Hematopoietic cell transplant nurse coordinators' perceptions of related donor care: a European survey from the EBMT Nurses Group

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Title Page

Title of the paper :

Hematopoietic cell transplant nurse coordinators' perceptions of related donor care: a European survey

Running title : **Related-donor care: a European survey**

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Hematopoietic cell transplant nurse coordinators' perceptions of related donor care: a European survey

Abstract

Allogeneic Hematopoietic Cell Transplantation (HCT) is a curative procedure for patients with haematological malignancies and immune deficiencies.

A human leukocyte antigen identical sibling is only available for 25-35% of patients in need. The improvement in haplo-identical transplantation has led to a marked increase in cell donation from relatives. Despite international recommendations, discrepancies in related-donors care exist between centres, particularly regarding medical suitability criteria, consenting procedures and donor follow-up. This European survey aimed to explore Hematopoietic Cell Transplantation Coordinators Nurses' (HCT-CNs) perceptions of related-donor (RD) care, in particular the association with the presence or not of an independent unit (IU). Ninety-three HCT-CNs from 76 EBMT centres responded, representing 19 countries (response rate: 27%).

Our results did not show a significant association between IU and HCT-CNs perceptions of related-donors care. We noted heterogeneity between the European HCT teams' practices regarding RD care. Qualitative data highlights related-donation ethical issues and the need for improvement in RD care. HCT-CNs' main concerns were: the necessary confidentiality to insure the voluntary status of RD, the perceived conflict of interest felt by professionals when managing both patients and RD, plus the psychosocial aspects of related-donation.

A full understanding of RD care issues requires an exploration of their experiences through a prospective study.

Introduction

Allogeneic Haematopoietic Cell Transplantation (HCT) is a curative procedure for patients with haematological malignancies and immune deficiencies.

A human leukocyte antigen (HLA)-identical sibling is available for only 25-35% of patients in need¹. For patients lacking a fully matched sibling donor, other cell sources are available such as unrelated donors (UD), umbilical cord blood units or an HLA-mismatched family donor (HAPLO)². The recent use of non T-cell depleted haploidentical HCT with new strategies to modulate donor T-cell alloreactivity has resulted in significant improvement of results.^{3, 4, 5, 6} These techniques have contributed to an increased number of HAPLOs in recent years^{7,8}. Cell donation from relatives presents lower financial costs and a faster availability but raises specific clinical and ethical issues¹.

The World Marrow Donor Association recommends that related donors (RD) be assessed by a physician from an Independent Unit (IU) and not involved with the recipient's treatment⁹. This independent evaluation is also required by the Joint Accreditation Committee Standards (JACIE).¹⁰ However, to date practices regarding RD recruitment, consent, medical assessment and follow-up are not standardised^{11, 12, 13, 14, 15}.

In the United States, despite significant improvements in patterns of practice, HCT teams (HCT-Coordination Nurses and HCT-physicians) remain involved in RD care in 38% of the participant centres, with these centres performing 79% of the American transplants^{11, 12}.

A European survey performed in 2005 identified that RDs were informed about harvesting procedures and donation processes by the recipient's transplant team in 57% of HCT units¹⁵. However, this survey is over a decade old, has several limitations (population selection, low participation rates, regional bias) and therefore cannot be taken as representative of current European practice.

The current practice of caring for both RD and recipient may affect ethical, psychosocial and medical aspects of RD care. Significant differences have been reported in the medical management of UD and RD regarding eligibility criteria (age limit, accepted co-morbidities) and donation parameters (GSF-doses, number of collections and collected volume)¹⁶.

The quality of information delivered, the adequacy of donor preparation and the emotional support provided by HCT teams have an impact on RD experience^{17, 18, 19, 20}. These essential tasks (e.g. provision of information, organization of donation process and emotional support) are primarily carried out by HCT-coordinators Nurses (HCT-CNs). A French survey highlighted the perceived conflict of interest felt by HCT-CNs when managing both the patient and RD impacting negatively on RD's information, consent and care. HCT-CNs suggestions to improve RD care were focused on ethical and psychosocial issues, from information provided prior to HLA typing to post-donation follow-up procedures²¹.

The negative effects of cell donation such as pain, fatigue, psychological morbidity and the risks of severe adverse events, have all been well described.^{22,23} However, the quality of the care offered to RD has not been investigated.

