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Original Research Article

Knowledge and attitudes of family health strategy professionals regarding the bone marrow transplant network

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ABSTRACT

Background: The bone marrow transplant (BMT) network includes factors from the moment donors sign up to the performance of the transplantation itself in specialized units. The current study aims to analyze the knowledge and attitudes of health professionals regarding this network.
Methods: This is a quantitative, exploratory, descriptive study with 63 participants. Data were collected by means of questionnaires that included questions on the profile of the professionals and the bone marrow transplant network.
Results: Professionals know what the national registry of bone marrow donors (REDOME) is (60.3%) and where registration can be done (68.3%). However, they were not registered as bone marrow donors (71.4%) and they did not know how to locate where patients' records were stored (77.8%) or the units where BMTs are performed (60.3%).
Conclusions: It is of utmost importance to stimulate the knowledge of professionals, particularly on those aspects related to recipients and transplant units.

Keywords: Hematology, Bone marrow transplant, Tissue donors, Health systems

INTRODUCTION

Oncohematological diseases, with tendency to chronicity, bring negative results to patients since treatments cause serious side effects which limit their daily activities. Therefore, the approach to these illnesses must not only include a series of treatments along with their benefits but also make patients aware of the bad consequences. Bone marrow transplant (BMT) is one of the treatments for oncohematological and some types of non-oncohematological diseases.[1] Using the patient's own bone marrow is not always possible, and finding a matched family donor is sometimes an impossible task. Thus, whenever unrelated donors are needed, they can be found among a pool of volunteers registered in a bone marrow bank, which is responsible for the search of a compatible match.

In Brazil, this bank is the National Registry of Bone Marrow Donors (REDOME), managed by the Brazilian National Cancer Institute (INCA) with data provided by state hematology and hemotherapy centers and non-governmental organizations (NGOs).[2] The Brazilian National Register of Bone Marrow Recipients (REREME) is available for the registration of patients who need a transplant.[3]

In 70% of BMT cases, the donor is unrelated to the recipient.[3] Therefore, the more people volunteer for donation, the more likely it will be to find a match between a donor and a patient. This number of volunteers can be increased once the general population is made aware of the existence of a bank, the importance to register as a donor, and the procedures on how to become a potential bone marrow (BM) donor.[4]

Public awareness campaigns at schools, companies and shopping malls are conducted aiming to answer questions and attract new bone marrow donors. The media plays a positive role, once it allows people to know about the registration process and sensitizes them for an altruistic action.[5]

Besides the registration process, it is important to understand how the transplant network is organized: diagnosis, the possibility of a treatment with BMT and the search for related donors or the identification of an unrelated donor through the REDOME. The process also includes the location of possible units where the procedure may be performed so that both donor and patient can be referred to the same unit.[6]

There are few studies involving health professionals, their knowledge on the subject and data regarding how many of them are registered as bone marrow donors. Actually, these professionals are the most suitable people to influence their patients and family members to become donors, answer questions as well as inform about the location of donation centers, transplantation units and procedures to patients with oncohematological diseases.

In brief, the study aimed to analyze the knowledge and attitudes of health professionals regarding the bone marrow transplant network.

METHODS

This is a quantitative, exploratory, descriptive study. The study comprised a population of nurses and doctors from the Family Health Strategy (FHS) staff. Data collection took place at Basic Family Health Units in Juazeiro do Norte, Ceará, Brazil from December 2015 to February 2016. Visits occurred on Mondays, Tuesdays and Fridays in the morning, and on Wednesdays and Thursdays in the afternoon. The questionnaires were applied individually and completed in about 5 minutes, respecting the availability of the professionals, at private and quiet places. The study protocol was approved by the Research Ethics Committee (REC) of the Centro Universitário Leão Sampaio (UNILEÃO) under the number 1.248.664.

The author previously elaborated a questionnaire since no tool for this purpose could be found in the literature. It included close-ended questions and some open-ended ones that required objective responses, such as how long they had been graduated and they had been working with FHS, where to storebone marrow patients’ and donors’ records and where to perform BMT. In order to describe the characteristics of the qualitative variables, absolute and relative frequencies were used; for quantitative variables, mean, median and minimum and maximum standard deviation were applied. The statistical package of choice was the 11.0 Data Analysis and Statistical Software for Professionals (STATA).

