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# Patients' Subjective Experiences of Outpatient- and Inpatient Care during Autologous Hematopoietic Stem Cell Transplantation – A Quantitative Questionnaire Study

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#### Abstract

**Background:** As early as 1997 it was stated that the outpatient model when patients are cared for in their homes (outpatient care) in connection with hematopoietic stemcell transplantation (hSCT), gave positive results regarding safety and effectiveness. But in the year of 2022, in many countries, it is still an offer and not a standard treatment. Despite long international and national experience of outpatient treatment at hSCT, many patients are still fully cared for in hospitals.

**Purpose:** To describe the patients' subjective experiences of outpatient (OP)- and inpatient (IP) care during autologous hematopoietic stem cell transplantation and to ensure the quality of care outside hospital environment as a form of care in order to improve the patient's experience of safety and security at autologous hematopoietic stem cell transplantation at a University Hospital in Sweden. And, to evaluate physicians' and nurses' assessment using a standardized assessment form of the patient's self-care ability when cared for outside the hospital.

Methods: A quantitative questionnaire study with pre-selected response alternatives and open-ended questions.

**Results:** Most patients, regardless of the form of care, OP or IP care, felt satisfied with the information given by the care provider. Nearly all of the patients who were cared for in hospital and who responded to the questionnaire, experienced anxiety during the care period compared with patients who were cared for in a home environment responding to the questionnaire, where the vast majority did not experience any anxiety during the care period.

**Conclusion:** Most patients indicate, as shown in other studies, that they felt satisfied with the care and information they received in connection with hematopoietic stem cell transplantation but patients in IP care felt more anxiety than patients in OP care. Regarding evaluating physicians' and nurses' assessment using a standardized assessment form of the patient's self-care ability when cared for outside the hospital, there were no notable differences in the assessment.

**Clinical relevance:** A questionnaire provides the healthcare provider with a basis for developing and improving in clinical care for patients receiving hSCT. Regarding attention to the mental well-being equated with the physical well-being it is a clinical task for healthcare providers. A well-developed basis for assessing the patient's level of care can ensure the best care.

Keywords: Patients' experiences • Outpatient care • Inpatient care • Stem cell transplantation • Questionnaire study

# Introduction

#### Background

Patients suffering from blood diseases and bone marrow failure such as acute and chronic leukaemia's, lymphomas, multiple myeloma and autoimmune disorders often need intensive treatment with chemotherapy and sometimes also need to undergo hematopoietic stem cell transplantation (hSCT) [1,2]. When stem cells are donated by another person, related or unrelated, the

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Received: 05 December, 2022, Manuscript No. jnc-22-82375; Editor Assigned: 07 December, 2022, PreQC No. P-82375; Reviewed: 14 December, 2022, QC No. Q-82375; Revised: 17 December, 2022, Manuscript No. R-82375; Published: 24 December, 2022, DOI: 10.37421/2167-1168.2022.11.562 treatment is called allogeneic hSCT. Alternatively, the patient's own stem cells are used, which is called autologous hSCT [3]. In Europe, a total of 48,512 people underwent hSCT in 2019 [4]. In Sweden, approximately 600 people undergo an autologous stem cell transplant and approximately 400 people an allogeneic stem cell transplant annually [5].

Patients treated with high-dose chemotherapy in connection with autologous hSCT are often cared for, for a long time in hospital (inpatient care), have a weakened immune system due to given treatment and thus run an increased risk of developing infections such as pneumonia, septicaemia and neutropenic fever with unknown genesis., They are often treated in isolation in single rooms with laminar airflow and air filtration. The long hospital stay also increases the risk of multi-resistant bacteria, which prolongs care time and patient suffering [6-9].

In a report by Jagannath S, et al. [10] it was stated that the outpatient model when patients are cared for in their homes (outpatient care) in connection with hSCT, gave positive results regarding safety and effectiveness. Patients treated in outpatient care (OP) have reduced antibiotic use, lower use/need for intravenous nutritional support in the form of intravenous total parenteral nutrition (TPN) [11]. Outpatient care means that the patient receives care outside the ward and can instead stay in the home or apartment that the hospital provides during the treatment period and several randomized

trials have shown the feasibility of outpatient hSCT as an optimal method of managing hospital length [12-14].

The Swedish Patient Act (2014: 821) [15] is for strengthen and clarify the patient's position, to protect the rights and interests' patients may have. It fortifies the right to be informed and take part in choices and evidence about the illness and various treatment options, including OP. The patient must also be told where he or she can obtain the care that they need.

