

Perception of Matched Sibling Hematopoietic Stem Cell Donor about Donation of Stem Cells

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ABSTRACT

Allogeneic hematopoietic stem cell transplantation (HSCT) is the curative treatment option for a variety of hematological disorders. Usually, stem cells for HSCT are obtained from matched related donors through bone marrow harvest or apheresis. Although stem cell donation is relatively a safe procedure, there are many psychosocial concerns among potential donors regarding the donation of stem cells and its possible complications. The present study aims to understand the experience of being a hematopoietic stem cell donor for a sick sibling. Eighty hematopoietic stem cell sibling donors were interviewed with a self-structured questionnaire comprising of 3 domains-intrinsic and extrinsic motivators and deterrents. Data were analyzed using descriptive and inferential statistics using IBM SPSS[®] Statistics version 20.0. The present study found that nearly half of them (47.5%) were <30 years of age with 52.5% being male, 57.5% were married and 53.8% were employed. 43.8% were graduates of which 7.5% had a family income of <Rs.5,000. 51.2% hailed from rural backgrounds. The majority of them (90%) of them had no co-morbidities. All of them underwent local anesthesia and had peripheral stem cells as the source of harvest. None of them had a previous history of stem cell donation. The majority of the matched sibling donors were primarily influenced by intrinsic factors (median score-3.2). The influence of the deterrents is lesser than the influence of the motivators (median score-1). There is a statistically significant association between gender and the influence of extrinsic motivators ($P = 0.024$), marital status and deterrents ($P = 0.003$), and age and deterrents ($P = 0.019$) in the hematopoietic stem cell donation process. Among the deterring facets, the emotional concern of being responsible for the outcome of the transplant was the major barrier (45%). The family concern of taking up the burden of being a donor and a family member is the least deterring facet (62.5%). Among the intrinsic motivating facets, positive feelings (87.5%) and family loyalty (81.3%) were the major motivating factors whereas reinvesting back into the community was the least intrinsically motivating factor (32.5%). Among the extrinsic motivating facets, complete awareness of the donation process through explanation was the highly motivating factor (93.8%). Family pressure/social obligation was the least extrinsically motivating facet (83.8%). The study highlights the role of intrinsic motivation in the stem cell donation process and warrants for further exploration.

Keywords: Allogeneic hematopoietic stem cell transplantation, Deterrent, Matched sibling stem cell donor, Motivators, Psychosocial concerns

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INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) Donors can be related or unrelated and if related, they are mostly siblings.^[1] Sibling donors have the dual role of being a family member as well as donor thus causing unique psychological concerns.^[2] Recipient's post-donation outcomes have also been linked to donor psychological functioning. Following HSCT, a recipient's health status often fluctuates, which causes ongoing donor stress.^[3] Donors have many concerns regarding the donation of stem cells and the possible complications, which make them reluctant to even get HLA typing done. There is limited literature on the psychosocial experience of adult sibling donors. The study will be beneficial in understanding the psychosocial motivators and deterrents that influence the experience of the matched sibling donor.

Objectives

1. To assess the perception of potential donors regarding stem cell harvest and its after effects
2. To identify the factors that motivate and deter donors from consenting
3. To determine the association between the perception of potential donors with selected demographic data.

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METHODS

The study utilized a cross-sectional survey design and the sample size was calculated based on a pilot study. A convenient sampling technique was used to enroll a sample of 80 matched sibling donors between the age group 18–70 years who were willing to participate in the study, visiting the Hematology outpatient department of a tertiary super specialty hospital in South India. Donors with cognitive impairment were excluded from this study.

Instruments

The data collection instrument was a self-structured questionnaire consisting of 2 parts.

Part A: Included demographic and clinical data, such as age, gender, marital status, education, occupation, income, and location. The clinical data included the source of stem cells, type of anesthesia, co-morbidities, and previous history of stem cell donation.

Part B: Included the Donor Perception Questionnaire. It is a self-structured questionnaire prepared after consultation with Hematologists and Psychologist. Content validity was performed by 5 experts in the field. It is a 4-point Likert scale with options: Not at all = 0, Not sure = 1, A little bit = 2, A moderate amount = 3, and Very much = 4. There are 20 questions that assess 3 domains: Deterrents (8 items), Intrinsic motivators (5 items), and Extrinsic motivators (7 items).

