



<http://www.diva-portal.org>

Postprint

This is the accepted version of a paper published in *European Journal of Cancer Care*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Bergkvist, K., Fossum, B., Johansson, U-B., Mattsson, J., Larsen, J. (2017)

Patients' experiences of different care settings and a new life situation after allogeneic haematopoietic stem cell transplantation.

European Journal of Cancer Care

<https://doi.org/10.1111/ecc.12672>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:shh:diva-2614>

Patients' experiences of different care settings and a new life situation after allogeneic hematopoietic stem cell transplantation

Bergkvist Karin, PhD, RN ^{1,2}, Fossum Björn, Professor, RN ^{1,3}, Johansson Unn-Britt, Professor, RN ^{1,3}, Mattsson Jonas, Professor, MD ^{4,5}, and Larsen Joacim, PhD, RN ⁶

¹Sophiahemmet University, Stockholm, Sweden.

²Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden.

³Department of Clinical Science and Education, Södersjukhuset, Karolinska Institutet, Stockholm, Sweden.

⁴Center for Allogeneic Stem Cell Transplantation, Karolinska University Hospital Huddinge, Stockholm, Sweden.

⁵Department of Oncology and Pathology, Karolinska Institutet, Stockholm, Sweden

⁶The Red Cross University College, Stockholm, Sweden.

Correspondence: Karin Bergkvist, Sophiahemmet University, P.O. Box 5605, SE-114 86 Stockholm, Sweden. Telephone + 46 8 406 29 56, E-mail karin.bergkvist@shh.se

Sources of funding: This study was funded and supported by grants from Sophiahemmet University, the Swedish Blood Cancer Society, and the Swedish Nursing Society.

ABSTRACT

Over the past 20 years, considerable health care resources have shifted from an inpatient to an outpatient setting. To be in an outpatient setting or at home after allogeneic hematopoietic stem cell transplantation (allo-HSCT) has been shown to be medically safe and beneficial to the patient. In this study we describe patients' experiences of different care settings (hospital or home) and a new life situation during the acute post-transplant phase after HSCT. Semi-structured interviews were conducted with 15 patients (six women and nine men) 29-120 days after HSCT. An inductive qualitative content analysis was performed to analyze the data. The analysis resulted in four generic categories: *To be in a safe place*, *To have a supportive network*, *My way of taking control*, and *My uncertain return to normality*. The findings showed that patients undergoing HSCT felt medically safe regardless of the care setting. The importance of a supportive network (i.e. the health care team, family, and friends) was evident for all patients. Both emotional and problem-focused strategies were used to cope with an uncertain future. Being at home had some positive advantages, including freedom, having the potential for more physical activity, and being with family members. The study highlights some key areas thought to provide more personalized care after HSCT.

Keywords: acute post-transplant phase, allogeneic stem cell transplantation, content analysis, home care, hospital care, patient experiences.

INTRODUCTION

Allogeneic hematopoietic stem cell transplantation (HSCT) may offer an option for cure and prolonged survival for many patients suffering from hematological malignancies.

Nevertheless, it is one of the most intensive forms of cancer treatment (Gyurkocza *et al.*, 2010). During the past decade, the toxicity and mortality associated with HSCT have been reduced due to several improvements (e.g., better genomic tissue typing, individualized pre-treatment, better treatment of infections, and improved supportive care). The number of patients eligible for HSCT has increased as a result of these improvements (Remberger *et al.*, 2011). The latest survey from the European Society of Blood and Marrow Transplantation (EBMT) reports that approximately 15,700 HSCTs are performed in Europe annually (300 in Sweden) (Passweg *et al.*, 2014)

Traditionally, the transplant process starts when the patient is admitted to the hospital to receive conditioning therapy and donated stem cells. The patient is then kept isolated during the pancytopenic phase, lasting approximately 2-3 weeks after HSCT, to await engraftment of the donated stem cells, i.e. the new hematopoietic system (Ringden and Le Blanc, 2005).

During this phase, patients will likely experience multiple side effects (e.g., fatigue, nausea, mucositis, pain, and loss of appetite) related to the chemotherapy, radiation, or both (Ringden and Le Blanc, 2005, Bevans *et al.*, 2008). Neutropenia and disruption of anatomical barriers as a result of mucosal damage and vascular intravenous devices alter the risk of infections during this phase (Ringden and Le Blanc, 2005). In addition, a major complication is acute graft-versus-host-disease (GVHD), an immunological reaction of donor immune cells. Acute GVHD usually develops within the first 3 months after HSCT and mainly affects the skin, the liver, and the gastrointestinal tract. Acute GVHD is significantly associated with increased morbidity and mortality after HSCT (Gyurkocza *et al.*, 2010).

