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Adult-related haematopoietic stem cell donor experiences and the provision of information and psychosocial support: A systematic literature review

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Title: Adult related haematopoietic stem cell donor experiences and the provision of information and psychosocial support: a systematic literature review.

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Conflict of interest statement

There are no conflicts of interest to disclose.

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Abstract

For blood cancer patients, haematopoietic stem cells (HSC) donated by a relative can be lifesaving. However, related donors can face significant physical and psychosocial challenges. As the demand for adult related HSC donors is increasing, it is important to review our understanding of adult related HSC donors' need for and availability of information and psychosocial support with a view to identifying gaps in the literature. A systematic review of relevant studies (2000-2017) was conducted using five databases with supplementary hand searching. Sixteen studies involving 1024 related HSC donors met the following criteria: English or Dutch language; peer-reviewed; sampled first-time related HSC donors; ≥ 18 years; haematological malignancies; assessed psychosocial aspects; retrospective or prospective; with or without comparison group. Data were abstracted, and study quality was assessed using the PRISMA criteria. Studies contained limited information on the provision of information and psychosocial support. Most studies addressed pre-donation information, none reported providing information or support to donors post-donation. Additionally, few studies formally assessed unmet needs. Recommendations include improved transparency of reporting for the availability, sources and timing of information and psychosocial support and the identification of unmet needs to enable the development of educational and psychosocial interventions for this invaluable donor population.

Keywords: adult related donor; haematopoietic stem cell transplantation; unmet needs, information, psychosocial support, systematic review.

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Introduction

Human leukocyte antigen (HLA) matched related HSC donors are considered optimal donors for allogeneic transplants based on their rapid availability and excellent long-term outcomes from their transplanted cells. For those without a fully HLA-matched sibling donor, HLA-haploidentical (half matched) related donors are now often favoured over HLA-matched unrelated donors, with excellent graft-versus-host-disease (GVHD) control and relapse free survival (Solh et al., 2016). This new treatment regimen considerably increases the number of siblings who may be eligible to donate and further extends the possibility of donation by parents and children.

Psychosocial impact of donation

In light of the recent and significant increase in demand for related donors, recognition of the associated psychosocial issues has also emerged. Researchers and clinicians alike have begun to acknowledge that related donors may be more at risk of negative emotional experiences than unrelated donors. Unlike unrelated donors, related donors are actively involved in the transplant process and witness first-hand the changes in their relative's health. Adult donors also often have a greater understanding of the seriousness of their relative's illness. Studies have observed distress, anxiety and worry regarding adult donors' own wellbeing and concerns for their ill relative, particularly if their relative died or developed complications, including GVHD (Wiener et al., 2008, Pillay et al., 2012, Van Walraven et al., 2012). In addition, the donor-recipient relationship, family dynamics and the perceived adequacy of preparation and emotional support can influence the emotional experiences of donors (Christopher, 2000, Van Walraven et al., 2012, Labott and Pfammatter, 2014).

The contribution of information and psychosocial support

The above research findings highlight the potential benefits of timely information and psychosocial support in alleviating distress in adult related HSC donors and improving the overall donation experience. Indeed, previous findings suggest that pain-related distress is inextricably linked to patients' perceived ability to cope with the stress caused by the procedure. For example, cancer studies have found that patients who received preparatory education regarding potential side effects reported improved quality of life and functioning (Chelf et al., 2001). A literature review of HSC donors by Garcia et al. (2013) suggested that the pain experienced by donors was associated with donors' mental preparation and expectations of donation. These findings are also in line with the wider theoretical literature suggesting one's perceived ability to cope with a difficult health-related event

1 can play an important part in mediating one's response and consequent emotions (Lazarus and Folkman, 1987,
2 Bandura, 1988).

3
4 In spite of evidence indicating the physical and psychosocial complications faced by related donors, less has
5 been written about the availability, sources and timing of information and psychosocial support and whether
6 they meet the needs of adult related HSC donors. To address this need, the present project aims to bring these
7 data together and create an overview of the information and psychosocial support adult related HSC donors
8 perceive as necessary to their well-being and the actual support they receive.

9 10 **Methods**

11 **Search strategy**

12 Cochrane Library, Embase, PubMed, PsychINFO and CINAHL were searched (1 January 2000 – 28 February 2017)
13 and included MeSH (PubMed) or Emtree (Embase) terms, as well as free-text words (Table S1). Additionally, the
14 following sources were searched using the MeSH: i) searches of the main haematology and blood journals
15 (Blood, Haematologica, Bone Marrow Transplantation, Biology of Blood and Bone Marrow Transplantation); ii)
16 Wiley Online Library, Nature, Psycho-Oncology, Supportive Care in Cancer; iii) Grey literature through Google
17 Scholar; iv) reference lists of identified eligible articles for relevant studies; v) hand search of identified eligible
18 articles for further research carried out by the authors.

19 20 **Selection criteria**

21 Articles were included if they reported on original research and were published in a peer-reviewed journal in
22 English or Dutch language. Articles were included if they were: observational; cohort; case control studies; with
23 or without a comparison group. Studies were included if they reported outcomes from first-time adult related
24 HSC donors; ≥ 18 years. Only articles reporting the psychosocial aspects of donation were included. This could
25 have been performed either prospectively or retrospectively. We were primarily interested in the psychological
26 issues surrounding families being treated for a haematological malignancy given they represent the vast
27 majority of patients and we felt the number for patients transplanted with non-malignant conditions would be
28 limiting. Nevertheless, the donors of patients transplanted for non-malignant conditions are likely to face a
29 similar suite of psychological issues given the recipient is inevitably being treated for a life-threatening
30 condition, and are exposed to similar potential transplant complications.

31 32 **Screening**

1 One author (NZ) identified potentially relevant articles by reviewing the titles and abstracts retrieved from the
2 bibliographic databases. Articles identified as potentially relevant were retrieved in full text. These were
3 screened by two assessors (NZ, JT) for inclusion. Dissertations, duplicate articles and abstracts were excluded.
4 Based on the inclusion criteria, several articles were excluded at different phases of this review. Consensus was
5 achieved through discussion and, when needed, consultation with a third assessor.