Deterrents are stimuli that discourage or intend to discourage an individual from engaging in an act. The facets include pain and discomfort, fear of health consequences, emotional concerns, lifestyle inconveniences, and familial concerns.

Intrinsic motivators are internal stimuli that influence willingness to engage in an act. The facets include positive feelings, moral duty, existential reasons, family loyalty, and reinvesting good health to the community.

External motivators are external stimuli or incentives that influence engagement in an act without an internal conviction. The facets include the perceived degree of risk, family pressure/social obligation, improved family ties, stronger sibling relationships, building a positive identity, social recognition, and religious conviction.

The Domain scores are graded in a positive direction. Higher scores denote the greater influence of that particular factor in the perception of the donor. The mean score of items within each domain is used to calculate the domain score. This will shed light on the extent of the influence of the particular factor in the way the donor perceives the donation process.

Data collection procedure

Ethical clearance was obtained from the Institutional Review Board. Informed written consent was obtained from donors before data collection. Data were collected by administering the questionnaires. It took about 15–20 min per donor. The privacy of the participants and confidentiality of information was maintained throughout the study.

Data Analysis

Descriptive and inferential statistics were used to analyze the data. All statistical analysis was performed using SPSS (IBM® SPSS Statistics version 20.0). The level of statistical significance was set at $P < 0.05$. Descriptive statistics was used to summarize the demographic variables, clinical variables, and level of influence of different domains (deterrents, intrinsic and extrinsic motivators) among donors. Chi-square was used to find the association between the perception of potential donors with selected demographic and clinical data.

RESULTS

Demographic and Clinical Variables

Nearly half of them (47.5%) were <30 years of age. The majority were male (52.5%) and were married (57.5%). More than half

(53.8%) were employed. A larger portion (43.8%) was graduates. A family income of <Rs.5,000 was seen in 7.5% while 51.2% hailed from a rural background. The majority of them (90%) had no comorbidities. All of them (100%) underwent a peripheral blood stem cell harvest and received filgrastim for 5 days. None of them had a previous history of stem cell donation.

The Level of Influence of Different Domains among Matched Sibling Donors

Figure 1 reveals that the majority of the matched sibling donors were primarily influenced by intrinsic factors (median score-3.2). The influence of the deterrents is lesser than the influence of the motivators (median score-1).

Association between the Perception of Potential Donors with Selected Demographic Data

Results indicate a statistically significant association between gender and the influence of extrinsic motivators ($P = 0.014$). Men (73%) were found to be more extrinsically motivated than women (median score ≥ 2.85).

There exists a statistically significant relationship between age and the role of deterrents ($P = 0.05$) in the hematopoietic stem cell donation process. Donors above the age of 40 years were more influenced by deterrents (median score ≥ 1.06).

There is a statistically significant association between marital status and deterrents ($P = 0.01$). Married individuals (76.2%, median score ≥ 1.06) were more likely to be deterred from the donation process than single individuals. There is a statistically significant association between location (rural) and intrinsic factors ($P = 0.051$). Donors hailing from rural areas were more likely to be more intrinsically motivated to donate.

The statistically significant relationship between occupation and extrinsic motivation ($P = 0.040$) highlighted that donors who were employed were more extrinsically motivated (72.1%).

DISCUSSION

This study explored the experience of matched sibling donors preparing for stem cell donation. The study explored the psychosocial factors that influence the donor's perception toward the donation process which ultimately determines their willingness to participate in stem cell donation. The study

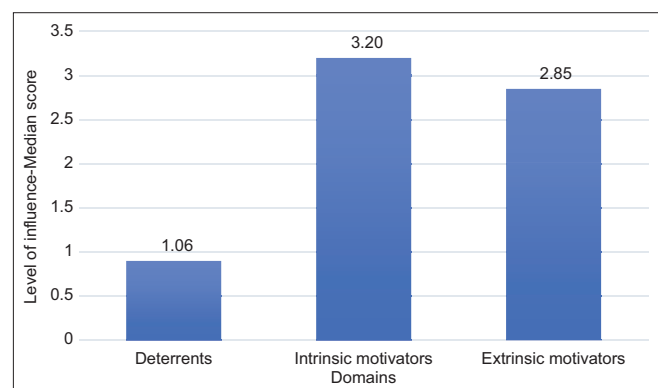


Figure 1: Level of influence of different domains among matched sibling donors

highlighted factors that motivate or deter the donor in relation to the donation process.

