



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



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### A B S T R A C T

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**Purpose:** Women with breast cancer often experience significant distress. Currently, there are no questionnaires aimed at identifying women's unique and possible changing indicators for distress in surgical continuity of care for breast cancer. We developed and tested three questionnaires specifically for this use.

**Methods and sample:** We first searched PubMed, CINAHL and PsycINFO to retrieve information on previously described indicators. Next, we conducted a focus group interview with 6 specialised nurses, who have extensive experience about consequences of breast cancer for women in surgical continuity of care. The questionnaire was tested on 18 women scheduled for breast cancer surgery. Subsequently, the women were debriefed to gain knowledge about comprehensibility, readability and relevance of items, and the time needed to complete the questionnaire. After adjustment, the questionnaires were field-tested concomitantly with a clinical study, which both consisted of a survey and an interview study.

**Key results:** Three multi-item questionnaires were developed specific to different time points in surgical continuity of care. The questionnaires share a core of statements divided into seven sub-scales: emotional and physical situation, social condition, sexuality, body image, religion and organisational factors. Besides the core of statements, each questionnaire has different statements depending on the time point of surgical continuity of care when it was to be responded to.

**Conclusion:** The questionnaires contain comprehensive items that can identify indicators for distress in individual women taking part in surgical continuity of care. The items were understandable and the time used for filling in the questionnaires was reasonable.

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### Introduction

According to the World Health Organisation (WHO), 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 with breast cancer during her life corresponding to 4549 women in 2012 and the prevalence of breast cancer has increased from 39.681 in 2002 to 58.202 in 2012 (Statens Serum Institut, 2012). The 5-year age standardised survival rate for breast cancer has increased from 78% (95% confidence

interval (CI): 76; 79) in 1998 to 84% (95% CI: 83; 86) in 2011 (Statens Serum Institut, 2013). This trend is probably due to the national mammography screening programme and better surgical and treatment possibilities. While multi-modality treatment regimens have improved survival they may have contributed to women experiencing prolonged period of distress.

A large proportion of women experience distress following diagnosis and treatment for breast cancer (Burgess et al., 2005; Mertz et al., 2012), probably due to thoughts regarding death (Ganz, 2008) and surgical consequences of treatment (Helms et al., 2008). Distress represents a continuum ranging from feelings of vulnerability, grief, and worry to depression, anxiety, panic, social isolation and existential and spiritual crisis (The National Comprehensive Cancer Network, 2011). Initial distress can be extreme, persistent and presage a psychiatric disorder such as major depression (Hegel et al., 2006). Failure to detect and treat

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severe distress may limit the outcome of cancer therapy, impact quality of life and ultimately adds cost to health care systems (Snowden et al., 2011). Therefore, timely recognition and treatment of the individual women's unique and changing distress is essential. In Denmark, the average length of hospital stay declined from 5 days in 2007 to 2.2 days in 2009 for women who had mastectomy and axillary node dissection and from 4.1 days to 1.0 day for women who had lumpectomy and axillary node dissection (Mertz et al., 2009). The short stay policy reduces the surveillance period and increases the risk that distress is unnoticed and therefore untreated.

An increasing number of questionnaires are used to identify and measure distress, but none of them specifically and comprehensively address individual women's unique and changing indicators of distress during surgical continuity of care for breast cancer. Either they are too generic or do not cover specific issues for women taking part in surgical continuity of care. In this respect, cancer specific tools may provide more relevant information for specific types of cancer to rapidly identify women's key concerns and link these to further tailored support. The distress thermometer is a tool for measuring the level of distress and is validated by Bidstrup et al. (2012) in a cohort of Danish women with newly diagnosed breast cancer. This validation also included a problem list regarding physical, psychological, social and spiritual/religious concerns. However, the problem list was developed for men with prostate cancer (Roth et al., 1998). As consequence, some potential indicators for women with newly diagnosed breast cancer were missing. In addition, the response options were dichotomous yes/no and did not sufficiently explore the extent of distress related to consequences of breast cancer in surgical continuity of care. Identification of individual women's unique and possible changing indicators of distress in surgical continuity of care is important for understanding the issues that these patients face to conduct further assessment and/or appropriate referrals. This knowledge may help developing individual support to women dealing with breast cancer which may ultimately qualify the continuity of care. There is a need for a questionnaire that comprehensively identifies indicators being important for the experience of distress in individual women taking part in surgical continuity of care, especially in a time when cancer care is accelerated and mainly based on standards. Therefore, we aimed to develop and validate the content of a questionnaire which encompasses comprehensive and specific indicators of distress relevant to women taking part in surgical continuity of care, to qualify care in Denmark.