When engraftment occurs, patients are discharged from the transplantation unit; during the rest of the acute post-transplant phase (i.e. the first 3 months after HSCT), the patient continues with weekly follow-up (i.e. 2-3 times/week) in an outpatient setting. During this phase, psychological distress and negative moods due to anxiety and depression are common (Pidala *et al.*, 2009). The risk for GVHD and the symptom burden makes supportive care and surveillance as well as reducing the burden of symptoms important treatment goals for health care professionals in the post-transplant period (Grant *et al.*, 2005).

In HSCT treatment in particular and in cancer treatment in general there has been a major shift over the past decades from care in a hospital setting to treatment and care for selected patients in outpatient settings, including the patient's home. The rationale underlying this shift has been described as the desire to improve patient experiences and quality of life, to avoid unnecessary hospitalization, to rationalize the use of hospital beds, and to improve cost-efficiency (Sive *et al.*, 2012). In 1992, Russell and colleagues reported some successful results of allo-HSCT treatment in an outpatient setting without protective isolation (Russell *et al.*, 1992). This finding served to motivate the implementation of home care at our center. Since 1998, selected patients at our unit have been offered treatment at home in the early neutropenic phase after allo-HSCT (Svahn *et al.*, 2000). Results have shown that home care is safe and even has several medical advantages (Svahn *et al.*, 2005, Svahn *et al.*, 2002, Svahn *et al.*, 2000). Some of the results from our center have been confirmed in other studies of outpatient care after allo-HSCT (Solomon *et al.*, 2010, McDiarmid *et al.*, 2010).

In an previous paper (Bergkvist *et al.*, 2013) we reported that, irrespective of care setting (i.e. home care or hospital care), patients were highly satisfied with the care and support given by the health care professionals during the pancytopenic phase, indicating that home care is at least as satisfying as being treated in a hospital environment. Thus, an important aspect of care in the patients' home or in a hospital setting during allo-HSCT is how it influences their

daily life during the acute post-transplant phase. One question concerns the pros and cons with these two care settings. Such knowledge is needed to be able to evaluate the care process and to further improve patient support. The aim of this study was therefore to describe patients' experiences of different care settings and life situation during the acute post-transplant phase after allo- HSCT.

METHODS

Setting

The study was carried out at a transplantation center in Sweden, located at a university hospital in a city that performs approximately 80-90 allogeneic HSCTs every year. It is a regional center for HSCT, where patients from other counties in Sweden and from other countries are also treated. Before HSCT, patients who fulfilled the criteria for home care had the opportunity to choose between hospital care and home care during the pancytopenic phase (Svahn *et al.*, 2002). The conditioning and stem cell intravenous infusions were administered in hospital in which all patients received conventional prophylaxis against bacterial (Olsson *et al.*, 2010) and fungal infections (Forslow *et al.*, 2010) associated with GVHD. Most patients who chose home care went to their homes on day 1 after HSCT. After discharge, all patients were treated at the outpatient clinic.

For home care, the following criteria had to be fulfilled: having a family member or friend who was able and willing to stay with the patient during the entire treatment at home; the temperature of the hot water had to be least 50°C; no pets or pot plants were allowed in the home; the bed linen used by the patient had to be laundered at least three times a week; and the patient's home had to be within 1-2 hours driving distance from the center. The home care nurse informed the patients and family members about hygiene routines at home. The home care patients were not restricted to one room but were free to move around. During the

pancytopenic phase, patients in home care were visited and cared for once a day (1-2 hours) by experienced nurses from the transplantation center. In addition, a physician called each afternoon to check on the patient's well-being and to make appropriate modifications regarding examination, treatment, medication, and patient management. If there were any signs of unstable vital parameters that could not be dealt with at home, the patient was re-admitted to the transplant center (Svahn *et al.*, 2002).

Patients receiving hospital care were treated in conventional single rooms with reversed isolation and air filtration. The room had a TV, a DVD player, and an exercise bicycle. The patients were encouraged to have a family member or a friend staying with them around the clock. We encouraged the patients to take a walk outside the hospital after 18:00 on weekdays and at any time during weekends. Nurses and physicians provided supportive care according to the patient's health status. Pot plants were not allowed in the ward because of the risk of infection.

Data collection

A descriptive qualitative design was adopted. Interviews were conducted from May to November 2012. A clinical nurse at the outpatient clinic assisted with recruitment of eligible patients. The patients were recruited 1-2 weeks after discharge from the unit. Inclusion criteria were as follows: patients had undergone HSCT, had to be >18 years old, and had to be able to read, speak, and understand the Swedish language. Furthermore, for the patient to continue in the study, the interview had to take place during the first 6 months post-HSCT. A letter describing the study was sent to the patients by the first author (KB). After 1 week, the patients were contacted by telephone and asked whether they would be willing to participate.

KB is a registered nurse with extensive experience in hematology and oncology nursing; at no time during the study, did she contribute to the care of the patients.

