

## ORIGINAL ARTICLE

# Perceptions of experiences of having a sibling stem cell donor

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## ABSTRACT

**Objective:** The aim was to explore stem cell recipients' perceptions of experiences of having a sibling donor from pre-transplantation to one year afterwards in order to support their learning process.

**Methods:** Ten adult recipients, five women and four men, with a mean age of 52 years (19-68 years) receiving stem cells from a sibling donor were included consecutively. We used a phenomenographic approach to analyse the 28 open-ended interviews that took place before transplantation and three months and one year afterwards.

**Results:** Ten categories emerged comprising 110 different perceptions pertaining to: Advantages, Acknowledgement, Risk evaluation, Complexity, Family impact, Non-directed donors, Self-identity, Facing the reality, Knowledge seeking and Caring encounters. Three distinct phases of the learning process were identified from before transplantation to one year afterwards, i.e., risk-benefit analysis, outcome expectations and facing the reality.

**Conclusions:** Before transplantation the recipients had many perceptions about having a sibling donor and focused on a thorough risk versus benefit analysis for both themselves and the donor. Three months after transplantation the recipients sought knowledge in order to have realistic expectations and comprehend their future. One year after transplantation the recipients had few perceptions and focused on facing the reality, irrespective of whether the outcome was good or bad. The generic perceptions of the recipients over time were that serious blood diseases are burdensome and lethal, while treatment should include continuity of care.

**Key Words:** Stem cell transplantation, Sibling donor, Qualitative study, Interviews, Learning process, Phenomenography

## 1. INTRODUCTION

The learning process of recipients of hematopoietic stem cells from a sibling donor has not been studied earlier. In this longitudinal phenomenographic study we explored recipients' perceptions of experiences of having a sibling donor from before transplantation to one year after the procedure.

The rationale behind this study is that allogeneic hematopoi-

etic stem cell transplantation (HSCT) is a strenuous treatment including the risk of severe complications and side effects. Healthcare professionals provide comprehensive information based on their understanding of the recipients' learning process and need for information from an outside perspective. Without knowledge of the recipients' learning process, i.e., how they perceive and understand the phenomenon of receiving stem cells from a sibling donor, there is a consid-

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erable risk that the information provided will include what the healthcare professionals consider important and fail to address the recipients' main concerns.

HSCT is an established treatment with a possibility to cure a variety of diseases, mainly haematological malignancies, with a 1-year recipient survival rate of 70%-80%.<sup>[11]</sup> The number of HSCTs is steadily increasing. In 2015 more than 30,000 HSCTs were performed worldwide,<sup>[2]</sup> 15,000 of which were in Europe.<sup>[3]</sup> Around 280 HSCTs are performed in Sweden each year. In around two thirds of HSCTs the stem cells are donated by unrelated registry donors and in one third by sibling donors. However, HSCT implies significant risks of acute complications, late side effects and even mortality.<sup>[4,5]</sup> It is well known from clinical experience and from the literature that HSCT considerably influences the patient's quality of life (QoL).<sup>[5-7]</sup> The most common complication after HSCT is graft-versus-host disease (GvHD), which directly or indirectly is the major cause of short-term (day 100) mortality. Acute GvHD occurs in 30%-50% of HSCT, usually within the first 100 days, while chronic GvHD occurs in 40%-70% of HSCT and usually occurs after more than 100 days post HSCT.<sup>[8]</sup> Acute GvHD mainly affects the skin, liver and gastrointestinal tract, while chronic GvHD can affect significantly more organs. GvHD has been shown to negatively influence the QoL in long-term survivors of HSCT.<sup>[9-11]</sup>

Knowledge about recipients' experiences of receiving stem cells from a sibling donor is limited. Immediately before HSCT, recipients experience being in a complex situation with various thoughts and emotions, including concerns about the sibling donor.<sup>[12]</sup> During the first year post-transplant the stem cell recipients' main concern is how to recompensate the sibling donor.<sup>[13]</sup>