In the year of 2001, patients planned for autologous hSCT were offered outpatient care at a university hospital in Sweden. It is still an offer and not a standard treatment. Despite long international and national experience of outpatient treatment at hSCT, many patients are still fully cared for in hospitals [16].

In a study by Bergkvist K, et al. [17] with 42 patients, 19 patients were cared for at outpatient basis and 22 in hospital care, after allogeneic hSCT. All patients were highly satisfied with the care during the post transplantation phase despite that the patients in homecare were more satisfied than patients in hospital care. It is therefore of interest to compare with patients treated with autologous hSCT.

All patients scheduled for hSCT are routinely asked regarding OP care in connection with hSCT. Patient is enrolled in the haematology department, formally responsible is the department head physician. Haematology ward is responsible for the patient care outside office hours. The document that is the basis for the question of OP care is a regional journal document at a University Hospital in Sweden.

#### Aim

The primary aim of this study was to describe the patients' subjective experiences of outpatient- and inpatient care during autologous hematopoietic stem cell transplantation and to ensure the quality of care outside hospital environment as a form of care in order to improve the patient's experience of safety and security at autologous hematopoietic stem cell transplantation at a University Hospital in Sweden. The secondary aim was to evaluate physicians' and nurses' assessment using a standardized assessment form of the patient's self-care ability when cared for outside the hospital.

### **Methods**

#### Design

A quantitative questionnaire study with pre-selected response alternatives and open-ended questions.

#### Study sample and setting

Patients diagnosed with myeloma or lymphoma, scheduled for autologous hSCT at a University Hospital in Sweden between February 2017 and February 2019, were consecutively asked to participate in a questionnaire study with questions specifically developed for this study, to feel safe at home and or in the hospital, at a University Hospital in Sweden. Inclusion criteria were age  $\geq$ 18 years and diagnosed with myeloma or lymphoma and planned for hSCT. The patients would also understand the Swedish language in speech, reading and writing. Exclusion criteria were whether the patient did not meet the requirements for OP care during hSCT. To be treated in OP care, the patients were evaluated by treating physicians and nurses regarding their physical and mental ability to cope with OP care.

Sixty-four patients were asked to participate in the study and chose to participate. Fifty-two patients fulfilled the study specific questionnaire (81%). All patients received preventive care according to the hospital's routines for hSCT, including oral care and infection prophylaxis. Patient characteristics and assessments are shown in Table 1.

#### **Outpatient care**

Patients in OP care will have regular contact with nurses daily by phone, once or twice a day. Every other day they get to see a physician at the hospital and have blood samples taken and possibly transfusions, depending on blood count. Depending physical status, the patients may need to come more often than every other day to the hospital ward. Patients living more than one hour driving distance from the hospital and still wanted to live in homelike environment, was offered to stay in an appartement nearby owned by the hospital.

During the entire transplantation period, the patient is enrolled to the haematological department and can get a room in the ward at any time if needed.

The patients could, at any time of the day, call the ward if they felt worse or had any questions.

Patients scheduled for OP care receives a brochure\* with information about what is important to consider for residents at home.

#### \*Your home environment

Because you are particularly sensitive to infections over the next few weeks, there are some things you and your relatives need to consider.

**Cleaning:** Use cleaning equipment. Use regular detergent. Use disposable cloth or kitchen paper instead of dishcloth or change the dishcloth daily. Keep the refrigerator clean. Clean the toilet daily. It is good to vacuum. Dishwashing detergents, disinfectants and hand disinfectants are provided by the department. When visiting the hospital, tell the hospital staff if the cleaning equipment is running out. The new toilet brush that you get from the hospital should replace the old one. If you want, you can get toilet paper from the ward. If you live in a hospital apartment, you need to clean when moving out. You will receive a special brochure that will give you more detailed information about the apartment and how to clean it.

**Earth:** There are fungal spores in the soil that can make you sick and therefore you must not dig into the ground, transplant or water the flowers. You who live at home need to move houseplants from the bedroom. There should be no flowers in the hospital apartment.

Water: The water temperature in your home should be 60 degrees. If you live in a rented or tenant apartment, you can check it with the property manager. If you live in your own house, you can regulate the temperature yourself. If you have your own well, the water should be boiled before it can be used (durable one day) otherwise you will have to use bottled water. If you live in a hospital apartment, you do not need to think about it. The water temperature is already ordered.

