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ORIGINAL ARTICLE

Determining the symptoms and coping methods of patients at home after hematopoietic stem cell transplantation

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Abstract

Aim This descriptive study was conducted to determine symptoms experienced at home in the early period by patients who received hematopoietic stem cell transplantation (HSCT), identify coping behaviors used by the patients in the management of symptoms and assess the quality of life of these patients.

Method The study included 200 patients who had received HSCT at a private hospital in Kocaeli in Turkey between October 2017 and November 2018 and been discharged. The data of the study were collected by using a patient information and interview form developed by the researcher, the Memorial Symptom Assessment Scale and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

Results The mean age of the patients was approximately 51, 39% ($n=78$) of the patients were female, 61% ($n=122$) were male, and the vast majority (82%) were married. The three most frequently experienced symptoms among the patients after being discharged were identified as pain (63%), weakness (48%), and loss of appetite (43%). It was found that the vast majority of the patients complied with coping behaviors reported in the literature, but these behaviors were partially effective. Clinical diagnosis, type of transplant, status of re-hospitalization of the being discharged, and number of problems experienced were identified as variables that were significantly effective on the treatment-related symptom experiences and many dimensions of the quality of life of the patients ($p<0.05$).

Conclusion It was determined that the patients who were included in this study experienced various symptoms on different levels and at different frequencies. Regarding the effectiveness of the approaches used by the patients in coping with the symptoms they experienced, it was determined that the approaches they used to cope with nausea-vomiting, fever and insomnia were effective, and those they used for weight loss and anxiety were ineffective.

Keywords Hematopoietic stem cell transplantation · Symptom management · Coping methods · Quality of life

Introduction

Today, hematopoietic stem cell transplantation (HSCT) is a method that is prevalently used in the treatment of cancer, malignant and benign hematological diseases, solid tumors, genetic disorders, and immunological diseases and offers hopes of long-term remission, while it has become a standard of care for many patients [1, 2].

HSCT is not a process that ends with stem cell infusion as a curative treatment option. It is a grave process for patients and their relatives which can lead to morbidity and mortality and cause toxic effects in organs and systems in the short- and long-term [3]. Therefore, patients are at risk in terms of post-transplant complication development. Symptoms encountered as a result of the treatment may be overlooked due to the patient's discomfort in talking about this issue and their inability to express side effects [4, 5]. In addition to this, HSCT may be a serious source of stress not only for the patient but also for the individuals who support them in their care. Thus, it is also necessary to evaluate the sources of support the patient will resort to [6, 7].

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The purpose of HSCT is not only to increase the rate of survival but also to sustain the quality of life of the patient. It is seen among studies conducted in this context that while the number of studies on evaluating the quality of life and care needs of patients receiving HSCT has increased in recent years, this number is still highly limited [5, 8]. In light of these data and the review made in this study, it was aimed to determine the symptoms experienced at home by patients who have received HSCT after they are discharged, identify the sociodemographic characteristics and characteristics related to the type of transplant that influence these symptoms, evaluate whether or not the coping behaviors used by patients in the management of symptoms and the education they receive are effective, assess their quality of life, determine recommendations for the development of nursing practices that will increase the adaptation of the patient and their family, and plan the appropriate interventions for meeting the patient's needs.

Material and method

This study was conducted with 200 patients who were discharged after having received hematopoietic stem cell transplantation at a private hospital in the province of Kocaeli in Turkey between October 2017 and November 2018, were continuing to be followed up at the hematology outpatient clinic, agreed to participate in the study, and met the inclusion criteria. Two hundred and thirty-five patients who had received hematopoietic stem cell transplantation and were discharged were evaluated for their inclusion in the study, and 35 patients were excluded as they did not meet the inclusion criteria.

The inclusion criteria were determined as being over the age of 18, not having a communication problem, being able to read and write in Turkish, having received HSCT and been discharged and voluntarily agreeing to participate in the study.

The data were collected with the method of face-to-face and telephone interviews lasting for 30 min on average using a patient information and interview form consisting of questions on the personal, health-related, and disease-related characteristics of the patients who were included in the study, the Memorial Symptom Assessment Scale (MSAS) and the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30). Disease- and treatment-related information was obtained from the medical records of the patients.