All patients were interviewed by KB at a time and place of their choosing (in the patients' home or in an outpatient room). An interview guide was developed that included the following information: the decision (why and how) as to where the patients were to be treated (home or hospital), the experiences of being treated in different care settings, the contact with health care professionals, the relationship with the family, and the patients' own health and daily life. The patients were asked to describe their experiences in these areas in relation to the acute post-transplant phase. Field notes were collected after each interview. The recorded interviews were immediately reviewed in an endeavour to obtain an immersed knowledge of the data. The material was saved for future reference. The interviews, lasting a median of 53 minutes (range 23-91 minutes) took place 29-120 days after HSCT. All interviews were audiotaped with the participants' consent and transcribed verbatim. Medical information on diagnosis, conditioning, stem cell source, donor type, and length of stay (i.e. from admission to discharge from the center), regardless of the care setting and re-admissions, was obtained from the patients' medical records.

Data analysis

Content analysis (CA) using an inductive approach was chosen to analyze the data. CA is a dynamic form of analysis of verbal data orienting towards summarizing the content of the data. The approach, which can be applicable at various depths, focuses on differences and similarities in the data (Krippendorff, 2004). The analysis began by reading the transcribed interviews to gain a sense of the overall content, first without any agenda, and second, with the study aim firmly in mind (Graneheim and Lundman, 2004). Next, sentences, or meaning

units, relevant to the aim of the study were digitally coloured and then cut and pasted into a separate document. All meaning units were condensed and labelled into a code that stayed true to the original text. All codes were continuously compared to identify differences and similarities. This process was done individually for each of the 15 interviews. Based on the codes, subcategories were developed (a subcategory is a group of codes sharing commonality). Finally, categories with an underlying meaning were developed. Interpretation of the categories was done as far as was reasonable and possible (Elo and Kyngas, 2008) to express the manifest content of the text (Graneheim and Lundman, 2004). When preliminary analyses of all interviews were completed by the first author, a comparison was made within the research team with five of the transcript codes to determine interrater reliability (Burnard *et al.*, 2008). In this study we did not rate a numerical index of agreement; instead, a consensus was reached by discussing codes in relation to the transcript. Similar codes were abstracted into categories and discussed extensively among the authors. Alternate subcategories or discrepancies were considered. The aims of these discussions were to strengthen trustworthiness and promote analytical rigor.

Research ethics

When research involves humans as participants or subjects, it is paramount to consider ethical issues. Such consideration is even more crucial with vulnerable patients and those who often have a high burden of symptoms after HSCT. The first author was aware of these issues throughout the interview process. The patients were given written and verbal information outlining the study, emphasizing the voluntary nature of their participation, and their right to withdraw consent at any time. They were also told that anonymity would be preserved and that quotations from the interviews would be formulated in such a way as to protect their

identification. The study was approved by the Regional Ethical Review Board (Dnr 2010/1531-31/2) and informed consent was obtained pre-emptively from all patients.

RESULTS

Sample

Nineteen patients were asked to participate. Four patients declined because of either a lack of interest or a high symptom burden. Thus, the final sample included 15 patients (six women and nine men), with a median age of 55 years (range 30 to 68 years). More than half ($n=9$) have had experience of both hospital and home care during the neutropenic phase. Acute leukemia was the most common diagnosis. Demographic and clinical characteristics of the sample are listed in Tables 1 and 2.

The findings are presented through the four categories listed in Table 3: *To be in a safe place*, *To have a supportive network*, *My way of taking control*, and *My uncertain return to normality*. Under each of the four categories, direct quotations are used to illustrate the patients' experiences associated with each category in their own words.

To be in a safe place

Most of the patients had experienced both home and hospital care during the neutropenic phase. Preparation for home care included a thorough cleaning of the house, storing pot plants, and checking the temperature of the tap water. Misunderstandings for some criteria became apparent, such as having pets at home and fear of doing the wrong things (e.g.,

hygiene routines). Their fear, however, was no longer an issue after contact with the homecare nurses. Some patients chose a special room in the home where they could spend most of their time during isolation. *The decision to be treated at home was based on knowledge* of the positive medical outcome, i.e. better survival, fewer incidences of severe GVHD, and less use of parenteral nutrition after home care. Information from the health care professionals led the patients to feel safe in their decision to receive home care.

She [the nurse] gave me information so that I could make the right decision.

Evelyn, 60 years

Patients felt safe at home because of the support they received (mainly from the nurse who visited the patients and checked their well-being every day using the same *care routines*). The close distance to the hospital in the event of deteriorated health and the around the clock telephone support from the transplantation unit were described as other factors promoting a feeling of safety.

It really felt safe at home. Oh yes... I only needed to make a phone call and I could talk to someone. And there was no sense of insecurity at all.

Stephen, 57 years

Some patients expressed several negative aspects of home care, such as a longer delay to medication changes compared with those at the hospital in which the change occurred directly. Because of a shortage of nursing staff, some patients had to stay in the hospital or visit the hospital, even though they had no medical condition requiring hospital admission. Positive advantages of being at home included eating better, more opportunities for physical activity, a sense of freedom, being with the family, the joy of being at home in their own environment, and the environment near the home. Altogether, these positive advantages helped the patients to live a more normal life. Some patients also noted that *the importance to*

of being at home probably helped them to recover more quickly and to reduce the level of discomfort.

