

# Identification of Psychological and Social Problems in Caregivers of Individuals Diagnosed with Hematologic Malignancy

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Received: June 25, 2020; Accepted: August 13, 2020; Published: January 29, 2021

## ABSTRACT

**Objective:** Caring for patients with hematological malignancy could lead to many problems in different aspects regarding the lives of caregivers. However, there is limited data on the emotional and social problems of caregivers, who deal with patients of hematological malignancy. The aim of this study is to determine the emotional and social problems in caregivers of individuals diagnosed with hematological malignancy.

**Methods:** The study was carried out descriptively to identify the emotional and social problems in the relatives of the patients diagnosed with hematological malignancy as their caregivers, as well as the factors affecting these problems. The data of the study were collected with the Introductory Information Form and Identification of Emotional and Social Problems Form that were administered to the relatives of the patients. The data were evaluated by using Spearman's Rho correlation analysis and the Logit analysis in Statistical Package for the Social Sciences software. **Results:** Among the caregivers, 59.8% were in the age

group of 30–51 years, and 66.2% were female. Of the caregivers, 70.1% had difficulty in fulfilling their responsibilities. Spiritual distress had the highest score among the emotional problems, and experiencing caregiver strain had the highest score among the social problems. In the Logit model, the changes in the professional life was the variable that affects the emotional and social problems the most and significantly. In addition, emotional problems were affected by the financial problems at a statistically significant level. **Conclusions:** In this study, it is suggested that the caregivers should be provided with certain conveniences in their professional lives based on the fact that the problem, which affected emotional and social problems the most, is the change in the professional life; it is recommended that further studies should be carried out on the caregivers.

**Key words:** Caregiver, hematological malignancy, social and psychological problems

## Introduction

Cancer ranks the second most common cause of death in Turkey and in the world,<sup>[1]</sup> and it is an important disease listed among the chronic diseases in terms of the

survival rate and incidence as well as the treatment and follow-up processes. Cancer is classified as hematologic and oncological. Hematologic cancer is heterogeneous in terms

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Website: [www.apjon.org](http://www.apjon.org)

DOI:  
10.4103/apjon.apjon\_53\_20

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**Cite this article as:** Karacan Y, Akkus Y, Ozcelik ET, Ali R. Identification of Psychological and Social Problems in Caregivers of Individuals Diagnosed with Hematologic Malignancy. *Asia Pac J Oncol Nurs* 2021;8:204-10.

of treatment options, results, and life expectancy.<sup>[2]</sup> According to the data of Hematological Malignancy Research Network (HMRN-2010-16), the hematologic neoplasm is 67.9 per hundred thousand, while the 5-year survival is 70.5%.<sup>[3]</sup>

Patients with advanced hematologic cancer face more psychological, mental, social, and physical problems, as well as fatigue, pain, and roles they experience compared to patients without metastatic cancer.<sup>[4,5]</sup> In addition, more prevalent symptoms are observed in this group as more aggressive treatment and more chemotherapy or biological agents are used compared to patients with solid tumors.<sup>[5]</sup> It is stated that these symptoms in hematologic cancer studies have increased the need for care,<sup>[2]</sup> and there is a need for different levels of care in relation to the severity, subgroup, type, and treatment side effects of the disease.<sup>[6]</sup> In the systematic review of Moghaddam *et al.*, the needs of care that were least addressed in the cancer patients were the informative approach (30%–55%) as well as psychological (18%–42%), physical (17%–48%), and functional fields (17%–37%).<sup>[7]</sup> In another study, 48% of hematologic cancer patients stated that they were less understood by the others, 44.1% stated that they needed more information about their future status, and 66.7% needed support.<sup>[8]</sup> These problems and needs may increase anxiety and depression, and reduce the quality of life in patients by affecting their everyday lives.<sup>[8]</sup> Cancer has a negative effect both on the patients and the caregivers or their relatives.<sup>[9]</sup>

In Turkey, caregivers are usually the relatives/friends of the patients and they assist in monitoring the symptoms of the patients and notifying the health-care team about their effects in addition to providing medical or home care.<sup>[10-12]</sup> This shows that caregivers always play a critical and important role in the care of patients during the disease process. However, caregivers could neglect their own health needs, personal care, psychological, and social problems due to the care they provide within this process. In the previous studies, it was observed that the caregivers could not get support from the family while carrying out the care activities, the younger caregivers required more support than the elderly,<sup>[13]</sup> the needs of the individual were affected by their social and cultural background, they encountered economic problems, and economic problems affected the social relations of the caregivers by causing stress.<sup>[14,15]</sup> In addition, it was determined that physical health was affected during caregiving,<sup>[16]</sup> psychological and somatic complaints occurred,<sup>[17]</sup> and problems such as anorexia, crying, exhaustion,<sup>[18]</sup> fatigue, social isolation,<sup>[19,20]</sup> disruption in social interaction,<sup>[21]</sup> blaming oneself,<sup>[22]</sup> unemployment, low income, failure to meet needs of the family, lack of

