

Does Being A Cancer Patient or Family Caregiver of A Cancer Patient Affect Stem Cell Donation Awareness?

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ABSTRACT

Objective: One of the most difficult challenges regarding hematopoietic stem cell transplantation in Turkey is finding donors for allogeneic transplantation candidates who do not have related donors. This study aims to determine whether there is any difference in the awareness of stem cell donation and transplantation between cancer and noncancer patients and their family caregivers. In addition, this study aims to determine the awareness of stem cell donation and transplantation in the entire study population. **Methods:** This descriptive study was conducted in Turkey using a data collection form comprising questions about demographics, stem cell transplantations, donations, and medical history. On analyzing the research data, variables were expressed as mean \pm standard deviation and as numbers (n) and percentages (%). The Chi-square and Fisher's exact tests were performed to evaluate differences

among cancer and noncancer diagnosed patients and their family members. **Results:** A total of 192 patients and 169 family caregivers participated in the study. In comparison with noncancer patients, cancer patients showed more awareness on what stem cell transplantation is, how lifesaving it is, and how to donate stem cells. Similarly, the family caregivers of cancer patients were more aware of what stem cell transplantation is and how to donate stem cells. **Conclusions:** The results of this study showed that cancer patients and their families were more aware of stem cell donation and transplantation; however, most of the patients and families did not know enough about the national registry program and how to donate stem cells.

Key words: Awareness, cancer, donation, stem cell transplantation

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Introduction

National and international guidelines and organizations recommend hematopoietic stem cell transplantation (HSCT) using hematopoietic progenitor cells from the patient (autologous HSCT) or a donor (allogeneic HSCT) as a potentially curative therapy for many life-threatening cancers and nonmalignant disorders.^[1-3]

The Worldwide Network for Blood and Marrow Transplantation (WBMT) stated that a total of 68,146 hematopoietic cell transplantations (HCTs) (31,926 allogeneic, 47%; 36,220 autologous, 53%) were reported by 1566 teams from 77 of the 79 countries known to have performed HSCTs for the year 2012 in the worldwide report.^[2] The Turkish Society of Hematology stated that a total of 3594 HCTs were performed in 77 HCT centers (53 adults and 24 pediatrics) in Turkey in 2015. Of those HSCTs, 1893 were autologous, whereas 1701 were allogeneic. In addition, it was stated that 1096 of them were from a related donor, 391 were from an unrelated donor, and 214 were haploidentical transplantations.^[4]

Although stem cell banking has been carried out by two universities in Turkey since 1999, these banks have only reached 60,000 donors.^[4] Currently, these universities are collaborating with the Republic of Turkey Ministry of Health (MoH) to increase stem cell donations in Turkey. One of the most difficult challenges about HSCT in Turkey has been finding unrelated donors for allogeneic transplantation candidates who do not have related donors. As a result of this, the TURKOK project was launched in 2014 in cooperation with the MoH and these two universities. TURKOK is the Turkish acronym for the Stem Cell Coordination Center of Turkey.^[4,5] The project aimed to establish a stem cell donor pool and stem cell bank in Turkey. Intending to recruit more donors, the MoH is collaborating with the Turkish Red Crescent as part of the TURKOK project. Furthermore, the TURKOK applied to become a member of the WBMT.^[5]

Prior studies on stem cell donation have shown that having a relative or friend who had previously donated stem cells, being a regular blood donor, having knowledge about stem cell donation, having an intrinsic desire to help others, and having discussions with family members about tissue and organ donation have all positively affected the decision to become a stem cell donor.^[6-8] On the other hand, it was stated that perceiving the recruitment staff as underinformed, being discouraged from donating, not having an intrinsic desire to donate, being encouraged by one's culture or religion to donate (knowing that donation is permissible in their religion), believing that there are risks to donation, having a high number of medical issues, not having the time, worrying about resources, and

having family concerns about donation were the factors associated with high levels of ambivalence toward stem cell donation.^[8-11]