The most common side effects of stem cell donation are fatigue, headache, bone pain, muscle pain and nausea, which are mainly transient.<sup>[14-16]</sup> Major complications after stem cell donation are uncommon, however, events such as deep vein thrombosis, splenic rupture and cardiac arrest have occurred.<sup>[17,18]</sup> The situation of sibling stem cell donors has only been investigated to a limited extent. The donors are in an exposed position having positive as well as negative experiences; e.g. anxiety, pain, guilt and increased self-esteem.<sup>[19,20]</sup> The HSCT donors' experiences are similar of those of individuals who donate solid organs and stem from a perception that one does what one feels one has to do.<sup>[21]</sup> A recent phenomenographical study reveals that sibling stem cell donors experience a learning process from before donation until one year after the donation, involving motive, obligation, responsibility, preparation, circumstances, recovery and relationship.<sup>[22]</sup> Their perceptions of their experi-

ences change over the first year and by that their need for education, information and support. It is clear that allogeneic HSCT and stem cell donation affect both the patient and the donor. Recipients are concerned about their sibling donor and also experience a sense of dependency and responsibility.<sup>[12]</sup> Thus, it is vital to understand their complete situation and learning processes to be able to provide person-centred information, care and support.<sup>[23]</sup> The aim was to explore stem cell recipients' perceptions of experiences of having a sibling donor from pre-transplantation to one year afterwards in order to support their learning process. The research question was; how do recipients of sibling stem cells perceive the phenomenon of stem cell transplantation based on their experience of receiving stem cells from a sibling?

## 2. METHODS

We applied the phenomenography in nursing research method as described by Sjöström & Dahlgren.<sup>[24]</sup> The starting point was to understand the different perceptions of experiences of having a sibling as donor that emerge and change over time. By identifying the recipients' learning process we can make transplant nurses aware of what topics to focus on during the various stages of the transplantation process. The analysis method was described in detail in Kisch & Forsberg, 2017.<sup>[22]</sup> Phenomenography is the empirical method for exploring the different ways in which people perceive, experience, assimilate, understand and form a conception of various phenomena and aspects of the surrounding world.<sup>[25]</sup> The methodological aim is to explain variations in perceptions of a phenomenon, in this case having a sibling stem cell donor. In phenomenographic investigations it is important to describe the differences and similarities in the perceptions of the experiences.<sup>[26]</sup>

### 2.1 Participants and sampling

During an 18-month period all HSCT patients transplanted with stem cells from a sibling donor at a University Hospital in Sweden were consecutively invited to participate in the study. The inclusion criteria were recipients and the corresponding donors aged 18 years or older with good competence in the Swedish language. When the recipients had their medical investigation and information pre-transplantation, ten recipients were informed about and invited to participate in the study by the first author (AK), and all ten, six women and four men, agreed to participate. The mean age of the recipients was 52 years (range 19-68 years). Demographics and characteristics of the ten recipients are presented in Table 1. All donors to the recipients participated in a corresponding longitudinal interview study.<sup>[22]</sup> The recipients and the donors were cared for by separate physicians and nurses.

**Table 1.** Demographics and characteristics of the recipients

Characteristics	n = 10
Age, years	
Mean age (range)	52 (19-68)
Sex	
Female	6
Male	4
Marital status	
Married/living together	6
Single	4
Diagnosis	
AML	3
NHL	2
MPD	2
ALL	1
CML	1
SAA	1
Stem cell source	
PBSC	9
BM	1
Gender of donor	
Female	5
Male	5
Relationship with donor	
Frequent contact	6
Occasional/no contact	4
Recipient status three months post-donation	
CR, doing well	4
Severe GvHD	5
Deceased	1
Recipient status one year post-donation	
CR, doing well	4
Severe GvHD	5
Deceased	1

*Note.* ALL = Acute lymphoblastic leukaemia; AML = Acute myeloid leukaemia; BM= Bone marrow; CML = Chronic myeloid leukaemia; CR = Complete Remission; GvHD = Graft versus Host Disease; MPD = Myeloproliferative disease; NHL = Non-Hodgkin lymphoma; PBSC = Peripheral Blood Stem Cells; SAA = Severe aplastic anaemia

## 2.2 Ethical considerations

The study was approved by the Regional Ethical Review Board of Southern Sweden (Dnr 541/2007). The participants were informed both verbally and in writing that participation was voluntary and they could withdraw from the study at any time without any negative consequences for themselves or their sibling donor.<sup>[27]</sup> Written informed consent was obtained by the first author (AK) before the first interview.