7 **Data extraction and synthesis**

8 Data were extracted independently by two authors (NZ, JT) using a customised Excel database and included:

- 9 • Study design
- 10 • Aim(s)
- 11 • Population, age, setting and sample size
- 12 • Comparison groups
- 13 • Measures
- 14 • Participant attrition
- 15 • Results
- 16 • Psychometric properties of the measures
- 17 • Education/information provided to related donors
- 18 • Bias and implications for practice

19
20 The subsequent synthesis of results was guided by the Preferred Reporting Items for Systematic Review and
21 Meta-Analyses (PRISMA) 27-item checklist (Moher et al., 2009). Any discrepancies between the two authors
22 were resolved through discussion. Ethics approval was not required.

24 **Results**

25 The electronic search strategy identified a total of 79 potentially relevant studies. Following the removal of
26 duplicates, 59 studies were screened for eligibility based on their abstract. Of these, a further 40 studies were
27 excluded for the following reasons: unrelated or paediatric donor only samples; physical impact assessment
28 only; non-haematological diseases, and; conference abstracts. Hard copies were obtained of the 19 full-test
29 studies. After inspection, 16 studies fulfilled the eligibility criteria and were included in this review (Figure 1). Of
30 the 16 articles, seven were quantitative, three were qualitative, and six were mixed-methods studies. Two
31 studies were conducted by one research group (Kisch *et al.* 2013, 2015).

1 **Study characteristics of included studies**

2 *Quantitative studies*

3 A total of six studies investigated the experiences of adult related HSC donors using a quantitative
4 methodological approach (Table 1). Four studies were conducted in the US, while the remaining two studies
5 were conducted in Europe (France and Austria). In total, 525 participants were studied, ranging from 23 to 171
6 participants per study. Leitner et al. (2009) included paediatric HSC donors within their sample; <50 years of age
7 ($n = 124$, 73%) and ≥ 50 years of age ($n = 47$, 27%) and differentiated between the two age groups in their results
8 and discussion. Across the studies, the ratio of males to females was even (50% were male vs 50% were
9 females).

10

11 Five studies carried out a prospective assessment of adult related HSC donation (range, four weeks before
12 granulocyte colony stimulating factor (GCSF) commencement to one year post HSC donation) and one study
13 retrospectively evaluated the experiences of adult related HSC donors (range, 0-11 years since donation). Data
14 collection varied among studies. Quality of Life (QoL) was assessed by two studies; one study used the SF-12
15 while another study asked donors to judge their general health condition and QoL on a modified visual analogue
16 scale. Emotional status was assessed using various scales including the State-Trait Anxiety Inventory, the Beck
17 Depression Inventory, the Profile of Mood States and the Brief Symptom Inventory, whilst the remaining two
18 studies used individually created numerical rating items.

19

20 Two studies, Labott and Pfammatter (2014) and Switzer et al. (2017) used validated measures to examine
21 participants' donation experiences. Measures addressed the donor–recipient relationship, physical and
22 psychological status, guilt and responsibility, self-esteem, ambivalence about donation and reactions to the
23 donation itself. In the remaining four studies, donor experiences were assessed using individually created open-
24 ended and closed items. Items by Chang et al. (2003) addressed the donor-recipient relationship, time taken off
25 from work, need for medical care after donation, and knowledge of transplant outcome. Fortanier et al. (2002)
26 asked donors how they subjectively anticipated the collection procedure, if they were satisfied with the
27 information provided, their general opinion about the procedure and symptom-specific questions. Retrospective
28 questions by Leitner et al. (2009) addressed the side effects and the influence of the procedure on donors'
29 health status and QoL using a numerical rating scale, while Rowley et al. (2001) prospectively asked donors
30 about their physical responses during the recovery period and change in emotional and physical status using a
31 numerical rating scale.

32

1 *Qualitative studies*

2 Three studies provided qualitative data on the experiences of adult related HSC donors. Christopher (2000)
3 asked 12 US bone marrow (BM) donors to describe their experiences, the positive and negative aspects, changes
4 in interpersonal relationships with the recipient and other family members and aspects that were stressful. At
5 the time of study participation, seven BM recipients were alive and five had died. Oliveira-Cardoso et al. (2010)
6 studied 20 Brazil BM donors pre-donation and immediately post-donation by asking about their perceptions
7 regarding their relative's illness, the transplant and donation, motivation and expectations related to the
8 process. The Swedish study by Kisch et al. (2015) included a sample of 10 BM and peripheral blood stem cell
9 (PBSC) donors. The authors assessed the experiences of being a HSC donor prior to donation using open-ended
10 questions regarding donors' thoughts and feelings when they got to know that their relative needed a HSC
11 donor for transplantation and when they were asked if they were willing to become that donor. In all three
12 studies, a thematic or content approach was applied for analysis of qualitative data (Marks and Yardley, 2004).

14 *Mixed-method studies*

15 There were seven studies identified as clearly using both a quantitative and qualitative approach to assess the
16 experiences of adult related HSC donors. Among them, four were conducted in Canada, Australia and the US and
17 the other three were completed in Europe (Sweden, The Netherlands, and the UK).

19 In four studies, participants were studied retrospectively 0-5 years post-donation (Kisch et al., 2013, Pillay et al.,
20 2012, Van Walraven et al., 2012, Wiener et al., 2008) while the remaining three studies carried out a prospective
21 assessment, of which one used a longitudinal design (Kennedy et al., 2003). In total, 457 donors were studied
22 using mixed-methods, ranging from 13 to 148 participants per study. Five studies reported a median age of
23 participants between 38 and 57 years and the remaining two studies reported a mean age between 18 and 52
24 years. Wiener et al. (2008) included HSC donors under 18 years of age within their sample; <18 years of age ($n =$
25 5, 36%) and ≥ 18 years of age ($n = 9$, 64%) and differentiated between the two age groups in their results and
26 discussion. Four studies included PBSC donors only, two studies included BM and PBSC donors and the
27 remaining study (Kisch et al. 2013) did not provide data regarding the donation type.

