Perceptions of experiences of having a sibling stem cell donor

Annika M. Kisch∗1,2, Anna Forsberg2,3

1 Department of Haematology, Skåne University Hospital, Sweden
2 Institute of Health Sciences, Lund University, Sweden
3 Department of Thoracic Surgery, Skåne University Hospital, Sweden

Received: April 13, 2018  Accepted: May 18, 2018  Online Published: May 22, 2018
DOI: 10.5430/cns.v6n4p59  URL: https://doi.org/10.5430/cns.v6n4p59

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 hematopoietic 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-

∗Correspondence: Annika M. Kisch; Email: annika.m.kisch@skane.se; Address: Department of Haematology, Skåne University hospital, Lund, S-221 85 Lund, Sweden.
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%. The number of HSCTs is steadily increasing. In 2015 more than 30,000 HSCTs were performed worldwide,[2] 15,000 of which were in Europe.[3] 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.[4,5] It is well known from clinical experience and from the literature that HSCT considerably influences the patient’s quality of life (QoL).[5–7] 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.[8] 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.[9–11]

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.[12] During the first year post-transplant the stem cell recipients’ main concern is how to recompensate the sibling donor.[13]

The most common side effects of stem cell donation are fatigue, headache, bone pain, muscle pain and nausea, which are mainly transient.[14–16] Major complications after stem cell donation are uncommon, however, events such as deep vein thrombosis, splenic rupture and cardiac arrest have occurred.[17, 18] 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.[19, 20] 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.[21] 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.[22] Their perceptions of their experiences 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.[12] Thus, it is vital to understand their complete situation and learning processes to be able to provide person-centred information, care and support.[23] 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 as described by Sjöström & Dahlgren.[24] 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.[22] 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.[25] 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.[26]

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.[22] 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 anemia

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.[27] 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                                                                 | Pre transplantation | Three months after transplantation | One year after transplantation | Category | Essence          |
|-----------------------------|------------------------------------------------------------------------------------------|---------------------|------------------------------------|--------------------------------|----------|------------------|
| The benefits of a sibling donor | # Receiving stem cells from a sibling is good                                            |                     | # Receiving stem cells from a sibling is best | # It is much easier to have a sibling donor | Advantages | Security         |
|                             | # Only full siblings can donate                                                            |                     | # It is less complicated having a sibling donor |                               |          |                  |
|                             | # There is a 25% chance that a full sibling is a match                                    |                     | # If you are a man it is better to receive from a brother than from a sister |                               |          |                  |
|                             | # Sibling donation leads to a better prognosis                                            |                     | # It is safer receiving from a sibling than from an unknown donor |                               |          |                  |
|                             | # 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                           |                     |                                    |                               |          |                  |

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 donation 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. However, 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      |
|-----------------------------|-------------------------------------------------------------------------------------------|----------------|--------------|
| 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 | Acknowledgement | Appreciation |
| Risks and consequences for the donor | # Donation is a major event for the donor  
# It is essential for the donors to let them be the centre of attention | 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              | # 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        |
| The donor-recipient relationship |                                                                                                                                  |          |                 |
| Three months after transplantation |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |          |                 |
| One year after transplantation   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |          |                 |
| Family involvement               | # The donation involves your entire family  
# It is hard for close relatives  
# Siblings who are not a match are relieved to escape  
# 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  | Non-directed donors | Possibility    |
| Donation from unrelated registry donors | # 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          |
|                                   |                                                                                                                                  |          |                 |
|                                   | # 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              | # 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  |          |                 |
| The recipient’s situation and responsibility |                                                                                                                                  |          |                 |
| Three months after transplantation | # As a patient, you have no choice  
# You cost society a lot of money  | Self-identity | Vulnerability   |
| One year after transplantation   |                                                                                                                                  |          |                 |

#### 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 phenomenon 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. The main objective of the phenomenographic method by Sjöström and Dahlgren 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          |          |                               |
|                      |                          | Facing    |                               |
|                      |                          | the reality |                               |
|                      |                          | Acceptance |                               |
|                      | Information aspects      |          |                               |
|                      |                          | Knowledge | Comprehensibility             |
|                      |                          | seeking    |                               |
|                      |                          |            |                               |
|                      | Continuity of care       |          |                               |
|                      |                          | Caring     | Loneliness                    |
|                      |                          | encounters  |                               |
|                      |                          |            |                               |

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. 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. 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, 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. 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. At this stage the sibling donors have moved on with their lives and do not wish to be rewarded. 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.