Extensive literature from Turkey and around the world have described factors associated with donating stem cells and knowledge about stem cell donation. However, most of these studies included people who had already resisted donating stem cells^[9,10,12] or were university students.^[13-15] To the best of our knowledge, this is the first study that focuses on the level of awareness of stem cell donation and transplantation in cancer and noncancer patients and their family caregivers. This study aims not only to determine any differences in the awareness of stem cell donation and transplantation between cancer and noncancer patients and their family caregivers but also to determine the awareness of stem cell donation and transplantation in the entire study population. Furthermore, this study aims to determine the awareness of participants about the national registry program. Our long-term aim is to use the results of this study for further actions in increasing awareness in the population regarding stem cell donation.

Methods

Setting and patients

This descriptive study was conducted in a training and research hospital in Ankara, Turkey, between January and August 2016. We recruited patients who were admitted to both inpatient services and outpatient clinics of medical oncology, hematology, and general medicine along with the patients' family members. Only patients who were 18 years of age or older with cancer or another chronic disease, who were able to understand and speak Turkish, who did not have communication limitations, and who were willing to participate in this study were included in the study. Family members who took part in the study met the same requirements as the patients with the exception of having a disease. Patients and family caregivers were not enrolled if they did not follow these inclusion criteria. There was no other specific criterion for exclusion from the study.

Data collection and sources

This study was approved by the hospital's Institutional Review Board (IRB) (Approval No. IRB #387). Researchers collected the data in inpatient services and outpatient clinics after written informed consent was obtained from each patient and family member in accordance with the Declaration of Helsinki. Data were collected via face-to-face interviews using a data collection form by the researchers at the medical oncology/hematology and internal medicine

inpatient services as well as outpatient clinics. Data collection took approximately 20 min for each participant. A data collection form was developed by the researchers based on a previous study in literature conducted on stem cell donation.^[9-14] The data collection form comprised questions on demographic/medical characteristics (age, diagnosis [for patients], gender, marital status, education status, living arrangements, employment status, and having relatives/friends who had stem cell transplantation) and stem cell donation/transplantations (knowing what stem cell donation/transplantation is, believing that stem cell transplantation is lifesaving, willingness to donate stem cells, having access to informational resources about stem cell donation/transplantation, and knowing about the National Stem Cell Bank).

Statistical analysis

The Statistical Package for the Social Sciences (SPSS) version 21.00 (SPSS Inc., Chicago, IL, USA) was used to analyze the data. Continuous variables were expressed as mean \pm standard deviation, and categorical variables were expressed as numbers and percentages. The Chi-square test and Fisher's exact test were performed to evaluate differences among cancer and noncancer diagnosed patients and their family members. $P < 0.05$ was accepted as the level of significance.

Results

Table 1 shows the demographic characteristics of a total of 192 patients and 169 family caregivers. The mean age of the patients was 41 ± 15.4 years. Of these patients, 56.3% had cancer, 51% were female, 63% were married, and 45.3% had completed higher education. In addition, 82.8% were living in urban areas and 56.3% were unemployed. The mean age of the family caregivers was 40.48 ± 13.04 years, and 82.2% were family caregivers of the patients. Of the family caregivers, 53.3% were female, 71.6% were married, 50.3% completed higher education, 84% were living in urban areas, and 52.1% were unemployed. Finally, 83% of the patients and 78.7% of the family caregivers did not have relatives or friends who had undergone stem cell transplantation [Table 1].

The comparison of patients' and family caregivers' awareness levels of stem cell donation and transplantation is shown in Table 2. It was found that, compared to noncancer patients, believing in stem cell transplantation as a lifesaving treatment ($\chi^2 = 7.790$, $P = 0.020$), knowing about stem cell donation ($\chi^2 = 7.276$, $P = 0.026$), and knowing how to donate stem cells ($\chi^2 = 7.600$, $P = 0.006$) were more statistically significant in cancer patients. It was found that, compared to noncancer patients' family caregivers, knowing about stem cell donation ($\chi^2 = 7.120$, $P = 0.028$) and