29 The experiences of donors were assessed using standardised questionnaires and individually created numerical
30 rating items (Kisch et al., 2013, Pillay et al., 2012, Wiener et al., 2008, Bredeson et al., 2004, Williams et al.,
31 2003). Additionally, studies included open-ended items and addressed the decision to donate, perceived
32 preparedness, the donor-recipient relationship, physical, emotional, cognitive and social wellbeing throughout

1 the process and concerns regarding the donation process. With respect to information and care needs and
2 provision, the included studies had different foci. Four studies addressed this question specifically (Kisch et al.,
3 2013, Pillay et al., 2012, Bredeson et al., 2004, Williams et al., 2003) while there was a more global approach in
4 two other studies (Van Walraven et al., 2012, Wiener et al., 2008). Analysis of qualitative data was based on
5 thematic or content analysis (Pillay et al., 2012, Van Walraven et al., 2012, Wiener et al., 2008, Williams et al.,
6 2003). In addition, authors considered the Pearson's chi-squared test, *t*-test, effect size, and the two-tailed
7 Fisher's exact test to analyse quantitative responses between different subgroups and the relative degree of
8 change from pre- to post-donation.

10 **Adult related HSC donor experiences**

11 We identified five themes about the donation experience; the transplant recipient's health condition, donation
12 decision, mental preparedness, emotional distress and family dynamics. Results regarding concerns and
13 incentives for each theme are provided in Table 2.

15 *Transplant recipient's health condition*

16 In six of the studies included, donors reported specific concerns related to the health status of the transplant
17 recipient. Two sources of distress emerged from this data: (a) worry about severity of recipient's disease and
18 fear of death and; (b) a sense of responsibility with associated guilt if the recipient's health continued to
19 deteriorate, or died. The extent to which donors felt responsible for the transplant outcome varied. For
20 example, some described their responsibility as limited to staying healthy before the procedure and others
21 stated that if the transplant failed, then they had personally failed their relative. Conversely, donors felt
22 personally satisfied and happy when the recipient's suffering had reduced due to a positive transplant outcome.

24 *Donation decision*

25 With respect to the decision to donate, nine studies specifically assessed donor's decision and motivation to
26 donate. Quantitative, qualitative and mixed-method studies reported that most related donors did not hesitate;
27 the decision to donate was a natural choice that required little consideration and they were willing to repeat the
28 experience. Expressions of happiness and gratitude about the opportunity to donate appear together with
29 descriptions of being anxious, concerned and having no choice (Christopher, 2000, Oliveira-Cardoso et al., 2010,
30 Van Walraven et al., 2012, Kisch et al., 2015).

1 Mentioned as motives for accepting the decision to donate were pressures from family members, religious
2 precepts, responsibility and a lack of choice in relation to the survival of their relative (Christopher, 2000,
3 Williams et al., 2003, Oliveira-Cardoso et al., 2010, Van Walraven et al., 2012, Kisch et al., 2013). Quantitative
4 results indicated that family members were influential in donors' decision making (Williams et al., 2003, Wiener
5 et al., 2008, Kisch et al., 2013). Almost half of the donors interviewed were asked to donate by the recipient or
6 another relative (Williams et al., 2003). Donors reported that the influence from relatives both facilitated and
7 complicated their decision to undergo HLA typing (Kisch et al., 2013).

8
9 Donors withheld information about the risks and inconveniencies associated with donation and avoided
10 expressing their own worries and hesitations to (a) protect their sick relative or own family members who were
11 worried about the donation procedure, or; (b) because they regarded their sick relative as in greater need of
12 familial attention than themselves (Pillay et al., 2012, Kisch et al., 2015).

13
14 Kisch et al. (2013) reported that information and positive care provision from Health Professionals (HP) were
15 perceived as being important by potential donors prior to deciding whether to undergo HLA typing. The method
16 for delivering HLA typing results varied; some donors received their typing results by regular mail, others
17 received this information by telephone from a HP or from the recipient or another relative. Donors who
18 underwent HLA typing but were not a match with the recipient preferred to receive the results through personal
19 contact with HP's and receive an explanation about the reason they were not selected to be a donor.

20 21 *Mental preparedness*

22 Donors identified an increased awareness of their own health once they were deemed eligible for donation.
23 They made efforts to ensure optimal health with the hope of maximising the success of the transplant for the
24 recipient, including dietary changes, daily exercise and smoking cessation (Christopher, 2000, Pillay et al., 2012).
25 Donors who had a long waiting period between being deemed eligible to donate and making the donation
26 experienced anxiety and uncertainty about their health status and whether the donation would actually proceed
27 (Christopher, 2000, Kisch et al., 2015).

28 Undergoing donation triggered anxiety for related donors. Most commonly, donors expressed concern regarding
29 self-administering GCSF injections, general anaesthetic and possible risks associated with BM or PBSC donation
30 (Williams et al., 2003, Pillay et al., 2012, Van Walraven et al., 2012). Levels of anxiety were high before the
31 collection procedure, particularly for PBSC donors (Fortanier et al., 2002, Williams et al., 2003) and older donors
32 (Wiener et al., 2008).

1
2 Most donors reported that they appreciated prior contact with the hospital and that the information obtained
3 from HP staff was helpful (Fortanier et al., 2002, Williams et al., 2003, Wiener et al., 2008, Kisch et al., 2013,
4 Labott and Pfammatter, 2014). However in seven of the studies included, donors wanted more information to
5 prepare themselves for donation (Christopher, 2000, Williams et al., 2003, Bredeson et al., 2004, Wiener et al.,
6 2008, Pillay et al., 2012, Van Walraven et al., 2012, Kisch et al., 2013). Some donors believed they were
7 unprepared for the severity or duration of pain post-donation (Christopher, 2000). Parent haploidentical donors
8 were dissatisfied with the information provided and believed that the information sessions tended to focus on
9 the child (Van Walraven et al., 2012), whereas sibling donors expressed the need for more preparatory
10 information about the transplant outcome and possible complications (Wiener et al., 2008). In one study,
11 majority of the donors expressed the wish that they had been offered the possibility of talking to a psychosocial
12 professional because of the difficulties of talking to relatives about their emotions (Kisch et al., 2015).

