RESEARCH ARTICLE

Evaluation of Quality of Life of Breast Cancer Patient Next-of-kin in Turkey

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Abstract

Introduction: Quality of life (QoL) issues are of importance in relatives of women with breast cancer (BC)as caregivers in neglecting their own needs due to care of a patient and also as women regarding the potential risk of themselves developing BC. The objectives in the present study were to compare the QoL of female relatives of women in treatment for breast cancer. To date, no study had examined multi-dimensional QoL in accompanying people as compared them into two groups of female relatives whose first degree and second degree. Methods: QoL of female relatives was assessed using the Quality of Life-Family Version (QOL-FV) scale. Relationships between socio-demographic characteristics and QoL scores were analyzed using the Mann-Whitney U, Kruskal Wallis and Crosstabs tests. Results: The mean age of the female relatives was 37.6 years, and nearly 48% had a university education. It was found that first degree relatives had worse QoL in all domains except physical well-being than second degree relatives. Conclusion: This study showed that being female relatives of BC, especially first-degree, affect QoL negatively. Health care providers are of an important role in the stage of information related to genetic influence of BC.

Keywords: Breast cancer - next-of-kin - female relatives - nursing - quality of life - Turkey

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Introduction

Breast cancer is the most commonly diagnosed cancer in women worldwide, with an estimated 1.4 million new cases diagnosed in 2008 (American Cancer Society, 2011). Based on current breast cancer incidence rates, experts estimate that one in eight women can be expected to be diagnosed with breast cancer at some point in her lifetime (NCI). In addition, many women have family members, who have experienced breast cancer, are worried related to genetic predisposition is responsible for 5–10% of all breast cancer (Chompret, 2004).

A diagnosis of breast cancer overthrows women and their accompanying people into unfamiliar situations which they must cope with a cancer treatment besides economical and psychological issues that are previously foreign to them. Women faced with such an unexpected diagnosis show different reactions. Some women though understand the diagnosis logically, may be difficult to accept it as the spiritual and emotional, others feel of guilt and blame as well as anger and rebellion can be seen. These issues are natural results of the disease. And studies indicate that women's Quality of life (QoL) is affected with multidimensional areas, including emotional, physical, sexual, and social domains (Yanez et al., 2011; Chopra and Kamal, 2012).

In addition, caregivers of breast cancer patients may be affected by various stressors not only the psychological but also the physical, spiritual, and behavioral aspects (Kim and Given, 2008; Gorji et al., 2012). Previous literatures showed risk for depression, anxiety, improper sleep and diminish QoL can increase in cancer caregivers (Awadalla et al., 2007; Chang et al., 2007; Northouse et al., 2005) and also they frequently report changes in their usual activities, including household and family activities, social and community activities, personal care, and occupational activities because of caregiving responsibilities (Coristine et al., 2003; Grunfeld et al., 2004).

Clearly, cancer affects a substantial number of individual's lives; women diagnosed breast cancer and their family members as well as their female relatives. Woman's female relatives faced with such an unexpected diagnosis have dilemma. On the one hand mostly they are the primary support to the patient as women in family, on the other hand they have potential risk of breast cancer just because to be a member of the same family. As we know QoL of caregivers can be affected the physiological and psychological. However, we lack information on how this reality of having a risk affects first and second degree family members.

Despite the growing body of literature about quality of life assessment on women diagnosed breast cancer and family members as accompanying person, little information is available about the effects of breast cancer on the quality of life of breast cancer patients' female relatives as accompanying person. We aimed to clarify this issue in the present study. The goal of our study was to describe QoL in a sample of Turkish women with a

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family history of breast cancer and to investigate whether QoL differs significantly between first - degree female relatives (FDFRs: mother, sisters and daughter) and second – degree female relatives (SDFRs: aunts, nieces and nephews, and grandmothers) controlling for age, education, marital status, income, and time of diagnosis. And also we aimed with this study to attract attention that the diagnosis of breast cancer is a poignant turning point for both in the lives of women and their kin relationships particularly first and second degree female relatives.

