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Family members' life situation and experiences of different caring organizations during allogeneic hematopoietic stem cells transplantation - A qualitative study

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## **ABSTRACT**

The aim of this study was to describe family members' life situation and experiences of care in two different care settings, the patient's home or in hospital during the acute post-transplantation phase after allogeneic hematopoietic stem cell transplantation (HSCT). Data were collected through semi-structured interviews with 14 family members (seven women and seven men). An inductive qualitative content analysis was used to analyze the data. The majority of the family members' ( $n=10$ ) had experiences from home care. The findings show the family members' voice of the uncertainty in different ways, related with the unknown prognosis of the HSCT, presented as *Being me being us in an uncertain time*. The data is classified into; *To meet a caring organization*, *To be in different care settings*, *To be a family member* and *To have a caring relationship*. Positive experiences such as freedom and security from home care were identified. The competence and support from the healthcare professionals was profound. Different strategies such as adjusting, having hope and live in the present used to balance to live in an uncertain time. The healthcare professionals need to identify psychosocial problems, and integrate the psychosocial support for the family to alleviate or decrease anxiety during HSCT, regardless of the care setting.

**Keywords;** allogeneic stem cell transplantation, experiences, family member, home care, hospital care, life situation

## INTRODUCTION

Allogeneic hematopoietic stem cell transplantation (HSCT) is an intensive treatment mainly for patients with hematological malignancies (Gyurkocza *et al.*, 2010). Approximately 13,500 HSCTs are performed in Europe annually, 300 of them in Sweden (Passweg *et al.*, 2013). Because of the complex and intensive nature of the HSCT procedure, most patients need a family member to assist them with their daily living during the HSCT (Beattie and Lebel, 2011).

Traditionally, HSCT has been performed as an inpatient procedure, where the patient is admitted to hospital to receive the conditioning, the donated stem cells, and then remains isolated during the neutropenic phase, approximately two to three weeks post-HSCT (Ringden and Le Blanc, 2005). During this phase, patients experience chemotherapy- and/or radiation-related side effects where fatigue, nausea, mucositis, loss of appetite, (Ringden and Le Blanc, 2005, Bevans *et al.*, 2008) and infection (Ringden and Le Blanc, 2005) are the most common. In addition, graft-versus-host -disease (GVHD) – an immunological reaction- is a major complication that can mainly affect the skin, liver, and the gastrointestinal tract, and is significantly associated with increased morbidity and mortality after HSCT (Gyurkocza *et al.*, 2010). During the acute post-transplant phase (i.e. three months post- HSCT), the patient continues with weekly follow-ups in the outpatient setting. During this phase the patients have an intensive need for support and care due to side effects, and they often need to be re-admitted (Grant *et al.*, 2005).

When Russell and colleagues (Russell *et al.*, 1992) described successful treatment of patients in an outpatient setting, it encouraged the process to implement home care. Since 1998, treatment at home during the early neutropenic phase after HSCT has been an option for patients treated at the transplantation center at Karolinska University Hospital (Svahn *et al.*,

2000). Home care has been reported to be safe and has medical advantages,(Svahn *et al.*, 2005, Svahn *et al.*, 2002, Svahn *et al.*, 2000) and this has been confirmed in other outpatient care settings (Solomon *et al.*, 2010, McDiarmid *et al.*, 2010). Another study showed that regardless of the care setting, patients report a high degree of satisfaction with the care and support given by the staff during the neutropenic phase (Bergkvist *et al.*, 2013) suggesting that home care is at least as satisfying as being treated in hospital.

In the literature, different terms are used for caregivers with a close relationship to the patient: e.g. family caregivers, spouse, family members, relatives, or next of kin. There may be some differences in meaning, but in this study we consider them to be synonymous. However, we define a family member as a person that the patient chooses to be related to, meaning they don't have to be related such as parent-children or partner, e.g. can be a friend (Wright and Leahey, 2009).

