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Attitude and Perception of Stem Cell Donors Regarding Donation of Hematopoietic Stem Cell

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Abstract

Background: Stem cell donation is crucial for bone marrow transplantation, a lifesaving procedure for various malignant and non-malignant disorders. This process requires recruiting a donor to extract stem cells capable of regenerating healthy cells in recipients. Despite the critical importance of donation, donor's decision to become a donor can be affected due to so many factors both positively and negatively.

Purpose: The study aimed to explore perceptions of stem cell donors regarding the donation process at a tertiary care hospital of Islamabad, Pakistan.

Methodology: A qualitative descriptive research design was employed, using convenience and purposive sampling to include ten participants. Data were collected through face-to-face interviews guided by a semi-structured format, which were audio-recorded and transcribed verbatim. The transcriptions underwent manual content analysis for categorization.

Findings: Three categories emerged from the data analysis: “Finding a Silver Lining,” “Moral Imperatives,” and “Physio-Psychosocial Hardships.” Initially, donors exhibited ambivalence and lacked sufficient understanding of the donation process but eventually consented to participate. Key motivating factors included familial bonds, family concerns, and a commitment to assist others. Despite this, donors faced significant practical challenges affecting various aspects of their daily lives.

Key Words: Stem cell donors, stem cell donation, perception, qualitative study.

Introduction

Cancer is a major global health challenge, remaining one of the leading causes of morbidity and mortality [1]. In 2020, there were 19.3 million new cases and 10 million deaths [2]. Projections suggest that the number of cases will rise to 28.4 million cases by 2040 [2]. Pakistan faces a similar surge, with an estimated annual incidence of 0.14 million new cancer cases and 0.1 million deaths, though these figures may be understated due to underreporting [3]. Additionally, nonmalignant hematological disorders, often due to consanguinity, are prevalent in the region [4], [5]. As a result, Pakistan faces a significant burden from both malignant and nonmalignant disorders, necessitating extensive therapeutic efforts.

Standard treatments for malignancies include chemotherapy and radiotherapy [6]. However, for some refractory cancers and certain nonmalignant conditions like aplastic anemia and β-thalassemia major, require advanced interventions such as bone marrow transplantation [6], [7], [8]. This procedure typically involves conditioning with chemotherapy followed by the infusion of stem cells from a healthy donor [10]. Except for autologous transplants, allogeneic transplants require HLA-matched donors.

Despite the critical role of medical fitness and HLA matching, donor willingness is crucial for successful stem cell donation. However, misinformation and lack of education about the donation process often hinder participation [11]. Many potential donors have limited knowledge about what the process entails [12], [13]. While there is substantial research on donor experiences post-donation, there is noticeable gap in literature regarding the perceptions and challenges faced by donors prior to donation, especially in Asia and Pakistan. Contextual differences can significantly influence donor perceptions and behaviors [14], highlighting the need for further research in this area.

Therefore, the aim of this study is to explore the perceptions and challenges of stem cell donors at a tertiary care hospital in Islamabad, Pakistan, to better understand the barriers to donation and improve donor recruitment and retention strategies in future.

Methods

The study employed a qualitative descriptive research design. Data collection began after receiving approvals from the departmental head, the Institutional Review Board, and the Ethical Committee of the participating healthcare institution. The main study question was "What is the perception of stem cell donors about donation?"

Participants:

The study targeted adult stem cell donors from a tertiary care hospital who had undergone HLA matching and were selected for donation. Inclusion criteria included: (1) Adult donors aged 18 years and older, (2) HLA-matched, and (3) Fluent in either Urdu or English. Interviews were conducted in a designated private room within the bone marrow transplant unit of the institution.

Sampling and Recruitment:

Participants were recruited using convenience and purposive sampling methods. Recruitment was managed by the bone marrow transplant coordinator, who is involved in assisting both donors and recipients throughout the pre-transplant process. The coordinator informed potential donors about the study, compiled a list of interested individuals, and arranged meetings with them.

