

EVALUATION OF THE AWARENESS OF STEM CELL DONATION

KÖK HÜCRE BAĞIŞÇILIĞI FARKINDALIĞININ DEĞERLENDİRİLMESİ

Çiğdem KEKİK ÇINAR^{1,2} , Ayşe Emel ÖNAL³ , Yasemin OYACI⁴ , Hülya GÜL³ , Nilgün BOZBUĞA⁵ ,
Fatma SAVRAN OĞUZ^{1,2} 

¹Istanbul University, Istanbul Faculty of Medicine, Department of Medical Biology, Istanbul, Türkiye

²Istanbul University, Istanbul Faculty of Medicine, Bone Marrow Registry Bank (TRIS), Istanbul, Türkiye

³Istanbul University, Center for Research and Practice in Community Medicine, Istanbul, Türkiye

⁴Istanbul University, Institute of Graduate Studies in Health Sciences, Medical Biology Program, Istanbul, Türkiye

⁵Istanbul University, Istanbul Faculty of Medicine, Department of Cardiovascular Surgery, Istanbul, Istanbul, Türkiye

ORCID ID: Ç.K.Ç. 0000-0003-2098-381X; A.E.Ö. 0000-0001-8321-6517; Y.O. 0000-0002-1338-0087; H.G. 0000-0002-2276-6184; N.B. 0000-0002-4401-5250; F.S.O. 0000-0002-6018-8936

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ABSTRACT

Objective: Many diseases, including bone marrow cancers (ALL, AML, etc.), lymphomas, hereditary anemia, and immune deficiencies, can be treated with hematopoietic stem cell transplantation (HSCT). Donors with Human Leukocyte Antigen (HLA) match are first sought from the patient's siblings, parents, and close relatives. If a suitable donor cannot be found within the family, the search for unrelated volunteer donors begins. HSC donor registry centers were created in order to pool volunteer donors. More than 40 million stem cell donors and 136 banks affiliated and collaborate with the World Marrow Donor Association (WMDA). These registry centers seek to find the most suitable stem cell donor for the patient by collecting tissue groups from the pool of donors and comparing them to tissue groups from patients who applied completely voluntarily. The purpose of this study is to determine the knowledge and attitudes toward stem cell donation of 5th year students at the Istanbul Faculty of Medicine and randomly selected adult members of society.

Material and Methods: The study included 285 students and 168 adults. Both groups completed a questionnaire with 21 questions using the interview under observation method.

Results: In a statistical comparison of student and public participants in terms of stem cell donation, the student group was found to be far more aware than the public participant group. When compared to the public participant group, the student group's desire to be stem cell donors was found to be very significant. The school in the student group and the written/visual media in the public participant group were extremely important in raising awareness.

Conclusion: The survey study we conducted revealed that the knowledge level of the public was insufficient, and the knowledge level of medical students was deficient. Information about stem cell donation should be disseminated in the written/visual media, in health institutions, and during the education period, in order to raise societal awareness and increase the number of donors in comparison to the country's population.

Keywords: stem cell, voluntary donation, stem cell transplant

ÖZ

Amaç: Hematopoetik kök hücre nakli (HKHN), kemik iliği kanserleri (ALL,AML vb), lenfomalar, kalıtsal anemiler ve immün yetersizlikler gibi birçok hastalığın tedavi seçeneğidir. Hastalara uygun insan lökosit antijen (HLA) doku tipine sahip vericiler öncelikle kişinin kardeşleri, anne-babası ve yakın akraba içi bireylerden taranır. Uygun verici aile içerisinde bulunamaz ise tarama, akraba olmayan gönüllü bağışçılar arasında yapılmaya başlanır. Gönüllü bağışçıları bir araya getirmek için hematopoetik kök hücre kayıt merkezleri oluşturulmuştur. 40 milyondan fazla kök hücre bağışçısı ile 136 kayıt merkezi Dünya Kemik İliği Donör Birliği'ne (WMDA) bağlı olarak işbirliği yapmaktadır. Bu çalışmanın amacı, İstanbul Tıp Fakültesi 5. sınıf tıp öğrencilerinin ve toplumdan rastgele seçilen yetişkin bireylerin kök hücre bağışına yönelik bilgi ve tutumlarını belirlemektir.