Visitors: Visitors must not have any ongoing infection such as colds or stomach problems. Meeting children goes well as long as they are not sick.

Pets: Be reluctant to have close contact. Have no animals in bed!\*

**Inpatient care:** All patients in IP care follow the hospital standard routine according for example nutrition, oral care and physical activity during the hSCT period.

#### Data collection

Standardized Hospital information of IP and OP care: When planned for autologous hSCT patients received written and oral information about their hSCT treatment, including medical information about side effects and practical information about physical activity and diet. Patients who were deemed suitable by physicians' and nurses to be treated outside hospitals and chose this, received specific written and oral information about OP care at the University Hospital, Sweden. The specific written information about OP care at the University Hospital has been presented and published in a previous study [11].

An invitation to participate in the study was given to the patients when they were enrolled in the University hospital for autologous hSCT during the period February 2017 to February 2019. They received information about the study both orally and in writing from the responsible nurse and had the opportunity to ask questions about the content of the study. The patients who chose to join the study gave their written consent. Patients answered the study specific questionnaire when they were discharged from the Haematology

department at the University hospital. The patients who did not respond to the questionnaire received a reminder of the study, including the questionnaire and a pre-stamped and addressed envelope, sent to the home address after discharge. For the secondary aim a standardized assessment document for physicians and nurses to fill in to assess the patient's ability to live at home in connection with hSCT, was available. The documentation has been prepared to be filled in in connection with visits and examinations prior to transplantation.

#### The Questionnaire contents

The questionnaire was developed implicitly for this study by physicians' and nurses with long experience (minimum 6 years) of haematological care at a University Hospital in Sweden. No questions about background such as income, religion, ethnicity, or previous cancer treatment were included.

One questionnaire, for patients cared for in hospital, with 13 questions with pre-selected alternatives to tick and open-ended questions. One equivalent questionnaire for the patients staying in the home/home-like environment, outpatient care, with 17 questions with pre-selection alternatives to tick and open-ended questions. A few questions distinguish the questionnaires. The study specific questionnaires were constructed and tested by three nurses and three patients who were not included in the study, to avoid misinterpretation of the questions. One question was clarified in the study-specific questionnaires after the subjects' comments. To evaluate the assessment of the patient's self-care ability when cared for outside the hospital during hSCT, the physicians' and nurses 'used a specific standardized assessment document especially developed for a University Hospital in Sweden.

#### The questionnaire

The questionnaire contained of 13 questions (Q1-Q13) for patients in IP care and 17 questions (Q1-Q17) for patients in OP care. Some questions were specific in relation to form of care, OP or IP care. The questionnaire consisted of questions with pre-selection alternatives to tick and open-ended question with only possibility of written answer (which will be presented in a separate manuscript). The preselection alternatives were marked with letters ranging from a to b, a to c, a to d, a to e and a to g. The questions are divided into two categories with the factor's safety and security as the main theme. Question 1-3, 7, 8, 10, 12 and 16 represent safety in the questionnaire for patients in OP care whereas Q 4 - 6, 9, 11, 13-15 and 17 represent security. Question 1-3, 6, 7 and 10 represent safety in the questionnaire for patients in IP care whereas Q 4, 58, 9, 11-13 represent security.

#### **Ethical considerations**

The informants received detailed oral and written information about the purpose of the study, as well as information about confidentiality and the possibility to cancel their participation at any time. All participants in the study gave informed consent. The study followed both the Declaration of Helsinki [18] and Sweden's national ethical guidelines [19]. The study was approved by the regional Research Ethics Committee, Uppsala, Dnr; 2016/521.

### **Data Analysis**

For demographic data descriptive statistics were used (Table 1). For comparison between patients in IP care and OP care, the unpaired t-test and Mann-Whitney U-test was applied to test differences between the two independent groups (IP- or OP care). Data were analysed with IBM SPSS statistics version 23.0. The questionnaires were entered into a data file where the letters of the answer options were coded with numbers. Data analysis with demographic data from sixty-four medical records were performed (100%). Fifty-two questionnaires (52/64, 81%) were analysed (Table 2-5). Only 64 analyses from patient study questionnaire were conducted and therefore statistic differences were not reported. The differences in this study between forms of care can be seen as a support for care providers who indicate direction for future care planning. The reported differences in this study can be due to trends to care planning. Only 64 patients were included in this study whereas IP and OP groups are not balanced in numbers of patients. Due to that no statistical differences were reported. Table 1. Patient characteristics, diagnosis, outpatient and inpatient care, physicians' and nurses' assessment of the patient's self-care ability when cared for outside the hospital during hSCT.

