ORIJINAL ARAȘTIRMA ORIGINAL RESEARCH

# **Being an Informal Caregiver in Bone Marrow Transplant Unit:** A Qualitative Study

## Kemik İliği Transplantasyon Ünitesinde Bakım Verici Olmak: Kalitatif Çalışma

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**ABSTRACT Objective:** The bone marrow transplantation (BMT) units are high-dependency areas, with patients requiring care. Patients in BMT are in need of intensive care due to the treatment applied and complications related to the treatment. This study explores informal caregivers' experiences and perceptions in (BMT) unit. Material and Methods: Individual interviews were conducted in a semi-structured form. Theoretical thematic analysis was used to analyze the interview data. A qualitative design was used to describe the caregivers' experiences in the BMT unit, the caregiving process, and what they felt while giving care, and their expectations. Individual interviews were conducted in a semi-structured form. 24 informal caregivers hospitalized in the BMT of a university hospital who agreed to participate in the study were included in İstanbul, Türkiye. Results: Three major and nine themes emerged from the data analysis: (1) caregiver's perception, (1a) daily life, (1b) difficulties experienced, (1c) social support, (1d) health problems; (2) thoughts and experiences (2a) feelings, (2b) changes in relationships, (2c) what if I became ill; (3) expectations; (3a) expectations from the future, (3b) expectations from institutions. Conclusion: It was understood in this study that the informal caregivers had difficulties while maintaining their daily lives, felt alone in the process of providing care, experienced a set of psychological problems after the diagnosis, were optimistic about the future, and had expectations from institutions.

Key

ÖZET Amac: Kemik iliği transplantasyonu (KİT) üniteleri, hastaların bakıma ihtiyaç duydukları ve bağımlılıklarının yüksek oldukları alanlardır. KİT ünitesindeki hastalar uygulanan tedavi ve tedaviye bağlı komplikasyonlar nedeniyle yoğun bakıma muhtaçtır. Bu çalışmada, KİT ünitesindeki informal bakım vericilerin deneyim ve algılarını araştırmak amaçlandı. Gereç ve Yöntemler: Bireysel görüşmeler yarı yapılandırılmış formla gerçekleştirilmiştir. Görüşme verilerinin analizinde teorik tematik analiz kullanılmıştır. Bakım vericilerin KİT ünitesindeki deneyimlerini, bakım verme sürecini, bakım verirken hissettiklerini ve beklentilerini betimlemek için nitel bir tasarım kullanılmıştır. Bireysel görüşmeler, yarı yapılandırılmış formla gerçeklestirilmistir. İstanbul'da bir üniversite hastanesinin KİT ünitesinde yatan ve çalışmaya katılmayı kabul eden 24 informal bakım verici dâhil edildi. Bulgular: Veri analizinden 3 ana ve ve 9 tema ortaya çıkmıştır: (1) bakım verenin algısı, (1a) günlük yaşam, (1b) yaşanan zorluklar, (1c) sosyal destek, (1d) sağlık sorunları; (2) düşünceler ve deneyimler, (2a) duygular, (2b) ilişkilerde değişiklikler, (2c) hasta olursam; (3) beklentiler, (3a) gelecekten beklentiler, (3b) kurumlardan beklentiler. Sonuc: Bu çalışmada, informal bakım verenlerin günlük yaşamlarını sürdürmekte zorlandıkları, bakım verme sürecinde kendilerini yalnız hissettikleri, tanı konulduktan sonra birtakım psikolojik sorunlar yaşadıkları, geleceğe yönelik iyimser oldukları ve kurumlardan beklentilerinin olduğu anlaşılmıştır.

ywords:	Bone marrow transplantation;	Anahtar Kelimeler: Kemik iliği transplantasyonu;
	informal caregiver; experiences; qualitative study	informal bakım verici; deneyimler; kalitatif çalışma