Gereç ve Yöntem: Çalışmaya 285 öğrenci ve 168 yetişkin dahil edildi. Her iki grup da gözlem altında görüşme yöntemiyle 21 soruluk bir anket doldürmüştür.

Bulgular: Öğrencilerin ve halktan katılımcıların kök hücre bağışı açısından istatistiksel karşılaştırmasında, öğrenci grubunun halktan katılımcı gruba göre çok daha bilinçli olduğu bulundu. Öğrenci grubunun kök hücre bağışçısı olma istekliliği, halktan katılımcıların istekliliği ile karşılaştırıldığında istatistiksel olarak anlamlı bulundu. Öğrenci grubunda okul, halktan katılımcı grubunda yazılı/görsel medya, farkındalıklarının artmasında son derece önemliydi.

Sonuç: Anket çalışmamız halkın bilgi düzeyinin yetersiz, tıp öğrencilerinin bilgi düzeyinin ise yeterli olduğunu ortaya koymuştur. Kök hücre bağışı ile ilgili bilgilendirmeler yazılı/görsel basında, sağlık kurumlarında ve eğitim döneminde yaygınlaştırılarak toplumsal farkındalığın artırılması ve bağışçı sayısının ülke nüfusuna oranla artması sağlanmalıdır.

Anahtar Kelimeler: Kök hücre, gönüllü bağış, kök hücre nakli

Corresponding Author/Sorumlu Yazar: Çiğdem KEKİK ÇINAR E-mail: cigdem.kekik@istanbul.edu.tr

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INTRODUCTION

In many cases, hematopoietic stem cell transplantation is used as part of the treatment or as the only treatment option for diseases classified as hematological malignancies, immune deficiencies, and inherited metabolic disorders.

Full Human Leukocyte Antigen (HLA) matched siblings are the best donors for stem cell transplant candidates. Only 25-30% of these patients, however, have full HLA matched siblings. An HLA-matched unrelated donor is required for patients who are unable to find a sibling donor. The first reports on the feasibility of stem cell transplantation from an HLA-matched unrelated donor were published in the early 1970s (1). Following these reports, the Anthony Nolan Stem Cell Registry was founded in the United Kingdom in 1974, and similar initiatives followed in a few years across Europe, America, and Asia (2). In 2022, there are 136 donor registry and approximately 40 million stem cell donors in 55 countries (3).

Nearly 700,000 donors are registered with Turkish donor registry (3). Türkiye has about 40 million people between the ages of 18 and 55, which is the age range for stem cell volunteer donors (4). In Türkiye, the ratio of volunteers to this age group remains at a very low level of 0.017. A large number of people must be screened in order to find suitable unrelated donors for thousands of people who are waiting for stem cell transplants. As a result, more stem cell volunteer donors are required. Only 1.2 percent of the eligible donors found between 2011 and 2020 were volunteer donors registered with Turkish donor registry, according to statistics from stem cell transplant candidates who applied to the The Turkish blood and bone Marrow donor registry of Istanbul Faculty of Medicine (Shortcode:TRIS-Turkish Registry of Istanbul). Ethnic differences are a key factor in HLA tissue typing, and the greater the number of stem cell volunteer donors in Türkiye, the more likely it is that patients will find a match. Despite the fact that the number of stem cell volunteer donors has increased in recent years, particularly as a result of social media calls, it is still not at the desired level. This can be attributed to a lack of information, concerns about the procedure used, and some beliefs and attitudes.

The aim of this study was to determine the knowledge, attitudes, and opinions of 5th year students from the Istanbul Faculty of Medicine and randomly selected members of the general public about stem cell donation.

MATERIALS and METHODS

The study included 285 students (Student group) who are 5th year students at the Istanbul Faculty of Medicine and 168 randomly selected individuals (Public group) who live in Istanbul's Silivri district. We calculated the sample size using the Open epi program. The prevalence of stem cell donation awareness among medical students was estimated to be 25%. The sample diameter was calculated to be at least 289 with a 5% margin of error at the 95% confidence level. 300 questionnaires were filled out by the students. 285 of these were completely filled out and evaluated. The prevalence of awareness was predicted to be lower in adults selected from the community, and

the prevalence was assumed to be 12% in Open epi, with a sample size of 163 people. 170 questionnaires were filled, of which 168 complete questionnaires were included in the study. Individuals who were invited and attended the training meetings, which were planned separately for students and adults, and who volunteered to fill out the questionnaires prior to the training were included in both groups. Without sampling, questionnaires were given to all groups on a voluntary basis.

