



## The experience of distress in relation to surgical treatment and care for breast cancer: An interview study



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### A B S T R A C T

#### Keywords:

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Distress  
Women  
Continuity of care  
Surgery  
Phenomenological-hermeneutic

**Purpose:** A diagnosis of breast cancer is a key turning point in a woman's life that may lead to her experiencing severe and persistent distress and potentially presaging a psychiatric disorder, such as major depression. In Denmark an increased standardization of care and a short hospital stay policy minimize the time of medical and nursing surveillance. Consequently, there is the potential risk that distress goes unnoticed, and therefore, untreated. Therefore, the purpose of this study was to explore the experience of distress in Danish women taking part in surgical continuity of care for breast cancer.

**Methods and sample:** A phenomenological-hermeneutic approach inspired by the French philosopher Paul Ricoeur was conducted to explore the experience of distress in relation to surgical treatment and care for breast cancer. Semi-structured interviews were conducted with 12 women who recently had surgery for breast cancer at six departments of breast surgery in Denmark from May 2013 to November 2013.

**Key results:** The understanding of the experience of distress in the period of surgical continuity of care for breast cancer is augmented and improved through a discussion related to four identified themes: A time of anxiety, loss of identities, being treated as a person and being part of a system, drawing on theory and other research findings.

**Conclusion:** Distress experienced by women in the period following diagnosis arises from multiple sources. Support and care must be based on the woman's individual experience of distress.

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### Introduction

Breast cancer is the most common cancer affecting women worldwide with an estimated 1.67 million new cases in 2012 (International Agency for Research on Cancer, 2012). In Denmark, one in every 9 women will be diagnosed during their life corresponding to 4549 women in 2012 (Statens Serum Institut, 2012). Receiving a diagnosis of breast cancer is a key turning point in a woman's life that may lead her to experience significant distress. Women in this situation are confronted with a number of challenges, particular the spectre of their own mortality. Furthermore, they are likely to experience distinct changes in their physical

appearance, such as loss or disfigurement of one or both breasts, scars from surgery and skin changes from radiotherapy (White, 2000).

Distress is commonly reported in the context of cancer, and extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling as depression, anxiety, panic, social isolation and existential and spiritual crisis (The National Comprehensive Cancer Network, 2013). Rates of distress differ between research studies depending upon a range of methodological issues such as different tools used to measure distress, and/or different time frames, but findings indicate that between one-third and one-half of all patients experience significant distress, particular in the first six months following diagnosis. Initial distress can be extreme, persistent and presage a psychiatric disorder such as major depression (Hegel et al., 2006). Up to 25% of breast cancer patients have been reported to use antidepressants at some time following

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their diagnosis even though the rates of prescriptions do not entirely reflect the rate of depression (Suppli et al., 2011). Failure to detect and treat severe distress may affect the outcome of cancer therapy, and adversely impact on the woman's quality of life both of which ultimately add cost to health care systems (Snowden et al., 2011). In Denmark, the average length of hospital stay is declining (Mertz et al., 2009). The short stay policy reduces the available time during which the health care team can monitor the women's progress and increases the risk that distress in the early period following diagnosis will go unnoticed and therefore untreated. There is evidence that the supportive care needs of the majority of women with breast cancer are not being adequately met, placing these women at even greater risk of developing distress (McGarry et al., 2013). Understanding the experience of distress in women taking part in surgical continuity of care is important for being able to identify the key concerns of these women and to inform development of appropriate interventions (Remmers et al., 2010). Surgical continuity of care is defined as the time period from diagnosis to start of adjuvant treatment or follow up. The purpose of this study was to gain an in-depth understanding of the experience of distress in women taking part in surgical continuity of care for breast cancer in Denmark.