Hematopoietic stem cell transplantation (HSCT) is used in malignant diseases requiring intensive chemotherapy (sometimes concomitant radiotherapy) and non-malignant diseases such as hemoglobinopathy.<sup>1</sup> In HSCT, patients face several problems due to the complex treatments implemented at high intensity and the nature of their disease. During HSCT treatment, fever, pain, mucositis and nausea-vomit-



ing are among the most frequently encountered complications. In the process of their intense treatment, patients also experience feelings like fear, isolation and depression.<sup>2</sup> Apart from this, patients also experience feelings such as fear, isolation, and depression during the treatment process.<sup>3</sup> It has been accepted for years that the stress that is experienced affects patients and their informal caregivers (ICs) throughout the disease process involving comprehensive care.<sup>4</sup> It was reported that, in proportion to the symptom load of the patient, ICs experienced even more stress than patients.<sup>5</sup> Caregiving can have positive consequences for the caregiver, including a sense of efficacy, of emotional closeness, and pleasure in preserving the patient's dignity.<sup>6</sup>

Being an ICs, on the other hand, is a time-consuming and stressful process that takes a person's entire day.<sup>7</sup> The caregiver burden is defined as "the extent to which caregivers perceive that their emotional or physical health, social life and financial status are suffering as a result of caring for their relatives".8 ICs experiences about the extent of caregiving having an impact on their psychological, social, financial, physical and spiritual functioning.<sup>9</sup> Caregiver burnout is a condition where ICs experience a state of physical, emotional, and mental exhaustion that can change their attitude towards the patient from care.<sup>10</sup> Anxiety and stress are more common in caregivers in advanced-stage cancer patients.<sup>11</sup> Supporting ICs aims to optimize patient care.<sup>12</sup> However, for this, first, it is needed to understand the perceptions of caregivers and their experiences during the caregiving process.

While the numbers of cancer diagnoses have increased every single year, researchers have started to investigate what the highest-quality and most accurate care for the patient is. Russell et al. stated that successful treatment may also be provided in the home environment and encouraged healthcare professionals regarding this issue. The purpose of this suggestion is to maintain the treatment process of the patient by increasing their quality of life in the home environment.<sup>13</sup> Care at home during the HSCT process has many medical advantages including a lower number of days with high fever and a lower level of need for total parenteral nutrition.<sup>14</sup> On the other hand, it was reported that patients experience high levels of psychological and emotional stress when they were left alone in the hospital environment.<sup>15</sup> Post-HSCT care is provided at home in many countries in the world. The purpose of preferring this practice is to protect the patient from nosocomial infections and provide them with an environment at their home where they can relax. However, to be able to utilize transplant facilities at home, the patient needs to have at least 2 caregivers. As they are not able to find caregivers, 80% of patients choose the option of getting treatment while hospitalized.<sup>16</sup> Previous studies have revealed that the protective isolation practiced in HSCT cases made patients feel trapped and led them to experience anxiety, depression, insomnia and feelings of loneliness.<sup>17</sup> Maintaining home-like care during HSCT can be achieved with ICs. For these and similar reasons, in Türkiye, ICs of patients are admitted to bone marrow transplant (BMT) units under certain conditions. The consensus on evidence-based care in BMT nursing in Türkiye 2018 revealed that 95.7% of units allowed companions. In the same consensus, having companions was found to be appropriate at a rate of 92.8%.18 At the unit in Türkiye where this study was conducted, to provide nosocomial infections, 1 patient relative is trained and allowed to stay as a caregiver. This way, ICs of HSCT patients support these patients and witness the experienced process.

It is seen that, in the literature, studies about caregivers have generally been conducted in the context of diseases like Alzheimer's and stroke. However, few studies have been carried out with caregivers of HSCT patients, and these studies have been mostly quantitative.<sup>19,20</sup> There have been a few qualitative studies and these studies have not reflected the perceptions, thoughts and feelings of ICs at BMT units.<sup>21-23</sup> Therefore, in this study, it was aimed to investigate the perceptions of ICs of HSCT patients at a BMT unit in Türkiye in depth.

### MATERIAL AND METHODS

#### STUDY DESIGN

The qualitative methodology is particularly suitable when little is known about a phenomenon. The thematic analysis uses a descriptive approach with a focus on lived experience, which refers to our experiences. The findings produced in a qualitative study stay close to the data as given, which allows the participants to express their perceptions.<sup>24</sup>

The study followed the principles of the Declaration of Helsinki. Ethical approval was obtained from the Haliç University Non-Interventional Clinical Researches Ethics Committee (date: April 30, 2019, no: 92). Participants were informed of the study and reminded of their right to withdraw from the study at any time without explanation. All caregivers signed an informed consent. The confidentiality and privacy of the participants were guaranteed. ICs were assigned numbers to replace their names and surname in the transcripts, and personal identifiers were removed from study documents.