Materials and Methods

Design

A descriptive, cross-sectional and non-experimental design was used to identify demographics and QoL of female accompanying persons of women with breast cancer.

Participants

From 01.6.2011 to 30.12.2011 two hundred sixty-five accompanying female relatives of breast cancer patients who have started or continued chemotherapy in oncology day clinic of Ege University Medical School Hospital, and Pamukkale University Medical School Hospital in two cities in western Turkey (Izmir and Denizli). Ethics approval was obtained from the Ethics Committee, and all participants gave fully informed written consent before the commencement of the study.

The study sample included 265 volunteer first degree female relatives and second degree female relatives of breast cancer patients. Women who had a prior diagnosis of cancer and younger than 18 years old were excluded. Data were collected with a Demographic Questionnaire, the Quality of Life-Family Version and the Breast Cancer Risk Assessment Tool (Okcin and Karadakovan, 2013).

Instruments

a) Demographic Questionnaire: Socio-demographic and medical data of women were collected from medical chart abstraction using structured questionnaires. For this study, several demographic and medical variables were used as potential covariates: age, race, marital status, education, number of live birth, kinship degree, history of breast disease, biopsy status, menopause situation, breastfeeding status, and perceived risk of breast cancer etc. And also the respondents were asked to evaluate their cancer risk potential by describing the perceived state: yes I have a risk, no I have not a risk or I do not know.

Table 1. Characteristics of the Women Studied

Variables	1st degree relatives (n=229)	2nd degree relatives (n=36)	P value
Mean age	38.3±13.8	33.3±12.9	0.034
Age at menarche (years)	12.8±1.43	13.2±1.36	0.189
Age at menopause (years)	N=59 47.7±5.08	N=9 44.3±7.76	0.427
Age at first live birth (years)	N=153 23.2±4.41	N=12 23.8±4.39	0.691
Duration of breastfeeding (month)	N=150 13.3± 7.93	N=12 14.5±4.52	0.505
Age at diagnosis in relatives	47.7±10.7	47.2±12.2	0.806
Time of diagnosis (month)	18.5±21.4	49.8±45.8	0.000
5-year risk	N=137 1.66±0.79	N=15 0.74±0.36	0.000
Lifetime risk	16.5±3.28	8.62±2.77	0.000
Marital status			
Single (77)	65 (84.4)	12 (15.6)	0.504
Married (155)	137 (88.4)	18 (11.6)	
Widow / divorced (33)	27 (81.8)	6 (18.2)	
Educational status			
Illiterate (12)	12 (100)		0.006
Primary (52)	18 (66.7)	9 (33.3)	
Secondary (74)	90 (90.9)	9 (9.1)	
University (127)	109 (85.8)	18 (14.2)	
Women's occupation			
Outside work (128)	104 (81.3)	24 (18.8)	0.018
Housewife (137)	125 (91.2)	12 (8.8)	
Household income			
spend < income (51)	48 (94.1)	3 (5.9)	0.115
spend = income (160)	133 (83.1)	27 (16.9)	
spend > income (54)	48 (88.9)	6 (11.1)	

b) The Quality of Life-Family Version (QoL-FV): is a thirty-seven item scale developed by Ferrell and Grant. It was adapted from the patient version QoL tool (Ferrell and Grant, 1995). The validity and reliability study for the Turkish version of the instrument was conducted by Okcin and Karadakovan (2013). It was re-adapted by Okcin for the Turkish culture and the subscales were renamed under four different groups than the original instrument and also number of items was reduced to thirty-one. According to re-adaptation names of new subscales were the conditions of psychological and spiritual well-being, physical health, the way of approach to diagnosis, and support and economic effect. The responses to the items range between 1 (worst outcome) to 10 (best outcome). Some items have reverse anchors and these are 1, 12-15, 17-28, 30, 31. The higher the score the greater the quality of life.

c) Breast Cancer Risk Assessment Tool (BCRA): It was developed by Gail and colleagues (1989) in order to determine the risk of developing breast cancer in women during the next 5 years period and lifetime. This tool only calculates risk for women 35 years of age or older.

