocrine N = 48**	**p-values**
Age				
Mean years (range) SD	58 (28-82) 11.8	66 (47-82) 8.8	50 (28-68) 8.5	< .0001
Menopause status				
Postmenopausal	57	43	14	
Premenopausal	38	4	34	< .0001
Type of surgery				
Mastectomy	28	12	16	
Lumpectomy	67	35	32	.501
Tumour stage				
I	59	32	37	
II	27	12	15	
III	9	3	6	.423
Receptor status[2]				
ER2 – positive	90	47	43	
ER – negative	5	0	5	.056
Histology				
Ductal	81	38	43	
Lobular	14	9	5	.261
Adjuvant therapy[3]				
Endocrine therapy	47	47	0	
EC+T ± endocrine etc.[4]	48	0	48	< .0001
Comorbidity				
No	51	19	32	
Yes	44	28	16	.014
Smoking				
Non-smoker	75	38	37	
Current smoker	20	9	11	.802
Alcohol units per week				
< 7	82	40	42	
≥ 7	13	7	6	.773

[2] 90 women were estrogen receptor positive, four were triple negative, and four HER-2 positive. Three of these women were also estrogen receptor positive.
[3] In addition to the 47 women prescribed endocrine medication at baseline, 36 women began endocrine treatment after completion of chemotherapy. 12 women were not assigned any endocrine therapy.
[4] Abbreviations: ER (estrogen receptor) and EC+T (epirubicin, cyclophosphamide, taxoterre).

7.1.2. CHANGES IN WEIGHT AND BODY COMPOSITION OVER TIME

Calculating changes in weight and body composition across 18 months in the total cohort and the two subgroups showed that factual changes belonged to the CG (Figure 7).

Figure 7. Factual weight changes over time



Estimating patterns of changes in weight and body composition revealed the importance of subgroup analysis (Appendix H). The average body weight changes in the total group across the four measurements showed a statistically significant, but small increase in weight of 0.9 kg ($p = .003$, 95 % CI 0.3-1.5 kg). A calculation of the association between changes in waist and weight in the total group showed an average positive association of 0.35 kg per cm increased waist ($p < .001$, 95 % CI 0.29-0.42 kg).

Examining the two groups separately the changes were mainly observed in the CG, with the greatest change found at six months with 1.6 kg weight gain and a small decrease at 12 months of 0.9 kg, increasing to 1.4 kg at 18 months. The changes found after six months in the CG were associated with an accumulation of body fluid, which during the following months returned to baseline levels. Weight, fat mass and waist circumference showed a statistically significant difference between baseline and 18 months and demonstrated that the increased weight at 18 months was associated with increased body fat and a small increase in waist circumference (Appendix H).

In the EG, no weight changes were observed from six to 18 months, and the total change from baseline to 18 months was a modest 0.4 kg. However, this group displayed a statistically significant difference in waist circumference in all measurements, but there were no significant changes in weight and body composition (Appendix H).

7.1.3. RELATIVE WEIGHT, FACTUAL WAIST AND RISK CALCULATED IN THREE WEIGHT GROUPS

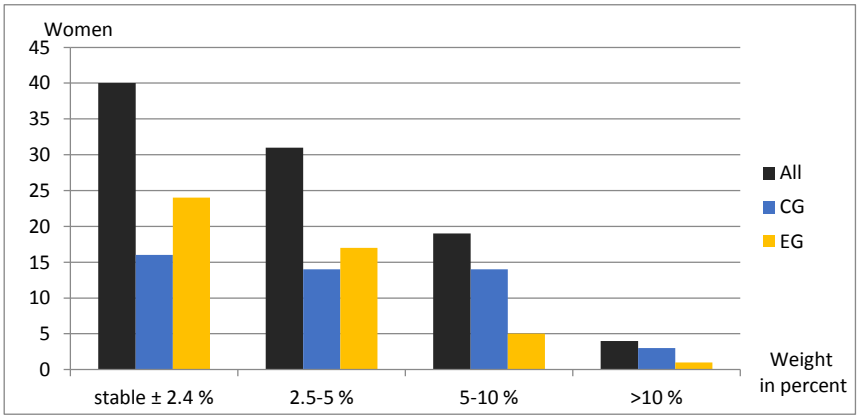
Examining the entire cohort from baseline to 18 months in the three weight groups, 40 women maintained a stable weight, and 54 women (one missing) experienced a weight change of ≥ 2.4 % either in the form of a weight loss (n = 16) or a weight gain (n = 38) (Table 5). Although the average changes in kilos were minor, the relative mean changes in weight gain were 5.5 % (range 2.5 to 20.5 %). The women, who lost weight, lost a mean of 5.4 % (range 12.7 to 2.5 %).

Table 5. Distribution of relative weight changes baseline to 18 months in groups

Weight changes (%)	n	Mean	SD	min	p25	median	p75	max
Stable weight (± 2.4 %)	40	0.2	1.4	-2.1	-0.8	0.5	1.2	2.3
Weight gain (≥ 2.4 %)	38	5.5	3.4	2.5	3.3	4.5	6.5	20.5
Weight loss (≥ 2.4 %)	16	-5.4	3.1	-12.7	-6.4	-4.1	-3.4	-2.5

Stable weight was primarily related to women in the EG group, and weight changes between 2.5 and 5 % were almost evenly distributed in the two treatment groups (14 in the CG group and 17 in the EG group). Major weight changes of 5-10 % and > 10 % were especially evident among women subjected to chemotherapy, as 17 out of 48 women receiving chemotherapy gained serious relative weight, compared to six out of 47 women who only received endocrine treatment (Figure 8).

Figure 8. Distribution of relative weight changes in treatment groups



Waist distribution in groups fluctuated in the groups as decreased waist circumference was observed in the weight gain group, and increased waist circumference was observed in the weight loss group (Table 6).

Table 6. Distribution of changes in waist (cm) baseline to 18 month in groups

Weight changes (%)	n	Mean	SD	min	p25	median	p75	max
Stable weight (± 2.4 %)	40	1.4	3.1	-5	-0.3	1	3.4	8.5
Weight gain (≥ 2.4 %)	38	3.8	4.3	-10	1	4	6	13.5
Weight loss (≥ 2.4 %)	16	-1.5	4.7	-12	-4.3	-1.75	1.3	8.5

Increased OR for weight gain versus stable weight was associated with premenopausal status, lumpectomy, stage III breast cancer, chemotherapy, and smoking. Only menopausal status and chemotherapy showed a statistically significant difference that disappeared when adjusted for age (Appendix I). Stage II breast cancer decreased the odds of weight gain, compared to stage I, but with no statistical significance.

Increased OR for weight loss versus stable weight was associated with premenopausal status, and comorbidity that adjusted for age became statistically significant. Although smoking and consuming more than seven units of alcohol a week showed increased OR, neither of these factors was statistical significant. Only stage III breast cancer was associated with a statistically significant risk of weight loss in both crude OR and adjusted for age (Appendix I).

7.1.4. SUMMARY

Changes in weight and body composition were modest when calculated for the entire group. Women who received endocrine treatment showed almost no weight changes, but showed statistically significant increased waist. The women who received chemotherapy displayed variations in weight, fat mass, total body water and waist during the measurement periode. The subsequent odds ratios showed a statistically significant increase in risk of weight gain among premenopausal women subjected to chemotherapy and an increased risk of weight loss among women suffering from stage III breast cancer.

7.2. MAIN FINDINGS OF STUDY II (PAPER 2)

The main findings of Study II explore the essential meaning of the phenomenon of changes in weight and body shape among women treated for breast cancer and how these changes influence the women's perception of body and self.

Analysing 12 interviews from a phenomenological viewpoint, guided by Dahlberg's reflective lifeworld approach, the essential meaning of changes in weight and body shape in association with treatment for breast cancer was revealed to be: the ambiguous transforming body – between a luxury problem and the risk of recurrence. The meaning is made up of three constituents: 1) the body – a

demanding stranger, 2) fighting to be the master of one's own life, and 3) accepting the bodily changes. In the following section, a summeray of the findings is described including abbreviated extracts of central quotes to provide the reader a sense of the context.

7.2.1. THE BODY – A DEMANDING STRANGER

The women experienced an unknown body that took the lead. An unrecognizable strange, unhealthy and unfamiliar body that inflicted a sense of: 'I do not recognise myself. I look so different […] it is not how I perceive myself' (P5). In addition to perceiving the body as ugly and undesirable with extended fat around the waist, the changed body limited the possibility of living as usual: 'It was not my body. It used to be strong, enduring and active. Now, it was heavier, bigger, hurting and refused to do what I wanted' (P8).

The increased weight disturbed the relationship between body and world, which facilitated a need to ignore the body: 'Instead of looking in the mirror, I focus away' (P11). The unrecognisable and unfamiliar body that hindered normal life and functions seemed to be divided into two, articulated as 'I' and 'it', respectively. The expression seems to reveal a changed body perception shifting from the unified body-subject 'I am my body' to a dissociated body-subject where the body has become an object the women refuse to look at.

Despite attempts to distinguish the body as an object from the unifying body-subject, the body remained in the foreground, and influenced self perception: 'I do not feel I have the right to be sad; [...] I could be dead […] so it is a luxury problem. […]. Next I consider myself as having a weak and cowardly character, because I am unable to manage these changes' (P11).

Fear of recurrence and losing one's normal sense of belonging seem to be underlying as invisible, but intentional threats that give these strong feelings meaning. It also shows how life experiences affect and are affected by embodied functional capacities and impact doings as well as beings. The bodily changes might be downplayed as luxury problems compared to the threat of death, which the women had just faced. However, they compared their present, embodied experience to their former body, hoping to return to their previous shape and agency.

7.2.2. FIGHTING TO BE THE MASTER OF ONE'S OWN LIFE

Awareness of the association between fat tissue and the risk of recurrence was a main incentive for fighting for weight maintenance or attempting to lose weight. 'I want to prevent recurrence and I don't want to look like this' (P3). Confronted by bodily changes, willpower and fighter genes stepped in as means of emphasising oneself as a responsible agent, feeling powerful, and being familiar with one's own

body. ‘Even though the medicine may induce weight gain, it is my responsibility. It is of no use to sit down and relinquish control’ (P12).

In addition to preventing recurrence, weight loss eased the women’s conscience and made it easier to be physically active and feel attractive. As the side effects faded away, the body changed from a body characterised by limitations to a body of possibilities in time, space, and mind and towards a unified body-subject able to decide. Thus, ‘nothing prevents me from going back to my former shape. Then I return to the person I was and shift attention away from the illness. Then I feel cured’ (P8).

Although having to force the body might be a sign of subject-object dualism, referring to ‘I’ indicated that forcing the body supported self-perception and identity as a responsible agent in the continuum towards health (feeling cured). The space increased and the body-subject seemed to move towards reintegration, displayed in the strong focus on ‘I’ in the language of the participants. Thus, understanding oneself as connected with the past, present, and future, the process of transforming into or maintaining one’s former self, diminished the experienced distance between past, present, and future.

7.2.3. ACCEPTING THE BODY CHANGES

Being aware of the relation between fat and breast cancer development, the only option might be acceptance of the demanding body signals which additionally seemed to relieve the burden of self-blame. Acknowledging body signals as cooperative signs and following them deliberately, waiting for time to come to regain control, gave new meaning to changes in weight and body shape. For example, eating in order to reduce nausea during chemotherapy might be a way of survival. It was my way of surviving. I thought: ‘Okay it is helpful now, and then I must focus on it [weight gain] later’ (P10).

Although weight gain had to be handled secondarily, the major goal of survival was competing with the women’s changed appearances and their attempts to make sense of these changes. Increasing age and vanity appeared to be a way of downplaying the influence of bodily changes: ‘but when you look in the mirror … ‘my God’. […] If the medication keeps the cancer away you have to deal with the weight and body changes … but still …’ (P4).

Underneath the ambivalence between changes in weight and body shape and the risk of recurrence, it was continuously apparent that the women preferred returning to their former life and body. Acknowledging that their former life had disappeared and fighting to come to terms with the present situation, occasionally weight loss counterbalanced loss of breast as ‘people in my surroundings not only focus on my missing breast, but on my weight loss’ (P7). However, body appearance and weight

continued to be a main theme, critical to the women's self-perception and ability to act.

7.2.4. SUMMARY

The constituents forming the essential meaning of the phenomenon of changes in weight and body shape contain an existential threat that binds the constituents of the phenomenon of the 'ambiguous transforming body' together. Underneath experiences of a demanding and strange body, attempts to become master of one's own life and accepting bodily changes, fear of recurrence, and death always seemed to loom large in the background. Due to knowledge of the association between fat and the risk of recurrence, the struggle to maintain or regain a healthy weight and body shape inflicted self-blame, shame, and ungratefulness and influenced the women's autonomy and self-perception. To deal with these feelings they felt a need to downplay the importance of their bodily changes.