#### **RIGOR AND TRUSTWORTHINESS**

To assure the qualitative study's trustworthiness, we followed the criteria of credibility, confirmability, dependability, and transferability.<sup>24</sup> Trustworthiness was followed to promote methodological rigor. The researcher should be able to give a short review of the findings so that they confirm participants' ideas.<sup>25</sup> To demonstrate credibility, the researchers collected all data to ensure consistency. She gave a list of initial coding with subcategories to participants who were willing to check these and give comments. Most participants agreed on those initial codes and subcategories. The opinions of the participants were validated to ensure the reliability of the data.<sup>25</sup> To established confirmability, the researchers who conducted the interviews had no relationship with the caregivers.

Several strategies were used to ensure credibility, including the use of auto taped interviews, verbatim transcription, two independent researchers conducting data analysis, interviewer triangulation. In keeping with the criteria of dependability audio recordings of the interviews and their transcripts were kept. Researchers carried about the interpretation of the data, and similarities and differences were discussed to guarantee dependability. Finally, to assure transferability, a detailed description of the method, context and caregivers was provided.<sup>26</sup>

#### SETTING AND PROCEDURE

IC's at or over the age of 18 who were able to speak Turkish and provided care without getting payment were included in the study. Appointments were arranged by determining the appropriate times with caregivers who satisfied the inclusion criteria. The purposive sampling method was used in this study.

24 ICs who agreed to participate in the study between May-December 2019 were included. A sociodemographic information form was filled out by the participants. After this, interviews were carried out with the caregivers by taking audio recordings in a room where these interviews would not be interrupted. A semi-structured interview form was utilized while conducting the interviews. The interviews consisted of open-ended questions for caregivers' perceptions (Table 1).

2 caregivers were interviewed on the day of each interview. After interviewing a caregiver, individual notes were written with the other researcher. Interviews were conducted one-on-one. Each interview took 20-30 min on average. The interviews were carried out by one researcher. The other researcher participated as an observer and took interview notes.

The participants were firstly asked about how their daily lives were affected after they became caregivers. They were asked about issues where they had difficulty and whether or not they had someone who could provide support when they had a difficulty. They were also asked about their health problems that

TABLE 1: Qualitative interview.						
Interview questions						
*You know we want to examine your caregivers' real experiences with the						
caregiving process. While you're here, you also have to go about your daily						
life. What are you experiencing?						
- What is your most difficult subject?						
- Can you get support?						
*Have you had any health problems that arose after you started giving care?						
*Have your thoughts and feelings changed after you started caring for the						
patient?						
*Have there been any changes in your relationships?						
*If you were you ill, would your family take care of you?						
*What are your future expectations for your patient?						
*What are your expectations from health institutions?						

emerged after they started to provide care, if any. Next, the researcher asked them about their thoughts and feelings while providing care for their patients. Finally, their expectations were asked, including their expectations. The interviewer focused on the perceptions of the caregivers while providing care, as well as their thoughts and feelings, and asked follow-up questions to obtain details throughout the interviews.

#### DATA ANALYSIS

The interviews were transcribed verbatim. Thematic analysis is a method used for defining, analyzing, and reporting themes within content.<sup>24</sup> The analysis was guided especially by theory on being a caregiver. Accordingly, the purpose was to define the situations and thoughts experienced by the caregivers. An iterative sampling process was used. Two researchers independently created codes manually. After this, all researchers gathered, had discussions on the codes and reached a consensus. The data collection process was completed when the coders decided that saturation had been achieved. At the last stage, the researchers checked the data to ensure that the themes were internally consistent and distinguishable from each other.

# RESULTS

Within the period of the study, 24 ICs were included. The study excluded 4 individuals as they were not ICs, 2 as they did not agree to participate in the study and 2 as they did not speak Turkish. The mean age of the ICs was  $40.79\pm7.07$  years, while the mean duration of the diagnoses of the patients was  $4.37\pm1.01$  months. The characteristics of the ICs are presented in Table 2.

#### THEMES

The codes were combined to constitute three major themes and nine subthemes that categorized the thoughts and feelings of the ICs as detailed below.