RESULTS

A total of 63 individuals were included in the final sample. Four professionals did not accept to participate, and 33 were not found in the health unit after visit 5. The majority of the studied group was composed of young females, namely 46 women at a median age of 38 years. Regarding the occupational category, the sample comprised 38 nurses and 25 doctors. As to the length of time the professionals had been graduated, the median number of years was 12; the mean time during which those professionals had been working with family health strategy (FHS) was 9.3 years (Table 1).

When it came to knowledge and attitudes concerning the bone marrow transplant (BMT) network, the professionals were firstly asked if they knew what REDOME is, and then if they were registered as bone marrow donors. A total of 38 (60.3%) answered "yes" to the first question, and 18 (28.6%) were registered as donors.

The professionals were also asked about the locations where the general public can sign up for donation. A total of 43 professionals (68.3%) reported that they knew where those places are (Table 1), and 34 (78.9%) mentioned the names of the places (Table 2); moreover, they not only recognized the regional blood center as the location responsible for registration but also cited events, campaigns and other health units that can help in the registration process.

Moving on with the questions, the professionals were asked if they knew where the registered donors' records were stored. A total of 25 (39.7%) participants answered that they did (Table 1), and 10 (40%) referred to REDOME (Table 2) as the data storage place.

Upon being asked about the criteria used for the evaluation of donor-patient matching, 25 participants (39.7%) gave the HLA system as the answer (Table 1).

Nevertheless, 49 participants (77.8%) informed that they did not know the place where patients' records were stored. The difference in rate rises to 17.5% when the given answers are compared with the ones related to the question on donors' records storage. Among the interviewees who stated to know where the recipients' records were stored, 3 (21.4%) mentioned REREME.

When asked if they knew the location of the centers where BMTs are performed, 38 (60.3%) professionals answered that they did not. Those who did (25 participants, 39.7%) were asked to mention at least one transplant center in Ceará, in the Northeast and in Brazil. Regarding the centers in the state of Ceará, 8 participants(32%) included places like the Hospital Universitário Walter Cantídio, Hospital da UNIMED de Fortaleza and Hospital São Carlos, 15 (60%) mentioned institutions where BMTs are not conducted or located just city, and 2 (8%) did not answer the question. The institutions where BMTs are performed in Ceará were mentioned, except for the Hospital Monte Klinikum.

Table 1: Profile of the studied professionals and their knowledge on the BMT network, Juazeiro do Norte, CE, 2016.

Variables	n	%
Gender		
Female	46	73.0
Male	17	27.0
Profession		
Nurse	38	60.3
Doctor	25	39.7
	Median	**p25-p75**
Age (in years)	38.0	33.0 - 49.0
Experience since graduation (in years)	12.0	5.0 - 19.0
	Mean (sd)	**Min-Max**
Experience with FHS (in years)	9.3 (5.9)	1.0 -20.0
Professionals who knew what REDOME is		
Yes	38	60.3
No	25	39.7
Professionals registered as BM donors		
Yes	18	28.6
No	45	71.4
Professionals who knew where to register as a BM donor		
Yes	43	68.3
No	20	31.8
Professionals who knew where the registered donors' records were stored		
Yes	25	39.7
No	38	60.3
Criteria to evaluate donor/recipient matching		
HLA system	25	39.7
ABO and Rh system	16	25.4
DNA	8	12.7
Unanswered	8	12.7
ABO/Rh system and HLA system	4	6.3
ABO/Rh system, DNA and HLA system	1	1.6
HLA and PAI	1	1.6
Professionals who knew where the recipients' records were stored		
Yes	14	22.2
No	49	77.8
Professionals who knew where BMT centers are located		
Yes	25	39.7
No	38	60.3

Percentiles 25-75. sd: standard deviation.

A total of 7 (28%) participants answered the question about BMT centers in the Northeast and the following institutions came up: Real Hospital Português de Benificência in Pernambuco, Fundação Hemope, Hospital Memorial São José and Instituto de Medicina Integral Professor Fernando Figueira (IMIP). One of the professionals (4%) mentioned an institution where BMTs are not performed, 4 (16%) remembered the city or the state but not the center, and 13 (52%) did not answer.

Finally, when it came to mentioning transplant centers in Brazil, there were 6 answers (24%) and the participants pointed out 2 institutions: INCA and Casa de Saúde Santa Marcelina. Five of them (20%) could locate the state, one (4%) mentioned that 70 centers in Brazil performed BMTs and 13 (52%) did not answer.

