RESEARCH COMMUNICATION

Comparision Quality of Life of Turkish Cancer Patients and **Their Family Caregivers**

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Abstract

Aim: The purpose of this study was to compare the quality of life (QoL) of cancer patients and their family caregivers and determine associations. Methods: A total of 93 paired patients and caregivers from an outpatient chemotherapy unit of the oncology units were recruited at a large university hospital in İzmir, all completing the Quality of Life Scale (QoLS). Results: The mean age of patients was 45.2 years, and of their family caregivers was 40.5. The results indicated that the patients perceived a poorer quality of life than their family caregivers. There was a middle and positive correlation between the social participation and work performance dimensions of patients' QoL and social participation and work performance dimension of family caregivers' QoL (r = 0.273, p<0.01). The study revealed that the gender, education level, employment and marital status were not statistically significant factors affecting the patients' quality of life (p> 0.05). Caregivers' employment status was found to have an affect on their quality of life (p < 0.05). Conclusions: Cancer affects not only the patients but also their family caregivers. Both should be taught communication skills, financial planning and distress management skills and be given spiritual support to decrease effects of cancer on their quality of life.

Keywords: Cancer patients - family caregivers - quality of life - nursing - the quality of life scale

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Introduction

Cancer is the second highest cause of death among adult after coronary disease in Turkey (Fadıloğlu, 2003). A cancer diagnosis influences patient's and indirectly their family caregiver's quality of life (QoL), and changes their everday lives in various ways (Yates, 1999; Saegrov, 2005). Quality of life is a multidimensional construct that incorporates the physical, mental, psychological, social and spiritual functioning of the individual. Patient's assessments of QoL is important outcome in treatment of cancer and measuring QoL from patient's and their family caregiver's perspective can be more information to understanding of how patients and their family caregivers react to cancer treatment (Montazeri, 2003; Blazeby et al., 2005). The first step in the process of providing appropriate care to cancer patients and their caregivers is knowing of the effect of the disease on their quality of life (Nuamah et al., 1999). Also, the second step is assessing the factors affecting their quality of life (Ferrans, 2000). Recently, a lot of research has demostrated that several socio-demographic factors posivitely affected patient's quality of life. These include higher education level (Uzun et al., 2004), younger age (Janz et al., 2005; Manuel et al., 2007; Akın et al., 2008) being not marital (Uzun et al., 2004; Akın et al., 2008) and maintaing employment status (Uzun et al., 2004; Filazoğlu and Griva, 2008). In a study by Awadalla it was found that caregivers who were male, older,married and had high level education had a higher quality of life (Awadalla et al., 2007).

In Turkey, two studies were published, by Kızılcı and, Gözüm and Akçay that compared various dimensions of QoL for patients and their family caregivers (Kızılcı, 1999; Gözüm and Akçay, 2005). In this study, family members have a better QoL than patients. Chen et al. found that only the social/family and functional dimensions of patients' QoL and total score for patients' QoL were associated with each dimension of their caregivers' QoL and with the total score (r = 0.27 - 0.44) (Chen et al., 2004). Physical and emotional dimensions of patients' QoL did not significantly influence spouse caregivers' QoL for any dimension nor for the total score. In an another study reported that a positive correlation was found between the patients' total QoL and the emotional, financial, and physical dimensions of caregiver QoL. No significant correlation was found with the social domain (McMillan and Mahon, 1994). Data from Mellon et al. found that cancer survivors reported significantly higher QoL than their family caregivers (Mellon et al., 2006).

Nurses should assess patient's and their caregiver's quality of life before, during and after treatment periods and educate them about adverse effects of cancer treatments and needed care. The study aimed therefore, to determine the factors affecting patient's and caregiver's quality of life and to compare the QoL of the cancer patients and their caregivers.