#### Caregivers' perception

**Subtheme.** Daily life-Most of the ICs had to continue their daily lives while providing care for their patients. Although the reasons for their difficulties varied, it was understood that they had difficulty in trying to participate in all aspects of life. "[It is] difficult... Strangely, my spouse was also diagnosed with cancer. She also received chemotherapy treatment. I have 2 cancer patients at home." (P15, F)

"I do it, I keep up with all. We have 2 children. I need to not only take care of the home but also be nice to my spouse." (P17, F)

*Subtheme-Difficulties experienced*-It was understood that the ICs mainly had difficulty regarding issues such as supplying medication and blood. Moreover, they also had difficulties originating from the existing conditions of the hospital.

"Going to the pharmacy tires me a bit. They prescribe drugs here, I go to the pharmacy, but the drug is not available sometimes." (P24, F)

"The issue of finding blood has put a lot of strain on us. We have been dealing with [trying to find] blood since the morning. One arrived but was not compatible. They want fresh blood, no recent medication or alcohol use. Donors arrive, but we can barely find one person from among four." (P18, F)

"I have difficulty because not only room at the hospital has a toilet. The most difficult part for the patient and their companion is this." (P21, F)

*Subtheme-Social support*-It was determined that, in general, there were individuals around the ICs from whom they could get support. However, they still did not want to receive support, and they preferred to take care of their patients by themselves.

"I have a daughter and a niece. My niece is also a nurse. They help." (P6, F)

"He has a[n older] sister who could help, I also have a[n older] brother. ...his sister could not even help herself. She has scoliosis, her condition is 2 times [harder]." (P1, F)

*Subtheme-Health problems*-It was found that, when the ICs started to take care of their patients, anxiety, insomnia, and complaints.

"Sadness, stress, sleeplessness... I am a huge crybaby. I restrained myself a lot to keep myself from crying in front of my mother. I thought of getting psychological support, but then, I did not know what type

	Ī	TABLE 2: Th	e sociodemogra	phic characteristic	s of the inform	al caregivers.			
Age (X±SD, N	linimum-Max	i <b>mum)</b> (40.79±7	.07; 27-66)						
Diagnosis tim	ne (Months) (≀ً	k±SD, Minimum	Maximum) (4.37±1.	01; 1.16-4.37)					
Relationship to How she/he									
Participants	Gender	patient	Working status	Financial difficulty	Marital status	Transplant type	about caring?		
1	Female	Wife	Retired	Yes	Married	Autologous	Partially enough		
2	Female	Wife	Housewife	Yes	Married	Autologous	Enough		
3	Female	Sister	Housewife	Yes	Single	Autologous	Enough		
4	Male	Child	Retired	Yes	Married	Autologous	Enough		
5	Female	Wife	Housewife	Yes	Married	Autologous	Enough		
6	Female	Wife	Housewife	Yes	Married	Autologous	Partially enough		
7	Female	Sister	Working	Yes	Single	Allogeneic	Partially enough		
8	Female	Mother	Housewife	Yes	Married	Allogeneic	Enough		
9	Female	Wife	Housewife	Yes	Married	Unrelated donor	Enough		
10	Female	Child	Housewife	Yes	Married	Autologous	Enough		
11	Male	Child	Working	Yes	Married	Unrelated donor	Enough		
12	Female	Child	Housewife	Yes	Married	Allogeneic	Partially enough		
13	Male	Husband	Working	Yes	Married	Unrelated donor	Not enough		
14	Female	Brother	Housewife	Yes	Married	Unrelated donor	Enough		
15	Female	Child	Retired	No	Married	Unrelated donor	Enough		
16	Male	Husband	Retired	Yes	Married	Autologous	Enough		
17	Female	Wife	Housewife	Yes	Married	Allogenic	Enough		
18	Female	Wife	Housewife	Yes	Married	Allogenic	Partially enough		
19	Female	Wife	Housewife	Yes	Married	Autologous	Not enough		
20	Male	Sister	Working	Yes	Married	Autologous	Enough		
21	Female	Sister	Housewife	Yes	Married	Allogenic	Enough		
22	Female	Brother	Housewife	No	Married	Allogenic	Enough		
23	Male	Husband	Retired	Yes	Married	Allogenic	Enough		
24	Female	Child	Housewife	Yes	Single	Allogenic	Partially enough		

SD: Standard deviation.

of drugs they would give me. I did not want to [receive psychological help] thinking that the drug they would give me could affect me, and I would not be able to help my mother. " (P8, F)

#### Thoughts and feelings

*Subtheme-Feelings*-The ICs experienced feelings like sadness, sorrow and concern in the caregiving process. It was understood that these feelings originated from remembering the past state of the patients or concerns about the future.

