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Psychosocial problems and needs of posttreatment patients with breast cancer and their relatives

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ABSTRACT

Purpose: The study assessed and compared the psychosocial needs of patients with breast cancer and of their relatives, the patients' and relatives' burden of illness, anxiety, depression and distress and assessed the patients' cancer treatment-related symptoms and identified relevant factors influencing patients' and relatives' needs.

Method: Seventy-two patients ($n = 72$) participated with a relative in a cross-sectional mail-survey, 1–22 months after cancer treatment.

Results: The patients reported needing help with psychological and sexual issues. They suffered from treatment-related symptoms. More treatment-related symptoms and depression were related to the patients' needs for supportive care. Their relatives' needs primarily concerned access to information and communication with health care professionals. Relatives had higher levels of anxiety (25.0% vs. 22.2%), depression (12.5% vs. 8.3%) and distress (40% vs. 34%) than patients. Higher levels of depression, younger age and having a disease themselves were associated with relatives' need for help.

Conclusion: Patients' and relatives' substantial needs and psychological problems require professional support even after completion of the patients' treatment. Continued assessment of the patients' and their relatives' needs and of the patients' symptoms provide the basis for purposeful counselling and education. Rehabilitation programs for patients and their relatives should be developed and implemented in clinical practice.

Introduction

Diagnosis and treatment of breast cancer are stressful events (Arman et al., 2002) and may result in a wide range of physical, psychological, and social effects that may influence the patient's needs (Boehmke and Dickerson, 2006; Kissane et al., 1998; McPhail and Smith, 2000; McPhail and Wilson, 2000; Schmid-Büchi et al., 2005; Shimozuma et al., 1999). Breast cancer not only causes substantial distress to the women themselves (Bleiker et al., 2000; McIllmurray et al., 2001) but also to their relatives who experience problems that may influence their needs (Hilton et al., 2000; Samms, 1999). However, little is known about how the relatives of breast cancer patients overcome cancer-related problems. What we know about their problems mainly comes from qualitative, descriptive research. These findings indicate that relatives experience fear, a sense of powerlessness, exhaustion, shock, disbelief and anger, sometimes resulting in depression. It is hard for them to see their partner suffering from cancer and cancer treatment (Hilton et al., 2000; Lethborg et al., 2003; Lindholm et al., 2002). They frequently place themselves in the role of "caregiver" and try to take control of the situation. But they often feel uninformed and unprepared to cope with this life crisis (Hilton et al., 2000; Kilpatrick et al., 1998; Lethborg et al., 2003; Samms, 1999). Relatives may perceive an ongoing burden of managing their own emotions whilst supporting the patient and the family (Hodgkinson et al., 2007a,c; Lewis et al., 2008). However, we do not know if they have the same needs for help as the patients.

Cancer survivorship is an ongoing challenge, both for patients and their relatives. After treatment, patients and their relatives do not return to a pre-cancer diagnosis state. They still have specific and unique needs (Hodgkinson et al., 2007c). Breast cancer patients ($n = 1051$) in the study of Hoybye et al. (2008)

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suffered from cancer or cancer treatment-related late effects before they started a rehabilitation program. Many of these patients suffered from fatigue (66%), lack of concentration (46%) and joint or muscle pains (49%), less from digestive (18%) and urinary problems (11%). Particularly endocrine symptoms may have a substantial impact on quality of life, mainly if the patients receive adjuvant systemic treatment for breast cancer (Ribi et al., 2007). Fear of the future and the threat of cancer recurrence resulting in a shortened life are stressful concerns for the patients even years after diagnosis (Lebel et al., 2007; McPhail and Smith, 2000; McPhail and Wilson, 2000).

Understanding the full impact of breast cancer on patients and their relatives is indispensable and clinically of prime importance in assessing the met and unmet needs of both groups. Need assessment is a direct measure of the divergence between the patients' or relatives' experiences and expectations (Soothill et al., 2001) and helps clinicians in focusing their care on those issues considered most relevant by patients and significant others (Rankin et al., 2000; Wen and Gustafson, 2004). Evaluation of the real demand for help and support even after the patients' cancer treatment may guide care planning, counselling and education of the women and their relatives (Bonevski et al., 2000; Sanson-Fisher et al., 2000; Sheppard, 2007; Wen and Gustafson, 2004).

