

Acceptance and Refusal Rates for Stem Cell Transplantation and Donation among Saudi Females

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Abstract

Background: The major obstacle to stem cell transplantation (SCT) therapy is finding a matching family donor. In Saudi Arabia, 60% of pediatrics and 30% of adult patients cannot find a matching donor in their family. Little evidence has been published worldwide to assess women's acceptance of SCT, and so this research analyzed awareness of SCT and the acceptance and refusal rates for stem cell donation among Saudi females.

Methods: A cross-sectional study was conducted with females living in Saudi Arabia. Voluntary questionnaires of 20 multiple-choice questions consisting of demographics, knowledge, and acceptance and refusal rates for SCT and donation were randomly distributed across social media platforms.

Results: A total of 474 participants completed the questionnaire. Participants showed low levels of basic knowledge regarding SCT: 20.9% gave the correct answer for stem cell sources, 27.6% were aware of SCT centers, and 36.9% were aware of the possible factors affecting the success of SCT. A low percentage (1.3%) of respondents were registered at the Saudi Stem Cell Donor Registry (SSCDR). The internet and social media, in particular, were the major sources of knowledge for half the participants. Interestingly, even though some participants expressed concerns, three-quarters stated their acceptance of SCT and donation, especially if there is a need.

Conclusion: The females' lack of knowledge about SCT and concerns about stem cell donation may contribute to the shortage of donor availability, suggesting a need to increase the level of awareness and motivation, particularly via health professionals.

Keywords: Stem cell transplantation (SCT), Saudi Stem Cell Donor Registry (SSCDR), hematopoietic stem cells (HSCs), bone marrow (BM), peripheral blood (PB), umbilical cord (UC)

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INTRODUCTION

Stem cells (SCs) are immature cells characterized by their capacity to self-renew and differentiate into various mature cell types.

Hematopoietic stem cells (HSCs), one of the most recognized types of SCs, have a powerful ability to enhance the function of damaged tissues or organs [1]. There are three sources for HSCs: bone marrow (BM), peripheral blood (PB), and umbilical cord (UC). BM is the primary site of hematopoiesis and the main source of HSCs. PB is the most commonly used source for stem cells. HSCs are mobilized from BM into PB after stimulation with hematopoietic growth factors, and

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then harvested from donors [2]. Umbilical cord blood (UCB) is a valuable and rich source of HSCs which is nowadays widely accepted and serves as an alternative source to PB and BM HSCs [3].

Recently, hematopoietic stem cell transplantation (HSCT) has been used as a lifesaving treatment and curative therapy for many disorders, including hematological disorders such as aplastic anemia, severe thalassemia, sickle-cell disease, leukemias, lymphomas [4], inherited metabolic disorders and a range of immunological disorders [5–6]. However, HSCT remains associated with many complications and significant treatment-related mortality.

Transplant-related mortality is significantly influenced by many factors such as age, disease stage, health condition, HLA matching, and the transplantation process [7]. It has been reported that donations from the younger generation produce more successful transplants and fewer complications [8]. Fully matched HLA siblings are the best donors and result in effective transplantation. In Saudi Arabia, adult patients have a greater chance of finding an HLA-matching sibling because most families have a large number of children [9–10]. However, this chance is reduced for pediatric patients [9–10]. Consequently, finding a large number of donors is recommended because an unrelated donor can be an alternative volunteer for patients who have no matching family members [11].

In that regard, several international and national organizations have been established to meet the demand for improved SCT. The American Society for Transplantation and Cellular Therapy is an international organization that can provide new resources to advance cellular therapy and bone marrow transplantation [12]. In Saudi Arabia, the Saudi Stem Cell Donor Registry (SSCDR) is a recognized local agency established in 2010 to provide a rich database of possible unrelated volunteers [13]. Until now, there are 79,742 registered donors in SSCDR [13].

Among Middle Eastern countries, Saudi Arabia was the first Arab country to achieve HSCT, in 1984. Currently, an estimated total of 500 allogeneic transplants are performed each year.

