Available online at **www.ijmrhs.com**

ISSN No: 2319-5886

International Journal of Medical Research & Health Sciences, 2021, 10(3): 17-24

Knowledge, Attitude and Motivation toward Stem Cell Transplantation and Donation among Saudi Population in Riyadh

Abdullah Bukhari[1], Reem Al Kabli[1], Esraá Khader[2], Mohammed Alrashed[2], Mohammed Alzahrani[2], Ibrahim Al Tamimi[3], Motasim Al Badri[3], and Amen Ahmed Bawazir[3*]

[1]College of Medicine, Taibah University, Madina, Saudi Arabia

[2]College of Pharmacy, King Saud Bin Abdul-Aziz University for Health Sciences, Saudi Arabia

[3]College of Public Health and Health Informatics, King Saud Bin Abdul-Aziz University for Health Sciences, Saudi Arabia

**Corresponding e-mail: bawazir56@gmail.com*

ABSTRACT

Objectives: *This study aimed to assess the knowledge, attitude, and motivation toward stem cell donation among the Saudi population in Riyadh, Saudi Arabia.* ***Methods:*** *A cross-sectional study was conducted in Riyadh City using the visitors to randomly selected Malls according to the geographical distribution of Riyadh. A sample size of 800 participants was calculated and distributed equally in 5 different regions in Riyadh city. The participants were asked to complete a questionnaire that addressed their knowledge, attitude, and perception toward stem cell transplantation and donation.* ***Results:*** *Population knowledge about stem cell transplantation and donation is low. Only (37.8%) have enough information about stem cell transplantation and donation. There is a positive correlation between the level of education and participant's knowledge regarding stem cell transplantation and donation. The increasing level of education was associated with a better understanding of stem cell donation and its role in therapy and saving lives. The study revealed that 39.3% of participants have willing for stem cell donation. The most common reason for not donating stem cells was the lack of information about stem cells and the value of the donation.* ***Conclusion:*** *Population knowledge about stem cell transplantation and donation needs to be increased to empower the willingness for stem cell donation. Probably a well-designed campaign for advocating stem cell donation becomes important in the country.*

Keywords: Stem cell, Transplantation, Donation, Saudi population, Knowledge, Attitude

INTRODUCTION

Stem cell transplantation is considered nowadays an important lifesaving therapy for various fatal blood diseases including cancers, certain inherited blood diseases, and some diseases of the immune system [1]. This type of cells differs from other cells in the body by having the ability to divide and renew them for long period as well as the ability to differentiate into all cells of the body [2].

Usually, Stem cells which are known as hematopoietic stem cells originate from bone marrow and have the ability to differentiate to all blood cell types [3]. These stem cells are used in patient therapy to replace their damaged bone marrow as a result of disease like leukemia or as a result of complication due to radiation exposure and chemotherapy [4]. This kind of therapy is considered to be one of the most effective and well-established procedures, which can be done by collecting stem cells either from bone marrow, peripheral blood, or umbilical cord blood from new-borns [5].

One of the main challenges that facing stem cell transplantation therapies is to find a perfect match; therefore it is important to find a large number of donors [6]. In this regard, many national and international organizations were established to satisfy the required need for stem cell transplantation. For example, the well-known international organization working in this field is the United State Bone Marrow Donor Organizations. The presence of this program

in the United State leads to an increase in the number of blood cancer patient's transplantation by 100% per year [7]. Moreover, in Saudi Arabia, there is a recently recognized local agency called Saudi Stem Cell Donor Registry that was established in 2010 and works to provide stem cells for both Saudi and Non-Saudi patients [8]. This national registry was the extension of the previously established program in 2007 which is known as the Stem Cell Therapy Program at King Faisal Specialist Hospital and Research Centre in Riyadh.

Few studies were conducted to assess the level of knowledge, and attitude of the population toward stem cells transplantation and donation. However, only a few populations (either general or specific students at different colleges) had inadequate knowledge about stem cell donation [9,10]. No available studies have been conducted among the population in Saudi Arabia regarding their awareness about stem cell donation. Therefore, this study aims to evaluate the knowledge, attitude, and practice toward stem cell transplantation and donation among the Saudi population.

This study aimed to assess the knowledge, attitude, and motivation toward stem cell transplantation and donation among the Saudi population in Riyadh, Saudi Arabia, and correlate it with their level of education. Also, to identify the major barriers, difficulties, and the willingness to become a Stem cell donor.