7.3. INTEGRATED MIXED METHODS INTERPRETATION (PAPER 4)

In this section, the main findings from Studies I and II are integrated with the aim to provide meta-inferences. The purpose of integrating the two studies is to expand the understanding of the phenomenon of changes in weight and body composition and the influence of the changes on the women's perception of body and self from the perspective of the women as unified bodies. The integration is described in Paper 4 and further developed in this thesis. After a staged reporting in Papers 1, 2 and 3, the findings are organised in a format that allows integration via joint displays, visual means of integrating and presenting mixed methods results (91). Thus, in this study integration is fulfilled through narrative integration via the staged reporting and through joint displays.

7.3.1. THE AMBIGUOUS TRANSFORMING BODY ASSOCIATED WITH RELATIVE WEIGHT CHANGES

Integration of the findings associated with relative weight changes are illustrated in three joint displays organised in 'themes-by-statistics' types where categorical data organise the presentation of themes and quotes (4,122). In our case, three relative weight groups provided the categories in which quantitative and qualitative data were organised. In the specific weight category, descriptive statistics illustrated in box plots were arranged with matching constituents and quotes (Figures 9, 10 and 11). The box plots aim to describe the distribution of relative weight and waist changes in an illustrative way that visualises outliers in addition to ranges. The quantitative results are further explained and elaborated by qualitative findings in text moving back and forth between the two datasets.

Organising data from Studies I and II across the individual studies takes on what Fetters and Freshwater call the 1 + 1 = 3 integration challenge (96). Illustrating findings by joint displays and further elaborating on the displays in text show how the understanding of the association between factual changes and the experiences of the transforming body may expand through integration and keep focus on the women as unified body-subjects.

7.3.1.1. The ambiguous transforming body with weight changes ± 2.4 %

Findings from Study I demonstrated weight variations between ± 2.4 % (stable weight) with a mean of 0.2 % (SD 1.4, range -2.1 % to 2.3 %). The limits of ± 2.4 % account for the diurnal variation per day and may in general be considered as insignificant. However, integrating the calculated weight changes with the women's experiences on the individual level, it appeared that the small weight changes combined with extended waist circumference had a deep impact on the women's perceptions of their bodies and selves.

Illustrated in box plots, the spread of weight in the stable weight group was distributed around a median of 0.5 % range -2.1 to 2.3 %. The waist changes fluctuated around a median of 1 cm range -5 cm to 8.5 cm. The box plot illustrated that weight varied more below the median, while waist varied most above median. This indicates that even small weight variations may contribute to large waist increases (Figure 9). Among the interviewed women small weight variations from -0.8 kg to 1.7 kg was displayed. In their statements the body appeared as a demanding stranger associated with sadness, feeling out of control, shame and self-blame for being concerned about such changes when death could have been an option. Conversely, their waist circumference varied from 0 cm to 10.5 cm.

The calculated association between weight changes and changes in waist circumference in the total cohort was - as mentioned - 0.35 kg per cm increased waist circumference. Although the women in Study II were deemed representative for the cohort, three of the interviewed women in the stable weight group had a larger increase in waist than this mixed model calculation through logistic regression. Thus, these women provided variation and nuances beyond the calculated result.

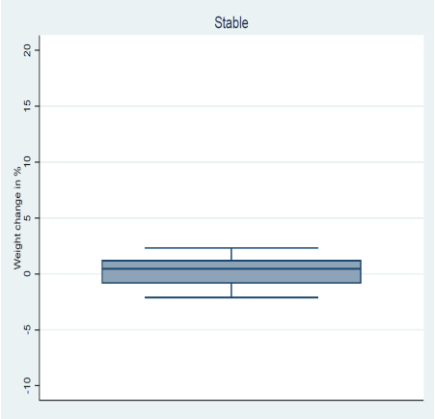
Feeling responsible, the women were unable to neglect it when the body changes became excessive. To cope, the women accepted the changes and interpreted them as side effects of cancer treatment, a necessary cost for being alive, or as an effect of normal ageing. However, the changed body figure insistently appeared in the foreground due to the increased waist circumference.

Figure 9. Joint display of weight changes ± 2.4 %

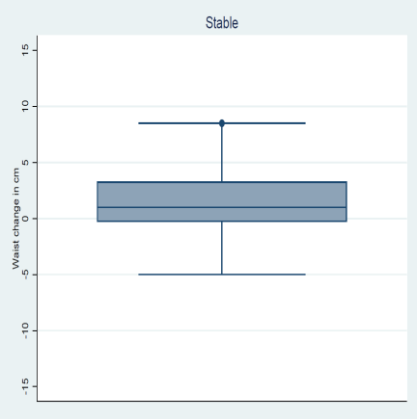
The ambiguous transforming body with stable weight ± 2.4 %

Quantitative results visualised in box plots

Weight in percent



Waist in cm



Qualitative findings: Constituents and quotations

The body – a demanding stranger
'Instead of looking in the mirror, I focus away [and compare myself with obese people] who do not deserve respect and display loss of control. Compared to being alive I do not feel I have the right to be sad, but I am so sick of the changes. I could be dead […] so it is a luxury problem. […] then I think, 'Am I too sensitive?' But I feel I have changed a lot. Next I consider myself as having a weak and cowardly character, because I am unable to manage these changes' (P11: 1.7 kg, 8.5 cm).

Fighting to be the master of one's own life
'Even though the medicine may induce weight gain, it is my responsibility. It is of no use to sit down and relinquish control' (P12: 1.3 kg, 5.5 cm).

Accepting the body changes
'The fat around the waist emerged despite eating low-fat. I know it can also be associated with my age, but… I know it is a question of vanity, but when you look in the mirror ... 'my God'. […]. If the medication keeps the cancer away you have to deal with the weight and body changes…but still' (P4: 1.1 kg, 6 cm).

Integrating the findings revealed that body distribution changes seem to contain a risk for pushing towards an emerging dissociation of the unified body, although the women talk about the changes in terms like 'I feel sad, I focus away, I know, etc.'. A central issue for the women's self-perception is to take responsibility for the bodily changes. Thus, not being able to control the body changes and the resulting serious influence on self-perception may be so harmful that further strategies such as

objectifying and neglecting may be applied to avoid confrontation with the changed body.

7.3.1.2. The ambiguous transforming body with weight gain > 2.4 %

Weight gain was evident among 38 women (Table 5). The interviewed women who gained weight > 2.4 % all belonged to the CG. Although women in the EG were also exposed to weight changes > 2.4 %, the majority of women in the weight gain group and particularly those with serious weight gains were observed in CG (Figure 8).

Just as stable weight with extended waist affected the women's perception of their body and self negatively, weight gains > 2.5 % similarly influenced the women's body and self-perception. The changes interfered with their sense of identity and integrity as they caused alienation from the former body perception and inflicted a sense of womanhood and perception of oneself as an autonomous human being. The changes tended to be a never-ending reminder of illness, with constant attention on signs and symptoms belonging to the breast cancer disease even though the women were considered cured. Thus, their perception of a body with increased weight and waist appears to be linked to loss of femininity and a body out of control which prevented habitual beings and doings.

In the group of interviewed women, factual weight gain varied from 2.6 kg to 10.4 kg. Illustrated in box plots, the spread of weight in the weight gain group was distributed around a median of 4.5 %. Below the median the distribution of 50 % of women was 2.4 % to 4.5 % (Figure 10). Above the median, the plot displayed an outlier of 20.5 %, and the upper whisker limit was approx. 9 %. This indicates a more reliable spread of relative weight gain ranging from 2.4 % to approx. 9 % (Figure 10).

The calculated waist changes fluctuated around a median of 4 cm (range -10 cm to 13.5 cm). The value -10 cm depicted an outlier most likely associated with an error in measurement when exploring intra-person measurements on the datasheet[5]. The lower whisker value was approx. -3 cm, a more reasonable minimum value. The interviewed women in this group increased their waist from 2 cm to 9 cm, but visualised, the spread of weight and waist in the weight gain group indicates that a weight gain > 2.4 % does not necessarily trigger an extended waist. Less than 25 % of the values showed decreased waist circumference between -3 cm and 0 cm, corresponding to 75 % of the women who increased their waist from 1 to 13.5 cm. As all the women in this group gained weight, there is an incongruence regarding

[5] On the datasheet it was added that the measurement was not in accordance with the participant's experience.

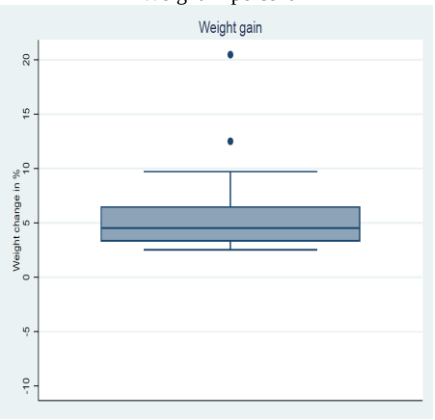
the calculation of the association between weight and waist of 0.35 kg/cm waist extension. This may be a question of a changed distribution of fat and fat free mass.

Figure 10. Joint display of weight gain > 2.4 %.

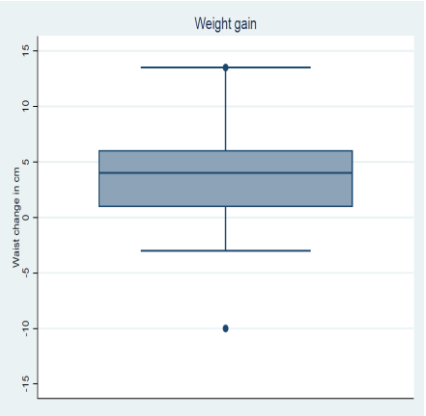
The ambiguous transforming body with weight gain > 2.4 %

Quantitative results visualised in box plots

Weight in percent



Waist in cm



Qualitative findings: Constituents and quotations

The body – a demanding stranger

'I do not recognise myself. I look so different […] it is not how I perceive myself. My weight gain is located in the trunk area. It is very unpleasant, and I have heard that it is very unhealthy. I am feeling so fat and unattractive. Fat women can look attractive and excess fat does not influence womanhood – if their shape is womanly. Now my belly is saggy. Looks like a sack. The distribution around the waist makes you look fat and unattractive. [....]' (P5: 4.4 kg, 9 cm).

Fighting to be the master of one's own life

[at a distance from chemotherapy the weight could begin to decrease] 'Now I am able to decide. There is nothing that prevents me from going back to my former shape. Then I return to the person I was and shift attention away from the illness. Then I feel cured' (P8: 2.6 kg, 2 cm).

Accepting the body changes

'I do not want to have excess weight, because now I am aware of the association between breast cancer and body fat. [But during chemotherapy] only eating could keep a lid on the nausea, so … I knew it was not for my own good, but it was the only way I could endure. It was my way of surviving. I thought, Okay it is helpful now, and then I must focus on it [the weight gain] later. I could not do more at the time' (P10: 10.4 kg, 4 cm).

However, integrating qualitative and quantitative findings regarding weight gain revealed that a changed body distribution was in foreground and influenced everyday life and triggered a distressing uncertainty with fear of recurrence. Self- and body perception fluctuated between perceiving oneself as a unified body subject and the body as an object with its own will. Although dissociation appeared as 'I do not recognize myself' and 'able to decide [over the body]' the unified body-subject appeared when acknowledging the inescapable body and accepting body demand as a way to come to terms with the present body.

7.3.1.3. The ambiguous transforming body with weight loss > 2.4 %

In the weight loss group, the 16 women were almost evenly distributed in the treatment groups with seven in CG and nine in EG. Although all women in this group displayed a weight loss > 2.4 %, serious weight loss was observed in CG as five of the seven women in this group had a weight loss > 5 %. By contrast one out of nine in the EG had weight loss > than 5 %. Mean weight changes in the weight loss group was -5.4 % (range -12.7 to - 2.5). The perceived changes - which for the two interviewed women varied from 5.7 kg to 9.4 kg and reduced waist from 3.5 cm to 5.5 cm - interfered with body and self-perception as depicted in joint displays.

Illustrated in box plots, the spread of weight in the weight loss group was distributed around a median of -4.1 kg displaying a distribution of 50 % women between -4.1% to -2.4%. Below the median, the plot displayed two outliers with -12 % and -12.7%, and the lower whisker limit was approx. -7.5 %. Thus, a more reasonable spread below the median was -7.5 % to -4.1 %. The waist changes fluctuated around a median of -1.75 cm (range -12 cm to 8.5 cm). Although the calculation of the association of 0.35 kg per cm increased waist was statistically significant ($p < .001$, 95 % CI 0.29-0.42 kg), the box plot revealed a more complex picture as more than 25 % of the women extended their waist from 1.25 cm to 8.5 cm despite weight loss (Figure 11).