Patient Information and Interview Form

The form was created by the researcher based on the review of the relevant literature and consisted of 45 questions on the descriptive characteristics of the patients, their health history, problems experienced after transplant and coping methods, and disease-related information.

Memorial Symptom Assessment Scale (MSAS)

MSAS, which is an instrument for assessing cancer-related symptoms developed by Portenoy, is a 32-item scale that allows the multidimensional analysis of the frequency, severity, and distress analyses of physical and psychological symptoms besides the prevalence of symptoms [9].

The validity and reliability study of the scale in Turkish was carried out by Yıldırım et al. (2011), and the Cronbach's alpha coefficient of the scale was found to be between 0.71 and 0.84 [10]. In our study, the Cronbach's alpha value of the scale was calculated as 0.90.

European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30)

The questionnaire is a prevalently used scale worldwide in the assessment of the health-related quality of life of cancer patients, and it was developed by Aaronson et al. [11]. Its validity and reliability study in Turkish was conducted by Güzelant et al. (2004), who determined that it is a valid and reliable tool for cancer patients in Turkish society. The Cronbach's alpha coefficient of the scale was determined as higher than 0.70 [12]. The scale consists of three dimensions as general health status, physical functioning and symptom management. Higher scores of general health status and lower scores of physical functioning and symptom management indicate higher quality of life [13].

Statistical analysis

In this study, the dimensions of MSAS and EORTC QLQ-C30 were formed by making the necessary calculations based on the explanations of the scales. The data were analyzed using the IBM SPSS Statistics 22 (IBM SPSS, Turkey) program. In the analyses, in addition to descriptive statistical methods (mean, standard deviation, median, frequency, percentage), Mann–Whitney *U* test was used in the analyses of the non-normally distributed quantitative data. Kolmogorov–Smirnov test was utilized to determine the normality of the distribution of the data on the dimensions of the scales for choosing the statistical methods to be used in investigating the relationships between these dimensions and the independent variables, and it was found that the data were not normally distributed. Mann–Whitney *U* test was used for the comparisons made based on the independent variables with two categories, whereas Kruskal–Wallis test was used for those made based on the independent variables with more than two categories. Correlation analysis was utilized to investigate the relationships between the continuous variables. The level of statistical significance was accepted as 0.05.

Ethical aspect of the study

Before implementing the data collection forms, information about the study was provided to the patients who were included, and their written informed consent was received. Approval was obtained before starting the study from the Anadolu Health Center Ethics Board with the decision dated 10.01.2018. Written permission was obtained from Prof. Yasemin Yıldırım to use MSAS. The study was conducted in compliance with the principles of the Declaration of Helsinki.

Results

The sample of the study consisted of a total of 200 patients with a mean age of 51.3 ± 15, of whom 39% (*n* = 78) were female, and 61% (*n* = 122) were male. Among the patients, the vast majority (82%) were married, 28% were university graduates, 72% lived with their spouse and family, 45% received help from their spouse, and 77% were not working due to their disease (Table 1).

Among the patients who participated in the study, multiple myeloma was the diagnosis with the highest rate as 39.5%, which was followed by lymphoma at 27.5% and leukemia at 22%. While 65.5% of the patients had received autologous transplantation, 15% had received allogeneic transplantation (Table 2).

In this study, MSAS and EORTC QLQ-C30 were presented to the patients to be filled out. Table 3 shows the mean, standard deviation, minimum, and maximum scores of the patients in each dimension of the two scales.

Table 4 presents the frequency, severity and distress status of the symptoms included in MSAS among the patients. The numbers and percentages of the patients experiencing symptoms in relation to the 32 items are shown.

The symptoms that were most frequently experienced by the patients in our study after having received HSCT and been discharged were pain (63%), weakness (48%), loss of appetite (43%), feeling bloated (38%), difficulty in concentrating (35%), and nausea (30%) in descending order (Table 4).

The status of the patients to experienced symptoms, their approaches in coping with these symptoms, and the individuals from whom they learned these approaches were investigated separately for each symptom. It was found that the patients usually received support from their case supervisor, the vast majority of them complied with coping behaviors reported in the literature, they used pharmacological and non-pharmacological methods together, and the education they received was generally adequate.

