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Needs of relatives of breast cancer patients – The perspectives of families and nurses

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ABSTRACT

Purpose: Breast cancer is not only a stressful event for those afflicted, but also for their family and friends. In Germany, attention and support from professional nurses is almost exclusively given to the patient. But even relatives require information and support in order to keep their anxiety levels low and strength up. The aim of this study is to survey those needs and the current level of satisfaction, as well as to ascertain which needs are perceived by nurses.
Method: Data were collected in a German-wide descriptive cross-sectional study surveying 242 relatives and 356 nurses from 150 randomly chosen certified breast care centers between August 2008 and February 2009. Two questionnaires developed for this study were used.
Results: The findings indicate that relatives need above all a) security and trust, followed by b) partnership of care and c) emotional support. Regarding satisfaction, relatives consider the need for "security and trust" to be most satisfied. Least fulfilled were those for "partnership of care" and "emotional support". The nurses regarded the importance of most of the relatives' needs to be higher than the relatives themselves. Even the fulfillment of needs was over-estimated.
Conclusions: The targeted and professional involvement of relatives in the care of breast cancer patients is still not common practice. An initial step toward better family nursing is viewing families as an integral part of the patient and intentionally planning contact.

Introduction

Cancer not only affects those with the disease; illness is always a family affair (Wright and Leahey, 2009). Viewed as a system, family members represent various elements in relationship to each other. When in balance this system means predictability, security and a sense of belonging to its members. The life-threatening illness of a family member, for instance breast cancer, can have such an impact on this balance that it leads to destabilization and loss of security and orientation for all members of this family system.

Reactions of relatives to a family member having cancer vary. Most often, the patient's partner carries a greater mental burden than the patient themselves (Hasson-Ohayon et al., 2009; Molassiotis et al., 2010). They are confronted with demands brought on by the illness, such as increased emotional support for the ill partner, the rearrangement of life's plans as well as taking on new tasks or roles within the family (Fletcher et al., 2009). The stresses and strains which relatives of cancer patients are subject to are shown in an extensive literature analysis from Stenberg et al. (2009). This cites that relatives not only suffer from mental burdens such as fear, depression, insecurity, helplessness and hopelessness, but also social burdens such as financial difficulties, problems with work and education, role problems and isolation. These burdens often manifest themselves in the form of physical complaints such as head and backache, sleeping disorders and fatigue, as well as loss of appetite and a decline in physical strength (Stenberg et al., 2009).

Partners, relatives of the family and close friends are not only co-sufferers, but also the major source of support for cancer patients (Arora et al., 2007; Hasson-Ohayon et al., 2009). They offer emotional stability and help get through the treatment and daily life. Their partners' emotional support is of great significance to women with breast cancer because it shields them from enormous mental suffering. This feeling of support not only helps reduce mental stress, but also boosts the womens' quality of life and self confidence (Arora et al., 2007).

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In order to offer this support, relatives need assistance, too. An overview of the needs of relatives of women afflicted with breast cancer is available in a literature analysis of English- language studies prepared by Schmid-Büchi et al. (2008). According to this analysis, the partners of these female patients need primarily emotional support in order to protect themselves from their own burden and to return to a "normal" life. Further, they need to be informed, in order to participate in decision-making processes and to support their partners in the best possible way. A survey by Rees and Bath (2000) came to the conclusion that relatives' need for information is, however, not always fulfilled by healthcare professionals.

The partners of breast cancer patients often put their own needs behind those of the patient (Hilton et al., 2000). For this reason, it should be no surprise that the psychosocial needs of relatives of cancer patients are barely satisfied (Tunin et al., 2010). That is even more significant, when one considers that family members whose needs remain unfulfilled display a greater decline in mental health (Kim et al., 2010), which in turn reduces their ability to give support.

Despite these findings and the insistence on family-oriented healthcare by the WHO (1999), nursing care in German hospitals almost always caters exclusively to the patient. Targeted support of relatives rarely occurs (Holtgräwe et al., 2007). When asked for reasons why the interaction with relatives is so difficult, nurses mention structural obstacles such as lack of time or the severity of illness of the patient (Åstedt-Kurki et al., 2001). However, personal inhibitions play a role as well. In one particular survey, only a third of the nurses questioned felt properly trained to meet the psychosocial needs of relatives. In particular, the nurses felt that the contact with suffering relatives was an emotional burden (Hallgrimsdottir, 2000).