All the answers provided by the participants were compared with the median ages and experience since graduation (Table 3). It could be observed that younger participants who had recently graduated answered "yes", but no statistical significance was found.

Table 2: Health professionals' knowledge concerning locations of registration, transplantation and bone marrow data storage, Juazeiro do Norte, CE, 2016.

Variables	n	%
Registration location for BM donors		
Hemoce*	21	48.8
Unanswered	9	20.9
Blood Centers	5	11.6
Blood Centers and e blood donation campaigns	2	4.7
Hemoce* and donation stands	1	2.3
Hemoce*and Municipal Health Secretariats	1	2.3
Hemoce* and blood drive staff	1	2.3
Campaigns	1	2.3
Hemoce* and accredited hospitals	1	2.3
Hemoce* and INCA	1	2.3
Donors' records storage location REDOME	10	40.0
Hemoce*	6	24.0
Data network	2	8.0
National registration bound to the Blood Center	2	8.0
Blood Bank	1	4.0
World Bank	1	4.0
Hemoce* and National Transplant Network	1	4.0
INCA	1	4.0
Unanswered	1	4.0
Recipients' records storage location		
Unanswered	4	28.6
REREME	3	21.4
REDOME	2	14.3
Hemoce*	2	14.3
INCA	1	7.1
National Data Bank	1	7.1
National Transplant network	1	7.1
BMT centers in Ceará		
Hemoce*	11	44.0
Hospital Universitário Walter Cantídio	6	24.0
Fortaleza	2	8.0
Unanswered	2	8.0
Hospital Geral de Fortaleza	1	4.0
Hospital da UNIMED de Fortaleza	1	4.0
Hospital Infantil Albert Sabin	1	4.0
Hospital São Carlos and Hospital Valter Cantídio	1	4.0
BMT centers in the Northeast of Brazil		
Unanswered	13	52.0
Hospital Português	3	12.0
Recife	2	8.0
Hemope**	2	8.0
Pernambuco state	1	4.0
Hospital Memorial São José	1	4.0
IMIP***	1	4.0
Bahia state	1	4.0
Hospital São Camilo	1	4.0

Variables	n	%
BMT centers in Brazil		
Unanswered	13	52.0
INCA	5	20.0
Rio de Janeiro state	2	8.0
São Paulo state	1	4.0
Casa de Saúde Santa Marcelina	1	4.0
Registro Nacional de Medula Óssea	1	4.0
70 centers in Brazil	1	4.0
In major capital cities	1	4.0

*Hemotherapy and Hematology Center of Ceará; **Hemotherapy and Hematology Center of Pernambuco; *** Instituto de Medicina Integral Professor Fernando Figueira.

Table 3: Association of age and experience since graduation with the knowledge on the BMT network, Juazeiro do Norte, Ceará, 2016.

Variables	Age (years)	Experience since graduation (years)
Professionals who claim to know what REDOME is.	Median (95%CI) p*	Median (95%CI) p*
No	38.0 (34.0; 49.8) 0.560	12.0 (10.0; 22.4) 0.361
Yes	38.0 (34.8; 43.0) 0000	12.0 (6.0; 16.6) 00000
Professionals who claim to know where to register as BM donors.		
No	42.5 (34.0; 54.5) 0.268	12.5 (6.1; 24.8) 0.473
Yes	37.0 (34.0; 41.4) 00000	12.0 (8.5; 15.4) 0000
Professionals who claim to know where the registered donors' records are stored.		
No	41.0 (35.3; 47.5) 0.160	12.5 (10.0; 18.2) 0.173
Yes	36.0 (33.2; 41.0) 00000	10.0 (5.0; 15.8) 00000
Professionals who claim to know where the patients' records are stored.		
No	39.0 (35.1; 44.8) 0.257	12.0 (10.0; 16.9) 0.367
Yes	36.0 (32.0; 42.4) 00000	10.0 (4.9; 18.1) 00000
Professionals who claim to know the location of BMT centers		
No	39.0 (34.5; 46.2) 0.933	12.0 (7.4; 16.5) 0.961
Yes	37.0 (34.0; 43.0) 00000	11.0 (7.3; 18.8) 0000

*Mann-Whitney. 95%CI: 95% confidence interval.