13 14 *Emotional distress*

15 Quantitative findings regarding related donors' emotional distress were mixed. Two studies (Rowley et al., 2001,
16 Labott and Pfammatter, 2014) identified no change in depression and mood from pre-donation to 30 days and
17 one year post-donation whereas Bredeson et al. (2004) found a negative effect on mood one week post-BM
18 donation and quality of life four week pre- versus post-BM donation.

19
20 Quantitative results regarding donors' reactions in the context of recipient experiencing adverse effects were
21 also mixed. Chang et al. (2003) showed that six months post-donation, related donors with deceased recipients
22 reported significantly higher depression than donors whose recipient survived, while Labott and Pfammatter
23 (2014) reported no changes in depression for donors whose recipient had died at one year post-donation.
24 Leitner et al. (2009) similarly found that recipient death did not negatively influence the rating of donors.
25 However Leitner et al. (2009) carried out a cross-sectional assessment and did not utilise a specific measure for
26 depression but rather a modified visual analogue scale of general health condition and QoL.

27 28 *Family dynamics*

29 The quality of the donor-recipient relationship influenced experiences at each stage of the donation process. If
30 the relationship with the recipient was good, the donor had little doubt about donating (Kisch et al., 2015).
31 Donors also expressed wishes about a future improvement in their relationship with their recipient (Kisch et al.,
32 2015). At the same, donors who reported a close relationship with the recipient also experienced a greater

1 sense of obligation to donate and anxiety about the possible consequences of the transplant (Kisch et al., 2015).
2 In contrast, Labott and Pfammatter (2014) found that a closer donor-recipient relationship was associated with
3 less anticipated responsibility and guilt if the transplant was unsuccessful. Following donation, donors reported
4 a closer relationship with the recipient (Christopher, 2000, Oliveira-Cardoso et al., 2010, Pillay et al., 2012) while
5 for others it did not change (Labott and Pfammatter, 2014).

6
7 Recipient relationships with other family members also affected the donation experience. Donors described
8 satisfaction, appreciation and a pleasant donation experience associated with positive family support
9 (Christopher, 2000, Williams et al., 2003, Pillay et al., 2012). However, when relationships were not supportive,
10 tensions prior to donation were exacerbated and donors described feelings of frustration, resentment and anger
11 (Christopher, 2000, Pillay et al., 2012).

12 **Information and psychosocial support**

13 A total of nine studies mentioned some aspect regarding the availability, sources and timing of information and
14 support given to and received by adult related HSC donors (see Table 3). Healthcare Professionals, including
15 Haematologists and Donor Coordinators were mentioned frequently (Christopher, 2000, Williams et al., 2003,
16 Pillay et al., 2012, Kisch et al., 2013). Other studies used more global terms such as 'medical team', 'HP team',
17 'SCT team' and 'transplant team' and did not specify individual staff members involved in the provision of
18 information and care (Wiener et al., 2008, Oliveira-Cardoso et al., 2010, Kisch et al., 2013, Labott and
19 Pfammatter, 2014). None of the studies examined included a psychosocial component or input from a
20 psychologist in their information and care routine.

21
22 Results regarding separate care pathways for the recipient and donor were mixed and underreported. Of the
23 sixteen studies examined, only three reported this data. Two studies reported that donors were cared for by a
24 physician and nurse not involved in treating the related recipient (Kisch et al., 2013, Kisch et al., 2015) while in
25 another study most donors received information from their related recipient's Haematologist (Pillay et al.,
26 2012).

27
28 Donors also sought information for themselves and accessed the internet, books and videos (Pillay et al., 2012).
29 One study reported that while majority of donors received both written and verbal information, 23% of donors
30 received verbal information only (Williams et al., 2003). Information about donation was also sought from
31 friends and family members (Pillay et al., 2012).

1 Authors (Kisch et al., 2013, Kisch et al., 2015) developed and introduced an information and care (IC) model for
2 potential related donors. The model primarily aimed to prevent any influence on the donors' decision-making by
3 separating all aspects of information and care for donors and recipients. Feedback from participating donors
4 indicated that they were satisfied with the information and care they received. However, the absence of
5 psychological outcome measures in the study design makes it difficult to evaluate whether there was a
6 significant improvement in the psychosocial outcomes for donors who experienced the IC model.

7 8 *Timing*

9 It is notable that most studies reported providing information to donors prior to donation. Information provision
10 during donation was reported by only one of the sixteen studies (Fortanier et al., 2002). No studies reported
11 providing information or support following donation.

12 13 **Discussion**

14 A systematic review of the literature was carried out in order to summarize existing quantitative and qualitative
15 findings on the experiences of adult related HSC donors and the information and psychosocial support provided
16 to them. Although existing literature has started to uncover the psychosocial complications faced by related
17 donors, less has been written about the availability, sources and timing of information and psychosocial support.

18
19 We included sixteen studies; seven were quantitative, three were qualitative and six were mixed-methods
20 studies. It has been shown that adult related HSC donors experience a broad range of positive and negative
21 emotions throughout the donation process. Motivations and perceived pressures for donating, the recipient's
22 health condition, donors' mental preparedness for donation and family dynamics emerged as important
23 determinants in shaping donors' emotional experiences.

24
25 Despite the anxiety and ambivalence related to the donation process, refusal to donate was zero. Our review,
26 however, highlighted a perceived lack of true choice among adult related HSC donors. Results showed that some
27 donors were asked to donate by their relative or another family member (Williams et al., 2003). Hence, refusal
28 to donate in such circumstances is very difficult. Current guidelines state that the decision to donate should be
29 free from pressure or coercion of any kind, yet the results of this review show that donors can feel pressured by
30 family members. This has implications for informed consent for donation, particularly given that some donors
31 received information from their relative's transplant team member (Pillay et al., 2012).

1 A supportive family network provided a significant source of support for donors, although family dynamics
2 either had a positive or negative influence. Some donors experienced conflict with family members, worsening
3 their experience. For other donors, family members provided support and validation of their generous act which
4 improved their experience.

