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Adult related haematopoietic stem cell donor care: Views of Transplant Nurses

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ABSTRACT

Purpose: The objective of this mixed-methods study was to explore the experiences and perspectives of Transplant Nurses (TNs) in caring for related donors (RDs).

Method: In this mixed-methods study, both quantitative and qualitative data were collected from semi-structured interviews with seven TNs from two clinical hospitals. Closed and multiple-choice questions regarding the organisation of RD care were administered in addition to an in-depth exploration of TN experiences and perspectives of RD care. Interviews were audio-recorded, transcribed, and qualitative data was subjected to thematic analyses.

Results: The analysis identified 5 themes relating to RD care: managing complex family dynamics and ambivalence; concerns about RD psychological adjustment; identifying and correcting RD misperceptions; limited guidelines and structured processes; limited training for the role and access to supervision. Five themes were identified describing the barriers to delivering RD care: RDs unwilling to express their concerns; language; time constraints; medical priority of clinicians; biomedical focus of TNs. All TNs agreed they would like additional training in the psychosocial management of RDs. TNs identified key areas for improvement, including psychosocial support and educational material.

Conclusions: Our results highlight the significant role of TNs in RD care, and underline issues specific to the current RD care environment. Lack of training for the role and limited guidelines addressing RD care management are key issues which may detrimentally affect RD care. The pivotal role of TNs must be acknowledged and supported by improving TN training and implementing clear guidelines for the management of RDs.

The trial has been registered on the publicly accessible register: www.clinicaltrials.gov site with the identifier ACTRN12617000407392.

1. Introduction

Haematopoietic stem cell (HSC) transplantation provides the only possible hope of cure for many otherwise incurable malignancies. The outcomes of HSC transplantation are strongly affected by the degree of matching between the donor and transplant recipient. Donor-recipient matching involves comparing tissue types, known as human leukocyte antigen (HLA) loci that distinguish 'self' from 'non-self'. A poorly HLA-matched donor-recipient transplant can lead to graft-versus-host-disease (GVHD), leading to increased morbidity and mortality (ABMTRR, 2016; Petersdorf, 2007; Petersdorf et al., 2001; Yang et al., 2018).

Given these issues, every effort is made to find the best possible HLA-matched donor. HLA types are inherited so HLA-identical siblings are preferred donor candidates since they have the greatest chance (25%) of being HLA-matched with the recipient (Petersdorf, 2007). For those without an identical HLA-matched sibling donor, HLA-haploidentical (half matched)-related donors are now typically chosen in favour of HLA-matched unrelated donors because of better GVHD control and relapse-free survival (Kanakry et al., 2016; McCurdy et al., 2017; Solh et al., 2016). Inclusion of HLA-haploidentical related donors extends the pool of donors to include parents and children.

Coinciding with the increasing activity in related donor (RD)

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transplants is the recognition of the important role that Transplant Nurses (TNs) have in caring for RDs (Polomeni et al., 2016). TNs are key members of the multidisciplinary transplant team. As the first point of contact for RDs, TNs are vital in educating RDs and providing care throughout the decision-making, testing and donation process. Although there are guidelines for TNs to respond to unrelated donors (URDs), there are no similar guidelines to assist them in responding to RDs (Anthias et al., 2016; Anthias et al., 2015; Clare et al., 2010; O'Donnell et al., 2010). Compared with URDs, RDs face different and complex issues.

RDs have a dual role; as family members they experience the challenges of a life-threatening illness of their family member. As donors, their cells offer the best possibility of ensuring the recipient's survival. Negative experiences, such as feeling anxious, isolated, responsible and guilty for poor transplant outcomes have been described (Garcia et al., 2013; Pillay et al., 2012; Williams et al., 2003; Zomerdijk et al., 2018). In addition, negative psychosocial outcomes have been reported for donors of recipients who died (Chang et al., 2003; MacLeod et al., 2003). Presently, there is no long-term follow-up of RDs. This is in contrast to the follow-up of URDs, whom are offered follow-up by donor registries annually for a minimum of ten years after donation (Aprili et al., 2013). As such, in the absence of follow-up support, these issues are not addressed for RDs.