Table 1: Demographic characteristics of patients and family caregivers

Characteristics	Mean \pm SD or n (%)	
	Patients (n=192)	Family caregivers (n=169)
Age (years)	41.00 \pm 15.43	40.48 \pm 13.04
Patient/family caregiver group		
Cancer*	108 (56.3)	139 (82.2)
Noncancer**	84 (43.8)	30 (17.8)
Gender		
Female	98 (51.0)	90 (53.3)
Male	94 (49.0)	79 (46.7)
Marital status		
Married	121 (63.0)	121 (71.6)
Single	71 (37.0)	48 (28.4)
Education status		
Primary graduate	55 (28.6)	40 (23.7)
High school	50 (26.0)	44 (26.0)
College or graduate degree	87 (45.3)	85 (50.3)
Living area		
Urban	159 (82.8)	142 (84.0)
Rural	33 (17.2)	27 (16.0)
Current employment status		
Employed	84 (43.8)	81 (47.9)
Unemployed	108 (56.3)	88 (52.1)
Having relatives/friends who have had stem cell transplantation		
Yes	32 (16.7)	36 (21.3)
No	160 (83.3)	133 (78.7)

SD: Standard deviation. *Breast cancer, colon cancer, lung cancer, testicular cancer, gastric cancer, leukemia, lymphoma, ovarian cancer, **Hypertension, diabetes, chronic heart disease, chronic anemia

Table 2: Patients' and family caregivers' knowledge and awareness of stem cell transplantation by disease group

Knowledge and awareness	Cancer patients (n=108), n (%)	Noncancer patients (n=84), n (%)	Cancer patients' family caregivers (n=139), n (%)	Noncancer patients' family caregivers (n=30), n (%)
Knowing what "stem cell transplantation" is				
Never heard about it	9 (8.3)	11 (13.1)	9 (6.5)	2 (6.7)
Heard about it but did not know exactly what it is	68 (63.0)	50 (59.5)	80 (57.6)	18 (60.0)
Heard about it and knew exactly what it is	31 (28.7)	23 (27.4)	50 (36.0)	10 (33.3)
χ^2 , P	1.149, 0.563		0.075, 0.963	
Believing that stem cell transplantation is a lifesaving therapy**				
Yes	97 (98.0)	64 (87.7)	118 (90.8)	27 (96.4)
No	-	2 (2.7)	4 (3.1)	-
Neutral	2 (2.2)	7 (9.6)	8 (6.2)	1 (3.6)
χ^2 , P	7.790, 0.020		1.212, 0.546	
Knowing what "stem cell donation" is				
Never heard about it	41 (38.0)	29 (34.5)	38 (27.3)	15 (50.0)
Heard about it but did not know exactly what it is	40 (37.0)	45 (53.6)	64 (46.0)	12 (40.0)
Heard about it and knew exactly what it is	27 (25.0)	10 (11.9)	37 (26.6)	3 (10.0)
χ^2 , P	7.276, 0.026		7.120, 0.028	
Knowing how to donate stem cells****				
Yes	23 (34.3)	7 (12.7)	32 (31.7)	1 (6.7)
No	44 (65.7)	48 (87.3)	69 (68.3)	14 (93.3)
χ^2 , P	7.600, 0.006		4.015, 0.045	
Donated stem cells****				
Yes	1 (1.5)	1 (1.8)	6 (5.9)	-
No	66 (98.5)	54 (98.2)	95 (94.1)	15 (100.0)
χ^2 , P	0.020, 0.888		0.940***, 0.332	
Willingness to donate stem cells****				
Yes	55 (82.1)	40 (72.7)	68 (67.3)	9 (60.0)
No	-	3 (5.5)	15 (14.9)	1 (6.7)
Neutral	12 (21.8)	12 (21.8)	18 (17.8)	5 (33.3)
χ^2 , P	4.229***, 0.121		2.325, 0.313	
Knowing the next step if stem cells match after stem cell donation****				
Yes	25 (37.3)	23 (41.8)	49 (48.5)	5 (33.3)
No	42 (62.7)	32 (58.2)	52 (51.5)	10 (66.7)
χ^2 , P	0.257, 0.612		1.210, 0.271	
Knowing what the "stem cell bank" is				
Never heard about it	39 (36.1)	34 (40.5)	41 (29.5)	11 (36.7)
Heard about it but did not know exactly what it is	33 (30.6)	29 (34.5)	46 (33.1)	13 (43.3)
Heard about it and knew exactly what it is	36 (33.3)	21 (25.0)	52 (37.4)	6 (20.0)
χ^2 , P	1.572, 0.456		3.333, 0.189	
Knowing about the national stem cell donation program (n=192)				
Never heard about it	95 (88.0)	77 (91.7)	114 (82.0)	29 (96.7)
Heard about it but did not know exactly what it is	9 (8.3)	7 (8.3)	13 (9.4)	1 (3.3)
Heard about it and knew exactly what it is	4 (3.7)	-	12 (8.6)	-
χ^2 , P	3.183, 0.204		4.295, 0.117	