Table 1 Distribution of personal characteristics

Personal Characteristics	Category	*n*	%
Age X ± SD (min–max)	51.3 ± 15 (17-78)		
Sex	Female	78	39
	Male	122	61
Marital status	Marries	164	82
	Single	36	18
Occupation	Homemaker	56	28
	Freelance	44	22
	Retired	37	18.5
	Student	19	9.5
	Laborer	15	7.5
	Civil Servant	14	7
	Engineer	8	4
	Manager	7	3.5
Education status	Literate	53	26.5
	Primary-secondary school	55	27.5
	High school	36	18
	University	56	28
Living with	Spouse and children	144	72
	Mother and father	31	15.5
	Friends	25	12.5
Being helped by	Spouse	90	45
	Children	38	19
	Family (mother and father)	37	18.5
	Mother	18	9
	Caregiver	9	4.5
	Relative	8	4
Income status	Poor	10	5
	Barely living by	85	42.5
	Moderate	73	36.5
	Good	23	11.5
	Well-off	9	4.5

Regarding the effectiveness of the approaches used by the patients in coping with the symptoms they experienced, it was determined that the approaches they used to cope with nausea-vomiting, fever, and insomnia were usually effective, those they used for mouth sores, difficulty in swallowing, loss of appetite, and changes in taste and smell, changes in the skin, weakness and diarrhea were usually partially effective, and those they used for weight loss and anxiety were generally ineffective.

In this study, it was determined that for coping with the symptom of nausea-vomiting, 86.4% of the patients took antiemetic medication, 71.2% regulated their nutrition, 55.9% paid attention to their oral hygiene, 50.8% called their case supervisor, and 39% took part in distracting activities.

Table 2 Distribution of disease-related characteristics

Disease characteristics	Category	*n*	%
Clinical diagnosis	Multiple myeloma	79	39.5
	Lymphoma	55	27.5
	Leukemia	44	22
	Aplastic Anemia–MDS*	13	6.5
	Other	9	4.5
Type of transplantation	Autologous	131	65.5
	Allogeneic	30	15
	**Haploidentical	7	3.5
	**Non-relative	32	16
Family history of disease	None	126	63
	Cancer	44	22
	Systemic disease	30	15
Frequency of Follow-Up	Based on doctor's recommendations	92	46
	When there is a problem	78	39
	Once–twice a month	30	15
Hospitalized after being discharged	Yes	32	16
	No	168	84
Reason for hospitalization	Not Applicable	168	84
	Infection	15	7.5
	GVHD-infection	5	2.5
	Other (nausea and vomiting or bleeding)	10	5
	GVHD*	2	1

***MDS* myelodysplastic syndrome, *GVHD* graft-versus-host disease. **Haploidentical and non-relative transplantation is included the type of allogeneic transplantation

In this study, it was determined that the symptom of weakness-fatigue, which is another symptom experienced by HSCT patients after their treatment and discharge, was experienced by about half of the patients in the early period after being discharged. It was found that to cope with this problem, 80.2% of the patients rested frequently, 68.8% went to bed early, 61.5% had sufficient amounts of sleep, 59.4% paid attention to their nutrition, and 14.6% did nothing.

In the analysis of the effects of the disease-related variables of the patients on their quality of life and symptoms, it was determined that these variables were significantly effective on the experience of symptoms and many dimensions of quality of life ($p < 0.05$) (Table 5). In the analysis of the effects of the diagnoses of the patients on their quality of life and symptoms after HSCT, significant differences were identified among the groups of diagnoses regarding treatment-related symptoms (psychological and overall), and physical, role, emotional, and cognitive functions were affected more ($p < 0.05$). There was a significant difference between the groups in terms of the effects of the types of transplantation on the quality of life and symptoms of the patients ($p < 0.003$). The quality of life of the patients who had received autologous transplantation was higher in comparison to the quality of life of others.

In our study, it was found that the patients who perceived their disease as an incurable disease, those who had difficulties after being discharged and those who were hospitalized again were affected by all treatment-related symptoms to a higher extent, their general health status was poorer, and their functional health was affected more ($p < 0.0000$).