Further differences have been observed regarding the consent of RDs. To ensure confidentiality and prevent coercion, the evaluation of a URD is never conducted by a physician in the transplant team caring for the recipient (Hurley and Raffoux, 2004). In contrast, RDs are frequently managed by transplant physicians in the same team as that caring for the recipient. (Anthias et al., 2015, 2016). O'Donnell et al. (2010) found that in over 70% of centres in the United States, transplant physicians assessing a RD were involved in the care of the recipient. In 2010, 52% of the respondents of a European Group for Blood and Marrow Transplantation Nurses Group survey indicated that RDs in their centre were consented by transplant physicians caring for recipients (Clare et al., 2010). These findings suggest that a conflict of interest could arise in the management of related donors at a substantial number of transplant centres.

The lack of accepted guidelines presents substantial challenges for TNs in their assessment, judgment and decision-making when caring for RDs. Assuming current transplant trends continue; the increasing demand for RDs will increase the burden of RD care on transplant centres and individual TNs. To avoid potential problems and to help TNs achieve best practice in RD care management, it is important to gain a better understanding of the current RD care environment from the perspective of TNs and to identify areas for improvement in RD care in the future. The views of TNs are important as they are the ‘gatekeepers’ to family members donating and are integral in implementing changes in clinical practice to benefit RDs.

This study investigates (1) the perceptions of TNs about the psychosocial implications of donation by RDs; (2) the role of TNs in RD care; and (3) the adequacy of current RD practices in addressing RD needs from the perspective of TNs.

2. Methods

2.1. Design

This study was designed as a mixed-methods design. We adapted a quantitative and qualitative semi-structured interview guide designed by Polomeni et al. (2016), consisting of 28 open, closed and multiple-choice questions (see Appendix 1). The interview guide comprised three main sections. The first two sections comprised closed and multiple-choice questions and the latter comprised open-ended questions. Each TN participated in one interview. The lead author (NZ) conducted all interviews in private in TNs offices and audio-recorded with consent. Information was entered on a structured template to record:

- Demographic characteristics (age, length of professional experience as a Nurse, in Haematology specifically and as a TN);
- A TN-reported description of the organisation of RD care in their transplant unit with a specific focus on: (1) the provision of information (verbal and written materials); (2) HLA typing procedures; (3) consent processes and health professionals involved; (4) financial support; (5) follow-up services; and (6) the availability and use of guidelines and formalised pathways.
- Open-ended questions encouraged TNs to share their perspectives of their own role in the care for RDs, the issues surrounding current RD practices, the challenges encountered during their experience as TNs, the provision of training and support for TNs and suggestions for improving RD care.

2.2. Participants

Eligible participants were identified according to their role and included certified Bone Marrow Transplant Nurse Coordinators and Apheresis Nurse Practitioners. These two professions were selected because they both play major roles in RD care; Bone Marrow Transplant Nurse Coordinators are responsible for the coordination, education and preparation of RDs for HSC donation and support RDs throughout the donation process. Apheresis Nurse Practitioners are responsible for conducting comprehensive health assessments, coordinating the collection of stem cells from the blood in a procedure called apheresis and delivering care to RDs. In this manuscript, we refer to these two professions collectively as “Transplant Nurses".

2.3. Recruitment

Eligible participants were recruited between November 2017 and April 2018 from two large adult HSC transplant units in Australia in two geographically distant locations that serve diverse (immigrant and non-immigrant), urban and rural populations. Eligible participants were initially approached via email or telephone by the lead author and verbal consent was obtained at this stage. Willing participants were then approached by the lead author, and both verbal and written informed consent was obtained.

2.4. Data analysis

Audio-recorded interviews were transcribed verbatim by the lead author. To ensure accuracy, the second author (JT) checked the transcripts against the original audio recordings and confirmed the transcripts were true to their original nature and practically suited to the purpose of analysis.

Frequency analyses and comparisons of quantitative data collected from semi-structured interviews were performed with the statistical software package SPSS version 25. Thematic analysis of the qualitative data was guided by Braun and Clarke (2006) six-stage thematic method. The data were analysed in the following process. All transcribed interviews were read and re-read to gain familiarity with the content. Initial codes were generated and categorised into RD care issues, barriers to delivering RD care and TN recommendations to improve RD care. The codes within each category were analysed separately to identify potential themes. The codes were organised and reorganised into different themes within each category until comprehensive definitions were generated for each category.

In keeping with the criteria for good thematic analysis as advocated by Braun and Clarke (2006), the themes were evaluated firstly against coded extracts of the data, and subsequently against the original transcriptions to ensure thematic accuracy, and to rule out oversight of any additional themes missed in earlier coding stages. To ensure a rigorous thematic approach, two researchers (NZ, JT) independently coded the data and met to determine whether they agreed with the codes and themes identified.