According to the Gail model the five-year and lifetime risk of developing breast cancer of participants were calculated by filling out the "Breast Cancer Risk Assessment Tool" electronically. Tool is useful to estimate an approximate number of women with a lifetime risk of ≥20% in the general the population (Graubard et al., 2010). And an estimated 5-year breast cancer risk ≥1.67% was considered high-risk (Abu-Rustum and Herbolsheimer, 2001).

Statistical analysis

Statistical analysis was performed with SPSS 10.0 software (SPSS, Inc., Chicago, IL, USA). Continuous variables were expressed as mean ± standard deviation, categorical variables as numbers and percentages. And descriptive variables were analyzed using crosstabs. Continuous variables were compared with the Independent Sample T test or Mann–Whitney U test, one-way ANOVA or Kruskal-Wallis. A P value of less than 0.05 was

Table 2. Effects of Sociodemographic and other Variables on QoL of Female Relatives

Variables		Physical health	Psychological and spiritual well-being	Approach to diagnosis	Support and economic effect	Total
Age (n)	≤39 (163)	4.97±1.10	5.97±1.39	2.38±2.01	5.71±1.61	4.76±1.02
40-49 (55)	5.08±0.67	5.79±1.58	1.66±1.45	5.04±1.80	4.39±0.92	
≥50 (47)	5.32±1.05	4.88±2.06	3.21±1.46	5.03±2.27	4.61±1.29	
P value	0.116	0	0	0.012	0.083	
Age at diagnosis	≤39 (65)	5.42±1.14	5.71±1.51	2.32±1.90	5.01±1.84	4.62±1.19
in relative	40-49 (105)	4.99±1.05	6.01±1.39	2.53±1.95	5.75±1.81	4.82±1.10
≥50 (95)	4.89±0.83	5.47±1.86	2.26±1.78	5.42±1.72	4.51±0.90	
	P value	0.003	0.061	0.579	0.035	0.114
Marital status	Single (77)	4.81±1.31	6.43±1.40	2.61±1.70	5.92±1.70	4.94±0.80
	Married (155)	5.21±0.85	5.75±1.41	2.17±2.04	5.46±1.64	4.65±1.14
	Widow / divorced(33)	4.91±0.87	4.08±1.79	2.83±1.30	4.30±2.25	4.03±0.94
	P value	0.016	0	0.082	0	0
Education	Illiterate (12)	5.78±0.66	3.60±2.52	2.28±1.03	3.81±2.89	3.87±1.32