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Materials and Methods

Sample, setting and ethic considerations

This paper outlines a comparative descriptive study carried out from July to October 2006 in the outpatient chemotherapy unit of the oncology units at a large university hospital in İzmir, Turkey. A total of 186 participants (93 patients and 93 caregivers) participated in the study. The study was approved by the ethics committees of the university school of nursing. Permission to conduct this study written consent was obtained from the oncology institute review board.

Procedures

The patients and family caregivers included in the study were told about the aim of the study. If they express interest in the study, the researcher met with them in the outpatient setting. All participants signed a written consent form prior to participation. In order to participate, patients and caregivers had to be 18 years of age or older, able to speak, read, write Turkish language, not suffer from auditory or visual impairment, had to have no history of mental health problems and was willing to participate to study.

The caregiver was identified by the patient as being the person who provided the most physical and/or emotional support during their illness. The researcher provided a verbal or written description of the study. The researcher read the questionnaire items to patients, as well as family caregivers who were illiterate and could not read questions and recorded their responses. Family caregivers who were literate completed the self-report questionnaires independently.

Instruments

In order to collect baseline demographic data, the researcher developed a patient information form. This was used to collect information related to the patient's demographic information such as age, gender, education level, employment status, and marital status. A family caregiver information form was also developed by the researcher in order to collect demographic information for each family caregiver.

The Quality of Life Scale (QoLS) was used to assess patients' and their caregivers' quality of life (Özyılkan et al., 1995). The scale consists of 42 items. The QoLS has eight subscales; general well-being, physical symptoms and activity, sleep dysfunction, appetite, sexual dysfunction, cognitive dysfunction, medical interaction and social participation and work performance.

Each item of the QoLS is scored on a 5-point likert type scale ranging from "fits me exactly" (1 point) to "does not fit me at all" (5 points). Twenty-five questions are assessed negatively and inversely and 17 questions are assessed posivitely. Scores of the scale vary between 42-210, the higher score, the higher the level of perceived QoL. The QoLS has been used extensively in various cancer populations and other disease populations in Turkey (Kızılcı, 1999; Arslan and Bölükbaş, 2003; Beşer and Öz, 2003; Solak and Aşer, 2003; Uzun et al., 2004; Gözüm and Akçay, 2005).

Statistical Analyses

Means, standard deviations, ranges and percentages were used to describe patient's and family caregiver's demographic informations. Independent t-tests, analyses of variance (ANOVA) were used to test whether a statistically significant difference in the mean subscale scores and total scores for patients and family caregivers could be demonstrated. Correlations between scores on the patient's and caregiver's quality of life scale were analyzed using Pearson correlation coefficients for each paired subscale score and for the total score in each case. Statistical significance was set at 0.05 for the purposes of the study.

Results

Ninety-six dyads of patients and caregivers were interviewed in oncology units of a large university hospital, composed the sample. Three of them declined to participate or did not completed the questionnaires accurately. Total ninety-three dyads of patients and caregivers (97%) completed questionnaires. Sociodemographic characteristics of all patients and their caregivers are presented in Table 1. The mean age of patients was 45.2 ± 15.5 . In contrast to family caregivers, the majority of patients were male. Less than half of the patients (40.9%) and family caregivers (41.9%) had completed their secondary school education. At the time of data collection, most patients and their caregivers were not currently employed. Most patients and their caregivers

Table 1. Socio-Demographic Characteristics of Patients and Family Caregivers

Characteristics	Patients		Family Caregivers		
	Number (%)		Number (%)		
	(n=93)		(r	n=93)	
Age, (mean \pm S.d.)	45.	45.2 (15.5)		5 (11.6)	
Gender					
Female	38	(40.9)	70	(75.3)	
Male	55	(59.1)	23	(24.7)	
Education level					
Illiterate	4	(4.4)	4	(4.4)	
Primary school	29	(31.2)	24	(25.8)	
Secondary school	38	(40.9)	39	(41.9)	
High school	8	(8.5)	15	(16.1)	
University	14	(15.0)	11	(11.8)	
Employment status					
Employed	18	(19.4)	34	(36.6)	
Unemployed	75	(80.6)	59	(63.4)	
Marital status					
Single	20	(21.5)	20	(21.5)	
Married	66	(71.0)	70	(75.3)	
Divorce	7	(7.5)	3	(3.2)	
Relationship to patient					
Spouse only			45	(48.3)	
Children only			22	(23.7)	
Mother-father			2	(2.2)	
Other			24	(25.8)	
Someone to share caregiving					
Yes			31	(33.3)	
No			62	(66.7)	
Health Problems					
Yes			23	(24.7)	
No			70	(75.2)	