Individuals who voluntarily participated in the survey were asked to answer 12 questions to determine the demographic characteristics of the participants, 3 questions to learn about their knowledge of stem cell voluntary donation, and 6 questions to determine their opinions about being a volunteer donor, all of which were answered using the observational interview method. The obtained data were analyzed with a 95 percent confidence interval using the "SPSS for Windows 21.0" program. The chi-square test was used to analyze the data, which was expressed as a percentage, mean, and standard deviation.

This study was supported by the Clinical Research Ethics Committee of Istanbul University (28.03.2018, no:491). This study was approved by the ethical review boards of Istanbul University, Istanbul, Türkiye, and conducted in accordance with the standards of the Declaration of Helsinki.

RESULTS

The mean age of the student group participating in the study was determined as 24.19±1.03, while the average age of the public group was determined as 45.4±12.5. Demographic data of both groups are shown in Table-1.

Table 1: Demographic data of participants

	Public Group N (%)	Student Group N (%)
Age		
18-35	49 (29.17)	282 (98.95)
36-50	57 (33.93)	3 (1.05)
51-80	62 (36.90)	0
Gender		
Male	55 (32.7)	149 (52.3)
Female	113 (67.3)	136 (47.7)
Education		
No education	1 (0.6)	0
Primary Education	35 (20.8)	0
High School	56 (33.3)	0
University /Undergraduate	76 (45.2)	285 (100)
Marital Status		
Married	113 (67.3)	3 (1.05)
Single	55 (32.7)	282 (98.95)
Monthly Income		
0	42 (25)	176 (61.75)
<1700 TL	34 (20.24)	84 (29.47)
1700-4000 TL	60 (37.71)	20 (7.02)
4000 TL +	32 (19.05)	5 (1.75)

When the public group's demographic data and willingness to be a stem cell donor were compared, there was no statistically significant difference. When the demographic data of the

student group and their desire to be a stem cell donor were compared, it was discovered that female students were statistically significantly more likely than male students to want to be a donor ($p < 0.0001$).

One hundred seventeen people (69.6%) from the public group stated that they had children. There was no statistically significant difference between the participants with and without children in terms of the criterion of wanting to be a stem cell donor.

Seventy-four percent of the general public and seventy-six percent of students have never donated blood before. When asked whether they would like to be a stem cell volunteer donor, 61% of the public group and 77% of the student group stated that they wanted to volunteer, and a statistically significant difference was found between the two groups ($p = 0.014$). The students were found to have given statistically significant correct answers to the questions we asked to assess their understanding of stem cell donation. 57 percent of the general public said they learned about stem cell donation from written and visual media, while 88 percent of students said they learned about it from schools and seminars (Table 2).

Table 2: Responses of the study groups about stem cell donation

		Public Group N (%)	Student Group N (%)	p
Attitude To Stem Cell Donation	Never donated blood	124 (73.8)	216 (75.78)	0.74
	Willing to be a stem cell donor	102 (60.71)	219 (76.84)	0.014
	Cares about who the donation is given	37 (22.02)	74 (25.96)	0.5
Knowledge levels on stem cell donation	The correct answer to the question of what is stem cell donation	107 (63.69)	257 (90.17)	<0.0001
	The correct answer to the question of where to donate stem cells	111 (66.07)	262 (91.92)	<0.0001
Ways to learn about stem cell donation	Written/ Visual Media	96 (57.14)	11 (3.85)	<0.0001
	School/ Seminar	15 (8.92)	251 (88.07)	<0.0001

DISCUSSION

Unrelated volunteer donors can be a source of stem cells for patients with hematological malignancies, immune deficiencies, and inherited metabolic disorders when a relative HLA compatible donor is unavailable (5,6). Donors registered in the databases of bone marrow and cord blood registry help patients find an HLA-matched unrelated donor in about half of the cases (7,8). The World Marrow Donors Association (WMDA), an international volunteer donor pool, was founded in 1994, and provides the opportunity to screen donors who may be suitable for a patient, not only from national but also from international donors. This study aimed to investigate the knowledge and attitudes of randomly selected individuals and medical faculty 5th year students about stem cell donation and to increase their awareness.