The first 3 weeks were very difficult for me. I was not prepared for it being so difficult. But the redeeming factor was that I was at home the fact that I could keep my head above water at all... I could at least be in my own bed; I could eat the food, .. I didn't have to eat hospital food. I could even go for walks along a street. It was fantastic.

Adam, 41 years

Some of the patients in home care were re-admitted because of neutropenic fever, infection, or pain. These events were fully expected, and as soon it was medically safe they returned home. A few patients remained in the hospital during the neutropenic phase because of severe and high symptom burden or because they lived too far away from the hospital.

To be in the hospital, the sense of *being isolated depended on the patient's different side effects* i.e., when they felt bad it didn't matter that they were isolated in a small hospital room. Further, living with restrictions due to isolation had little effect on the patients because they knew that these restrictions would be for a limited time. *"When you are ill, you have a different outlook"*. *David, 28 years*

The days were filled with assessments and *care routines* from the health care professionals, which the patients experienced as bothersome. However, after some time in the hospital they understood the reason for the intensive care and that enhanced their feeling of safety. They described the negative *surroundings of the hospital* (i.e. the room's furniture and a sterile-like environment). Other negative aspects included the food and sleep interruption because of care routines during the night and in the early morning hours. All patients agreed, however, that the hospital was the safest care facility if in poor health.

To have a supportive network

To undergo HSCT entails meeting the health care team over a long period in the hospital, at home, and in the outpatient clinic. Patients described the health care professionals' *high degree of competence* and their long experience of HSCT care. Because of the result of the high quality of care, patients expressed confidence both in the team and in the HSCT procedure. The patients identified a number of positive factors in the meetings with the health care professionals, including *personalized care planning* and a strong sense of encouragement. The enthusiasm and engagement of the health care professionals working in the transplantation center were characteristic of the team. Continuity in the health care team was another important factor for why the patients felt supported and reassured.

I have faith in them; they can do their job. They are genuinely interested in this. They are very enthusiastic... exactly, that's it. That's why it feels very safe—that they have it in them, that they really believe in it.

John, 60 years

Patients experienced individualized care, especially in receiving *adequate and timely management of symptoms*. However, many patients reported that the interventions were primarily medically focused and they missed having time to talk to the nurses about their feelings and about their unique problems. For example, when experiencing anxiety, the nurses provided anxiety drugs but did not always have the time to talk with the patients about their anxiety or worries.

Many hospitalized patients had companionship with family members or friends during their stay. The patients were particularly pleased at having a family member willing to stay at home with them and with the feeling of 'doing this together', but they also expressed the general *importance of family members*.

I don't think... I would have been able to go through this without him. I have no one else who could take care of me. Otherwise, I would probably have needed to be in the hospital for 3 months.

Eric, 59 years

The patients reported variation in *support from friends* and colleagues at work. The importance of informing others about the HSCT was expressed, even though they felt that it was very difficult to explain the different phases of the transplantation. During the neutropenic phase, the patients were kept isolated, irrespective of the care setting, which led to a change in their contact with friends and colleagues. They stayed in contact through 'Skype' conversations and many text messages and calls via a mobile phone. When the patients were interviewed, they were at the beginning of the early recovery period. Thus, they had to consider 'their premature immunological system', which meant less physical contact with the outside world.

My way of taking control

The patients experienced common side effects and adverse events (e.g., fatigue, pain, nausea, and eating problems) from the effects of the HSCT procedure. *The approach* and attitude towards handling the side effects and HSCT varied from individual to individual. Some patients mentioned the intense battle they experienced, whereas others expressed surprisingly little distress or concern in response to their situation. Before the HSCT, there had been several information meetings. For some patients, it had often been difficult to assimilate all this information and to predict how things would transpire. One strategy was to gradually take in information during the pre-HSCT phase. The patients mentioned the complexity and difficulty in understanding the HSCT. The patients underlined the importance of receiving frank and positive information. Therefore, one way of taking control was *to gain knowledge* based on their personal needs. Knowing more also meant that the patients could be involved in care decisions.

But to be able to contribute and understand why these medicines are used in this way-- we do this so that we are not going to be treated like a package or a thing, an object that can be looked past... without being part of it. This has been very important to me.

Eric, 59 years

One strategy to manage a high symptom burden was to set up short-term (1 day or 1 week) goals . Another approach was to establish daily routines to structure the care trajectory. The impact of GVHD was evident in all patients. Some already had experienced a condition of GVHD, whereas others feared it and some even expressed a wish to develop a mild form of GVHD because of its known anti-leukemia effect.

Many patients were grateful for having the opportunity to be treated with HSCT though they also had feelings of uncertainty in dealing with the anxiety of not knowing whether the HSCT would be successful. To manage this uncertainty *living in the here and now* was described as being an effective strategy.

