Original Article

Care Burden and Quality of Life of Caregivers of Cancer Patients with Stem Cell Transplantation

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Abstract

Background: Physical, mental and social changes occur in family members who care for stem cell transplant patients, depending on their care burden. These changes negatively affect their quality of life. A failure to identify and meet the needs of family caregivers the early period may adversely affect the physical health of both patients and caregivers and their ability to adapt to treatment. Therefore, emphasizing the needs and health conditions of caregivers is of vital importance in protecting the quality of life of both individuals who face a life-threatening disease, and their families.
Objective: The primary purpose of this study is to evaluate the care burden and quality of life of family members who care for stem cell transplant patients, and to determine the relationship between care burden and quality of life, and the secondary purpose is to evaluate the effect of care burden on caregivers' quality of life.
Methods: The population of this descriptive and correlational study consisted of 110 cancer patients who had hematopoietic stem-cell transplantation and 110 family members caring for them in a university hospital. Data were collected using a personal information form, the Quality of Life Scale-Family Version, and the Zarit Burden Interview. Mann-Whitney U test, independent samples t test, Pearson's correlation analysis and stepwise model linear regression analysis were used to analyze the data.
Results: The mean age of the cancer patients was 35.01±14.85 years, 50.6% of them had autologous transplantation. The mean age of the individuals who participated in the study was 39.56 ± 11.77 years, 75.3% of them are female, 47.2% did not have an income, and 57.3% had other dependents. The Zarit Burden Interview and the Quality of Life Scale-Family Version mean scores were 43.82 ± 13.77 and 124.73±27.91, respectively. As the care burden of caregivers increased, their quality of life total scale and subscales mean scores decreased. Marital status and income level affected the quality of life of caregivers.
Conclusion: The majority of caregivers of cancer patients with stem cell transplantation were female. The caregivers had high care burden and low quality of life. Accordingly, there was a significant negative relationship between the care burden and quality of life of caregivers.

Keywords: Stem cell transplantation, cancer, care burden, quality of life, nurse

Introduction

Stem cell transplantation is used to treat benign and malignant bone tumors, solid tumors, genetic disorders and some immunological diseases (Ljungman et al., 2010). Serious symptoms such as infections, pulmonary, cardiac, psychosocial and nutritional problems, nausea, vomiting, mucositis, and diarrhea are observed in the post-transplant period. The care needed by the patient increases in

parallel with the severity and number of symptoms experienced by the patient (Asano-Mori, 2017; Azevedo et al., 2017; Ros-Soto et al., 2019). On the other hand, technological developments, early diagnosis and treatment possibilities increase the life expectancy of cancer patients, causing family members to play a longer role in the caregiving process (Ge & Mordiffi, 2017; Spatuzzi et al., 2017). As a result, the care burden of caregivers of patients with stem cell transplantation increases.

Care burden refers to the physical, emotional, social and financial difficulties that a caregiver perceives due to patient care (Zarit et al., 1980). Caring for a sick individual is a challenging process that brings about many difficulties and affects caregivers in a multifaceted way (Celer et al., 2018). This may bring along several consequences such as inability to spare time for oneself, restriction of freedom, change in the way of work or job loss, difficulties in marriage, fail to fulfill family responsibilities and social roles, and inadequacy in daily life activities, which may deteriorate physical and mental health of caregivers (Azevedo et al., 2017; Celer et al., 2018; Spatuzzi et al., 2017). Physical, mental and social changes due to the care burden of family members can decrease their quality of life. Studies reveal that care burden affects the quality of life of family caregivers (Lim et al., 2017; Rha et al., 2015; Wu et al., 2020; Yildiz, Dedeli, & Pakyuz, 2016). Family members who care for cancer patients may have to deal with various physical, social and economic problems during the care process. A decrease in the caregiver's quality of life may negatively affect the quality of both patient care and life (Yildiz, Dedeli, & Pakyuz, 2016; Ugur, 2006). A failure to identify and meet the needs of family caregivers in the early period negatively affects both their health and the patient's health and treatment compliance (Spatuzzi et al., 2017). Therefore, emphasizing the needs and health conditions of caregivers is of vital importance in protecting the quality of life of both individuals who face a life-threatening disease, and their families (Lim et al., 2017; Rha et al., 2015; Wu et al., 2020). For this reason, reducing the care burden on family members and increasing their quality of life are considered among the important goals of health care (American Academy of Hospice and Palliative Medicine et al., 2004). While caring for cancer patients and their families, family caregivers should take care of the patient and their family as a whole and should plan and provide the care accordingly, considering the burden of care and in order to have a quality of life at the desired level. In Turkey, there are no studies to examine the relationship between care burden and quality of life in family caregivers of stem cell recipients, and the effects of care burden on caregivers' quality of life.

