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## "The ambiguous transforming body" – A phenomenological study of the meaning of weight changes among women treated for breast cancer



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#### ABSTRACT

*Background:* Changes in weight and body-shape are well known side effects among women treated for breast cancer. Caring for these women requires knowledge of how they perceive these bodily changes. However, knowledge on weight changes and how such changes influence the women's perception of their bodies and selves is limited.

*Objective:* To describe the essential meaning of the phenomenon of changes in weight and body-shape in women treated for breast cancer and how these changes influence the women's perception of body and self.

*Design:* The study design is guided by existential phenomenology as a unifying framework and descriptive life-world research as the methodological approach. Data consisted of 12 individual interviews.

*Setting:* The study was conducted at a department of oncology at a Danish university hospital in 2014.

*Participants:* Women with changes in weight and body-shape were invited to participate in the study for purposeful selection. Inclusion procedure took place when the women attended the outpatient clinic at one year follow-up.

*Results:* The essential meaning "The ambiguous transforming body – between a luxury problem and fear of recurrence" was formed by three interrelated constituents: (1) the body – a demanding stranger; (2) fighting to be the master in one's own life, and (3) accepting the bodily changes.

*Conclusion:* Weight changes may induce a feeling of being in transition between a former well-known body and a current strange demanding body. Interpreting the bodily changes in the light of being alive, the weight changes appeared as a luxury problem. However, knowing that excess fat can cause breast cancer, the women are caught in a dilemma because the medication is supposed to contribute to long-term survival and at the same time is a possible contributor to weight gain. Being alive but unable to avoid bodily

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http://dx.doi.org/10.1016/j.ijnurstu.2015.10.011 0020-7489/© 2015 Elsevier Ltd. All rights reserved. changes, the changes influenced the women's self-perception as autonomous agents and provoked self-blame, shame and feelings of ungratefulness. Thus, relieving the burden of changes in weight and body shape is not only a question of appearance, but encompasses the desire for life and anxiety of death.

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#### What is already known about the topic?

- Women with breast cancer suffer from numerous side effects during and after their cancer treatment.
- Weight changes are a well-known side effect since chemotherapy and endocrine treatment revealed on the scene of cancer treatment.
- Weight changes influence the women' quality of life and can lead to early death and recurrence of the disease.

### What this paper adds

- Weight changes may induce a feeling of staying in transition between a former well-known body and a current strange demanding body.
- The women interpret the bodily changes in the light of current knowledge of the association between excess body fat and risk of recurrence and weight changes as a luxury problem and vanity and feel caught in a dilemma between the medication as vital for survival and as a contributor to unhealthy changes in weight and bodyshape.
- The bodily changes are not only a question of appearance, but encompass the desire for life and anxiety for death and difficulties in relieving the burden of body changes.

#### 1. Introduction

Understanding bodily expressions, the meaning and the influence of illness on everyday living are central aspects in nursing practice that serves as a precondition for providing nursing care (Henderson, 1997). Caring for women during and after treatment for breast cancer requires knowledge of how patients experience bodily changes. Knowledge on the perception of changes in weight and body-shape associated with breast cancer is limited and there is a lack of awareness on how these changes manifest and influence the women's perception of their bodies and selves. Thus, the aim of this article was to describe the essential meaning of the phenomenon of changes in weight and body-shape in women treated for breast cancer and how these changes influence the women's perception of body and self.

#### 2. Background

Changes in weight and body-shape among women with breast cancer are a well-known side-effect from cancer treatment (Cappiello et al., 2007; Demark-Wahnefried et al., 2012; Mayer, 2013; Makari-Judson et al., 2014). Studies using questionnaires on quality of life report

weight gain as distressing (Kjaer et al., 2011; Ganz et al., 2011; Rosenberg et al., 2013). Weight gain following breast cancer diagnosis is also found to be associated with poorer prognosis and overall health, self-image and quality of life (Makari-Judson et al., 2014). Wilmoth et al. (2004) found that quality of life was affected by fatigue, weight gain and altered sexuality as symptoms were experienced concurrently and compounded. Other side effects from cancer treatment such as loss of hair and breast are found to lead to a sense of losing parts of own identity (Ogle and Ullstrup, 2006; Hansen, 2007; McKean et al., 2013). Even though several unexpected and distressing symptoms in the years after active cancer treatment could burden and influence the women's identity, changes in weight and body-shape were not mentioned in a study by Rosedale and Fu (2010). However, changes in pre-cancer body associated with weight gains were found to impact negatively on selfesteem and quality of life (Helms et al., 2008).

To elaborate on this complex issue, a comprehensive literature research was conducted. Only three studies with a qualitative design reported on the influence of weight changes during and after cancer treatment among breast cancer survivors. One research group studied African American breast cancer survivors based on a transactional model of stress and coping. Being a constant reminder of the breast cancer diagnosis, weight gain and weight loss were mainly perceived as stressors that had to be managed with a healthier life-style or clothing-style. The influence of weight changes on the women's body perception was not described (Halbert et al., 2008). A grounded theory study of women who had suffered from breast cancer showed that weight changes were clustered with vulnerability and control, stress and living well, and uncertainty and confidence (Maley et al., 2013). Brunet et al. (2013) explored women's experience of their bodies posttreatment for breast cancer in interviews analyzed with an interpretative phenomenological approach. The analysis revealed that changes in weight and body-shape were tied to negative thoughts and emotions as well as lack of control. Furthermore, the changes prevented the women from displaying a desired body and made them use various strategies to reduce the discrepancy between their body before and after cancer treatment. Changes in body and weight were central elements in the analysis; however, data were obtained between 2 and 31 years after the women completed their treatment and the authors recommend further research to support these data in other groups and contexts (Brunet et al., 2013).

In illness, normal orientation in the world and perception of body changes as a result of disease equals loss of predictability (Carel, 2012; Frank, 2013; Merleau-Ponty, 2014). The literature above shows that changes in

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