European Journal of Oncology Nursing 17 (2013) 22–29

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Factors associated with supportive care needs of patients under treatment for breast cancer

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Keywords:
Breast cancer
Needs
Psychosocial
Distress
Anxiety
Support
Interpersonal relationship
Symptom perception
Symptom management

ABSTRACT

Purpose: This study aimed at gaining insight into supportive care needs and cancer treatment-related symptoms, and to determine factors associated with supportive care needs.
Breast cancer and its treatment cause emotional trauma and health complaints. These lead to supportive care needs in some patients, while others are more able to cope with these consequences themselves. To be able to address these needs, it is important to identify patients' needs at the time they arise.
Methods: Women ($n = 175$) with newly-diagnosed breast cancer, under treatment in two Swiss breast cancer clinics, participated in a cross-sectional survey. Standardized instruments were used: Supportive Care Needs Survey, Cancer- and Cancer Treatment-related Symptom Scale, Hospital Anxiety and Depression Scale, Distress Thermometer, and Interpersonal Relationship Inventory.
Results: The patients' most needed help with psychological issues. Many had treatment-related symptoms like fatigue (87.7%), hot flashes (71.5%), and a changed body appearance (55.8%). The majority suffered from distress (56.2%), fewer from anxiety (24.1%) and depression (12.1%). Physical and social impairment, impaired body image, distress, anxiety and depression, a lack of social support and conflicts in their personal relationships were associated with supportive care needs.
Conclusions: The findings can help to identify more vulnerable patients with unmet needs and a higher demand for support. Assessment of patients enables health care professionals to provide support and counselling. In these assessments, the patients' relationship to close relatives should also be addressed.

Introduction

A diagnosis of breast cancer frequently causes patients an emotional trauma which is reflected in increased feelings of vulnerability, loss of control and uncertainty (Arman et al., 2002; Schmid-Büchi et al., 2005). Patients experience stress and loss of energy. Cancer treatments such as surgery, chemo-/radio- and hormonal therapy may lead to a large number of health complaints and endocrine symptoms (Hoskins, 1997; Wengstrom et al., 2000; Hunter et al., 2004). Patients need psychosocial support from close relatives and from health care professionals in order to manage the challenges of everyday life and complete an effective adjustment process (Landmark et al., 2008). To provide the best possible support, the experiences and needs of breast cancer patients must be understood. Equally important is to know more about factors that may influence the patients' needs. This knowledge may help to specify assessments and the real demand for support.

Background

Results from scientific research on the adjustment and recovery process during and shortly after treatment for breast cancer are ambiguous. Schou et al. (2005) reported that women with breast

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doi:10.1016/j.ejon.2012.02.003

cancer scored significantly lower on emotional-, cognitive- and social functioning than the general female population, even up to one year after surgery. On the other hand, DiSipio et al. (2008) found that the patients' quality of life was comparable to the general female population, with the exception that younger patients perceived reduced emotional well-being. In a lot of research on the consequences and on the outcome of breast cancer treatment, the patient's quality of life provides meaningful information, but used alone may not adequately assess persistent symptoms (Ganz, 2000; Ganz et al., 2004; Mols et al., 2005; Cleeland, 2007). The specific measurement of symptoms is more indicative and more important, because symptoms impose a significant burden upon the patient and frequently lead to specific care needs (Burkett and Cleeland, 2007; Henry et al., 2008). Fatigue, perceived cognitive impairment and mood problems were three symptom clusters identified by Bender et al. (2005) for breast cancer patients across different phases of the disease.

The patients' ability to successfully adapt to their diagnosis and treatment depends not only on their body's physical response but also on their emotional well-being (Bertero and Chamberlain Wilmoth, 2007). Patients may suffer from psychological distress, even in an early stage of breast cancer with a relatively good prognosis (Bleiker et al., 2000). Physical and psychological adjustment to breast cancer is not the same for all women. Some women steadily improved with time, whereas others show marked deteriorations in functioning (Helgeson et al., 2004).