The Research Committee of the EBMT Nurses Group have supported this European survey with the aim of exploring HCT-CNs perceptions of RD care, focusing on the comparison between HCT-CNs working in an IU with those from a Non-Independent Unit (NIU).

Methods

Ethical approval was not required for this survey.

The primary objective was to study the associations between unit type (IU or NIU), reported RD care organization and difficulties met by HCT-CNs. The secondary objective was to search for potential factors associated with donor difficulties (practical, financial, relational and psychological).

An electronic survey was designed, accessible to all HCT-CNs registered in EBMT adult centres performing HCT. The survey was released in April 2016. HCT-CNs were contacted via an email, which included a direct web-link to the survey and invited to participate. The request was repeated several times until the end of September 2016.

The survey consisted of 47 questions divided in three topics: A) HCT-CNs characteristics (age, professional experience); B) units' donation procedures (information provision for potential donors, HLA test procedures, consent process, availability of financial support and donor follow-up) and C) HCT-CNs' perceptions of the RD care.

The survey included single and multiple choices questions. Open-ended questions were also asked in order to gain HCT-CNs' opinion about processes relating to RD care, RD

concerns and suggestions on possible ways to improve the organization of related donation (See Appendix 1).

Statistical methods

All categorical data were presented using frequency counts and percentages.

The two groups of responders (those working in IU versus NIU) were compared by using χ^2 statistics. Factors associated with IU or NIU with a p value less than 0.10 in univariate analysis were included in a multivariate logistic regression model for binary variables. Results were presented as odd ratios (OR) and 95% confidence intervals (CI). Statistical analyses were performed with SPSS 24.0 (SPSS Inc, Chicago, IL, USA).

Thematic analysis

The answers to open-ended questions were subject to thematic analysis using the Framework approach: researchers identify a priori themes from existing knowledge of the topic and used these to guide and structure the analysis. The Framework approach allows for a combination of theme-based and case-based analyses, which was appropriate in this study. This method, with clear steps to follow, is recognized as rigorous and systematic in qualitative analysis^{24, 25}.

We used NVIVO software to manage qualitative data²⁶. Two investigators independently coded the answers, and a third investigator reviewed this coding and participated in the thematic analysis. The interpretations given by the three investigators were then validated by other co-authors (consensual validity). An example of the analysis procedure using the framework method can be seen in Appendix 2.

Results

HCT-CNs characteristics

An overall response rate of 27% was achieved with 93 HCT-CNs from 76 EBMT centres, representing 19 countries replying. France, United Kingdom, The Netherlands and Italy accounted for 65% of all responders.

Table 1: shows socio-demographic characteristics, academic qualifications and professional experience of the HCT-CNs. Seventy-six percent of responders had worked in haematology units for over 10 years and 69% possessed more than 6 years' experience as an HCT-CN.

Organisation of RD care

Table 2a: summarizes responses relating to organization of RD care. Forty-eight percent of respondents worked in an IU.

HCT-CNs' perceptions of RD care

Table 2b: summarizes replies pertaining to difficulties experienced by HCT-CNs when undertaking RD care. HCT-CNs reported that their role in RD care was mainly related to information provision (80%), psychosocial support (70%) and follow-up (54%). Twenty-nine percent of HCT-CNs reported conflict of interest when caring for both RD and recipients, 81% responded that they had experienced demanding situations and 61% perceived that related-donation had been difficult for the RD and/or the recipient.

Comparison of RDs care organization according to IU

Table 3: summarizes the results of the comparison between IU and NIU with regard to care of RD, the existence of different pathways for recipients and RD.

The HCT team were the first to address the issue of stem cells donation with the patient [44% IU vs. 31% NIU, p=NS] and with the potential RD [66% IU vs. 62% NIU, p=NS]. Patients were requested to contact potential RD in 27% of IU and in 13% of NIU [p=NS]. There was no difference between IU and NIU regarding the information provided to the RD in relation to donation / transplant before HLA typing and materials such as booklets were frequently available [62% IU vs. 73% NIU, p=NS]. A specific interview to provide information to a compatible RD was organized at the time of the pre-donation work-up in 91% of IU and 92% of NIU [p=NS].

The organization of RD follow-up was no different between IU and NIU. Most of the units (78%) did organize a RD follow-up: a single evaluation during the first year post-donation [76% IU vs. 81% NIU, p=NS].