Diagnosis	Myeloma	Lymphoma	Total (n=64)
Women	14	8	22
Men	30	12	42
Age, $\leq$ 60 yrs. of age (range 44-60)	15	12	27
Age, ≥ 50 yrs. of age (range 61-71)	29	8	37
Outpatient care	32	10	42
Inpatient care	12	10	22
Assessed by physicians	32	15	47
Assessed by nurses	34	12	39

Table 2. The questionnaire consists of four equal questions, Outpatient- Inpatient care (OP, IP) on the factor safety, Q1, Q2, Q3 and Q6/7.

Questions (Q)	Outpatient care (OP) (n=36)	Inpatient care (IP) (n=16)
Q 1. Do you think that you received sufficiently clear information about the possible forms of care that are offered, such as the opportunity to, during your care during stem cell transplantation, be allowed to stay at home or live in one of the ward's apartments (OP)?	yes, I'm happy with the information I received (n=31) yes, I'm relatively happy, but it can get better (n=2) no, I'm not happy with the information I received (n=1)	yes, I'm happy with the information I received (n=14) yes, I'm relatively happy, but it can get better (n=2)
Q 2. When did you receive information about how the care in the ward would be for you? IP) When did you receive information about the possibility of care in the home or the ward's apartment? (OP)	In connection with the planning call before your stem cell harvest (n=31) When hospitalized in connection with the harvest of your stem cells. (n=3)	In connection with the planning call before your stem cell harvest (n=6) When hospitalized in connection with the harvest of your stem cells. (n=7) When hospitalized in connection with stem cell transplantation (n=2)
Q 3. Did you receive both written and oral information about your care in connection with stem cell transplantation	Yes, I received both oral and written information (n=33) No, I only received oral information (n=1)	Yes, I received both oral and written information (n=15) No, I only received written information (n=1)
Q 6. How would you describe your experience of being cared for in the ward during your stem cell transplant period? (IP)		Very satisfied (n=10) Satisfied (n=5) Pretty satisfied (n=1)
Q 7. How would you describe your experience of being cared for in a home environment during your stem cell transplant period? (OP)	Very satisfied (n=20) Satisfied (n=8) Pretty satisfied (n=4) Not content at all (n=1)	

The standardized assessment document for physicians and nurses to fill in to assess the patient's ability to live at home in connection with hSCT, the empirical data, was processed manually. Our results concerning standardized assessment document are reported with descriptive statistics in continuous text [20].

# Results

This manuscript reports the results of the patient questionnaire as well as physicians' and nurses' assessment of the patient's outpatient treatment. The primary aim of this study was to describe patient subjective experiences of OP- and IP care during autologous hSCT and to ensure the quality of care outside hospital environment as a form of care in order to improve the patient's experience of safety and security. Sixty-four patients participated in the study,

Questions (Q)	Outpatient care (OP) (n=36)	Inpatient care (IP) (n=16) lived with a close relative (n=2) Lived alone (n=14)
Q4/Q4. During your period of care in the ward or at home or alternatively one of the ward's apartments; did you live with any relatives in the room / home, or did you live alone? (OP/IP)	lived with a close relative (n=28) Lived alone (n=6)	
Q5/Q6. Were you bothered by any side effects during your care period that made it difficult for you to manage your day with regard to food, walks or socializing with relatives? (IP). What was the main reason why you were admitted to the ward for further care? (OP)	fever (n=16), nausea / vomiting (n=3), other (n=7)	Troubled by: fever (n=8), nausea / vomiting (n=4), stomach upset (n=3)
Q5. How long did you stay in the home environment during your transplant period, that is, the time after the stem cell transplant? (OP)	The entire care period (n=8) more than half the care period (n=9) less than half the care period (n=14) less than three days (n=3)	
Q8/Q8. How did you experience that the contact with the ward (when you were called by a nurse) worked when you were in a home environment (OP)? How did you experience that the opportunity to contact the staff in the ward worked (IP)?	Worked well (n=32) worked reasonably well (n=1) worked less well (n=1)	Worked well (n=14) worked reasonably well (n=2)
Q9/Q11. Did you feel anxious at any point during your stay in the ward? (IP) Did you feel any anxiety about staying in a home environment instead of in a hospital at some point? (OP)	Never (n=28) sometime (n=5) quite often (n=1)	Never (n=9) sometime (n=6) often (n=1)
Q12/Q14. What support would you get from tips and advice about nutrition and physical activity via mobile and computer when you yourself wish during the day at the ward /at home (IP/OP)?	Very large support (n=2) quite large support (n=8) small support (n=16) no support at all (n=5)	quite large support (n=1) small support (n=8) no support at all (n=3)