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. 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 can 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.

Acknowledgements

We wish to express our sincere gratitude to the recipients who took part in this study and contributed their valuable time and experiences. We also want to thank The Blood Cancer Foundation [In Swedish: Blodcancerfonden] for the financial support, which made it possible to perform this study.

Conflicts of Interest Disclosure

The authors declare they have no conflicts of interest.

References

[1] Sureda A, Bader P, Cesaro S, et al. Indications for allo- and auto-SCT for haematological diseases, solid tumours and immune disorders: current practice in Europe. Bone Marrow Transplantation. 2015; 50(8): 1037-1056. PMID: 25796672. https://doi.org/10.1038/bmt.2015.6
[2] Niederwieser D, Baldomero H, Szer J, et al. Hematopoietic stem cell transplantation activity worldwide in 2012 and a SWOT analysis of the Worldwide Network for Blood and Marrow Transplantation Group including the global survey. Bone Marrow Transplantation. 2016; 51(6): 778-785. PMID: 26901703. https://doi.org/10.1038/bmt.2016.18
[3] Passweg JR, Baldomero H, Bader P, et al. Use of haploidentical stem cell transplantation continues to increase: the 2015 European Society for Blood and Marrow Transplant activity survey report. Bone Marrow Transplantation. 2017; 52(6): 811-817. PMID: 28287639. https://doi.org/10.1038/bmt.2017.36
[4] Ljungman P, Bregni M, Brune M, et al. European Group for Blood and Marrow Transplantation. Allogeneic and autologous transplantation for haematological diseases, solid tumours and immune disorders: current practice in Europe 2009. Bone Marrow Transplantation. 2010; 45(2): 219-234. PMID: 19584824. https://doi.org/10.1038/bmt.2009.141
[5] Pidala J, Anasetti C, Jim H. Quality of life after allogeneic hematopoietic cell transplantation. Blood. 2009; 114(1): 7-19. PMID: 19336756. https://doi.org/10.1182/blood-2008-10-182592
[6] Kisch A, Lenhoff S, Zdravkovic S et al. Factors associated with changes in quality of life in patients undergoing allogeneic haematopoietic stem cell transplantation. European Journal of Cancer. 2012; 48(6): 1356-1365. PMID: 22519415. https://doi.org/10.1011/j.1365-2141.2012.01356.x
[7] Lee SJ, Kim HT, Ho VT, et al. Quality of life associated with acute and chronic graft-versus-host disease. Bone Marrow Transplantation. 2006; 38(4): 305-310. PMID: 16819438. https://doi.org/10.1038/sj.bmt.1705434
[8] Apperley J, Masszi T. Graft-versus-host disease. In Apperley J, Carrreras E, Gluckman E, Masszi T. ed. The EBMT – ESH handbook on haematopoietic stem cell transplantation. Paris: Litoprint; 2012. 216-233 p.
[9] Chiiodi S, Spinelli S, Ravera G, et al. Quality of life in 244 recipients of allogeneic bone marrow transplantation. British Journal of Haematology. 2009; 110(3): 614-619. PMID: 19997973. https://doi.org/10.1046/j.1365-2141.2000.02053.x
[10] Pallua S, Giesinger J, Oberguggenberger A, et al. Impact of GvHD on quality of life in long-term survivors of haematopoietic transplantation. Bone Marrow Transplantation. 2010; 45(10): 1534-1539. PMID: 20228854. https://doi.org/10.1038/bmt.2010.5
[11] Wong FL, Francisco L, Togawa K, et al. Long-term recovery after hematopoietic cell transplantation: predictors of quality-of-life concerns. Blood. 2010; 115(12): 2508-2519. PMID: 20089962. https://doi.org/10.1182/blood-2009-06-225631
[12] Kisch A, Bolmajo I, Lenhoff S, et al. Having a sibling as donor: Patients’ experiences immediately before allogeneic haematopoietic stem cell transplantation. European Journal of Oncology Nursing. 2014; 18(4): 436-442. PMID: 24721180. https://doi.org/10.1016/j.ejon.2014.03.004
[13] Kisch AM, Forsberg A. Patients’ main concerns about having a sibling stem cell donor – a grounded theory study. The Open Nursing Journal. Forthcoming 2018. https://doi.org/10.2174/18744302166012010046
[14] Burns LJ, Logan BR, Chitphakdithai P, et al. Recovery of Unrelated Donors of Bone Marrow: A Prespecified Analysis from the Phase III Blood and Marrow Transplant Clinical Trials Network Protocol 0201. Biology of Blood and Marrow Transplantation. 2016; 22(6): 1108-1116. PMID: 27013014. https://doi.org/10.1016/j.bbmt.2016.02.018
[15] Fortanier C, Kuentz M, Sutton L, et al. Healthy sibling donor anxiety and pain during bone marrow or peripheral blood stem cell harvesting for allogeneic transplantation: results of a randomised study. Bone Marrow Transplantation. 2002; 29(2): 145-149. PMID: 11850709. https://doi.org/10.1038/sj.bmt.1703338
[16] Miller JP, Perry EH, Price TH, et al. Recovery and safety profiles of marrow and PBSC donors: experience of the National
[17] Halter J, Kodera Y, Ispizua AU, et al. Severe events in donors after allogeneic hematopoietic stem cell donation. Haematologica. 2009; 94(1): 94-101. PMid: 19059940. https://doi.org/10.3324/haematol.13668

