

Study on the Construction of Family Support System for Unrelated Hematopoietic Stem Cell Donation Volunteers

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Abstract: There are millions of patients in urgent need of hematopoietic stem cell transplantation in China, but the matching success rate of unrelated hematopoietic stem cells is only $1/400 \sim 1/10000$. Since the establishment of China Bone Marrow Bank in 1992, only more than 14,000 patients have been successfully matched. According to the survey, a large number of volunteers in China will eventually choose to refuse to donate hematopoietic stem cells, which is closely related to the public's lack of understanding of hematopoietic stem cell donation. Unrelated volunteers can get less support from family members than related hematopoietic stem cell donors, which leads to their lower donation rate. Therefore, it is of great practical significance to study the family support system of unrelated hematopoietic stem cell donation volunteers.

Keywords: unrelated hematopoietic stem cell donation, family support system, regret to donate

1. Introduction

According to the statistics of China Red Cross Foundation in 2018, there are currently more than 4 million patients in urgent need of hematopoietic stem cell transplantation in China. Leukemia alone has an annual increase of more than 30,000 patients. At present, it is recognized by the medical community that the effective method to treat leukemia is to transplant hematopoietic stem cells that match the patient. However, the coincidence rate of HLA is only $1/400 \sim 1/10000$ in unrelated relationships (Department of Hematology, Beijing Hospital, 2008), which is undoubtedly a fatal blow to the huge number of leukemia patients in China.

The complete steps of unrelated hematopoietic stem cell donation include warehousing, matching, initial matching, mobilization, high matching, signing consent form, physical examination, peripheral blood sampling and so on. Due to the low success rate and long waiting time of matching, the volunteers in storage can't always keep their enthusiasm for donation, and their intention to donate will gradually decrease with the passage of time. In addition, their understanding of the donation process is not clear. Even if the matching is successful, they will easily feel uncomfortable in the donation process, such as fear, nervousness and helplessness. Even some volunteers will take the behavior of regretting the donation at the stage of transplant operation, which is fatal to patients. In addition, the risk intensity of unrelated hematopoietic stem cell donors in the donation process is much higher than that of relatives. In addition, volunteers are more likely to show negative emotions because their families don't understand or even obstruct the donation work, thus greatly increasing the rate of repentance. The rate of non-related hematopoietic stem cells in China is as high as 70%[3]Far more than other countries. However, the contrition rate of relative donors is much lower than that of unrelated donors[4]. This is closely related to the family support they have. Therefore, high-quality and high-level family support is of great significance in alleviating the psychological anxiety of unrelated hematopoietic stem cell donors before donation and reducing the rate of hematopoietic stem cell repentance.

2. The concept of family support system

2.1 The origin of family support system

In the early 1970s, the concept of family support system first appeared in foreign countries, as a subsystem belonging to social support system. As an independent concept, family support system began to be studied in the 1980s, but the research direction is mostly only for the nursing of the elderly and disabled people, which is relatively limited. In contrast, the domestic research started relatively late, and the research direction mainly focused on family education. By the beginning of the 21st century, family support system has been widely used in all aspects of society, and its research direction has begun to change from the internal essence, structure, function, cycle and influence to ameliorate a social phenomenon, and to formulate corresponding feasible countermeasures.

2.2 Differentiation and optimization of family structure

The differentiation of family structure promotes the individualization of family members, and people's senses of family responsibility and cooperation spirits are gradually weakened. Socialized pension mode and the birth of a second child are of great benefit to the optimization of family structure of unrelated hematopoietic stem cell donors, at the same time, they can improve their ability to resist family risks, promote family stability, and to some extent, achieve the effect of 'raising children to prevent old age'.

In addition to the above, the differentiation of family structure has brought great changes in family origin, economy and derivative functions. With the support of system ecology theory, the family ecosystem can be optimized through its subsystems, including individual, interpersonal and social levels, so as to seek a coordinated and interactive model between the family and the external environment, thereby effectively improving the good moral quality of unrelated hematopoietic stem cell donors.

2.3 Content of Family Support System

Family support system refers to an organic combination of internal and external conditions that can support the family and ensure that it can perform its functions normally. It mainly includes two parts, namely, internal support system and external support system[1]. Internal support system refers to the emotional support within the family, which is mainly based on blood relationship, including the emotional connection between husband and wife, children and other relatives; External support system refers to all kinds of support from outside the family, that is, the sum of the security conditions that the family can get in society, such as material support, emotional support and information support provided by communities, hospitals and schools[2]. In terms of ensuring the normal implementation and stable development of family functions, the internal and external systems complement each other and are inseparable.