To summarize, there remains a lack of knowledge concerning the relatives' specific needs and whether they have the same needs for help as the patients. Breast cancer causes emotional problems in both the patients and their relatives. The patients' cancer treatment may impose a burden. However, we do not know enough about how these problems may influence the needs of the patients and their relatives.

Aim of the study

Therefore, the aim of this study was to assess and compare: (1) the met and unmet psychosocial needs of patients and of their relatives; (2) the patients' and relatives' burden of illness, anxiety, depression and distress; (3) to assess the patients' cancer and cancer treatment-related symptoms after medical treatment; and (4) to identify relevant factors influencing patients' and relatives' needs.

Methods

Research strategy and context

For this study, we approached all breast cancer patients in two hospitals in Switzerland, Zurich area who, following the diagnosis, underwent subsequent cancer treatments such as surgery, chemotherapy and/or radiotherapy, who were within 1–24 months after completion of these treatments and who were not undergoing another cancer treatment during this period (except endocrine treatment).

The potential study participants ($n = 485$) listed in the databases of the two hospitals were invited by mail to participate in the study, under the condition that they had no advanced cancer and cancer treatment. They were also requested to invite an adult relative to participate. They received the study documentation and the questionnaires for themselves and their relatives. A relative was defined as a close person (connected by blood or affinity), who was emotionally involved with the patient and identified by the patient as her primary source of emotional and physical support (adapted from Northouse et al., 2002 and Hilton et al., 2000). Relatives decided independent of the patient whether or not to participate.

Research design and recruitment strategy

Patients and their relatives were recruited by mail for a cross-sectional survey. A cross-sectional design is appropriate to describe relationships among phenomena at a fixed point in time and when a theoretical framework is guiding the analysis (Polit and Hungler, 1999). This study was based on a prior qualitative study and a literature review which provided a tentative model (Schmid-Büchi et al., 2005, 2008).

Not all patients who received their cancer treatment in one of the two hospitals also returned there for their clinical follow-up medical cancer care. Many consulted their private oncologist for the follow-ups. As a result, a face-to-face recruitment would hardly have been possible, and therefore the necessary information was gained from the databases of the two hospitals. For this study, 485 questionnaires were mailed, of which 15 were returned to the sender and 22 patients had died in the meantime. After 3 weeks, a written reminder (including questionnaires) was sent to non-responders. Reasons for patients and relatives not to participate in the survey were language problems (not reading/speaking German) ($n = 11$). Some patients or relatives sent back an incomplete ($n = 10$) or a blank questionnaire ($n = 19$) and eight patients had advanced cancer and cancer treatment and were therefore not eligible for the sample. The other potential participants did not respond, some of them because of advanced cancer. The final survey sample included 128 patients (overall response rate of 28.6%; $n = 448$) and 78 relatives, 72 were pairs. The response rate for pairs was 56.25%. For this paper we analyzed the data of the 72 pairs.

Ethical considerations

The study complies with the principles laid down in the Declaration of Helsinki (1964) and in the current version. Patients and relatives who participated in the study gave their informed consent. Ethics approval was obtained from the Institutional Review Board of the Canton of Zurich, Switzerland (No: 05/18.11.2004).

Measures and instruments

German versions of self-reported instruments were used in the Supportive Care Needs Survey (SCNS-SF34), Cancer and Cancer Treatment-related Symptom Scale (CTSS) for patients, the Psychosocial Need Inventory (PNI) for relatives, and the Hospital Anxiety and Depression Scale (HADS), the Distress-Thermometer (DT) and the Pictorial Representation of Illness and Self-Measure (PRISM) for patients and relatives. To confirm the accuracy of the German versions of the SCNS-SF34, CTSS and PNI, factor analyses were conducted with data of the current study, and from a second study in which patients under treatment for breast cancer ($n = 176$) and their relatives ($n = 104$) were measured with the same instruments as in this study (paper submitted).

Supportive Care Needs Survey (SCNS-SF34) (Bonevski et al., 2000)

Patients' needs were measured with the German version of the SCNS (Holdener-Mascheroni, 2003). The SCNS contains 34 items designed to measure patients' perceived needs in five core domains: psychological (10 items), health system and information (11 items), physical and daily living (five items), patient care and support (five items) and sexuality (three items) (Sanson-Fisher et al., 2000). The patients indicated their level of need for help in the last month on a five-point scale, scoring from no need, low, moderate, and high need; and a not applicable/satisfied category. For this investigation, a sixth domain was added with four items