*Chi-square test, **It was asked to patients who stated that they heard/knew about stem cell transplantation (n=172 patients) (n=158 family caregivers), *** Fisher's exact test, ****It was asked to patients who stated that they heard/knew about stem cell donation (n=122) (n=116 family caregivers)

knowing how to donate stem cells ($\chi^2 = 4.015, P = 0.045$) were more statistically significant in cancer patients' family caregivers. There were no other statistically significant differences between cancer and noncancer patients and their family caregivers ($P > 0.05$) [Table 2].

Table 3 summarizes the results regarding the knowledge and awareness of stem cell transplantation and donation of the participants without separating the status of cancer and noncancer. Of the participants, 8.6% of them had never

heard about stem cell transplantation before, 59.8% had heard about it but did not know exactly what it is, and 31.6% had heard about it and knew exactly what it is. In addition, 93.0% of the participants stated that they believe that stem cell transplantation is lifesaving. Of the participants, 34.1% had never heard about stem cell donation before, 44.6% had heard about it but did not know exactly what it is, and 21.3% had heard about it and knew exactly what it is. Moreover, 96.6% of the participants had never donated

Table 3: Participants' knowledge and awareness of stem cell transplantation (n=361)

Knowledge and awareness	n (%)
Knowing what "stem cell transplantation" is	
Never heard about it	31 (8.6)
Heard about it but did not know exactly what it is	216 (59.8)
Heard about it and knew exactly what it is	114 (31.6)
Sources of information about stem cell transplantation ^{*,Y}	
Television	163 (49.3)
The Internet	112 (33.9)
Health-care professionals	95 (28.7)
Relatives/friends	98 (29.6)
Newspaper/magazine	62 (18.8)
Other ^{***}	22 (6.6)
Believing that stem cell transplantation is a lifesaving therapy ^Y	
Yes	307 (93.0)
No	6 (1.8)
Neutral	17 (5.1)
Knowing what "stem cell donation" is	
Never heard about it	123 (34.1)
Heard about it but did not know exactly what it is	161 (44.6)
Heard about it and knew exactly what it is	77 (21.3)
Sources of information about stem cell donation ^{*,Y}	
Television	120 (50.0)
The Internet	76 (31.9)
Health-care professionals	67 (28.1)
Newspaper/magazine	53 (22.2)
Relatives/friends	53 (22.2)
Other ^{***}	15 (6.3)
Knowing how to donate stem cells ^Y	
Yes	63 (26.4)
No	175 (73.5)
Donated stem cells ^Y	
Yes	8 (3.3)
No	230 (96.6)
Knowing the next step if stem cells match after stem cell donation ^Y	
Yes	102 (42.8)
No	136 (57.1)
Having any relatives/friends who donated stem cells ^Y	
Yes	24 (10.08)
No	214 (89.9)
Willingness to donate stem cells ^Y	
Yes	172 (72.3)
No	19 (7.9)
Neutral	47 (19.7)
The reasons for unwillingness to donate stem cells ^{*,†}	
I do not know how to donate	22 (33.3)
I think it is harmful to my health	15 (22.7)
I think it is painful	10 (15.1)
Other ^{***}	11 (16.6)
Knowing what the "stem cell bank" is	
Never heard about it	125 (34.6)
Heard about it but did not know exactly what it is	121 (33.5)
Heard about it and knew exactly what it is	115 (31.9)
Sources of information about the stem cell bank ^{*,‡}	
Television	132 (55.9)
The Internet	82 (34.7)

Contd...