There are four main HSCT units distributed in different provinces of Saudi Arabia. These centers are King Faisal Specialist Hospital and Research Centre (KFSH&RC) and Prince Sultan Military Medical City (PSMMC) in Riyadh, King Faisal Specialist Hospital and Research Centre (KFSH&RC) in Jeddah, and King Fahad Specialist Hospital in Dammam (KFSH) [14]. A total of 6,184 HSCTs were performed in these centers between 1984 and 2016 [14]. Nowadays, the number of HSCT centers is rapidly increasing, which should soon contribute to making HSCT more accessible [14].

However, stem cell transplantation remains a public health concern and its application is still a controversial therapeutic procedure for patients and donors. Many studies have evaluated medical students' knowledge and attitudes towards SCT worldwide [15–18], but few studies have been conducted among the general population [19–20]. A cross-sectional study conducted among pregnant women in India found a low level of knowledge about the beneficial use of stem cell therapy [27]. Also, it has been reported that women's knowledge regarding the possibilities of UCB banking is insufficient in Poland [28]. Bawazir et al. reported that, even though females were more aware of SCT than males, their knowledge is still limited [19].

This research analyzes women's awareness, knowledge, and attitudes toward SCT and donation in Saudi Arabia. It also presents an analytical study based on extrapolating the most important reasons for accepting or rejecting this kind of therapy.

MATERIALS AND METHODS

This cross-sectional study was conducted between January and April 2021 with randomly selected females living in Saudi Arabia. Data were collected using a self-administered questionnaire generated on Google Forms. It was distributed online in February 2021 through social media applications: WhatsApp, Facebook, and Twitter. The questionnaire contained three sections, with a total of 20 questions. The first section consisted of six questions about the demographic characteristics of participants (nationality, age, educational level, city, and

registration status in SSCDR). The second section consisted of seven questions to assess participants' basic knowledge regarding the concept of stem cells in terms of definition, sources, SCT centers in Saudi Arabia, the best age for donation, how to prepare patients for transplantation, the possible factors that affect the success of SCT, and the main source of SCT knowledge. The last section was made up of eight variables. These variables aimed to discover any history of stem cell donation among participants, measure the acceptance and rejection rate towards SCT and stem cell donation, and identify reasons that might motivate or demotivate subjects from becoming donors.

Excel software was used for data entry and statistical analysis. All study variables were analyzed using frequency tests and the results presented as numbers and percentages. Categorical groups were compared using the Chi-square test. A $p < 0.05$ indicated statistical significance.

Ethical considerations

The study was approved by the research committee at Taif University in Saudi Arabia.

RESULTS

Sociodemographic characteristics of the study population

Sociodemographic characteristics of the study sample included participants' nationality, gender, age, city, educational level, and registration status in SSCDR (Table 1). Before the statistical analysis, raw data were checked to detect any incompleteness or inaccuracies. Some 75 participants' responses were omitted because they were incomplete, while 474 responses were used for analysis. The majority of participants were Saudi (95.1% (n=451)), between 18 and 26 years of age (67.3% (n=319)) and were at high school level and below (56.8% (n=269)). Overall, 72.2% of participants (n=342) were from the Mecca region and almost all (98.7% (n=468)) were not registered with the Saudi stem cell donor registry (Table 1).

Table 1. Demographic Characteristics of the Participants (n=474)

Participant Characteristics	Percentage (n)
Nationality	
Saudi	95.1% (n=451)
non-Saudi	6.8% (n=32)
Age	
18–26 year	67.3% (n=319)
27–39 year	12% (57)
40–49 year	14.8% (70)
>50 year	5.9% (28)
City	
Mecca region	72.2% (n=342)
Outside Mecca region	27.8% (n=132)
Educational level	
Medical university level	11% (n=52)
Non-medical university level	32.3% (n=153)
High school and below	56.8% (n=269)
Registration in Saudi Stem Cell Donor Registry	
Registered	1.3% (n=6)
Not registered	98.7% (n=468)

Level of basic knowledge about stem cells and SCT

To obtain an objective idea of the basic

knowledge that the women had regarding stem cells and SCT, the subjects were asked seven questions (Table 2 and Figure 1).