Data Collection

Data were collected by the primary researcher using a semi-structured interview guide designed to explore various aspects of the stem cell donation experience. The guide included questions focused on motivating factors for donation and impeding factors and challenges faced by donors during recruitment. Face-to-face interviews were conducted in either Urdu or English, based on the participants' language preference. All interviews were audio-recorded to ensure accuracy in data capture. To enhance the depth of understanding, probing techniques were employed to clarify responses. Additionally, field notes were meticulously taken to document participants' emotions and provide further context for their responses. Interviews took place in a designated private room within the bone marrow transplant unit of the institution. Prior to participation, written informed consent was obtained from all participants. Data saturation was achieved with 10 participants, indicating that no new themes emerged and sufficient depth of information was gathered.

Analysis:

The data were transcribed by a bilingual language expert proficient in both Urdu and English. Transcripts were then cross-verified with the audio recordings to ensure completeness and accuracy. Field notes were compiled to facilitate data validation and to provide additional context for the interviews. The primary researcher and thesis supervisors independently analyzed the data using Creswell & Creswell's (2018) method of content analysis [15]. The analysis process involved several steps:

1. Familiarization: The data were read multiple times to achieve a deep understanding and comprehension of the content.

2. Coding: Codes were extracted using both in-vivo (directly from participants' words) and interpretative approaches [16]. This dual approach ensured that both explicit and implicit meanings were captured. The complete list of codes was validated against the transcripts to ensure their relevance and accuracy, and any irrelevant information was discarded.

3. Categorization: Categories and sub-categories were identified based on similar codes. This step involved grouping codes that conveyed a common meaning, ensuring a structured and coherent categorization of the data.**4.**

4. Compilation and Writing: In the final stage, the data were systematically compiled and written in an organized manner, utilizing the established categories, sub-categories, and codes.

Study Rigor

To ensure study rigor, Lincoln and Guba's criteria for trustworthiness were applied using strategies proposed by Anney (2014) [17], [18]. Different measures were taken to ensure credibility, dependability, conformability, and transferability. Credibility was maintained through several methods: audio recording of interviews, probing for clarification, taking detailed field notes, and thorough transcription. Dependability was ensured by meticulously recording and double-checking data, as well as employing member checking during data collection. Transcribed data were cross-verified with audio recordings to identify and address any discrepancies. Conformability was achieved by independently coding the data, double-checking interviews and transcriptions, and providing a transparent explanation during the consent process. Transferability was addressed by organizing the study findings in a clear and presentable manner. Detailed efforts to maintain rigor are discussed further in the study.

Ethical Consideration

The study was conducted following approval from the Institutional Review Board, Ethical Committee, and the departmental head of the selected healthcare facility. Informed written consent was obtained from each participant, ensuring voluntary participation and agreement. Participants were granted the right to withdraw at any time during the study. Anonymity and confidentiality were strictly maintained. Data were shared only with the research committee during the analysis phase. Data is saved in personal computer with code for five years according to institutional policy.

Results:

The study findings are organized into two comprehensive sections. The first section outlines the demographic and clinical characteristics of the participants. The second section presents the results of the data analysis, categorized into three main themes. Each theme encompasses sub-categories that provide detailed insights derived from the participants' data. Table 1 illustrates the demographic and clinical characteristics of the participants.

Table 1: Demographic and Clinical Characteristics of the Participants

Age Yrs.	Gender	Marital Status	Qualification	Occupation	Relationship with Recipient	Recipient Diagnosis	Harvest type	HSCT type
45	F	Married	Under-Matric	Housewife	Sister	AMBL	Peripheral Harvest	AHSCT
33	M	Married	Masters	Engineer	Brother	AMBL	Peripheral Harvest	AHSCT
53	M	Married	Bachelors	Retired	Brother	AMBL	Peripheral Harvest	AHSCT
59	M	Married	Matric	Retired	Brother	MDS	Peripheral Harvest	AHSCT
18	F	Single	Graduating	Student	Cousin	ALL	Peripheral Harvest	HHSCT
31	F	Married	Bachelors	Housewife	Sister	AA	Peripheral Harvest	HHSCT
32	M	Married	Matric	Business-man	Uncle	TM	Peripheral Harvest	AHSCT
41	F	Married	Bachelor	Housewife	Sister	AA	Bone marrow harvest	HHSCT
20	M	Single	Graduating	Student	Brother	TM	Bone marrow harvest	AHSCT
33	F	Married	Bachelor	Housewife	Sister	AML	Peripheral Harvest	AHSCT