Table 1
Transplant Nurses demographic characteristics.

Variable	*N*
Age	
30–40	2
41–50	5
Gender	
Male	0
Female	7
Professional experience as a Nurse	
6 ≤ 10 years	1
> 10 years	6
Professional experience in Haematology	
6 ≤ 10 years	3
> 10 years	4
Professional experience as a Transplant Nurse	
< 2 years	2
2 ≤ 5 years	2
6 ≤ 10 years	3

2.5. Ethical considerations

This study formed part of a larger study aiming to investigate the psychosocial impact of HSC donation on adult RDs, registered at www.anzctr.org.au as ACTRN12617000407392. The study protocol was approved by the Human Research Ethics Committees of the University of Queensland (Ref: 2016001438) and the Royal Brisbane & Women's Hospital (Ref: 16/QRBW/207).

3. Results

3.1. Quantitative data

3.1.1. Demographic characteristics

All of the TNs working at the adult HSC transplant units ($n = 7$) gave consent to participate in our study. The TN participants consisted of six Bone Marrow Transplant Nurse Coordinators and one Apheresis Nurse Practitioner. All TNs were female and highly experienced with over half of the participants having over 10 years' experience working in Haematology and a minimum of 1 year as a TN. Table 1 shows the demographic characteristics of TNs.

3.1.2. Organisation of related donor care

Table 2 reports TNs' responses to questions about the organisation of RD care in their transplant unit. Each transplant unit had completely independent paths for donors and recipients. Potential donors were verbally informed about the donation by a TN before HLA typing and written information was provided by most TNs. Potential donors received their HLA typing results confidentially prior to the recipient being informed in order to protect the volunteer status of the donor. On the day of the pre-donation check-up, RDs met with a TN and occasionally with a BMT Physician, a Registrar or a Haematologist. Five TNs stated institutional support was available in their transplant unit for RDs with financial challenges, whereas two stated there was not. TNs organised a post-donation follow-up via telephone within one week of donation. None of the RDs received follow-up beyond this timeframe.

3.1.3. Challenges in related donor care

TNs' responses to questions about the challenges encountered in related donor care are reported in Table 3. When asked if TNs believed RD needs were addressed in their unit, four TNs said yes, whilst three said no. All TNs had encountered challenges when caring for RDs, including reluctant donors ($n = 7$); conflicting family relationships ($n = 6$); RD language barriers and/or sociocultural differences ($n = 6$); socioeconomic difficulties ($n = 6$); conflict of interest between recipients' needs and donors' reluctance ($n = 3$); doubts about the informed consent of the donor ($n = 2$); and doubts about the free choice of the donor ($n = 2$).

Table 2
Quantitative results: responses to questions about the organisation of related donor care.

Questions	*N*
In your unit, are there two completely independent pathways for donors and recipients?	
Yes	7
No	0
Who usually contacts the potential donor to ask them to perform tissue type typing?	
The recipient	0
Haematologist	0
Bone Marrow Transplant Physician/Registrar	0
Transplant Nurse	7
Are potential donors informed about donation and the transplant *before* tissue type typing?	
Yes	7
No	0
If yes, by whom?	
Haematologist	0
Bone Marrow Transplant Physician/Registrar	0
Transplant Nurse	7
Is there written information available for donors about donation?	
Yes	6
No	1
Is there written information available for donors about transplant issues?	
Yes	0
No	7
To whom are tissue type typing results communicated?	
The recipient	0
All potential donors	6
Compatible donor(s)	1
By whom are tissue typing results communicated?	
Haematologist	0
Bone Marrow Transplant Physician/Registrar	0
Transplant Nurse	7
At the pre-donation check-up, which professionals would meet with the donor?	
The recipient	0
Haematologist	1
Bone Marrow Transplant Physician/Registrar	3
Transplant Nurse	7
If the donor has financial challenges, is institutional support (e.g. travel expenses) available?	
Yes	5
No	2
Does your transplant unit organise a donors' follow-up?	
Yes	7
No	0
If yes, by which means?	
Consultation	0
Telephone interview	7
Questionnaire	0

Most TNs had experienced situations in which donation proved to be challenging for the potential donor and/or for the recipient, namely relational ($n = 4$); financial ($n = 3$); practical ($n = 3$); and psychological challenges ($n = 2$). Although RDs were followed up within one week of donation, TNs believed there should be follow-up ($n = 6$) and psychosocial support ($n = 6$) beyond this timeframe, particularly in cases of recipient death. Other areas highlighted for improvement included financial assistance ($n = 3$); the choice to donate, or not ($n = 1$); and information ($n = 1$). While four TNs felt they had adequate access to supervision, three did not. Although TNs were highly experienced in their roles, all TNs agreed they would find it helpful to have access to a specifically designed educational resource for staff working with RDs.