The primary purpose of this study is to evaluate the care burden and quality of life of family members who care for cancer patients with stem cell transplantation, and to determine the relationship between care burden and quality of life of family caregivers, and the secondary purpose is to evaluate the effect of care burden on caregivers' quality of life.

Materials and Methods

Study Type, Sample and Plan: The population of this cross-sectional study consisted of 110 cancer patients who had hematopoietic stem-cell transplantation (HSCT) and 110 family members caring for them in a university hospital. The sample included patients and caregivers who met the study inclusion criteria. The inclusion criteria for patients were as follows: being over 18 years of age, having no psychiatric diagnosis, and having no communication problems. The inclusion criteria for caregivers were as follows: being over 18 years of age, being a family member of the patient, having no psychiatric diagnosis, and having no communication problems. Since 18 caregivers were not family members of their patients and three patients did not want to participate in the study, the sample consisted of 89 patients and 89 family caregivers. A verbal and written consent was obtained from the participants. The research questionnaires were collected by the researcher using face-to-face interview method at the bone marrow center of the university hospital between January 1, 2018 and January 30, 2019. Those who participated in the study were informed about the study. The questions were read to the patients and their caregivers, and then their answers were recorded by the researcher.

Data collection tools: Data were collected using a personal information form developed by the researchers, the Quality of Life Scale-Family

Version (QOL-FV), and the Zarit Burden Interview (ZBI).

Personal Information Form: The form was composed of two parts, where the first one included questions for patients and the second one for caregivers. The first part included nine questions in total to determine the patients' age, gender, marital status, diagnosis, income status, type and time of stem cell transplantation, use of assistive vehicles (walking stick, walker, etc.), and additional diseases. The second part included 8 questions about the caregivers' age, gender, marital status, income level, social security, dependents, degree of proximity to the patient, and additional disease.

Quality of Life Scale-Family Version (QoL-FV): The scale was developed by Ferrell and Grant to evaluate the quality of life of family members of cancer patients, and adapted to Turkish language by Okcin (Ferrell et al., 1995; Okcin & Karadakovan, 2012). The scale consists of 31 items and four subscales, including Physical Health Condition, Psychological and Spiritual Health Condition, Approach to Diagnosis, and Support and Economic Effect Condition. The Cronbach's alpha value of the scale was reported as 0.90. The scale items are scored between 0 and 10 points, where "10" refers to the best and "0" to the worst. The scale is interpreted on the basis of total score and subscale scores, where a higher score indicates a higher quality of life (Okcin & Karadakovan, 2012). In this study, the Cronbach's alpha coefficient of the scale was found to be 0.83.

Zarit Burden Interview (ZBI): The scale was developed by Zarit et al.(1980), and adapted to Turkish language by Inci and Erdem (2008) (Inci & Erdem, 2008; Zarit et al., 1980). This 22-item scale is used to evaluate the stress experienced by caregivers of individuals in need of care or the elderly. This is a Likert type scale, scoring between 0 and 4. The minimum and maximum scale scores are 0 and 88, respectively. A higher score indicates a higher distress (Inci & Erdem, 2008).

The Cronbach's alpha reliability coefficient of the scale was found to be 0.95. In this study, the Cronbach's alpha reliability coefficient was determined as 0.89.