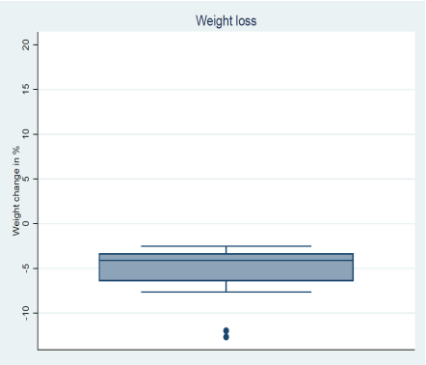
Compared with increased waist and weight that inflicted alienation and dissociation of the unified body-subject, it seemed that a weight loss > 2.4 % strengthens one's self-identity and induces a feeling of being able to act autonomously. Besides increasing the self-confidence, weight loss promoted the ability to be in motion and thus enabled an eased everyday life. It was also perceived as a successful means of preventing recurrence, turning the attention away from the cancer illness towards a positive body perception. The quotes indicate that weight loss in some cases may be intentional and may be a way to counterbalance negative experiences regarding loss of breast.

Figure 11. Joint display of weight loss > 2.4 %.

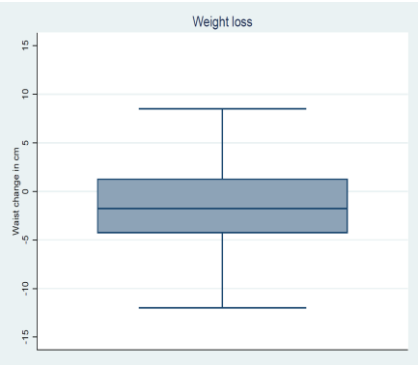
The ambiguous transforming body with weight loss > 2.4 %

Quantitative results visualised in box plots

Weight in percent



Waist in cm



Qualitative findings: Constituents and quotations

To be the master of one's own life

'I do not want to look like this, and I will do whatever I can to prevent recurrence. [Also incentivised by] my fighter gene – to be the master of my own life and knowing the increased risk of recurrence. With weight loss it is easier to be physically active and do good things for my body. I feel attractive and less anxious of recurrence and ease my conscience' (P3: - 5.7 kg, -3.5 cm).

Accepting the body changes

'With my weight loss I look well. It promotes a positive feeling. At the same time, I have lost my breast, which induces a negative feeling. Now people in my surroundings not only focus on my missing breast, but also on my weight loss. So now we have something positive to discuss regarding my body. […] I am riding on a male bike and now I get on the bike like a man. Before I was unable to do this, I did not have the balance and strength' (P7: - 9.4 kg, -5.5 cm).

In the quotes from this weight group, it may be noticed that both women were overweight at diagnosis and decreased their waist circumference. In this context, the changed body distribution does not seem to stand out in the foreground as an essential figure against the background. Instead, it seems that the eased body movement and the appearance in social settings prevail. Perceiving a lighter body may provide a sense of femininity, control, and trusting oneself as an autonomous agent able to improve habitual beings and doings. The counterbalance between loss of breast and positive attention contributes to adding distance to the cancer disease. However, a tendency of a dissociated self was observed when speaking of 'do good

things for my body' and 'something to discuss regarding my body', but there was no tendency to perceive the body as a stranger. Thus, the unified body-subject still seems to be under pressure despite the positive body perception associated with weight loss > 2.4 %.

7.3.2. THE AMBIGUOUS TRANSFORMING BODY IN THE PAST, PRESENT, AND FUTURE

Integration of the findings associated with changes in weight and body composition over time is illustrated in two joint displays (Figures 12 and 13). The categories of the two treatment groups, CG and EG, and the time aspect organise a condensed description of the women's experiences. These joint displays are not pure 'themes-by-statistics' types (4,122) as the themes are absent, but the descriptions are based on the essential meaning of the ambiguous transforming body. The presentation of the women's bodily experiences in a time perspective demonstrated how a selected sample 12 – 18 months after diagnosis interpreted their bodily changes in the light of the past, present, and future.

7.3.2.1. The ambiguous transforming body during and after chemotherapy

The majority of stable weight is observed in the EG group, and although the 2.5% to 5% changes are almost evenly distributed in the groups, the serious changes > 5% appear in 17 women in the CG compared to six in the EG (Figure 3). The women belonging to the CG (n=48) were mainly premenopausal with less comorbidity than the EG (Table 2). The women in the CG displayed several statistically significant changes in body composition variables (Appendix H). The changes fluctuated over time and could impact the women's health as body fat mass increased at 18 months. Interviewing a selected sample between 12 – 18 months after breast cancer diagnosis demonstrated how they interpreted their bodily changes in the light of the past, present, and future (Figure 12).

Staying in the present, but talking about the past, the women compared their body changes during chemotherapy with their bodies before the diagnosis. Six months from diagnosis the women had an average increase of 1.6 kg in total body water. Comparing the changed body with their initial body, the women described their body as extremely changed and uncomfortable. In addition, it seemed that the changed body obstructed their everyday being and doing as the body had changed from a cooperating body to a body almost perceived as an enemy.

At 12 months from baseline, the average changes were decreasing, but now the weight gain of 0.9 kg was associated with excess fat mass. Despite the minor changes, some women experienced their present body as unfamiliar and felt confronted by a transformed identity, new reality, and self-perception. As the body had to be obeyed during chemotherapy, some women now felt responsible for taking

care of the bodily changes. Although the changes still obstructed their normal beings and doings, some women felt that the body was on its way back to the former weight and shape. At this time interval from chemotherapy, the women articulated how they wished to control their bodies in order to return to their normal weight and shape in the future. In their attempts to regain a friendly and effortless body, they strove to find a new balance between demands, desire, and energy and thus be able to perform activities related to everyday beings and doings.

Figure 12. The ambiguous transforming body during and after chemotherapy.

The ambiguous transforming body – during and after chemotherapy (n = 7)			
← **Past**	←	**Present** →	**Future**
Before diagnosis	**Six months from baseline**	**12 months from baseline**	**18 months from baseline**
Baseline (mean)	Six months difference	12 months difference	18 months difference
Weight kg 71.1 FM kg 24.4 TBW kg 34.1 Waist cm 92.6	Weight kg 1.6 (p = .002) FM kg – 0.7 (p = .094) TBW kg 1.6 (p <.001) Waist cm 1.3 (p = .037)	Weight kg 0.9 (p = .076) FM kg 0.8 (p = .057) TBW kg 0.0 (p = .763) Waist cm 0.9 (p = .136)	Weight kg 1.4 (p = .007) FM kg 1.4 (p = .001) TBW kg 0.0 (p = .929) Waist cm 2.1 (p = .001)
Before diagnosis the body used to be strong, enduring and active. Independently of either having a normal weight or being overweight in advance, some women expressed that they felt content with their weight and looks. In the past it was easier to lose weight or to control weight although the weight might fluctuate up and down.	During chemotherapy, the body turned into a sick and unknown body that changed uncontrollably. The body was no longer perceived as a friend, but as uncomfortable and heavy, unattractive, big, hurting, and fat. The body became an unrecognisable stranger that had to be obeyed.	After chemotherapy, the body was still unfriendly, strange, sensitive, and fragile without power. The women felt responsible for taking care of the changes that still remained and for some increased. Unless the body turned back to normal weight and shape, the changes demanded the women to adapt to a new reality and a transformed self-perception, which was the hardest challenge.	Talking about the future, the women longed for an unnoticed and effortless body. They wished to keep doing well for the body by being active, eating healthy things and controlling hunger. Returning to the pre-cancer weight may provide distance from the cancer illness and induce a feeling of being cured. In addition, maintaining a weight loss was a means of preventing recurrence.
The body-subject seemed to be remembered as a unity in cooperation *'I was my body'.*	The body–subject divided into an object with the body as *it* as opposed to the subject as *I* expressed as *'me and the body'.*	The body–subject still divided as *it* against the subject as *I.* However moving towards a reintegration into the unified body–subject	Longing for the unified body–subject towards *"I am my body"*

However, at 18 months the average weight showed an increasing tendency, with 1.4 kg fat mass compared to baseline measurement. In addition, the waist circumference demonstrated a statistically significant difference compared to baseline measurement. Thus, it can be questioned whether the wish to regain an effortless and unnoticed body was fulfilled at that time.

The experience of being a unified body-subject seems to fluctuate during the course of adjuvant treatment. The body changes during and after chemotherapy were

compared with former body perception as a unified body-subject that turned into a dissociated subject-object relation striving towards reconciliation.

7.3.2.2. The ambiguous transforming body associated with endocrine therapy alone

The physical changes related to women in the EG (n = 47) were minor, but statistically significant with respect to changes in waist circumference during all measurements. The body changes in these women did not fluctuate as in the CG. In the EG, only five women were exposed to weight changes > 5 % (Figure 8). However, in line with the quantitative results it was not the weight changes which were of concern to the women interviewed (n =5), but the extended waist circumference (Figure 13).

Figure 13. The ambiguous transforming associated with endocrine therapy.

The ambiguous transforming body – associated with endocrine treatment alone (n = 5)

← **Past**	←	**Present** →	**Future**
Before diagnosis	**Six months from baseline**	**12 months from baseline**	**18 months from baseline**
Baseline (mean)	Six months difference	12 months difference	18 months difference
Weight kg 69.1 FM kg 24.1 TBW kg 32.9 Waist cm 91.8	Weight kg 0.4 (p = .197) FM kg 0.0 (p = .982) TBW kg 0.3 (p = .238) Waist cm 1.9 (p < .001)	Weight kg 0.4 (p = .212) FM kg 0.2 (p = .506) TBW kg 0.1 (p = .632) Waist cm 1.6 (p= .002)	Weight kg 0.4 (p = .171) FM kg 0.2 (p = .587) TBW kg 0.2 (p = .491) Waist cm 1.7 (p = .001)
Before the diagnosis, the waist circumference was smaller, and it was suitable to wear clinging clothes. It was easier to lose weight or to control weight although the weight might fluctuate up and down.	During endocrine treatment the body changed, which reminded the women of their cancer illness and the need for medication to avoid recurrence. The attention on maintaining a healthy body was enhanced and the increased waist circumference was associated with being unhealthy. Interpreting the changes as a consequence of medication and at the same time as a sign of ageing seems to prevent a strong division of the unified body-subject.		Talking about the future the women still hoped the body would return to its former shape when the five years endocrine medication was finished. Meanwhile they maintained attention on minimising the changes through intentional actions (clothing and diet).
The body-subject seemed to be remembered as a cooperating unity *'I was my body'*.	The body–subject seems divided in *it* and *I* but towards reintegrating into the unified body –subject expressed as *'I and my body'*.		Longing for the unified body–subject towards *'I am my body'*.

Regarding their body perception in terms of the past, the women remembered that their body could change, but the changes were manageable. However, at the time of interviewing the changes were perceived as uncontrollable side effects that reminded them of their cancer illness and the need for medication to avoid recurrence. Waist circumference was statistically significantly changed at 12 months. Mean age in the EG was higher (66 years, range 47 - 82) compared to the CG (50 years, range 28 -

68) (Table 2), and the women interpreted the changes as a consequence of medication and also a sign of ageing.

Talking about the future, the women were hoping to regain the former unified body-subject, but at 18 months the increased waist circumference remained. The enlarged waist circumference was associated with developing an unhealthy body figure that could indicate increased abdominal fat. The total body fat increased by 0.2 kg during the 18 months which does not seem to be in accordance with the women's experiences of their changed body.

The attempt to take intentional action has seemingly not provided the expected result. However, collaborating with the changed body by keeping an eye on nutrition, being physically active, or hiding the body changes with an altered clothing style, the women tried to come to terms with what they perceived as unpreventable changes. This seems to prevent a strong division of the unified body-subject as the body-subject changed from 'I was my body' to 'I and my body'.

7.3.3. THE 'FIT' OF INTEGRATION

Although in explanatory quantitative mixed methods studies it is usual that qualitative findings explain quantitative results, the qualitative findings in this study expanded and complemented the issue under investigation. Illustrated in joint displays and further elaborated in text provided a deeper understanding of what can be at stake when women in adjuvant treatment for breast cancer are concerned with changes in weight and body shape. Integrating the two data sources provided new and interesting angles on the topic.

Integrating relative weight changes with factual changes in waist circumference and the constituents and integrating findings in a time perspective expanded insight into how even stable weight and weight gain combined with enlarged waist influenced the women's self and body perception. In these weight groups, in particular the changed body distribution revealed as foreground and was associated with risk of dissociation of the unified body-subject. In contrast, in weight loss combined with decreased waist, the eased movement and the opinions regarding weight prevailed in the foreground as figure in social settings. Integrating the two data sources in a time perspective provided insight into how the women could perceive their bodies as dissociated from self independent of belonging to the CG or the EG.

As the two data sources provided information regarding 'two sides of the same coin', integration provided complementary aspects of the studied phenomenon and insight into experiences of changes connected to a body and self-perception related to a unified-body subject. These findings will be further discussed in the next chapter.