3.1.4. Qualitative data

Analysis of the qualitative data identified additional findings relevant to TNs' experiences and perspectives of RD care issues. A summary of the themes identified as relevant to current RD care issues from the perspective of TNs is presented in Table 4 below and discussed in detail in the following section, with illustrative quotes.

Table 3
Quantitative results: responses to questions about the challenges in related donor care.

Questions	*N*
In your opinion, are related donors' needs addressed in your unit?	
Yes	4
No	3
To what extent do you feel that the concerns of donors are addressed in your unit?	
Not at all	0
A little	1
Moderately	2
Mostly	3
Very much	1
Can you indicate if any of the following challenges have arisen for you?	
Reluctant donors	7
Conflicting family relationship	6
Conflict of interest	3
Donors' difficulties in understanding the donation and transplant process	6
Doubts on the informed consent	2
Doubts on free choice	2
Socioeconomic difficulties	6
Have you ever seen family situations in which donation was challenging for the donor?	
Yes	5
No	2
If yes, what kind of challenges:	
Practical	3
Financial	3
Relational	4
Psychological	2
If you had a magic pot of money, what things would you like to see provided for related donors?	
Information	1
Confidentiality	0
Anonymity	0
The choice to donate – or not	1
Financial assistance	3
Psychosocial support	6
Follow-up	6
Do you feel you have adequate access to supervision to equip you with the necessary knowledge and skills to support the donor and their family going through challenges?	
Yes	4
No	3
Do you think a specifically designed educational resource would be helpful for staff working with related donors?	
Yes	7
No	0

3.2. Related donor care issues

3.2.1. Managing complex family dynamics and ambivalence

The first theme highlights the unique position of TNs to sustain the wellbeing of the family. Because of the frequent contact with the RD, transplant patient and their families, TNs learn about support needs and function as a "relational bridge", translating the perspectives of clinicians and other members of the transplant team to the RD and vice versa. However, TNs emphasised that dealing with family dynamics and pre-existing tension in donor-recipient relationships was a complex task for which they had received minimal training.

Prior to donation, TNs highlighted their role in gauging the donor-recipient relationship and handling strained relationships. Notably, a poor relationship with the recipient and/or family members contributed to RD ambivalence during the assessment process. In such cases, RDs expressed worry, uncertainty, doubt and reluctance to donate. In one instance, the TN described a potential donor expressing reluctance to donate only after HLA typing was completed and compatibility had been established. The TN described uncertainty about how to deal with this situation and offered to tell the recipient that the prospective donor was not a match:

- *I've had a lot of people when I've tissue typed them, and they'll go, "I don't want to do this." Or "We don't get on." Or whatever family issues. And so I actually say to them then when I'm tissue typing them, which is separate to this job, "Well we don't need to tell them"* N-04

When family conflicts persisted throughout the donation process, TNs found themselves in conflicting situations in which they were required to intervene:

- *In fact I've had multiple where they actually don't speak so I've needed to ensure that they don't run into each other in the corridors and what not.* N-03

3.2.2. Concerns about RD psychological adjustment

Within the donor population, RDs form a special group as they are likely to be more vulnerable than URDs. For RDs, consenting to HSC transplantation as a life-saving treatment is difficult and distressing, but this would not compare with the devastation of losing a loved one. TNs expressed concern about the welfare of RDs who displayed fearful and anxious behaviour during the initial information session, including concern that their anxiety could worsen post-donation, particularly if the recipient's health declined.

- I usually at that point would go, "I don't think this person is appropriate to donate." The angst and the distress, and I would say I would be worried about their compliance on those reasons. N-01
- You need to gauge that there's not going to be some terrible angst, or anxiety, or it's going to be held over them for the rest of their life. N-03

This theme highlights the lack of psychoeducation provided to RDs to cope with the dual challenge of being a family member and donor. Frequently, donors give verbal consent to donate prior to the initial

Table 4
Summary of themes identified by Transplant Nurses.