## Methods

We conducted the study from March 2012 to March 2013 at the Department of Breast Surgery, Aalborg University Hospital, Denmark. To provide evidence of relevant items that comprehensively cover the construct distress in women taking part in surgical continuity of care for breast cancer, a literature search, a focus group interview and a pilot study including debriefing formed the basis for questionnaire development. Also, a psychologist and a social worker, doctors and nurses from six departments of breast surgery contributed to selection of items relevant for the target population. Quotations and domains or themes from the literature review and focus group interview were converted into items. The questionnaires were field-tested concomitantly with a clinical study investigating distress in women taking part in surgical continuity of care. In total, 1079 women filled 1, 2 or 3 questionnaires during surgical continuity of care. Many women wrote quotes in the questionnaires to complement their answers and some commented on the items. All quotations were included in the assessment of completeness and appropriateness of content. Also, an interview

study with 12 women who had participated in the survey was conducted. Quotations from the questionnaires and the interview study were used to estimate content validation (Table 1).

## Ethics

Participants in the focus group and the pilot study were informed both orally and in writing about the study and its aim and informed consent prior to participation. In Denmark, this study does not need to be approved by an ethical committee, but ethical principles from the Helsinki Declaration were followed (World Medical Association, 2013). The study was approved by the Data Protection Agency (journal number. 2008-58-0028).

## Literature search

We searched PubMed, CINAHL and PsycINFO online databases for English and German articles to identify indicators associated with distress in surgical continuity of care. We also searched for articles concerning organisational factors corresponding to surgical continuity in care, because we assume that could impact the level of distress. We considered that the articles covered indicators of distress from a patient perspective. Because of the large variation in the terminology of distress and the often unpredictable indexing, a research librarian at Aalborg University Hospital assisted with the searches. All searches were carried out by the end of March 2012 (Fig. 1). The first author read all titles and abstracts for inclusion or exclusion of references. Criteria for inclusion were: women who had surgical treatment for breast cancer, articles concerning organisational factors related to surgical treatment and care for breast cancer. Exclusion criteria were: men with breast cancer, treatment and care related to recurrence, genetic counselling and prophylactic treatment.

The first author read all included articles and reviewed the reference lists of these articles. If a study used a questionnaire, it was assessed in order to collect well articulated questions from existing questionnaires. Furthermore, items from an American question bank were reviewed in order to use already well formulated questions (The Assessment Center Instrument Library, 2013).

## Focus group interview

We performed a focus group interview with 6 specialist nurses from the Department of Breast Surgery, Aalborg University Hospital who have extensive experience on characteristic signs and consequences of breast cancer for women taking part in surgical continuity of care. The aim of this focus group interview was to complement the indicators identified by the literature review and to verify that the identified indicators from the literature review were comprehensive and relevant. The nurses had between 2 and 21 years of experience and had worked in The Department of Breast Surgery from 2 to 7 years.

We developed a thematic guide to lead the discussion but the interview was still unstructured enough to allow for the discovery of supplementary indicators for distress. The opening question was "What do you think of when I say women with newly diagnosed breast cancer?" This was succeeded by a discussion of the nurses' experiences of women's distress from the time point when the women were diagnosed on an outpatient basis, during hospitalisation and until the women were given the final answer based on the histological examination. The group discussion was audio recorded onto a minidisc and subsequently transcribed using the transcription program Express Scribe. Data analysis was performed inspired by the content analysis of Steinar Kvale, which consists of reading the interview in its entirety, determination of meaning units and formulating of themes (Kvale and Brinkmann, 2009).

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