## 2.3 Data collection

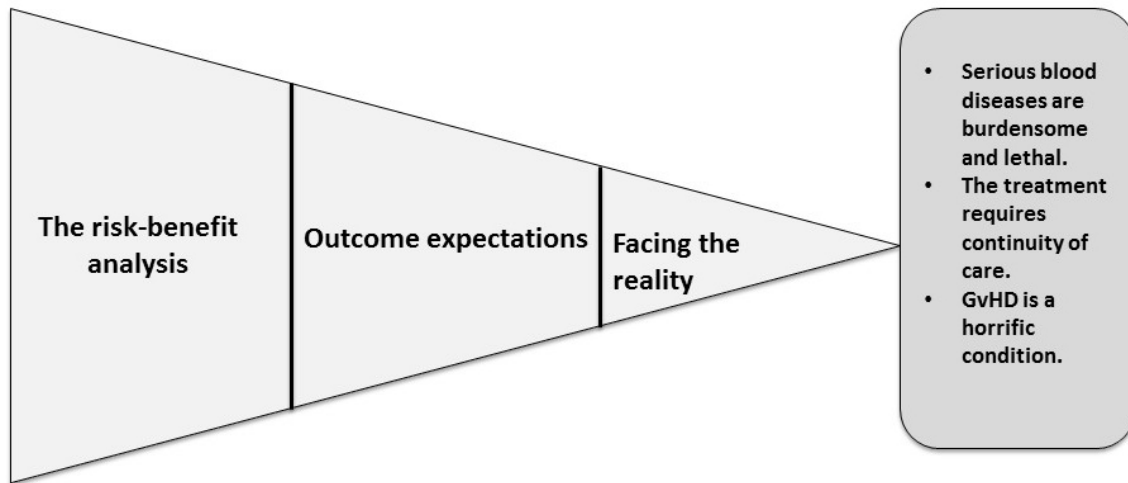
Face-to-face interviews with the recipients were performed by the first author (AK) on three occasions. The first occasion was immediately pre-transplantation, when eight recipients were interviewed on the day of admission, one on the day prior to admission and one eleven days before admission, followed by further interviews at three and twelve months.

The interviewer is a clinical nurse specialist with several years of experience of stem cell transplantation and donation. However, she was not involved in the care of the recipients in this study. The 28 interviews were performed at a time and place chosen by the recipients, mainly in a secluded room at the hospital. One recipient died due to transplantation-related complications just before the three-month follow-up and thus only participated in the first interview.

The interviews began with an open question: "Can you tell me about your thoughts and feelings when you became aware that you needed a stem cell donor for transplantation?" followed by: "What did you feel and think when you were told that a sibling could become your donor?" and "Can you please tell me now, three months/one year after transplantation, what being transplanted with stem cells from your sister/brother was like?" Additional questions were posed to encourage the recipients to expand on their experiences and thoughts about having a sibling donor and also to deepen the information given in the previous interviews. The interviews, which carried on for 14 to 121 minutes (median 53 mins), were digitally recorded and transcribed verbatim. The pre-transplantation interviews were longer than the post-transplantation interviews, while those performed at the one-year follow-up were fairly short.

## 3. RESULTS

The findings are illustrated by ten categories based on the 110 perceptions identified, i.e., Advantages, Acknowledgement, Risk evaluation, Complexity, Family impact, Non-directed donors, Self-identity, Facing the reality, Knowledge seeking and Caring encounters, which are presented in Tables 2-6. The findings are described in a form that is close to the informants' actual statements. The outcome space reveals three distinct phases of the learning process from before transplantation to one year afterwards (see Figure 1). In the risk-benefit analysis phase, the recipients weigh the risks against benefits for themselves as well as for the donor in order to make an informed decision to undergo transplantation. Three months after HSCT their focus is on Outcome expectations, which involves trying to obtain knowledge in order to have realistic expectations and comprehend their future. One year after HSCT, the recipients are Facing the reality, regardless of whether they are doing well or the outcome is poor. Before transplantation there are numerous perceptions about having a sibling donor. However, one year after HSCT there are fewer perceptions with less variation. They perceive that the donor has continued with her/his life and focus on their own situation. The common perceptions among the recipients over time were that serious blood diseases are burdensome and lethal, their treatment requires continuity of care and that GvHD is a horrific condition to endure.