Similar to other cancer populations,(Li *et al.*, 2013, Given *et al.*, 2012) family caregivers are often the main source of emotional and practical support for the patient undergoing HSCT, (Beattie and Lebel, 2011) and at home also to monitor the patient in a higher degree. In the context of HSCT in particular, the role extends beyond emotional support to include providing increasingly more complex management of symptoms (Gemmill *et al.*, 2011).

Recently, a study pointed out that family caregivers may be at risk of psychological distress as a result of their role in providing care for a partner undergoing HSCT (Sabo *et al.*, 2013).

Furthermore, it has been reported that caregiver distress is highest before HSCT and decreases over time during the post-HSCT phase. Female gender and a high patient symptom burden are factors that have been shown to be associated with higher levels of distress (Beattie and Lebel, 2011). Thus, an important aspect of care in the patient's home or in the hospital during HSCT is how it influences the daily life of the family members, structure and roles in the family relation. To our knowledge, there is a limited knowledge about family members'

experiences in different care settings during the acute post-transplant phase. Such knowledge is needed when the care system is being changed, to be able to evaluate the care and support given, and to improve the support for family members. The aim of this study was to describe family members' life situation, and experiences of care from two different care settings- in the patient's home or in hospital during the acute post-transplantation phase.

## **METHODS**

### **Setting**

The study was carried out in an urban area with a large transplantation center. The center is the largest of its kind in Sweden, performing approximately 80-90 allogeneic HSCTs every year. It is a regional center for HSCT, but patients from other counties in Sweden and from other countries are also treated there.

### **Home care**

The following criteria must be fulfilled before patients destined for home care could return home after the HSCT: a family member or friend who were able and willing to stay with the patient during treatment at home; the temperature of the hot water had to be at least 50°C; no pets or potted plants were allowed; the bed linen used by the patient had to be laundered three times a week; and the patient's home had to be within one to two hours' driving distance from the center. During the early neutropenic phase, patients in home care were visited and cared for on a daily basis by experienced nurses from the transplantation center, and each afternoon a physician called the patient to check his/her well-being, and to make appropriate modifications regarding examination, treatment, and medication. If there were any signs of unstable vital parameters that cannot be taken care of at home, the patient were re-admitted to the transplant center (Svahn *et al.*, 2002).

## **Hospital care**

Patients treated in hospital were isolated in laminar- airflow rooms, they were allowed to have a family member or friend with them around the clock and after 6pm they were allowed to go outside the hospital. The Swedish Social Insurance system supported the family members, i.e. gives benefits for the care of a closely related person. This means that the family member could be off work with financial support based on annual income and on the extent to which he/she were working (Socialdepartementet, 2010).

## **Sample and data collection**

A descriptive qualitative design was used. Interviews were conducted with a total of fourteen participants, during the period May to November 2012. Participants were recruited through an earlier study (unpublished) with patients who received an HSCT. Patients were asked to nominate a family member who assisted them with their daily living and provided the researcher information on how to contact the family members. Inclusion criteria regarding choice of family member for a patient were: member of the patient's immediate family, over 18 years old, read, speak and understand the Swedish language. Furthermore, the interview had to take place within six months after the HSCT. A letter about the study was sent out by the first author (KB). The family member was contacted by telephone to ask whether he/she was interested in participating in the study. The first author is a registered nurse with considerable experience of hematology and oncology nursing, and did not contribute to the care of the participants or the patients.

All participants were interviewed by KB at a time and place chosen by the participant. An interview guide was developed regarding decision about the care setting, contact with healthcare staff, the family member's role in the care given, their relationship with the patient, and the participant's own health and life situation. The participants were asked to describe

their experiences regarding these areas during the acute post-transplantation phase. During the interviews, questions were followed up such as: “what do you mean?” or “please could you describe this in more detail?” A pilot interview was conducted to test the interview guide, but this was not included in the study due lack of the inclusion criterion “member of the patient’s immediate family”. Field notes were collected after each interview. The recorded interviews were immediately listened through to get an immersed knowledge of the data, and saved for future reference. The interviews with the family members were conducted between 4 -16 weeks after the patient’s HSCT, and lasted for an average of 94 min (range 35-136 min). All interviews were recorded electronically with the participant’s consent and transcribed verbatim.