The data analysis identified three main categories: "Finding a Silver Lining," "Moral Imperatives," and "Physio-Psychosocial Hardships," each with its respective subcategories, as detailed in Table 2.

Table 2: Categories and sub-categories emerged from data

Categories	**Sub-categories**
Finding a Silver Line	1. Seeking Information **2.** Decision Making
Moral Imperatives	1. Social Obligations 2. Spiritual Conduct
Physio-Psychosocial Hardships	1. Physical Hardships 2. Psychological Hardships **3.** Socioeconomic Hardships

Finding a Silver Line

Nearly all participants perceived the process of bone marrow transplantation and stem cell donation as "finding a silver lining," indicating that despite various challenges, they held hope for the survival of their recipients. Consequently, the majority sought information about stem cell donation. Most participants received counseling from healthcare professionals about the process, while a few were informed by family members. Some donors independently researched procedural details through digital media and actively sought clarification. One participant expressed: “So, at that time we weren’t aware of anything related to that. Then we started research from the internet. Few of the doctors here, they also told us that, but yes when I started a little research regarding that the doctors use to basically match first. Then I got to know regarding the whole procedure of this donation” (Male, 33 years). Similarly, one donor demonstrated a proactive approach to bone marrow transplantation and stem cell donation by seeking information about the procedure even before any formal decision was made by the healthcare team: “I have read about this on the 10th May (when the recipient was diagnosed), and I knew that if someone is suffering from Blood Cancer, he has to go through the bone marrow transplant, and if a bone marrow is being matched with somebody, so he or she should donate her bone marrow to the patient” (Female, 18 years). Conversely, a few donors were not involved in obtaining information, as narrated by one participant: “I don’t know about this process a lot. The doctor told me that I have to give my bone marrow, I have to donate my blood. Just the doctors told me this thing” (Male, 32 years). Remarkably, some participants emphasized that understanding the procedure is crucial for making an informed decision as a donor. One participant illustrated: “Then I read, saw, and understood the procedure more deeply because I had to understand it basically, as I have thought and made up my mind for that. But definitely, a person should know and have some information related to how things will run, and how beneficial it is for the patient (recipient)” (Male, 20 years). Some donors had to counsel their parents before deciding on stem cell donation, as mentioned by one participant: “My parents were already very worried about my elder sister [recipient] and refused the donation, but I told them how easy that is going to be. I was only thinking about my sister, only to donate, so I decided about this” (Female, 31 years). Correspondingly, some participants counseled their recipients. In one case, although it was a necessary choice for the recipient to survive, he was too concerned about the donor’s health. One donor recounted: “I am his elder brother. Even though my younger brother [recipient] was reluctant [I have arthritis] about this decision, I said no, I will do it” (Male, 33 years). Additionally, a few donors sought their spouses' approval before making the decision, as Amina expressed: “Definitely, I have asked my husband…and I can only take this step after his consent and permission…If he wouldn’t agree, so then definitely I wouldn’t be able to do it then” (Female, 45 years). After obtaining information about the procedure, most donors described the decision-making process as a critical aspect of stem cell donation. They noted the necessity of mental preparation. One donor highlighted: “I read about the procedure more deeply, I read, saw, and understood it more deeply. Because I had to understand it basically, as I have thought and made up my mind for that. But definitely, a person should know and have some information too related to that. After getting all the information, I decided to donate” (Male, 33 years).