time,<sup>[20]</sup> excessive consumption of alcohol or sleeping pills<sup>[8]</sup> and decrease in quality of life were experienced by the caregivers. These problems experienced by the caregiver could affect him/herself as well as his/her caregiving ability to the patient, and even increase the severity of the problems experienced by the patient.<sup>[23,24]</sup>

It is recommended that nurses provide psychological strength training to the caregivers of the cancer patients, teach them coping methods, and provide them with professional and individual psychosocial support.<sup>[11,25]</sup> Thus, both the patient and the relative will be able to cope better with the risk of having cancer and provide effective protection.<sup>[23]</sup> Quality care, in which caregiver is understood and the needs of the caregiver are addressed, could reduce the care costs potentially by ensuring that the caregiver performs care and interventions at home.<sup>[24]</sup>

Referring to the studies in Turkey was found to be limited in hematologic malignancies of the work of caregivers for determining the psychological and social problems. In a study, it was determined that the quality of life was affected by 46.6%, and that body pain and mental health were the most affected areas.<sup>[26]</sup> In addition, caregivers are more affected because patients frequently apply to the hospital due to developing complications. Therefore, determining the psychosocial and emotional problems of caregivers of patients diagnosed with hematological malignancy will help to develop programs for care services.

## Methods

The study was carried out descriptively to identify the psychological and social problems in the relatives of the patients diagnosed with hematologic malignancy as their caregivers, as well as the factors affecting these problems.

The study was carried out with the relatives of patients who applied to a Hematology Clinic of University Hospital between the July 2, 2010, and June 30, 2011, and received treatment and care due to the diagnosis of hematologic cancer. The number of patients who presented to the outpatient clinic with the new diagnosis was ten patients on average per month. Approximately 120 patients were reached within 1 year. The sample of the study was determined with 77 patient relatives, who were over 18 years old and literate, volunteered to participate in the study, and provided primary care.

Data were collected by the Introductory Information Form and Identification of Psychological and Social Problems Form that were administered to the relatives of the patients.

### Introductory information form

The introductory information form consists of two parts that include questions related to the caregiver and

the patient. Questions regarding the caregiver were related to the age, gender, marital status, socioeconomic status, working status, degree of relation to the patient, the state of sharing the same home with the patient, duration of marriage if married, the change in professional life, the year/hour allocated to caregiving, the state of receiving support from another for caregiving, having chronic diseases, experiencing financial issues and having difficulties in fulfilling own responsibilities. The questions about the patient were related to age, gender, marital status, socioeconomic status, diagnosis, and health status. [13,24,27]

### Identification of psychological and social problems inventory

The form, which was tested for reliability and validity by Babaoglu and Oz in 2003, consists of 52 items. There are 13 subgroups in the form, 7 of which address psychological problems, and 6 of which address social problems. Subgroups of psychological problems are spiritual distress, hopelessness, anxiety, ineffective individual coping, decisional conflict, fear, and depressive affect. The subgroups of social problems are experiencing caregiver strain, inability to maintain daily tasks, change in social interaction, deficient diversional activity, and role performance, and social isolation. Each item has three choices scored between 0 and 2. The total scores are calculated by assigning 2 points to “yes,” 1 point to “sometimes,” and 0 points to “no.” [27]

### Statistical analysis

IBM Statistical Package for the Social Sciences Statistics for Windows, version 20.0 (Chicago, USA) and Stata were used for the data analysis. Categorical variables were expressed as *n* (%) normally distributed continuous variables, as mean ± standard deviation; and nonnormally distributed continuous variables, as median (minimum–maximum). Spearman’s Rho Correlation Analysis and Logit analysis were performed to evaluate the significance level of 1% and 5%.

### Ethical approval

Approvals were obtained from the Ethics Committee of Uludag University (Approval No. 2010-8/4) and from the department that would carry out the study, written informed consent form was obtained from the patients.