Everything depends on how it goes. Thus far, it has gone well, so it all feels good. But I don't know what will happen next week. I have to live with this worry all the time. But it seldom gets as bad as you think [laughs]. It almost always turns out better and you learn to live with it. There is something positive about that, because you become more... yes, you live more in the here and now... I appreciate things more, in fact. It's strange that you have to go through something like this just for it to be like that, but in my case it is certainly like that...

Helen, 52 years

My uncertain return to normality

The patients were in the early recovery phase at the time of the interviews. They reflected on the time and who they were before HSCT. They had had different expectations about HSCT. Those who (mistakenly) thought it was a major invasive procedure were surprised to discover that it was 'only an intravenous infusion'. Living with the side effects of HSCT proved to be challenging, especially not knowing how long the effects would last.

The hope and expectation of being cured was another important issue for the patients. It was obvious to the patients that they had an *uncertain future*, with the risk of relapse and even death. In cases of relapse the majority of the patients chose to undergo a second HSCT. The patients realized that they were at the start of a *long recovery process*, including having to live and deal with numerous medical follow-ups. All patients stated that the restrictions pertaining to food, hygiene, and contact with animals were a major obstacle to normal living. They also expressed uncertainty about how and for how long they would have to live with these restrictions. The majority of the patients missed a more personal and dynamic guideline with regard to *the restrictions* in relation to their own health and life situation. Finally, the narratives of all the patients depicted how their own body had changed, expressing a strong desire to return to the person they were before the HSCT. Despite their fears, the patients hoped for a normal everyday life.

I want a normal, everyday life because I know that there is an everyday life. But right now it feels very awkward that there lacks an everyday life [laughs]. It's the everyday life that you miss, nothing else. Boring, everyday life, that's what you want. You don't want, what should I say, anything big, such as a trip to Thailand... You want an everyday situation that is normal.

Susan, 55 years

DISCUSSION

In this study we describe patient experiences in care settings and their life situation during the post-transplantation phase after HSCT. The main findings could be identified in terms of four categories: *To be in a safe place, To have a supportive network, My way of taking control, and My uncertain return to normality.*

A majority of our patients had experienced both home and hospital care. Regardless of the caring context, all patients felt that they were *in a safe environment*. This finding is consistent

with our previous study in which the feeling of security was based on the staff's high competence level and different care routines (Bergkvist *et al.*, 2013). In this study different factors were related to safety: care routines, receiving continuously updated information, and the skill and competence of the health care providers. Competence has been described as a blessing, as a security, and as a guarantee of a positive outcome (Coolbrandt and Grypdonck, 2010). Feelings of safety in home care patients were also related to the daily meetings with the health care professionals and the possibility of having 24-hour contact with the transplantation center. Some of the patients had to stay at the hospital because of a nursing shortage. This circumstance highlights the need for a more flexible organization with sufficient health care personnel to be able to fulfil the patients' wish to be treated at home.

Over the past two decades, there has been an increasing tendency for selected patients to be treated in outpatient settings or at home during chemotherapy or after HSCT. One major justification for this choice of treatment is the growing imperative to improve patient experience (Sive *et al.*, 2012, Solomon *et al.*, 2010, McDiarmid *et al.*, 2010, Svahn *et al.*, 2000, Russell *et al.*, 1992). Still, what does it mean for the patient to be at home? We have already reported that patients in home care tend to be more satisfied with care in general than patients in hospital care (Bergkvist *et al.*, 2013).

In this study we can add knowledge how patients experienced their home care as a feeling of freedom and connectedness. Several advantages of living at home as compared with a hospital setting emerged, including eating better, opportunity for greater integrated physical activity, and being part of a more pleasant and familiar environment. Some patients noted that being at home might helped in recovering more quickly from the HSCT. Compared with hospitalization, receiving care at home, in addition to being less stressful, made it possible to live a more normal life despite side effects and restrictions. The home plays a central role in the lives of most people. It is a place of permanence, hope, peace, and comfort, allowing

independence and serving as an arena for one's own routines (Holmberg *et al.*, 2012, Williams, 2002). Further, Roush and Cox suggested that the meaning and function of the home can be seen as a familiar place of comfort, as a center for everyday experiences, free time, and social life, but also as a protector of privacy, identity, and safety (Roush and Cox, 2000).

The patients felt that being with the family was essential, as indicated by the category *To have a supportive network*. Patients with home care needed a family member or friend to stay with them during the pancytopenic phase. In an earlier study the most common reason for declining home care was not having a family member as a support person at home with the patient (Frey *et al.*, 2002). All of our patients reported having a family member willing to provide support and encouragement at home. We can only speculate that this can be the result of several factors: a good family relation, the individual's private financial situation, distance to the hospital, and family member involvement in decision making together with the patients regarding care and the care setting. On the other hand, family members may feel strong social pressure to participate in home care. In a recent study family members reasoned that home care was a family matter but that the final decision was ultimately entrusted to the patient (Bergkvist *et al.*, 2016). This finding suggests that it might be difficult for family members to refuse to accept the home care alternative, i.e. they comply with the patient's decision regardless of their own position.