CHAPTER 8. DISCUSSION

In this chapter, a joint discussion of the study is presented. The joint discussion aims to synthesise and articulate the overarching lessons from the two studies and the integrative mixed methods interpretation. In addition, it contributes to illustrating how an understanding of the women as unified body-subjects can expand our knowledge of factual bodily changes and their influence on the women's perception of body and self.

8.1. EXPERIENCING THE BODY WITH CHANGES

Diagnosed with breast cancer and receiving adjuvant therapy, the women are confronted by a strange and unfamiliar body, striving to maintain mastery in their own life and accepting bodily changes. As a changing entity, the body may become visible when everyday unreflective 'being-in-the-world' breaks down and the relationship between body and world is disturbed (123, p.41). Understanding the meaning of the ambiguous transforming body thus involves a reflection on how the changes appear because 'it is impossible to separate things from their way of appearing' (84, p.70). To illustrate how the bodily changes 'appear-in-themselves-for-the-women', the relationship between factual changes and the meaning of the changes were depicted in joint displays. In the next section, a discussion based on existent literature aims to expand the acquired knowledge

8.1.1. RELATIVE WEIGHT CHANGES ASSOCIATED WITH INCREASED WAIST – ESSENTIAL FOR BODY AND SELF PERCEPTION

Out of 95 women, 40 women's weight remained stable from baseline to the measurement at 18 months. Offhand, this might indicate that the women had been able to balance their energy intake (124). However, regardless of stable weight, weight gain, or weight loss, the women's body and self-perception were influenced. Among women with stable weight ± 2.4 % or weight gain > 2.4 %, the changed body became a stranger that reminded the women of their illness, affected their sense of womanhood and self-respect and questioned their ability to maintain control. Particularly, it seemed that the increased waist circumference was of concern as these changes signalled an unhealthy body in discomfort whereas regaining their former figure reminded them of being cured. To move to a higher level of comfort when the women perceived the body as dis-eased and disobedient (12), they endured and found meaning in their condition by interpreting the discomfort as side effects of medication or normal ageing.

Looking into treatment groups, minor weight changes were primarily seen among women in the EG, and major changes of 5-10 % and > 10 % were especially evident

among women who were given chemotherapy. This corresponds with studies that report chemotherapy to be the main contributor with respect to weight gain (33,34,58). Findings from the quantitative data analysis showed that being premenopausal and receiving chemotherapy and estrogen receptor antagonist treatment increased the odds ratio for weight gain calculated from baseline to 18 months. Thus, it seems that these women deserve special attention. However, independently of treatment group, analysing the whole cohort in three weight groups and integrating the findings revealed that not just weight, but particularly extended waist deeply impacted the women's perception of themselves as unified body-subjects.

Perceiving the body as an unknown stranger, the women as unified body-subjects were dissociated in 'I' and 'it' and were longing for their normal body and identity. Investigating the effect of getting a breast reconstruction to 'feel like me again' was found to be a core category in another study (54). Interpreting this core category with findings from our study, it seems that the influence of changes in weight and body composition on the women's perception of body and self creates the same wish to regain former body and former self. However, as a breast reconstruction may support returning to the 'pre-cancer' being (55), it seemed that intrusive and unmanageable changes in weight and body composition prevented the women from getting that feeling. Changes in weight and body composition may thus be regarded as a critical factor that needs caring assistance from health professionals, equalised to coping with a missing breast. Acknowledging the serious impact on the women expands an understanding of the essential meaning of changes in weight and body composition and the women as unified body-subjects.

Despite the women's attempts to downplay the changes, the body appeared as a transforming ambiguous body, and even minor weight gain and slightly extended waist led to a negative self-perception. Although these changes seem to be insignificant, some of the women felt extensive changes in their body or fought to maintain their pre-cancer body weight and shape. However, having a disobedient body that hindered normal life and induced a loss of self-confidence, the women also feared recurrence. The women changed visibly and invisibly. Visible changes are found to provoke disruption between body and self (72,115), which confirms the findings in this mixed methods study. In addition, Brunet et al. found that visible weight changes like weight gain may affect overall self-worth (72). Thus, the sense of one's own value or worth as a person may be in play.

Although women are found to be concerned with a changed weight distribution (74), no studies in the qualitative literature review elaborated on this topic. It is confirmed that weight gain influences identity and impose negative attitudes towards oneself (71,72,75,125) contrasted by weight loss that may strengthens self-identity and sense of being able to act autonomously, and thus increased self-confidence (125). In addition, it has been demonstrated that women treated for breast cancer want to

gain control over their health with respect to weight gain and weight loss loss (71,72,75). This also plays a significant role in the present study where it was demonstrated that stable weight, weight gain, or weight loss seem to be continuously related to a fear of recurrence and death due the possible association with fat tissue exposure to estrogen (23). As weight loss can be associated with illness (73,75), the positive reaction to weight loss was particularly found among women who were overweight prior to breast cancer diagnosis (75). Thus, weight loss in overweight women may be voluntary (126), incentivised by a wish to obtain a healthier lifestyle (46).

The interviewed women with weight loss were overweight at baseline. In this context, weight loss turned the attention away from illness, but was still connected with a fear of recurrence. When the attention was focused on preventing the risk of recurrence, the meaning of weight loss was associated with being able to take care of one's body and self as an autonomous responsible agent. Seeking predictability in an unpredictable context during and after cancer treatment, the women tried to discipline their body (127) in an attempt to be master of their own lives, keep autonomy, personal agency, and capability to carry out certain actions. In addition, the changed bodies made the women feel attractive, their body movements were eased, and their relationship with the world was positively affected. Interpreting voluntary or involuntary weight loss as bodily changes towards a healthier lifestyle thus induced a positive reaction.

The positive reaction may also be associated with prejudices in modern society where the female body is seen as an expression of one's identity and is preferred to be slim and toned (52). Being heavy before, the reaction to the changes may be a sign of a changed relationship with the women's lifeworld. Thus, not only concerns about health and recurrence, but also the social context may be of essential importance. Although weight loss seems to promote a positive body perception, the integration revealed that increased waist circumference may be experienced even with weight loss. Thus, we must question whether weight loss with increased waist induces the same positive reaction as we have already demonstrated that stable weight and weight gain combined with increased waist affected the women extensively and led to a dissociated body-subject.

Particularly weight gain is observed to be a constant reminder of illness and a treatment without end (73) even though the women are considered cured after their cancer treatment. This paradox can induce a discrepancy between the women and their family and friends who may regard the women as cured (55), thus preventing the women from sharing their feelings with people in their social circle. In addition, we found the paradox revealed in the women's narratives as they interpreted their feelings as vanity when death could have been an option. Thus, connected to self-perception and identity, changes in weight and body composition expand and go

beyond appearance and being cured, involving an existential level in a lifeworld context of concern for the unified body-subject.

Interpreting the changes as vanity and downplaying them as normal ageing may be a sign of resignation or acceptance. This resignation and acceptance may contribute to reintegration with the world and life with new limits (12). However, in the effort to remove the traces of illness and return to the same body and self as before breast cancer treatment, a disciplinary course of action might also encompass fragmentation, dissociating the body into an object. Without paying attention to these strategies there is a risk that changes in weight and body composition could prove just as long-term and persistent as the late side effect from cancer treatment found in other studies (73,75).

8.1.2. THE UNIFIED BODY-SUBJECT IN THE PAST, PRESENT, AND FUTURE

Visible weight gains are observed to affect self-worth and induce negative emotions long-term approx. 24 years after competed treatment (73) and up to 31 years from diagnosis (72). The women in the present study are interviewed between 12 and 18 months from diagnosis. From a time perspective, the present is always experienced on a horizon of the past and future (15,20). Integrating measured weight and body composition longitudinally with the women's experiences created a clearer picture of how changes in fat, fat free mass, and total body water appeared to be in the foreground of the women's lifeworld context in terms of past, present, and future. In illness this means that the habitual body acts as a reference point for the present body and highlights how the present body may be mutilated and obstructed in beings and doings (84).

The biggest change in measured weight and body composition - except for the waist - was observed at six months among women receiving chemotherapy. This is in accordance with other studies that report increasing weight after completion of chemotherapy (35,62,66). During and immediately after chemotherapy, the women perceived a body with comprehensive changes, out of control, an object separate from their initial self-perception. Perceived as heavy, hurting, big, and fat, the body was an entity that had to be obeyed. Compared to the habitual body that used to be strong, enduring, and active, during chemotherapy the body turned into a sick and unknown body. The body-subject turned into 'I' and 'it'.

Although changes are found to level off at 12 months (30,62,66), other studies report increasing weight at that time (68,69), and some point at premenopausal status as a risk factor for weight gain (36,63,65). These different findings seem to be rediscovered in the joint displays as some women experienced a body on its way to becoming normal, while others experienced a body with remaining and increasing changes. In this context, the body could be perceived as unfriendly, fragile, and

sensitive. Aiming to reconcile with this transformed identity, the experience of the present reality and self-perception could be experienced as transitionally staying in the present body while longing for the habitual body.

A healthy transition may be perceived as well-being and involves development and movement from one state to another (128). However, staying in between two states one can feel homeless and lost (129). Statements like 'it was not my body' indicate separation and could be a sign of feeling homeless, while the metaphor 'being the master of one's own life' points at an attempt to not go into a homeless existence. Struggling to feel at home in one's body may thus be associated with an unfinished transition and discomfort.

At 18 months, waist circumference was significantly increased statistically in both women receiving chemotherapy and women receiving endocrine treatment alone. Contrary to the study of Francini et al. (58) which reported weight loss in postmenopausal women given aromatase inhibitors, the women from EG gained 0.4 kg during 18 months, but waist circumference increased statistically significantly during the three measurements from baseline. This may indicate a changed distribution, and even though fat mass remained stable it is possible that the distribution has changed with increased fat mass in the trunk area. Increased fat mass in the trunk area may be anticipated to impact general health and is a variable associated with metabolic syndrome (28,130).

The increased weight in women from the CG now consisted of increased fat mass. Thus, the struggle to avoid exposure to estrogen from fat tissue (23) was not successfully accomplished by these women. However, in this study, the fat mass is measured for the whole body. Thus, the results cannot verify the possible changed fat distribution. The association between metabolic syndrome and breast cancer is particularly seen among postmenopausal women (130). As the waist increase was evident and statistically significant among those women in the EG who were exposed to hypertension, screening for metabolic syndrome may be relevant despite the minor weight gain in this group.

Although the women seemed to move towards a unified body-subject at 18 months, the risk of dissociating in object and subject still persisted. Understanding the body as an inseparable unity (15,82,83) may contribute with additional understanding as it may be due to the inseparable body-subject that far-reaching changes in the sense of self appear (83). Talking about their experiences in dissociating terms might be the only way the women were able to express the intrusive changes and the impact on their self-perception and thus also their identity. Thus, an attempt to draw a map of the landscape of the essential meanings of changes in weight and body composition - 'the world-in-itself-for the women' - must be considered.

Independently of whether they belonged to the EG or the CG, the women were focused on their body appearance and weight, and it seemed that regaining a pre-cancer weight and body - which had previously remained unnoticed and required no effort - was essential. Some wanted to regain former waist circumference or lose weight and others to keep their weight loss. Even if the present ties past and future together and always appears as 'nows' (20), the past and future appeared as figures in the foreground against their lifeworld experiences, i.e. the background.

In accordance with other studies (72,75,76,131), the women were all increasingly focused on doing well for their bodies by being active and eating healthily. Long-term survival served as an internal motivational factor (132), but returning to a pre-cancer body also provided distance from the cancer illness and a feeling of being cured. However, body composition changed over time although the women aimed to find a new balance between demands, desires, and energy and to regain a friendly body, able to support everyday beings and doings.

Talking about the future brought hope for a cured, unnoticed, and effortless pre-cancer body aiming to be the master of one's own life. The women struggled against capitulation to unpredictability and disorder, and with long-term survival as an internal motivational factor (132), the women increased their attention on doing well for their body by being active and eating well, thus disciplining the body.

According to Frank (127), disciplining the body may be a way of fighting against bodily changes and maintaining control. Fearing disfigurement, the women attempted to discipline the body and avoid capitulation to unpredictability and disorder (127) in their efforts to remove the traces of illness and return to the same or a slimmer body. Their struggle to avoid exposure to estrogen from fat tissue (23) was, however, often not successful, as any weight gain at 18 months consisted of increased fat mass. In addition, a disciplinary way of action might encompass fragmentation and dissociation from the body as 'it'. Thus, striving to find a new balance between demands, desire, and energy to regain a friendly body might be in contrast to regaining the feeling of a unified body.

Our study demonstrated that changes in weight and body composition could promote disruption between body and self, and it is demonstrated that women short- and long-term may feel seriously transformed (55). Thus, the changes demand attention from the professionals. However, it is shown that health professionals may refrain from taking the women's body perception seriously (71). In the worst case this can prolong and aggravate illness and suffering as shown in the studies that included women for qualitative investigations at a long distance from diagnosis (71-73,76).

