

ORIGINAL ARTICLE

Management of related donor care: a European survey

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Donating BM or peripheral stem cells is a challenging process that requires a considerable commitment on the part of the donating individual, especially when there is a relationship between donor and recipient. In order to develop a better understanding of related donor management, the research subcommittee of the European Group for Blood and Marrow Transplantation-Nurses Group (EBMT-NG) designed a questionnaire to survey European transplant centres. This questionnaire investigated several key areas, including guidelines, patient information, donor consent and follow-up services. It was distributed to a sample of delegates ($N=150$) at the 2005 meeting of the EBMT-NG. Guidelines for the information given to patients were primarily from local (33, 52%), and a combination of local and national (13, 21%) sources. Transplant information was predominantly given to related donors by the recipient's transplant team (36, 57%). A total of 33 (52%) centres indicated that donors were also consented by transplant doctors, whereas 16 (25%) identified that consent was obtained by doctors who were not connected with the transplant team. At present, there is a lack of recognized standardized guidelines for the management of related donors. The development of such guidelines would assist in maintaining patient autonomy, confidentiality and access to accurate and objective information.

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Introduction

An important factor that distinguishes related donors from unrelated donors is the relationship between donor and recipient. The principal differences are the maintenance of unrelated donor anonymity and the avoidance of a relationship between donor and recipient during the acute phase of treatment. In 2006, the outcomes of 9661 allogeneic stem cell transplants performed throughout Europe were reported to the European Group for Blood and Marrow Transplantation (EBMT); of these, 4838 (50%) were from HLA-identical siblings and 539 (5.5%) were from other family members.¹ Unrelated donors benefit from standardized care guidelines and clinical pathways established by national and international donor registries and associated organizations.^{2,3} This is not the case for related donors, for whom structured processes are currently limited. Where guidelines do exist, they are general donation guidelines and focus on the requirements of centres to provide a basic level of information regarding the physical processes of donation,⁴ or refer to the standards of practice for unrelated donors.⁵ Another significant issue is the fact that, in contrast to unrelated donors, related donors do not have the support or advice of an independent donor advocate.

Donating BM or peripheral stem cells is a challenging process that requires a considerable commitment on the part of the donating individual.

The inconvenience and discomfort associated with stem cell donation are subjectively limited in the donors' experience, suggesting that the concepts of 'gift' of donation and familial 'solidarity' partly compensate for pain and psychological stress.⁶ Responses to the donor experience are consistent with the 'heightened intimacy' between recipient and donor.⁷ These more intimate, familial relationships are increasingly recognized as important in the physical as well as psychological welfare of related donors.

The relationship between donor and recipient is notably different for related donors, given that they already have a relationship with the associated family and carers. Although the need for anonymity and confidentiality may be acknowledged by healthcare providers, in practice this

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may not always be realized. Williams *et al.*,⁸ commenting on sibling donors, concluded that there was a lack of confidentiality regarding donation, and that this compromised the traditionally volunteer status of the donor.

A study from the Marseille transplant group identified several important psychosocial factors associated with stem cell donation from within a family. Despite the relatively high levels of pain associated with donation, none of the donors in the study asked for treatment to be stopped. Moreover, at the end of the process, 85% ($n=22$) of the donors rated the procedures as either 'very easy' or 'quite easy'. All of the donors associated the act of donation with 'saving somebody's life', and, perhaps more importantly, donors reported a sense of 'duty' underpinning their action to donate.⁹ This sense of moral obligation is most likely stronger within family units and could explain differences in the attitudes between unrelated and related donors.

The aim of this project was to establish an understanding of related donor care and management across EBMT member facilities. We wished to determine clinical practice with respect to the availability and use of guidelines and patient information, the arrangements for follow-up, and awareness of the concerns of related recipients and their donors.

Materials and methods

Utilising a target population of nurses closely involved with the transplant process, the research group designed a three-part quantitative and qualitative self-administered questionnaire, consisting of 26 open, closed and multiple-choice questions. Areas of investigation included availability and use of guidelines and patient information, their content and dissemination, related donor consent processes, related donor concerns and follow-up services. The research subcommittee distributed the questionnaire to a consecutive sample of delegates at the Twenty-first Annual Meeting of the European Group for Blood and Marrow Transplantation-Nurses Group (EBMT-NG), Prague, Czech Republic, 2005. The completed questionnaires were analyzed for centre repetition, with the intention of closely matching respondents to our target population. When deciding who should represent a particular centre in the event of multiple respondents, we used a stratified analysis using a hierarchical bias. This focused on the level of individuals' involvement with related donor care, together with the number of years of experience in the transplantation setting. As a result, 13 (17%) respondents were removed from the data ($n=63$).

Results

A total of 150 questionnaires were distributed, with 76 (51%) completed tools being collected. The questionnaires ($n=63$) were disseminated across a broad cross section of nations. The largest number of respondents came from countries within the European Union (54), with the UK completing 22 (34%) questionnaires, followed by The

Netherlands with 6 (9%) respondents, and Sweden, Germany and Italy with 5 (8%) each.

