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Family caregivers of women with breast cancer in Iran report high psychological impact six months after diagnosis

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ABSTRACT

Purpose: To explore how family caregivers of women with breast cancer in Iran describe the areas in life which are important to their quality of life (QoL), and to determine which areas in life that are influenced by having a family member with breast cancer.
Methods: The study is descriptive and prospective. A total of 88 family caregivers of women newly diagnosed with breast cancer were interviewed using the Schedule for the Evaluation of Individual Quality of Life (SEIQoL-DW) at a time close to diagnosis and then again at 6 months after. Interviews were analyzed by manifest inductive qualitative content analysis.
Results: Areas related to the categories *Own and Family health*, and *Relationships* were considered to be the most important to QoL. A majority of the family caregivers reported that concerns categorised as *Psychological impact* had high influence on QoL shortly after diagnosis and the following six months. Other areas that were frequently mentioned at both time points were categorized as *Focus on family health*, *Concerns about the disease*, and *Change in family relationship*. Positive aspects in life were also reported as a consequence to the breast cancer diagnosis.
Conclusions: High psychological impact is a concern of family caregivers six months after diagnosis of breast cancer. It is imperative that family caregivers are given early attention, and the opportunity to express their perceptions and needs, as this may lead to a better understanding of their experience, thus providing guidance for supportive interventions.

Introduction

Family caregivers provide care that can be physically, emotionally, socially, and financially demanding and might result in a neglect of their own needs (Schubart et al., 2008). Studies show that family caregivers of breast cancer patients report a significant decline in quality of life (QoL) during the time of disease and treatment (Awadalla et al., 2007; Grunfeld et al., 2004; Wagner, 2004; Zahlis and Lewis, 2010). Moreover, the experience of distress in family caregivers of patients with cancer may have a negative effect on their ability to care for and give support (Weitzner et al., 1999). In Iran, the most common primary female cancer is breast cancer (Mousavi et al., 2009) with a mortality rate of 2.7 per 100, 000 inhabitants (Mousavi et al., 2008). Over time, the incidence rate of breast cancer has increased (Mousavi et al., 2009), but improvements in early detection together with advanced and individualized treatments have led to a marked decline in mortality (Shulman et al., 2010). Similar to the trends in the Western countries, Iranian patients are experiencing a shift from institutional care to home care putting more demand on the whole family. Another change in recent years in the Iranian society is the change in family structure from being traditionally extended to nuclear. Furthermore, in the population there are increases in age at marriage, age of parents at the time of having their first born child and in the numbers of unmarried men and women (Abbasi-Shavazi et al., 2009). Nowadays, Iranian women have a higher level of education and employment rates and more often contribute to family income. In addition, there is an increase among younger women, as early as in their 40s, of being diagnosed with breast cancer (Mousavi et al., 2008). Consequently, various changes of trends in society and family life may cause a negative influence to the situation of a family caregiver.

In a previous study, we used a standardized QoL instrument, the Caregiver Quality of Life Index-Cancer (CQOLC) (Weitzner et al.,

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1999), and found that around half of family caregivers of women with breast cancer in Iran showed a stable QoL, some (34%), improved their QoL and others (15%), decreased their QoL over 6 months (Khanjari et al., 2012a). These results were somewhat contradictory to the negative effects on QoL that have been reported in other studies (Awadalla et al., 2007; Grunfeld et al., 2004; Wagner, 2004; Zahlis and Lewis, 2010). The use of standardized instruments for QoL issues is often criticized as they consist of predetermined areas making it difficult to capture aspects most relevant for each individual (Calman 1984). Moreover, such instruments mostly focus on negative aspects as a consequence of illness and impairments whereas any positive aspects may be neglected. In the present study we employed the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW), which is an individualized method allowing each person to identify and determine the components of her or his QoL (Hickey et al., 1996). It has previously been applied in different populations, including: elderly people (Mountain et al., 2004), young adults (Sundberg et al., 2010), stroke patients (LeVasseur et al., 2005) patients with cancer (Wettergren et al., 2004), and caregivers of patients with amyotrophic lateral sclerosis (Olsson et al., 2010). By using an individualized method, the objective of this study was to further explore QoL in a sample of family caregivers of women with breast cancer in Iran. Specific research questions were: 1) Which areas in life are important to QoL?; and 2) Which areas in life are influenced by having a family member with breast cancer?

