

Rising of public medical awareness is the most important motivating factor for hematopoietic stem cell donation in Saudi Arabia

Omar B. Alfraidy¹, Hind H. Alharbi¹, Mona N. Alrehaili¹, Mohammed B. Alfridy¹, Reem S. Alkabli¹, Turki A. Alwasaidi^{2,3}

¹Medical student at College of Medicine at Taibah University, Almadinah Almunawarah, Saudi Arabia.

²Internal Medicine Department, College of Medicine at Taibah University, Almadinah Almunawarah, Saudi Arabia.

³Hematology Department, Prince Mohammed Bin Abdulaziz Hospital, National Guard Health Affairs, Almadinah Almunawarah, Saudi Arabia.

Abstract

BACKGROUND: Allogeneic hematopoietic stem cell transplantation (HSCT) is considered as curative treatment approach for many hematological malignancies and other diseases^{1,2}. Human leukocyte antigen (HLA) matched donor availability is one of the main obstacle that could prevent patient from getting the best available treatment approach. The goal from this study is to identify barriers and motivators of hematopoietic stem cell (HSC) donation among Saudi Arabia society that might expand donation in the future.

METHODS: A cross-sectional, self-administrated questionnaire, study carried out in Almadinah Almunawarah. The targeted participants were all visitors of the stem cell donation campaigns that were running in Taibah University and in one of the shopping malls in Almadinah Almunawarah between 22nd and 29th of October 2015. Participants' age must be above 15 years old. The statistical analysis has been performed using the Statistical Package for the Social Sciences (SPSS), version 22.0, with applying Chi Square analysis.

RESULTS: The questionnaires that have been completed and included in the analysis were 605, while 15 were excluded due to incomplete data. Of the included participants, 65.8% were males and 34.2% were females, with age ranged between 15-65 years old. The age of most participants from both genders consider young age, which was younger than 45 year old (97%). The rising medical awareness and an easy access to the HSC donation registry by increasing the donation centers will increase the recruitment of donors as those were suggested by 59.7% and 40.7% of participants, respectively. Other factors such as identifying or knowing the recipient to the donor and financial motivations were considered as important motivators for 37.2%, and 7.1% of participants, respectively. Religious and financial motivations were suggested by 23% and 10%, respectively, as the most effective methods to increase number of HSC donation (Figure1). The social media was suggested by 52.4% of participants as the best way to increase awareness of HSC donation, while 31.4%, 4%, 8.3%, and 1.8% of participants were suggested increasing awareness through university and school, TV and Radio advertising, establishment of awareness lecture and seminars, and journals and magazines advertising, respectively. The fear of needles, procedures or its complications was the highest factor (44.6%) of preventing participants of potential donation. While the small number of donation centers, presence of a health issue, concern about the elapsed time for donation and unsure of usefulness of the donation

Corresponding author:

Dr. Turki Alwasaidi, MD, FRCP(C), P. O. Box 51084 ,College of Medicine, Taibah University, Almadinah Almunawarah, Saudi Arabia, Postal Code 41543, Telephone: +966569179178, e-mail: alwasaiditu@ngha.med.sa

were preventing 36%, 18%, 10%, and 6% of participants, respectively. However, there were 12 (2%) participants indicated previous bad experience.

CONCLUSION: Saudi society needs an easy access to Saudi Stem Cell Donor Registry (SSCDR), beside the interment campaigns events, throughout the year; with rising of public awareness about HSC donation to correct misconceptions about HSC donation that likely going to improve recruitment of potential donors to SSCDR.

Keywords: Saudi Stem Cell Donor Registry; Registry; hematopoietic stem cell; donors; hematopoietic stem cell transplantation

BACKGROUND

Allogeneic hematopoietic stem cell transplantation (HSCT) is considered as curative treatment approach for many hematological malignancies and other diseases¹⁻². Human leukocyte antigen (HLA) matched donor availability is one of the main obstacle that could prevent patient from getting the best available treatment approach. The chance to find HLA-matched sibling is only 25% for each sibling who is welling and fit for donation. In Saudi Arabia, 30% of adult patients and 60% of pediatrics patients cannot find a matching related donor³. Therefore, Saudi Stem Cell Donor Registry (SSCDR) for unrelated donors, under King Abdullah International Medical Research Center (KAIMRC)-National Guard Health Affairs, was established in 2011 to provide large database for potential matched unrelated donors. The national campaigns that were organized by SSCDR in different cities are considered one of the activities and the efforts to increase the awareness and increase the recruitment but the database of donors was growing slowly, which reached to 11,000 potential donors at end of 2015. The goal from this study is to identify barriers and motivators of hematopoietic stem cell (HSC) donation among Saudi Arabia society that might expand donation in the future.