MATERIALS AND METHODS

Design and Setting

This is a cross-sectional study that was conducted at different malls in the capital city of Saudi Arabia, Riyadh. Malls were selected randomly according to the geographical distribution of Riyadh. Five Malls from Central, North, South, East, and West of Riyadh were included in the study. The number of the participants was obtained equally from these malls. The included participants were anonymous, and they were asked to complete a demographic data sheet in addition to general questions that addressed their knowledge, attitude, and motivation toward stem cell donation. The questionnaire was distributed in the Arabic language, and then translated into English (back-translation).

Inclusion/Exclusion Criteria

This study includes general Saudi adults who are living in Riyadh city, with an age of 15 years old and above, from both genders. The study excluded Non-Saudi adults or Children less than 15 years.

Sample Size

The sample size was calculated using the Cochran formula (1977). As there was no previous study in Saudi Arabia that assessed the knowledge and attitude of the public about stem cell donation, the expected prevalence for the knowledge was estimated to be 50%. The power of the study was 80% within a 95% confidence interval. Accordingly, the calculated sample size was 384 participants. However, as this study is a cluster-based type, the sample size was powered by the average Design effect (D) of 1.5, 2, and 2.5. Thus, the pre-final calculation produced a sample size of 768 participants. The sample was further increased by 5% to the account of the contingency such as non-response, the incompleteness of the questionnaire, or recording error. Therefore, the total sample was 800 participants (160 participants from each mall). The results with a p-value <0.05 will be considered statistically significant.

Data Collection Methods, Instruments Used, Measurements

A self-administered questionnaire was used as a study tool. The questionnaire includes 20 items that cover the following topics: socio-demographic variables (age, sex, education level), variables that measure the level of knowledge (knowledge about the nature of the stem cell, stem cell donation, use of the stem cell, source of the stem cells, source of information, benefits from stem cells donation), what they think about stem cells donation, what the future of stem cells in Saudi Arabia, Attitude toward donating Stem cell, reasons for not donating, willingness to donate in the future, Practices of SCD, blood donation or organ donation. The original questionnaire was in English; however, it was translated into Arabic Language and then was back-translated to English. The tool will be piloted and will be analyzed to measure its reliability, validity as well as consistency using a 5% sample of participants. The enrolled participants in the pilot phase of the study will be excluded in the main part of the study. Coding of the answers will be established by the investigators.

Data Management and Analysis Plan

SPSS software statistical program (Ver. 20, USA) was used for statistical analysis. Descriptive analysis was used for categorical variables and the chi-square test was applied to identify the main factors under study by using the statistical

significance. Backward logistic regression was also used to find the association between factors related to level of knowledge, attitude, and practices. Results were considered significant when the p-value was <0.05.

Ethical Considerations

The study was conducted after the approval was obtained from the KAIMRC (King Abdullah International Medical Research Center) IRB committee at Riyadh. The participants were enrolled in the study after getting verbal consent from them.

RESULTS

Socio-demographic Characteristics

A total of 800 participants from different malls in Riyadh, Saudi Arabia filled the questionnaire. 370 participants (46.2%) were between 21 and 30 years, 408 (51%) were female, 60% were at secondary school or below level, and 40% were at the university level.

Table 1 Socio-demographic characteristics of the participants

Variables	Characteristics	No. (%)
Age Mean (± SD) Range 15-65 years.		27.9 ± 9.6 years
Age group	≤ 20 years	193 (24.1)
	21-30 years	370 (46.2)
	>30 years	237 (29.6)
Gender	Female	408 (51.0)
	Male	392 (49.0)
Education level	Secondary and below	479 (59.9)
	University	321 (40.1)

Level of Knowledge

Findings regarding the knowledge of the Saudi population (Table 2) showed that approximately two-thirds of the respondents had limited knowledge about stem cell transplantation and donation (62.2%), and the rest (37.8%) showed good knowledge of this matter (p=0.107). 140 (46.4%) within the age group 21-30 years had enough knowledge, and 238 (47.8%) of females showed limited knowledge.