DISCUSSION

Upon analyzing the profile of the subjects from the current study, it can be observed that the obtained results coincide with other studies performed with health professionals.[7,8] Two of them, one with workers from BMT units[8] and the other with health professionals from hospital institutions in Zagreb, Croatia, revealed that most of the professionals were female nurses with a mean age of 40 years and over 5 years of experience in BMT units.[7]

The first results showed that the professionals know what REDOME is, but they are not registered as donors. According to some researches, health professionals recognize the importance and the need of organ and tissue donations despite the fact they themselves are not donors.[7,9]

It is paramount that more health professionals volunteer as donors and that they provide more information regarding the donation process. As they have a direct contact with patients and family members, their voluntary act would set an example to the latter, and maybe sensitize them towards organ and tissue donations.

One of the possible strategies to meet this need is to develop educational actions during the students' professional training. It is necessary to provide a deeper approach to organ and tissue donation throughout college years and stimulate ethical discussions with precise information on how to become a donor.[10] In turn, whenever students actively participate in actions during their professional education, they feel motivated to become donors.[11]

When professionals are asked about the place where to register as a bone marrow donor, it can be noted that they know the answer; however, issues like the lack of motivation to become a donor and to stimulate others may be the reason for the low rate of registered BM donors among the studied participants.

Professors included in a study state that transplants must be seen as an act of social responsibility, and they mention laziness and thoughtlessness towards others as reasons not to volunteer as bone marrow donors.[12]

A different study conducted with donors and non-donors revealed that 15% of non-donors would only volunteer in favor of family members.[5] Such data shows the need to strengthen donation drives with campaigns that raise questions related to solidarity, social responsibility and help to others. This finding is similar to the ones obtained in studies with health professionals.[7,9]

The poor knowledge of the participants in relation to the place where donors' records are stored reflects the low number of volunteers among this group, since donors are informed about it upon registration as well as the importance of keeping their records updated with correct address and telephone number.

The HLA is the major histocompatibility system in humans, and it most influences the comparison of genetic characteristics between donors and patients.[12] Only a related donor will be a total match, ideally a sibling with identical HLA status.[13,14] As such donors are not always available, whenever a transplant is needed, a search for unrelated matching donors is conducted.

The higher the matching rate, the less likely it will be for the patient to have a graft rejection or other complications after the transplantation.[14] Hence, a higher number of volunteers widens the possibility to find unrelated matches, especially in Brazil, a country of great miscegenation where there are some genetic characteristics that can be found only in one ethnic group.[4]

The medical staff is in charge of including the patient in the REREME whenever an unrelated donor is needed, once cross-matching recipients and potential donors make the search registered in the REDOME.[15] Therefore, it is of utmost importance that health professionals know where such records are stored so that treatment can be carried out. In addition, diseases that require transplants need to be treated as fast as possible.[2]

Upon recognizing REREME as a databank of recipients, health professionals are able to provide not only patients but also the National Center of High Complexity Regulation (CNRAC) with correct information, thus making transplantation processes more quickly.[15]

When asked about transplant centers, professionals came up with more right answers regarding those in Ceará. As to the location of the centers in the northeast of the country, all the mentioned institutions were in the state of Pernambuco. This observation may be the result of the fact that many professionals from the area where the study was conducted usually apply for universities in that state. Due to the geographic proximity, patients search for treatment centers in Pernambuco as well. It is worth mentioning, though, that there are transplant centers in the states of Rio Grande do Norte and Bahia in the Northeast.

Transplant centers can be found in the northeast, center west, southeast and south of the country, among which 70 perform BMTs. The question on the identification of these centers was asked in order to verify if professionals could indicate to patients where BMTs are conducted in the state of Ceará and out of it, since many of them need to leave the state to be treated.

The studied professionals know the aspects of the bone marrow transplant network, especially when it comes to the donation process. They know what REDOME is, where volunteers can register for donation, but they themselves are not donors. However, the knowledge is not so vast regarding reception.

Results show that it is necessary to increase the number of BM donors among family health strategy professionals. The volunteer registration department from hemocenters should organize educational actions on themes related to the transplant network, thus shedding more light on the process of donation and reception.

The fact that only doctors and nurses were included posed limitations to the current study. As a result of the addition of other health professionals to future studies, it will be possible not only to have a broader profile of their knowledge but also to increase the number of BM donors among higher education professionals

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