### **Data analysis**

The analysis started with several readings of the transcribed text in order to search for meaning and a deeper understanding of the entire text (Graneheim and Lundman, 2004). The interviews were analyzed with a qualitative inductive content analysis with open coding, and creation of subcategories. Abstraction and interpretation of the data (generic and main categories) was done as far as was reasonable and possible (Elo and Kyngas, 2008) to express the latent content of the text (Graneheim and Lundman, 2004). To strengthen the trustworthiness in the analysis, a comparison was made with four of the transcript subcategories, by three of the authors (KB, JL, BF) and consensus was reached by discussing the categories in relation to the transcript. The main category, all the generic categories and subcategories were discussed extensively between all authors (Table 1).

### **Research ethics**

Participants were given written and verbal information outlining the study, the voluntary nature of their participation, and their right to withdraw. They were also made aware that

confidentially would be preserved and that quotations from the interviews would be formulated in such a way to protect participants from being identified. Written consent was obtained from all participants. The Regional Ethical Review Board approved the study (Dnr 2010/1531-31/2).

## RESULTS

### Participants

Fourteen family members (7 male and 7 female) participated in the study. The median age of the participants was 54 (range 34-77). Most of the participants ( $n = 10$ ) were wife/husband/partner to a HSCT recipient. The majority ( $n = 9$ ) had a university degree and were working ( $n = 10$ ). Ten of the participants had experience of home care during the acute post-transplantation phase (Table 2).

The analysis resulted in one main category *Being me being us in an uncertain time*. Furthermore the analysis resulted in four generic categories *To meet a caring organization*, *To be in different care settings*, *To be a family member* and *To have a caring relationship* with subcategories presented in Table 1.

### **Being me and being us in an uncertain time**

The family members were living in an uncertain time of their life reflects the family members' experiences of the overall unknown prognosis of the HSCT- and the invasive, life-threatening nature of the treatment itself. The family members gave a voice related to live in an uncertain time in different ways.

### **To meet a caring organization**

Although the focus from the healthcare professionals was on giving care and support to patients, the *received support* was a strong component in the interviews with the family members. One participant, however, expressed the feeling of receiving support indirectly, i.e., by seeing the care and support given to his wife, he also felt cared for.

The need for specified competence is necessary for the healthcare professionals who work in the transplantation settings. Participants described the *significance of competence* in the healthcare team, and the high quality of care given made them feel *confidence* both in the team and in the HSCT.

*First and foremost, they have a kind of talent for expertise. You know they are good, there is no worry. I've never been worried when they have treated my wife. There is a security that they know they don't need to talk about, but they give it out; it's there, the security of professional competence. I relax completely... I've done it from the first moment ... they know what they are doing.*

To experience the enthusiasm, empathy and humor of the healthcare professionals working in the transplantation center was part of *different personal characteristic* were expressed to be unique for this center, and person-centered care was also experienced.

*I participated. They asked me and I asked them questions. We had a nurse at home; she was absolutely fantastic. I must say, absolutely wonderful. She just blended in. Suddenly she was there and we would have a stranger in the house, but there were no problems.*

Going through the HSCT, means meeting the healthcare team over a long period of treatment in hospital, or at home and in the outpatient clinic. They felt that the healthcare team was there for them and was genuinely interested in them, as persons, not only as family members and this was a base for *a good relationship*.

### **To be in different care settings**

The majority of family members had experiences from home care. Decisions about home care were discussed within the family; often the patient had the final “decision”. *Being at home* during the early neutropenic phase meant some preparation at home such as cleaning the house, store potted plants and checking the temperature of tap water. Families had pets that had to be cared for during isolation, and during the post- HSCT period. The home care nurse visited the homes to check the housing standards and went through the specific guidelines on hygiene and isolation. Sometimes families chose a special room for the patient to spend most of his/her time during isolation. Family members with home care questioned whether they would manage if the patient became ill? The participants were aware that they should not be involved in any medical or nursing care. On the other hand, some family members described situations of complex assessment of the patient’s health.