8.1.3. THE MEANING OF THE DISSOCIATED BODY-SUBJECT

Integrating qualitative and quantitative findings in this mixed methods study by taking a philosophical stance in existential phenomenology aimed at overcoming the gap between the body as an object and a subject, offering a unifying understanding of the lived body. Changes regarding the biological body (Körper) have been described, and the lived body (Leib) has been taken into account. Thus, a first person's view has been integrated with a third person view. Understanding the body as an inseparable unity (15,82,83), essential for a healthcare practice and nursing in particular, provided embodied knowledge even though it may be difficult to put into words.

According to Merleau-Ponty, the unified body-subject or the lived body is anchored in the world, unable to escape itself and intentionally directed towards things or events always perceiving and perceived. The women's changed perception of body and self became visible when they communicated the intentional meaning of the changes as they appeared. The language contributed to rediscovering that 'actual presence of myself to myself' (20, p.xxix). Thus, the women's embodied knowledge that normally is unreflective and hidden in a taken-for-granted everyday life was presented through the changed body, expressed as a dissociated body-subject and articulated in 'I' and 'it'.

'Objectifying' the body could be a way to manage the inescapably changed body, which entailed a loss of abilities, interrupted everyday life, and hindered 'I can'. The new demanding and strange body gave rise to the taken-for-granted body being put out of play. Dissociating the body-subject in language may thus be an illustration of how changes in weight and body composition can contribute to feelings of discomfort and prolonging of illness. Attempts to discipline the body to regain former body can push towards alienation as well as comfort. Conversely, if the women had had the power to control the changes we could question whether it had been easier for them to reconcile with the (new) habitual body and move towards reintegration or maintaining a unified body-subject.

CHAPTER 9. METHODOLOGICAL CONSIDERATIONS

This chapter provides a critical reflection on how this mixed methods study, guided by existential phenomenology and reflective lifeworld research, meets various scientific criteria.

9.1. ASSESSMENT OF QUANTITATIVE, QUALITATIVE AND MIXED METHODS RESEARCH

For decades, researchers have discussed how we can assess the validity and rigor of quantitative and qualitative scientific work, and different types of vocabulary have been used in different traditions (87,133). Independently of tradition, every method must be used rigorously (4,95) and analysed in its own frame of logic (87,98). Dahlberg et al. (15) propose the criteria of objectivity, validity, and generalisation as useful in this assessment, as they may distinguish scientific research from everyday activities. In scientific investigations, a main conception is that it must be possible for the reader to follow the researcher's reasoning. It is also important to maintain a certain distance to the studied phenomenon, at the same time acknowledging that the researcher is always part of the research process. Validity refers to the trustworthiness of findings which may guide health professionals in their clinical work in general and with the individual patient. Finally, it must be possible to generalise findings to people outside the specific study (15). Thus, Dahlberg et al. refer to both internal and external validity.

Mixed methods aim to complement the strengths and overcome limitations regarding quantitative and qualitative methods. In assessing a mixed methods study, the general validity is dependent on the validity of the individual studies. However, in mixed methods studies some additional issues must be considered. In the attempt to develop a vocabulary for scientific criteria of mixed methods research, Onwuegbuzie and Johnson (134) suggest to consider what they label as representation, legitimation, and integration. They argue that representing lived experiences using words and numbers may be difficult. Legitimations refer to acquiring findings and/or make inferences that are dependable, trustworthy, transferable, and/or confirmable. Finally, they stress that integration must be addressed. Dealing with representation and integration particularly legitimation issues must be addressed during the entire project. The following assessment of the validity of Studies I and II involves scientific criteria suggested by Dahlberg et al. (15) and Onwuegbuzie and Johnson (134). The latter will be addressed when assessing the mixed methods, specifically regarding legitimation that encompasses representation and integration issues.

9.1.1. STRENGHTS AND LIMITATIONS OF STUDY I

Study I was a descriptive prospective cohort study that used a quantitative design. The study provided a third person perspective that focused on the biological body (Körper) and involved quantitative data collection and analysis. Thus, Study I provided data on factual changes and displayed a map of the 'world-in-itself'. Disconnected from the experiences of the changes, the data were analysed in their own frame of logic as requested by mixed methods researchers (87,98) .

During the research process, bias can occur e.g. at sample level, if the researcher deliberately includes participants who may respond in a certain way (135). Therefore, the objectivity of Study I is strengthened by relying on consecutive (random) inclusion. However, the groups of women who were deemed eligible, but were not included, were older and mainly postmenopausal. If these women had agreed to participate, the sample would presumably have been older with fewer women in the CG group and more in the EG group. Still, the included women were representative of the population of women treated for breast cancer.

All the analyses were conducted in collaboration with a statistician and provided important knowledge of the actual sample. By chance, the two treatment groups turned out to be of equal size. As they displayed different characteristics, a direct comparison was not possible, but we were able to perform a subgroup analysis. This subgroup analysis showed that analysing data in a pooled sample delimited the knowledge of the individual women in need of intervention in order to maintain weight.

Due to very few drops-outs, an almost complete dataset and a high response rate were secured. In addition, repeated measurements of the same sample (within subject) and just a few missing data supported the reliability of the data and thus their validity. To ensure the accuracy of the measurements, the weight device was calibrated regularly. In addition, the Tanita was compared with a BioScan 920-II that is used in other scientific investigations. This comparison showed no significant statistical difference between the two scales (Appendix G). However, the requirements for gaining valid data that minimised intra- and interday variations in body fluid relied on the women's adherence to the recommendations and were not as controllable. As they were well informed about the requirements and asked to empty their bladder prior to the measurement, it may be reasonable to anticipate a valid measurement over time regarding the within subject measure.

Regarding waist measurement, it was initially the plan that clinical nurses should perform this measure during the women's visits to the outpatient clinic. As measurements of waist-hip circumference may be difficult, measurements at navel level were chosen as a variable for waist. To strengthen the validity of the measurements, possible changes were confirmed based on the women's body feeling

and a note was made. Due to organisational changes in the clinic, the majority of the measuring was undertaken by the PhD student with assistance from one nurse from the clinical research unit. A few measurements were undertaken by clinical nurses. Some of these referred to outliers in the analysis. Except for the few outliers, and on the basis of two persons measuring the majority of women, the data are considered robust although there is a big variation in waist values.

The purpose of Study I was to describe the extent and patterns of changes in weight and body composition among women treated for breast cancer in a Danish context. The number of participants was discussed in the research group. In planning the present study, it was observed that prospective studies on changes in weight and body composition were conducted using samples consisting of 20-76 women (36,38,57,58) or as much as 272 women (69). Thus, 100 women were anticipated sufficient to describe the extent and pattern of these changes. However, dividing the cohort into the CG, the EG, and three weight groups - with small samples - limited the generalisability of the findings. This means that some results have to be interpreted with caution. For example, although the p-values for the odds ratios in weight loss and gain were statistically significant for women with stage III breast cancer compared to stage II, the risk of type 1 errors was high. The generalisability of findings from the sample to the entire population of women treated for breast cancer is thus questionable. Still, the findings may provide health professionals with knowledge that is relevant in their daily practice, particularly concerning women subjected to chemotherapy.

9.1.2. STRENGHTS AND LIMITATIONS OF STUDY II

Study II was a descriptive, phenomenological study that used a qualitative design. The study provided a first person perspective that focused on the lived body (Leib) and involved qualitative data collection and analysis. Thus, Study II provided data on the women's lived experiences and displayed a map of the 'world-for-them'. Although the women revealed how they experienced their factual changes, the focus of the analysis was on the essential meaning of the changes. Thus, these data were also analysed in their own frame of logic as requested by mixed methods researchers (87,98).

In phenomenological investigations, data collection must involve a minimum of presumptions as well as an effort to avoid being guided by the literature, a priori framework, or theory (15,80,136). In this study, a focus group was conducted and analysed before the individual interviews were carried out. This analysis provided the thematic and dynamic dimensions of the interview guide and a reservoir of questions in everyday language (Paper 1). Although the analysis of the focus group formed a conscious part of the PhD student's presumptions during the interviews and the subsequent analysis hereof, this may still have biased the final analysis. However, the open frame and explorative questions have taken this limitation into

consideration, as such questions allowed the women to narrate their experiences without restrictions.

Furthermore, the threat against objectivity and validity may be minimised through transparency and by maintaining an open mind throughout the research process, while attempting to maintain a scientific, phenomenological approach (15,86,137). With regard to transparency, Norlyk and Harder (137) point at the importance of clarifying one's philosophical stance. In accordance with central ideas and values in nursing, the overriding perspective of existential phenomenology and reflective lifeworld research has been explicated.

The scientific phenomenological approach was supported by additional attempts to bridle my 'natural' attitude. Posing broad, open questions and open-ended follow-up questions, the participants were allowed to narrate their experiences from their natural attitude. Staying faithful and laying out the women's experiences as illustrated by extracts of the analysis and quotes from the participants in Paper 2 may provide the reader with an opportunity to follow reasoning throughout the analysis.

Objectivity and internal validity may also be enhanced by member-checking and intercoder agreement (5,81). However, as member-checking is performed based on a natural attitude and not a scientific one, it is - according to Norlyk and Harder (137) - irrelevant. Instead, discussions in the research group were emphasised in order to challenge each other's impressions and ideas, 'keep wondering', and prevent premature closure of the analysis (15,86). In addition, an intercoder agreement was applied, as six interviews were coded by co-authors and compared with the PhD student's codes.

To obtain external validity, the findings of a phenomenological investigation must direct the reader to her own experience (81,137) which means that the findings must be recognisable. Recognisable findings contribute to their generalisability, but the findings can only be said to be generalisable when new knowledge, if any, is transformed into practical actions (138). The generalisability of the findings beyond the context of the 12 women thus relies on how the findings are recognised and used.

So far, the findings have solely been recognised by the research group and external reviewers and discussed with an international audience. However, the sample was included purposively and aimed to be heterogeneous with respect to age, treatment, and bodily changes. To obtain such heterogeneity, inclusion criteria were followed and the interviews were conducted between 12 and 18 months after breast cancer surgery and initiation of adjuvant antineoplastic treatment. Three women declined participation. Their measured changes were more extensive than those of the 12 women who participated. Reasons for the decline were not sought, and it is unclear

whether interviews with these women would have influenced the findings. Nevertheless, the variation in the present sample has provided detailed descriptions of the women's experiences which were in line with previous findings. In addition, the findings further expanded and elaborated our understanding of the women's experiences. Thus, it can be argued that the findings may be transferred to women faced with similar conditions, while at the same time acknowledging that lifeworld phenomena can never be exhaustively explored (15).

9.1.3. INTEGRATION – STRENGHTS AND LIMITATIONS

The integrative mixed methods interpretation aimed to expand the understanding of the women as unified bodies and thus display a map showing 'the-world-in-itself-for-them'. Integration throughout the study - and particularly the integrative mixed methods interpretation - takes on the challenge of integration as recommended by Fetters and Freshwater (96). As the assessment of scientific quality should account for the entire research process, the strengths of using mixed methods depend on how the requirements for mixed methods studies are met, i.e. the combination of qualitative and quantitative methods, rigorous use of methods, integration of data collection, and/or data analysis and/or results (4,95). A salient point is the integration which must be part of the research process (91,97).

In the present study, integration has taken place at: 1) the sample level, 2) by integrating findings from a focus group into an interview guide for individual interviews, and 3) by integrating the main findings of Studies I and II into joint displays, through the integrative mixed methods interpretation and the subsequent discussions and conclusion. This integration justifies the use of a mixed methods design and demonstrates how mixed methods may expand and elaborate the investigated phenomenon in a way that goes beyond the benefits of single methods studies (4,87,91,139). Although the benefits of conducting mixed methods studies on complex health-related issues are indubitable, this type of research takes time and a research team (139), and it can therefore be a challenging assignment for a PhD study.

One of the supposed weaknesses of mixed methods research is that the researcher must be adept in both qualitative and quantitative research and numerous research methods (139). In addition, mixed methods which are considered a natural complement to traditional quantitative and qualitative research methods (139) require special attention. Even though mixed methods are still under development and an expansive and creative form of research (93), some of the above-mentioned issues must be addressed. In the mixed methods community, a new vocabulary is suggested with regards to scientific criteria. In the following, legitimation is used as a term that replaces validity (134).

Integration of data on the sample level that aims to provide inferences and statistical generalisations from sample to population, constructing meta-inferences from the quantitative and qualitative inferences, may be problematic. Onwuegbuzie and Johnson point out a threat for sample integration legitimation, which may occur if the sample of the qualitative component is much smaller than or belongs to a different population than the quantitative sample (134). However, the aim of integration in this study was not to provide generalisation to the whole population of women treated for breast cancer. Instead, we wanted to expand the meaning of bodily changes and thus contribute to facilitating a mutual understanding among women as unified body-subjects and health professionals.

