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The Bottom Line

Donor Ambivalence Exposed

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In this edition of Transplant and Cellular Therapy, Gutierrez-Aguirre et al. [1] explore moral distress surrounding peripheral blood stem cell (PBSC) donation from related donors. Moral distress (MD) is attributed to feeling of constraints, knowing the right thing to do yet unable or unwilling to act on it [2].

A population that has not been well-dissected, otherwise healthy allogeneic stem cell donors, develop physical and psychological symptoms at varying points throughout their time under medical care. From initial HLA typing to post-donation, fluctuating emotions of hesitation to beneficence can lead to feelings of ambivalence. [1] Motivations to donate can be complex. Main themes that arise can include: a desire to save someone's life, family loyalty, religious conviction, building a positive identity, fear of invasive procedures, along with social pressure and obligations [3]. Evaluating the emotional and personal impact on volunteer donors is warranted.

We're introduced to three independent surveys given to 60 PBSC donors to evaluate MD, anxiety, and overall symptoms: questionnaire to assess moral distress (MDQ), the STAI questionnaire and the ESAS questionnaire. Evaluating symptoms prior to mobilization, on collection day (prior to apheresis), and 24 hours after donation aids in capturing a subjective assessment throughout the treatment period. Results of the MDQ showed that most donors were initially happy to be the selected donor (95%), wanted to help a sick family member (98%), or had offered to be the donor from the beginning (75%). Yet substantial proportions of donors felt that they were not given the opportunity to accept or refuse (28%), decided to be the donor because they were the only compatible option (49%), and had some level of anxiety (44%). The first administered STAI questionnaire further showed high anxiety from donors (63.3%) that decreased significantly throughout mobilization and collection (48.2% and 30% respectively) [1]. Anticipatory anxiety surrounding the unknown, a potential painful procedure, and use of G-CSF could have contributed to this elevated worry. The ESAS, a psychometrically validated tool, is patient-centered and used worldwide. Although few validation studies have been completed in non-cancer populations [4], this questionnaire captures 10 patient-reported symptoms (pain, fatigue, nausea, depression, anxiety, drowsiness, lack of appetite, discomfort, shortness of breath, and insomnia). During stem cell donation, all donors experienced at least one of these symptoms throughout their treatment. Follow up of the MDQ assessments show relief and happiness (97%) from PBSC donation. Additionally, donors perception of obligation decreased after donation (12% to 5%) [1].

The strengths of this study are the correlation between the newly developed MDQ with the ESAS and STAI (already previously validated tools) and links to MD [1].

As transplantation has evolved, greater attention is focused on protecting donors through advocacy resources. Donors have reported a burden of responsibility and desire for increased reassurance from the medical team [1, 3]. Donors can become emotionally invested, often worried about recipient treatment outcomes. Self-blame and exacerbated grief can surface if the recipient experiences adverse outcomes [3]. It is crucial to recognize the wide impact of donation and involve donor advocacy in parallel with the medical team. The Foundation for the Accreditation of Cellular Therapy (FACT) describes a donor advocate as an individual distinct from the cellular therapy recipient's primary treating physician whose main obligation is to protect the interests, well-being, and safety of the donor. The donor advocate may help the donor understand the process, the procedures, and the potential risks and benefits of donation [5]. Although all donors could benefit from an advocate, one is only required for allogeneic donors who are minors or mentally incapacitated [5]. Allowing a donor advocate to be a part of all donor encounters in this study would have been beneficial. Throughout solid organ donation, independent donor advocacy is required for all donors; how this is delineated is left up to the individual transplant center [6]. If there is coercion for donation, ambivalence, and marked symptoms of anxiety, fear, lack of appetite, and insomnia further evaluation is needed [1].

THE BOTTOM LINE

Donors are likely to have mixed feelings and symptoms throughout the donation period of stem cell mobilization and collection [1]. It is important to increase awareness to of the care team, to improve support and education for the donor, and to provide an environment of autonomy. The MDQ, STAI, and ESAS are all tools to increase MD awareness and decrease a potential deleterious effect of donation. Efforts to minimize coercion and support the emotional challenges of donation are warranted [3].

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