*Sometimes I felt that the next morning was far away, if something happened or if she was feeling bad, but then you could always call and ask. That's the advantage of the hospital, because they are always there. Sometimes I hesitated, wondering if she had to feel this bad. Like when she had a splitting headache or had bad nausea for a while. Then I thought that maybe it was something I needed to check more often. We hardly dared to go to bed at night as, I mean it was many hours between going to bed until and waking up*

Positive things being at home were described as freedom and being able to live a normal life. They saw how the environment at home strengthened their partner and for their own part, they did not have the pressure to travel to the hospital on a daily basis. They felt safe at home

because of the support, mainly from the home care nurse. The close distance from the hospital was described by family members at home as safe, in case if the health status of the patient deteriorated they returned to the hospital.

*Of course you wondered how it would be to be at home. It felt good, because they said that if something were to happen than he could go back. If we realize after two days that we do not want to be home, he can come back to the hospital, 'cos he had a bed there. I'm very pleased that he has been at home. I think you get well faster if you are at home. It feels like that, because he has get up and walk, as we have stairs at home.*

Few negative aspects of home care were expressed. Due to shortage of staff patients had to stay or visit the hospital not for medical reason. The patients received the conditioning and the donated stem cells in hospital. A few patients continued to stay in hospital during the neutropenic phase because, they were from other counties or they could not return to home care due to severe side effects. Neutropenic fever, infection, or pain was reason for patients in home care to be re-admitted. Family member expressed that this was expected and as soon it was medically safe, the patient returned home again. *Being in hospital*, a negative aspect was the lack of supportive environment, but they were always welcome to stay with the patient around the clock.

*Knowing how to live with the specific guidelines* at home and in hospital was described by family members. Family members in home care also described the importance of following them, but that they were also difficult to live up to sometimes. Families with younger children described them as a risk factor for infection. Children in kindergarten/daycare had to stay at home during the isolation period. Living under isolation had little effect on the family members, because they knew that this was supposed to be for a limited time. Isolation, the increased risk of infection for the patients, and their health status were reasons for a reduced social life with friends.

*We decided when we got this chance that we would follow them (the guidelines) to the letter. We would in any case not be able to go back and say that if we had not done that, then maybe would have gone well. So we've been really good. I think we were so focused; we had to (do it)! One cannot throw away such a chance.*

The family members' *responsibility* was described in different ways. Family members described taking an active part in the support to the patient regardless of care setting, although to a greater degree in home care. In hospital, family members had a more passive role and they concentrated on being a good companion. Family members in home care took care of the

household, prepared food, cleaned, and checked the well-being of the patient. They stated that the briefing given to them was not to be involved in any healthcare duties. However, one family member had to handle an intravenous infusion and felt confident performing that task a few times. Family members described their part in helping the partner to be in a better mood.

*It was very clear to me- my role in home care. I took care of the home and made sure that everything would be in good condition and work for him when he was isolated. It was very much my role.*

### **To be a family member**

They described their *approach* to HSCT and to the patient in their own unique way. A common strategy among the family members was to let the patient be in charge and they adjusted their life in relation to the patient's health status. For some of the family members, this was a way to *manage* the situation.

*He is more pedantic than I am, so he could say anything like.... "Do you know?", I was not annoyed, but I just tried to be just like him on board this boat, from the abyss somehow. We could laugh about it. He got to decide everything and normally I can be really annoyed if this happens to me, but in this case it became very peaceful for him. He was the captain. Sometimes I could say .." I see you have lot of pain" but I couldn't say it too often, or "how are you", I had to think about what I was saying.*

The need for one's time was expressed as being important- like running tour, writing, having an old routine, to have some routine at home but also for the family members staying in hospital. *To manage the HSCT*, the support from friends, neighbors, and work colleagues was essential for all family members. Meeting other family members with the same experiences was expressed as an unexpected source of support. Altogether this was *the supporting surrounding*.