5
6 It is important to highlight the results of donors unwilling to express their concerns about being a donor. Donors
7 regarded their ill-relative in greater need of familial attention than themselves and minimised their own role.
8 The perceived responsibility to donate can be a heavy burden to accept and the results show that donors wish
9 to talk to a psychosocial professional (Kisch et al., 2015). This is also an important challenge for Donor
10 Coordinators who play a major role in providing donor information and support throughout the donation
11 process (Polomeni et al., 2016).

12
13 Donors expressed the need for more information regarding concerns for their own health and that of the
14 recipient. Fear, nervousness and anxiety were reported in relation to GCSF injections, general anaesthetic and
15 possible risks associated with both BM and PBSC donation methods. Parent haploidentical donors in particular
16 were dissatisfied with the information provided about the aspects related to the donation process (Van
17 Walraven et al., 2012). This is an important finding in light of the increasing use of haploidentical donors who are
18 often parents and warrants future research priority in the related HSC donor setting. The very fact that parents
19 have the dual role of caregiver and donor renders them psychologically vulnerable in a manner that is different
20 from other donor groups. Their needs should be carefully assessed in order to provide adequate preparation for
21 the transplantation procedure and the donation process, including information and psychosocial support.

22
23 Following donation, fluctuations in the recipient's health status and donors' active participation in the process
24 were primary sources of distress for donors. Donors expressed depression, grief, guilt and devastation if the
25 recipient did not survive. Indeed, the unpredictable nature of haematological malignancies and potential for
26 sudden deterioration can have devastating effects on donors. As depression was associated with recipient death
27 at six months post-donation, the findings demonstrate the importance of offering psychological support to
28 donors whose recipient does not survive. Since these results were lower than those reported one year post-
29 donation (Labott and Pfammatter, 2014), they may reflect a transient reaction to donors' loss as suggested by
30 the authors Chang et al. (2003). Indeed, it is plausible that emotional functioning improves much later post-
31 donation, while donors experience reduced emotional functioning immediately post-donation. The converse
32 was also true. Donors felt personally satisfied and happy when the recipient's suffering had reduced due to a

1 positive transplant outcome. Overall, these results suggest that donors whose recipient does not survive are at
2 more risk for negative psychosocial impact and as such represent an obvious group where enhanced
3 psychological support may need to be targeted in a timely manner.

4
5 The availability and sources of information was mentioned only infrequently in the literature. HPs, including
6 Haematologists and Donor Coordinators were mentioned most frequently by studies. Other categories,
7 including printed and electronic materials, friends, family and external counsellors were mentioned infrequently.
8 With the exception of one study (Kisch et al., 2013), there was lack of detail provided about the information
9 donors received throughout the donation process. For example, studies reported that donors thought meeting
10 with the transplant team prior to donation was helpful but failed to provide any further detail regarding the
11 content and delivery mode of the information provided. The issue which remains is whether any parallels can be
12 drawn between the management of related HSC donors as mentioned in the literature and current
13 recommendations and guidelines for the care of related HSC donors (Clare et al., O'Donnell et al., 2010, Van
14 Walraven et al., 2010, Anthias et al., 2015).

15
16 None of the studies examined reported providing psychosocial support to donors. Donation can be a positive
17 experience, however, related donors can become emotionally invested and experience psychosocial difficulty
18 throughout the process, particularly if the transplant is unsuccessful. In the kidney donor care setting, it is
19 recommended that all related donors undergo a psychosocial assessment (Goldfarb, 2005, Dew et al., 2007).
20 Like kidney donation, the HSC donation experience is influenced by physical and psychosocial factors and it must
21 be seen in a broader context, requiring both physical and psychosocial care. This is also in line with the global
22 move toward person-centred care, an approach that views the individual as a whole person with
23 multidimensional needs (WHO, 2007). Whilst this does not permit us to draw definitive conclusions, it has
24 identified a gap in the literature that can, and perhaps should, guide future transparency of reporting on the
25 information and psychosocial support available to related donors.

26
27 A crucial component to providing quality care is the ability to accurately time the provision of information.
28 Empirical findings for patients undergoing HSC transplantation demonstrate the importance of providing
29 particular information at particular moments in time (Oberoi et al., 2017) and we believe this is also an
30 imperative component of providing quality care for adult related HSC donors. Most of the literature addressed
31 pre-donation information and the findings indicate that donors appreciated this as it allowed them to
32 immediately alleviate their concerns with HPs. The fear and anxiety reported by donors prior to donation also

1 demonstrates the importance of preparing them adequately regarding the range and severity of possible
2 physical and emotional pain.

3
4 Insufficient attention was paid to the needs of donors post-donation. None of the studies reported providing
5 information or psychosocial support to donors following donation, despite adverse recipient events, including
6 death. This contrasts with the findings of this review that indicate donors related to deceased recipients
7 experience more depressive symptoms (Chang et al., 2003). Just as transplant recipients have a program of
8 scheduled pre- and post-transplant appointments, post-donation follow-up is equally important, particularly for
9 donors whose recipient does not survive, as this review suggests.

10

11 *Limitations and directions for future research*

12 There are a few methodological limitations of this review that also need to be noted. Measures and outcomes
13 for QoL and emotional functioning were not homogenous, which made comparison across studies challenging.
14 Additionally, a number of studies used individually-created numerical rating items. The use of tools that have
15 not been previously validated may reduce the reliability and validity of results. In addition, the time lapse
16 between PBSC donation and interview varied considerably for studies that were retrospective in design (range, 0
17 – 11 years). Reports were limited to what the donor remembered and wished to share about the donation
18 experience.