Table 3. The questionnaire consists of five equal questions on the factor security, Q4/Q4, Q5/6, Q8/Q8, Q9/11 and Q12/14.

Table 4. Four questions that distinguish inpatient (IP) and outpatient (OP) care on the factor safety, OP=Q10, 12, 16, IP=Q10.

Questions (Q) OP=Q10, 12, 16, IP=Q10	Outpatient care (OP) (n=36)	Inpatient care (IP) (n=16)
Q10 Did the food and drink work satisfactorily in the ward? (IP) Q12 Did the food and drink work satisfactorily in a home environment? (OP)	Yes, all the time (n=18) Yes, more than half the time (n=7) Not so good most of the time (n=6) Did not work at all (n=3)	Yes, all the time (n=9) Yes, more than half the time (n=3) Not so good most of the time (n=4)
Q10 Did your planned visits to the department work well? (OP)	Worked great (n=31) With varying degrees of satisfaction (n=2)	
Q16 Would you have appreciated receiving short messages via text message with encouragement to exercise physically and tips on simple movements? (OP)	Yes (n=3) Maybe (n=15) No (n=14)	

22 (34%) of those patients were treated in IP care and seven patients (11%) received OP care throughout the treatment period. Thirty-five patients (55%) scheduled for OP care combined IP and OP care due to side effect-related reasons.

Fifty-two patients (81%) out of 64 patients answered the questionnaire on patient's experience of safety and security at autologous hSCT. Among them, 36 patients were treated outside hospital environment and 16 at hospital the entire treatment period. Most patients, regardless of the form of care, IP or OP, felt satisfied with the information given by the care provider prior to their stem cell transplantation (Q 1, 2, 3) (Table 2). Most patients cared for in hospital were alone, no relatives or friends staying with them, during the care period compared with patients who were at home where the majority lived with close relatives or friends (Table 3). Nearly all of the patients who were cared for in hospital and who responded to the questionnaire, experienced anxiety during the care period compared with patients who were cared for in a home environment responding to the questionnaire, where the vast majority did not experience any anxiety during the care period (Table 3). Some questions were specific in relation to form of care, IP- or OP care. About the factor concerning safety, the questionnaire consists of two equal questions IP and OP care (Q6 IP/Q7 OP (Table 2), IP Q10/OP Q12), (Table 4).

Regarding the factor security, five questions were equal (IP/OP Q4/Q4, OP/IP Q6 and Q5, OP/IP Q8/Q8, OP/IP Q11/Q9, OP/IP Q14/Q12) (Table 3)

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and six questions concerning security differed in answers from IP and OP patients (OP Q5, Q9, Q13, Q15 and IP Q7 and Q11) (Table 5).

The secondary aim was to evaluate physicians' and nurses' assessment of the patient's self-care ability when cared for outside the hospital during hSCT.

In the standardized assessment document for physicians and nurses to complete to assess the patient's ability to live at home in connection with hSCT, there were no notable differences in the assessment. A total of sixty-four (64) patients could be assessed. Some standardized assessment documents were not fully completed by physicians and nurses. Forty-seven (47) patients were assessed by physicians and thirty-nine (39) patients were assessed by them as suitable for OP care and 6 patients were assessed unsuitable and one patient was not at all suitable. Forty-six (46) patients were assessed by registered nurses, while forty-one (41) patients were assessed suitable for OP care and 6 patients were assessed as unsuitable and one patient was not at all suitable for OP care.

Twelve patients (19%) of the 64 participating patients in the study, did not respond to the study-specific questionnaire. Of the 52 patients who responded to the study specific questionnaire, 4 patients (8%) were not assessed by physicians and nurses.