Table 2 Level of knowledge on nature of stem cell

Variables		Limited knowledge No. (%)	Enough knowledge No. (%)	p-value
Age group	≤ 20 years	134 (26.9)	59 (19.5)	0.023
	21-30 years	230 (46.2)	140 (46.4)	
	>30 years	134 (26.9)	103 (34.1)	
Gender	Female	238 (47.8)	170 (56.3)	0.020
	Male	260 (52.2)	132 (43.7)	
Education level	Secondary and below	309 (62.0)	170 (56.3)	0.107
	University	189 (38.0)	132 (43.7)	

Knowledge about Stem Cell Donation

The majority (40%) of the respondents reported that information about stem cell donation was obtained from the Internet. The remaining participants reported that they obtained information from other sources such as television programs, friends, social media, magazines, and journals (28.5%, 27.7%, 27.6%, 17.5%, and 11.5%, respectively). No significant differences were found in the sources of information between respondents with enough or limited knowledge about stem cell donation (Table 3).

Table 3 Source of knowledge (Yes answer) on stem cell donation among the participants

Sources of knowledge	Limited knowledge No. (%)	Enough knowledge No. (%)	p-value
Knowledge on stem cell donation			
Internet	68 (13.7)	79 (26.2)	0.000
Social media	42 (8.4)	58 (19.2)	0.001
Magazine	25 (5.0)	35 (11.6)	0.001
Journals	18 (3.6)	24 (7.9)	0.008
Friends	51 (10.2)	53 (17.5)	0.003
Television programs	55 (11.0)	53 (17.5)	0.009
Perception on the source of stem cells			
Brain is the source	30 (6.0)	13 (4.3)	0.296
Spinal cord is the source	107 (21.5)	106 (35.1)	0.001
Umbilical cord is the source	37 (7.4)	43 (14.2)	0.002
Blood is the source	31 (6.2)	37 (12.3)	0.003
Bone is the source	25 (5.0)	33 (10.9)	0.002
Information related to stem cell donation			
Saudi stem cell donor registry knowledge	37 (7.4)	51 (16.9)	0.00
Registered for Stem cell donation	2 (0.4)	4 (1.3)	0.142
Willing to donate	182 (36.5)	132 (43.7)	0.044
Willing to donate organ	198 (39.8)	146 (48.3)	0.017
Donated blood	202 (40.6)	130 (43.0)	0.489
Reasons for unregistered on stem cell donation			
Health issues is the Reason	29 (5.8)	42 (13.9)	0.001
Side effect	75 (15.1)	68 (22.5)	0.008
Religion	10 (2.0)	11 (3.6)	0.161
Not knowing the place	88 (17.7)	72 (23.8)	0.034
Don’t know that it’s possible to donate	340 (68.3)	136 (45.0)	0.000
Other reasons	8 (1.6)	13 (4.3)	0.021

Perception on the Source of Stem Cells

It has been revealed that most of the respondents (56.6%) believed that the spinal cord is the source of stem cells. Others believed that the umbilical cord, blood, bone, or brain is the source of stem cells (21.6%, 18.5%, 15.9% and 10.3% respectively). No significant differences were found in the perception of the respondents on the source of stem cells between those with enough knowledge and limited knowledge except for those who thought that the brain is the source of stem cells (p=0.296) (Table 3).

Information Related to Stem Cell Donation

Several questions within the questionnaire were used to assess the participant’s information related to stem cell donation.

Only six (1.7%) of the respondents registered for stem cell donation (Four with enough knowledge, and two with limited knowledge, p-value=0.142).

88 (24.3%) of the respondents knew about the Saudi stem cell donor registry (p=0.142), 83.6% donated blood during their life (p=0.489), 88.1% showed a willingness to donate an organ (p=0.017), while 80.2% showed a willingness to donate stem cell in the future (p=0.044).

Reasons for Unregistered on Stem Cell Donation

For those who did not show a willingness to donate stem cells in the future, the majority (476 participants) don't know that it is possible to donate, 143 of the respondents expressed fear of donation side effects which prevent them from donating, 160 don't know where to donate, 71 considered health issues they cause for rejecting donation, 21 reported that religion is the reason, and 21 reported other reasons for that. No significant differences were found in the opinions regarding the causes which prevent the participants from donating between those with enough knowledge and limited knowledge except for those who referred the reason for religion (Table 4).