*My jogging has been like meditation -to be able to be alone, yet not think of anything. Cos when you go to bed ... thoughts could come ... things that you have no control over, but when I run, I am with myself, it's just me and I don't think about anything .It has probably been my escape, where you can turn off completely although you are awake. I started working pretty quickly. I am so thankful we have great friends and neighbors who have taken care of the children and cooked dinner when I came home. It has been delightful, that so many people could be so wonderful, and that got me to manage everything ... ..... .it is really important you dare to let people help you ... I'm the kind of person who thinks that I can handle it myself, or I do it by myself, but I started to asked for help*

Gratitude was expressed as having the opportunity to go through the HSCT (for some patients the last hope for cure), but also many feelings of uncertainty. The majority of the family members felt a strong hope for cure. To live during the HSCT trajectory led to trying to take one day at a time and see the good things in life, analyzed as *to live here and now*. When interviewed, some had changed their life values and asked themselves what was important in life.

*We have received so much that is positive as individuals, all of us who have gone through this. We have been enriched by more than has actually been taken out of us. So far..... I have really realized, or really understood -it sounds pathetic- but I could put other thoughts aside and more begin to grasp what it really means to live - life. I would never have changed my work, for example, if this hadn't happened. It was something I had been thinking about for a while. But I have appreciated what is the little in life that means something, and it's, I intend to work more on it and yes, here and now*

Family members with children also expressed the effects of HSCT on the children, and the importance to involving them in the HSCT process in their own circumstances. Because of the patients' poor health, the family member took all responsibility for the family.

The majority of the family members described the possibility of *being able to work* during the neutropenic phase as something positive. Family members in home care, received sickness benefit quality income for care of closely related person from the Social Insurance system. To be able to have contact with their work was expressed as a "lifeline" and a sign of normal life. It was of great importance that the participants had work that was flexible, i.e. by agreement with their employer, they could decide when and where to work.

*Now I have the privilege of being able to work from home; I have taken out this related payment. I have tried to use as few days as possible, as you never know what is going to happen. .. My working days are sort of should I say, with one leg at work and the other at home as a caregiver.*

### **To have a caring relationship**

Family members often described their *relationship* as being changed but mostly in a positive way, with signs of a stronger relationship. The responsibility for the relationship was expressed as being equal. In contrast, expressions as their relationship became a "care relationship" were expressed. Issues of when will "we" return to a normal relationship that they had before the HSCT were raised.

*Our relationship has become stronger during this period, but at the same time it's becoming an ill-healthy relationship. I am healthy and take care of her and she is sick and needs help, so we're not like husband and wife. It gets more like I'm a caregiver but you grow into such a role.*

The majority of the family members had an intimate basis, acquired through the years of their relationship, and many referred to "we" (*we are ill and we manage the HSCT*). The patient's health often involved rapid and uncertain fluctuations, and the family members themselves felt the "ups and downs". Seeing their partners with side effects made them physically ill, and they worried a lot. Physical symptoms such as heart rush; skin rash and gastric problems were reported by the family members. The uncertain outcome led to worries and anxiety at different stages in all family members.

They also stated that their views on health and illness had altered, due to fact that the patient's health could rapidly change. Their good conditions like good financing, the right time in life to be ill was expressed to be in advantage to manage the HSCT.

*I feel - what he's feeling ..... that's it. So when I come home, he has had a few days when he's been very tired. Then I get gastritis directly, because then I go around and wonder: damn now there's something going on in his body. We feel all along, I would almost say. Because this is something you do, hopefully that, living in a situation such as we do. If we decide, this we will do, as a sick person you need to involve family members too, because if you don't ... you won't cope*

Thoughts about *the uncertain future*, the family members raised concerns about the long recovery period. There were still many restrictions in their life when interviewing, and the health of the patients often changed rapidly and made it difficult to plan for the future, both in a short term and in the long term. It was also too early to know the overall outcome of the HSCT. Feelings of uncertainty were expressed by all family members, due to the fear of relapse and whether it would be possible to have another HSCT. Finally, thoughts about the fact not knowing if the HSCT was a curative treatment.