Data evaluation: Data were evaluated using the SPSS (Statistical Package for Social Science) 24.0 package program. Frequency, percentage, mean, and standard deviation were used in the analysis of descriptive characteristics of patients and caregivers. Min and max values, number, percentage, mean and standard deviation were used in the analysis of ZBI and QoL-FV scores. Pearson' correlation analysis was used to examine the relationship between time of transplantation and quality of life, and the relationship between care burden scale and quality of life scale. Kruskal Wallis test was used to evaluate the effects of disease diagnosis and marital status on care burden and quality of life. Mann-Whitney U test was used to assess the effects of use of assistive devices and social security on care burden and quality of life. Independent samples t test was used to examine the effect of income status on care burden and quality of life. A stepwise model of linear regression analysis was conducted to evaluate the predictors of quality of life. Statistical significance was accepted as $p < 0.05$ at α = 95% confidence interval.

Ethical Considerations: Before conducting the study, an ethical approval (2018-3/6) and necessary institutional permissions were obtained from the hospital where the study was conducted. Patients and their family caregivers who participated in the study were told that their information would be kept confidential and that they could leave the study whenever they wanted.

Study limitations: Data were collected from one single hospital, which is considered a limitation of the study. Study results are valid only for individuals who participated in this study.

Results

The mean age of the cancer patients was 35.01±14.85 years and the average time of bone marrow transplantation was 48.38±34.73 months. Of the patients, 56.2% were female, 53.9% had no income, 86.5% had social security, 32.6% were diagnosed of acute myeloid leukemia (AML), 50.6% had autologous transplantation, 85.4% did not use any auxiliary tools (walking stick, wheelchair, etc.), and 65.2% had no non-cancer disease. In addition, the mean age of the family caregivers was 39.56±11.77 years. Of them, 75.3% were female, 77.5% were married, 47.2% had no income, 86.5% had social security, 57.3% had dependents other than the patient, 68.5% were 1st degree proximity to the patient (mother, father, sibling, etc.), and 69.7% had chronic diseases (diabetes, hypertension, etc.) (Table 1).

The caregivers' ZBI and QoL-FV mean scores were 43.82 ± 13.77 and 124.73±27.91 (70-194), respectively (Table 2). A negative correlation was found between the caregivers' QoL-FV mean scores by transplantation time (r=0.-213, p=0.046). In addition, there was a negative relationship between the ZBI total score and the QoL-FV subscales of Psychological and Spiritual Health Condition (r=-0.231, p=0.029), Physical Health Condition (r=-0.582, p=0.000), Support and Economic Effect Condition (r=-0.493, p=0.000), and QoL-FV total score (r=-0.552, p=0.000).

Table 1. Introductory Characteristics of Cancer Patients and Caregivers

Characteristics of cancer patients		**N (89)**	**%**
Sex	Female	50	56.2
	Male	39	43.8
Marital status	Married	46	51.7
	Single	37	41.6
	Divorced	6	6.7
Income	No	48	53.9
	Yes	41	46.1
Diagnosis	Acute lymphocytic leukemia	16	18.0
	Acute myeloid leukemia	29	32.6
	Non hodgkin lymphoma	12	13.5
	Multiple myeloma	26	29.2
	Hodgkin lymphoma	6	6.7
Type of bone marrow transplant (BMT)	Autologous BMT	45	50.6
	Allogeneic BMT	33	37.1
	Autologous ± Allogeneic BMT	11	12.4
Use of auxiliary tools	No	76	85.4
	Yes	13	14.6
Comorbid disease	No	58	65.2
	Yes	31	34.8
Age (mean ± SD, years)		35.01±14.85	
Duration of BMT (mean ± SD, months)		48.38±34.73	
Characteristics of caregivers		**N (89)**	**%**
Sex	Female	67	75.3
	Male	22	24.7
Marital status	Married	69	77.5
	Single	15	16.9
	Divorced	5	5.6
Income	No	42	47.2
	Yes	47	52.8
Dependents	No	38	42.7
	Yes	51	57.3
Chronic disease	No	62	69.7
	Yes	27	30.3
Severity of care burden	No care burden	4	4.5
	Mild	31	34.8
	Moderate	43	48.3
	Severe	11	12.4
Age (mean ± SD, years)		39.56±11.77	