Discussion

Hematopoietic stem cell transplantation (HSCT) that is carried out following the stage of high-dose preparation is associated with high morbidity and mortality rates, and serious complications are likely to arise after transplantation [14]. In this study, the symptoms experienced by the patients in the sample after they were discharged following HSCT treatment were investigated with the Memorial Symptom Assessment Scale (MSAS), and the three most frequently encountered symptoms among the patients were pain, weakness and loss of appetite, whereas the symptoms experienced most severely and in the most distressing sense were loss of appetite, weakness, and nausea.

In other studies in the literature conducted in the same context, it was observed in general that similar symptoms have been seen at different rates. It was considered that these

Table 3 Statistics of the patients' MSAS and EORTC QLQ-C30 Scores ($n = 200$)

	Mean	Standard deviation	Minimum	Maximum
Symptoms (MSAS)				
Global Distress Index	0.38	0.42	0	2.5
Physical symptoms	0.48	0.49	0	2.94
Psychological symptoms	0.22	0.4	0	2.06
All symptoms	0.33	0.36	0	2.51
Quality of life (EORTC-C30)				
General health status	72.92	20.98	0	100
Functional health				
Physical function	79.57	18.88	13.33	100
Role function	83.83	16.95	16.67	100
Emotional function	93.92	12.35	33.33	100
Cognitive function	97.75	8.63	33.33	100
Social function	69.58	20.08	0	100
Symptoms				
Fatigue	22.5	22.15	0	100
Nausea-vomiting	11.92	21.87	0	100
Pain	16.42	16.41	0	100
Dyspnea	5.33	13.55	0	66.67
Insomnia	4.5	17.9	0	100
Loss of appetite	27.5	33.99	0	100
Constipation	0.5	7.07	0	100
Diarrhea	7.17	24.3	0	100
Financial difficulties	32	20.83	0	100

differences may have occurred due to differences in the types of transplantation of patients, their clinical diagnosis, different preparation regimens, other comorbid diseases, and developing complications in different studies. Additionally, the different sizes of the samples of different studies may also have affected the results on the rates of these symptoms.

In the study conducted by Oğuz (2012) on 69 patients who had received HSCT treatment, the three most frequently encountered symptoms were identified as weakness, changes in the taste of food, and unhappiness [15]. Bergkvist et al. (2014) examined the post-transplant general health, symptom development and self-efficacy of patients who had received allogeneic transplantation ($n = 117$) and determined that the patients frequently experienced fatigue, sexual dysfunction, lack of energy, and weakness [16].

Nausea-vomiting, which is one of the symptoms experienced by patients who are discharged after having received HSCT treatment, may bring about problems such as a lack of appetite, nutritional problems, fluid-electrolyte imbalance, weight loss, difficulty in adjustment to the treatment, and fatigue [17]. Therefore, the effective management of symptoms carries great importance in terms of the course and success of the treatment and increasing the quality of life of the patient. In this study, it was determined that for coping with the symptom of nausea-vomiting, 86.4% of the patients took antiemetic medication, 71.2% regulated their nutrition, 55.9% paid attention to their oral hygiene, 50.8% called their case supervisor, and 39% took part in distracting activities. It was seen in similar studies in the literature that as opposed to the cases in our study, these studies have usually been conducted with only patients receiving chemotherapy treatment. In one of such studies conducted by Okten (2012), it was observed that patients used similar approaches to those in our study at different rates in the management of nausea-vomiting, and as in our study, the use of antiemetics was in the first place [18]. Can et al. (2011) investigated pharmacological non-pharmacological methods used by patients and found that the patients preferred pharmacological methods at a rate of 72.5% in the management of physical symptoms [19].

In this study, it was determined that the symptom of weakness-fatigue, which is another symptom experienced by HSCT patients after their treatment and discharge, was experienced by about half of the patients in the early period after being discharged. It was found that to cope with this problem, 80.2% of the patients rested frequently, 68.8% went to bed early, 61.5% had sufficient amounts of sleep, 59.4% paid attention to their nutrition, and 14.6% did nothing. The results reported in the study by Okten (2012) were similar to those in our study, and spending the day resting/lying down was in the first place (87.5%) among the approaches in coping with this problem in their study [18]. Similarly, in their study on fatigue, Richardson and Ream (1997) observed that 47.4% of the participants in their study stated that they alleviated their fatigue by lying down/limiting their daily activities [20].