*It's there presumably, little residue, and what they find remnants of, knows neither the doctor nor we. It could have been better in the sense, that she had been cured. I had hoped everything was completely gone, but now it's not. But then it's a pretty positive picture with, except just that ..... maybe it was not a curative treatment. But we have at least probably postponed the whole process, and then you can get another chance with other medication. So on one hand you can see: this has gone well and on the other hand I don't know so much about the future.....*

## DISCUSSION

The main finding from this study *Being me and being us in an uncertain time* shows the complexity of HSCT and its impact on family members living with uncertainty within different areas for an indefinite period. Several studies (Cooke *et al.*, 2011, Bishop *et al.*, 2011, Bevans *et al.*, 2010, Siston *et al.*, 2001) have described the psychological effects on the family members during the acute post- transplantation phase after the HSCT. The uncertainty for the family members in our study was profound, and was expressed in thoughts such as; “*will it work?*”, “*will the treatment succeed*” or “*will my partner survive?*” Family members have earlier described the HSCT as “*riding a roller-coaster in the dark*” (Wilson *et al.*, 2009). In this study, some family members also raised the question “*will I be able to manage my partner at home during the neutropenic phase?*”

Penrod has defined uncertainty as a discomfoting state that is mediated by feelings of confidence and control. One way to reduce uncertainty is to create a new normal in which control and confidence are increased (Penrod, 2007). To manage their uncertainty, the family members in this study adjusted their life according to the patient’s health status, took time for them, managed to have routines in the daily life, and tried to live in the here and now, presented in *To be a family member*.

In the early post-HSCT recovery, uncertainty has been reported by family members, (Sabo *et al.*, 2013, Langer *et al.*, 2003) especially in the long term (Bishop *et al.*, 2011). Our findings confirm this, and the healthcare team should pay more attention to identifying and supporting the family members. Further, uncertainty has been reported to have a great impact on caregiver burden (Cooke *et al.*, 2011). Caregiver burden has been defined as a multidimensional, bio-psychosocial reaction from an imbalance of care demands in relation to caregivers’ personal time, social role, physical and emotional states, and financial resources. All this can result from the stress of providing care and it may manifest as feelings of

loneliness, isolation, and fearfulness (Given *et al.*, 2004). In this study, we did not specifically study caregiver burden; instead, the family members were asked to freely share their negative and positive experiences regarding the care and their own life situation. Furthermore, in this study the majority of family members were involved in home-based care. Data were also collected in the acute post-transplantation phase; the family members' relatives had had the HSCT with a range from 4-16 weeks previously. In the general oncology population, caregiver burden has been identified as a good predictor of depression in family members (Rhee *et al.*, 2008). In the future, it would be of interest to investigate with a prospective longitudinal design, whether there are any differences in caregiver burden between family members involved in home care and those involved in hospital care.

Uncertainty was also expressed because of the health of the patient was unpredictable and conditions could change rapidly, leading to fear in the daily life. This made it difficult to make plans- both in the short time and for the future, earlier described (Sabo *et al.*, 2013, Wilson *et al.*, 2009). The uncertainty that arises along the HSCT-trajectory and its effect on the family members has been reported to give a poorer life satisfaction (Cooke *et al.*, 2011).

To be isolated during the HSCT has earlier been described as a negative experience that leads to a reduced social life (Wilson *et al.*, 2009, Aslan *et al.*, 2006, Siston *et al.*, 2001). In the present study, the majority of the family members were at home, so the isolation was experienced for a limited time and be able to be at home was therefore a sign of a normal life. The positive effect to be at home and living a normal life has been reported (Holmberg *et al.*, 2012). Roush and Cox stated that the meaning and function of home can be described as a familiar place for comfort, as a center for everyday experience, time and social life, and as a protector of privacy, identity, and safety (Roush and Cox, 2000). Feeling secure at home has further been linked to know that the healthcare team will support the family caregiver (Stajduhar *et al.*, 2008). The home can be the best place for care because of the familiar

surroundings, the maintenance of daily activities, and preservation of self-esteem and dignity (Holmberg *et al.*, 2012). This result is derived from *To be in different care settings*.