By multivariate analysis (Table 4), IU were associated with a higher number of donors (≥ 20 per year) (OR: 1.63; 95% CI: 1.14-2.32; p=0.007) and less frequent communication of results of HLA typing to the patients (OR: 0.33; 95% CI: 0.12-0.89; p=0.03). No other significant differences were found between IU and NIU.

Comparison of HCT-CNs' perceptions of RD and difficulties in RD care according to the type of unit

For 73% IU vs. 71% NIU of HCT-CNs, RD needs are addressed in their unit, $p=NS$. HCT-CNs experienced difficulties in RD care in both IU and NIU (80% vs. 82%, respectively, $p=NS$). Forty-five per cent of the HCT-CNs agreed with the following statement: « The only way to protect RDs' free choice to give or not, is to organize RDs' care within a fully independent unit ». In NIU, there was a trend towards agreement with this statement in respondents who perceived conflicts of interest (40%) vs those who did not (17%) ($p=0.086$). See Table 3.

Qualitative data

Themes identified from analysing HCT-CNs comments were related to ethical and psychological matters associated with RD care. Ethical issues were mainly linked to doubts about assuring freedom of choice to RD. HCT-CNs experienced helplessness when facing RD ambivalence or even withdrawal of donation. They considered RD care “very medically driven” and stressed the need of psychological support.

Some HCT-CNs believe that a completely IU is required to offer a RD the necessary conditions for free choice and quoted examples of conflict of interest. Respondents who disagreed with this proposition considered that having separate care pathways for RD and recipients, in the same HCT-Unit could be the answer to the ethical concerns associated with RD care.

These differing opinions reflect HCT-CNs' own perspective on related-donation and their role in RD care. Related-donation is perceived as being driven by family's history and emotional links, so that different kinds of care organization couldn't influence RD dilemma. Conversely, HCT-CNs see their professional skills as the answer to demanding situations, which could raise conflict of interest between RD difficulties and recipients' needs. Illustrative quotations of qualitative data are shown in Table 5.

Discussion

The expertise and professional experience of responders to our survey provide a valid basis for discussing the different ways to improve RD care.

We aimed to explore HCT-CNs' point of view about RD care organization and independent unit relevance. Our hypothesis was that a specific Unit for donor care^{28,29}

would ensure RD safety, anonymity and confidentiality. This is a crucial issue in RD care and its' feasibility has been discussed by different authors^{9, 27,30,36}. In our study, we did not find any association between IU, RD care organisation and difficulties in RD care. The only factor associated with the presence of an IU was a greater number of RD seen per year. This may indicate that for HCT units caring for a smaller number of RD, it may be difficult to organise an independent unit.

Our results show that current RD care organization does not always prevent ethical issues and may generate conflict of interest for HCT teams. Previous studies have shown that ethical issues, namely the lack of anonymity and confidentiality, are related to practical aspects of RD care: contact with potential donors, information before HLA typing and HLA results' disclosure^{11,12,14,15}.

The first contact is a relevant issue for a potential RD who, asked to donate by the recipient or by another close relative, may feel that they have no real volunteer status^{21,31}. In our survey, initial contact was made by HCT teams in the majority of centres.

Providing exhaustive information before HLA typing is one way to avoid related donation to become a « mandatory act »⁹. Additionally, RD understanding of the HCT process may temper « unrealistic expectations » and decrease their emotional distress when recipient's outcome is not favorable³². In our study, most of the respondents declare that a potential RD was informed about donation and transplant before HLA typing with a written information (booklet), whereas in Clare et al.¹⁵ survey, a quarter of respondents used only verbal methods to inform a RD.

As previously noted in American centres¹², HLA typing results may be disclosed to the patients. Such a disclosure is clearly a breach of confidentiality since the results are the 'property' of the potential RD. In our study, HLA typing results were first communicated to the patient in more than half of the cases.

This point illustrates that current practices could be improved. Patterns of recruitment, assessment and care of the RD still lead HCT teams to be in conflict of interest. Quoting El-Ghariani and Dalle³⁶, "a major dilemma in donor ethics is the fact that assessing harm and inconvenience to one person (the donor) in relation to expected benefits to another". In our survey, 81% of HCT-CNs reported difficulties in RD care and 29% have been torn between the recipients' and the donors' needs.