	Literate (126)	5.00±1.06	5.79±1.60	2.57±1.94	5.64±1.55	4.75±0.97
	High-literate(127)	5.05±0.98	5.89±1.38	2.20±1.87	5.42±1.85	4.64±1.09
	P value	0.039	0	0.279	0.003	0.022
Women's occupation	Outside work (128)	5.12±0.89	5.88±1.25	2.33±1.92	5.32±1.66	4.66±1.11
	Housewife (137)	5.00±1.13	5.61±1.88	2.43±1.84	5.57±1.92	4.65±1.01
	P value	0.345	0.164	0.669	0.269	0.921
Household income	spend < income (51)	4.52 ±0.91	5.77±2.20	2.39±1.38	5.31±1.81	4.50±1.05
	spend = income (160)	5.11±1.00	5.71±1.48	2.27±1.84	5.36±1.88	4.61±0.98
	spend > income (54)	5.41±0.99	5.80±1.34	2.68±2.33	5.85±1.51	4.94±1.25
	P value	0	0.926	0.388	0.186	0.077
Menopausal Status	Postmenopausal (68)	5.38±0.94	4.97±1.91	2.48±1.72	5.03±1.97	4.47±1.15
	Premenopausal (197)	4.94±1.02	6.01±1.40	2.34±1.93	5.59±1.73	4.72±1.02
	P value	0.002	0	0.586	0.027	0.087
A history of breast	Yes (37)	4.63±0.94	5.21±1.69	2.37±1.53	5.01±2.25	4.31±0.92
disease	No (228)	5.13±1.02	5.83±1.59	2.38±1.93	5.52±1.72	4.71±1.07
	P value	0.006	0.032	0.982	0.193	0.03
Perceived cancer risk	Yes (183)	5.20±0.97	5.98±1.63	2.23±1.88	5.53±1.64	4.74±1.05
	No (19)	4.54±0.30	4.37±1.51	3.03±1.18	4.76±1.04	4.18±0.54
	I do not know (63)	4.79±1.19	5.45±1.33	2.63±1.98	5.42±2.34	4.57±1.17
	P value	0	0	0.011	0.029	0.044
5-year risk*	Low (91)	4.95±0.86	5.54±1.34	2.05±1.38	4.98±1.29	4.38±0.83
	High (61)	5.43±0.92	5.02±1.95	2.53±1.80	5.13±2.28	4.53±1.30
	P value	0.002	0.057	0.062	0.645	0.385
Lifetime risk*	Low (142)	5.15±0.95	5.38±1.65	2.32±1.58	5.09±1.78	4.49±1.06
	High (10)	5.06±0.05	4.58±1.12	1.17±0.95	4.30±1.03	3.78±0.20
	P	0.634	0.036	0.019	0.096	0.017
Degree of kinship	1st (229)	5.03(1.04)	5.59(1.62)	2.14(1.72)	5.32(1.87)	4.52(1.02)
	2nd (36)	5.20(0.89)	6.72(1.16.)	3.92(2.09)	6.27(1.03)	5.53(0.92)
	P value	0.369	0	0	0.003	0
Time of diagnosis	≤1 year (145)	5.06±1.12	5.24±1.71	2.60±2.22	5.50±1.92	4.60±1.21
	≥1 year (114)	5.01±0.89	6.31±1.26	2.03±1.28	5.36±1.69	4.68±0.83
	P value	0.739	0	0.016	0.559	0.545