**Figure 1.** The three phases of learning among sibling stem cell recipients from before transplantation to one year afterwards, where an understanding of three key aspects occurred

**Table 2.** Perceptions regarding the benefits of a sibling donor

Domain	Variations of perceptions			Category	Essence
	Pre transplantation	Three months after transplantation	One year after transplantation		
The benefits of a sibling donor	# Receiving stem cells from a sibling is good # Only full siblings can donate # There is a 25% chance that a full sibling is a match # Sibling donation leads to a better prognosis # Sibling donation is the ultimate # If no sibling is a match you have to wait for treatment # Not all siblings are a match # The match with a sibling is better than with an unknown donor	# Receiving stem cells from a sibling is best # It is less complicated having a sibling donor # If you are a man it is better to receive from a brother than from a sister # It is safer receiving from a sibling than from an unknown donor	# It is much easier to have a sibling donor	Advantages	Security

**3.1 Category 1: Advantages**

Perceptions regarding the benefits of having a sibling donor are presented in detail in Table 2. The perceptions were consistent about the fact that having a sibling donor was advantageous. The recipients had many thoughts and perceptions about this pre-transplantation, e.g., that a sibling was the ultimate donor and implied a better prognosis. After three months there were fewer perceptions and even less after one year. All perceptions of the advantages of a sibling donor were based on the sense of security.

**3.2 Category 2: Acknowledgement**

The recipients reported many thoughts and perceptions about the significance of the donation for the donor (see Table 3). The perceptions mainly concerned the fact that the donor was making a huge effort and a great difference, thus she/he should be in focus and acknowledged. Although the perceptions about acknowledging the donor decreased over time, one year after HSCT the recipients still perceived that do-

nation was a major event for the donors and they should be acknowledged. The driving force behind this was that the donor deserves appreciation.

**3.3 Category 3: Risk evaluation**

Before HSCT the recipients thought a great deal about the risks and consequences of donation for the donor (see Table 3). The perceptions varied from donation being demanding and implying extensive medical risks for the donor to donation leading to almost no risks for the donor, all of which was based on their concern for the donor. These perceptions were still present three months afterwards, but were gone after one year.

**3.4 Category 4: Complexity**

The relationship with the sibling donor was of great concern (see Table 4), as was the complexity involved in having a sibling as a donor. These perceptions differed a great deal. Before HSCT the recipients perceived themselves as

dependent on the sibling, that the donation strengthened their relationship and implied being indebted to the sibling. These perceptions were driven by an ambiguity about having a sibling donor. Three months after HSCT there were still many different perceptions, while one year after transplantation the relationship with the donor was of no concern.

**3.5 Category 5: Family impact**

Stem cell transplantation involves the family (see Table 4). The various family members of both of the recipient and the donor were involved and affected in different ways by the situation. These perceptions remained through the first year after HSCT and included a sense of burden.

**3.6 Category 6: Non-directed donors**

Perceptions about receiving stem cells from an unrelated registry donor mainly occurred before transplantation. How-

ever, these thoughts still remained after three months (see Table 4). The perceptions were partly about the knowledge of registries with voluntary, non-directed donors and partly about the fact that it seemed more frightening and uncertain to have an unknown donor. These perceptions were based on looking for possibilities for an alternative if no sibling was available. One year after HSCT no perceptions about non-directed donors were mentioned.

**3.7 Category 7: Self-identity**

Transplantation with a sibling donor involved a degree of vulnerability. In Table 5 we present the recipients' various perceptions about their own situation, responsibility and self-identity in this context. These perceptions were especially evident before transplantation and some still remained three months post HSCT. However, after one year they were gone.