Super-ordinate themes	Sub-ordinate themes
Related donor care issues	Managing complex family dynamics and ambivalence
	Concerns about related donor psychological adjustment
	Identifying and correcting related donor misperceptions
	Limited guidelines and structured processes
	Limited training for role and access to supervision
Barriers to delivering related donor care	Related donors unwilling to express their concerns
	Language
	Time constraints
	Medical priority of clinicians
	Biomedical focus of Transplant Nurses
Transplant Nurses recommendations to improve related donor care	Psychological support
	Educational material
	Communication skills training

information session and this makes it difficult for TNs to initiate strategies aimed at assisting RDs to develop ways to cope with the difficulties they experience.

3.2.3. Identifying and correcting RD misperceptions

Donor misperceptions of the donation and transplant process were also identified. RDs often wrongly believed that stem cells were extracted from the bone marrow with anaesthesia, believing a painful procedure was necessary:

- Patient says: “Oh God, I was thinking all this time that I was going to have a bone marrow harvest and everyone's told me how painful it is?” N-01

One TN, in recognising the potentially negative emotional consequences that might be expected if the transplant fails, also expressed the following view:

- I would suggest that they may not be fully aware of what their role as the donor is going to be. N-07

A lack of counselling and appropriate education for RDs before consent is apparent. Volunteer unrelated donors decide for themselves whether to join the register or not *after* having knowledge of the risks and side effects of HSC donation and transplantation. RDs on the other hand are directly approached with the request for HLA typing for their relative *before* having any knowledge of HSC donation and transplantation and often at the same time the recipient is identified as a candidate for transplantation. Given the severity of the patient's illness and urgency about initiating treatment, potential RDs may have limited time to make a decision and are prone to having unmet information needs and misconceptions.

3.2.4. Limited guidelines and structured processes

Although HSC donation has been practiced for over 60 years, guidelines for RD care have been lacking for a long period. TNs reported that their unit lacked formal guidelines and structured processes to guide them in addressing RD concerns. The absence of a protocol for RD follow-up after recipient death was identified as a barrier to delivering quality care. TNs noted that encountering RDs after the recipient's death was relatively common. Although it wasn't part of routine care, TNs felt they needed to address any responsibility, grief and guilt. Where guidelines did exist, these referred to the donor as a stem cell product rather than as an individual. This lead to inconsistencies in procedures, even in a single centre:

- The guidelines, TGA guidelines, they're all about the product. They're not necessarily about donor care. So donor care is very much about each individual centre, and about the experience of the clinicians within that centre. N-06
- The biggest thing that probably people have is they donate and then the patient dies, and then we see them in the corridor. But we don't ever set up counselling or anything like that. N-04

3.2.5. Limited training for the role and access to supervision

TNs felt they did not have adequate access to supervision to equip them with the necessary skills and knowledge to support to RDs going through challenges. As such, TNs relied on their own judgment or obtained guidance from colleagues when faced with challenging situations, inevitably giving rise to variations in practice:

- Trust me, there is no training for a transplant coordinator. You just walk in the door, "Here's the keys, do your best.” So if there's a curly question, I literally have nowhere to go, other than a physician who, they're awesome at what they do, but they don't understand the perspective of what we do inherently. N-06
- If I do encounter a tricky situation, I'll always talk to the other coordinators about it who have been in that role. N-02
- And, it would be quite difficult, I think, for someone who's been inexperienced to deal with that. N-05

3.3. Barriers

3.3.1. RDs unwilling to express their concerns

Regarding their role in caring for RDs, TNs discussed barriers that limited their ability to provide psychosocial care. In some cases, donors were reluctant to express their concerns because they regarded their ill relative as being in greater need of attention than themselves and undervalued their own role. The interviews showed that TNs feel that RDs should be acknowledged by the families for their efforts and supported in their role as donor, since they are important, valuable and benefit their loved one's life.

- I think that many donors are probably actually quite apprehensive and quite fearful of the process but they're very reluctant to share that given the magnitude of what their sibling is about to embark on compared to their own needs. It's such a small step compared to the actual transplant that the magnitude of what they're going through seems almost irrelevant. N-03

3.3.2. Language

Donors often feel overwhelmed by the medical language used in discussion about the donation and transplantation. This can be particularly challenging for donors from another country. Donors from overseas with limited or no English proficiency presented a difficult challenge to TNs who raised their concerns about potential errors in translation when an interpreter facilitated communication:

- I find it sometimes quite difficult. Even when you've got an interpreter there, you're like, “Is the interpreter actually getting what I'm saying? Are you actually understanding what I'm saying to you?” I have no way to verify that. N-05

