European Journal of Oncology Nursing 17 (2013) 389–395

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Hospital care or home care after allogeneic hematopoietic stem cell transplantation – Patients' experiences of care and support

Karin Bergkvist [a,b,*], Joacim Larsen [a,c], Unn-Britt Johansson [b,d], Jonas Mattsson [a,e], Britt-Marie Svahn [a,e]

[a] Department of Laboratory Medicine, Therapeutical Immunology, Karolinska Institutet, Stockholm, Sweden
[b] Sophiahemmet University College, Stockholm, Sweden
[c] The Red Cross University College, Stockholm, Sweden
[d] Department of Clinical Sciences Danderyd Hospital, Division of Medicine, Karolinska Institutet, Stockholm, Sweden
[e] Center for Allogeneic Stem Cells Transplantation, Karolinska University Hospital Huddinge, Stockholm, Sweden

Keywords:
Allogeneic stem cell transplantation
Hospital care
Home care
Patient satisfaction
Pancytopenic phase
Mixed methods analysis

A B S T R A C T

Purpose: Treatment at home during the pancytopenic phase after allogeneic hematopoietic stem cell transplantation (HSCT) has been an option for patients at our center since 1998. Earlier studies have shown that home care is safe and has medical advantages. In this study, we present patients' experiences of care and support while being treated in hospital or at home during the acute post-transplantation phase.

Method: Patients ($n = 41$, 22 in hospital care and 19 in home care) answered the SAUC questionnaire at discharge (when home, or from hospital). Both statistical analysis and deductive content analysis were used.

Results: The patients were highly satisfied with the care and support during the acute post-transplantation phase. Patients in home care were found to be more satisfied with care in general than patients in hospital care. The importance of safety, empathy, and encouragement from healthcare staff were expressed regardless of where care was given. Patients also felt that receipt of continuous, updated information during treatment was important and they had a strong belief in HSCT but were uncertain of the future regarding recovery.

Conclusions: The main findings of this study were that in comparison to hospital care, home care does not appear to have a significant negative effect on patients' experiences of care and support during the acute post-transplantation phase. In addition patients in home care felt safe, seen as a person and encouragement seem to empower the patients at home. Thus, this study may encourage other transplantation centers to provide home care if the patients want it.

Introduction

Allogeneic hematopoietic stem cell transplantation (HSCT) is a well-established treatment option for hematological diseases and inborn errors of metabolism and is now also offered to elderly patients and patients with co-morbidities. Allogeneic stem cell transplantation can offer an opportunity for long-term disease control and potential cure (Mattsson, 2008). During the last decade, toxicity and mortality associated with HSCT have been reduced due to several improvements such as better pretreatment and genomic tissue typing, improved supportive care and treatment of infections (Mattsson, 2008; Remberger et al., 2011). The treatment is still associated with substantial risk of morbidity and mortality.

Mainly two conditioning regimen are used before the HSCT, the myeloablative conditioning (MAC) and the non-myeloablative also called reduced intensity conditioning (RIC). The myeloablative conditioning regimes consist of high doses of chemotherapy sometimes in combination with radiation. Type of conditioning is decided from various aspects such as patient's disease, age, donor and co-morbidity (Gyurkocza et al., 2010).

After the conditioning and infusion of donated stem-cells, the patient becomes pancytopenic with a high risk of infections, fatigue, and graft-versus-host disease (GVHD) (Gyurkocza et al., 2010). During this period, patients are often treated in single rooms with reversed isolation and air filtration, or in rooms with laminar airflow (Schlesinger et al., 2009).

* Corresponding author. Sophiahemmet University College, P.O. Box 5605, SE-114 86 Stockholm, Sweden. Tel.: +46 8 406 29 56; fax: +46 8 10 29 09.
E-mail address: karin.bergkvist@shh.se (K. Bergkvist).

1462-3889/$ – see front matter © 2012 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ejon.2012.12.004