METHODS

STUDY DESIGN AND PARTICIPANTS

A cross-sectional study carried out in Almadinah Almunawarah, Saudi Arabia. The targeted participants were all visitors of the stem cell donation campaigns that were running in Taibah University and in one of the shopping malls in Almadinah Almunawarah between 22nd and 29th of October, 2015. Participants' age must be above 15 years old and willing to participate.

DATA COLLECTION AND ANALYSIS

A self-administrated questionnaire as a study tool for data collection has been used in this study. The questionnaire was designed to assess the barriers that prevent people from stem cell donation and motivators that encourage them for donation including religious motivations and it was prepared in a simple and clear Arabic language. The statistical analysis has been performed using the Statistical Package for the Social Sciences (SPSS), version 22.0, with applying Chi Square analysis.

RESULTS

A total number of 620 self-administrated questionnaires were distributed among visitors of the stem cell donation campaign during the study period. The questionnaires that have been completed and included in the analysis were 605, while 15 were excluded due to incomplete data. Of the included

participants, 398 (65.8%) were males and 207 (34.2%) were females, with age ranged between 15-65 years old. The age of most participants from both genders consider young age, which was 66.6%, 19.7%, 10.7%, 2%, and 1% of participants' age ranged between 15-25, 26-35, 36-45, 46-55, 56-65 years, respectively (Table 1). Regarding the educational level 429 (70.9%) participants are carrying bachelor degrees, 139 (23.0%) participants are carrying High school degree or diploma degree, 31 (5.1%) participants are finished primary or intermediate school, while 4 (0.7%) are illiterate (Table 1).

Table 1: Participants' characteristic

Educational Level		Age					Total
		(15 – 25)	(26 -35)	(36 – 45)	(46 – 55)	(56 – 65)	
Illiterate	Male	1	0	2	1	0	4
	Total	1	0	2	1	0	4
Primary intermediate	Male	10	5	2	2	0	19
	Female	3	6	1	1	1	12
	Total	13	11	3	3	1	31
High school/Diploma	Male	48	15	11	3	0	77
	Female	38	17	7	0	0	62
	Total	86	32	18	3	0	139
Bachelor	Male	225	45	23	2	2	297
	Female	77	30	19	3	3	132
	Total	302	75	42	5	5	429
No Answer	Male	1	0	0	0	0	1
	Female	0	1	0	0	0	1
	Total	1	1	0	0	0	2

MOTIVATORS ENCOURAGING HSC DONATION

Increase medical awareness and an easy access to the HSC donation registry by increasing the donation centers will increase the recruitment of donors as those were suggested by 59.7% and 40.7% of participants, respectively. However, other factors such as identifying or knowing the recipient to the donor and financial motivations were considered as important motivators for 37.2%, and 7.1% of participants, respectively (Table 2).

Table 2: Factors may motivate HSC donation.

Motivators	YES n (%)	NO n (%)
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Medical awareness	361 (59.7 %)	230(38%)
Availability and easy access of HSC donation centers	246 (40.7%)	346(57.2 %)
Identifying or knowing the recipient to the donor	225(37.2 %)	365 (60.3 %)
Financial motivations	43 (7.1 %)	549 (90.7 %)

Most of participants (64%) are suggested increase medical awareness as the most effective method to increase number of donors in Saudi Arabia, while 23% and 10% suggested religious and financial motivations, respectively, as the most effective methods (Figure1). Further, social media was suggested by 317 (52.4%) of participants as the best way to increase awareness of hematopoietic stem cell donation, while 31.4%, 4%, 8.3%, and 1.8% of participants were suggested increasing awareness through university and school, TV and Radio advertising, establishment of awareness lecture and seminars, and journals and magazines advertising as the best way to increase awareness of stem cell donation, respectively.