The present study found that the majority of the matched sibling donors were primarily influenced by intrinsic factors to donate than extrinsic motivators. The role of deterrents in the donation process was found to be of lesser influence than motivators. Our findings agree with existing literature that states motivation to be of fundamental importance in the donation process. Potential donors with intrinsic commitment to donate, rather than extrinsic pressure, were found to be less ambivalent about donating.^[4]

Previous studies have concluded that even if a strong primary motivation is in place, it is fundamental that the potential donor receives the help and support of the medical staff at every point of the interaction throughout the donation process. The results of a previous study report that new recruits, for stem cell donation, who reported that they still had questions about the donation process were more ambivalent, as were those who reported a higher number of concerns about the medical and work-related aspects of donation.^[4] The results of the present study also indicate complete awareness regarding the donation process to be a highly motivating factor (93.8%) for sibling donors in the donation process. Therefore, the study highlights the need for the provision of comprehensive preparatory information regarding the possible physical and emotional ramifications of donation, before the actual event.

Our study found that men (73%) were found to be more extrinsically motivated than women (median score ≥ 2.85) in the donation process. Interestingly, though not statistically significant, women (55.3%) were found to be more likely to be deterred (median score ≥ 1.06) from the donation process. This is consistent with a study that reports how the factor of risk negatively affected women more than men and negatively affected those with family responsibilities more than single donors.^[5] These findings from earlier research also lends support to the results of the present study that indicate the married individuals to be more deterred from the donation process than unmarried donors.

Literature also states that there exists a significant correlation between gender and feelings of fear which was found to be greater among females, possibly because women have more involvement with the family.^[6] This is of pertinence to the present study as this may have been a reason why women may be less motivated than men for donation.

Analysis of the results highlighted a correlation between the age of the donor and the influence of deterrents in the donation process. The study highlighted the greater influence of deterrents among donors aged 40 years and above. The influence of deterrents was found to be lesser for donors below the age of 30 years. This finding is contrary to previous research which states no significant relationship between the age of the donor and the donation process.^[6]

Existing literature highlights the psychosocial impact of donation to be multidimensional in nature characterized by interactions among pragmatic aspects of the donation process; family dynamics; perceived adequacy of preparation and emotional support; and uncertainty related to health outcomes for the recipient and donor.^[7] The results of the present study are consistent with the finding that the perception of the donor is influenced by a myriad of psychosocial factors. Significant psychosocial factors in the present study are emotional

experiences, the role of family, and preparatory information regarding the donation process.

The emotional concern of being responsible for the outcome of the transplant was identified to be the major barrier among the donors (45%). This finding is consistent with earlier research that states guilt and responsibility for the outcome, despite an understanding at an intellectual level that donors were not responsible for the negative outcomes (emotional concerns) among sibling donors (Pillay *et al.*, 2012). Other important motivating factors prevalent among the donors were positive feelings (87.5%), family loyalty (81.3%) strengthening sibling relationships (77.5%), and family ties (75%).

A striking finding in the present study is the role of family both as a motivator and a deterrent within the Indian context. Being a collectivist culture, in India, family ties are important. They did not feel burdened by having to play the dual role of a donor and family member. The majority of them saw the donation process as a means to strengthen their relationship with their sibling. Yet, they reported feeling that the responsibility for the outcome of donation rested on them which was the major deterrent to donate. It is also interesting to note that family ties were primarily a motivating factor whereas reinvesting back into the community was identified to be the least motivating factor intrinsically. This highlights the paradoxical role of family in the stem cell donation process.

CONCLUSION

The present study found that the majority of the HSCT sibling donors were primarily influenced by intrinsic factors such as positive feelings and family loyalty to donate. The influence of deterrents in the donation process is lesser than the influence of motivators. Therefore, it can be concluded that motivating factors have a greater influence in the stem cell donation process than deterrents. The findings will help the HSCT Nurse coordinators to understand the donor's perception and the factors influencing the donation process.

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