## Results

### Patient characteristics

According to the findings obtained from the study, among the patient relatives included in the study, the mean age of participants was 41.90 ± 12.85 years, 66.2% were

female, 77.9% were married, 40.3% were the spouse of the patient, 77.9% lived in the same household with the patient, 35.1% were homemakers, and 48.1% had an underbalanced budget. Moreover, 70.1% of the caregivers stated that they had difficulty in fulfilling their responsibilities, and 37.7% stated that they experienced mental problems. Looking at the data related to the patients, the mean age of patients was 51.12 ± 16.37 years, 51.9% were male, 79.2% married, 49.4% underbalanced budget, 29.9% of the patients had Acute lymphoblastic leukemia and 70.1% remission stage based on the statements of the caregivers [Table 1].

Considering the duration of care they provided for their patients, while 50.6% of them provided 0–1 year, 50% provided full-time care beside the patient, 59.7% continued to provide care for the patient, by themselves.

The distribution of the mean sizes for psychological and social problems is presented in Table 2. Looking at the intervals of change, mean and median values, spiritual distress among psychological problems, and caregiver strain among social problems had the highest scores despite having the same maximum scores.

The results of the Spearman’s Rho correlation analysis, which was performed on psychological and social problems to analyze the relationships of the relation to the patient, living in the same house, change in professional life, the duration of caregiving, financial difficulties, affecting the

**Table 1: Caregivers’ and patients’ characteristics (n=77)**

Caregivers’ characteristics	n (%)
Female (yes)	51 (66.2)
Married (yes)	60 (77.9)
Spouse of patient (yes)	31 (40.3)
Underbalanced budget (yes)	37 (48.1)
Homemaker (yes)	27 (35.1)
Same household with the patient (yes)	60 (77.9)
Receiving support	31 (40.3)
Difficulty in fulfilling their responsibilities (yes)	54 (70.1)
Mental problems (yes)	29 (37.7)
Age (years), mean±SD	41.90±12.85
Care time (years), mean±SD	2.36±1.94
Patients characteristics	n (%)
Male	40 (51.9)
Married	61 (79.2)
Underbalanced budget	39 (49.4)
Diagnoses	
Leukemia	36 (46.8)
Lymphoma	19 (24.7)
Multiple myeloma	17 (22.1)
MDS	5 (6.5)
Disease status	
Remission	54 (70.1)
Relaps	16 (20.8)
New treatment	7 (9.1)
Age (years), mean±SD	51.12±16.37

SD: Standard deviation; MDS: Myelodysplastic syndrome

responsibilities of their own, problems experienced and the socioeconomic status of the patient, are presented in Table 3.

According to the results of the correlation analysis, the factor that affected both psychological and social problems the most was the changes in professional life ( $P < 0.01$ ). In addition, psychological problems were affected by financial problems at a statistically significant level ( $P < 0.01$ ).

The Logit method was used on psychological and social problems to examine the effects of relation to the patient, living in the same house, changes in professional life, the duration of caregiving, financial difficulties, affecting their responsibilities, the problems experienced, and the socioeconomic status of the patient. Accordingly, psychological and social problem scores were firstly divided into two categories of data over the median. Logit models were as follows:

Psychological/social problems =  $\beta_0 + \beta_1$  Relation to the patient +  $\beta_2$  Living in the same house +  $\beta_3$  Change in professional life +  $\beta_4$  Duration of caregiving +  $\beta_5$  Hours of caregiving per day +  $\beta_6$  Financial difficulties +  $\beta_7$  Affecting responsibilities +  $\beta_8$  Problems experienced +  $\beta_9$  Socioeconomics.

The logit analysis results are presented in Table 4.

Looking at the results of the analysis, changes in professional life was the variable that affected the psychological and social problems the most and significantly within the system that included all variables in the Logit model, unlike the correlation analysis.

## Discussion

The most important aim of this study is to determine the psychological and social problems in caregivers of patients diagnosed with hematologic malignancy. It is the strongest aspect of our study is to determine the psychological and social problems of informal caregivers of individuals diagnosed with hematologic malignancy. Overall, this paper is meaningful to the research in informal caregiving and can contribute to the literature by enriching the data about informal caregivers of individuals with cancer. This study was carried out in a single clinic with a small number of patients and the burden and life quality of the caregivers were not evaluated. These are among our most important limitations. Therefore, the results of this study could only be generalized to this group.