In our case, integration was fulfilled on the sample level. The women in the interview study represented a small subsample from the entire cohort and were deemed representative at the inclusion. Thus, the sample of Study II was considered representative for Study I. For feasibility reasons, the purposeful selection was based on preliminary quantitative data from Study I and not the final results. In a purely explanatory, sequential design, using final results from the quantitative component might have provided data on women with weight gain and decreased waist circumference and women with weight loss and increased waist. The interview further contributed with a wealth of rich data material, and the integrated mixed methods interpretation revealed new aspects with respect to stable weight, weight gain, and weight loss – giving rise to new questions. However, from a sample integration legitimation point of view, it can be questioned whether integrating repeated, quantitative measurements with 12 individual interviews is sufficient.

According to Creswell (4), the threat to the validity of a study related to sample integration particularly refers to convergent designs. As the present study follows a partly convergent, sequential design, measuring 95 women four times, it seems out of the question to interview the same amount of women as this would have required a lot of additional time and provided an unmanageable body of data for qualitative analysis. Moreover, this amount of qualitative data would be inconsistent with the fundamental assumption in phenomenological studies and thus inconsistent with the claim of conducting and analysing the individual studies in their own frame of logic by quotes, constituents, and meanings - and in numbers and percentages, respectively. With that said, the study might have benefitted from more interviews conducted over a longer period of time, comparing the women's perception of the changed body with changes in body composition.

Another threat to mixed methods studies relates to the researcher's ability to systematically design a study that combines two or more methods in a way that accounts and compensates for weaknesses and strengths regarding the methods. In assessing this weakness minimisation legitimation (134), the applications of different methods and data analysis complemented each other as the quantitative data analysis provided breadth and the qualitative data analysis provided depth. The

added value of integrating the two datasets provided additional knowledge that was not obtainable with single studies alone.

Assessing the requirements of combining qualitative and quantitative methods leads to reflections on the insider-outsider legitimation. This refers to the degree to which an insider and outsider view is presented. Applying a first person and third person perspective and assuming a phenomenological attitude during the entire process, while remaining faithful and faithless throughout the process (88), was a means not to remain ethnocentric or go native (134). In addition, skilled researchers were involved in analysing the qualitative and quantitative data and assessing the integrative mixed methods interpretation. As the two datasets were considered equal, the two viewpoints were deemed balanced. Likewise, taking a philosophical perspective in existential phenomenology contributed to keeping focus on the body as a unifying entity.

According to Onwuegbuzie and Johnson, sequential legitimation must be considered as the study applied a partly explanatory, sequential design. However, questioning whether conducting an explorative, sequential mixed study would have provided different inferences is not relevant for this study as a main interest was to provide knowledge of the influence of changes in weight and body composition. Interviewing women before antineoplastic adjuvant treatment for breast cancer would have obstructed the purposeful selection of women for this study.

Finally, Onwuegbuzie and Johnson point at paradigmatic, mixing legitimation and commensurability legitimation (134). In Chapter 4, the philosophical perspective for this study is described and arguments for the link to critical realism and thus mixed methods are provided. Taking a philosophical stance in existential phenomenology provided an understanding of the women as unified body-subjects that was in accordance with applying a mixed methods design for the study. The attempt to overcome the dualism regarding the biological body and the lived body and applying different methods that are normally considered incommensurable displayed a more moderate position as argued by several mixed methods researchers (4,5,89,134).

In the nursing community, mixed methods and integration of qualitative and quantitative methods have met some resistance based on the argument that the methods belonged to incommensurable paradigms (9,140). Belonging to a humanistic tradition, the focus on nursing practice was claimed to be the experience of illness explored through qualitative enquiries. Investigation of diseases on the other hand was claimed to be the focus of medicine, using quantitative methods (9). From this perspective, integration or reconciliation seems to be out of question. Understanding nursing as an integrated part of health science, multiple theories and methods must be applied for the purpose of relieving suffering and promoting comfort in dealing with complex health-related issues, while conducting multi-methods studies may maintain a dualistic perspective in research regarding human

beings. Instead, the moderate position in the present study is an example of a dialogue between mental models containing a set of assumptions, understandings, predispositions, values, and beliefs, including basic philosophical assumptions as suggested by Greene (89, p.53).

The moderate position maintained both/and instead of either/or, recognising internal and external realities and the interaction between the two provided meta-inference greater than the sum of its parts. The integrative mixed methods interpretation expresses what Onwuegbuzie and Johnson call the Gestalt switch. This is a switch between figure and background and between quantitative results and qualitative findings in an iterative process in which a third viewpoint is created.

CHAPTER 10. CONCLUSION

This chapter sums up the findings from Studies I and II and the integrative mixed methods interpretation with existential phenomenology as an overriding viewpoint. Combining research methods and applying existential phenomenology as an overriding viewpoint for the purpose of enhancing health and comfort is in accordance with central values in nursing and healthcare. From this perspective, patients are perceived not simply as bodies in need of care, but as persons who may need assistance in finding meaning in the face of illness and suffering. On this background, understanding the women as unified body-subjects aimed at expanding our knowledge of factual bodily changes and their influence on the women's perception of body and self.

In Study I, changes over 18 months were revealed to be modest, but statistically significant with respect to weight, fat mass, and waist circumference. Analysing subgroups and calculating odds ratios focussed attention on the group of women in adjuvant treatment with chemotherapy. These women seemed to be more exposed to bodily changes than women receiving endocrine therapy alone. Women in endocrine therapy increased their waist and remained stable in other body composition variables. In contrast, body composition variables fluctuated among the women receiving chemotherapy. These women had an increased risk of weight gain and statistically displayed significantly increased fat mass and waist circumference at 18 months.

Independent of treatment regimes, Study II revealed the ambiguous transforming body. Perceived as a demanding stranger, the women tried to dissociate themselves from the body, dividing the body-subject into 'I' and 'it', respectively. The women attempted to fight these changes by perceiving the body as an object that could be forced to cooperate. When they succeeded in forcing the body to maintain or gain normal weight and shape, the body-subject remained dissociated, but now the women perceived themselves as responsible agents on their way back to their pre-cancer self and habitual state. Acknowledging that the changes could be out of control, the women had to cooperate with and listen to the body. Although they still longed for the habitual body, they accepted the present body. Consequently, they seemed to adapt to and increasingly accept another/new self, while maintaining responsibility and power. Coming to terms with a (new) habitual body, the body-subject moved towards reintegration and away from illness.

Independently of treatment regimens and across the three weight groups, the final integration of the two studies underscored that even small weight changes in association with increased waist circumference influence the women extensively. The integrative mixed methods interpretation demonstrated that changes analysed by means of statistical tools in a pooled sample neither account for nor correspond with

the perceived changes. This challenges the quantitative findings, suggesting that weight changes in general are overestimated.

Across the groups, even small changes can trigger fear of recurrence, shame, and self-blame and a dissociated body and self may be considered as the only way to cope with unmanageable changes. 'Objectifying' the body can be a way to manage the inescapably changed body, entailing a loss of abilities, interrupting everyday life, and hindering 'I can'. On one hand, disciplining the body in an attempt to be master of one's own life, to keep autonomy, personal agency, and capability to carry out certain actions may encompass fragmentation and dissociation of the body.

On the other hand, interpreting the changes as vanity and downplaying them as normal ageing may be a sign of resignation or acceptance. This resignation or acceptance may contribute to reintegration with the world and life with new limits. Striving towards reconciliation and unifying the present body with a 'new' habitual body, health professionals need to acknowledge that the present body and self-perception is determined by the former perception of body and self and wishes for the future. Lack of understanding of the women's experiences may push towards bodily alienation and social changes, challenge self-identity and integrity, and contribute to prolonged and aggravated illness and suffering.

CHAPTER 11. IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

The overriding framework of existential phenomenology and various mental models and methods provided comprehensive insight into the women's experiences of bodily changes. The present study has revealed that there is incomplete knowledge as to how weight and body composition measured in kilograms and centimetres affect these women, as even small changes may hold deeply existential meanings. Thus, without clarifying the women's subjective experiences, the objective findings alone would be of limited value and inconsistent with a care-oriented nursing perspective (7,11). Instead this perspective stresses that the women are not physical bodies but persons who might need assistance in finding meaning in the experience of their illness and suffering (8,10).

The findings showed that some women are at risk of developing an unhealthy weight and body composition with a wide range of relative weight changes, intertwined with a variety of conditions. Although rehabilitation for cancer patients, including women treated for breast cancer, has been established through the city councils, not all women choose or are able to utilise this offer. Furthermore, the encounter with and adaptation to a healthcare system that values effectiveness may prevent patients from expressing their needs and concerns (113). In addition, with respect to weight changes a question of vanity may prevent some women from asking for help. Thus, to decrease risk and prevent further health related side effects, nursing interventions may be considered on the organisational, population and individual level (6).

To provide comfort and help for the women may be the responsibility of healthcare professionals (12,13). In order to identify women with increasing or decreasing weight during follow-up visits and to investigate the psycho-social and physical factors influencing their weight development, an assessment should be made at 12 – 18 months. All women are potentially at risk of changes in weight and body composition and should receive attention. However, according to this study special attention should be given to younger, premenopausal women treated with chemotherapy.

Implementation of individual interventions with respect to physical, psychological, and social concerns in the transition period from patient to survivor has proven to reduce cancer-specific distress (141). Clinic-based weight management programmes for breast cancer patients have proven to be effective (142). McCaughan et al. suggest that a nurse-led service during follow-up visits might be a relevant option for these women (51). In addition, to ensure future health and comfort for the women, it may be relevant to develop an assessment tool and interventions

focussing on nutrition and physical activity as a part of survivor care plans linked to rehabilitation initiatives across sectors. Concrete suggestions for women in this transition period might address how to minimise weight-related side effects. However, the question is whether 'fixing or normalisation' of the changed body contributes to a feeling of wholeness, a unified body-subject, as no direct correlation is found between the degree of changes and the women's experiences.

From a phenomenological and hermeneutical point of view, the Dutch philosopher Jenny Slatman suggests that body evaluation in oncology aftercare involves a narrative approach (143). Before deciding any interventions, the health practitioners must enter a joint, narrative work with the women. In collaboration with the professionals, the narrator may tell, build, and interpret her story aiming to deal with the present situation with special focus on how she values her physical appearance and sense of wholeness (143). From this stance, it may be possible to support the woman in the transition from one habitual body to a new one, while taking her body perception seriously, independently of how the changes are displayed quantitatively. Furthermore, it may provide health professionals with directions for interventions that may influence the women's perception of body and self in a positive way and thus provide comprehensive care for these vulnerable women. Finally, this may be in accordance with a caring perspective and thus contribute to strengthen the life courage of the suffering women (11).

Implementation of this joint orientation in a busy outpatient clinic may be a challenge. In line with a mixed methods approach, long-term follow-up regarding body composition may be manageable as data collection on a BIA is a cheap, easy, and non-invasive procedure. This will provide data on factual changes and knowledge of long-term changes. However, combining these measurements with breast cancer quality of life questionnaires is not sufficient to develop sensitivity to individual body experiences as they do not contain an adequate vocabulary for the experiences (143). Paying attention to how the women talk about their body, and developing and organising a vocabulary in a theme guide from the women's expressions of body changes may provide the professionals with a tool for use in clinical settings. This may be an assignment for future research.

Although this study has added to previous knowledge of the extent and influence of changes in weight and body composition on women's body and self-perception, future research calls for several contemplations.

As data collection with BIA is a cheap, easy, and non-invasive procedure, long-term follow-up may be manageable in a busy outpatient unit, combined with a questionnaire on body and self-perception. Applying these instruments may provide further understanding of the association between observed and experienced changes and consider the critique regarding unequal sample sizes as suggested by Creswell (4). In the present study, the serious changes in weight and body composition were

mainly found among women receiving chemotherapy, although some of these women were able to maintain or regain their pre-cancer body weight and shape during 18 months. Future exploration of psycho-social factors regarding these differences may provide health professionals with insight into critical mechanisms and coping strategies that may lead to extensive changes or support stable weight.

Furthermore, it might be interesting to investigate the association between bodily changes and adherence to current recommendations for physical activity that aim to contribute to the general well-being and health, decrease fatigue, and prevent recurrence (28). Awareness of the women's knowledge of the association between fat mass and breast cancer, adherence or lack of adherence to these recommendations may hold essential meaning of what can influence their spirit and life force during and after cancer treatment.