According to the WMDA's data from 2020, 59 percent of the 40 million donors were between the ages of 26 and 45, with 57 percent of these donors being women, and 13 percent were between the ages of 18 and 25, with 60 percent of these donors being women. According to surveys, women are more likely to donate than men (9,10). There was no statistically significant difference between the public group's age and gender data, and their willingness to be a stem cell donor. Female students were statistically significantly more likely than male students to want to be a donor in the student group.

When obtaining written consent from donors, it is critical that they are fully informed. Protecting the donor's identity, having a physical examination and psychological evaluation by impartial physicians, explaining exactly how the stem cell or bone marrow will be taken and other procedures will be done, and verbally explaining that the patient's life will be in danger if the decision is changed at the last stage are all necessary. The donor should be given enough time to make a decision (11). When we look at the WMDA 2020 data, we can see that countries with a high level of education have a large donor pool. Individuals with a high level of education are more willing to volunteer and donate blood on a regular basis, according to studies. (6,7). There is a direct correlation between donating blood and being a stem cell donor, according to a Mayo Clinic survey of medical school students (12). When the number of stem cell volunteer donors is compared to the population of the countries, the United Arab Emirates has 0.54 percent, Iran has 0.00007 percent, Türkiye has 0.08 percent, Germany has 8.3 percent, and the United States has 2.5 percent (11). Aside from religious and ethnic differences, the countries' high national income is a major factor in determining these rates. In our survey, 78.5 percent of the public group had a high school or higher education level compared to the 5th year students. When compared to the public group, the student group wanted to be a donor at a statistically significant level. This situation can be explained by the medical students' knowledge of stem cell donation and stem cell collection procedures. While our study found no statistical significance in terms of blood donation, it

was discovered that 74 percent of the public and 76 percent of the student groups had never donated blood before.

Individuals with and without children showed no significant differences in their willingness to volunteer. In a study conducted in the United States, medical students were randomly given questionnaires containing emotional or rational information about stem cell donation, and those who completed the questionnaire with emotional information stated that they would be a significant donor (13). Some volunteers stated that having a child motivated them to become a stem cell donor, while others stated that they gave up volunteering after having a child in interviews conducted with volunteer donors registered with the The Turkish blood and bone Marrow donor registry of Istanbul Faculty of Medicine. They claim that they are refusing because they may need a transplant for their own children in the future and will be unable to donate stem cells again.

The increase in the number of donor candidates registered in the system in recent years can be attributed to more widely available technological opportunities, as well as promotion/information activities carried out in various branches such as the press and social media networks (11). Unfortunately, there are no regular programs or public service announcements in Türkiye's written or visual media to raise awareness or inform the public about stem cell donation. It is requested to be a donor through a patient, campaigns are organized for this, and the information is not fully provided, especially in the social media news. For example, announcements are made that it will be sufficient to donate 3 tubes of blood only once to become a donor. Most of the donors won in these ways, when called for other patients, unfortunately either do not remember being a donor or give up volunteering by stating that they are a donor only for the patient for whom the campaign is made. We asked our participants, "Does it matter to whom their donation will be given?" To the question, 26% of the student group and 22% of the public group answered "yes, it is important". These rates imply a loss of about a quarter of the data pool.

Fifty seven percent of the general public said they learned about stem cell donation from written and visual media, while 88 percent of students said they learned about it from schools and seminars. We can both expand our donor pool and have more conscious and permanent donors by informing the public through written and visual media, as well as raising student awareness through seminars on being a volunteer donor during their educational period.

World Donor Day is celebrated on the third Saturday of September each year. Raising awareness of stem cell donation through various activities such as media, social communication networks, NGOs, schools and organizations will contribute both to the treatment of patients and to the country's economy.

Ethics Committee Approval: This study was approved by Istanbul University Istanbul Faculty of Medicine Clinical Research Ethics Committee (Date: 23.03.2018, No: 2018/354).

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