Table 4 Factors associated with knowledge regarding stem cell donation

Factors	Poor knowledge No. (%)	Good knowledge No. (%)	Univariate Model			Multivariate Model		
			OR	95% C.I	p-value	AOR	95% C.I	p-value
Age group								
≤ 20 years	134 (26.9)	59 (19.5)	1			1		
21-30 years	230 (46.2)	140 (46.4)	1.38	0.95- 2.00	0.024*	1.31	0.90-1.91	0.039*
>30 years	134 (26.9)	103(34.1)	1.75	1.17-2.60		1.69	1.13-2.54	
Gender								
Female	238 (47.8)	170 (56.3)	1		0.020*	1		0.024*
Male	260 (52.2)	132 (43.7)	1.41	1.056-1.88		1.4	1.05-1.88	
Education level								
Secondary and below	309 (62.0)	170 (56.3)	1		0.108			0.21
University	189 (38.0)	132 (43.7)	1.27	0.95-1.70		1.21	0.90-1.63	
Knowledge of Saudi SCDR								
No	496 (99.6)	298 (98.7)	1		0.001*			0.224
Yes	2 (0.4)	4 (1.3)	2.53	1.61-3.97		2.91	0.52-16.28	
Fear of donation side effects								
No	423 (84.9)	234 (77.5)	1		0.008*			0.030*
Yes	75 (15.1)	68 (22.5)	1.64	1.14-2.36		1.51	1.04-2.19	

OR: Odds Ratio; AOR: Adjusted Odds Ratio, * Significant p-value; SCDR: Stem Cell donation Registry; [a]: considering those responding with 50% and more on correct answers of knowledge

DISCUSSION

Since the establishment of the local Saudi Stem Cell Donor Registry in 2010, no comprehensive assessment of the public knowledge about stem cell donation and transplantation has been conducted. This study highlighted the level of knowledge and barriers of stem cell donation in a random sample of the general Saudi population.

The current study found approximately two-thirds of the respondents with limited knowledge of stem cell donation and transplantation, while only 37.8% showed a good level of knowledge. However, this low level of knowledge is expected among the general population, particularly when 45% reported unreliable sources of information about stem cells such as internet websites and social media.

A study, conducted among the Saudi population in the Al-Ahssa region four years ago, found 59% of the participants familiar with the term "stem cells". In contrast to reports from developed countries, where 93% of the participants in the Chakrabarti, et al. study were aware of the term [11]. However, familiarity with terminology is not a good measure of in-depth knowledge about stem cells. More questions should be used to explore the dimensions of this knowledge. Despite the familiarity of study participants with the "stem cells" term, Al-Abdulqader, et al. found only 25% of the participants have a willingness to donate their stem cells [11]. Thus, many people may hear about the term "stem cells" in the media but they may be still far from good knowledge which based on correct information. Furthermore, the internet websites and social media were reported as main sources of information by 47% of the participants in the Al-Ahssa region.

In the literature, many studies used various tools to assess the knowledge about stem cell donation and transplantation which resulted in a wide variation of this knowledge, even in the same country [12,13]. In the present study, respondents

who correctly answered half (or more) number of the questions were considered to have a high knowledge (37.8%), while those who answer less were considered to have poor or limited knowledge (62.2%).

A higher proportion of knowledgeable people were found among 1019 randomly selected Greek citizens since 48% of the respondents were aware of donation and storage of umbilical cord blood [14]. However, this higher proportion does not mean a higher level of knowledge due to different questions and response scales (0=nothing to 4=very much) used among Greek citizens. In another hand, a Malaysian study used three levels of knowledge about stem cell donation (low, moderate, and high) found 92% had a moderate level of knowledge [15].

Studies among health workers and medical specialties usually report a high level of knowledge about stem cell donation. A study that included female health workers in the Qassim region found 56% with moderate knowledge, 31.2% with good knowledge, and only 12.85 with poor knowledge [16]. Moreover, more than 80% of the Hong Kong midwives answered the questions about stem cell donation correctly [17]. The medical knowledge acquired during clinical practice enables health workers to answer many questions correctly even in the absence of special education or training in stem cell donation. In the present study, when the general population was investigated, respondents who had either good knowledge or poor knowledge addressed that Internet, Social Media, Television program, and Friends were the major resources from where they get their background, these resources are considered unreliable and could not be correct always. Due to their dependence on these unreliable resources, questions of using the spinal cord as a source of stem cell donation were associated with high false answers. About 57% of the participants think that the spinal cord is a possible source of stem cell donation. This case is less likely to occur when questioning health workers.