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APPENDICES

Appendix A. Literature search – quantitative phase

Key words quantitative search phase

Updated November 2015	PubMed (896 entries)	Cinahl (226 entries	Embase (1813 entries)
Breast neoplasms	**MeSH** Breast neoplasms **Free text:** Breast neoplasms Breast cancer	**CINAHL Headings** Breast neoplasms **Free text:** Breast neoplasms Breast cancer	**Emtree** Breast cancer **Free text:** Breast neoplasms Breast cancer
Body weight	**MeSH** Body weight Body weight changes Weight gain Weight loss Overweight Obesity **Free text:** Weight loss Weight reduction Weight gain Weight change* Overweight Obesity Obese	**CINAHL Headings** Body weight Body weight Changes Weight gain Weight loss Obesity **Free text:** Weight loss Weight reduction Weight gain Weight change* Overweight Obesity Obese	**Emtree** Body weight Weight change Weight gain Weight reduction Obesity **Free text:** Weight loss Weight reduction Weight gain Weight change* Overweight Obesity Obese
Adjuvant treatment	**MeSH** Chemotherapy, Adjuvant Antineoplastic agents Aromatase inhibitors Estrogen antagonists **Free text:** Chemotherapy Antineoplastic agent* Aromatase inhibitors Estrogen antagonists	**CINAHL Headings** Chemotherapy, Adjuvant Antineoplastic agents Aromatase inhibitors Estrogen antagonists **Free text:** Chemotherapy Antineoplastic agent* Aromatase inhibitors Estrogen antagonists	**Emtree** Adjuvant chemotherapy Antineoplastic agent Aromatase inhibitor Antiestrogen **Free text:** Chemotherapy Antineoplastic agent* Aromatase inhibitors Estrogen antagonists

Search strategy quantitative search phase.

(("Breast Neoplasms"[Mesh] OR breast neoplasms[tw] OR breast cancer[tw]) AND ((((((((("Body Weight"[Mesh] OR "Body Weight Changes"[Mesh]) OR "Weight Gain"[Mesh]) OR "Weight Loss"[Mesh]) OR weight loss[tw]) OR weight reduction[tw]) OR weight gain[tw]) OR "Overweight"[Mesh]) OR "Obesity"[Mesh]) OR (weight change[tw] OR weight changes[tw])) OR overweight[tw]) OR (obesity[tw] OR obese[tw]))) AND (((((("Chemotherapy, Adjuvant"[Mesh] OR "Antineoplastic Agents"[Mesh]) OR "Aromatase Inhibitors"[Mesh]) OR "Estrogen Antagonists"[Mesh]) OR chemotherapy[tw]) OR antineoplastic agent[tw]) OR aromatase inhibitors[tw]) OR Estrogen Antagonists[tw])

Selection process quantitative search phase

Literature search updated November 2015	**PubMed 896**	**CINAHL 226**	**Embase 1831**
Sorted by language English or Nordic from 2004.	↓	↓	↓
Including titles with weight changes (loss and gain), chemotherapy, endocrine therapy, body composition, obesity. Excluding titles dealing with men, children, animals, biomedical research and other cancer forms than breast cancer	91 ↓	**27** ↓	91 ↓
Reviews and papers without abstract deleted	26 ↓	27 ↓	43 ↓
Abstracts read and papers selected for full text readings	23 ↓	8 ↓	34 ↓
Assessed for relevancy and duplicates deleted from Cinahl and Embase	↓	3 ↓	14 ↓
Retrospective and prospective studies measuring weight across time displayed in kg, BMI, patterns or body composition terms, during and after current antineoplastic treatment selected for the final review from 2004 and ongoing	16	0	3

Appendix B. Literature search qualitative phase

Key words qualitative search phase

Opdated November 2015	PubMed 1807 papers	CINAHL 534 papers	PsycINFO 378 papers
Breast neoplasm	**Thesaurus**: Breast Neoplasms Survivors **Free text:** Breast cancer	**Thesaurus**: Body weight Weight gain Weight loss **Free text**: Breast cancer	**Thesaurus**: Breast neoplasms Survivors
Body weight	**MeSH:** Body weight Weight gain Weight loss **Free text:** Weight changes Weight gain Weight loss Body weight Body image	**CINAHL Headings**: Body weight Body weight changes Weight gain Weight loss **Free text**: Weight changes Weight gain Weight loss Body weight Body image	**Thesaurus**: Body weight Weight gain Weight loss **Free text**: Weight changes Weight gain Weight loss Body weight Body image
"Qualitative"	**MeSH**: Quality of life Stress, Psychological adaptation, Psychological femininity Gender identity Self concept **Free text**: Coping Body perception Femininity Gender identity Quality of life Body experience Self concept Body image	**CINAHL Headings**: Quality of life Stress, Psychological adaptation, Psychological coping Sex role Gender identity Self concept **Free text**: Coping Body perception Femininity Gender identity Quality of life Body experience Self concept Body image	**Thesaurus**: Quality of life Psychological stress Coping behavior Adaptation Femininity Gender identity Self concept Self perception **Free text**: Coping Body perception Femininity Gender identity Quality of life Body experience Self concept Body image

Search strategy qualitative search phase.

((((("Breast Neoplasms"[Mesh] OR "Survivors"[Mesh]) OR ("breast neoplasms"[MeSH Terms] OR ("breast"[All Fields] AND "neoplasms"[All Fields]) OR "breast neoplasms"[All Fields] OR ("breast"[All Fields] AND "cancer"[All Fields]) OR "breast cancer"[All Fields])) AND (((((("Body Weight"[Mesh] OR ("body weight"[MeSH Terms] OR ("body"[All Fields] AND "weight"[All Fields]) OR "body weight"[All Fields])) OR ("weight gain"[MeSH Terms] OR ("weight"[All Fields] AND "gain"[All Fields]) OR "weight gain"[All Fields])) OR ("weight loss"[MeSH Terms] OR ("weight"[All Fields] AND "loss"[All Fields]) OR "weight loss"[All Fields])) OR ("body weight changes"[MeSH Terms] OR ("body"[All Fields] AND "weight"[All Fields] AND "changes"[All Fields]) OR "body weight changes"[All Fields] OR ("weight"[All Fields] AND "changes"[All Fields]) OR "weight changes"[All Fields])) OR ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields]))) AND ((((((((((("Quality of Life"[Mesh] OR "Stress, Psychological"[Mesh]) OR "Adaptation, Psychological"[Mesh]) OR "Femininity"[Mesh]) OR "Gender Identity"[Mesh]) OR ("adaptation, psychological"[MeSH Terms] OR ("adaptation"[All Fields] AND "psychological"[All Fields]) OR "psychological adaptation"[All Fields] OR "coping"[All Fields])) OR (("human body"[MeSH Terms] OR ("human"[All Fields] AND "body"[All Fields]) OR "human body"[All Fields] OR "body"[All Fields]) AND ("perception"[MeSH Terms] OR "perception"[All Fields]))) OR ("femininity"[MeSH Terms] OR "femininity"[All Fields])) OR ("gender identity"[MeSH Terms] OR ("gender"[All Fields] AND "identity"[All Fields]) OR "gender identity"[All Fields])) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields])) OR ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields])) OR ("self concept"[MeSH Terms] OR ("self"[All Fields] AND "concept"[All Fields]) OR "self concept"[All Fields]))) AND "2014/09/24 15.00"[MHDA] : "2015/09/21 15.00"[MHDA]

Selection process qualitative search phase

Literature search updated November 2015	**PubMed 1807**	**CHINAL 534**	**PsycINFO 378**
Sorted by language English or Nordic. Excluding titles dealing with men, children, animals, biomedical research and other cancer forms than breast cancer	101 ↓	57 ↓	66 ↓
Abstracts read carefully and all papers with breast cancer, body image, breast cancer survivors, quality of life, weight changes, weight gain, weight loss in abstracts or key words were selected (overview, reviews, original research using qualitative and quantitative methods)	34 ↓	31 ↓	3 ↓
Papers read carefully to select original research using a qualitative approach to gain knowledge of the experience of changes in weight and body shape associated with current cancer treatment among women with breast cancer	14 ↓	7 ↓	3 ↓
Papers selected and described in the review of the literature.	5	0	1

Appendix C. Participants information quantitative component

Vægtændring hos kvinder med brystkræft under og efter behandling

Deltagerinformation

Kære

Onkologisk Afdeling vil med denne information spørge, om du vil deltage i en videnskabelig undersøgelse. Vi vil sætte fokus på de vægtændringer, især vægtøgning, der kan være et problem i efterforløbet hos kvinder, der behandles medicinsk for brystkræft.

Vægtøgningen måles ofte i kilo. Det betyder, at vi ikke ved, hvordan vægtøgningen er fordelt på fedt og fedtfri masse. Dét vil vi gerne have mere viden om, så vi kan forbedre vores vejledning i forbindelse med vægtændringer.

Hvis du vil deltage i undersøgelsen betyder det, at du vil blive målt omkring taljen og vejet på en speciel vægt ca. hvert halve år i forbindelse med din behandling eller kontrolbesøg – i alt 4 gange. Vejningen vil blive foretaget af en sygeplejerske. For at vejningen bliver foretaget så nøjagtig som mulig, bliver du vejet med bare fødder. Desuden er det hensigtsmæssigt, at du:

- er udhvilet og ikke har trænet 24 timer før målingen
- at du har tømt din blære
- ikke har indtaget alkohol inklusiv vin 24 timer inden vejningen, da det kan påvirke din væskebalance

Din deltagelse i undersøgelsen vil ikke medføre ekstra besøg i afdelingen.

Deltagelse i undersøgelsen er frivillig. Du kan, på et hvilket som helst tidspunkt, trække dit tilsagn tilbage, uden at det vil få konsekvenser for din nuværende eller evt. fremtidige pleje og behandling.

Undersøgelsen er anmeldt til Datatilsynet og drøftet med Videnskabsetisk Komité Region Nordjylland, og hvis du ønsker at deltage i undersøgelsen, skal du underskrive og datere en samtykkeerklæring. De oplysninger, vi registrerer, vil blive behandlet fortroligt. Det vil blandt andet sige, at det ikke vil være muligt at genkende dig, når resultaterne af undersøgelsen bliver offentliggjort eksempelvis i et videnskabeligt tidsskrift.

Har du spørgsmål til denne undersøgelse, er du velkommen til at ringe på nedenstående telefonnumre.

Venlig hilsen
Ansvarlig for undersøgelsen
Udviklingssygeplejerske Birgith Pedersen, ph.d. studerende
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Appendix D. Comparison of included and eligible, not included participants

	Included N = 95	Eligible, not included N = 30
Age		
Mean years (range)	58 (28-82)	64 (45-84)
Menopausal status		
Premenopausal	38 (40 %)	5 (16.1 %)
Postmenopausal	57 (60 %)	25 (83.3 %)
Tumour Stage		
I	59 (62.2 %)	14 (46.7 %)
II	27 (28.4 %)	14 (46.7 %)
III	9 (9.4 %)	2 (6.6 %)

Appendix E. Comparison Tanita and BioScan

	Demografi				BioScan 920-II Helkropsmåling					Tanita BC-418 MA Helkropsmåling					Difference Bioscan - Tanita				
Nr	Dato	Alder (år)	Køn (0-1)	BMI (kg/m²)	FM (%)	FM (kg)	FFM (kg)	TBW (l)	IMP50 (ohms)	FM (%)	FM (kg)	FFM (kg)	TBW (l)	IMP50 (ohms)	FM (%)	FM (kg)	FFM (kg)	TBW (l)	IMP50 (ohms)
1	30-06-2015	57	0	22,8	29,8	17,5	41,1	30,4	557	31,4	18,4	40,1	29,4	696	-1,57	-0,95	0,95	0,98	-139
2	30-06-2015	47	0	18,5	18,1	8,5	38,5	28,8	592	18,8	8,8	38,1	27,9	720	-0,69	-0,29	0,39	0,86	-128
3	01-07-2015	46	0	23,5	29,2	20,4	49,4	36,4	533	32,2	22,4	47,3	34,6	659	-3,00	-2,05	2,05	1,84	-126
4	02-07-2015	60	1	21,7	15,9	10,7	56,8	43,2	444	13,3	9,0	58,4	42,8	546	2,60	1,73	-1,63	0,42	-102
5	02-07-2015	86	1	20,1	18,2	10,3	46,1	35,6	466	13,5	7,6	48,7	35,7	560	4,71	2,65	-2,65	-0,12	-94
6	03-07-2015	60	0	25,1	37,8	22,9	37,6	26,7	643	37,4	22,6	37,9	27,7	731	0,42	0,28	-0,28	-0,99	-88
7	03-07-2015	66	0	16,4	21,7	8,5	30,5	21,9	757	21,2	8,3	30,7	22,5	889	0,50	0,16	-0,16	-0,65	-132
8	03-07-2015	26	1	26,8	26,1	20,7	58,6	43,0	505	27,0	21,4	57,9	42,4	649	-0,86	-0,67	0,67	0,55	-144
9	27-07-2015	69	0	22,5	30,2	21,1	48,7	35,8	532	32,2	22,5	47,2	34,6	658	-1,99	-1,45	1,45	1,18	-126
10	28-07-2015	62	1	26,8	27,4	23,0	61,0	45,0	451	25,0	21,1	63,2	46,3	533	2,41	1,92	-2,22	-1,33	-82
	Middeltal	**57,9**	**0,4**	**22,4**	**25,5**	**16,3**	**46,8**	**34,7**	**548,0**	**25,2**	**16,2**	**47,0**	**34,4**	**664,1**	**0,3**	**0,1**	**-0,1**	**0,3**	**-116,1**
	SD	**15,9**	**0,5**	**3,4**	**6,9**	**6,1**	**10,0**	**7,7**	**96,6**	**8,3**	**6,8**	**10,5**	**7,7**	**106,2**	**2,4**	**1,5**	**1,6**	**1,0**	**22,4**
		FM (%)	**FM (%)**			**FM (kg)**	**FM (kg)**				**FFM (kg)**	**FFM (kg)**			**TBW (l)**			**IMP50 (ohms)**	**IMP50 (ohms)**
		29,8	31,4			17,5	18,4			41,1	40,1			30,4	29,4			557	696
		18,1	18,8			8,5	8,8			38,5	38,1			28,8	27,9			592	720
		29,2	32,2			20,4	22,4			49,4	47,3			36,4	34,6			533	659
		15,9	13,3			10,7	9,0			56,8	58,4			43,2	42,8			444	546
		18,2	13,5			10,3	7,6			46,1	48,7			35,6	35,7			466	560
		37,8	37,4			22,9	22,6			37,6	37,9			26,7	27,7			643	731
		21,7	21,2			8,5	8,3			30,5	30,7			21,9	22,5			757	889
		26,1	27,0			20,7	21,4			58,6	57,9			43,0	42,4			505	649
		30,2	32,2			21,1	22,5			48,7	47,2			35,8	34,6			532	658
		27,4	25,0			23,0	21,1			61,0	63,2			45,0	46,3			451	533
	T-Test	**p=**	**0,745**			**p=**	**0,791**			**p=**	**0,780**			**p=**	**0,418**			**p=**	**5,3E-08**
	Parret																		**<0,001**