## Discussion

This study wants to elevate the patient's voice and give the caregiver

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Questions (Q)	Outpatient care (OP) (n=36)	Inpatient care (IP) (n=16)
Q5. How long did you stay in the home environment during your transplant period, that is, the time after the stem cell transplant? (OP)	The entire care period (n=8) more than half the care period (n=9) less than half the care period (n=14) less than three days (n=3)	
Q7. How did you feel that the contact with the staff in the department worked? (IP)		Worked well (n=16)
Q9 How did you experience that the opportunity to contact the department by phone worked when you were staying in a home environment? (OP)	Worked well (n=25) worked reasonably well (n=1) worked less well (n=1) was never relevant (n=6)	
Q11. What help and support from the staff in the department did you lack? (IP)		Wanted to meet the same person more often (n=3) opportunity to be accompanie by staff at activities, walks or company at meals (n=3)
Q13. What do you think should be included as help and support from the department in care in the home environment? (OP)	Daily home visits by a nurse (n=4) opportunity to have their central venous catheter cared for at home (n=3) opportunity to get intravenous fluid administered in the home (n=4) opportunity to get intravenous nutrition administered in the home (n=1) opportunity to have blood samples taken at home to avoid visits at the hospital (n=5) daily opportunity to order food from the department (n=1)	
Q15. How do you see the possibility of being able to have daily contact and ask questions to the responsible nurse in the ward, via text message on a mobile phone or on a computer? This as extended contact forum in addition to the routine currently offered for care in the home environment. (OP)	It would be very helpful (n=2) it would be of some help (n=11) it might be helpful (n=12) it would not be of any help (n=2)	

Table 5. Six questions that distinguish inpatient (IP) and outpatient (OP) care on the factor security. OP=Q5, 9, 13, 15, IP=Q7, 11.

the opportunity to improve care outside the hospital ward based on patients' experiences. The researchers felt that there was a knowledge gap where a quantitative survey study could provide information about patients' experiences of being cared for in IP or OP care. Patients' experiences were summarized in two themes safety and security based on the study questionnaire. The results show that the patients were well informed by the care provider and were generally satisfied with the information. From the compiled results of the questionnaire, it can be deduced that most patients, regardless form of care (IP or OP care), felt satisfied with the information prior to their stem cell transplantation regarding care in hospitals or in the home environment. This is consistent with a study by Bergqvist K, et al. [17] where patients in the hospital care group (IP) and the home care group (OP) expressed high satisfaction with the care and support during the acute post-transplantation phase. We interpret the results from the guestionnaire in this study that the patients feel safe with the information in connection with hSCT (Table 2). More than half of the group, both IP and OP care, felt that the food situation was satisfactory (Table 4). which we interpret as the patients feeling safe with the nutrition part of the care. It is not in line with earlier studies which state that patients in OP care have a higher degree of food intake [11]. Also, Nicolau JE, et al. [21] reported that frequency of oral nutrition in the outpatient model has been associated with lower probability of side effects.

Nearly all patients who were cared for in hospital were alone during the care period compared with patients who were at home where the majority lived with close relatives or friends (Table 3). Even though most of the patients treated in IP care were alone, they felt that the opportunity to contact the health care providers in the ward was very good, which we perceive as that they felt secure during the treatment period. The experience of being secure in contact with the treating department and nurse, *via* daily phone calls, worked very well during the OP care. This agrees with patients in IP care who also felt secure during the care period (Table 3). The sense of security seems to be the same wherever the patient was cared for. Six questions that differentiated between inpatient care (IP) and outpatient care (OP) about the factor security were in the study questionnaire (Table 5). Of the patients who answered the questionnaire, 17 out of 36 of those who stayed in OP care spent the entire period of care or more than half of the period of care at home. The results show

department supported or help to them to stay at home, this in addition to the daily routine contact. They also wanted the opportunity to have blood samples taken at home and to have their central venous catheter cared for and to get intravenous nutrition administrated at home. Of the patients who were cared for in IP care and answered the question about what they lacked and wanted in terms of support from the care staff. 6 out of 16 stated that they wished to see the same staff more often and to have company for walks and meals. (Table 5). Among the patients who were cared for in hospital less than half experienced anxiety during the care period compared with patients who were cared for in a home environment where the vast majority did not experience any anxiety during the care period (Table 3). Current research demonstrates that transplant recipients experience significant psychological distress, with elevated anxiety prior to hSCT [22]. A high incidence of psychological distress after hSCT, including anxiety, has been observed [23]. Therefore, interventions to improve the patient's coping skills may reduce anxiety. This means that knowledge must increase among physicians and nurses regarding these issues so that the patient can feel secure. The researchers recommend rigorous selection criteria as mandatory for routine use of the OP care method. Caregivers such as physicians and nurses play a critical role in the success of outpatient care. Using a standardized assessment form, for assessing the patient's possibility of OP care are needed to evaluate this aspect of care [16]. To move forward with the question of being cared for inpatient or at home in conjunction with hSCT, we suggest that the study design be carried out in a national perspective and that an article review be compiled as a basis for this. In this study, the patients were given space and alternative to write their own reflections following the pre-selected alternatives in the survey. Compilation of those responses will be presented in a separate script.