In HSCT cases, symptoms and quality of life have critical importance [21]. Previous studies have reported that many aspects of quality of life in patients receiving HSCT treatment are affected on different levels [15, 22]. In their study carried out with 441 patients, Brice et al. (2017) emphasized that there is a reduction in the quality of life of patients due to reduced physical functions, cognitive changes, changing living conditions, social losses, reduced functional properties and the necessity of long-term follow-up [23]. Kiely et al. (2016) investigated quality of life and symptom load in patients diagnosed with multiple myeloma who had received HSCT, and they found a significant reduction in these patients' quality of life ($p < 0.0001$) [24]. Likewise, in their study carried out with 248 patients who had received HSCT, Hjermstad et al. (2004) determined that the quality of life of the patients deteriorated due to transplantation, it was significantly lower in the patients who had received allogeneic transplantation ($p < 0.0001$), and the symptom of fatigue continued even after 3 years following transplantation [25].

Table 4 Frequency, severity, and degree of distress of HSCT-related symptoms of the patients ($n = 200$)

	Prevalence		Frequency (%)				Severity (%)				Distress (%)				
	n	%	Very rarely	Sometimes	Frequently	Almost always	Mild	Moderate	Severe	Highly severe	None	Some	Above-moderate distress	High distress	Excessive distress
Difficulty concentrating	70	35	12.9	64.3	21.4	1.4	60.0	35.7	4.3	0.0	17.1	67.1	12.9	2.9	0.0
Pain	126	63	9.5	75.4	13.5	1.6	61.9	35.7	1.6	0.8	20.6	59.5	17.5	1.6	0.8
Lack of energy	96	48	2.1	17.7	70.8	9.4	3.1	50.0	43.8	3.1	2.1	16.7	46.9	31.3	3.1
Cough	64	32	17.2	60.9	20.3	1.6	39.1	50.0	9.4	1.6	10.9	54.7	29.7	3.1	1.6
Feeling nervous	27	14	33.3	51.9	14.8	0.0	66.7	29.6	3.7	0.0	11.1	70.4	14.8	3.7	0.0
Dry mouth	58	29	27.6	65.5	6.9	0.0	70.7	25.9	3.4	0.0	19.0	63.8	15.5	1.7	0.0
Nausea	59	30	0.0	22.0	71.2	6.8	1.7	57.6	35.6	5.1	0.0	15.3	54.2	25.4	5.1
Feeling drowsy	13	7	15.4	76.9	7.7	0.0	38.5	53.8	7.7	0.0	7.7	46.2	38.5	7.7	0.0
Numbness/tingling in hands/feet	43	22	7.0	20.9	67.4	4.7	7.0	48.8	44.2	0.0	2.3	14.0	55.8	27.9	0.0
Difficulty sleeping	13	7	0.0	53.8	30.8	15.4	7.7	76.9	7.7	7.7	0.0	15.4	69.2	7.7	7.7
Feeling bloated	76	38	28.9	61.8	7.9	1.3	57.9	36.8	5.3	0.0	10.5	64.5	18.4	6.6	0.0
Problems with urination	23	12	17.4	43.5	26.1	13.0	30.4	30.4	39.1	0.0	8.7	26.1	30.4	34.8	0.0
Vomiting	27	14	37.0	51.9	11.1	0.0	55.6	33.3	11.1	0.0	14.8	51.9	22.2	11.1	0.0
Shortness of breath	12	6	33.3	58.3	8.3	0.0	58.3	41.7	0.0	0.0	8.3	58.3	33.3	0.0	0.0
Diarrhea	18	9	0.0	11.1	72.2	16.7	0.0	16.7	66.7	16.7	0.0	5.6	27.8	44.4	22.2
Feeling sad	19	10	31.6	63.2	5.3	0.0	57.9	36.8	5.3	0.0	5.3	63.2	26.3	5.3	0.0
Sweats	29	15	34.5	55.2	6.9	3.4	75.9	17.2	3.4	3.4	17.2	69.0	6.9	6.9	0.0
Worrying	27	14	11.1	77.8	11.1	0.0	18.5	74.1	7.4	0.0	3.7	44.4	44.4	7.4	0.0
Problems with sexual interest or activity	0	0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Itching	13	7	15.4	76.9	7.7	0.0	76.9	15.4	7.7	0.0	7.7	84.6	0.0	7.7	0.0
Lack of appetite	85	43	0.0	40.0	55.3	4.7	0.0	54.1	41.2	4.7	0.0	4.7	68.2	22.4	4.7
Dizziness	18	9	16.7	61.1	22.2	0.0	27.8	50.0	22.2	0.0	0.0	33.3	55.6	11.1	0.0
Difficulty swallowing	9	5	0.0	88.9	11.1	0.0	11.1	77.8	11.1	0.0	0.0	11.1	77.8	11.1	0.0
Feeling irritable	5	3	20.0	80.0	0.0	0.0	80.0	20.0	0.0	0.0	0.0	100.0	0.0	0.0	0.0
Mouth sores	9	5	0.0	0.0	0.0	0.0	0.0	11.1	77.8	11.1	0.0	0.0	55.6	44.4	0.0
Change in the way food tastes	15	8	0.0	0.0	0.0	0.0	20.0	33.3	40.0	6.7	13.3	6.7	53.3	26.7	0.0
Weight loss	22	11	0.0	0.0	0.0	0.0	40.9	54.5	4.5	0.0	0.0	77.3	18.2	4.5	0.0
Hair loss	72	36	0.0	0.0	0.0	0.0	2.8	91.7	5.6	0.0	19.4	37.5	43.1	0.0	0.0
Constipation	1	1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	100.0	0.0	0.0	0.0	0.0	100.0