Appendix F. Participants information focus group

Vægtændring hos kvinder med brystkræft under og efter behandling

Deltagerinformation fokus gruppe

Kære

Tusind tak fordi du vil deltage i en uformel samtale om dine oplevelser af ændringer i vægt og kroppens facon under og efter din behandling for brystkræft. Samtalen vil finde sted i et møderum i onkologisk afdeling og der vil være mellem 5 -7 andre deltagere.

Samtalen vil blive optaget på diktafon og efterfølgende udskrevet og analyseret. I denne proces vil der ske en anonymisering. Det vil sige, at dine beskrivelser ikke kan henføres til dig. Analysen vil blive brugt til at udarbejde en interviewguide, der skal bruges til individuelle interview i et ph.d - projekt.

Ph.d- projektet omhandler vægtforandringer under og efter behandling for brystkræft og indeholder to dele.

Første del består i registrering af ca. 100 kvinders vægt på en "Body composition analyzer" gennem 18 måneder. Det vil sige, at kvinderne bliver vejet på en vægt, der kan udskille forskellige parametre som fedtmasse, fedtfri masse, måle BMI m.m. Desuden registreres maveomfang.

Anden del består af interview med ca. 15 kvinder, der har oplevet vægtforandringer. Interviewet foretages ca. et år efter behandlingens start. Det er til dette interview, jeg skal udarbejde en guide med spørgsmål. Interviewet forventes at bidrage til at skabe mere viden om, hvilken betydning kropslige forandringer i forbindelse med vægtændringer kan have for disse kvinder.

Nedenstående spørgsmål kan overvejes inden vi mødes, men det er væsentligt at få drøftet det, der er betydningsfuldt for dig:

- Hvilke tanker du har gjort dig om vægtforandringer
- Hvilken betydning har de haft for dig
- Hvilke sammenhænge ser du i forhold til eventuelle vægtændringer

- Hvordan du har taklet evt. vægtændringer

Deltagelse i undersøgelsen er frivillig. Du kan, på et hvilket som helst tidspunkt, trække dit tilsagn tilbage, uden at det vil få konsekvenser for din nuværende eller evt. fremtidige pleje og behandling. Hvis du ønsker at deltage i undersøgelsen, skal du underskrive og datere en samtykkeerklæring. De oplysninger, vi registrerer, vil blive behandlet fortroligt.

Undersøgelsen er anmeldt til Datatilsynet og drøftet med Videnskabsetisk Komité Region Nordjylland.

Mange hilsner
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Appendix G. Participants information qualitative component

Vægtændring hos kvinder med brystkræft under og efter behandling

Deltagerinformation – individuelle interviews

Onkologisk Afdeling/Speciale for kræftbehandling
Aalborg Universitetshospital

Kære

Tak fordi du har sagt ja til at deltage i undersøgelsen vedrørende vægtændringer og vægtens fordeling mellem muskler og fedt i forbindelse med behandling for brystkræft. Du er nu blevet vejet og blevet målt omkring livet flere gange. Disse data indgår i kvantitative beregninger og vi forventer at få mere viden om sammenhængen mellem behandling, udvikling af vægtændringer samt hvorledes ændringerne fordeler sig.

Vi vil også gerne have mere viden om, hvad eventuelle kropslige forandringer i forbindelse med vægtændringer kan betyde for den enkelte kvinde. Til dette ønsker vi at foretage interviews med ca. 15 kvinder.

Derfor vil jeg spørge, om du kunne være interesseret i at lade dig interviewe om, hvad eventuelle vægtforandringer har betydet for dig. Interviewet vil foregå, hvor du ønsker det. Dvs. hjemme hos dig eller på hospitalet og vil vare ca. en time. Interviewet vil blive optaget på diktafon og efterfølgende udskrevet og analyseret. I denne proces vil der ske en anonymisering. Det vil sige, at dine beskrivelser ikke kan henføres til dig.

I interviewet vil jeg være inspireret af en interviewguide, som jeg har udarbejdet på baggrund af et fokusgruppeinterview, men da det handler om at få så mange nuancer frem som muligt, har du mulighed for at fortælle netop det der er vigtigt for dig.

Nedenstående spørgsmål kan overvejes inden interviewet, men alt relateret til din oplevelse af vægtændringer er væsentligt for undersøgelsen at få frem:

- Hvordan oplever du forandringerne og hvordan bliver du opmærksom på dem?
- Hvilken betydning har forandringerne for din opfattelse af dig selv og din krop?
- I hvilke situationer bliver du opmærksom på dine vægtforandringer?
- Hvad tænkte/følte du da du oplevede forandringerne?
- Hvilke sammenhænge ser du i forhold til eventuelle vægtændringer?
- Hvordan du har håndteret evt. vægtændringer?

Undersøgelsen er anmeldt til Datatilsynet og drøftet med Videnskabsetisk Komité Region Nordjylland. Deltagelse i undersøgelsen er frivillig.

Du kan, på et hvilket som helst tidspunkt, trække dit tilsagn tilbage, uden at det vil få konsekvenser for din nuværende eller evt. fremtidige pleje og behandling.

Hvis du ønsker at deltage i undersøgelsen, skal du underskrive og datere en samtykkeerklæring.

De oplysninger, vi registrerer, vil blive behandlet fortroligt. Det vil blandt andet sige, at det ikke vil være muligt at genkende dig, når resultaterne af undersøgelsen bliver offentliggjort eksempelvis i et videnskabeligt tidsskrift.

Har du spørgsmål til denne undersøgelse, er du velkommen til at ringe på nedenstående telefonnumre.

Venlig hilsen
Udviklingssygeplejerske Birgith Pedersen, ph.d. studerende,
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Appendix H. Estimated patterns of changes in weight and body composition

	Weight kg			FM kg			FFM kg			TBW kg			Waist cm		
	Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI	
Baseline	70.1	67.7;72.5		24.3	22.5;26.0		45.8	44.8;46.8		33.5	32.8;34.3		92.2	89.4;94.5	
n = 95	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P
Six months	1.0	0.4-1.6	.001	-0.4	-0.9-0.2	.221	1.4	0.9-1.8	<.0001	1.0	0.7-1.3	<.0001	1.6	0.8-2.4	<.0001
12 months	0.7	0.1-1.3	.033	0.5	<0.0-1.1	.063	0.1	-0.3-0.6	.609	0.1	-0.3-0.4	.617	1.3	0.5-2.1	.002
18 months	0.9	0.3-1.5	.003	0.8	0.2-1.3	.006	0.1	-0.3-0.6	.623	0.1	-0.3-0.4	.629	1.9	1.1-2.7	<.0001
	Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI	
Baseline	69.1	65.6-72.7		24.1	21.6-26.7		45.0	43.5-46.5		32.9	31.8-34.0		91.8	88.4-95.3	
n = 47 (EG)	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P
Six months	0.4	-0.2-1.1	.197	0.0	-0.7-0.7	.982	0.4	-0.3-1.1	.254	0.3	-0.2-0.8	.238	1.9	0.9-2.9	<.0001
12 months	0.4	-0.2-1.1	.212	0.2	-0.5-1.0	.506	0.2	-0.6-0.9	.644	0.1	-0.4-0.7	.632	1.6	0.6:2.7	.002
18 months	0.4	-0.2-1.1	.171	0.2	-0.5-0.9	.587	0.2	-0.5-1.0	.505	0.2	-0.3-0.7	.491	1.7	0.7-2.7	.001
	Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI		Mean	95% CI	
Baseline	71.0	67.8-74.2		24.4	22.1-26.8		45.6	45.4-47.8		34.1	33.2-35.0		92.5	89.4-95.6	
n = 48 (CG)	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P	Est.diff.	95% CI	P
Six months	1.6	0.6-2.6	.002	-0.7	-1.6-0.1	.094	2.3	1.8-2.8	<.0001	1.6	1.3-2.0	<.0001	1.3	0.1-2.5	.037
12 months	0.9	-0.1-1.9	.076	0.8	- 0.0-1.6	.057	0.1	- 0.4-0.6	.728	0.0	-0.3-0.4	.763	0.9	-0.3-2.1	.136
18 months	1.4	0.4-2.4	.007	1.4	0.5-2.3	.001	0.0	- 0.5-0.5	.929	0.0	-0.4-0.3	.896	2.1	0.9-3.3	.001

Abbreviations: FFM (fat free mass), FM (fat mass), TBW (total body water)

Appendix I. Estimated odds ratio for weight groups

	n baseline	Weight gain (< 2.4 %) vs stable weight (± 2.4 %) Baseline to 18 months				Weight loss (> 2.4 %) vs stable weight (± 2.4 %) Baseline to 18 months			
		Crude OR (95 % CI)	p-value	Adj.OR (age) (95 % CI)	p-value	Crude OR (95 % CI)	p-value	Adj.OR (age) (95 % CI)	p-value
Menopausal status									
Postmenopausal	57	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
Premenopausal	38	2.9 (1.14-7.51)	.025	2.5 (0.53-11.4)	.250	1.6 (0.46-5.39)	.464	3.0 (0.46-20.23)	.249
Type of surgery									
Mastectomy	28	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
Lumpectomy	67	1.8 (0.65-5.02)	.257	1.9 (0.67-5.48)	.229	0.6 (0.18-2.03)	.429	0.6 (0.19-2.03)	.426
Tumor Stage									
I	59	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
II	27	0.5 (0.20-1.54)	.253	0.5 (0.18-1.53)	.241	0.9 (0.22-3.50)	.871	0.9 (0.22-3.50)	.854
III	9	3.8 (0.40-36.82)	.243	3.8 (0.38-37.92)	.256	12.5 (1.21-128.66)	.034	12.5 (1.21-128.84)	.034
Receptor status									
ER[2] - pos	90	1 (ref) [1]		1 (ref)		1 (ref)		1 (ref)	
ER - neg	5					0.6 (0.09-3.76)	.557	0.6 (0.08-3.75)	.550
Histopathology type									
Ductal	81	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
Lobular	14	1.1 (0.31-3.64)	.923	0.9 (0.27-3.45)	.968	0.8 (0.15-4.51)	.809	0.8 (0.14-4.50)	.803
Adjuvant therapy									
Endocrine therapy	47	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
EC+T ± endocrine [2]	48	2.6 (1.03-6.41)	.043	1.8 (0.54-6.20)	.330	1.2 (0.36-3.77)	.797	1.4 (0.29-6.92)	.668
Comorbidity									
No	51	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
Yes	44	1.2 (0.49-2.99)	.672	1.8 (0.67-5.09)	.232	3.3 (0.96-11.31)	.058	4.3 (1.07-17.24)	.040
Smoking									
Non smoker	74	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
Current smoker	21	2.5 (0.77-8.16)	.129	2.5 (0.77-8.70)	.125	3.2 (0.77-13.07)	.108	3.2 (0.77-13.16)	.107
Alcohol units pr. week									
< 7	82	1 (ref)		1 (ref)		1 (ref)		1 (ref)	
≥ 7	13	1.06 (0.28-4.00)	.931	1.3 (0.33-5.24)	.682	1.6 (0.34-7.74)	.548	1.6 (0.33-8.04)	.554

[1]. OR not calculated because there are no ER negative in the EG. [2]Abbreviations: ER (estrogen receptor), EC+T (epirubicin, cyclophosphamide, taxoterre)

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