Many patients reported that HSCT is a complicated procedure but that they nevertheless had trust in the health care providers making the right decisions, which was another part of *the supportive network*. Furthermore, the patients felt that they received strong encouragement from the health care staff. In two previous studies nurses found that giving positive feedback is essential for trust (Coolbrandt and Grypdonck, 2010, Sabo, 2011). Because the HSCT is

delivered within a tightly structured protocol designed for maximum treatment efficacy and survival, it is important to offer the patients opportunities to express their own treatment preferences and involvement in treatment decision making, so the care becomes person-centered without taking medical risks. One example is how health care professionals have faith in the patient's ability to be at home. Importantly, in daily hospital routines nurses need to identify situations that could be more personalized and permit patients to exercise a degree of control over their own daily life, as well as to take a more active role in their own care. Person-centered care is driven by the patient's needs and preferences, and has been shown to improve patient satisfaction, participation, and safety (Zucca *et al.*, 2014, TS *et al.*, 2014).

The patients also acknowledged the importance of receiving candid and individualized information and being able to participate in the care process, which were contained in the category *My way of taking control*. Many patients took an active part in understanding their treatment and obtained adequate answers from the health care staff. Well-informed patients are more likely to adhere to treatment recommendations, which are essential for outcome and safety (Murphy *et al.*, 2012).

Facing a life-threatening illness and then undergoing an HSCT and a recovery phase involve a long transition period for the patients. In the final category *My uncertain return to normality* the uncertainty was evident in all patients in the post-transplantation period and confirms recent findings (Dunn *et al.*, 2016). Findings from that study described how the uncertainty was experienced at every stage of the illness, including insecurities about the return home. This uncertainty, to be at home, cannot be confirmed in our findings. To be at home was a safe place for the patient. In this study all patients expressed hope for a lasting cure. Hope has been identified as one important coping strategy during HSCT (Saleh and Brockopp, 2001). Although the patients were interviewed in the early recovery phase, some noted that what was

normal before the disease and HSCT had changed after these events. Some patients described a change in values about what was important in life, indicating a transition to a new life situation. However, this change often takes a longer time than patients expected. Another potential way to reduce uncertainty is to create a new life in which control and confidence are increased (Penrod, 2007). Assistance from health care staff in helping patients seek and identify realistic goals may facilitate their integration into a new life situation (Johansson *et al.*, 2012). As described by the patients, many of the restrictions after HSCT were an obstacle to having a normal life and that individual advice in addition to standard guideline care was needed to overcome these restrictions. This study highlights the need for a more personalized care, especially during the long recovery phase.

Our findings add knowledge and insight into patient experiences of different care settings and an altered life situation, which may help health care professionals to gain a better understanding of the care pathway of their patients. Our study was limited because the sample size was small and was conducted at only one center. The generalizability of our findings is probably influenced by external factors such as differences in care between hospitals or the context of health care in Sweden. Even so, because it concerned fundamental considerations for the patients, the main results of this study may be applicable to HSCT patients in other settings. Different categories and areas of code might have emerged if we included patients from more ethnically diverse populations.

One strength of the study was that most the patients had received both hospital care and home care. Another strength was the variation in the patients' age, sex, time since HSCT, and medical and socioeconomic characteristics. We have increased the credibility further by presenting details of the setting, participants, data collection, and analysis, as well as making

our interpretation of the data more tangible to the reader through incorporation of quotations from the patients' narratives. We allowed the reader to confirm or reject the credibility and transferability of the present results. An advantage of this study is that the interviewer was a nurse and was able to establish an atmosphere of safety, which may have led to the participants feeling unrestrained to share their experiences and thus provide subtle and rich statements. The authors' different pre-understandings contributed to critical reflections and analysis that added to the trustworthiness of the data.

CONCLUSIONS

The findings contribute to our understanding of patient experiences of different care settings and their life situation during HSCT. The main findings are applicable regardless of care setting. Our findings showed that the patients felt safe in both home and hospital settings. The supportive network (i.e. the health care team, family, and friends) was a vital factor in the care of the patients. The patients used emotional or problem-focused strategies, or both, to take control of an uncertain future. Home care had positive advantages over hospital care: a more natural eating experience, opportunity for greater integrated physical activity, and a more pleasant and familiar environment.

Legends

Table 1. Demographic characteristics of the patients

Table 2. Clinical characteristics of the patients

Table 3. Overview of the categories identified from the analysis of the interviews.