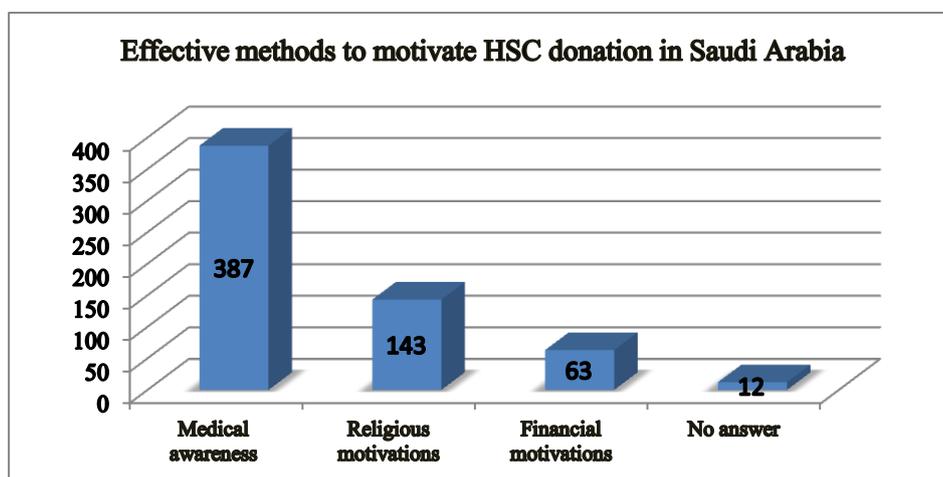


Figure 1: Effective methods to motivate HSC donation in Saudi Arabia

BARRIERS THAT MAY PREVENT HSC DONATION

The fear of needles, procedures or its complications was the highest factor (44.6%) of preventing participants of potential donation. While the small number of donation centers, presence of a health issue, concern about the elapsed time for donation and unsure of usefulness of the donation were preventing 36%, 18%, 10%, and 6% of participants, respectively. However, there were 12 (2%) participants indicated previous bad experience (Table 3).

Table 3: Barriers may prevent participants from HSC donation

Barriers	YES n (%)	NO n (%)
The fear of needles, procedures or its complications	244 (44.6 %)	296 (48.9 %)

There is no enough or accessible HSC donation centers	220 (36.4%)	346(57.2 %)
Presence of a health issue	109 (18 %)	459 (75.9 %)
Concerns about the elapsed time for donation	64 (10.4 %)	504 (83.3 %)
Unsure of usefulness of the donation	37 (6.1 %)	531 (87.8 %)
Previous bad experience	12 (2 %)	556 (91.9 %)

DISCUSSION

The database for the potential matched unrelated donors in Saudi Stem Cell Donor Registry (SSCDR) considered small when it's compared with other international registries' databases. The improvement in knowledge about hematopoietic stem cell transplantation (HSCT) correlates to great HSC donation intention^{4,5,6}. This study, showing the rising of medical awareness considered the most encouraging factor for HSC donation in Saudi Arabia that likely related to lack of knowledge about HSC donation. Further, the medical awareness was more important than the religious motivations and financial motivations to participants as that will correct many of misconceptions about HSC donation.

Medical awareness about HSC donation through social media and schools and universities seems to be the most effective ways to improve knowledge, which were followed by TV and Radio advertising, establishment of awareness lecture and seminars, and journals and magazines advertising that might be effective in targeted population. Medical awareness will help to decrease the effect of barriers of HSC donation that may prevent donation; by explaining the procedure, process of HSC donation, suitability of donors and potential complications from donation to the donors that are not significant when it's compared to the benefits for the society. However, financial motivations are not an important factor for most of participants in our study, which was expected in our society.

Saudi Stem Cell Donor Registry (SSCDR) center in Riyadh that has many collaborated satellite centers in other cities that called ambassador's centers, which running the HSC complains from time to time through the year. Presence of fixed centers for HSC donation that accepting registration in SSCDR all the time through the year; are an important factor to improve the recruitment rate of HSC donors that will increase the database of SSCDR rapidly in the future.

There are limitations to our study that including small sample of participants and it was run in one city of Saudi Arabia. Finally, we concluded from this study, the Saudi society needs an easy access to Saudi Stem Cell Donor Registry (SSCDR), beside the interment campaigns events, throughout the year; with rising of public awareness about HSC donation to correct misconceptions about HSC donation that likely going to improve recruitment of potential donors to SSCDR.

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