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Original Article

Challenges faced by bone marrow registries in India

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ABSTRACT

Aim: To identify the major challenges faced by bone marrow donor registries in India.**Materials and methods:** HLA typing, using the Sequence specific oligonucleotide probe (SSOP) Luminex-xMap technology, was performed for all 18,000 donors. Haplotype analysis was performed using the Arlequin software.**Results:** In a cohort of 18,000 donors only 19% patients could find a donor at 10/10 low resolution level. The chances of finding a donor at high resolution 10/10 level is even less. The major challenges faced are lack of awareness, patient's economic status, unavailability of unrelated matched donors, lack of funding for function of registry and high donor dropout rates.**Conclusion:** As cost is a major challenge, we need to strive to increase donor pool and also take major steps to decrease the donor dropout rates by increasingly motivating potential donors and trying to help them overcome any myth or fear from donating stem cells.

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1. Introduction

Hematopoietic stem cell transplantation (HSCT) is the transplantation of multipotent hematopoietic stem cells, usually derived from bone marrow, peripheral blood, or umbilical cord blood. It is a medical procedure in the fields of hematology, most often performed for patients with certain cancers of the blood or bone marrow, such as multiple myeloma¹ or leukemia.²

The success of HSCT depends on finding cell donors who are closely matched genetically; as the degree of mismatching increases, the success of unrelated donor HSCT falls accordingly.³ A patient's ideal donor is a genetically matched sibling.

Using unrelated adult donors to facilitate HSCT has provided a major opportunity for patients without a matched sibling donor. This was the driving force that encouraged development of Marrow donor registries in world. The first registry was established in UK for a patient called Anthony Nolan who required an unrelated donor way back in 1974.

In India many attempts to establish a marrow donor registry have been made by various groups. DATRI Blood Stem Cell Donors Registry and Marrow Donor Registry India (MDRI) are currently the two major registries working in India. As of April 2014, Datri has successfully facilitated 52 Blood Stem Cell transplants and have a database of more than 56,000 registered donors.⁴

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Marrow donor registry India (MDRI) was established in 2009 with the aim of helping patients searching for an unrelated donor to undergo stem cell transplantation. From 2009 to till date MDRI has about 18,000 voluntary donors that have pledged their stem cells.

2. Challenges faced by MDRI in past 5 years after its establishment

1. Lack of awareness: People are unaware of the terms such as stem cell donations and hence are reluctant to come forward and register with us. MDRI conducts awareness programs and counseling sessions for all those who wish to register as donors. The aim of these awareness programs is to break the myths and clarify doubts in the minds of potential donors in order to help them make informed decision regarding becoming a donor. We have achieved the number of 18,000 donors after 5 years of establishment of MDRI (see Table 1).
2. Lack of funds for treatment: Patients in India come from poor to middle class families and most of the times are unable to complete treatment and hence undergoing a bone marrow transplant is a great financial challenge to the patient and their families. The cost of HSCT in USA would cost an Indian patient about 150,000 US\$ whereas HSCT in India would cost about 30,000 US\$. When Indian donors are available for transplant and additional 20,000 US\$ are saved per transplant which are used as fees to search and procure matched stem cells from abroad.
3. Lack of matched donors: As it is a known fact worldwide that only 25–30% patients will find a matching donor from his/her family. The remaining donors will have to look for an unrelated donor outside their family. India is the second most populated country in the world with population of 1.27 billion and has been subjected to different waves of immigration. With 22 official languages, India has amalgamation of various ethnicities, cultures, languages, marriages within communities which have resulted in unique gene pool.

HLA genes are most polymorphic in human genome. HLA genes play a central role in immunity and are responsible for graft rejection in hematopoietic stem cell transplantation. As the HLA loci depict an immense degree of polymorphism and extensive tight-linkage among loci, it helps to determine

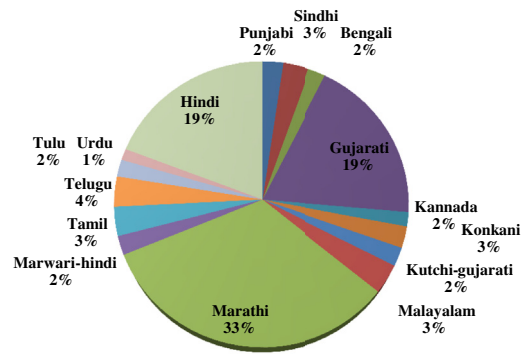


Fig. 1 – Distribution of donors in 16 linguistic groups.

genetic relatedness amongst population and population migration pattern etc. The distribution of MDRI donors based on the languages spoken is given in Fig. 1.

Indian haplotypes show some unity in diversity in their HLA gene inheritance. Although many common haplotypes are seen across all linguistic groups some unique HLA haplotypes distinguish one group from another. Being a registry this knowledge will help us understand the HLA genetics of Indian population and help us find suitable matched donors for the patients in need for transplant. Tables 2 and 3 show the common and unique haplotypes in MDRI donors.

All these variations suggest the inbuilt customs and traditional practices of marriage system generate unique pools of genes in spite of the same geographical region. Unique haplotype patterns in each group reveals that more donor drives have to be concentrated on those groups that are poorly represented in the donor pool. This will increase the chances of finding the match within the same linguistic group.

4. Lack of funds for function of registry: As marrow donor registries in India are not supported by the state or central government of India. Each functioning registry is dependent on funding from various private organizations. Few patients and their families who understand the problems faced by registries help in fund raising. Each step in the functioning of the registry from organizing donor camps, testing of donors for HLA typing, maintenance of the laboratory and wages of staff requires a large financial backup which is very difficult to achieve.

5. Donor dropout rates: Control of the donor dropout rates at important stages before transplant remains a major challenge faced by all registries worldwide. At MDRI we initiated donor searches in 2012 when registry reached donor

Table 1 – Annual donors recruitment in MDRI.

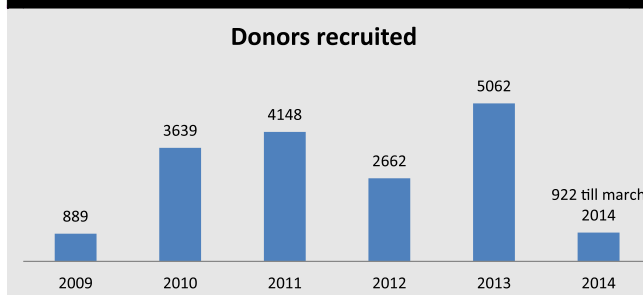


Table 2 – Most common HLA haplotypes in MDRI donors.

| A | B | DR | Rank in 16 groups | HAP-frequency % |
|------|------|---------|--------------------------|-----------------|
| A*33 | B*44 | DRB1*07 | Rank one in 7 groups | 3.041% |
| A*01 | B*57 | DRB1*07 | Rank one in 3 groups | 2.395% |
| A*02 | B*40 | DRB1*15 | Rank one in Urdu group | 1.797% |
| A*24 | B*40 | DRB1*15 | Common across all groups | 1.2% |

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