3.3.3. Time constraints

Due to circumstances, TNs often had limited time to build trust and rapport with RDs. The brief duration of contact with donors and the urgency of the transplant reduced the opportunities for TNs to deliver psychosocial care:

- They travel from other places, and then they're gone. Try and get social work in that small window, it's very difficult. N-05
- It's been on my CNC services plan for five years now … to develop succession planning. I'm getting to that, as soon as we finish planning those hundred transplants this year, we'll get to that. N-06

3.3.4. Medical priority of clinicians

Time pressures not only affected TN-RD communication but also communication between transplant staff. TNs raised concerns regarding the transplant team functioning to issues of time. For example, TNs described situations where donors had been upset because their tissue typing results were disclosed prematurely by the doctor during the recipient's clinical visit.

- All the doctor is thinking is, “Am I transplanting or not?” “Have I got a donor or not?” They aren't aware of family dynamics and everything and they don't really care about them. N-01
- The coordinator communicates those results, unless the doctor sometimes does it accidentally. The doctor has, because I've heard them do it, but we don't. N-04

The disclosure of such confidential information does not protect the donors’ interests and in effect, may give them little opportunity to

refuse donation. Again, the lack of established procedures in place is recurrent and strong across the different themes.

3.3.5. Biomedical focus of TNs

Although TNs described confidence attending to the biomedical and practical needs of RDs, TNs' confidence and willingness to assume full responsibility for delivering psychosocial care to RDs appeared less robust. For example, one TN suggested that resources for managing financially challenged donors and taxi vouchers were the highest priority to improve care.

- So, whether they have some kind of psychology referral at that time of work up would be really nice, yeah … a psychologist kind of work up. N-02
- You know, if it's a guy who's 40 years old, who's a tradie, he's not going to have the big counselling talk, he's just not interested. N-04

3.4. Transplant Nurses' recommendations to improve related donor care

3.4.1. Psychological support

In light of the issues above, TNs made suggestions for improving RD preparation and care, notably the donors' psychological support. TNs emphasized that psychosocial support should be part of routine care. One TN suggested group support for RDs prior to donation. A pre-donation mental health assessment was also suggested to identify donors who might merit additional support:

- 1 in 5 donors don't speak English, which is a lot, but 5 in 5 donors have psycho-social problems. So, I would say psycho-social support would be at the top. N-07
- Yeah, yeah, yeah. Even a pre-donation assessment, a mental assessment. N-05
- Psychosocial absolutely. Maybe an offer to facilitate a group session with the, I think with the group patient donor if they chose to take it with emotional support would be beneficial long term for the donor. N-03

While not expressed by all TNs, one TN made it clear that she experienced difficulty in communicating with RDs and lacked sufficient confidence in assessing RDs with psychological distress:

- Because I'm not a psychologist, so I don't know what questions to ask. Yeah. And I don't know the cues, as well. Maybe the nonverbal cues that they're giving off. N-05

3.4.2. Education material

Improving the format, content and language of written information provided to RDs as suggested by TNs may help better prepare donors for the donation and transplant. TNs recommended having both web-based and paper-based materials available for younger and older donors. One TN also emphasised that the language should be sensitive to haploidentical donors who are not a full match:

- If you've got some little whippersnapper 20-year old who's technologically savvy, but if you've got a 55-year old … sometimes we'll say to people, "Have you got an email address?" "No, I haven't got that" so you need to go old school and paper-based. We also need to update it around the haplo donors as well. We need to tone down that language because we need to be sensitive to haplo donors now, they're not a full match. N-01

3.4.3. Communication skills training

All TNs agreed they would like additional training in order to provide psychosocial support for RDs. Training focused on communicating effectively was identified as an especially important skill they would like to gain, because TNs often encountered opportunities (face-to-face, telephone or email) to speak with RDs whose recipient had died.

- It would be great if we could bring them and say to them, "I'm so sorry to hear the loss of your brother or sister, how you going with everything?" To be able to have the chat, to probably maybe even have training in that conversation sort of thing. N-01

In this respect, TNs also emphasized the importance of improved education for ward staff working with RDs, in order to minimise any confusion or additional stress that might be placed on RDs. TNs stated that donors often failed to communicate with ward staff looking after their ill-relative as they had limited knowledge of the donation process:

- An opportunity for the staff caring for the patient to further understand what's involved with it for the donor. They're down there looking after the patient, often no idea what the actual process behind the donor is. The donor might ask them questions, they don't know the answers. N-03

4. Discussion

Unlike URDs, RDs are actively involved in the transplant process and witness first-hand the changes in their relative's health. RDs are in a position of fulfilling both family member and donor roles, which may entail psychological vulnerability in that their role differs from that of URD groups. As a duty of care, transplant units must therefore be aware of and respond to the needs of RDs.