Table 2. The Caregivers' Mean Scores on the QoL-FV and Subscales (n=89)

Scales	Mean ± SD
Psychological and Spiritual Health Condition	37.01±13.27
Physical Health Condition	52.87±12.17
Approach to Diagnosis	20.79±11.15
Support and Economic Effect Condition	14.04±6.03
QoL-FV Total score	124.73±27.91
ZBI	43.82±13.77

Table 3. The Relationship between the Caregivers' QoL-FV and ZBI Mean Scores

	Psychological and Spiritual Health Condition		Physical Health Condition		Approach to Diagnosis		Support and Economic Effect Condition		QoL-FV Total Score		ZBI	
	r	p	r	p	r	p	r	p	r	p	r	p
ZBI	-0.231	0.029	-0.582	0.000	-0.169	0.113	-0.493	0.000	-0.552	0.000	-	-
Duration of BMT (mean ± SD, months)	-0.144	0.177	-0.092	0.393	-0.202	0.058	-0.118	0.273	-0.213	0.046	0.185	0.083

Table 4. Comparison of Care Burden, Quality of Life Scale and Subscales Mean Scores According to Some Variables

	Physical Health Condition	Psychological and Spiritual Health Condition	Approach to Diagnosis	Support and Economic Effect Condition	QoL-FV Total Score	ZBI
	X±SD	X±SD	X±SD	X±SD	X±SD	X±SD
Disease diagnosis						
Acute lymphocytic leukemia	39.56±11.67	57.31±13.74	23.06±9.91	16.56±4.11	136.50±25.12	39.25±11.28
Acute myeloid leukemia	34.79±13.79	50.93±13.42	22.44±12.88	13.93±6.49	122.10±28.76	45.48±12.76
Non hodgkin lymphoma	30.83±12.69	51.58±4.07	17.83±10.77	9.75±3.16	126.19±28.99	46.83±15.24
Multiple myeloma	40.00±14.07	52.61±11.44	19.11±10.62	14.46±6.42	129.16±31.87	42.80±16.56
Hodgkin lymphoma	40.33±8.95	54.16±15.75	20.00±8.80	14.66±7.68	124.73±27.91	46.33±6.68
p[a]	0.123	0.725	0.551	**0.026***	0.482	0.126
Patient's Marital Status						
Married	37.30±12.96	53.30±11.79	21.69±11.37	14.39±6.66	126.69±28.36	44.36±11.83
Single	38.64±13.35	53.78±12.35	20.35±11.58	14.18±5.28	126.97±26.59	41.72±15.90
Divorced	24.66±9.99	44.00±12.32	16.66±5.42	10.50±4.80	95.83±17.38	52.50±11.50
p[a]	**0.043***	0.266	0.616	0.320	**0.023***	0.277
Caregiver's Marital Status						
Married	36.18±12.33	53.13±12.32	20.59±10.98	13.84±6.04	123.75±28.92	44.91±13.43
Single	44.26±15.88	50.86±13.42	23.13±13.39	15.80±6.25	134.06±25.21	36.46±15.20

Divorced	26.60±7.95	55.40±4.66	16.60±3.84	11.60±4.77	110.20±9.31	50.80±3.42
p[a]	**0.032***	0.725	0.567	0.249	0.106	0.083
Use of Auxiliary Vehicle by Patient						
No	37.93±13.63	53.00±12.99	21.02±11.31	14.81±5.92	126.77±28.99	42.13±14.03
Yes	31.61±9.65	52.15±5.47	19.46±10.46	9.53±4.68	112.76±16.63	53.69±6.04
p[b]	0.125	0.843	0.553	**0.003****	**0.043***	**0.003****
Patient's Income Status						
No	36.79±12.89	51.39±9.45	21.16±12.07	12.45±5.34	121.81±26.57	45.31±15.51
Yes	37.26±13.85	54.60±14.27	20.36±10.10	15.90±6.31	128.14±29.35	42.07±11.34
p[c]	0.867	0.216	0.738	**0.007****	0.288	0.271