The number of international studies dealing with the needs of relatives of cancer patients has risen in the last few years. However, there is still a lack of scientific investigation into the situation for relatives in Germany. Therefore, the aim of this study is to (1) ascertain the self-assessed wishes and needs of the relatives of breast cancer patients. Further, (2) an external assessment of the relatives' needs, from a nurse's standpoint, is carried out. The nurses' perspectives should give an impression of which needs of relatives they perceive and which barriers, inhibitions, burdens, etc, possibly prevent more intensive and helpful contact between nurses and relatives. Finally, (3) a comparison of the relatives' self-assessment to the external assessment by nurses is made, in order to expose possible discrepancies. The study should contribute to improving family-oriented care for women with breast cancer.

Methodology

Research was carried out as a descriptive cross-sectional study. Data collection took place between August 2008 and February 2009, in which convenience sampling from relatives and nurses was carried out in certified breast care centers in Germany.

Subjects

In order to recruit nurses as well as relatives, 150 breast care centers were chosen throughout Germany. Selection of the breast care centers took place with the help of the statistical analysis software SPSS, in which all 281 certified breast care centers at the time of the investigation (2008) were assigned random numbers. Arranged in ascending order, the breast care centers in the first 150 positions were included in the study. Relatives and nurses were recruited from these centers. Randomization was applied to reduce systematic bias.

Procedure

In recruiting, the directors of nursing of the breast care centers each received ten sets of questionnaires. A set of questionnaires was comprised of separate parts for nurses and relatives. Each nurse and relative received an information sheet requesting participation and assuring anonymity and voluntariness, a questionnaire with instructions for completion and a postage-paid envelope addressed to the research group. In a letter, the director of nursing was requested, when possible, to distribute the ten sets of questionnaires to the nurses who were employed in the breast care centers, and to ask for their participation.

On the information sheet, the nurses were asked to do two things: 1. complete the nursing questionnaire themselves and send it back and 2. Pass on the questionnaire set for the relatives to a breast cancer patient. There was no restriction on patients in a certain stage of disease. These patients should have passed on the questionnaire to a relative themselves. Assuming that today's women do not limit the definition of family members to husbands and children, those persons whom the patient herself found to be relatives were included in this investigation. Inclusion criteria were that the relatives should have visited the patient at least once in hospital and should be at least 18 years of age.

Ethical considerations and data protection

Both the nurses and the relatives were assured in written form of the voluntariness of participation and anonymity. The postage-paid sending of the completed questionnaires directly to the research team, without a return address, preserved anonymity for both groups. The study was submitted to and approved by the ethics committee of the University of Osnabrueck.

Instruments

In surveying the needs of relatives, two proven instruments which have been repeatedly employed in nursing scientific investigations were modified and used (Bijttebier et al., 2000; Maxwell et al., 2007; Redley and Beanland, 2004).

The (1) Critical Care Family Needs Inventory (CCFNI) (Leske, 1991), based on a literature review, was developed to survey the needs of family members. The original instrument contains 45 items, with which the *importance* of needs can be assessed using a four-point Likert scale as follows: 1 = not important, 2 = slightly important; 3 = important; 4 = very important. The internal consistency of the CCFNI (Cronbach's alpha: .88 to .98) can be regarded as satisfactory to good. The retest reliability and the construct validity were also checked and considered good.

The (2) Needs Met Inventory (NMI) (Warren, 1993) was developed on the basis of the CCFNI and includes the same 45 items. However, the NMI surveys the degree of *fulfillment* of needs. Likewise, the answers are arranged on a four-point Likert scale: 1 = never met; 2 = sometimes met; 3 = usually met; 4 = always met. However, there are no psychometric data for this instrument.

As both instruments survey the needs of family members in the hospital setting, but are aimed at relatives of intensive care patients, it was necessary to adapt the questionnaire to the context of the investigation. For this purpose, the instruments were translated into the German language and the items were checked for suitability of content by the research team. In doing so, two aspects were taken into consideration: 1) whether the needs are relevant to relatives of breast cancer patients and 2) whether fulfilling these needs correlates with the professional tasks of nurses in Germany. Items not relating to these aspects were omitted. The questionnaire was supplemented with items taken from qualitative