Table 3: Contd...

Knowledge and awareness	n (%)
Health-care professionals	61 (25.8)
Newspaper/magazine	53 (22.4)
Relatives/friends	43 (18.2)
Other ^{***}	10 (4.2)
Knowing about the national stem cell donation program	
Never heard about it	315 (87.3)
Heard about it but did not know exactly what it is	30 (8.3)
Heard about it and knew exactly what it is	16 (4.0)
Sources of information about national stem cell donation program ^{*,Y}	
Television	34 (73.9)
The Internet	18 (39.1)
Health-care professionals	8 (17.3)
Newspaper/magazine	13 (28.2)
Relatives/friends	4 (8.6)

*Multiple answers were selected, **School, other patients, ***Just do not want, have not had any change, I think people do something with my genes because of health problems, I am scared of giving blood, [†]Percentages were calculated for individuals who stated that they heard/know about stem cells (n=330), [‡]Percentages were calculated for individuals who stated that they heard/know about stem cell donation (n=238), [§]Percentages were calculated for individuals who stated that they were not willing (or neutral) to donate stem cells (n=66), [¶]Percentages were calculated for individuals who stated that they heard/know about stem cell bank (n=236), ^{||}Percentages were calculated for individuals who stated that they heard/know about national stem cell donation program (n=46)

stem cells, 73.5% did not know how to donate, 89.9% did not know anyone who had donated, 57.1% did not know what to do if stem cells matched after donation, and 72.3% of the participants stated that if they could, they would donate stem cells. The participants who did not want to donate stem cells or were not sure about donating stated that they did not want to donate because they did not know how (33.3%) and they thought donating would be harmful to their health (22.7%).

According to the participants' responses regarding the stem cell bank, 34.6% of the participants had never heard about the stem cell bank before, 33.5% had heard about it but did not know exactly what it is, and 31.9% had heard about it and knew exactly what it is [Table 3]. Most of the participants stated that they had heard about stem cell transplantation and donation mostly from television, the Internet, and health-care professionals [Table 3].

Discussion

To our knowledge, this is the first study to evaluate whether there were any differences in the awareness of stem cell donation and transplantation between cancer and noncancer patients and their family caregivers. One of the statistically significant results of this study was that, in comparison with noncancer patients, cancer patients showed more awareness in what exactly stem cell transplantation is, how lifesaving it is, and how to donate stem cells. Similarly, cancer patients' family caregivers were more aware of what exactly stem cell transplantation is and how to donate. This was not a surprise because HSCT is

the most specific treatment option for malignant disease.^[1] It is likely that these people are more sensitized to and more informed about HSCT. Not surprisingly, the family caregivers are influenced by their contact with patients in need of a stem cell transplant.

Another result of this study showed that, although most of the patients and family caregivers (without distinguishing between cancer and noncancer) were aware of what stem cell transplantation and stem cell donation were, they did not know how to donate stem cells. In addition, most of the patients and family caregivers stated that they were willing to donate stem cells even though almost all (96.6%) had never donated stem cells before. This result was not surprising because stem cell donation is still not at the desired level in Turkey.^[5] In another study conducted in Turkey, all the participants who were voluntary blood donors had never donated stem cells, similar to the results of our study.^[16]