Table 2. Patients and Family Caregivers Quality of Life Scores

Scales (QoLS)	Patient	Family Caregiver	Mean Difference	t	df	p
	Mean \pm S.d.	Mean \pm S.d.				
General well-being	21.0 ± 4.8	25.7± 4.8	-4.7*	-6.8	184	0.000
Physical symptoms and activity	22.1 ± 4.7	26.0 ± 6.0	-3.9*	-4.9	173.9	0.000
Sleep dysfunction	7.3 ± 2.2	8.0 ± 2.5	-0.6	-1.9	184	0.050
Appetite	4.2 ± 2.0	5.7 ± 1.7	-1.5*	-5.4	175.0	0.000
Sexuality dysfunction	10.9 ± 3.4	12.6 ± 3.2	-1.7*	-3.5	184	0.000
Cognitive dysfunction	17.9 ± 4.7	18.3 ± 4.3	-0.3	-0.5	184	0.557
Medical interaction	10.1 ± 2.6	12.0 ± 2.5	-1.8*	-4.8	184	0.000
Social participation and work performance	22.4 ± 4.3	25.6 ± 4.6	-3.1*	-4.8	184	0.000
Total quality of life	95.8 ± 16.2	111.7 ± 20.0	-15.91*	-5.675	178.0	0.000

^{*}p< 0.05 independent t-test; A higher score represents a higher degree of quality of life

were married. Forty-eight caregivers were patients' spouse. Most family caregivers didn't share caregiving with anyone, and 75.2 % reported having health problems themselves (Table 1).

The mean quality of life scores for each dimension of the QoL are presented in Table 2. Patients' quality of life scores were lowest on the general well-being (t= -6.8, p=0.000), physical symptoms and activity (t= -4.9, p=0.000), appetite (t= -5.4, p=0.000), sexuality dysfunction (t= -3.5, p=0.000), medical interaction (t= -4.8, p=.000) and social participation and work (t= -4.8, p=0.000). Statistically significant differences were

Table 3. Socio-Demographics and Total Quality of Life

Characteristics	Total Scores of	Total Scores of Quality of Life			
	Patients				
Age, mean (SD)	Mean ± SD				
Gender					
Female	13.6 ± 20.4	t=0.19			
Male	13.5±21.9	p=0.848			
Education level					
Illiterate	$13.\pm 33.9$				
Primary school	12.6 ± 9.1	F = 1.293			
Secondary school	13.3 ± 19.9	p = 0.274			
High school	13.7 ± 20.7				
University	14.4 ± 17.6				
Employment status					
Employed	13.6 ± 20.9	t = 0.17			
Unemployed	13.5 ± 21.4	p = 0.863			
Marital status					
Single	13.6±15.4	F=0.06			
Married	13.5 ± 22.9	p = 0.937			
Divorced	13.3±21.9				
	Caregivers				
Gender					
Female	15.5 ± 26.1	t = -1.0			
Male	16.8 ± 26.6	p = 0.317			
Education level					
Illiterate	15.3 ± 28.5				
Primary school	15.6 ± 27.4	F = 1.274			
Secondary school	15.6 ± 25.4	p = 0.282			
High school	14.8 ± 28.1				
University	17.3 ± 21.2				
Employment status					
Employed	16.5 ± 24.0	t = 2.49			
Unemployed	15.2 ± 26.3	p = 0.014*			
Marital status					
Single	15.6 ± 26.2	F=0.99			
Married	15.8 ± 26.1	p = 0.375			

13.7±29.1

also found in the total quality of life scores of patients and caregivers (t= -5.675, p=0.000). Patients' sleep dysfunction (t= -1.9, p=0.050) and cognitive dysfunction (t= -0.5, p=0.557) dimension of QoL scores were not significantly different than caregivers' sleep dysfunction and cognitive dysfunction dimension of QoL scores.