Table 4 (continued)

	Prevalence		Frequency (%)				Severity (%)				Distress (%)				
Swelling of arms or legs	5	3	0.0	0.0	0.0	0.0	20.0	80.0	0.0	0.0	20.0	0.0	80.0	0.0	0.0
"I don't look like myself"	27	14	0.0	0.0	0.0	0.0	0.0	81.5	14.8	3.7	0.0	11.1	74.1	14.8	0.0
Changes in skin	41	21	0.0	0.0	0.0	0.0	0.0	58.5	39.0	2.4	0.0	9.8	68.3	19.5	2.4

In this study, all findings in relation to the assessment of the quality of life of the patients based on different variables were obtained within the first month after the patients had been discharged. In other studies, it has been observed that HSCT affects the quality of life of the patient negatively in different periods after their discharge. As a result of their study which included 2800 patients, Grulke et al. (2012) highlighted the finding that the quality of life of the patients who were hospitalized was lower, and this level reached the pre-transplant level after about 1 year following transplantation [26]. A similar study conducted by Hensel et al. (2001) reported results like those in this study, and it was emphasized that most symptoms and scores returned to normal only after 3–6 years [27].

It is very significant to diagnose possible problems early in all transplant types. In addition to the symptoms experienced after HSCT, our study is valuable since it contributes to the evaluation of the variables affecting these symptoms, the coping behaviors used by patients in the management of symptoms and evaluation of their quality of their life, and determination of suggestions that will led to development of nursing practices and the planning of appropriate needs, which will increase the adaptation of the patient and his family.

The information obtained in light of all findings and assessments in this study is important in terms of providing the guidance and support needed in the experience of transplantation. Moreover, this information can be utilized in the assessment of relevant mechanisms and development of effective interventions in studies to be carried out in the future to investigate post-HSCT symptoms. What is more, treatment methods to be developed by examining the symptom-related experiences and coping methods of patients will shed light on the improvement of quality of life.

The fact that the sample size in this study was large and the assessment not only symptoms experienced after HSCT but also the variables influencing these symptoms, coping methods used by the patients for the management of symptoms and their quality of life together was a strength of this study. On the other hand, the fact that this study was conducted at a single center was a limitation.