A study conducted in Turkey to explore the knowledge and motivations of voluntary blood donors toward allogeneic hematopoietic stem cell donation showed that 91% of participants had never received information about hematopoietic stem cell donation and transplantation and 80% of them wished to receive such information.^[16] In this study, the most frequent reasons for the patients' and family caregivers' unwillingness to donate stem cells were not knowing how to donate and the belief that stem cell donation would be painful or harmful to their health. Similar to the results of this study, previous studies reported that the most frequent reasons for not being willing to donate were the inconvenience, the fear of pain and health problems, the cost, the lack of knowledge of a donor registry, the lack of trust in the health-care system, and their age and religion.^[12,17-19] It is important for the public to understand that a procedure like stem cell donation carries no significant risks to a donor's health and could help increase donation rates and save a patient's life. This is important because insufficient information may discourage a person from donating. In a review of the common short-term physical and psychological reactions to the donation process, which concentrated specifically on the possible influential factors, Billen *et al.* described the psychological aspects of donation such as "feeling like a better person as a result of donation" and "personal satisfaction and gratitude for an opportunity to donate."^[20] Similarly, another review by Garcia *et al.*, which synthesized published qualitative studies on the motivations and perspectives of bone marrow transplantations, identified "saving or improving someone's quality of life" as a common motivational reason regarding the decision to donate bone marrow.^[19] Most of the patients and family

caregivers who knew about stem cell transplantation and donation stated that they had learned about stem cell transplantation and donation through television, the Internet, and health-care professionals. Similarly, previous studies reported that most people who knew about donation had witnessed advertisements or promotional materials regarding organ donation on television and the Internet.^[21,22] Organ donation is a social necessity because transplantation is not possible without public collaboration. Informing the public may be accomplished more successfully by using mass media, educational brochures, lectures by health-care professionals, and the Internet.

Another important result of the current study was that most of the patients and family caregivers did not know about the national stem cell donation program. This result is not surprising because the data were collected only 1½ year after the national stem cell donation program was launched in Turkey. Even though the MoH had been advertising the national program during that time period, it may not have been enough to make an impact on the public. We recommend the planning of further research to get current data and compare these results in order to learn whether the situation has changed. Several studies have showed that those who had been informed about stem cell transplantation and the national stem cell donation program were significantly more willing to donate stem cells.^[6,17,18]

Limitations

There are several limitations of this study. The first one is the generalizability of this study. This is a single-center study that was conducted in one of the largest cities in Turkey. Even though these results give an idea about the situation, they cannot be generalized to other populations. Another limitation in this study can be the noninclusion of control participants without disease. Finally, using a survey such as the one in this study may have resulted in relatively insignificant knowledge and a superficial understanding of the phenomena.

Conclusion

The results of this study show that cancer patients and their family caregivers are aware of stem cell donation and transplantation; however, most of the patients and family caregivers do not know enough about the national stem cell donation program and how to donate. Based on the results of this study, we recommend that health-care professionals and government officials focus on increasing educational activities for patients, families, and the public regarding the stem cell donation process and the national stem cell donation program by using mass media and social networking. We also recommend that government departments such as the Turkish Ministry of National

Education and Religious Affairs Administration encourage the public to donate stem cells by providing positive encouragement. Transplantation and its known therapeutic benefits are not possible without the cooperation and support of health-care professionals, government, and the society as a whole.^[23] Educating the public about stem cell donation – showing that donation is not harmful to a donor's health and donation is permissible in their religion – may help change the negative perspectives and motivate the public to donate. Moreover, emphasizing the positive aspects of donation may also help motivate the public to have an intrinsic commitment to donate. Confidence in health-care professionals and sufficient knowledge of stem cell transplantation are essential because they can help decrease the fears about the negative perceptions of stem cell donation and make it easier for people to volunteer. As health-care professionals, nurses should be leading educational activities to encourage patients, families, and the public to donate not only in hospital settings but also in the public sphere. We believe that nursing schools can lead these kinds of activities by collaborating with other health-care professionals. Social media can be one of the most effective ways to reach the public in order to send out positive messages about stem cell donation.

We believe that further research is needed to investigate the levels of public awareness regarding the national stem cell donation program and to determine the prevalence of stem cell donation in order to see how the situation changes. Furthermore, we suggest that more qualitative researches should be conducted to better investigate the associated factors of stem cell donation and people's willingness or unwillingness to donate stem cells.

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Conflicts of interest

There are no conflicts of interest.

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