As in many studies, most of the caregivers were observed to be female in our study. Although it has changed in recent years, the person who is in charge of primary care in the family is still the female in our society; the daughter or the wife usually undertakes the role of the caregiver.<sup>[14,27-31]</sup> The high cost of care in the hospital environment and the desire

**Table 2: Distribution of mean sizes for psychological and social problems**

Distributions	Median	Minimum	Maximum	Mean±SD
Spiritual distress	7	2.00	8.00	6.30±1.38
Hopelessness	6	0.00	8.00	5.56±2.16
Anxiety	5	0.00	8.00	5.26±2.16
Ineffective individual coping	5	0.00	8.00	4.83±2.04
Decisional conflict	6	1.00	8.00	5.68±2.17
Fear	5	1.00	8.00	5.05±1.99
Depressive affect	5	1.00	8.00	5.23±1.83
Psychological problems total	37	19.00	56.00	37.91±10.51
Experiencing caregiver strain	5	0.00	8.00	5.32±2.11
Inability to maintain daily tasks	5	0.00	8.00	5.09±2.01
Change in social interaction	5	0.00	8.00	5.08±2.06
Deficient diversional activity	5	0.00	8.00	5.14±2.04
Change in role performance	5	0.00	8.00	4.95±2.07
Social isolation	5	0.00	8.00	5.09±2.02
Social problems total	32	1.00	48.00	30.68±10.60

SD: Standard deviation

**Table 3: Results of the Spearman's rho correlation analysis between psychological and social problems, and research factors**

Factors	Psychological problems	Social problems
Relation to the patient	0.203	0.090
Living in the same house	0.136	0.087
Change in professional life	0.437*	0.363*
Years of caregiving	-0.023	0.059
Hours of caregiving per day	0.016	0.040
Financial problems	0.298*	0.117
Affecting responsibilities	-0.054	0.020
Problems experienced	-0.117	0.088
Socio-economics	-0.116	-0.038

\* $P < 0.05$  was considered statistically significant

of patients to spend their last period at home has caused the spread of home-based care in cancer patients in recent years.<sup>[32]</sup> In the present study, the majority of the caregivers were observed to live in the same house with the patient. This may prevent the caregiver, who spends a long time in hospital care, from maintaining care activities at home as well as balancing care and domestic life.

In the present study, the subgroup of spiritual distress was observed to have the highest score among the psychological problems of the caregivers. Spiritual care is an important part of holistic care, which has not fully been understood; and healthcare professionals are not able to discuss spiritual care with patients and their relatives.<sup>[33]</sup> Spirituality is a universal and internal dimension in the search for the meaning of the existence in human beings, which includes the purpose and values of being human, without having to mediate with a religious institution. In addition, spirituality emphasizes the connection with the self, nature, and the sacred.<sup>[34]</sup> Spirituality helps individuals cope with the disease due to its psychosocial and physiological effects in many



Table 4: Results of the logit model regarding psychological and social problems

Factors	Psychological problems				Social problems			
	Model		Marginal effects		Model		Marginal effects	
	Coefficient	P	Coefficient	P	Coefficient	P	Coefficient	P
Relation to the patient	0.215	0.324	0.038	0.315	0.060	0.769	0.012	0.768
Living in the same house	0.783	0.358	0.140	0.350	0.484	0.529	0.101	0.525
Change in professional life	2.070	0.001*	0.372	0.000*	1.775	0.002*	0.370	0.000*
Years of caregiving	-0.060	0.686	-0.011	0.685	0.093	0.501	0.019	0.497
Hours of caregiving per day	-0.590	0.351	-0.106	0.341	-0.279	0.634	-0.058	0.633
Financial problems	1.069	0.095	0.192	0.075	0.459	0.446	0.096	0.440
Affecting responsibilities	0.051	0.934	0.009	0.934	0.332	0.565	0.069	0.562
Problems experienced	-0.078	0.623	-0.014	0.621	0.119	0.433	0.025	0.426
Socio-economics	0.581	0.353	0.104	0.344	0.422	0.463	0.088	0.458
Constant	-6.127	0.018			-5.587	0.017		
$\chi^2$	23.73				13.46			
$\chi^2$ (P)	0.005				0.143			
R <sup>2</sup>	0.222				0.126			
Log-likelihood	-41.447							
Observation	77				77			

\*P&lt;0.01 was considered statistically significant

cultures.<sup>[35]</sup> In the literature review, no studies related to spiritual distress have been found in those who care for patients diagnosed with hematologic malignancy. Several studies reported that spirituality is one of the needs that are not addressed in caregivers of cancer patients.<sup>[35,36]</sup> However, caregivers are the most important people who can ensure that patients are supported spiritually.

It was observed that the scores obtained by the caregivers in the subgroup of decisional conflict were the second-highest score among psychological problems. It was defined as decisional conflict *Uncertainty about course of action to be taken when choice among competing actions involves risk, loss, or challenge to values and beliefs.*<sup>[37]</sup> Both patients and caregivers could experience conflicts in decision-making on various cases related to the diagnosis and treatment process after the diagnosis of cancer.<sup>[38]</sup> In the literature review, no studies were on “decisional conflict” in caregivers. In their study, Bansal *et al.* stated that it affected the decision of the caregiver or the family member regarding the patients with prostate cancer.<sup>[39]</sup> Family support is very important in the treatment option. Therefore, it is important to consult the opinions of the family members while identifying the treatment options.