that daily contact via mobile or computer with the nurse in charge in the care

### Limitations

The study was conducted in a specific hospital and country and may not be totally equal in accordance with outpatient and inpatient care in other countries which could be seen as a limitation. However, the findings are transferable in that they can be used by researchers and healthcare providers to gain a better understanding of the need of standardised assessment documents. One limitation is that we did not include the next of kin which would have broadened our knowledge about their experiences of OP and IP care. The sample size was relatively small; however, Sweden is a small country (10.5 million inhabitants) and this diagnose group is not very common. The low number of recruited patients in IP care is a limiting factor, a minimum of 20 is a golden standard when conducting research in science [24]. The previous study recruited 22 patients in IP care. Patients cared for in OP care were twice as many. Our intention was not to achieve comparable groups as our knowledge of the care environment was that most patients were treated as outpatients at the clinic the study refers to. Our aim was to study patients' experience of safety and security within IP or OP care.

# Conclusion

Despite of small differences in the informants' answers from the questionnaires, patients seem to be satisfied with the information regarding IP and OP care.

It is difficult to draw any general conclusions from this study, but it may form the basis for future major studies on OP care. A national study should be conducted in Sweden where the same basis for medical and nursing assessment of suitability to be cared for in OP care can form the basis. As many patients who are cared for in OP care are readmitted to the ward due to side effects, preventive work should be improved. Discussions should be held on how care can be improved according to the patients' wishes with, for example, home visits by nurses from the treating clinic to relieve the patient from hospital visits. Questions that can be highlighted are what kind of care should be conducted in the OP care and by whom. It should be a matter of course to be able to provide the patient with nutritional support, antibiotic administration and blood sampling at home. Studies comparing cost IP and OP care should be carried out in Sweden. Extensive economic, social, technical and human resources are needed to do this development with the aim of elaborate a national OP care program.

In view of the presented results from this study regarding patient satisfaction and the reduced risk of treatment-related complications, there is reason for more patients to be cared for an outpatient basis. Studies also show the importance of maintaining satisfactory nutritional status during the care period and maintaining physical activity, which can be facilitated when living outside the care ward in a hospital. Physicians and nurses play a critical role in the success of outpatient care and rigorous selection criteria should be mandatory as a matter of routine to ensure the patient receives the right level of care, OP or IP care.

#### **Relevance to clinical practice**

Collecting information from the patient *via* a questionnaire provides the healthcare provider with a basis for developing and improving care for hSCT. Paying attention to the mental well-being equated with the physical well-being is a big task for healthcare, which should be emphasized. Furthermore, a well-developed basis for assessing the patient's level of care can ensure the best care for the patient while at the same time providing society with a financial benefit

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# **Conflict of Interest**

The researchers state no conflict of interest.

### **Author Contribution**

The first author designed the study. Both authors did the data discussion and wrote, finalised and approved the manuscript together.