REFERENCES

- Bergkvist K., Larsen J., Johansson U. B., Mattsson J. & Fossum B. (2016) Family members' life situation and experiences of different caring organisations during allogeneic haematopoietic stem cells transplantation-A qualitative study. *European journal of cancer care*.
- Bergkvist K., Larsen J., Johansson U. B., Mattsson J. & Svahn B. M. (2013) Hospital care or home care after allogeneic hematopoietic stem cell transplantation--patients' experiences of care and support. *Eur J Oncol Nurs* **17**, 389-395.
- Bevans M. F., Mitchell S. A. & Marden S. (2008) The symptom experience in the first 100 days following allogeneic hematopoietic stem cell transplantation (HSCT). *Support Care Cancer* **16**, 1243-1254.
- Burnard P., Gill P., Stewart K., Treasure E. & Chadwick B. (2008) Analysing and presenting qualitative data. *British dental journal* **204**, 429-432.
- Coolbrandt A. & Grypdonck M. H. (2010) Keeping courage during stem cell transplantation: a qualitative research. *Eur J Oncol Nurs* **14**, 218-223.
- Dunn E., Arber A. & Gallagher A. (2016) The Immediacy of Illness and Existential Crisis: Patients' lived experience of under-going allogeneic stem cell transplantation for haematological malignancy. A phenomenological study. *Eur J Oncol Nurs* **21**, 90-96.
- Elo S. & Kyngas H. (2008) The qualitative content analysis process. *Journal of advanced nursing* **62**, 107-115.
- Forslow U., Remberger M., Nordlander A. & Mattsson J. (2010) The clinical importance of bronchoalveolar lavage in allogeneic SCT patients with pneumonia. *Bone marrow transplantation* **45**, 945-950.
- Frey P., Stinson T., Siston A., Knight S. J., Ferdman E., Traynor A., O'gara K., Rademaker A., Bennett C. & Winter J. N. (2002) Lack of caregivers limits use of outpatient hematopoietic stem cell transplant program. *Bone marrow transplantation* **30**, 741-748.
- Graneheim U. H. & Lundman B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today* **24**, 105-112.
- Grant M., Cooke L., Bhatia S. & Forman S. (2005) Discharge and unscheduled readmissions of adult patients undergoing hematopoietic stem cell transplantation: implications for developing nursing interventions. *Oncology nursing forum* **32**, E1-8.
- Gyurkocza B., Rezvani A. & Storb R. F. (2010) Allogeneic hematopoietic cell transplantation: the state of the art. *Expert review of hematology* **3**, 285-299.
- Holmberg M., Valmari G. & Lundgren S. M. (2012) Patients' experiences of homecare nursing: balancing the duality between obtaining care and to maintain dignity and self-determination. *Scandinavian journal of caring sciences*.
- Johansson E., Larsen J., Schempp T., Jonsson L. & Winterling J. (2012) Patients' goals related to health and function in the first 13 months after allogeneic stem cell transplantation. *Support Care Cancer* **20**, 2025-2032.
- Krippendorff K. (2004) *Content Analysis. An Introduction to Its Methodology*, Sage Publications, London.
- Mcdiarmid S., Hutton B., Atkins H., Bence-Bruckler I., Bredeson C., Sabri E. & Huebsch L. (2010) Performing allogeneic and autologous hematopoietic SCT in the outpatient setting: effects on infectious complications and early transplant outcomes. *Bone marrow transplantation* **45**, 1220-1226.
- Murphy C. C., Bartholomew L. K., Carpentier M. Y., Bluethmann S. M. & Vernon S. W. (2012) Adherence to adjuvant hormonal therapy among breast cancer survivors in clinical practice: a systematic review. *Breast cancer research and treatment* **134**, 459-478.
- Olsson R., Remberger M., Hassan Z., Omazic B., Mattsson J. & Ringden O. (2010) GVHD prophylaxis using low-dose cyclosporine improves survival in leukaemic recipients of HLA-identical sibling transplants. *European journal of haematology* **84**, 323-331.