considered statistically significant for all tests. Multiple logistic regression analysis model was performed to assess the effect of independent risk factors over total QoL scores.

Results

The 265 women consisted of 229 (86.4%) first degree relatives and 36 (13.6%) second degree relatives, mean age 37.64 years. Table 1 shows that the first and second degree female relatives were well matched by age at first period, age at menopause, age at first live birth, duration of breastfeeding, and age at diagnosis in relative (P>0.05). FDFRs were significantly older than SDFRs (P<0.034). Just over half of the women were predominantly married (58.5%), mainly housewives (51.7%), and nearly 48% had up to high school education.

With regards to demographic features of the relatives; the mean age (p=0.034), time since diagnosis (p=0.001), education level and work rates of FDFRs were found significantly higher than in scores of SDFRs. We used a mathematical model (the Gail Model) for estimating individual breast cancer risk, and it was found that 44.5% of FDFRs have 5-year risk, whereas 7.3% of them have lifetime risk. There was a statistically significant associations were observed between cancer risk and kinship degree (p=0.001). No statistically significant associations were observed among age at menarche, age at menopause, age at first live birth, duration of breastfeeding, age at diagnosis in relatives, marital status and income level (p>0.005).

The quality of life scores according to demographic variables are presented in Table 2. Psychological-

Table 3. Results of Multiple Regression Analysis when Total QoL was Taken as a Dependent Variable

Variable	Standardized regression coefficient	t	p	R^2	Adjusted R Square
Educational status	0.032	0.533	0.595	0.168	0.155
Marital status	-0.226	-3.712	0.000		
Degree of kinship	0.318	5.548	0.000		
Presence of breast disease	0.047	0.810	0.419		

Quality of life = 3.843 + 0. 032 (education) + -0.226 (marital status) + 0. 318 (degree of kinship) + 0. 047 (presence of breast disease)

spiritual wellbeing and support-economic effect domains decreased, whereas approach to diagnosis scores increased with increasing age ($p< 0.05$). QoL scores of female relatives have been found to be influenced by the patients' age at diagnosis. Physical health domain of relatives, whose patient's diagnosed BC at 39 years old and before, was found higher than the other age groups ($p=0.003$), whereas support and economic effect domain was found lower than 40-49 age group ($p=0.027$).

There was a significant difference between QoL and marital status of the relatives. Singles had the lowest physical health domain ($p=0.016$) whereas had the highest psychological and spiritual well-being domain. Widow or divorced relatives had the lowest support and economic effect, and overall QoL ($p=0.001$) than single or married relatives.

There was a significant difference between education level and QoL. QoL mean scores were lower for all domains except physical well-being in illiterate relatives than literate or high-literate relatives ($p< 0.05$). There was no statistically difference between employment status and QoL ($p> 0.05$). The physical life qualities of relatives whose income is less than their expense is lower than the ones whose income is higher than expenses ($p< 0.0001$). Concerning menopausal status, postmenopausal female relatives had the highest physical well-being domain ($p=0.001$), whereas they had the lowest psychological and spiritual well-being ($p=0.000$), and support and economic effect domains ($p=0.027$).The physical ($p=0,006$), psychological ($p=0,032$) and total life qualities ($p=0,030$) of women having breast illness was found to be lower.

In terms of perceived cancer risk, the sub dimensions of life quality of the ones who thinks they carry cancer risk is higher compared with the others while their approach status to the diagnosis was found to be lower compared with the ones who think they carry no cancer risk. ($p< 0.05$).

When quality of life according to cancer risk was examined, the physical well being of women having 5 years of cancer risk was found to be high ($p=0,002$) while psychological and spiritual well-being, approach to diagnosis and total QoL domains of the women who carry high cancer risk was found to be lower. ($p< 0.05$). When kinship degree of accompanying relatives was examined in regard to QoL, QoL mean score of FDFRs in all domains except physical well-being were found significantly higher than scores of SDFRs ($p< 0.01$). Considering diagnosis periods, it was found out that the psychological and spiritual well-being of the patient relatives improved while their status of approaching to diagnosis worsened. ($p< 0.05$).

When regression analysis was made considering total quality of life as dependent variable, the F value where the general meaningfulness of regression model is tested, was calculated as 13,831 and is significant. ($p=0,000$) It was determined that being widow/divorced and being first degree relative.

Discussion

In women population, 1 in 8 women is effected negatively of being diagnosed breast cancer while a portion of the women who was not diagnosed yet are effected as they are relatives with women who are diagnosed. This effect is more in the relatives accompanying the patient who were diagnosed. In general, women show greater activity and more consistent interactions with members of generations above and below them than do men (Fischer, 1986). Therefore the care givers in Turkish community are generally the women relatives of the patients.

A first degree relative has at least a 50% and a second degree relative has a 25% genetic link to a person (Genetic education, 2005). A person's first degree female relative is a mother, daughter or sister. Mothers and daughters are often described as "linked lives" (Fischer, 1986). And as we know communication and closeness is greater between sister-sister siblings than in sister-brother or brother-brother combinations. Though research on the mother-daughter bond in a cancer context is rare, scientists have found that mothers and daughters do share the breast cancer transition physically, psychologically and socially (Fischer, 2008). Therefore, generally first degree female relative's interactions are more powerful in all aspects. In our study where we examined QoL according to relationship degree, all aspects of life quality except physical health (FDFRs) were found to be lower. If we generally assume that the physical health of the accompanying people are good, it is possible that the life quality being lower compared with all other domains is related with their consciousness that the cancer risk is higher in first degree relationship depending on the FDFRs education levels. On the other hand, although FDFRs feel more responsible in giving care to their relatives who receive treatment, their insufficiency may be the reason why their life quality decreased.