Moral Imperatives

The second category identified during data analysis was moral imperatives, subdivided into social obligations and spiritual conduct. Participants indicated that motivations such as familial ties, sibling bonds, and Human Leukocyte Antigen (HLA) matching were primary factors, while some chose to donate based on religious and humanitarian principles. One participant, driven by familial love, narrated excitedly: “I don’t know anything about it; I am just doing it for my brother” (Female, 41 years). A donor, who was the uncle of the recipient, described his decision as obligatory due to the lack of other matches within the family: “Everybody has given their samples for matching, but none of them got matched, and mine got matched, so then I have to do it definitely. He is my nephew; he is my sister’s son. So, definitely I had to do it by every means” (Male, 32 years). Another donor faced a similar situation. As the recipient's cousin, she felt her decision was the only viable option since the recipient was the only son of his parents and she was a match: “XYZ (Recipient) has no siblings. My uncle and aunty have only XYZ in their life, and I am a good match for him, so I have to do it anyway" (Female, 33 years). Conversely, one participant expressed that her decision to become a donor was not solely due to her blood relation but out of a broader humanitarian perspective: "I didn't think that the patient is my sister; I consider her as a patient actually. She is actually a human being, so that's why I was determined to help her and that's it" (Female, 31 years). Almost all donors related their decision of stem cell donation to their spiritual conduct. One donor articulated: "First of all, Allah has created one human being so that he could help other human beings" (Male, 53 years). Similarly, another participant decided to donate stem cells based on religious guidance: "Our Holy Prophet (PBUH) said that 'The one who has saved one person, has saved the whole humanity'" (Female, 20 years). Participants' narratives revealed that, after becoming donors, they experienced a sense of gladness and contentment. Their emotions were a blend of excitement and concern. Ahmed quoted excitedly: "I am happy! I have this feeling in myself that, if somebody's life could be saved by us, if I could be responsible for the help of somebody, then I am glad for that with all my heart" (Male, 59 years). Some donors reported feeling more comfortable and relaxed during the donation process due to their faith in Allah Almighty. As Amina quoted: "As long as I have a firm belief in Allah the Almighty, everything will run smoothly" (Female, 45 years).

Socio-economic Hardships

Participants discussed several socio-economic issues encountered during the stem cell donation process. One participant highlighted the impact on their livelihood: "Just we have left everything behind, our business is there, as I have to stay here for the next 2 to 3 days. So, see problems are there" (Male, 32 years). Another donor, who worked in a firm, mentioned the challenges of managing work and donation: "But wherever you are working, like I have to inform them about that, 'This is a kind of a surgery, and I am working there being a donor.' So, yes it needs efforts to manage things multiple times as in whole process I had to come here on and off" (Male, 33 years). Participants also discussed the financial burden of medical care, including hospital bills, rental housing in the city, and transportation expenses. One participant noted: "I live in sector XYZ on rent. Monthly I had to pay 21,000, and had to pay a separate bill for electricity and gas also" (Female, 41 years). She also discussed the costs of transportation and food: "Except that I had to bear the expenses of transport too, like have to give 500-500 every time I come and go back from the hospital. So, it makes a total of 1000 daily as the transport cost which is too much for us. Except that one has to face a lot for the food too" (Female, 41 years). Some donors experienced significant anxiety over treatment expenses, as expressed by one participant: "It is really very difficult for a person to survive in this time of inflation. I could say that only death is a better option for a poor person because it is really very difficult for a poor person to survive" (Male, 59 years).

Discussion

The study findings revealed a significant lack of recognition regarding bone marrow transplantation and stem cell donation among participants, many of whom encountered these concepts for the first time. Bone marrow transplantation is a relatively recent treatment modality in Pakistan, with limited centers providing this service, leading to general unawareness and restricted access [19].