### References

- Jo, Jae-Cheol, Byung Wook Kang, Geundoo Jang and Sun Jin Sym, et al. "BEAC or BEAM high-dose chemotherapy followed by autologous stem cell transplantation in non-Hodgkin's lymphoma patients: Comparative analysis of efficacy and toxicity." Ann Hematol 87 (2008): 43-48.
- Hügl, Thomas and Thomas Daikeler. "Stem cell transplantation for autoimmune diseases." *Haematologica* 95 (2010):185-188.
- Khaddour, Karam, Caroline K. Hana and Prerna Mewawalla. "Hematopoietic stem cell transplantation." In StatPearls. StatPearls Publishing, 2021.
- Passweg, Jakob R., Helen Baldomero, Christian Chabannon and Grzegorz W. Basak, et al. "Hematopoietic cell transplantation and cellular therapy survey of the EBMT: Monitoring of activities and trends over 30 years." *Bone Marrow Transplant* 56 (2021): 1651-1664.
- 5. https://vavnad.se/hematopoetiska-stamceller/
- Kris, Mark G., Paul J. Hesketh, Mark R. Somerfield and Petra Feyer, et al. "American Society of Clinical Oncology guideline for antiemetics in oncology: Update 2006." J Clin Oncol 24 (2006): 2932-2947.
- Sauer Heilborn, Annette, Diane Kadidlo and Jeffrey McCullough. "Patient care during infusion of hematopoietic progenitor cells." *Transfusion* 44 (2004): 907-916.
- Jones, Jeffrey A., Muzaffar H. Qazilbash, Ya Chen T. Shih and Scott B. Cantor, et al. "In hospital complications of autologous hematopoietic stem cell transplantation for lymphoid malignancies: Clinical and economic outcomes from the Nationwide Inpatient Sample." *Cancer* 112 (2008): 1096-1105.
- Owattanapanich, Weerapat, Kittima Suphadirekkul, Chutima Kunacheewa and Patompong Ungprasert, et al. "Risk of febrile neutropenia among patients with multiple myeloma or lymphoma who undergo inpatient versus outpatient autologous stem cell transplantation: A systematic review and meta-analysis." BMC Cancer 18 (2018): 1-9.
- Jagannath, S., D.H. Vesole, M. Zhang and K.R. Desikan, et al. "Feasibility and cost-effectiveness of outpatient autotransplants in multiple myeloma." *Bone Marrow Transplant* 20 (1997): 445-450.
- 11. Svanberg, Anncarin. "To be safe at home or at hospital after autologous stemcell transplantation: Why readmission to hospital." *J Nurs Care* 8 (2019).
- Shah, Nina, A. Megan Cornelison, Rima Saliba and Sairah Ahmed, et al. "Inpatient vs outpatient autologous hematopoietic stem cell transplantation for multiple myeloma." *Eur J Haematol* 99 (2017): 532-535.
- Shrthi, Ganechappa Kodad, Sutherland Heather, Limvorapitak Wasithep and Abou Mourad Yasser, et al. "Outpatient Autologous Stem Cell Transplants for Multiple Myeloma: Analysis of Safety and Outcomes in a Tertiary Care Center." *Clin Lymphoma Myeloma Leuk* 19 (2019):784-790.
- Yip, Hao Meng, Kwee Yong, Dunnya De-Silva and Neil Rabin, et al. "Assessing the safety of autologous stem cell transplant pathway via ambulatory care for patients with multiple myeloma." *Hematol Oncol Stem Cell* 14 (2021): 160-162.
- https://www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/patientlag-2014821\_sfs-2014-821
- Martino, Massimo, Annalisa Paviglianiti, Mara Memoli and Giovanni Martinelli, et al. "Multiple myeloma outpatient transplant program in the era of novel agents: state-of-the-art." Front Oncol 10 (2020): 592487.
- Bergkvist, Karin, Joacim Larsen, Unn-Britt Johansson and Jonas Mattsson, et al. "Hospital care or home care after allogeneic hematopoietic stem cell transplantation-Patients' experiences of care and support." *Eur J Oncol Nurs* 17 (2013): 389-395.
- World Medical Association. "World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects." Jama 310 (2013): 2191-2194.
- 19. http://www.codex.vr.se/forskningmanniska.html

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- 20. https://www.bokus.com/bok/9789144122885/forskningshandboken-forsmaskaliga-forskningsprojekt-inom-samhallsvetenskaperna/
- Nicolau, José Eduardo, Leila Maria Magalhães Pessoa de Melo, Daniel Sturaro and Rosaura Saboya, et al. "Evaluation of early hospital discharge after allogeneic bone marrow transplantation for chronic myeloid leukemia." Sao Paulo Med J 125 (2007): 174-179.
- 22. Alice, Polomeni, Moreno Enrique, Schulz-Kindermann Frank and Enric Carreras,

et al. "Psychological morbidity and support." The EBMT Handbook: Hematopoietic Stem Cell Transplantation and Cellular Therapies [Internet]. 7th edition, Springer, 2019.

- Hermioni L, Amonoo, Christina N Massey, Melanie E Freedman and Areej El-Jawahri, et al. "Psychological considerations in hematopoietic stem cell transplantation." *Psychosomatics* 60 (2019):331-342
- 24. https://www.nngroup.com/articles/summary-quant-sample-sizes/Dec.05-2022

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