Table 2. Participants' knowledge about SCT (n=474)

Questions	Response (% and n)
What is the most appropriate definition of stem cells?	
Correct answer: undifferentiated cells that have the ability to produce most of the body's specialized cells	77.8% (n=369)
Wrong answer: harmful cancer cells	2.1% (n=10)
I don't know	20% (n=95)
What do you think is the source of stem cells?	
Correct answer: all of the bone marrow, peripheral blood, and umbilical cord	20.9% (n=99)
Wrong answer (chose only one source)	62.4% (n=296)
I don't know	16.7% (n=79)
Have you heard of SCT centers in the Kingdom of Saudi Arabia?	
Yes	27.6% (n=131)
No	72.4% (n=343)
What is the best age for stem cells donation?	
Correct answer: 18–49 years	67.7% (n=321)
Wrong answer: 50 years or older	2.5% (n=12)
I don't know	29.7% (n=141)
What is the best way to prepare a patient for receiving stem cells?	
Correct answer: the patient receives high doses of chemotherapy and immunosuppressive medications	47.9% (n=227)
Wrong answer: direct injection with stem cells	22.6% (n=107)
I don't know	29.5% (n=140)
What factors affect the success of stem cell transplantation?	
Correct answer: all of the patient's age, health, and type of disease, donor's age general health, and relative relation	36.9% (n=175)
Wrong answer: chose only one answer(	41.8% (n=198)
I don't know	21.3% (n=101)
What is your source of knowledge about SCT?	
Education	18.8% (n=89)
Social media and internet	56.3% (n=267)
TV show	12.9% (n=61)
TV show	12% (n=57)

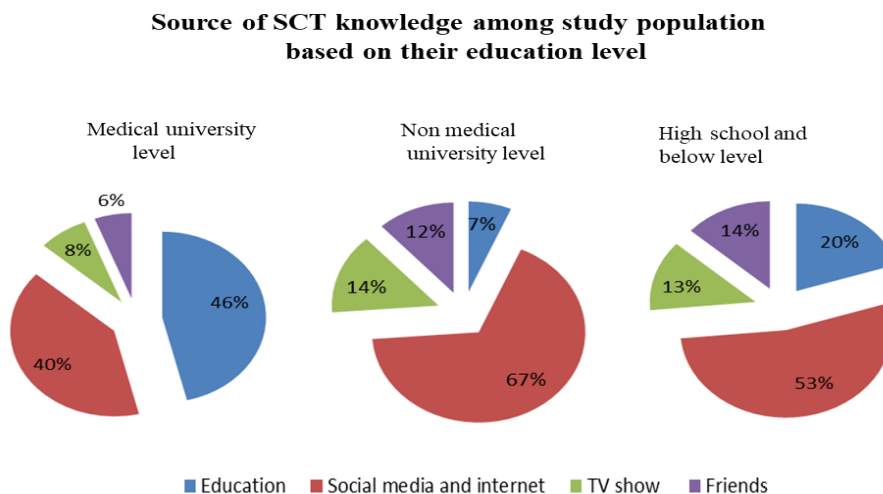


Figure 1. Sources of knowledge about SCT among the study population

The findings showed that approximately three-quarters of the subjects (77.8%, $n=369$) answered the stem cell definition correctly, but when asked about the sources from which stem cells are collected, the majority (62.4%, $n=296$) gave the wrong answer, while 20.9% ($n=99$) gave the correct answer, and 16.7% ($n=79$) did not know the answer (Table 2).

In addition, it was found that only 27.6% ($n=131$) of the subjects who took the survey were familiar with SCT centers in Saudi Arabia, whereas the rest (72.4%, $n=343$) were not aware of them. The study also found that more than half of respondents (67.7%, $n=321$) knew the best age for donation, and around half (47.9%, $n=227$) were aware of how to prepare patients for receiving stem cell transplants. However, when subjects were asked about the possible factors affecting the success of SCT, only 36.9% ($n=175$) of participants answered correctly (Table 2).