"I am very saddened. It is indescribable. For instance, she sees everything on Instagram, cries and gets sad. She says, 'my friends are going out and having fun'. She is not a small child, either; I cannot fool her. All patients around us have died, and she says, 'it is my turn now'." (P15, F) *Subtheme-Changes in relationships*-It was seen that, after the ICs started provided care, their relationships changed in a positive direction, and they became more tolerant.

"In our relationship, yes, I guess we bonded more. Now, she cries even when I am going home, and I cry, too. I say, 'I will be back, stop crying'." (P7, F)

"Of course, it changed. I said, 'I shall see my grandchildren even if it is for 2 hours'. He said to me, 'I am now your grandchild, I am your everything'." (P9, F)

#### What if I became ill...

It was observed that most of the ICs would prefer to be in the shoes of their patients. Some of them also said their patients had taken care of them in the past.

"(gets watery eyes) If only I were ill instead of her. She says, 'I would not do what you are doing now', but I know she would, she would as much as her strength would allow." (P16, M)

However, there were also ICs who stated that others would not or could not take care of them if they got ill.

"I do not think so at all. My husband is unable to deal with trouble. We have been married for 21 years, but he is not a person who has held my hand and taken to the doctor. I do not suppose he would bear with me this much." (P2, F)

#### **Expectations**

*Subtheme-Expectations from the future*-Although the expectations of the ICs appeared to be full of hope, their expressions suggested that they had anxiety, doubt and fear.

"Doctors have told us since 2004 that having a child is out of the question. She wants to become a mother, and I want to become a father." (P13, M)

Subtheme-Expectations from institutions-The ICs had expectations from institutions for their desire to provide care for their patients more easily. These expectations were observed to be recommendations originating from the problems they experienced themselves or as a result of the events they witnessed.

"The problem is that the toilets are not inside the room, and all patients are at a disadvantage regarding patient privacy. The state should, please, support the hospital." (P1, F)

### DISCUSSION

It was determined that the majority of caregivers are women. It was also found that only four caregivers were working. ICs fulfill the duty of providing unpaid care. Often spouses take on the role of ICs. In studies conducted with ICs, it is stated that caregivers are related to caregiver burden such as gender, marital status, family income, duration of caregiving, daily caregiving time, caregiver support, transplantrelated complications. In addition, due to these problems, their caregiver burden increases and their quality of life decreases.<sup>20</sup>

In this study, it was determined that the ICs had to additionally deal with their daily-life affairs while providing care for their patients and were strained. HSCT is a complicated process. In this period, the patient needs ICs in the physical, psychological and financial sense as much as they need the medical assistance of healthcare professionals. Studies conducted with ICs of HSCT patients have reported that caregivers supported their patients in many areas of their lives including medication management, emotional and financial support and helping their dailylife activities.<sup>27</sup> The fact that patients require support in many areas leads their caregivers to experience burden. Similar to this study, a study conducted with HSCT patients determined that they experienced moderate and severe levels of burden.<sup>20</sup>

Although caregiver burden develops for different reasons in cases of different diseases, it emerges especially when support is not received. In this study, it was learned that the ICs had difficulties while providing care for their patients and could not get support. Other studies conducted with caregivers of cancer patients have also found that caregivers experienced burden. A study conducted with ICs of allo-HSCT patients revealed that the participants experienced burden and they found it most difficult to cope with uncertainty about the future by 79% and their own emotions by 70%.23 Another study conducted with HSCT patients also reported that issues such as receiving help in caregiving, treatment-related complications, relapse and the duration of caregiving affected caregiver burden at a rate of 75.4%.<sup>20</sup> Similar to the literature, the nature of the disease and the difficulty of the treatment process also cause caregivers to experience burden and have reduced quality of life.<sup>28</sup>