3. The role of family support system in unrelated hematopoietic stem cell donation

3.1 Family internal support system

The support system within the family represents the support that the family can provide. The two main reasons for the successful volunteers to regret donating are their own fear and the opposition of their families[5]. The understanding, support and companionship of family members can effectively alleviate the fear of family members and effectively improve volunteers' determination to donate. Due to the unclear donation process, a large number of volunteers' family members' cognition of hematopoietic stem cell donation still stays at the stage of extracting bone marrow. They often try their best to stop volunteers' donation because of concerns about the safety of donors and doubts about the safety of surgery. If the volunteers' cognitive level of donation knowledge can be improved and the wrong cognition of donation can be reduced, the emotional support from the family will change from negative to positive, thus promoting the smooth development of hematopoietic stem cell donation.

3.2 Family external support system

Family external support system refers to the security conditions that families can get in society, including policies, welfare and honor incentives that donors can enjoy. Compared with the support within the family, donations can be enjoyed externally, including material incentives and spiritual incentives. Material incentives mainly refer to the policy incentives for hematopoietic stem cell donors issued by local governments, such as the policy of giving priority to the children of donors in Wenzhou, which reduces the social pressure on donors; Taizhou proposed that the donation of hematopoietic stem cells to save people should be included in the scope of courageous reward. The specific reward standard is to award certificates to hematopoietic stem cell donors, and each person will be rewarded with 10,000 yuan each time. Spiritual encouragement mainly refers to the actual publicity and later media interviews of the donors by the local Red Cross and the government after their successful donation. Popularizing the glorious deeds of donors to the public can not only enhance the awareness of hematopoietic stem cell transplantation in the whole society, but also create a good atmosphere of 'I am for everyone and everyone is for me' in the society.

3.3 The relationship between the internal and external systems of the family

Family internal support system is the foundation of family external support system, which is the guarantee of family internal support system.[6]Through the integration of the internal support system and the external support system of the family, the trinity donation promotion model of 'society, donor and family' is established. The integration of society, patients, donors and families will help donors get psychological comfort and spiritual encouragement when they donate physically and face unknown fears, improve their sense of experience in the process of donation, enhance their sense of gain, reduce

the pressure on medical workers, make the donation work go smoothly, and reduce the rate of repentance of hematopoietic stem cells.

4. Countermeasures and suggestions for establishing a family support system for unrelated hematopoietic stem cell donation[7]

4.1 Improve the donation knowledge level of the families of volunteers in storage

We can promote the cooperation between major universities and the local Red Cross Society, so that "stem donation can enter the campus", starting with college students, and further enhance the whole family's awareness of hematopoietic stem cell donation. In addition, the social practice activities of "going to the countryside" can be carried out, so that college students can go deep into the grassroots, popularize what they have learned to the whole society, and eliminate the common misunderstanding of hematopoietic stem cell donation, thus improving the understanding level of hematopoietic stem cell donation in the whole society.

4.2 Strengthen the positive attitude of volunteers' families to donation

Measures to enhance enthusiasm include perfecting and implementing the method of awarding honor to volunteers and the policy of giving priority to blood donation to donors' children. The sense of honor and practical help brought by it will help stimulate the internal commitment of donors' families to support hematopoietic stem cell donation. While publicizing and educating the donation of hematopoietic stem cells, we must introduce and improve relevant laws and policies to protect the smooth progress of the donation of hematopoietic stem cells and the dignity and rights of donors and their families. Only in this way can we enhance the enthusiasm of the whole society for the donation of hematopoietic stem cells.

4.3 Actively publicize the donation-related policy information to the families of volunteers in storage

In general, the donor's family needs the corresponding policy support from the society, and the existence of information gap to a great extent reduces people's enthusiasm for donation. For example, in Wenzhou, donors can enjoy rich social benefits, including policies to settle down, children's priority in blood donation, medical insurance, etc., but the awareness of such policies among the citizens is not high. Therefore, government departments should broaden the publicity channels and increase the publicity of policy welfare to popularize relevant policy information to the society.

5. Conclusion

In this paper, we discussed the factors influencing the construction of family support system for unrelated hematopoietic stem cell donation volunteers, aiming to reduce the regret rate of hematopoietic stem cell donation volunteers, and we will further explore in the future, in order to make greater contributions to the extension and improvement of hematopoietic stem cell donation rate.

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