[18] Pulsipher MA, Chitphakdithai P, Logan BR, et al. Lower risk for serious adverse events and no increased risk for cancer after PBSC vs BM donation. Blood. 2014; 123(23): 3655-3663. PMid: 24735965. https://doi.org/10.1182/blood-2013-12-542464

[19] Kisch A, Bolmsjo I, Lenhoff S, et al. Being a haematopoietic stem cell donor for a sick sibling: Adult donors’ experiences prior to donation. European Journal of Oncology Nursing. 2015; 19(5): 529-535. PMid: 25813531. https://doi.org/10.1016/j.ejon.2015.02.014

[20] Pillay B, Lee SJ, Katona L, et al. The psychosocial impact of haematopoietic SCT on sibling donors. Bone Marrow Transplantation. 2012; 47(10): 1361-1365. PMid: 22343670. https://doi.org/10.1038/bmt.2012.22

[21] Kisch AM, Forsberg A, Fridh I, et al. The Meaning of Being a Living Kidney, Liver or Stem Cell Donor - A Meta-Ethnography. Transplantation. 2018.

[22] Kisch AM, Forsberg A. Sibling stem cell donors’ perceptions of experiences of donation. Clinical Nursing Studies. 2017; 5(4): 23-31. https://doi.org/10.5430/cns.v5n4p23

[23] Ekman I. Person centeredness within health care. From philosophy to practice [in Swedish]. Liber: Stockholm; 2014.

[24] Sjöström B, Dahlgren LO. Applying Phenomenography in nursing research. Journal of Advanced Nursing. 2002; 40(3): 339-345. PMid: 12383185. https://doi.org/10.1046/j.1365-2648.2002.02375.x

[25] Marton F. Phenomenography. Describing conceptions of the world around us. Instructional Science. 1981; 10(2): 177-200. https://doi.org/10.1007/BF00132516

[26] Patton MQ. Qualitative Research Evaluation Methods. 3rd. ed. Sage: London; 2002.

[27] World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013; 310(20): 2191-2194. PMid: 24141714. https://doi.org/10.1001/jama.2013.281053

[28] Bevans MF, Mitchell SA, Barrett JA, et al. Symptom distress predicts long-term health and well-being in allogeneic stem cell transplantation survivors. Biology of Blood and Marrow Transplantation. 2014 Mar; 20(3): 387-95. PMid: 24355521. https://doi.org/10.1016/j.bbmt.2013.12.001

[29] Norkin M, Hsu JW, Wingard JR. Quality of life, social challenges, and psychosocial support for long-term survivors after allogeneic hematopoietic stem-cell transplantation. Seminars in Hematology. 2012 Jan; 49(1): 104-9. PMid: 22221790. https://doi.org/10.1053/j.seminhematol.2011.10.004

[30] Valkova V, Jircikova J, Trnkova M, et al. The quality of life following allogeneic hematopoietic stem cell transplantation - a multicenter retrospective study. Neoplasma. 2016; 63(5): 743-51. PMid: 27468878. https://doi.org/10.4149/neu_2016_511

[31] Kisch A, Forsberg A. The core of stem cell donation – a grounded theory study. The Open Nursing Journal. 2017; 11: 73-83. PMid: 28839511. https://doi.org/10.2174/18744364601711010073

[32] Calman KC. Quality of life in cancer patients – an hypothesis. Journal of Medical Ethics. 1984; 10(3): 124-127. PMid: 6334159. https://doi.org/10.1136/jme.10.3.124