The results of this study demonstrated that the ICs experienced psychological problems such as fear, concern, inattentiveness, and sleep problems. This issue was confirmed by quantitative studies conducted with caregivers of HSCT patients, and accordingly, caregivers experienced the fear of the relapse of the cancer most.<sup>20</sup> Again, caregivers also experienced fear due to the effects of the treatment that is administered and the fact that the disease is unpredictable.<sup>29</sup> As known, throughout the HSCT process, side effects like infection, organ-specific complications, secondary cancers and graft versus host disease may develop.<sup>30</sup> These possible complications increase the fear and concerns of caregivers. Depending on the symptoms experienced by the patient, caregivers experience fatigue, sleep disturbance, pain, physical problems and loss of appetite.<sup>31</sup> A study conducted in Türkiye similarly reported that symptoms including interpersonal sensitivity, compulsive symptoms, hostility, somatization, phobic anxiety and depression were encountered in HSCT patients and their relatives.<sup>32</sup> These psychological symptoms experienced by caregivers remain even years after the transplantation, and they are seen 3.5 times more prevalently in especially spouses in comparison to the general population.<sup>33</sup>

ICs who were included in this study also expressed a set of problems originating from the physical environment of the institution and those they observed in other caregivers in their caregiving process. These problems were their necessity to use communal toilets and that caregivers coming from outside the province do not have accommodation facilities. The literature review in this study did not reveal any previous study on the effects of the physical conditions of the hospital on the caregiver. Nevertheless, a qualitative study conducted with children aged 6-18 reported that the children said the showers and toiled in their corridor were inadequate in terms of providing privacy, and private toilets and showers should be included in every room.<sup>34</sup> Therefore, it is thought that it was natural for the caregivers included in this study to demand more privacy for their patient at a unit where adult patients stayed. Similarly, previous studies have found that caregivers of cancer patients experience financial difficulties besides physical, social and psychological difficulties after the diagnosis of the patient.<sup>20,27,35</sup> Thus, the financial difficulties that are experienced do not allow the patient's relative to stay in accommodation facilities like hotels and hostels. For this reason, caregivers are not able to go to a hotel to rest, and they constantly

stay at the hospital. The caregivers who were aware of how difficult this situation is stated that they had expectations about this issue for other caregivers though not for themselves.

#### STRENGTHS AND LIMITATIONS

This study had a few limitations. One of these was that caregivers who did not speak or understand Turkish were not included in the study. The fact that these caregivers would not be able to communicate with the researcher due to their language barrier suggests that they would experience communication problems at other times, too. A caregiver experiencing communication problems could provide much more different perspectives. Hence, it may be recommended for future studies to include caregivers who do not speak Turkish by utilizing the services of an interpreter. Another limitation of the study was that it was carried out at a single BMT unit. Although this issue makes it more difficult for the results of the study to be generalized to the entire population of Türkiye, it was considered significant that this study was conducted at the adult BMT unit of a prominent university hospital in Türkiye.

On the other hand, the strengths of the study are that caregivers are not always in the BMT unit, and therefore the work with caregivers is usually the study done at home after discharge. Therefore, it is important because the study is done with caregivers in the unit as companions. It is important to understand the experiences of caregivers in the process that requires intensive care while the patient is being treated at the hospital.

## CONCLUSION

Consequently, in this study, it was determined that the ICs of HSCT patients had difficulties in the caregiving process, could not receive support and experienced especially psychological problems. Moreover, it was revealed that the caregivers had expectations from institutions regarding their need to provide care for their patients more easily. Although the thoughts and experiences of caregivers towards caregiving are not negative, they should be supported to reduce their burden. During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

#### **Conflict of Interest**

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

### Authorship Contributions

Idea/Concept: Dilek Baykal, Gülbeyaz Can, Fatma Bilgin, İpek Yönal Hindilerden, Meliha Nalçacı; Design: Dilek Baykal, Gülbeyaz Can, Fatma Bilgin, İpek Yönal Hindilerden, Meliha Nalçacı; Control/Supervision: Dilek Baykal, Gülbeyaz Can, Fatma Bilgin, İpek Yönal Hindilerden, Meliha Nalçacı; Data Collection and/or Processing: Dilek Baykal, Gülbeyaz Can; Analysis and/or Interpretation: Dilek Baykal, Gülbeyaz Can; Analysis and/or Interpretation: Dilek Baykal, Fatma Bilgin; Literature Review: Dilek Baykal, Gülbeyaz Can; Writing the Article: Dilek Baykal, Gülbeyaz Can, Fatma Bilgin, İpek Yönal Hindilerden, Meliha Nalçacı; Critical Review: Dilek Baykal, Gülbeyaz Can, Fatma Bilgin, İpek Yönal Hindilerden, Meliha Nalçacı; References and Fundings: Dilek Baykal, Gülbeyaz Can.