Role

Respondents reported a variety of job titles: 14 (22%) described their position as BMT coordinators, 11 (18%) as clinical nurse specialists or advanced practice nurses in either BMT or apheresis, 7 (11%) as senior nurses or nurse managers. A total of 18 (29%) respondents, the biggest single grouping, identified themselves 'simply' as 'haematology nurse' or 'just' 'nurse'. The lack of any definitive description of these nurses' duties limits our understanding of their degree of involvement with donor care at a level relevant to this survey; however, with over a third (25, 40%) of nurses identifying themselves as either BMT coordinators or clinical nurse specialists, we feel, we have a good response rate from clinical team members directly involved in the transplant process.

Information

The majority of information for related donors came from the respondent's own centre (33, 52%) alone and 5 (8%) centres used national sources alone, whereas 13 (21%) centres used a combination of national and local sources, and 10 (16%) centres cited international sources either alone or in combination with local and/or national guidelines. This information is given to related donors predominantly by the recipient's transplant team: by a transplant physician at 25 (40%) centres, by nurses at 11 (18%) centres and by a combination of the two at 12 (19%) centres. In contrast, 10 (16%) respondents indicated that related donors received information from healthcare professionals who were not connected with the transplant team.

In 33 (52%) centres related donors are 'consented' by the transplant doctors, whereas in 16 (25%) centres consent for stem cell donation is taken by doctors who are not connected with the transplant team (Table 1).

When considering how information was given to related donors, 23 (36%) centres gave information to donors by a combination of written and verbal methods; 19 (30%) centres also included telephone conversations; and 17 (27%) centres reported using only verbal methods.

Table 1 Related donor informed consent ($N=63$)

Intervention/Action	Number	Percentage (%)
Transplant doctor	33	52
Doctor not involved in recipient care	16	25
Transplant team nurse/other	2	3
No response	2	3
Doctor + nurse not involved in recipient care	2	3
Doctor + nurse from the transplant team	6	10
Transplant doctor + nurse not involved in recipient care	1	2
Doctor not involved in recipient care + transplant nurse	1	2

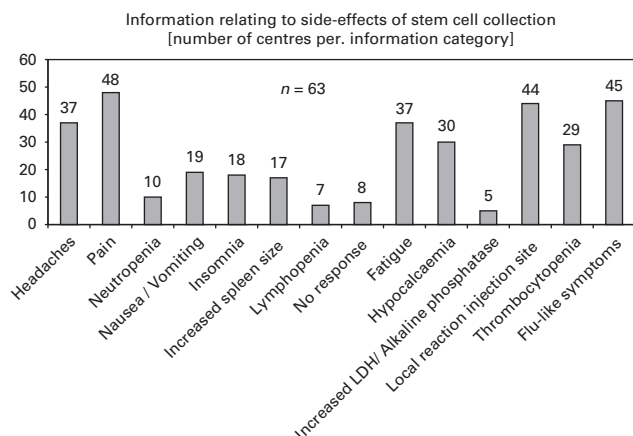


Figure 1 Information relating to the side effects of stem cell collection (number of centres per information category).

Side effects

Centres were asked which side effects of stem cell donation were covered in the information given to donors (Figure 1). Pain predictably featured prominently (48, 76%), although it was not reported by all centres. Fatigue (37, 59%) and flu-like symptoms (45, 71%) were also reported frequently.

Donation

Once suitability to donate had been established, 54 (86%) centres reported that potential related donors are informed of the match by a member of the recipient's transplant team: in 31 (49%) centres this information was given by a transplant physician, in 19 (30%) by a nursing member of the transplant team and in 4 (6%) by a combination of the two. The remaining 7 (11%) centres used various combinations of doctors and nurses not involved with the recipient's care working together with members of the transplant team. Two (3%) respondents did not provide an answer to the question.

With respect to the timing of the provision of this information, 18 (29%) respondents reported that the recipients were informed at the same time as potential donors; 25 (40%) indicated that recipients were told after the potential donor had agreed to donate, and in 7 (11%) cases the recipient was informed before the potential donor had agreed. Two (3%) centres reported that the recipient was not informed of potential donor suitability at all, which seems unlikely.

If a potential donor was not suitable for donation, 56 (89%) of the responding centres reported that the donor was told the true reason why they were unsuitable. Seven (11%) respondents did not answer this question fully. With respect to the information provided to the recipients, 25 (40%) centres informed the recipients of the true reason for unsuitability, whereas 27 (43%) respondents indicated that recipients were not told the true reason a potential donor could not donate stem cells. There were 11 (18%) non-responses.

Follow-up

Respondents were asked what provision their centres made for follow-up care of their donors (Table 2). A total of 38 (60%) of the responding centres identified a follow-up

Table 2 Related donor follow-up care (*N* = 63)

Intervention/action	Number	Percentage (%)
Combinations of prescriptions, information and letter from local doctor	2	3
Transplant team follow-up (doctor +/or nurse)	4	6
Out patient department +/or local doctor follow-up	4	6
Out patient department + blood test +/or various follow-up	14	22
Out patient department +/or telephone follow-up	8	13
No follow-up	2	3
Limited—non-specific follow-up	6	10
No response	23	37

service; however, of these, 6 (10%) responses indicated only limited follow-up provision, whereas only 2 (3%) centres offered no follow-up care at all. The majority of centres provided follow-up that included a visit to an outpatient facility (26, 41%). However, 23 (37%) centres did not respond to the question. Although overall a third of respondents (25, 40%) could be thought of as having good knowledge of the different aspects of the transplant process (given their role description), it is curious to note the high non-response rate.

