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

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ABSTRACT

Purpose: Women with breast cancer often experience distress. This cohort study investigated the prevalence of distress, predictors of distress, and changes in distress during surgical continuity of care for breast cancer (from diagnosis to commencement of adjuvant treatment).
Methods: The participants were 1079 women with breast cancer who were recruited between April 2013 and May 2014 from 11 breast surgery departments in Denmark. Distress was evaluated using the Distress Thermometer (DT) and predictors of distress were assessed with a self-administered questionnaire at the time of diagnosis (T1), at discharge (T2), and by the start of adjuvant treatment or follow-up (T3). Repeated measures ANOVA, simple and multiple linear regression, and mixed effects regression models were used to identify predictors and estimate changes in distress.
Results: At T1, 249 (24.3%) women reported no or minimal distress, 298 (29.1%) moderate distress, and 407 (39.8%) severe distress. The mean distress was 5.5 points on the DT, which decreased by 0.70 (95% confidence interval (CI) −0.80, −0.54) points from T1 to T3. Predictors of distress were time since diagnosis, age, prior or concurrent intake of antidepressants or sedative medicine, prior emotional status, children living at home, feelings regarding femininity and attractiveness, and hospital.
Conclusions: More than two-thirds of women with breast cancer experienced moderate or severe distress. Mean distress decreased slightly during surgical continuity of care. However, for some women, distress remained unchanged or even worsened. These findings highlight the need to identify the individual women with distress and offer them adequate support and care.

1. Introduction

Breast cancer is the most common cancer among women, with an estimated 1.67 million new cases reported in 2012, corresponding to 25% of all cancers worldwide. Breast cancer ranks as the fifth-leading cause of death from cancer overall, and caused 522,000 deaths in 2012 (Ferlay et al., 2013). In Denmark the 5-year, age-standardized, survival rate for breast cancer has increased from 76% [95% confidence interval (CI): 75, 77] in 1998–85% (95% CI: 84, 86) in 2013 (Engholm et al., 2015) which is likely attributable to screening programmes and new treatment modalities.

Despite a good prognosis, up to 77% of women suffer from significant distress during the cancer trajectory (Hegel et al., 2006; Mertz et al., 2012; Ploos van Amstel et al., 2013; Sheppard et al., 2014; Stafford et al., 2013). In the oncological context, distress is recognized as a broad concept that can range from common feelings of vulnerability, sadness, and fear to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (Holland et al., 2013).

Fear of dying and the distinct changes in physical appearance resulting from treatment are common causes of distress in breast cancer patients (Remmers et al., 2010; White, 2000). Initial distress can be extreme and persistent, and may lead to clinically significant psychiatric disorders, such as major depression (Hegel et al., 2006). Moreover, up to 65% of women with breast cancer indicate that

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their supportive needs are not adequately met, potentially exacerbating their distress (McGarry et al., 2013). Failure to detect and treat severe distress may limit the outcome of cancer therapy, negatively affect the quality of life, and ultimately cause an increase in costs to health care systems (Snowden et al., 2011). Therefore, timely recognition and treatment of distress is essential.

For all types of breast cancer surgery, the length of hospital stay has decreased (Marla et al., 2013). As a result, there is also a reduction in the available direct medical surveillance period. The reduction in length of stay and an increased standardization of care (Holen and Ahrenkiel, 2011) increase the risk that distress will remain unnoticed and untreated in women taking part in surgical continuity of care for breast cancer. Worldwide, the surgical treatment regimens for breast cancer are similar, whereas the surgical continuity of care differs with regard to length, number of visits, and whether the patients are hospitalised. In Danish hospitals, surgical continuity of care for breast cancer extends from the time of diagnosis to the start of adjuvant treatment or follow-up, corresponding to 6–8 weeks. The surgical continuity of care encompasses outpatient visits and often hospitalisation in relation to breast cancer surgery, although surgery is being increasingly performed on an outpatient basis. In most Danish hospitals treating women with breast cancer, continuity of care has been a priority, as well as nursing care, which is primarily conducted by specialist nurses. However, in recent years, this has changed due to hospital budget cuts.

The existence of distress in the overall cancer trajectory is well documented in terms of anxiety (Budden et al., 2014; Vahdaninia et al., 2010), depression (Fann et al., 2008), fear of recurrence (Dunn et al., 2015; Oxlad et al., 2008), and fatigue (Kjaer et al., 2011; McGarry et al., 2013). However, little is known about the occurrence and evolution of distress during surgical continuity of care. Hegel et al. (2006) found that 41% of women with breast cancer rated themselves as being distressed prior to having surgery, while Agarwal et al. (2013) demonstrated that the likelihood of reporting distress was highest within the first 30 days after receiving a diagnosis of breast cancer. A Danish study found that 77% of women were distressed at the time of diagnosis with breast cancer with the most frequent factors associated with distress being worry, nervousness, sleep disturbance, fatigue, sadness, fear, and memory or concentration problems (Mertz et al., 2012).