This issue had not been raised by Clare *et al.*¹⁵ or by any other authors before the publication of the French survey²¹ in 2016. This last study indicated that even with a

specific care pathway for RDs, HCT-P and/or HCT-CN could be involved in discussion regarding the recipients. Having information about recipients' diagnosis and personal circumstances may influence the HCT team's capacity to cope with reticence to donate. For O'Donnel et al.¹¹, the conflict of interest experienced by HCT teams could explain the differences observed between RD and UD management (medical criteria for recruitment and treatment). Anthias et al.²⁷ discuss pros and cons of the UD Registry's involvement in RDs management, as a way to reduce organisational discrepancies between UD and RD care, to homogenize donors' suitability criteria and to avoid potential conflicts of interest.

In our study, although one-third of HCT-CN's reported conflict of interest when caring for both RD and recipient, 55% of them considered that different pathways within the same HCT unit would be a suitable answer to ethical issues in RD care. According to our qualitative data, this opinion is linked to HCT-CN's representations of related-donation inherent dilemmas, but could also be partly related to HCT-CN's concerns about losing their current pivotal role in RD care.

HCT-CN's asked for more manpower and for the standardization of RD care. They emphasized that psychosocial needs of the RD are not met by the current organization of care. HCT-CN's referred to RD feelings of "being neglected", worrying about HCT failure and longing to be reassured by medical teams³². In light of the HCT-CN's comments, follow-up should consider the psychological condition of a RD, especially in cases of severe complications such as GvHD, relapse or death of the recipient. Studies comparing bereaved and not-bereaved RD reveal contradictory results regarding psychological condition^{33,34}, but qualitative studies have shown that despite their intellectual understanding of HCT process, a RD may feel guilty in cases where the recipients have experienced adverse outcomes³².

Van Walraven et al.³⁵ have drawn attention to the experience of parents requested to become donors in haplo-identical HCT. The authors stress the difficulty of managing the dual role of donor and caregiver for their ill child. We could also hypothesize that the inversion of roles may be challenging for both donors and recipients when children are asked to give HSC to their parents. Although the psychosocial impact of related-donation has been demonstrated, these issues of haplo-identical transplantation should be further explored.

Our survey has raised significant questions, but it has several limitations. The participation reached 27% of the EBMT centres. Although 19 countries participated in the survey, we cannot ascertain its representativeness among all EBMT centres.

We decided to exclude pediatric HCT units, because care of children raises specific issues, notably the parents' participation during the all procedure.

In depth interviews could be of interest to complete our qualitative data, and enhance understanding of HCT-CNs work conditions and ethical dilemma.

Conclusion

Our survey showed the heterogeneity of practice within European HCT teams relating to the care of the RD. Qualitative data highlights related-donation ethical issues and the need for improvement in RD care. The necessary confidentiality to insure the voluntary status of a RD and the psychosocial aspects of related-donation are HCT-CNs' main concerns. Despite the perceived conflict of interest felt by professionals when managing both recipients and RD, a completely IU is not recognized by all HCT-CNs as being the solution to RDs care ethical issues. A full understanding of RD care issues requires an exploration of RD experiences through a prospective study.

Conflict of interest

The authors declare no conflict of interest

Supplementary information is available at Bone Marrow Transplantation's website:

Appendix 1 - The questionnaire

Appendix 2 - Example of Framework analysis' process

Appendix 3 – List of participant countries and centres

References

1. Boo M, van Walraven SM, Chapman, J, Lindberg B, Schmidt AH, Shaw BE. on behalf of the World Marrow Donor Association. Remuneration of hematopoietic stem cell donors: Principles and perspective of the World Marrow Donors Association. *Blood*, 2011; 117 : 21–25.
2. Kekre N, Antin JH. Hematopoietic stem cell transplantation donor sources in the 21st century: choosing the ideal donor when a perfect match does not exist. *Blood* 2014; 124(3):334-343.
3. Bashey A, Zhang X, Sizemore CA, Manion K, Brown S, Holland HK et al. T-Cell-Replete HLA-Haploidentical Hematopoietic Transplantation for Hematologic Malignancies Using Post-Transplantation Cyclophosphamide Results in Outcomes Equivalent to Those of Contemporaneous HLA-Matched Related and Unrelated Donor Transplantation. *J Clin Oncol* 2013 ; 31:1310-1316.
4. Martinez C, Gayoso J, Canals C, Finel H, Peggs K, Dominietto A et al (2017) Post-Transplantation Cyclophosphamide Based Haploidentical Transplantation as Alternative to Matched Sibling or Unrelated Donor Transplantation for Hodgkin Lymphoma: A Registry Study of the Lymphoma Working Party of the European Society for Blood and Marrow Transplantation. *J Clin Oncol*. 2017 ; 35(30):3425-3432.
5. Raiola AM, Dominiato A, di Grazia C, Lamparelli T, Gualandi F, Ibatici A, et al Unmanipulated Haploidentical Transplants Compared with Other Alternative Donors and Matched Sibling Grafts *Biol Blood Marrow Transplantation*; 2014; 20 :1573-1579.
6. Kanate AS, Mussetti A., Kharfan-Dabaja MA. Reduced-intensity transplantation for lymphomas using haploidentical related donors vs HLA-matched unrelated donors. *Blood* 2016;127(7):938-947.
7. Passweg JR, Baldomero H, Bader P, Bonini C, Cesaro S, Dreger P, Mohty M. Hematopoietic SCT in Europe 2013: Recent trends in the use of alternative donors showing more haploidentical donors but fewer cord blood transplants. *Bone Marrow Transplantation* 2015 ; 50 : 476–482.
8. Passweg JR, Baldomero H, Bader P, Bonini C, Duarte RF, Dufour C et al. for the European Society for Blood and Marrow Transplantation (EBMT). Use of haploidentical stem cell transplantation continues to increase: the 2015 European Society for Blood and Marrow Transplant activity survey report. *Bone Marrow Transplantation* 2017; 52(6):811-817.

9. Van Walraven SM, Nicolo-de-Faveri G, Axdorph-Nygell UA, Douglas KW, Jones DA, Lee SJ, on behalf of the World Marrow Donors Association Ethics and Clinical working groups. Family donor care management: Principles and recommendations. *Bone Marrow Transplantation* 2010 ; 45 : 1269–1273.
10. JACIE. International standards for hematopoietic cellular therapy product collection, processing and administration. [<http://www.jacie.org>].
11. O'Donnel PV, Petersen TL, Confer DL, Rizzo JD, Pulsipher MA, Stroncek D, Anderlini P. Practice patterns for evaluation, consent and care of related donors and recipients at hematopoietic cell transplantation centers in the USA. *Blood* 2010 ; 115, 5097–5101.
12. Anthias C, Shaw BE, Kiefer DM, Liesveld JL, Yared J, Kambl RT et al. Significant Improvements in the Practice Patterns of Adult Related Donor Care in US Transplantation Centers. *Biol Blood Marrow Transplant* 2017; 22: 520-527.
13. Coluccia P, Crovetto G, Del Fante C, Dallavalle FM, Laszlò D, Ferremi P et al. Screening of related donors and peripheral blood stem cell collection practices at different Italian apheresis centres. *Blood Transfus* 2012; 10: 440–447.
14. Anthias C, Peniket A, Kirkland K, Madrigal JA, Shaw BE. Variations in practice in UK transplant centers: results of a related donor care survey *Bone Marrow Transplantation* 2016 ; 51 : 1612–1614.
15. Clare S, Mank A, Stone R, Davies M, Potting C, Apperley JF, on behalf of the Research Sub-committee of the European Group for Blood and Marrow Transplantation Nurses Group. Management of related donor care: A European survey. *Bone Marrow Transplantation* 2010 ; 45 : 97–101
16. Halter JP, van Walraven SM, Worel N, Bengtsson M, Hägglund H, Nicoloso de Faveri G, Confer D. Allogeneic hematopoietic stem cell donation – standardized assessment of donor outcome data: A consensus statement from the Worldwide Network for Blood and Marrow Transplantation (WBMT). *Bone Marrow Transplantation* 2013 ; 48 : 220–225.
17. Muzenberger N, Fortanier C, Macquart-Moulin G, Faucher C, Novakovitch G, Maraninchi D, Blaise D. Psychosocial aspects of hematopoietic stem cell donation for allogeneic transplantation: How family donors cope with this experience. *Psychooncology* 1999 ; 8 : 55–63.
18. Christopher KA. The experience of donating bone marrow to a relative. *Oncology Nursing Forum* 2000 ; 27 : 693–700