When we compared the answers of the participants to the knowledge assessment questions based on their educational level, we found that four questions (SC definition, sources, best age for donation, and patient preparation) were answered correctly by 98.1%, 61.59%, 78.8%, and 76.9%, respectively, of subjects, who were at the medical university level. Only two questions

(SC definition and best age of donation) were answered correctly by 72.5% and 68%, respectively, of the non-medical university-level group and 77% and 65.4%, respectively, of the subjects who had high school level education or below (data not shown). Statistically, there is a significant difference between the levels of basic knowledge among females based on their medical background ($p=0.002$). When participants were asked about their main source of knowledge, the response was social media and the internet for most (56.3%, $n=267$), followed by education (18.8%, $n=89$), TV shows (12.9%, $n=61$), and finally friends (12%, $n=57$) (Table 2). When these data were analyzed based on the educational level of the study population, the analysis showed that the majority of the subjects at the non-medical university level (67.3%, $n=103$) and at the high school level and below (53.2%, $n=143$) relied mostly on social media and the internet as the main source of their information (Figure 1).

Experience with donation and attitude toward SCT

After assessing participants' knowledge, we assessed donation experience and estimated the rate of SCT acceptance and refusal among participants using several questions in the last section of the questionnaire (Table 3).

Table 3. Participants' history and attitude towards SCT

Questions	Response (% and n)
Is stem cells transplantation a lifesaving therapy?	
Yes	90.1% (n=427)
No	9.9% (n=47)
If you have donated any kind of stem cells, how was your experience in the donation process?	
Very good	0.8% (n=4)
Good	0.6% (n=3)
Bad	0.8% (n=4)
I have not donated before	97.7% (n=463)
What was the reason for the donation?	
Help a known patient	0.8% (n=4)
Help an unknown patient	0.8% (n=4)
For myself	0.6% (n=3)
I have not donated before	97.7% (n=463)
Do you accept or reject SCT?	
Accept	91.2% (n=432)
Reject	8.9% (n=42)
Would you accept SCT if you needed treatment?	
Accept	95.4% (n=452)
Reject	4.7% (n=22)
If there is a need to donate stem cells to save the life of a family member, would you accept the donation?	
Accept	97.5% (n=462)
Reject	2.5% (n=12)
What is the reason for your acceptance of stem cell donation?	
Helping patients	72.4% (n=343)
Knowing about its importance	16.2% (n=77)
I reject donation	11.4% (n=54)
What is the reason for declining stem cell donation?	
I have no reason	22.4% (n=106)
Fears of pain & complications	33.8% (n=160)
Unaware of SCT centers	11.8% (n=56)
Unaware of SCT importance	9.9% (n=46)
Lack of staff competence	10.9% (n=52)
Financial costs	7.4% (n=35)
Religious issue	3.8% (n=19)

The results showed that the majority of participants (90.1%, n=427) agreed that SCT is a lifesaving therapy. Moreover, 2.3% of subjects (n=11) had a history of donation with variable reflections and reasons. Interestingly, out of those who had donated stem cells, 1.5% (n=7) reported that their experience with donation was very good or good, while only 0.8% (n=4) had had a bad experience. Finally,

0.8% (n=4) of participants had donated stem cells to recipients related to them, 0.8% (n=4) or had donated to unrelated recipients, while 0.6% (n=3) had donated stem cells to be saved for their future possible use.

Regarding the general level of SCT acceptance or rejection among responders, the majority of the participants (91.2%, n=432) accepted it. In addition, the results showed that

95.4% (n=452) were willing to accept treatment with stem cells if they required it, and 97.5% (n=462) were also willing to donate stem cells if a member of their family were to need them.

This section was also designed to investigate factors that contribute to motivating or declining stem cell donation. It revealed that helping patients and saving their lives was the main motivator for stem cell donation (72.4%, n=343) followed by an awareness of the importance of SCT (16.2%, n=77).

Despite the high rate of donation and SCT acceptance among most participants, some factors could contribute to decreasing their willingness to donate. These obstacles were investigated, and the results determined that fear of pain and complications associated with the donation process were the main factors that might influence 33.8% (n=160) of participants not to donate; 11.8% (n=56) of respondents reported that their lack of awareness of SCT centers prevented them from donating. Additionally, a lack of staff competence, unawareness of the importance of SCT, and financial costs were other reasons for declining to donate for 10.9% (n=52), 9.9% (n=46) and 7.4% (n=35) of subjects, respectively. Finally, 3.8% (n=19) considered religious issues that could be associated with this kind of therapy as a reason for rejecting donations. However, 22.4% (n=106) of participants said nothing would influence their desire to donate stem cells.