Due to considerable individual variability in the reaction of breast cancer patients to their illness and treatment, we do not know enough about why some patients have supportive care needs while others have no needs and why some women have unsatisfied needs. Identifying patients with unsatisfied needs in an early stage of their treatment provides the opportunity to address these needs and enhance the quality of care (Bonevski et al., 2000; Wen and Gustafson, 2004). Therefore, factors predicting patients' needs have to be identified. Unsatisfied needs and patients' symptom burden have a significant impact on patients' well-being during treatment and also on their long-term adjustment (Holmes and Warelow, 1997; Wen and Gustafson, 2004; Janz et al., 2007). Generally, it seems that the greatest change in adjustment occurs within a 4–13 month period after diagnosis (Helgeson et al., 2004). Emotional distress and problem-solving within 3–7 months following diagnosis significantly predict long-term emotional distress (Lebel et al., 2008). For that reason, professional support and counselling may be required and should begin as soon as possible. It is therefore clinically of prime importance to assess the patients' needs.

Need assessment allows a direct measure of the discrepancy between the patients' experiences and expectations and their own perception of their need for help (Bonevski et al., 2000). If a need has been identified, action is recognised as desirable. Inaction may result in dissatisfaction and persistence of the need (Holmes and Warelow, 1997). Needs assessment helps clinicians to focus their care very early on those issues considered most important by patients (Wen and Gustafson, 2004). Need assessment in oncology should include a direct and comprehensive assessment of the multidimensional impact of cancer on the lives of patients and address important domains of physical, functional, emotional, social and spiritual well-being as well as practical needs (Ferrell and Hassey Dow, 1997; Bonevski et al., 2000; Soothill et al., 2001). Psychological and needs of physical daily living domains were the most frequently reported unmet needs in scientific research findings of cancer patients, followed by needs for health information and access to health care and support (Sanson-Fisher et al., 2000; Soothill et al., 2001; Harrison et al., 2009; White et al., 2012; Butow et al., 2012). In the review by Butow et al. (2012) rural patients appeared to have higher needs than urban patients in the domains of physical daily living and less access to resources due to the fact of long distances to the health care centres. Harrison et al. (2009) found in their review that spiritual needs and those within, communication and sexuality were the least frequently investigated. Further, the prevalence of needs appeared highest and had the largest variation during the treatment phase than in any other time point of the cancer illness.

Close relatives are the most important source of support for patients with breast cancer (Raupach and Hiller, 2002; Marlow et al., 2003; Schmid-Büchi et al., 2005). Several studies demonstrate that the patients' perception of the close relatives' emotional involvement and supportive or unsupportive behaviour may influence their adjustment and recovery process (Figueiredo et al., 2004; Manne et al., 2005; Wimberly et al., 2005; Romero et al., 2008). Patients with more social support report better quality of life, while lack of social support is a risk factor for decreased psychological adjustment (Pistrang and Barker, 1995; Northouse et al., 2002). The perception of distress or the ability to discuss problems may affect the satisfaction with a relationship (Mesters et al., 1997; Manne et al., 2006). The experience with breast cancer may strengthen the patients' relationships, but research also showed that previously strong caring relationships suffered negative changes and pre-existing relationship problems may intensify (Holmberg et al., 2001). Tilden et al. (1994) found that existing measurements often only measure the network structures and perceived support. But in Tilden's opinion, reciprocity and conflict are part of human relationships, too (Tilden et al., 1994). Therefore, we should know more about the relationship issues of breast cancer patients and which aspects of relationship are important and how they are related to the patients' needs.

There is a need to identify factors which may identify breast cancer patients early on who, while under treatment, are more vulnerable and have greater unsatisfied psychosocial needs, and therefore a higher demand for support and counselling.

Aim

The aim of the study was to gain insight into patients' cancer treatment-related symptoms and supportive care needs, and to determine factors associated with supportive care needs.

Methods

Research design

Breast cancer patients from two hospitals in the Zurich area of Switzerland were consecutively recruited for a cross-sectional survey in the breast cancer centre during the time they received cancer treatment.

Sampling and research procedure

For this study, for a convenience sample of the two hospitals between October 2005 and February 2007, we consecutively approached all breast cancer patients who underwent cancer treatment such as chemotherapy and/or radiotherapy within 1–12 months (mean 4.2 months) after the breast cancer diagnosis. Nurses of the two hospitals contacted the patients and explained the study. Patients were eligible for participation if they signed the informed consent, were at least 18 years of age and were able to understand German. The study was explained to 279 potential participators. A total of 175 patients signed the informed consent and completed the questionnaire (response rate 62.7%). Reasons not to participate in the survey were: some patients decided not to