In the researches made, it is stated that increasing care load affects the physical and mental health of the care giver negatively. Therefore the caregiver family members are defined as secret patients (Parks and Novielli, 2000; Morimoto et al., 2003) and adopting the mental and other changes occurring in patients is more difficult for family members who do not live in the same house. (Coristine et al., 2003).

The most significant aspect of QoL mentioned as psychological well-being in many studies (Vanderwerker et al., 2005; Wagner et al., 2006; Badger et al., 2007) although QoL has multidimensional aspects (Ogce et al., 2008; Yanez et al., 2011; Chopra and Kamal, 2012). Studies examining demographic variables and psychosocial characteristics of caregivers related to QoL found that being a woman, younger age, single, lower socioeconomic status, unemployment, low education

(Mellon et al., 2006; Gorji et al., 2012) and also lack of personal and social support (Ogce et al., 2008) affect the QoL negatively. In the present study found that being a widow/divorced, illiterate, and also having breast history affect the total QoL negatively.

By applying the Gail Model to the study groups, we found that FDFRs 5-year risk and also lifetime risks significantly higher. Schonfeld et al. have found 5-year risk nearly 14% in their study (2010). The Gail model substantially over predicts the number of breast cancers among women who has a family history of breast cancer, as like our results.

When QoL is examined according to the perception of women whether they carry cancer risk or not, their life quality was found to be high in all sub dimensions except the status of approach to diagnosis of the ones who think they carry cancer risk. This makes us think that women can utilize strategies of struggling with cancer risk consideration. The approach to diagnosis sub dimension includes the feeling of anxiety, grief and depression of relatives after cancer diagnosis, a second cancer fear in family members, fear of cancer relapse, fear of metastasis and uncertainty of future of family members. It was also understood from the study results that female relatives are insufficient in overcoming cancer diagnosis and should be supported.

It was understood that the psychological and spiritual well-being of relatives of the women who were diagnosed cancer more than 1 year ago improve, while their approach status to diagnosis is worse. Family members may show furious reaction after cancer diagnosis and review the meaning of their lives (Hoga et al., 2008). And also the first year after diagnosis is difficult time due to treatment procedures, the psychological and spiritual well-being domain might be affected by the female relatives' wishes for patients dealing with cancer. Elisabeth Kübler Ross (1995) emphasizes that patient relatives also face the stages denial, anger, bargaining, depression and acceptance and should also be helped and directed for so that they can take care of the patient. The health crew should be supportive and directive for the decisions to be taken about the treatment in order to reduce the stress levels of patients and accompanying patient relatives. When diagnosis period exceeds one year, the decrease of approaching to diagnosis status points of accompanying relatives can be explained as the increasing anxiety for understanding the occurring events in their patients.

It was determined in the study that the variables which have the greatest effect on total life quality are marital status (being widow / divorced) and relationship degree (being first degree relative). There are a number of limitations associated with the present study. Of note is the cross-sectional design, which limits our ability to draw causal explanations for our findings. Also lack of data related to the breast cancer patients.

In conclusion, interactions of female relatives are of critical importance in terms of women's adjustment and well-being. However kin communication can function both effectively and ineffectively in women's adjustment to cancer. With that female relative's psychological and physical health and in this context their QoL is of great importance. So QoL of female relatives must be considered as well as women with BC. In this sense, health professionals should guidance for female relatives in how to protect themselves for their potential risk as well as how to communicatively adjust in a healthy manner. Future research is needed to better understand the QoL in all aspects of female relatives of women with breast cancer.

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