[a] *Kruskal Wallis Test,* [b] *Mann Whitney U Test,* [c] *Student's t test, *p<0.05, **p<0.01*

Table 5. Quality of Life Predictors According to Regression Analysis

	Unstandardized Coefficients		Standardized Coefficient		Sig.	F	Sig.	R2
Model	**B**	**Std. Error**	**Beta**	**t**	**P**			
1								
(Constant)	173.725	8.316		20.889	.000	38.100	0.000[a]	.305
Care Burden	-1.118	.181	-.552	-6.173	.000			
2								
(Constant)	180.177	8.633		20.871	.000	22.403	0.000[b]	.343
Care Burden	-1.148	.178	-.567	-6.463	.000			
Caregiver's income status (none)	-10.866	4.875	-.195	-2.229	.028			
3								
(Constant)	178.579	8.492		21.029	.000	17.079	0.000[c]	.376
Care Burden	-1.083	.177	-.535	-6.130	.000			
Caregiver's income status (none)	-10.574	4.779	-.190	-2.213	.030			
Patient's marital status (divorced)	-20.585	9.628	-.186	-2.138	.035			

[a] Predictors: (Constant), Care Burden [b] Predictors: (Constant), Care Burden, Caregiver's income status (none)
[c] Predictors: (Constant), Care Burden, Caregiver's income status (none), Patient's marital status (divorced)

Accordingly, as the care burden of family caregivers increased, their quality of life subscales and total score averages decreased (Table 3).A statistically significant difference was found between the patient's mean scores on the Support and Economic Effect Condition subcale by diagnosis (KW=11.070, p=0.026), where those with acute lymphoblastic leukemia (ALL) had higher mean score. Single patients had higher mean score on the QoL-FV total scale (KW=7.532, p=0.023) and physical health condition subscale (KW=6.292, p=0.043), where the statistical difference between them and others was significant. The difference between the caregivers' mean scores on the physical health condition subscale by marital status was also significant (KW=6.860, p=0.032). A statistically significant difference was found between the caregivers' mean scores on the ZBI (KW=8.853, p=0.012), QoL-FV total scale (U=320.000, p=0.043), and Support and Economic Effect Condition subscale (KW=9.036, p=0.011) according to the patient's use of assistive devices. The support and economic effect subscale mean score of those with income and social security was higher than that of those without income and social security, where the difference between them was statistically significant (t=-2.786, p=0.007; U=284.000, p=0.032) (Table

4).The stepwise linear regression analysis revealed that in model 1, care burden was the first predictor and had a great effect (30.5%) on the quality of life. Care burden, lack of caregiver income, and divorced marital status for patient were other predictors and had a cumulative effect on the quality of life (37.6%) (Table 5).

Discussion

In this study, 75.3% of the caregivers were female. In their study conducted to determine the care burden of caregivers of patients who underwent stem cell transplantation, Akgul and Ozdemir (2014) reported that 69.1% of the caregivers were female (Akgul & Ozdemir, 2014). Rha et al. (2015) conducted a study with caregivers of cancer patients, and reported that the majority of caregivers (79.2%) were women (Rha et al., 2015). Abbasi et al. also reported that the majority of caregivers of cancer patients were women, by emphasizing the increased role women in cancer care in many societies (Abbasi et al., 2020). In the present study, the ZBI mean score of caregivers was 43.82 ± 13.77. A Turkish study found the care burden mean score of caregivers of patients with stem cell transplantation as 28.41±13.90 (Akgul & Ozdemir, 2014). Rha et al. reported the ZBI mean score of caregivers of cancer patients as 36.45±12.57 (Rha et al., 2015). A study with caregivers of cancer patients in Africa reported their care burden mean score as 29.16±12.08 (Yusuf et al., 2011). Kahriman and Zaybak found the care burden mean score of family caregivers of cancer patients in oncology and hematology clinics as 34.16±16.39 (Kahriman, & Zaybak, 2015). Stem cell transplantation, in which a high dose chemotherapy is applied to patients, causing serious complications such as pulmonary, cardiac, psychosocial and nutritional problems, nausea, vomiting, mucositis and diarrhea, increases the need for care of cancer patients (Cutler et al., 2001; Eapen et al., 2004; Giebel et al., 2003). Oksuz et al. (2013) reported that caregivers of patients who received three cycles or more of chemotherapy had a statistically significantly higher care burden than those who received three cycles or less of chemotherapy (Oksuz et al., 2013). In this context, the high care burden of the caregivers in this study can be explained by the inpatient treatment and increased care need of their patients during the stem cell transplantation process.