**Table 3.** Perceptions of the donor's process

Domain	Variations of perceptions			Category	Essence
	Pre transplantation	Three months after transplantation	One year after transplantation		
The significance of donation for the donor	# The donor makes a sacrifice # The donor should be in focus # The donor receives a good health check-up # The donor is not left alone during the donation # The donor feels important and useful # The donor should be treated as an important person and that she/he is making a difference # The donation might have to be repeated	# The donor has moved on after three months # The donor needs to know that she/he has been useful # Donation is a huge effort	# Donation is a major event for the donor # It is essential for the donors to let them be the centre of attention	Acknowledgement	Appreciation
Risks and consequences for the donor	# The donation does not involve any major risks # Donation involves some risks # The risks for the donor are small and it is a minor intervention # The donor can get blood clots from the syringes # The donor may suffer from calcium deficiency # Donation is demanding # The donor grows from making the donation	# Donation is not very dangerous # The donor grows from making the donation # Donation is not painless # Donation gives the donor a sense of value # Donation is not risk free		Risk evaluation	Conscience

**3.8 Category 8: Facing the reality**

In Table 6 several perceptions about the disease and the treatment are presented, demonstrating that the recipients faced the reality from before until one year after transplantation. Before HSCT the perceptions were many and multifaceted, including the complexity of donation and transplantation and the risks and advantages of the treatment. After three months all perceptions concerned GvHD. One year afterwards the

main perceptions were about the rehabilitation. All of these perceptions were based on an acceptance of the situation.

**3.9 Category 9: Knowledge seeking**

There were several different perceptions about the information provided to the recipients themselves as well as to the donor and other family members (see Table 6). All perceptions involved knowledge seeking, which was driven by a wish for comprehensibility.

**Table 4.** Perceptions of relationships involved in donation

Domain	Variations of perceptions			Category	Essence
	Pre transplantation	Three months after transplantation	One year after transplantation		
The donor-recipient relationship	# It is complicated having a sibling donor # The contact with the donor becomes closer # The donation means a special bond # The transplantation may lead to dependency # The treatment leads to the reunification of siblings # The relationship will not change # The relationship becomes stronger # The donation implies indebtedness	# It is the disease and not the donation that makes the siblings closer # Receiving stem cells from a donor means being dependent # As a recipient, you feel you are in debt to the donor # A sibling donor makes it easier to deal with the indebtedness		Complexity	Ambiguity
Family involvement	# The donation involves your entire family # It is hard for close relatives # Siblings who are not a match are relieved to escape	# Close relatives are affected by the fact that a sibling donates	# Close relatives have to be involved # HSCT affects children, friends and family	Family impact	Burden
Donation from unrelated registry donors	# There are donor registries all over the world # It is possible to find a solution even if your sibling is not a match # Registry donors donate voluntarily without being related and make an active choice # It is more frightening receiving from an unrelated than from a related donor	# It would have been different with an anonymous donor		Non-directed donors	Possibility

**Table 5.** Perceptions of the recipient’s situation

Domain	Variations of perceptions			Category	Essence
	Pre transplantation	Three months after transplantation	One year after transplantation		
The recipient’s situation and responsibility	# As a recipient, I get the donor’s blood type and immune system # I cannot influence who becomes the donor # It is the recipient’s responsibility to meet relevant healthcare professionals # The recipient should find out how the donor is affected # Being in need of stem cells is a punishment	# As a patient, you have no choice # You cost society a lot of money		Self-identity	Vulnerability

**3.10 Category 10: Caring encounters**

Perceptions regarding continuity of care appeared after transplantation and involved caring encounters (see Table 6). These perceptions did not exist before transplantation but became evident afterwards and were driven by the sense of loneliness during the post-transplant recovery.