Methods

Design

The study is descriptive and prospective at two time points: The first, T1, was 2–3 weeks after the woman and her family caregiver were informed of a diagnosis of breast cancer; the second time point, T2, was 6 months later.

Participants

All newly diagnosed women with breast cancer were consecutively invited to be included in the study during a period of 22 months at two urban University hospitals in Tehran. The inclusion criteria were: i) being newly (2–3 weeks) diagnosed with breast cancer and ii) no previous cancer history. A hundred and seventy-five-women were eligible whereas 25 (14%) declined participation, thus not willing to give their consent for a family caregiver to be contacted regarding the study. The inclusion criteria for the family caregivers were i) being older than 18 years, ii) knowing how to read and understand Farsi, iii) no history or current psychiatric or neuropsychological disorder, and iv) no history of cancer. Twenty-one family caregivers declined participation. Thus, 129 family caregivers (86% of those contacted) consented to participate in the study. There were 41 drop-outs: 39 family caregivers who declined further participation at T2, and two individuals (one patient and one caregiver) that died during the study period. The final sample consisted of 88 family caregivers (68% of those that consented to participate) participating at both T1 and T2.

Materials

The SEIQoL-DW is an interview-based method to assess QoL (Hickey et al., 1996). In this study the Swedish extended, modified, and evaluated version of SEIQoL-DW was used (Wettergren et al., 2005). The measure generates areas of importance for quality of life which is the original generic part (SEIQoL-G), and the extended disease-related part (SEIQoL-DR), *i.e.* aspects that may be affected by the disease. In the generic part, the respondents answer an open-ended question: “If you think about your life as a whole, what are the most important things, both good and bad, in your life at present that are crucial to your quality of life?” In the disease-related part the respondents were asked, “If you think about the fact that your relative has breast cancer, what in your life is influenced, both positively and negatively, by this?” In both versions, the respondents are asked to nominate five areas. The Swedish version of the SEIQoL was translated into Farsi in line with accepted guidelines for translation and cultural adaptation (Jones et al., 2001).

Demographic data (age, marital status, occupation status, level of education, and relationship to the patient) were collected.

Procedure

During a 2-year period, newly diagnosed patients with breast cancer were approached with information about the study and asked for their consent that a main family caregiver be contacted. Subsequently, the family caregivers were informed about the study and informed consent was obtained from those willing to participate. The interviews, which lasted for 15–45 min, were performed face-to-face at T1, and for practical reasons, by phone at T2 by the first author.

The study was approved by the Iranian Ethical Board of Research in the Ministry of Health and Medical Education and the Iran University of Medical Sciences. An information letter disclosed the purpose of the study, the name of the research institute, the researchers involved in the study, confidentiality of the participants, and their right to withdraw from the study at any time.

Data analysis

During the interview, notes were taken as close to verbatim as possible, and the participants were asked to verify their statements to make sure that their intentions and feelings were fully described. Subsequently the interviews were transcribed and merged into one text document. The analysis was performed according to manifest inductive qualitative content analysis whereas words and sentences that share the same meaning are classified into smaller categories (Elo and Kyngäs, 2008). The first step of the analysis was to read the unit of analysis through several times to make sense of the data. The next step was open coding, while reading the text, notes were written and codes created describing the central characteristics of the content. The codes were then transferred to a coding sheet where similar codes were grouped together and by comparing differences and similarities numerous times, categories were created. Repeated discussions took place among the first and the third author regarding boundaries and central characteristics of each category which were then revised until a final agreement was obtained. Central characteristics of categories and categories were, after translation into English, discussed and modified together with the other two authors until a consensus was reached.

The Chi-square test was used for nominal data when comparing independent groups and the Student's unpaired *t*-test was computed for continuous data. All statistical calculations were conducted using the Statistical Package for the Social Sciences (SPSS) software (version 14.0; SPSS Inc, Chicago, Ill).

Results

Sample characteristics

Demographic characteristics of the study sample are presented in Table 1. There were no statistically significant differences

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