- Passweg J. R., Baldomero H., Peters C., Gaspar H. B., Cesaro S., Dreger P., Duarte R. F., Falkenburg J. H., Farge-Bancel D., Gennery A., Halter J., Kroger N., Lanza F., Marsh J., Mohty M., Sureda A., Velardi A., Madrigal A., European Society For B. & Marrow Transplantation E. (2014) Hematopoietic SCT in Europe: data and trends in 2012 with special consideration of pediatric transplantation. *Bone marrow transplantation* **49**, 744-750.
- Penrod J. (2007) Living with uncertainty: concept advancement. *Journal of advanced nursing* **57**, 658-667.
- Pidala J., Anasetti C. & Jim H. (2009) Quality of life after allogeneic hematopoietic cell transplantation. *Blood* **114**, 7-19.
- Remberger M., Ackefors M., Berglund S., Blennow O., Dahllof G., Dlugosz A., Garming-Legert K., Gertow J., Gustafsson B., Hassan M., Hassan Z., Hauzenberger D., Hagglund H., Karlsson H., Klingspor L., Kumlien G., Le Blanc K., Ljungman P., Machaczka M., Malmberg K. J., Marschall H. U., Mattsson J., Olsson R., Omazic B., Sairafi D., Schaffer M., Svahn B. M., Svenberg P., Swartling L., Szakos A., Uhlin M., Uzunel M., Watz E., Wernerson A., Wikman A., Wikstrom A. C., Winiarski J. & Ringden O. (2011) Improved survival after allogeneic hematopoietic stem cell transplantation in recent years. A single-center study. *Biology of blood and marrow transplantation : journal of the American Society for Blood and Marrow Transplantation* **17**, 1688-1697.
- Ringden O. & Le Blanc K. (2005) Allogeneic hematopoietic stem cell transplantation: state of the art and new perspectives. *Apmis* **113**, 813-830.
- Roush C. V. & Cox J. E. (2000) The meaning of home: how it shapes the practice of home and hospice care. *Home healthcare nurse* **18**, 388-394.
- Russell J. A., Poon M. C., Jones A. R., Woodman R. C. & Ruether B. A. (1992) Allogeneic bone-marrow transplantation without protective isolation in adults with malignant disease. *Lancet* **339**, 38-40.
- Sabo B. M. (2011) Compassionate presence: The meaning of hematopoietic stem cell transplant nursing. *Eur J Oncol Nurs* **15**, 103-111.
- Saleh U. S. & Brockopp D. Y. (2001) Hope among patients with cancer hospitalized for bone marrow transplantation: a phenomenologic study. *Cancer nursing* **24**, 308-314.
- Sive J., Ardeshtna K. M., Cheesman S., Le Grange F., Morris S., Nicholas C., Peggs K., Statham P. & Goldstone A. H. (2012) Hotel-based ambulatory care for complex cancer patients: a review of the University College London Hospital experience. *Leukemia & lymphoma* **53**, 2397-2404.
- Solomon S. R., Matthews R. H., Barreras A. M., Bashey A., Manion K. L., Mcnatt K., Speckhart D., Connaghan D. G., Morris L. E., Jr. & Holland H. K. (2010) Outpatient myeloablative allo-SCT: a comprehensive approach yields decreased hospital utilization and low TRM. *Bone marrow transplantation* **45**, 468-475.
- Svahn B. M., Bjurman B., Myrback K. E., Aschan J. & Ringden O. (2000) Is it safe to treat allogeneic stem cell transplant recipients at home during the pancytopenic phase? A pilot trial. *Bone marrow transplantation* **26**, 1057-1060.
- Svahn B. M., Remberger M., Myrback K. E., Holmberg K., Eriksson B., Hentschke P., Aschan J., Barkholt L. & Ringden O. (2002) Home care during the pancytopenic phase after allogeneic hematopoietic stem cell transplantation is advantageous compared with hospital care. *Blood* **100**, 4317-4324.
- Svahn B. M., Ringden O. & Remberger M. (2005) Long-term follow-up of patients treated at home during the pancytopenic phase after allogeneic haematopoietic stem cell transplantation. *Bone marrow transplantation* **36**, 511-516.
- Ts J. A., Olsson L. E., Ekman I. & Carlstrom E. (2014) The impact of organizational culture on the outcome of hospital care: after the implementation of person-centred care. *Scandinavian journal of public health* **42**, 104-110.
- Williams A. (2002) Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Soc Sci Med* **55**, 141-154.

Zucca A., Sanson-Fisher R., Waller A. & Carey M. (2014) Patient-centred care: making cancer treatment centres accountable. *Support Care Cancer* **22**, 1989-1997.

Table 1. Demographic characteristics of the patients

	Total (n=15)
Sex, n	
Female	6
Male	9
Age	
Median age (range)	55 (30-68)
Marital status, n	
Married/cohabiting	11
Divorced	3
Single	1
Living situation, n	
Single-person household	3
Household includes children < 18 years	6
Household includes only adults	6
Education, highest, n	
High school (12 years)	4
College/university	11
Occupational status, n	
On sick leave, <65 years old	12
Old-age pensioner, >65 years old	3

Table 2. Clinical characteristics of the patients

	Total (n=15)
Diagnosis, n	
Acute leukemia	8
Chronic leukemia	3
Lymphoma	2
MDS	1
Myeloma	1
Conditioning, n	
MAC	5
RIC	10
Stem cell source, n	
PBSCs	15
Donor type, n	
MUD	12
Sib	3
aGVHD at data collection, n	
None	9
Yes	6
Care setting^a, n	
Hospital care	4
Hospital care and home care	9
Home care	2
Re-admission^b, n	8
Median length of stay^a, days (range)	27 (22-36)
Median time since HSCT at data collection, days (range)	66 (29-120)

Abbreviations: GVHD, graft-versus-host disease; MAC, myeloablative conditioning; MDS, myeloid dysplastic syndrome; MUD, matched unrelated donor; PBSCs, peripheral blood stem cells; RIC, reduced-intensity conditioning; Sib, HLA-identical sibling.

^a during the pancytopenic phase.

^b during the pancytopenic phase with home care.