DISCUSSION

Stem cell transplantation is a promising strategy for treating several types of life-threatening illnesses. Although stem cell-based therapy has attracted increasing attention and shown considerable progress, its clinical application remains limited. The major obstacle is finding a matching family donor. There is increasing demand for voluntary donors and long waiting lists for SCT worldwide. In Saudi Arabia, 60% of pediatrics and 30% of adult patients cannot find a matching donor in their family [21]. Lack of knowledge and concerns about donations contribute to the shortage of donor availability. Knowledge about, and

awareness of, SCT were found to be insufficient among females.

The current study aimed to evaluate the knowledge of females and the acceptance and refusal rate for SCT and stem cell donation in Saudi Arabia. In general, it found that, despite the fact more than two-thirds of respondents were familiar with the concept of stem cells, they had inadequate information about SCT and stem cell donation. This was especially so in terms of the sources of stem cells, as only 20.9% answered correctly, factors affecting the success of transplants (only 36.9% gave the right answer), and SCT centers (72.4% of participants had never heard of them).

Similar to our finding, Bawazir et al. [19] reported that the level of knowledge about SCT and stem cell donation among the females in Riyadh is considered to be low. Another study evaluated the level of awareness of cord blood banking among the Saudi public and found that 65.7% of the females had inadequate knowledge of CB donation and its uses [22]. Moreover, women's knowledge of UCB banking in Poland was unsatisfactory, while their attitude towards UCB donation was mostly positive [28]. Additionally, a case-control study was conducted at SC donor registration campaigns at King Faisal Hospital, Riyadh, to emphasize the awareness and attitudes of the Saudi population regarding SCT; it found that, although 41.7% of participants were aware of SCs, 93% had a low level of knowledge [20].

A recent integrative review was conducted to assess parents' knowledge and attitudes toward UCB donation and banking using several electronic databases. This review revealed that parents' awareness of cord banking and/or donation was identified as low, but they had positive attitudes towards donation with CB. In addition, the review reported that parents' information sources were found to be inconsistent, varied, and fragmented. Hence, it identified health professionals as the preferred source of information for parents [23]. It is therefore important to highlight that reliable sources are crucial in providing the public with correct information and increasing its

awareness of SCT. In agreement with this, our findings showed that, generally, participants with a medical background had a greater amount of knowledge than others (data not shown). This can be justified by the fact that subjects with a medical background rely on education as a major source of information, whereas respondents with non-medical backgrounds depend mostly on social media and internet sources which may be unreliable, and so they tend to have little knowledge.

Furthermore, this study found that a low percentage (1.3%) of participants had registered at SSCDR (Table 1), which could be attributed to educational background, since 89% (n=422) of the respondents were at non-medical university level or secondary school level or below. A study conducted in Jazan, Saudi Arabia, revealed that 9% of medical students were registered at SSCDR and 61.2% of the registered donors were females [17]. Also, it has been indicated that registered participants were more likely to express better knowledge and attitudes than the unregistered [17].

Females within medical fields are expected to have reasonable knowledge regarding stem cell transplants and the Saudi stem cell donor registry. A previous study was conducted among medical school students in Rhode Island in the US to assess attitudes about joining the BM Registry. The results of this study indicated that 50% of the students favored being registered [15].

More recently, it was confirmed that healthcare sciences students at Jouf University in Saudi Arabia exhibited medium to high levels of awareness about stem cells and the significance of their medical application [18]. Also, Almaeen et al. [18] found that half of their sample's medical students were aware of SSCDR, and it was significantly related to their knowledge score [18]. In addition, there is evidence that nursing students possessed moderate to good knowledge scores and positive attitudes about stem cell therapy [16].