### REFERENCES

- Guilcher GMT, Truong TH, Saraf SL, Joseph JJ, Rondelli D, Hsieh MM. Curative therapies: allogeneic hematopoietic cell transplantation from matched related donors using myeloablative, reduced intensity, and nonmyeloablative conditioning in sickle cell disease. Semin Hematol. 2018;55(2):87-93. [Crossref] [PubMed] [PMC]
- Castagna A, Mcmonagle L, Eeltink C, Liptrott S. Transplantation through the generations. In: Kenyon M, Babic A, eds. The European Blood and Marrow Transplantation Textbook for Nurses: Under the Auspices of EBMT. 1<sup>st</sup> ed. Cham (CH): Springer; 2018. [Crossref] [PMC]
- Holochwost SJ, Robb SL, Henley AK, Stegenga K, Perkins SM, Russ KA, et al. Active music engagement and cortisol as an acute stress biomarker in young hematopoietic stem cell transplant patients and caregivers: results of a single case design pilot study. Front Psychol. 2020;11:587871. [Crossref] [PubMed] [PMC]
- Breitbart WS, Alici Y. Psycho-oncology. Harv Rev Psychiatry. 2009;17(6):361-76. [Crossref] [PubMed]
- Bergkvist K, Winterling J, Kisch AM. Support in the context of allogeneic hematopoietic stem cell transplantation-the perspectives of family caregivers. Eur J Oncol Nurs. 2020;46:101740. [Crossref] [PubMed]
- Anderson EW, White KM. "It has changed my life": an exploration of caregiver experiences in serious illness. American Journal of Hospice and Palliative Medicine. 2017;35(2):266-74. [Crossref] [PubMed] [PMC]
- Krol M, Papenburg J, van Exel J. Does including informal care in economic evaluations matter? A systematic review of inclusion and impact of informal care in cost-effectiveness studies. Pharmacoeconomics. 2015;33(2):123-35. [Crossref] [PubMed]
- Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist. 1986;26(3):260-6. [Crossref] [PubMed]
- Gillen G. Caregiving after stroke. Stroke Rehabilitation. 4th ed. Missouri: Elseiver. 2016. p.309-27. [Crossref]
- Upton KV. An investigation into compassion fatigue and self-compassion in acute medical care hospital nurses: a mixed methods "1study. J Compassion Health Care. 2018;5(1):7. [Crossref]
- Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, Watzke H, et al. Informal caregivers of advanced-stage cancer patients: every sec-

ond is at risk for psychiatric morbidity. Support Care Cancer. 2016;24(5):1975-82. [Crossref] [PubMed]

- Ugalde A, Gaskin CJ, Rankin NM, Schofield P, Boltong A, Aranda S, et al. A systematic review of cancer caregiver interventions: Appraising the potential for implementation of evidence into practice. Psychooncology. 2019;28(4):687-701. [Crossref] [PubMed] [PMC]
- Russell JA, Poon MC, Jones AR, Woodman RC, Ruether BA. Allogeneic bone-marrow transplantation without protective isolation in adults with malignant disease. Lancet. 1992;339(8784):38-40. [Crossref] [PubMed]
- Svahn BM, Remberger M, Myrbäck KE, Holmberg K, Eriksson B, Hentschke P, et al. Home care during the pancytopenic phase after allogeneic hematopoietic stem cell transplantation is advantageous compared with hospital care. Blood. 2002;100(13):4317-24. [Crossref] [PubMed]
- Prieto JM, Atala J, Blanch J, Carreras E, Rovira M, Cirera E, et al. Role of depression as a predictor of mortality among cancer patients after stem-cell transplantation. J Clin Oncol. 2005;23(25):6063-71. [Crossref] [PubMed]
- Frey P, Stinson T, Siston A, Knight SJ, Ferdman E, Traynor A, et al. Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. Bone Marrow Transplant. 2002;30(11):741-8. [Crossref] [PubMed]
- Biagioli V, Piredda M, Mauroni MR, Alvaro R, De Marinis MG. The lived experience of patients in protective isolation during their hospital stay for allogeneic haematopoietic stem cell transplantation. Eur J Oncol Nurs. 2016;24:79-86. [Crossref] [PubMed]
- Can G, Erdal S, Koçubaba Ş. Kemik İliği Nakli Hemşireliğinde Kanıta Dayalı Bakım-Konsensus 2018. 1. Baskı. İstanbul: Nobel Tıp Kitapevi; 2020.
- Bagcivan G, Ozen N, Bayrak D, Cinar FI. Does being a cancer patient or family caregiver of a cancer patient affect stem cell donation awareness? Asia Pac J Oncol Nurs. 2019;7(1):36-43. [Crossref] [PubMed] [PMC]
- Xie L, Shen C, Shi Y, Li H. Caregiver burden among primary family caregivers of patients undergoing hematopoietic stem cell transplantation: a cross-sectional study from Suzhou, China. Cancer Nurs. 2021;44(6): E556-E66. [Crossref] [PubMed]