Consequently, it was determined that the patients who were included in this study experienced various symptoms on different levels and at different frequencies after their HSCT treatment, many aspects of their quality of life were affected on different levels, and the patients needed guidance and support in their processes of achieving symptom management. The following may be recommended in line with the findings obtained in this study:

- Detailed education for every symptom management must be provided to patients to reduce their anxiety, increase their treatment compliance, prevent treatment-

Table 5 Quality of life and symptoms after transplantation ($n=200$)

	n	Global Distress Index	Physical symptoms	Psychological symptoms	All symptoms	General health status	Physical function	Role function	Emotional function	Cognitive function	Social function
Clinical diagnosis		X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD
Aplastic anemia–MDS	13	0.47 ± 0.45	0.53 ± 0.47	0.36 ± 0.52	0.46 ± 0.41	66.03 ± 23.93	69.74 ± 22.54	80.77 ± 16.45	90.38 ± 13.54	93.59 ± 10.84	64.1 ± 19.06
Lymphoma	55	0.35 ± 0.4	0.44 ± 0.42	0.23 ± 0.41	0.29 ± 0.31	73.33 ± 18.03	80.97 ± 18.74	83.03 ± 16.82	93.48 ± 13.19	97.58 ± 7.47	70.91 ± 23.4
Leukemia	44	0.48 ± 0.53	0.6 ± 0.66	0.3 ± 0.46	0.48 ± 0.5	64.02 ± 23.07	75.45 ± 18.29	80.68 ± 16.84	90.91 ± 14.24	97.73 ± 10.54	65.53 ± 21.98
Multiple myeloma	79	0.33 ± 0.37	0.43 ± 0.41	0.13 ± 0.32	0.26 ± 0.27	79.85 ± 17.88	83.12 ± 18.17	87.55 ± 16.77	96.31 ± 10.4	98.31 ± 8.27	71.73 ± 16.53
Other	9	0.32 ± 0.32	0.46 ± 0.5	0.25 ± 0.27	0.28 ± 0.27	62.96 ± 28.6	74.07 ± 17.14	75.93 ± 16.9	95.37 ± 8.45	100	70.37 ± 18.22
χ2 KW		2.447	0.793	11.4	9.834	18.785	12.158	10.145	10.096	10.445	4.289
p		0.654	0.939	0.022	0.043	0.001	0.016	0.038	0.039	0.034	0.368
Type of transplantation											
*Non-relative	32	0.6 ± 0.43	0.72 ± 0.52	0.41 ± 0.44	0.54 ± 0.37	59.11 ± 19.9	69.58 ± 19.82	78.13 ± 15.52	87.76 ± 12.7	96.88 ± 8.92	60.94 ± 20.13
Allogeneic	30	0.46 ± 0.59	0.61 ± 0.7	0.3 ± 0.51	0.49 ± 0.57	63.61 ± 24.22	72.22 ± 20.57	81.67 ± 18.75	90.28 ± 17.66	94.44 ± 14.07	65 ± 23.3
*Haploidentical	7	0.17 ± 0.25	0.23 ± 0.34	0.03 ± 0.08	0.24 ± 0.22	72.62 ± 22.93	81.9 ± 15.26	80.95 ± 15	97.62 ± 4.07	100	71.43 ± 20.89
Autologous	131	0.31 ± 0.36	0.4 ± 0.39	0.16 ± 0.35	0.25 ± 0.25	78.44 ± 18.08	83.56 ± 17.13	85.88 ± 16.73	96.06 ± 10.35	98.6 ± 6.87	72.65 ± 18.61
χ2 KW		15.083	14.012	20.858	25.484	28.201	22.53	7.963	22.492	8.069	11.324
p		0.002	0.003	0.000	0.000	0.000	0.000	0.047	0.000	0.045	0.010
Frequency of follow-up											
1–2 a month	30	0.55 ± 0.56	0.5 ± 0.48	0.5 ± 0.64	0.42 ± 0.41	70.28 ± 20.49	74.67 ± 22.79	73.89 ± 19.42	86.11 ± 18.87	93.33 ± 14.91	64.44 ± 23.46
Based on doctor's recommendation	92	0.28 ± 0.33	0.39 ± 0.39	0.13 ± 0.29	0.26 ± 0.27	77.36 ± 18.3	83.19 ± 16.67	86.96 ± 14.99	96.74 ± 7.91	99.09 ± 3.8	73.55 ± 18.18
When there is a problem	78	0.43 ± 0.43	0.57 ± 0.57	0.2 ± 0.33	0.37 ± 0.42	68.7 ± 23.23	77.18 ± 19.15	83.97 ± 16.87	93.59 ± 12.38	97.86 ± 9.05	66.88 ± 20.19
χ2 KW		9.737	4.976	10.911	6.763	6.184	6.672	11.773	10.91	6.805	6.729
P		0.008	0.083	0.004	0.034	0.045	0.036	0.003	0.004	0.033	0.035
Hospitalized after being discharged											
Yes	32	0.93 ± 0.57	1.06 ± 0.67	0.7 ± 0.64	0.81 ± 0.53	46.09 ± 19.4	54.17 ± 20.02	63.54 ± 17.16	78.13 ± 19.94	89.58 ± 17.84	47.4 ± 24.72
No	168	0.27 ± 0.28	0.37 ± 0.35	0.12 ± 0.24	0.24 ± 0.22	78.03 ± 17.05	84.4 ± 14.26	87.7 ± 13.92	96.92 ± 7.16	99.31 ± 3.81	73.81 ± 15.96
z		−6.6	−6	−6.9	−6.7	−7.2	−7.1	−6.7	−7	−5.8	−5.8
p		0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
Difficulty after being discharged											
Yes	45	0.68 ± 0.59	0.8 ± 0.66	0.5 ± 0.59	0.59 ± 0.52	60 ± 23.07	69.19 ± 24.59	72.22 ± 21.32	83.89 ± 19.25	92.22 ± 16.13	56.67 ± 25.72
No	155	0.29 ± 0.31	0.38 ± 0.37	0.13 ± 0.27	0.25 ± 0.25	76.67 ± 18.81	82.58 ± 15.72	87.2 ± 13.8	96.83 ± 7.31	99.35 ± 3.23	73.33 ± 16.4