4.1. Related donor care issues

Regarding the psychosocial issues faced by RDs, TNs raised concerns about managing family dynamics and ambivalence. A poor relationship with the recipient and/or family members caused potential RDs to be filled with ambivalence regarding their decision to donate. Despite this, some RDs proceeded to donate regardless. The experience of TNs shows that these RDs may have felt pressured or even compelled to donate in the family context. Pressures to donate have been reported in previous publications. Williams et al. (2003) conducted interviews with 17 RDs and explored issues surrounding the decision experience. Nearly half of the donors were asked to donate by the recipient or another relative, giving them little opportunity to refuse.

Given their knowledge that their decision directly impacts the recipient's medical status, RDs may perceive they have no choice but to donate, causing high levels of distress and ambivalence, as expressed by the TNs in our study. The question of whether the decision to donate is really voluntary when the donor is under undue pressure to donate from family members is questionable. In this respect, transplant centres should establish procedures to ensure that family members who are prospective donors are appropriately counselled regarding their right to refuse HLA typing or donation.

TNs also expressed concern regarding RD misperceptions of the donation and transplant process. We were not able to document what information had been given to RDs. However, as this was uniformly reported it would seem likely that the extent of information given was inadequate, poorly communicated and/or not offered in a timely manner (i.e. before consent). Furthermore, the sense of urgency about the decision to donate that can exist once the recipient has been identified as a candidate for transplantation can limit time to access information.

The need for improved preparatory information has been previously raised. Zomerdijk et al. (2018) reviewed 16 studies on the provision of information for RDs. In seven of the studies, donors expressed the need for more information to mentally prepare themselves for donation (Bredeson et al., 2004; Christopher, 2000; Kisch et al., 2013; Pillay et al., 2012; Van Walraven et al., 2012; Wiener et al., 2008; Williams et al., 2003). Williams et al. (2003) found that while majority of donors

received both written and verbal information, 23% of donors received verbal information only. Furthermore, the written information that was provided to these donors was actually produced for transplant patients. This theme highlights an issue of paramount importance which needs to be addressed by all centre undertaking RD transplantation.

Findings from previous publications regarding RDs' preferences for accessing information and support indicate that RDs appreciate prior contact with the hospital and that the information obtained from HPs was helpful as this allowed them to immediately alleviate their concerns (Fortanier et al., 2002; Kisch et al., 2013; Labott and Pfammatter, 2014; Wiener et al., 2008; Williams et al., 2003). In light of TNs' suggestions for improving RD care, we consider that there is a need for improved information before consent. Written information should not only be delivered before consent but also clearly emphasize the voluntary nature of donation and that the RD has the right to refuse HLA typing or donation.

4.2. Role of Transplant Nurses in related donor care

Whilst TNs are equipped to cater to the biomedical needs of RDs, the interviews revealed that TNs also attend to the psychosocial needs of RDs pre- and post-donation. TNs are well placed to provide holistic care and appear willing to deliver psychosocial care for RDs. However, they expressed concern about lack of access to supervision. While they felt supported by their TN colleagues, those colleagues had no more training than did the TNs themselves and medical staff were often preoccupied with medical aspects of transplantation and had limited knowledge of the dynamics surrounding related donation. The scant support leaves TNs to rely on their own experience and judgment in dealing with challenging situations.

A possible explanation for this behaviour is that medical staff might base their care on the assumption that the transplant patient is the suffering person at whom the care is aimed, whereas the RD is a healthy individual (Eriksson et al., 2006; Forsberg et al., 2004). In other words, RDs might be considered as non-patients by medical staff, in contrast to the recipients who are the 'real patient' (Van Walraven, 2015). The medical profession has assumed for a long time that family members are naturally motivated by the prospect of saving the life of a loved one (Switzer et al., 1997). The first transplantation researchers reached similar conclusions; altruistic/humanitarian motives for donating were most commonly reported (Fellner and Schwartz, 1971; Paulhus et al., 1976). However, one must also consider the possibility of negative emotions such as feelings of coercion, anxiety, guilt and responsibility, especially in cases of recipient death. Psychological issues may be difficult to address if the value of RD care management is perceived as being of minor interest by medical staff.