- Bergkvist K, Larsen J, Johansson UB, Mattsson J, Fossum B. Family members' life situation and experiences of different caring organisations during allogeneic haematopoietic stem cells transplantation-a qualitative study. Eur J Cancer Care (Engl). 2018;27(1). [Crossref] [PubMed]
- Xie L, Li H, Jing XC. Qualitative study on the experience and needs of caregivers of patients with hematopoietic stem cell transplantation. Chinese J Pract Nurs. 2017;033(024):1885-8.
- Kisch AM, Bergkvist K, Alvariza A, Årestedt K, Winterling J. Family caregivers' support needs during allo-HSCT-a longitudinal study. Support Care Cancer. 2021;29(6):3347-56. [Crossref] [PubMed] [PMC]
- Sundler AJ, Lindberg E, Nilsson C, Palmér L. Qualitative thematic analysis based on descriptive phenomenology. Nursing Open. 2019;6(3):733-9. [Crossref] [PubMed] [PMC]
- Holloway I, Galvin K. Qualitative Research in Nursing and Healthcare. 4th ed. Chichester, West Sussex, UK: John Wiley & Sons; 2017.
- Anney VN. Ensuring the quality of the findings of qualitative research: looking at trustworthiness criteria. Journal of Emerging Trends in Educational Research and Policy Studies. 2014;5:272-81. [Link]
- Sannes TS, Simoneau TL, Mikulich-Gilbertson SK, Natvig CL, Brewer BW, Kilbourn K, et al. Distress and quality of life in patient and caregiver dyads facing stem cell transplant: identifying overlap and unique contributions. Support Care Cancer. 2019;27(6):2329-37. [Crossref] [PubMed] [PMC]
- Hu X, Peng X, Su Y, Huang W. Caregiver burden among Chinese family caregivers of patients with lung cancer: a cross-sectional survey. Eur J Oncol Nurs. 2018;37:74-80. [Crossref] [PubMed]

- Sabo B, McLeod D, Couban S. The experience of caring for a spouse undergoing hematopoietic stem cell transplantation: opening Pandora's box. Cancer Nurs. 2013;36(1):29-40. [Crossref] [PubMed]
- Applebaum AJ, Bevans M, Son T, Evans K, Hernandez M, Giralt S, et al. A scoping review of caregiver burden during allogeneic HSCT: lessons learned and future directions. Bone Marrow Transplant. 2016;51(11): 1416-22. [Crossref] [PubMed] [PMC]
- Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. JAMA. 2012;307(4): 398-403. [Crossref] [PubMed] [PMC]
- Çuhadar D, Tanriverdi D, Pehlivan M, Kurnaz G, Alkan S. Determination of the psychiatric symptoms and psychological resilience levels of hematopoietic stem cell transplant patients and their relatives. Eur J Cancer Care (Engl). 2016;25(1):112-21. [Crossref] [PubMed]
- Bishop MM, Beaumont JL, Hahn EA, Cella D, Andrykowski MA, Brady MJ, et al. Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivormatched controls. J Clin Oncol. 2007;25(11):1403-11. [Crossref] [PubMed]
- Schalkers I, Dedding CW, Bunders JF. '[I would like] a place to be alone, other than the toilet'--Children's perspectives on paediatric hospital care in the Netherlands. Health Expect. 2015;18(6):2066-78. [Crossref] [PubMed] [PMC]
- Salsman JM, Danhauer SC, Moore JB, Ip EH, McLouth LE, Nightingale CL, et al. Systematic review of financial burden assessment in cancer: Evaluation of measures and utility among adolescents and young adults and caregivers. Cancer. 2021;127(11):1739-48. [Crossref] [PubMed] [PMC]