**4. DISCUSSION**

**4.1 Methodological considerations and study limitations**

To our knowledge this is the first longitudinal phenomenographic study of recipients of sibling stem cell donors. Phenomenography was chosen as the method for this study since it is the empirical method to investigate different ways persons perceive, experience, understand and conceptualize phe-

nomenon and the surrounding world. In phenomenographic studies the most important finding is descriptions of similarities and differences of what (first order perspective) and how (second order perspective) persons perceive the world.<sup>[26]</sup> The main objective of the phenomenographic method by Sjöström and Dahlgren<sup>[24]</sup> is the exploration of perceptions of experiences of something, not only the perceptions. This means that the respondents’ perceptions are based on the experiences of a phenomenon, in this study having a sibling stem cell donor and the sibling relationship, and that the respondents assign a meaning to the experiences, which forms the perceptions. We argue that phenomenography is the ultimate method for our aim, to explore stem cell recipients’ perceptions of experiences of having a sibling donor

from pre-transplantation to one year afterwards in order to support their learning process, to ensure trustworthiness. In our analysis to define first and second order perspective a

great variations of the recipients' perceptions of experiences emerged, presented in Tables 2-6.

**Table 6.** Perceptions of disease and care related aspects

Domain	Variations of perceptions			Category	Essence
	Pre transplantation	Three months after transplantation	One year after transplantation		
The disease and the treatment	# Stem cell donation and transplantation are extremely complex and a bit experimental # Transplantation implies a lot of chemotherapy # Transplantation is comprehensive # The treatment is not harmless # The treatment is vital # It is a long and protracted treatment # A large proportion of recipients become healthy # It leads to very long sick leave # You will not be fully restored to health # You will never be cured, just feel more healthy # If you are strong you will survive the treatment # The treatment makes you ugly and you lose your hair # Relapse implies new transplantation and chemotherapy # GvHD is complicated and may lead to death # It is good not to participate in the donor's conversation # Written information is very important # It is good for the donor to receive the results of the matching before the recipient # The recipient should not be informed about what the donor is going through # Positive information is important # The maximum amount of information is good # The donor's close relatives should also be informed # Continuous information to recipient and donor is important # Donor and recipient should be kept apart # The donor should be given correct and balanced information # You should not receive information about the donation process # The information should contain survival statistics # Reading too much is not good	# The donors' cells cause GvHD # GvHD means having an additional complex disease # Written information is excellent # It is better to know the details of the donor's process afterwards rather than before # Information about recovery is important # It is important that the donor is updated about the recipient's progress and process # The recipient should be aware of the risks for the donor early in the process	# Blood cancer is a horrific and fatal disease # Exercise programmes should be a natural part of the treatment # Recovery takes a long time # GvHD is good if it is controlled # The patient should be informed about what the donor is going through # Information about GvHD should be given prior to transplantation and at discharge	Facing the reality	Acceptance
Information aspects				Knowledge seeking	Comprehensibility
Continuity of care		# Continuity in the caring relationship is good # As a patient, you have the responsibility to express your needs # Lack of continuity in encounters with physicians is bad	# Continuity in caring relationships contributes to a sense of security # Continuity of physicians is valuable	Caring encounters	Loneliness

Interviewing recipients of sibling stem cell donors over a period of one year can be considered a unique design that contributes to the understanding of their learning process and educational needs. The longitudinal approach made it possible to reveal changes in the recipients' perceptions and learning process. The sample size of ten informants might be considered small. However, it is a common and acceptable

sample size in phenomenographic studies. The fact that 28 interviews were conducted implies a rich amount of data. The transferability is limited because the study was performed in only one country and thus reflects a single caring tradition. Nevertheless, we believe that the recipients' situation does not differ much between countries. All recipients have the same kind of life-threatening disease and being transplanted

with sibling stem cells probably includes similar experiences.

The interviewer's profound pre-understanding from working as a nurse in the HSCT setting for many years could have had an impact on the interpretation and analysis. However, she was not involved in the care of the recipients in the study, while the second author has no experience of this context but extensive experience and knowledge of qualitative research, which ensures the confirmability and trustworthiness of the study.