Many TNs in this study perceived difficulty caring for RDs and lacked confidence in their ability to assess and manage complex psychosocial difficulties. This is likely to be a consequence of insufficient training in this area. The International Society of Nurses in Cancer Care issued a position statement on Cancer Nursing Education, stating that "in addition to individual nurses having a responsibility to seek educational opportunities, employers and institutions have responsibilities for a well prepared workforce" (International Society of Nurses in Cancer Care, 2013). An article in The Lancet Oncology Journal (The Lancet Oncology, 2015) highlighted the chronic shortages in nurses worldwide, calling for changes to be made at an educational and legislative level to combat the increasing number of nurses needed in patient cancer care. While the need for educational support is clear, resources and training are currently limited for TNs as this study has shown. Additional support and appropriate training are needed to improve the confidence and ability of TNs to deliver psychosocial care.

There is evidence that communication skills training can have beneficial effects on behaviour change in health professionals working with cancer patients, their families and/or carers (Gilligan et al., 2018; Moore et al., 2004). A brief communication training program for TNs that addresses common issues in RD care using role-play sessions could help TNs gain the appropriate confidence, knowledge and skills to assess and manage RDs. This aligns with guidelines for communication skills training issued by The American Society of Clinical Oncology, which emphasize skills practice and experiential learning using role-play, direct observation of patient scenarios, and other validated techniques (Gilligan et al., 2018). Given the critical role that TNs play in RD care as shown by this study, we encourage transplant centres to consider the value of communication skills based training to improve transplant nursing practice and RD outcomes.

4.3. Adequacy of current related donor care practices

Our findings confirm that structured processes for the ethical and psychosocial management of RDs are currently limited. Consequently, in situations where a donor expresses psychosocial difficulty, the donor is managed differently by different TNs. This variation in practice is undesirable, creates confusion and places TNs at risk of inappropriate practices. The concerns expressed by TNs surrounding reluctant donors and conflicting family relationships illustrate the urgent need for standardised guidelines to ensure RDs' needs are considered and acted upon.

Interestingly, a comparable discussion is being held in the field of living kidney and liver donors, where inconsistencies and lack of concreteness have been observed in the guidelines for the psychosocial screening of donors. Duerinckx et al. (2014) conducted a review of guidelines for the psychosocial screening of kidney and liver donor candidates. The authors found that there was no consensus, nor strong evidence or concrete guidance on what to screen for, how to handle identified psychosocial problems, leading to huge variability in practices and the risk that psychosocial issues might be overlooked. There is therefore a substantial need to further investigate and develop this challenge globally and perhaps across all donor-populations.

4.4. Limitations

The respondents represent a sample from two centres in Australia and as such we must acknowledge that these results may not be representative of practices elsewhere. In addition, the results were obtained among TNs with average 11 years of experience. The results may not be generalised to TNs with less experience, although younger TNs may find the psychosocial requirements of dealing with RDs even more challenging than those with more life experience. The interviews were conducted by the author (NZ) who is also employed at one of the participating transplant centres; this may have influenced participant responses. Whilst the thematic analysis method adopted in this study offers a flexible approach to the analysis of the data, this flexibility means that a wide variety of interpretations could potentially be drawn from multiple researchers. The categorisation of TNs' perspectives into specific themes in order to create a cohesive "big picture" comes at the cost of presentation of the fine-grained accounts of each individual (Braun and Clarke, 2006). Finally, our study is limited by a failure to include the views of RDs and their preferences for support.

5. Conclusion

TNs describe concerns about the informational and psychosocial needs of RDs and the lack of clear referral pathways to access expert assistance. TNs highlight the need for improved RD information prior to obtaining consent, including details of the donation process which emphasizes the voluntary nature of donation and the right of the RD to refuse HLA typing or donation.

TNs are acutely aware of the complexity of balancing urgent treatment for the recipient against the needs of RDs and are well placed to provide holistic care. However they report lack of professional confidence and training to respond to challenges such as complex family

dynamics, donor ambivalence and distress after recipient death. Guidelines for the care of RDs comparable for those currently used by health professionals working with URDs are urgently required.

Further research is also needed to improve RD care. Future studies should prospectively examine RD preferences for information and psychosocial support before, during and after donation. A multi-centre study examining the experiences and perspectives of RDs is currently ongoing.

Declaration of interest

None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2019.05.012.

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