Alongside knowledge assessment, acceptance and refusal rates were measured among our participants. It has been shown that three-quarters of respondents accepted stem cell transplantation and donation, especially if there is a need. It was also found that helping patients and saving lives was the main motivator for donation (72.4%). Similarly, Al Mojel et al. [20] established that, even though the academic knowledge of Riyadh's population was insufficient, the majority accepted the idea of stem cell donation, and relieving patients' pain was the main motivating factor. In addition, women who support donations with UBC in Poland considered that helping their children and other relatives was the most vital reason [28].

Despite the high rate of accepting stem cell donations and SCT among the majority of our participants, there are many concerns regarding registering as a donor. Similar to other studies [17, 20], pain and complications associated with the donation process are frequent reasons that prevent participation in SC donation. This indicates the need to improve medical care so there are fewer complications and a faster recovery, which may encourage more members of the population to become donors [16–17, 20].

Commonly, the lack of correct information about SCT and the value of stem cell donation contributes to the public's negative attitude towards donation. Similar concerns have been raised in Korea and Malaysia [25–26], indicating a need to increase levels of awareness and motivation by providing comprehensive educational campaigns and counseling programs, and by clarifying the place and role of SCT centers.

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معدل قبول ورفض زراعة الخلايا الجذعية والتبرع بها بين السعوديات

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² العلوم الأساسية، كلية العلوم الطبية التطبيقية، جامعة الباحة، الباحا، المملكة العربية السعودية.

الملخص

أهمية البحث: العقبة الرئيسية أمام علاج زرع الخلايا الجذعية هي العثور على متبرع عائلي مطابق. في المملكة العربية السعودية، 60% من طب الأطفال و 30% من المرضى البالغين لا يجدون متبرعاً مطابقاً في عائلاتهم. تم نشر القليل من الأدلة في جميع أنحاء العالم لتقييم قبول الإناث لزرع الخلايا الجذعية. هدف البحث: يهدف هذا البحث إلى تحليل الوعي بزراعة الخلايا الجذعية ومعدل قبول ورفض التبرع بالخلايا الجذعية بين السعوديات. طريقة البحث: أجريت دراسة مقطعية لإشراك الإناث القاطنات في المملكة العربية السعودية. تم توزيع الاستبيانات الطوعية المكونة من 20 سؤالاً متعدد الخيارات تتكون من التركيبة السكانية والمعرفة ومعدل القبول والرفض تجاه زراعة الخلايا الجذعية والتبرع بشكل عشوائي عبر منصات وسائط اجتماعية مختلفة. نتائج البحث: أكمل 474 مشاركاً الاستبيان. أظهر المشاركون مستويات منخفضة من المعرفة الأساسية فيما يتعلق بزراعة الخلايا الجذعية: 20.9% أعطوا الإجابة الصحيحة لمصادر الخلايا الجذعية، 27.6% كانوا على علم بمراكز زرع الخلايا الجذعية و 63.9% كانوا على دراية بالعوامل المحتملة التي تؤثر على نجاح زراعة الخلايا الجذعية. تم تسجيل نسبة منخفضة (1.3%) من المستجيبين في السجل السعودي للتبرع بالخلايا الجذعية. الإنترنت، ووسائل التواصل الاجتماعي على وجه الخصوص، كانت المصادر الرئيسية للمعرفة لنصف المشاركين. ومن المثير للاهتمام، أنه على الرغم من أن بعض المشاركين أعربوا عن مخاوفهم، فقد صرح ثلاثة أرباعهم بقبولهم لزرع الخلايا الجذعية والتبرع بها، خاصة إذا كانت هناك حاجة. الخلاصة: إن افتقار الإناث إلى المعرفة حول زراعة الخلايا الجذعية ومخاوفها تجاه التبرع بالخلايا الجذعية قد يساهم في نقص توافر المتبرعين، مما يشير إلى الحاجة إلى زيادة مستوى الوعي والتحفيز، خاصة من خلال المهنيين الصحيين.

الكلمات الدالة: زراعة الخلايا الجذعية، السجل السعودي للتبرع بالخلايا الجذعية، الخلايا الجذعية المكونة للدم، نخاع العظام، الدم المحيطي، والحبل السري.