19

20 If we are to move forward and create or adapt interventions to enhance psychosocial functioning in adult
21 related HSC donors, then improved transparency of reporting for the availability, sources and timing of
22 information and psychosocial support is needed. A detailed description of the objectives addressed,
23 components, theoretical underpinnings (e.g. self-efficacy theory), validation/review by experts, other links
24 included to information and support websites, delivery mode and timing could enhance future studies.
25 Most studies examined QoL, anxiety and depression in this donor cohort, only a few studies assessed unmet
26 needs. Addressing psychological distress alone is not sufficient to inform future strategies for addressing unmet
27 needs (Oberoi et al., 2017). Clinicians aiming to prioritise health services to improve donors' QoL should be
28 guided by an understanding of their donors' anxiety and depression levels as well as their unmet needs. Further
29 research is needed on donors' unmet needs to improve related donors' QoL. Validated measures, such as the
30 Supportive Care Needs Survey (SCNS-SF34) (Boyes et al., 2009) and the Sibling Cancer Needs Instrument (SCNI)
31 (Patterson et al., 2014) would be useful to assess donor unmet needs in different need domains, including

1 psychological and emotional needs, physical and daily living needs and information needs at different time-
2 points of the donation experience.

3

4 Findings to date indicate potential areas for educational and psychosocial interventions. Intervention research
5 should focus on developing and evaluating interventions that target the known psychological predictors of
6 maladjustment, namely, recipient death, responsibility, guilt, prior anxiety and depression, low family social
7 support, and maladaptive coping, particularly repression of emotions and concerns. However, barriers that
8 might prevent donors from accessing and attending face-to-face interventions need to be taken into account.

9 Related HSC donors often come from interstate, international, rural and remote areas which makes face-to-face
10 follow up problematic. In addition, donors' reluctance to express their concerns might suggest stigma associated
11 with seeking psychosocial assistance and a preference to self-manage.

12

13 Given that 86% of Australians have access to the internet at home (ABS, 2016) web-based interventions appear
14 a logical format for increasing access to information and psychosocial support for all HSC related donors. Such
15 interventions have already been shown to be beneficial in offering information and support to family caregivers
16 of patients with cancers (Northouse et al., 2014, Kaltenbaugh et al., 2015) and will likely provide similar benefits
17 for adult related HSC donors. Self-guided web-based interventions particularly can remove the barriers
18 discussed above in a cost-effective and accessible way (McAlpine et al., 2015). Along with anonymity, privacy
19 and convenience of utilising a program whenever and wherever at the participant's own pace, self-guided web-
20 based interventions can be easily updated and provide links to other resources (Barak et al., 2009, McAlpine et
21 al., 2015).

22

23 In summary, this review has illuminated the landscape of literature dealing with the experiences of adult related
24 HSC donors and has highlighted the insignificant attention paid to the availability of information and
25 psychosocial support. Given that adult-related, often parental, HSC donors are increasingly being utilised in
26 transplant programs world-wide, this is an issue of urgent and international importance for cancer care
27 providers needing to offer timely information and care to their patients as a component of good clinical practice.
28 Future research to attend to these methodological gaps is necessary for the development and implementation
29 of educational and psychosocial interventions that will better meet the information and psychosocial care needs
30 of adult related HSC donors.

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2 Figure Legends**3 Figure 1.** The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram

4

5 Table Legends**6 Table 1.** Characteristics of the studies included**7 Table 2.** Results of related donor experiences**8 Table 3.** Results of information and support services provided to donors.

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10 Supplementary Material Legends**11 Supplementary Table 1.** Search strategy for the different databases. Search strategy: Stem cell transplant AND**12 Donors AND Psychosocial,** applying the listed synonyms for the different databases.

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Table 1.

Author(s), Country	Donation Type	Sample size (Age, range)	Design	Time point	Comparison group	Inclusion criteria specified?	Instruments used for measurement validated?	Attrition reported?
Quantitative								
Rowley <i>et al.</i> (2001) USA	BM and PBSC	69 (22-63)	Prospective	Days before and after donation: Day -3 (third day of GCSF); Day -1 (fifth day of GCSF and first day of apheresis collection); Day +1; Day +7; Day +14; Day +21; Day +28; 6 months	BM or PBSC donors	Yes	Yes ^{1,2} and No	Yes
Fortanier <i>et al.</i> (2002) France	BM and PBSC	70 (mean age 36.5)	Prospective	<u>BM group:</u> Day before donation; Immediately after donation; 4hrs after donation <u>PBSC group:</u> Before first GCSF injection; Before the apheresis collection, i.e. after 5 GCSF injections on day 5; During the apheresis collection; Post-donation (day 6 or 7).	BM or PBSC donors	No	Yes ^{3,4} and No	Yes
Chang <i>et al.</i> (2003) USA	BM	23 (mean age 37.6)	Prospective	Pre-donation; Within 2 weeks post-donation; 6 months post-donation	No	Yes	Yes ^{1,5,7,8} and No	Yes
Leitner <i>et al.</i> (2009)	PBSC	171 (11-72)	Cross-	Median of 4 (range, 0.2–11) years post-	No	No	Yes ⁴ and No	N/A

Austria		≥ 50 years (n = 47)	sectional	donation				
Labott & Pfammatter (2014) USA	PBSC	28 (20-74)	Prospective	Pre-donation; 30 days post-donation; 1-year post-donation	No	No	Yes ^{6, 9, 10, 11, 12, 13, 14}	Yes
Switzer <i>et al.</i> (2017) USA	PBSC	164 (18-76)	Prospective	Within 4 weeks prior to first GCSF; 4 weeks post-donation; 1 year post-donation	Older vs younger related donors	Yes	Yes ^{9, 15, 16, 17, 18, 19}	Yes
Qualitative								
Christopher (2000) USA	BM	12 (25-58)	Retrospective	Within the first year post-donation (mean, 9.25 months)	No	Yes	No	N/A
de Oliveira-Cardoso <i>et al.</i> (2010) Brazil	BM	20 (18-42)	Prospective	Pre-donation; Immediately post-donation	No	Yes	No	Yes
Kisch <i>et al.</i> (2015) Sweden	BM and PBSC	10 (26-66)	Prospective	1-18 days pre-donation (median, 4.5 days pre-donation)	No	Yes	No	N/A
Mixed-method								
Kennedy <i>et al.</i> (2003) Australia	BM and PBSC	59 (14-66)	Prospective	28 days post-donation; 3 months post-donation; 12 months post-donation; 24 months post-donation	BM or PBSC donors	No	No	Yes
Williams <i>et al.</i> (2003) UK	PBSC	17 (21-59)	Prospective	Pre-donation; Immediately post-donation	No	No	Yes ^{3, 4} and No	Yes
Bredeson <i>et al.</i> (2004) Canada	BM and PBSC	184 (15-74)	Prospective	Pre-donation; 1 week post-donation; 4 weeks post-donation	BM or PBSC donors	No	Yes ^{6, 20} and No	Yes
Wiener <i>et al.</i> (2008) USA	PBSC	14 (9-28) ≥ 18 years	Cross- sectional	0.3-4 years post-donation (mean, 1.8)	No	Yes	No	N/A