To determine whether socio-demographic variables were associated with QoL the mean total scores for QoL of the groups on socio-demographic characteristics of patients were compared as also shown in Table 3. In this study, it was found that the gender (t= 0.19, p = 0.848), education level (F= 1.293, p= 0.274), employment status (t = 0.17, p = 0.863), marital status (F= 0.06, p = 0.937) did not affect the patient's total quality of life (Tablo 3).

Also, there was no statistically significant difference between caregiver's total quality of life scores and their gender (t=-1.0, p=0.317), education level (F=1.274, p=0.282), marital status (F=0.99, p=0.375). But, the employment status affected the caregivers' quality of life. When the mean total quality of life scores were examined according to the employment status, caregivers who employed reported that had statistically significant higher mean quality of life scores than caregivers who did not employ (t=2.49, p=0.014) (Table 3).

Patient's physical symptoms and activity, sleep dysfunction, appetite, sexuality dysfunction, cognitive dysfunction, medical interaction and total QoL scores were not significantly correlated with any subscale nor total scores of caregiver's QoL. However; there was a middle level positive correlation (r = 0.273, p = 0.008) between patient's social participation and work performance scores of QoL and caregiver's social participation and work performance scores of QoL at the 0.01 significance level in a two tailed test of significance.

Discussion

The aim of this study was to determine the factors affecting patients' and their caregivers' quality of life. In this study, it was determined that cancer patients' quality of life was not to be affected by gender, marital status, education level and employment status, which is consistent with past studies (Given et al., 1994; Kızılcı, 1999; Pınar et al., 2003; Uzun et al., 2004; Yeşilbalkan et al., 2005; Turgay et al., 2008).

In this study, consistent with the findings in the study by past studies the quality of life with cancer patients was not affected by gender (Given et al., 1994; Pınar et al.,

Divorced *p<0.05

Öznur Usta Yesilbalkan et al 2003; Yeşilbalkan et al., 2005).

The findings of this study revealed that marital status was not affected patients' quality of life. In similar studies was found that cancer patients' quality of life is not affected by marital status which is consistent with our study findings (Kızılcı, 1999; Pınar et al., 2003; Uzun et al., 2004; Turgay et al., 2008). In another study conducted with Turkish breast cancer patients was reported that marital status was found to be significant factors in quality of life (Filazoğlu and Griva, 2008). Filazoğlu et al. stated that women who were married reported higher quality of life than those who were not married, which is consistent with a study findings by Akın et al. (Akın et al., 2008; Filazoğlu and Griva, 2008).

In contrast to many studies, in this study cancer patients' educational status was not affect their quality of life (Pandey et al., 2005; Güner et al., 2006). Similarly, in the studies of Turkish cancer patients were found that education was not reported not to affect quality of life (Yeşilbalkan et al., 2005; Turgay et al., 2008). In contrast our study findings, in a study by Uzun reported that women with lower education had stastistically poorer QoL than did women with higher education (Uzun et al., 2004). In the study by Akın educational level was found to be significant factor in the different dimensions of quality of life (Akın et al., 2008). In another Turkish study was reported that patients with cancer who higher education had higher quality of life (Kızılcı, 1999).

Although employment status have been reported to affect quality of life and some of its dimensions (Uzun et al., 2004; Akın et al., 2008; Filazoğlu and Griva, 2008). Filazoğlu et al. stated that women who employed reported higher levels of quality of life (Filazoğlu and Griva, 2008). However, in this study, consistent with the findings in the study by Akın employment status was not significant factor in quality of life with cancer patients (Akın et al., 2008).