In the present study, it was observed that the scores obtained by the caregivers in the subgroup of “caregiver strain” were the highest among the social problems. It was defined by the Oncology Nursing Society *Caregiver strain and burden encompasses the difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver’s psychological and physical health that can occur when care demands exceed resources.*<sup>[40]</sup> Looking at the studies on caregiver strain, it was observed that there were

studies on caregivers of the elderly (98%), childhood period cancers (78%), and prolapse (73.8%); however, the review of this subject was limited in relatives of patients diagnosed with cancer, and the most frequently studied subjects were burden and distress<sup>[41-43]</sup> Miaskowski *et al.* determined that the relatives of cancer patients who experienced pain had poor health conditions and high levels of caregiver strain.<sup>[44]</sup> Lohne *et al.* indicated that 20% of the caregivers, who cared for their families, experienced caregiver strain.<sup>[45]</sup> In their study, Kazi and Ghosh found that among the caregivers of the patients diagnosed with head-and-neck cancer receiving radiation therapy, 58.3% experienced physical strain, and 95.8% experienced economic strain.<sup>[46]</sup> Bicer and Ozcebe compared the caregivers of cancer patients to the control group and reported that 42% of the caregivers experienced caregiver strain due to the cases such as psychological changes, changes in schedules, and personal plans as well as sleep disorders.<sup>[47]</sup>

In the current study, the scores obtained in the *Deficient diversional activity* subgroup among the social problems were observed to be the second-highest score. *Deficient diversional activity a nursing diagnosis approved by the North American Nursing Diagnosis Association, defined as the experiencing by an individual of decreased stimulation from, interest in, or engagement in recreational or leisure activities. Formerly called diversional activity deficit.*<sup>[48]</sup> Fatigue, hopelessness, and spending most of the time with the patient could cause changes in the Deficient diversional activity for the caregivers of cancer patients. In the study by Babaoglu and Oz on the spouses providing palliative care to the cancer patients, the Deficient diversional activity was the second most frequent problem that was mentioned.<sup>[27]</sup> There have been

studies on caregivers of cancer patients in terms of leisure activities and their effects. In addition, leisure activities are reported to treat physical functions as well as increasing psychological wellness.<sup>[49]</sup>

The result obtained in the Logit model is closely related to the general approach of the Turkish society toward professional life. In the Turkish culture, the existence of individuals in society requires them to produce; the productive individuals could easily adapt to other social problems. Particularly, the theory of social identity indicates that the professional lives of individuals formed the social identity regardless of their income, and the absence of this identity would lead individuals to experience social and psychological problems.<sup>[50]</sup> In their study, Sherwood *et al.* mentioned that the caregivers of cancer patients experienced changes in their professional lives to be able to provide support in the diagnosis process and daily life activities.<sup>[51]</sup> De Moor *et al.* stated that 8% of the caregivers of cancer patients left their jobs for more than 2 months, 25.0% changed their jobs, and 12.2% lost job opportunities such as losing offers, changing jobs, postponing looking for jobs or getting promoted. In the same study, 8% of the caregivers were found to leave their jobs for more than 2 months based on paid leave (2.1%), unpaid leave (2.8%), or a combination of the two (3.2%), and these caregivers, who experienced long term change in employment, cared for patients of chemotherapy or transplantation.<sup>[52]</sup> Longacre *et al.* reported that almost half (48%) of the caregivers of cancer patients who were employed had to leave their office early or leave their jobs for caregiving, 24% had to shorten their working hours or shifted from full time to part-time employment, and 11% retired early or stopped working.<sup>[12]</sup> Gaugler *et al.* stated that the caregivers working per hour were affected more negatively in terms of their physical and mental health compared to those who worked on salaries.<sup>[53]</sup> As indicated in the previous studies, the professional lives of the caregivers were affected negatively.

## Conclusions

The results of this study indicate that providing care in patients with hematologic malignancy causes psychological and social problems, and change in business life is the most effective factor in the problems. Therefore, it is suggested that the cancer patients should be supported financially, certain conveniences should be provided in the health system and working environment in terms of reducing job loss, and employers should make changes in the working environments. Considering the importance of the concept of caregiving-job loss, the emerging need for reviewing the job and employment basis of family care requirements could set a step for a new randomized study. Moreover, it is suggested that the concept of caregiving by caregivers

should be discussed, they should be supported spiritually and their spiritual requirements should be identified.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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