		(n = 9)						
Pillay <i>et al.</i> (2012) Australia	PBSC	22 (33-68)	Cross-sectional	0-3 years post-donation (mean, 1.59 years)	No	No	No	N/A
van Walraven <i>et al.</i> (2012) The Netherlands	PBSC	13 (28-48)	Cross-sectional	0.4-5 years post-donation (median, 2.7)	No	No	Yes ²¹ and No	N/A
Kisch <i>et al.</i> (2013) Sweden	Not identified	148 (20-77)	Retrospective	0-4.5 years post-HLA typing.	Related donors vs non-related donors	Yes	No	N/A
<p><i>Notes.</i> Abbreviations of instruments: MPQ, McGill Pain Questionnaire¹; BPI, Brief Pain Inventory²; STAI, State-Trait Anxiety Inventory³; VAS, Visual Analogical Scale⁴; BDI, Beck Depression Inventory⁵; POMS, Profile of Mood States⁶; NPRS, Numerical Rating Scale of Pain⁷; BS-11, Box Scale of Pain⁸; Ambivalence⁹; Donation Experience¹⁰; Guilt and Responsibility¹¹; KPS, Karnofsky Performance Status Scale¹²; Better Person¹³; ARI, Autonomy and Relatedness Inventory¹⁴; SF12v2, 12-Item Short Form Health Survey¹⁵; BSI, Brief Symptom Inventory¹⁶; Health-related QoL of bone marrow versus PBSC donors: a pre-specified subgroup analysis from a phase III RCT—BMTCTN protocol 0201¹⁷; Factors associated with attrition from a national bone marrow registry¹⁸; Donating stimulated peripheral blood stem cells vs. bone marrow: do donors experience the procedures differently?¹⁹; SF-36, 36-Item Short Form Health Survey²⁰; UCL, Utrecht Coping List²¹</p>								

Table 2.

Issue	Authors of relevant research	Results concerns	Results incentives
Transplant recipient	Qualitative		
	Christopher (2000)	Fear and sadness about deteriorating health. Grief and sense of responsibility associated with recipient death.	Relief from recipient's suffering.
	Kisch <i>et al.</i> (2015)	Worried about not being able to donate while waiting for HLA/health investigation results. Worried about severity of relative's disease and evident risk of dying. Sense of responsibility associated with unsuccessful transplant.	
	Mixed-method		
	Bredeson <i>et al.</i> (2004)	25% of PBSC donors worried about experimental nature of transplantation and possible ramifications for the recipient.	
	Wiener <i>et al.</i> (2008)	Sense of responsibility and guilt for transplant complications.	
	Pillay <i>et al.</i> (2012)	Distress regarding fluctuations in recipient's health status. Sense of responsibility and guilt if recipient health continued to deteriorate.	Relief from recipient's suffering.
	van Walraven <i>et al.</i> (2012)	Despair, frustration and sorrow in response to hearing that no HLA compatible donor was available. Fear of losing one's child. Guilt and diminished self-esteem associated with recipient death.	New hope. Transplant put life into a new perspective.
Donation decision	Quantitative		
	Labott & Pfammatter (2014)		> 80% willing to donate again. Would encourage someone else to donate.
	Qualitative		
	Christopher (2000)	Theme 'doing what it takes when a relative has cancer' guided decision-making.	Satisfaction and gratitude for donating. Little or no hesitation. Willing to donate again.
	de Oliveira-Cardoso <i>et al.</i> (2010)	Sense of responsibility to save their relative's life. Motives included pressures from family members and religious precepts.	Glad to have the opportunity to donate. Also willing to donate BM to a stranger.

	Kisch <i>et al.</i> (2015)	Anxious, concerned and obliged. Withholds worries, hesitations and information about risks associated with donation. Caring about other relatives who do not donate.	Gratitude and happiness for donating without hesitation. Available and ready to help.
	Mixed-method		
	Williams <i>et al.</i> (2003)	47% asked to donate by either the recipient or another relative 77% cited family bond as the main influence. Instantaneous decisions.	Satisfaction and pride for donating. No hesitation. Willing to donate again.
	Pillay <i>et al.</i> (2012)	Withholds expressing difficulties as sick recipient regarded in greater need of familial attention.	Sense of satisfaction and new hope. Little hesitation. Majority willing to donate again.
	van Walraven <i>et al.</i> (2012)	Feelings of powerlessness/having no choice.	No hesitation. Hope for a cure.
	Kisch <i>et al.</i> (2013)	HLA typing results delivered by regular mail (70%), from recipient or another relative (8%). 10.8% preferred to have received HLA results by telephone from a HP. 17% reported influence from relatives that facilitated or complicated their decision.	Information, HP's respect for donors' privacy, confidence in HP's and positive care provision were important before deciding whether to undergo HLA typing.
Mental preparedness	Quantitative		
	Fortanier <i>et al.</i> (2002)	Pre-donation STAI scores higher in PBSC (45) than BM donors (35).	STAI scores decreased regularly during the process and became very low immediately post-donation. Majority satisfied by explanations given during collection procedure.
	Labott & Pfammatter (2014)	54% indicated no Ambivalence while 3 donors reported significant ambivalence (5-7 on the 7-point scale)	Majority felt totally prepared at each time-point.
	Qualitative		
	Christopher (2000)	Those who experienced pain and discomfort post-donation reported they were not adequately prepared for its severity and duration and described desire for telephone follow-up with clinicians. Hearing 'war stories' about the process contributed to anxiety levels. Made efforts to optimise health, concerned about own health and impact on transplantation.	