The family members in this study described in different ways how their health was affected, and symptoms of distress occurred. Sabo reported that a third of family caregivers showed signs of depression (Sabo *et al.*, 2013). During the acute transplantation phase also appears to be a time for a high degree of distress in family members (Sabo *et al.*, 2013, Fife *et al.*, 2009). The negative effects on the family members can be explained by protective buffering, which refers to a social support phenomenon in which one in the relationship attempts to minimize the stress of the other in certain situations (Hagedoorn *et al.*, 2000). Langer showed that family caregivers buffered the patients more than the patients buffered their family caregiver, which led to poorer mental health (Langer *et al.*, 2009). Finally, family caregivers with experiences of combined care settings have shown less anger, anxiety and fatigue (Grimm *et al.*, 2000).

Family members and patients each contributes to the quality of life of the other were evident in *To have a caring relationship*. Thus, caring for family members is likely to have a positive effect on the person who is receiving care. Interventions to help family members structure the uncertainty should be developed further and tested. Limited interventions such as education, psychosocial support, and self-care for the family caregivers of HSCT recipients have been reported (Gemmill *et al.*, 2011). Recently, it has been showed that caregivers participating in a problem-solving form of education during HSCT period increased their self-efficacy and they had reduced symptoms distress (Bevans *et al.*, 2014). Because the family member has the highest distress in pre-transplant period (Beattie and Lebel, 2011) we suggest that they would benefit from more targeted support during this phase, to boost them to prevent and handle the uncertainty during the HSCT. In this study the family members described support, competence and a good relationship as *To meet a caring organization*. But as the uncertainty was so

evident the care for the family members has potential for improvements. The HSCT coordinator and/or the home care team should work close to both the patient and the family member, and should- as a routine before HSCT -assess caregiver well-being, caregiver burden, and the need for support. Integration of caregiver assessment concurrently with patient assessment might be helpful in identifying those family members who are at risk of psychological distress and caregiver burden in order to implement interventions of support. Because of the long trajectory of HSCT treatment and recovery, frequent reassessment and flexibility in individual intervention are needed (Gemmill *et al.*, 2011).

Although the aim of this study was to enhance our understanding of family members' experiences of care settings and their own life situation, the sample limits the ability to extend the findings beyond this study group, as we know that our type of home care and outpatient (Solomon *et al.*, 2010, McDiarmid *et al.*, 2010) care are performed differently. We believe that larger studies following family members over an extended period will be necessary to more fully understand the nature of being a family member during HSCT.

By presenting details of the setting, participants, data collection, analysis, and by choosing representative quotations from interviews, (Elo and Kyngas, 2008, Graneheim and Lundman, 2004) we allowed the reader to confirm or reject the credibility and transferability of the result of this study. The family members were selected by the patients; however there were additional persons labeled as family members in the sphere of the patients, who did not participate in the study. This raises questions about family members who were not asked to participate, and whether their stories or other patterns might have emerged in the findings. On the other hand, one of the inclusion criteria was to have experiences from the care setting the patient had been in, and our aims were to gain more knowledge about the most responsible family members. The inability to recruit family members from culturally and ethnographically diverse backgrounds may have adversely influenced the results. Including culturally diverse

groups might have been helpful in understanding the caregiving experiences and highlights if specific resources of support were needed. We note the equal gender distribution of our sample. An advantage we have identified was that the interviewer was a nurse and created an atmosphere of safety. This may have led that the participants felt freely to share their experiences and gave rich statements. The author's different pre-understanding, contributed to critical reflections and analysis which add to trustworthiness.

## **CONCLUSION**

The findings contribute to our understanding of family members' experiences of different care settings and their life situation during HSCT. The uncertainty associated with the HSCT has been highlighted in this study. Family members are involved in complex patient support during the HSCT trajectory. Positive experiences of home care such as freedom and security were identified. Finally, the importance of meeting a professional caring organization during the HSCT was expressed.

Based on our findings, nurses in the transplantation team can play a key role in identifying psychosocial problems and supporting family members - alone or together with patients - to prevent uncertainty throughout the HSCT trajectory, regardless of the care setting.

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