Due to similar reasons, many studies assessed the level of knowledge among college students in different medical and health specialties found a reasonable level of knowledge. A study that was conducted in Riyadh, Saudi Arabia, measured the knowledge and attitude of nursing students toward stem cell therapy. The finding revealed that 62.3% of the students had fair knowledge [18]. Another study showed that 81% of nursing students, in Malaysia, had moderate knowledge about stem cell donation [15].

In this study, age was significantly associated with the level of knowledge with 46.4% of participants who had good knowledge about stem cell donation and transplantation was aged 21-30 years old. Similarly, Karagiorgou, et al. considered age as a significant predictor of knowledge about stem cell donation and storage among Greek citizens, but the majority of the knowledgeable participants were in the older age group (33-41 years old) [14].

The female gender included in the present study was significantly more knowledgeable than the male gender, which is consistent with the results reported in Greek adults when 59.4% of females were aware of stem cell donation in comparison to 40.6% of males [14]. This difference can be attributed to the greater exposure among females, especially at the maternal age, to the educational materials regarding umbilical cord blood donation and storage [19].

Generally, the level of education is an important determinant of health literacy which subsequently affects the knowledge about diseases and health issues [20]. However, the present study did not find a significant association between educational level and knowledge about stem cell donation or storage. Differently, several studies found a significant association between educational level and knowledge about donation, storage, or transplantation of stem cells. Karagiorgou, et al. found that 66% of those aware of umbilical cord blood as a source of stem cell donation have a university level of education, in comparison to only 1% of those who have a primary level of education [14].

Different categorizations of educational level may be responsible for these contradicting results. In the present study, we categorized education levels into two groups, people with university level and those with secondary level or less, while other studies categorized education into three or four categories.

A survey that included five European countries found 76% of pregnant women were agree to donate umbilical cord blood to public banks [21]. Similarly, we found 88 (24.3%) of the respondents were aware of the Saudi stem cell donor registry and 80.2% showed a willingness to donate stem cells in the future. However, this high willingness rate did not reflect the rate of donation; only six participants (1.7%) of the willing participants were already registered in the stem cell donation registry. Previous studies showed a positive attitude towards organ or tissue donation among the Saudi population, however, the donation rate is still low in comparison to other countries [22]. Furthermore, a study that measured willingness to donate bone marrow among different races in the United States showed that 90% of the respondents were aware that transplantation saves lives, and 30% would be willing to become a donor [23]. Knowledge

and behaviors regarding the bone marrow registry were evaluated by conducting a study among College and Medical Students in Rhode Island (Medical students, Pharmacy students, Hard sciences, Humanities, and Graduate students), results of this study revealed that half of the respondents had the willingness to participate in the registry [24].

This study investigated reasons why the participants were not willing to register in the stem cell donation registry. Among participants who did not show a willingness to donate stem cells in the future, 83.8% do not know about or where the stem cell donation registry. Thus, lack of knowledge was the main barrier to the willingness to stem cell donation. Conduction of educational campaigns is important to increase the level of knowledge and subsequently improve the donation rate. More educational effort should be implemented by arranging for a suitable campaign, advertising, and counseling program for the population is recommended to increase the level of knowledge and motivation toward stem cell donation.

CONCLUSION

This study found a low level of knowledge about stem cell donation and transplantation with two-thirds of the Saudi general population had limited knowledge. The level of Knowledge was higher in young adults and females in comparison to other age and gender groups. Further education campaigns and advertisement about the importance of the donation as a matter of saving life is needed at the level of the community.

DECLARATIONS

Authors' Contributions

Abdullah Bukhari conceived the project idea, designed the study, approved the methodology, data analysis, and writing and editing the manuscript. Reem Al Kabli, Amen Ahmed Bawazir, Esraa Khader, Ibrahim Al Tamimi, Mohammed Alrashed, Mohammed Alzahrani, participated in the data collection and managed the study data. Analysis of the data was conducted by Abdullah Bukhari and Motasim Al Badri. All authors read and approved the final manuscript submitted to the journal.

Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This study has not received any funding.

Ethics Approval and Consent to Participate

Institutional Review Board at King Abdullah International Medical Research Centre (KAIMRC; # RSS15/042). Saudi Arabia has provided ethics approval for this study. Informed consent was obtained from all participants.

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