Table 5 (continued)

	n	Global Distress Index	Physical symptoms	Psychological symptoms	All symptoms	General health status	Physical function	Role function	Emotional function	Cognitive function	Social function
z		−4.5	−4.2	−4.9	−5.1	−4.4	−3.5	−4.4	−5.2	−4.5	−4
p		0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
Health status (*n* = 200)											
r		-0.385	-0.379	-0.328	-0.43	0.5	0.447	0.382	0.302	0.195	0.29
p		0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.006	0.000
Number of problems (*n* = 200)											
r		.874**	.845**	.757**	.904**	−.701**	−.760**	−.667**	−.773**	−.559**	−.662**
p		0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

χ^2_{KW} chi-squared Kruskal–Wallis. *Haploidentical and non-relative transplantation is included the type of allogeneic transplantation

related complications, and contribute to their more active participation in their decision-making and care processes.

- The content of education should be planned in an individualized manner by considering the problems that are determined and the needs of the patients.
- Counseling services that patients can utilize regarding the solution of the problems they experience at home 24 h a day should be planned. Additionally, applications for mobile phones may be developed to make symptom management at home easier.
- To prevent and reduce HSCT-related symptoms, the use of symptom management models developed with up-to-date, evidence-based studies at clinics should be made prevalent.
- Research should be conducted on the pathogenesis of the symptoms experienced by patients, and treatment options should be created accordingly.
- More studies should be conducted with larger populations for determining the symptoms experienced by patients in the transplantation process, how these symptoms will affect quality of life and factors influential on these symptoms and for increasing quality of life.

Author contribution Hematopoietic stem cell transplantation (HSCT), which can cause morbidity and mortality in the short and long term, and cause toxic effects in many tissues, organs and systems, is a severe process for patients and their relatives. The symptoms seen as a result of the treatment can be overlooked due to the discomfort experienced by the patient in talking about this issue and the inability to express its side effects. For these reasons, it is very significant to diagnose possible problems early in all transplant types. In addition to the symptoms experienced after HSCT, our study is valuable since it contributes to the evaluation of the variables affecting these symptoms, the coping behaviors used by patients in the management of symptoms and evaluation of their quality of their life, and determination of suggestions that will led to development of nursing practices and the planning of appropriate needs, which will increase the adaptation of the patient and his family.

Data availability Applicable.

Code availability Not applicable.

Declarations

Ethics approval Applicable.

Consent to participate Applicable.

Consent for publication Applicable.

Conflict of interest The authors declare no competing interests.

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