Of those respondents who did not provide an answer to this question, nearly half (10, 16%) identified themselves as either BMT coordinators or some sort of senior nurse or clinical nurse specialist. Why these experienced practitioners did not respond is a difficult question to answer and needs further examination.

Discussion

This European survey of related donor care has identified that donors are receiving the majority of their information about harvesting procedures and the donation process from the recipient's transplant team; moreover, that same team is, in the majority of cases, soliciting the informed consent for the procedure.

The self-selection that results from a survey of this type is a design limitation, and as such we must conclude that these results may not be representative of the practice elsewhere. The response rate of 51% is rather low, but given the circumstances of population selection (conference setting and language issues), we believe it to be an encouraging level of participation. The respondents represent a sample of the European nations; we accept that a considerable proportion were from the UK, potentially introducing a regional bias.

Within these limitations, our results suggest that some recipients are informed of the donor's ability to donate at the same time as the donor is informed, and only in a minority of cases before the donor is informed of their status. This potentially removes the protection and confidentiality that donors might need while they decide if they wish to donate stem cells; however, the majority of centres report that recipients are told about a donor's status after the donor has been informed.

This survey did not identify potential conflicts of interest within the family unit other than the points made about the timing of information regarding the donor's status, but was not designed to address these issues in detail. It should be noted that there was a degree of variation in respondents' details as to the information provided to recipients about a donor's suitability to donate: of the 21 respondents who cited reasons, the majority (10, 48%) cited unsuitability to donate, whereas 7 (33%) identified either confidentiality or the donor's wishes as the reason for not providing the true reason for non-donation to the recipient.

An earlier study has addressed sibling donor perceptions of the psychological aspects of stem cell donation. Here, it was noted that donors donated even if their personal relationship with their sibling was poor.⁸ This suggests that strong family relationships are an integral part of the donation process for related donors, but does not distinguish between the desire of the donor to assist the patient irrespective of the nature of their relationship and the possibility that external pressures were in place to encourage donation. Williams⁸ concluded that the only realistic way to deal with the issue of donors being consented by the recipients' transplant team is for them to be counselled by independent clinicians and for donors to be informed first if they are a match for their relative. We feel that further enquiry is needed in this area, perhaps exploring how related donors feel about the way they are prepared for the transplant process. Without this perspective it is not possible to gainfully speculate about the mechanics of preparing to donate.

The voluntary status of donors is an important aspect of donation and underpins several ethical principals of the transplantation process: a person's right to freely choose whether or not to participate in treatment, and to be correctly and fully informed of their consent to treatment.

There was a high level of non-response to the survey question dealing with guidelines, and only 3 (5%) respondents cited international guidelines as a source of patient information in their centre.

This might suggest the need for improved guidance for transplant centres regarding related donor management and care. Follow-up care was variable across the responding centres. This variety in practice could be because of a lack of standardized guidelines for follow-up care; the relatively high non-response rate to questions regarding the provision of follow-up care (23, 37%) could indicate that a sizable number of the respondents might not have been involved in donor care and follow-up after donation; however, given that 10 (44%) individuals, of the 23 non-responders, identified themselves as BMT coordinators, clinical nurse specialists or some other senior nursing post involved in transplant, this is probably not the complete answer. We believe that more work needs to be done on the various methods of related donor follow-up to obtain a fuller understanding of the provision of related donor care after donation.

The World Marrow Donor Association has clearly stated the level of responsibility a centre has to donors: 'Every time a donor is to be asked to donate any type of cell product, it is the responsibility of the donor centre/registry

to ensure that the donor's autonomy, wellbeing and needs are maintained'.¹⁰

This commitment to excellence should relate to all donors and the protections afforded to unrelated donors should be applied fully to the community of related donors. Some European centres have developed centre-specific guidelines that may also help in the development of international guidelines and standards.¹¹

Related donor guidelines could be incorporated into existing regulatory frameworks to better monitor uniformity of standards.

Collaborative working arrangements between regulatory bodies, international accreditation agencies, government regulators and local transplantation centres suggest the best methodology to harmonize existing guidance with new related donor-specific guidelines; accreditation by the Joint Accreditation Committee of the International Society for Cellular Therapy and the European Group for Blood and Marrow Transplantation offers one such potential avenue, combining elements of standardized guidance with a robust quality management structure. Future research in related donor care should perhaps focus on the experiences and opinions of both recipients and donors, and we suggest that this survey could be utilized to provide a baseline of current practice across Europe to assist in developing effective survey tools and methods.

In summary, the research subcommittee of the EBMT-NG suggests that robust European evidence-based guidelines are needed to address the particular needs of related donors and to guarantee that independent and impartial information is available to uphold the highest standards of informed consent.

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