## 4.2 Discussion of the findings

One of the key findings in this study is the recipients' distinct learning process, which involves three separate phases as illustrated in Figure 1. The identification of a learning process enables the transplant nurse to tailor her/his educational interventions to each phase of the transplantation process. Before transplantation the perceptions about having a sibling donor vary a great deal, while one year afterwards there are fewer perceptions and the recipients focus solely on their own situation. This result is in line with studies on patients going through HSCT and their quality of life. Complications as well as physical and mental problems after HSCT are common and have a great influence on the life of the patients.<sup>[28-30]</sup> During the risk-benefit analysis phase the recipients face uncertainty because they know very little about HSCT. They therefore try to grasp the situation and learn as much as possible to make an informed decision to undergo transplantation. In this phase the perceptions include evaluation of the risk for the sibling donor and the complexity of the donor – recipient relationship, which also was shown in the study by Kisch et al.<sup>[12]</sup> where the recipients expressed great concerns about the sibling donor immediately before HSCT. In this phase the recipients' perceptions also include the meaning of unrelated donation and concerns about self-identity, which includes responsibility. As a consequence, the pre-transplant evaluation should be structured according to the recipients' areas of concern in order to provide the optimum conditions for facilitating informed consent. In addition, the pre-evaluation should start with the questions: What do you know? and What would you like to know? to ensure that the starting point of the educational conversation is the recipient's own knowledge.

In the Outcome expectations phase, the recipients learn about the post-HSCT period to develop realistic expectations and comprehend their future. This phase includes most of the pre-transplant perceptions, but with less variation, indicating a more focused learning process based on less uncertainty.

When one year has passed all the recipients are in the Facing the reality phase, irrespective of the HSCT outcome. At this

time point the perceptions regarding risk evaluation, relationship with the donor and responsibility are gone. Instead, the recipients are focused on their own situation and perceive that the donor has moved on with her/his life. GvHD has previously been shown to negatively influence the QoL of recipients after HSCT,<sup>[9-11]</sup> which was also evident in this study where those suffering from GvHD one year after HSCT had a strenuous time struggling with their overall life situation and health. The fact that they were simultaneously thinking about how to reward their sibling donor probably increased the negative affect on their QoL.

Differences were identified when comparing the findings with the learning process of sibling stem cell donors.<sup>[22]</sup> Before HSCT, the recipients focus on the risk-benefit analysis for themselves as well as for the donor, while the donors focus on their great sense of responsibility for the recipient. Furthermore, the donors did not consider the donation optional and perceived themselves as the recipient's last chance. Thus, information and education about donation and transplantation are essential. Three months after transplantation the recipients focus on seeking knowledge to have realistic expectations about the HSCT outcome and one year afterwards they face the reality, regardless of their condition. After donation and transplantation the sibling donors are instead focused on the outcome, their own follow-up and the relationship with the recipient. One year after HSCT the recipients have a sense of gratitude towards the donor and want to thank her/him while at the same time struggling with their own health.<sup>[13]</sup> At this stage the sibling donors have moved on with their lives and do not wish to be rewarded.<sup>[31]</sup> In the same way as the recipients' and the donors' perceptions of their experiences change over the course of the first year, their need for education, information and support also changes. The knowledge and understanding about their different learning processes enable healthcare professionals in general and transplant nurses in particular to provide person-centred education, care and support.<sup>[23]</sup>

## 4.3 Clinical implications

To improve the recipients' QoL it is essential that the discrepancy between their expectations and experiences is discussed, addressed and followed-up throughout the entire HSCT process by clinical transplant nurses, in accordance with Calman's gap hypothesis.<sup>[32]</sup>

Continuity of care within a sustainable caring relationship is of great importance for these recipients as the diseases themselves are burdensome, where GvHD is an additional serious disease with adverse and long-term problems including frequent disappointments. All of this has an impact on the recipients' families, sometimes including the sibling donor,



who are often heavily weighed down and stressed, which could imply a sense of burden for the recipients. Continuous documentation of the information provided, the educational conversation and the recipients' main concerns is essential for the provision of continuity of care.

#### 4.4 Further research

To verify the result and enable generalization, our findings have to be tested in a larger sample by means of quantitative research. Investigating whether they also apply to recipients of stem cells from unrelated registry donors and to kidney recipients would add valuable knowledge and understanding to clinical care.

### 5. CONCLUSIONS

Persons experiencing HSCT go through a complex learning process with an extensive amount of perceptions that change

from pre-transplantation to one year afterwards. This learning process demands continuity within a caring relationship, where the transplant nurse adapts the education to the various phases of the patients' learning.

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### CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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