		Delayed procedure associated with concern about health status.	
de Oliveira-Cardoso <i>et al.</i> (2010)		Ambivalence between trusting the possibility of a cure and the inevitability of recipient death. Being 'chosen' for donation triggered anxiety. Anxiety regarding general anaesthetic.	
Kisch <i>et al.</i> (2015)		Symptom anticipation and inconveniences. Desire for talking to a psychosocial professional due to difficulty of talking to relatives about their emotions. Delayed procedure associated with concern about whether donation will be performed.	Appreciated confidentiality of care, i.e. separate care of donor and related recipient.
Mixed-method			
Williams <i>et al.</i> (2003)		24% very anxious upon arrival at the unit and reported high STAI scores (>40). Sources; fear of the unknown and pain associated with anaesthetic injection. 77% received both written and verbal. Need for more written information; descriptions of BM and PBSC methods, GCSF administration and potential long-term effects.	Valued information received. Seeing apheresis machine was very helpful.
Bredeson <i>et al.</i> (2004)		10% BM and 14% PBSC symptom anticipation and management.	
Wiener <i>et al.</i> (2008)		Procedure and physical harm. Older adults more nervous than younger donors. Almost 1/3 thought additional preparation sessions to be helpful. Need for more information about transplant outcome and complications.	Informational session with transplant team staff was useful.
Pillay <i>et al.</i> (2012)		Nervous about self-injecting GCSF and associated risks. Donation information provided by recipient's haematologist. Insufficient information about severity of symptoms and long-term impacts. Made efforts to optimise own health to provide sick relative with the best chance of survival.	
van Walraven <i>et al.</i> (2012)		Experimental character of haploidentical transplant. Long-term effects of GCSF. Dissatisfied with the donor information, sessions tended to focus only on recipient.	
Kisch <i>et al.</i> (2013)		5-10% reported dissatisfaction with 1 or more aspects of information provision. Chance to discuss remaining questions with HP by telephone was important.	HP care provision was positive. Written information found to be comprehensive.

Emotional distress	Quantitative		
	Rowley <i>et al.</i> (2001)	BM and PBSC donors reported minimal fluctuations emotional status.	
	Chang <i>et al.</i> (2003)	Death of recipient associated with significantly higher depression scores at 6 months post-BM donation.	
	Leitner <i>et al.</i> (2009)	Death of recipient did not negatively influence donor ratings.	No negative influence of PBSC donation on health status and QoL.
	Labott & Pfammatter (2014)	Total mood disturbance and depression low overall and did not significantly change 1 year after versus before donation.	
	Switzer <i>et al.</i> (2017)	Older donors reported fewer family/work concerns, and less perceived responsibility if the transplant was unsuccessful compared to younger donors.	
	Mixed-method		
	Bredeson <i>et al.</i> (2004)	BM donation associated with persistent moderate negative effects on QoL at 4 week post-donation versus small effects with PBSC donation. BM donation associated with statistically worse total mood disturbance at 1 week post-donation versus no changes for PBSC donors.	
	Pillay <i>et al.</i> (2012)	68% emotional distress was most challenging aspect of donation and 41% physical discomfort. 27% desired more emotional support from the hospital. 46% suggested post-donation follow-up care to improve preparation and hospital-provided emotional support.	
Family relationships	Quantitative		
	Labott & Pfammatter (2014)	Donor-recipient relationships did not change over time.	Closer and more positive donor-recipient relationships were associated with less anticipated guilt and responsibility.
	Qualitative		
	Christopher (2000)	Non-supportive family relationships associated with frustration, resentment and anger.	Donors described satisfaction associated with positive family support. Donor-recipient relationships were strengthened.
	de Oliveira-Cardoso <i>et al.</i> (2010)		Donor-recipient relationships were strengthened
	Kisch <i>et al.</i> (2015)	Closer donor-recipient relationship associated with greater sense of obligation to donate and responsibility for the sick relative connected with feelings of anxiety about the consequences of the transplantation.	Wishes were expressed about a future improvement in donor-recipient relationship following donation. No or little doubt about donating if donor-recipient relationship is good.

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	Mixed-method		
	Williams <i>et al.</i> (2003)		Support from others, encouragement and understanding were appreciated.
	Wiener <i>et al.</i> (2008)		Improved donor-recipient relationships

Table 3.

Category	Authors of relevant research	Subcategory	Stage in the donation process
Healthcare Professionals	Quantitative		
	Fortanier <i>et al.</i> (2002)	Procedure explained by medical team during course of collection procedure.	During donation
	Labott & Pfammatter (2014)	Medical team screened donors for medical issues and informed donors on what to expect throughout the process.	Pre-donation
	Qualitative		
	Christopher (2000)	Procedure explained, questions answered, met with clinician, given contact number.	Pre-donation
	de Oliveira-Cardoso <i>et al.</i> (2010)	Met with HP team pre-donation.	Pre-donation
	Mixed-method		
	Williams <i>et al.</i> (2003)	82% cited consultant as information source 12% combination consultant and nurse 6% combination consultant and recipient 94% reported receiving comprehensive information about procedures, risks and pain.	
	Wiener <i>et al.</i> (2008)	Donors met with the transplant team.	Pre-donation
	Pillay <i>et al.</i> (2012)	Related recipient's Haematologist 68% Donor Coordinator 50% General Practitioner 5%	Pre-donation
Printed/Electronic materials	Kisch <i>et al.</i> (2013)	Donor Coordinator A physician and nurse not involved in the care of the recipient.	Pre-donation Not specified
	Mixed-method		
	Williams <i>et al.</i> (2003)	77% donors received both written and verbal information, although the written information was designed for autologous donors, remaining donors reported they had received verbal information only.	Pre-donation
	Pillay <i>et al.</i> (2012)	Internet 45% Books 32% Videos 18%	Pre-donation
Friends/Family/External counsellors	Kisch <i>et al.</i> (2013)	Written information booklet about HLA typing and HSC donation	Pre-donation
	Mixed-method		
Other	Pillay <i>et al.</i> (2012)	Friends/family 14%	Pre-donation
	Qualitative		

	Kisch <i>et al.</i> (2015)	Information and care model	Pre-donation
	Mixed-method		