In the present study, caregivers' quality of life was not affected by gender. Kızılcı stated that male caregivers had better quality of life than female caregivers (Kızılcı, 1999). Gözüm et al did not examine the effect of sociodemographic variables in quality of life (Gözüm and Akçay, 2005). In the study by Adawalla it was found that caregivers who was male had much significantly higher quality of life (Adawalla et al., 2007).

In our findings showed that education level was not significant factor in caregivers' quality of life. However, Adawalla et al reported that education was associated with higher caregiver QoL scores (Adawalla et al., 2007).

Several studies reported that caregivers who married had much higher quality of life (Kızılcı, 1999; Adawalla et al., 2007). However, in our findings showed that caregivers' marital status was not affected their quality of life.

In this study, consistent with the findings in the study by Adawalla the quality of life were negatively affected in caregivers who not maintaing employment status (Adawalla et al., 2007).

The other aim of this study was to compare the QoL cancer patients and their family caregivers, determine if the QoL of the patients is associated with the QoL of their family caregiver. It was identified two main findings

from this study. First, overall quality of life in this study sample of family caregivers were higher than patients. In this study, it was thought that this result is benefical for patients. Family caregivers having better quality of life may more help and more support their patients. Also, the results of this study consistent with previous two reports about the QoL of family caregivers of patients with cancer in Turkey (Kızılcı, 1999; Gözüm and Akçay, 2005). However, the data of the present study is in contrast with a study by Kutner (Kutner et al., 2006). They reported that proxies rate QoL lower than patients. Mellon et al. found that cancer survivors reported that significantly higher QoL, less fear of cancer recurrence, and more support than their family caregivers (Mellon et al., 2006). Chen et al. reported that spouse caregivers' QoL scores were the lowest on the emotional dimension and relatively highest on the physical and social aspects (Chen et al., 2004).

Second, "the social participation and work performance" was important both patients and their family caregivers. Although lower correlation coeefficients between patients and family caregivers' social participation and work performance were found, social participation and work performance aspects of patients' QoL play a significant role in determining the social participation and work performance of their family caregivers. In this study, interesting finding was that patients' all dimensions of QoL did not correlate with caregivers' total and subdimensions of QoL (except social participation and work performance). This finding is consistent with previous findings (Chen et al., 2004). In another study by Mcmillan et al was found that no significant correlation was found with the social domain (Mcmillan and Mahon, 1994). However, these authors did not report which dimensions of patients'QoL were associated with caregivers' QoL. Also, in this study, it was thought that this lack of correlation may be partially due to the Turkish patients tendency to not to clearly report their feelings even when they are severely distressed. Hence, family caregivers may not perceive patients' status.

The results of this study may not generalize the following limitations. First, the number of sample was small. Second, in this study a cross-sectional design was used. A longitudinal study would provide a more comprehensive understanding of cancer patients' and their family caregivers' quality of life. Finally, the findings of this study could be culturally spesific and the study would need to be replicated in different cultural settings. In the future study, this limitations should be take into consideration.

In conclusions, in this study, caregivers have better QoL than patients. Findings showed that gender, marital status, education level and employment status did not affect factors the quality of life in 93 patients with cancer. In this study also revealed that caregivers' quality of life was not affected by gender, education level and marital status. Only, In this study, maintaining employment status was affect the QoL of caregivers. Previous researches have demostrated that several socio-demograhic factors were affected both patients and caregivers' quality of life. Therefore, one possible strategy for improving the caregiver's QoL is to improve the patient's QoL. Oncology nurses should assess affecting factors of

patient's and caregiver's OoL and inform communication skills, financial planning, distress management skills, and spirituality topics would affect patients and caregivers burden and QoL.

This study was one of the few studies of QoL to include mix cancer patients population and their caregivers. We think that the findings of this study will be a basis for future studies.

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