Additionally, the scarcity of literature on stem cell donation in the Pakistani context further limits public knowledge and access to information. Socio-economic conditions also exacerbate this issue, as many patients cannot afford these costly treatments [19].Both physicians and patients often exhibit a lack of awareness, focusing on symptomatic management rather than comprehensive diagnosis, attributable to limited training in oncology and hematology and resource constraints [20]. This finding aligns with a study conducted in India, where 98.8% of individuals had minimal knowledge about stem cell donation [13]. Such knowledge deficits affect decision-making regarding stem cell donation [11]. Despite the ease of information access in the digital era, concerns about the validity and authenticity of scientific knowledge persist. The current study found that while most participants sought information from various sources such as healthcare professionals, peer donors, and digital media, a few relied solely on provided information.

Donors who actively sought information were more engaged in the donation process, making independent decisions and often persuading their families and recipients. This desire for knowledge correlated with educational status and familial role; less educated and married female donors tended to adopt a more passive approach, which may be linked to lower educational levels and cultural norms where females often defer to male decision-makers [21].Participants' decisions were heavily influenced by personal and familial relationships, with many viewing their choice to donate as obligatory due to blood ties.

In Pakistan, mixed unrelated donor (MUD) transplants are not performed due to regulations by the Human Organ Transplantation Authority (HOTA) [22], resulting in a preference for related donors who often have strong sibling bonds. This finding is consistent with research indicating that many donors make their decisions based on emotional and relational factors rather than conscious deliberation [23] [24] [25].Donors in this study also exhibited optimism, driven by a sense of performing a noble act, fulfilling divine will, and hoping for the recipient's recovery. This aligns with literature suggesting that the decision to donate stem cells is often influenced by the desire to engage in good deeds [26].Participants faced various physio-psychosocial hardships during the donation process. Most were well-prepared, with their mental readiness linked to the education provided by healthcare team. They reported physical challenges, such as pain from granulocyte-stimulating factor (GCSF) injections, and heard concerning stories about potential side effects and limitations, which initially caused ambivalence but were eventually clarified through medical advice and online research. This supports previous findings where concerns about disease transmission and donation effects impacted decision-making [11].

Psychological distress was prevalent among donors, particularly related to the procedure and concerns for the recipient and family. This aligns with another study highlighting anxiety about the donation process and familial worries [27]. The high level of anxiety can be attributed to the novelty of stem cell donation for most participants and the severe condition of the recipient, exacerbating the stress of managing hospitalizations, family responsibilities, and financial concerns.

Socio-economic hardships were also notable, with donors expressing worries about work, education, personal lives, and the costs associated with stem cell donation. These findings are consistent with previous research [11] [24] .The high financial burden is likely a result of Pakistan's limited healthcare budget (0.75%) and the prevalence of out-of-pocket health expenses [19] [28].The use of private services further compounded the financial strain on participants.

Strengths and Limitations of the study

This study is the first of its kind to explore stem cell donors' perceptions of donation in Pakistan. However, the study's limitations include its focus on a single hospital setting, which may not fully capture the experiences of donors from other regions or institutions. Future studies should aim to include a larger and more varied sample across different healthcare settings to provide a more comprehensive understanding.

Recommendations

Based on the findings, several recommendations are proposed for healthcare organizations, clinical practice, education, and future research. Healthcare teams should provide donors with comprehensive information about the stem cell donation procedure. This could include creating and distributing a detailed booklet or a donor-specific video to help donors better understand and assimilate the information. Establishing a network of stem cell donors could facilitate peer experiential learning. Such networks might assist new donors in making informed decisions by sharing experiences and guidance. Government-level financial assistance should be considered to support patients who cannot afford the associated costs of stem cell donation. This could alleviate some of the socio-economic barriers faced by potential donors. Future research should focus on evaluating the effectiveness of these interventions to enhance donor experiences and outcomes. Studies should also explore the impact of educational resources and peer support on donor decision-making and well-being.

Conclusion

The study findings provided a detailed insight into stem cell donors' perceptions. Donors expressed a range of emotions and faced various challenges, influenced by factors such as understanding of the procedure, personal and familial relationships, and socio-economic conditions. Addressing the physical, psychological, and financial challenges faced by donors, requires extensive efforts at the national, local and family levels. The study has proposed several recommendations to improve the donor experience and mitigate these obstacles.

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