In this study, the QoL-FV mean score of caregivers was 124.73±27.91, whereby they were considered to have moderate quality of life. Yildiz et al. (2015) found the QOL-FV mean score of caregivers of cancer patients, who received outpatient or inpatient treatment, as 187.0±3.7, whereby they had a high quality of life. The authors also determined that the caregivers' mean score was 40.5±17.5 for the Physical Health Condition subscale, 60.6±3.0 for the Approach to Diagnosis subscale, 79.9±1.6 for the Psychological and Spiritual Health Condition subscale, and 22.9±3.6 for the Support and Economic Effect Condition subscale. In the present study, the QoL-FV total and subscales mean scores of caregivers were lower than those found by Yildiz et al. (Yildiz et al., 2016). This study found a statistically significant negative relationship between the ZBI and QoL-FV total scores ($r=-0.552$; $p=0.000$). A statistically significant moderate negative correlation was found between the ZBI and QOL-FV subscales of physical health condition and support and economic effect condition ($p <0.005$). There was no relationship between the ZBI and QOL-FV subscale of approach to diagnosis, whereas a statistically significant weak negative correlation was found between the ZBI and QOL-FV subscale of psychological and spiritual health condition. Rha et al. reported a statistically significant moderate relationship between the care burden, which was measured using the ZBI, and quality of life, which was measured using the Abbreviated World Health Organization Quality of Life Questionnaire, in caregivers of cancer patients (Rha et al., 2015). Gaston-Johansson et al. (2004) found a moderate correlation between the subjective care burden and total quality of life in caregivers of breast cancer patients who underwent stem cell transplantation ($r=–0.418$, $p<0.01$). They also concluded that the high care burden was associated with the low quality of life in caregivers of stem cell transplant patients (Gaston-Johansson et al., 2004). Celer et al. (2018) reported that as the care burden increased, the quality of life decreased in caregivers of breast cancer patients (Celer et al. 2018). This study found that care burden was the first predictor of the quality of life of family caregivers and had a great effect (30.5%) on the quality of life. Care burden, lack of caregiver income, and divorced marital status for patient

were the predictors of the quality of life of caregivers, and had a cumulative effect of 37.6% on the quality of life. Abbasi et al. argued that care burden and income status of caregiver were important determinants of the quality of life of caregivers. In the same study, the caregiver's income and marital status explained 54% of the variance in the quality of life (Abbasi et al. 2020). Moreover, a population-based large-scale study compared the quality of life in cancer patients and their family members in Korea, and determined that not only the quality of life of the family member who provided primary care for the cancer patient but also the quality of life of all family members were significantly lower than the other group. In this context, the study suggests that the responsibility of caring for cancer patients extends over all family members (Lee et al. 2015).

Conclusion: The majority of caregivers of cancer patients who underwent stem cell transplantation were female. The caregivers had high care burden and low quality of life. There was a negative relationship between the care burden and quality of life of caregivers. In other words, the quality of life of caregivers with high care burden was low, whereas the quality of life of those with low care burden was high. Based on the results of this study, relevant interventions to reduce the care burden should also be implemented, considering that the care burden of these people is also important for the interventions planned to increase the quality of life of caregivers of cancer patients who underwent stem cell transplantation.

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