19. Williams S, Green R, Morrison A, Watson D, Buchanan S. The psychosocial aspects of donating blood stem cells: The sibling donor perspective. *Journal of Clinical Apheresis* 2003 ; 18 : 1–9.
20. Pillay B, Lee SJ, Katona L, De Bono S, Warren N, Fletcher J, Burney S. The psychosocial impact of hematopoietic SCT on sibling donors. *Bone Marrow Transplantation* 2012 ; 47 : 1361–1365.
21. Polomeni A, Bompont C, Gomez A, Brissot E, Ruggeri A, Belhocine R, Mohty M. Current practices for screening, consent and care of related donors in France: haematopoietic stem cell transplantation coordinator nurses' perceptions. *European Journal of Cancer Care* 2016 ; 00:1–15. doi: 10.1111/ecc.12612
22. Halter J, Kadera Y, Ispizua AU, Greinix HT, Schmitz N, Favre G, Gratwohl A. Severe events in donors after allogeneic hematopoietic stem cell donation. *Haematologica* 2009 ; 94 : 94–101.
23. Siddiq S, Phamphilon D, Brunskill S, Doree C, Hyde C, Stanworth S. Bone marrow harvest versus peripheral stem cell collection for haematopoietic stem cell donation in healthy donors. *Cochrane Database Systematic Review* 2009 ; 21(1): CD006406. doi:10.1002/14651858.CD006406
24. Ward DJ, Furber C, Tierney S, Swallow V. Using FrameworkAnalysis in nursing research: a worked example. *Journal of Advanced Nursing* 2013 ; 69(11), 2423 :2431.
25. Smith J., Firth J. Qualitative data analysis: the framework approach. *Nurse Researcher* 2011 ; 18(2), 52–62.
26. NVivo Qualitative Data Analysis Software Version 8. QSR International Pty Ltd, 2008.
27. Anthias C, vanWalraven SM, Sorensens, de Faveri GN, Fechter M, Cornish J et al. Related hematopoietic cell donor care: is there a role for unrelated donor registries ? *Bone Marrow Transplantation* 2015; 50 :637-641.
28. Muramatsu H, Kimura S, Ichinohe T, Ashihara E, Ishikawa T, Maekawa T, Uchiyama T. Consulting clinic for related family donors in hematopoietic stem cell transplantation. *Bone Marrow Transplantation* 2008 ; 41 : 1073–1075.
29. Kisch A, Dykes J, Lindmark A, Lenhoff S. A proposed plan for the management of adult sibling donors. *Bone Marrow Transplantation* 2008; 42: 357–358;

30. Billen A, Madrigal JA, Shaw BR. A review of hematopoietic stem cell donation experience: is there room for improvement? *Bone Marrow Transplantation* 2014; 49:729-736.
31. Kisch A, Lenhoff S, Bengtsson M, & Bolmsjö I. Potential adult sibling stem cell donors' perceptions and opinions regarding an information and care model. *Bone Marrow Transplantation* 2013 ; 48, 1133–1137.
32. Garcia MC, Chapman JR, Shaw JP, Gottlieb DJ, Ralph A, Craig JC, Tong A. Motivations, Experiences, and Perspectives of Bone Marrow and Peripheral Blood Stem Cell Donors: Thematic Synthesis of Qualitative Studies. *Biol Blood Marrow Transplant* 2013; 19 :1046-1058.
33. Switzer GE, Dew MA, Magistro CA, Goycoolea JM, Twillman RK, Alter C, Simmons RG. The effects of bereavement on adult sibling bone marrow donors' psychological well-being and reactions to donation. *Bone Marrow Transplantation* 1998 ; 21 :181–188.
34. Chang G, McGarigle C, Koby D, Antin JH. Symptoms of pain and depression in related marrow donors: Changes after transplant. *Psychosomatics* 2003;44:59-64.
35. Van Walraven SM, Ball LM, Koopman HM, Switzer GE, Ropes-de Jong CM, de Jong A, et al. Managing a dual role - experiences and coping strategies of parents donating haploidentical G-CSF mobilized peripheral blood stem cells to their children. *Psycho-Oncology* 2012 ; 21:168-175.
36. El-Ghariani K, Dalle JH. Ethical issues in HSCT. IN: Carreras E, Dufour C, Mohty M, Kröger N. (eds). *The EBMT Handbook*, SpringerOpen, 2019, pp. 245-249. <https://doi.org/10.1007/978-3-030-02278-5>