### Method

A phenomenological-hermeneutic approach inspired by the French philosopher Paul Ricoeur was used to explain and understand the experience of distress in women taking part in surgical continuity of care for breast cancer (Ricoeur, 2002). Semi-structured interviews were applied to encourage the participants to talk about their experiences of distress in order to uncover the meaning content. According to Ricoeur a description is not sufficient to obtain a profound understanding of the life experience. The interview texts contain a surplus of meaning which necessitates an interpretation process. This process seeks to generate an understanding that exceeds the actual interviews (Ricoeur, 1979, 2002).

### Ethical aspects

All participants had previously provided informed consent to participate in a survey, which was included in a mixed methods study together with this interview study. Twelve women from the survey study additionally agreed to be interviewed by the first

author. They were given written and oral information and informed that the data would be anonymised. The study was approved by the Data Protection Agency (journal number 2008-58-0028).

### Data collection

Data collection was obtained through individual interviews with 12 women aged 37–87 years who had recently undergone surgery for breast cancer in one of six breast surgery departments in Denmark. The women were interviewed before the start of adjuvant treatment or follow-up, except for one woman, who had just started chemotherapy. The phenomenological perspective was expressed as the participants were asked to tell about their experience of distress in relation to the time period of surgical continuity of care for breast cancer in a descriptive and clarified way. The approach was open with the interviewer asking supplementary questions to elaborate the experience of distress. Furthermore, an interview guide was used to deepen the answers that the woman gave in the survey to further explore the experience of distress. The interviews were conducted from May through November 2013 and the participants were given a choice regarding the location of the interview. Ten interviews took place at home, and two in the hospital. In order to capture variation in the sample a purposeful sampling strategy was chosen to cover demographic and clinical characteristics, such as age, children living at home, method of surgery and level of distress. Clinical characteristics are presented in Table 1. The duration of the interviews varied between 15 and 68 min and were taped and transcribed verbatim to text by the first author.

### Data analysis and interpretation

The text comprised the data that was subject for the analysis and interpretation. The analytic and interpretation process consisted of three levels: a naive reading, structural analysis, and critical analysis and discussion. The naive reading was a first reading of the interview texts to achieve an immediate understanding of the meaning content. Next, the structural analysis was describing units of meaning (what is said) and next identifying and formulating units of significance (what is talked about) leading to development of themes and patterns (Ricoeur, 1979). In this step of the analysis the explanatory aspect is seen (Ricoeur, 1973). The final step, the critical analysis and discussion, was to make a

**Table 1**  
Clinical demographics of participants.

Number	Age	Marital status	Children living at home or not	Employment	Surgery
1	45	Married	2 Living at home <14 years	Nurse	Mast. + SN
2	37	Married	2 Living at home <10 years	Sales assistant	Lump. + Axil.
3	87	Living alone	2 Adults, not living at home	Retired	Mast. + Axil.
4	47	Living with a partner	2 Living at home <18 years	Factory worker	Lump. + SN
5	61	Living alone	2 Adults, not living at home	Retired	Lump. + SN
6	48	Married	1 Living at home and 1 not living at home <23 years	Clerk	Lump. + SN
7	69	Married	2 Adults, not living at home	Retired	Mast. + Axil.
8	70	Living alone	2 Adults, not living at home	Retired	Mast. + SN
9	52	Married	1 Adult, not living at home	Therapist	Mast. + SN
10	48	Married	2 Living at home <14 years	Teacher	Lump. + Axil.
11	47	Living with a partner	1 Living at home <21	Kitchen assistant	Lump. + SN
12	67	Married	2 not living at home <19	Clerk	Mast. + Axil.

Mast. = mastectomy means that the breast is removed.

Lump. = lumpectomy means that the tumour and the surrounding tissue are removed.

SN = sentinel node is based on the assumption that the removal of the lymph from the breast to the armpit takes place in a certain order. SN is the first lymph node(s) that receive lymph from the breast.

Axil. = axillary clearance – the tissue situated caudally for vena axillaris is removed containing 10–20 lymph nodes.

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