Despite these important findings, there is still a lack of information to assist clinicians in identifying the patients are greatest risk for distress. To begin to answer this question and extend the research in this important area, this study aimed i) to determine the prevalence of distress in women at the time of diagnosis of breast cancer, ii) to measure changes in distress during surgical continuity of care for breast cancer, and iii) to identify predictors of distress.

2. Methods

2.1. Study design and participants

Participants for this cohort study were recruited from April 2013 through May 2014 from 11 departments of breast surgery in Denmark. Eligible participants were women with newly diagnosed breast cancer who required surgery. No other criteria were required. The women were invited by a nurse to participate in the study at the time that they received their breast cancer diagnosis. All women were given study information verbally and in writing, and gave informed consent before participating. A telephone number and an email address were offered as a means for participants to ask any further questions they had regarding the study.

The nurses in the participating departments registered 1504 eligible individuals, 139 of which declined to participate and 249 of which were excluded by the nurses due to being too distressed, anxious and/or depressed, already participating in other projects, or having diminished mental resources. In 37 additional cases, the nurses did not have the time to provide information about the study and distribute the questionnaire, or they forgot to distribute the questionnaire(s). Three questionnaires were provided to each patient at different times over the course of their treatment. Questionnaire I was distributed at time of diagnosis (T1), questionnaire II at discharge (T2), and questionnaire III at the outpatient visit for test results based on pathology (T3). In total, 1079 women consented to participate in the study, of which 757 (70%) completed all three questionnaires, 110 (10%) completed questionnaires I and II only, and 54 (5%) completed questionnaires I and III only. Furthermore, 103 (9%) women completed only questionnaire I, 18 (1.6%) women completed only questionnaire II, and 21 (1.9%) women completed only questionnaire III. The mean age of the 1079 women was 60 years (standard deviation (SD) 10.75, range 38–89 years). The study was approved by the Data Protection Agency (journal number 2008-58-0028).

2.2. The distress thermometer and the questionnaires

Participant distress was assessed using the Distress Thermometer (DT) at T1, T2, and T3. The DT is a visual numerical scale from 0 to 10, where '0' represents no distress and '10' represents the highest level of distress. As there is no universal accepted threshold value for distress on the DT, the selection of the threshold depends on the purpose of the procedure. In general, higher thresholds minimize the risk of false positive results, and lower thresholds minimize the risk of false negatives. We categorized the levels of distress as no or minimal distress (DT score 0–3), moderate distress (DT score 4–6), and severe distress (DT score 7–10). The participants also completed a self-administered questionnaire, accompanying the DT, to assess their indicators of distress (Jorgensen et al., 2015). The questionnaire was specific to the three time points, but shared a core of statements divided into seven subscales: emotional situation (24 items; e.g. *I am afraid of the future*), physical situation (9 items; e.g. *I have trouble sleeping at night*), social condition (10 items; e.g. *I worry about my future work situation*), sexuality (3 items; e.g. *I feel sexual attractive*), body image (6 items; e.g. *I am satisfied with my body image*, *when I am dressed*), religion (1 item; *I have a religious or spiritual faith that helps me in my situation with breast cancer*), and organisational factors (5 items; e.g. *I have a contact person*). In addition to these core statements, each questionnaire contained specific statements reflecting the time point of surgical continuity of care. For example, the T2 questionnaire included *"I felt safe at discharge"*, and the T3 questionnaire included *"Because of cancer cells in my lymph nodes I had all lymph nodes removed"*. The content of the questionnaires was validated in an earlier study (Jorgensen et al., 2015). Most items were rated on an ordered categorical scale: to a great extent, to some extent, to a minor extent, and not at all. A few items were measured on a binominal scale (yes or no). The three questionnaires were distributed separately at each measurement point. An envelope was handed out together with each questionnaire and the participants were encouraged to hand in each questionnaire at the next visit to the hospital. Moreover, a pre-stamped envelope was provided for the return of the questionnaire at T3, because the participants would not necessarily be returning to the hospital.

If a participant had completed and returned the first two questionnaires, but had not returned the third within two weeks, the first author (LJ) called them to ask if they had received the third questionnaire at the hospital. If not, a questionnaire including a pre-stamped envelope was sent to them. If they had received the questionnaire at the hospital, they were encouraged to complete it.