When Russell et al. (1992) had described successful treatment of patients in an outpatient setting, we were encouraged to try home care for patients being treated at our unit. The assumption was that patients in home care would have a better quality of life than patients in hospital care. Since 1998 it has been possible for patients to choose between hospital care and home care after HSCT Svahn et al. (2002) found that home care during HSCT had several medical advantages, such as fewer days with fever and with total parenteral nutrition (TPN). Patients in home care also showed less GVHD, lower transplant-related mortality (TRM) and improved survival compared to a control group who were cared for at the hospital (Svahn et al., 2005). In a study of 100 patients treated outpatient showed a low non-relapse mortality (NRM) comparably with traditional in-patient care (Solomon et al., 2010). Another study also showed a lower NRM among patients in outpatient care at day 100 (McDiarmid et al., 2010). Outpatient care (McDiarmid et al., 2010; Solomon et al., 2010) and home care (Svahn et al., 2000) has been reported to be medically safe for the patients. During their period in hospital, most HSCT patients experience the highest level of psychological and emotional distress (Fife et al., 2000; Prieto et al., 2005) and have many physical symptoms (Larsen et al., 2004). Reducing the burden of symptoms is therefore an important treatment goal for the healthcare staff, and there is a strong need for support and care throughout the transplantation period. However, patients' own experiences of home care have not yet been documented. The aim of present study was therefore to describe and compare patients' satisfaction and experiences of care and support during the acute post-transplantation phase after HSCT when being treated in hospital or at home.

Patients and methods

Patients

Patients who underwent HSCT during 2006–2009 were asked to participate in the study. Inclusion criteria were age $\geq$ 18 years, ability to read, speak, and understand the Swedish language. Patients fulfilling the criteria for home care (see under Clinical setting "Home care"), had an opportunity to choose home care during the acute post-transplantation phase. The conditioning and stem cell infusion were given in hospital to all patients. All patients were given conventional prophylaxis against CMV (Forslow et al., 2010) and GVHD (Olsson et al., 2010). The patients were discharged when an absolute neutrophil count (ANC) of more than 0.2×10^9/l for two continuous days had been reached, and if there were no complications requiring attention (Svahn et al., 2000).

Altogether, 41 patients were included in the study, 22 in hospital care and 19 in home care. The median age of patients in hospital care was 51 years and 56 years in home care. Most patients were married or cohabiting and acute leukemia was the most common diagnosis. The majority received reduced intensity conditioning (RIC) and peripheral stem cells. Demographic and clinical characteristics are listed in Table 1.

The median length of stay in hospital was 23 (18–48) days and the median time in home care was 19 (15–59) days. The patients in home care returned to their home in median 1 (0–10) days after HSCT. During the pancytopenic phase, nine patients of 19 in home care were re-admitted to hospital, a total of 12 hospitalization episodes. One patient in home care was re-admitted four times and the other patients were re-admitted one time each. Patients stayed in hospital for a median of 4 (0–13) days. Reasons for re-admission were infections ($n = 7$), mucositis ($n = 1$), eye complications ($n = 1$), nausea ($n = 1$), headache ($n = 1$), and a sick family caregiver ($n = 1$).

Table 1
Demographic and clinical characteristics ($n = 41$).

Variable	Home care ($n = 19$)	Hospital care ($n = 22$)	*P*-value
Age, median (range)	56 (32–67)	51 (33–65)	0.46
Gender: (n)			0.16
Female	7	13	
Male	12	9	
Civil status: (n)			0.26
Married/Cohabiting	15	17	
Unmarried	4	2	
Divorced	–	2	
Diagnosis: (n)			0.43
Acute leukemia	9	10	
Chronic leukemia	2	2	
Lymphoma	1	5	
MDS/MPS	5	3	
Myeloma	–	1	
Solid tumor	1	1	
PNH	1	–	
Donor: (n)			0.69
MUD	14	15	
Sibling	5	7	
Stem cell source: (n)			0.64
PBSCs	17	19	
BM	2	2	
CB	–	1	
Conditioning: (n)			0.49
Reduced intensity conditioning (RIC)	14	14	
Myeloablative conditioning (MAC)	5	8	

MDS/MPS: myelodysplastic syndrome/myeloproliferative syndrome; PNH: paroxysmal nocturnal hemoglobinuria; MUD: matched unrelated donor; PBSCs: peripheral blood stem cells; BM: bone marrow; CB: cord blood.

Informed consent was obtained from all patients, and the study was approved by the Ethics Committee of Karolinska University Hospital, Karolinska Institutet (Dnr 449/97).

Clinical setting

Hospital care

Patients were treated in conventional single rooms with reversed isolation and air filtration. The room included a TV, a DVD-player, and an exercise bicycle. Patients were encouraged to have one family member or friend stay with them. The patients could take a walk outside the hospital after 18:00 h on weekdays and at any time during weekends. Clothes and sheets were cleaned three times a week. Supportive care was given by nurses and physicians according to the patient's health status. Pot plants were not allowed in the ward due to the risk of infection by fungi and bacteria.

Home care

Most patients left hospital on day + 1 post-HSCT. Specific criteria had to be fulfilled before the patients destined for home care could return home: a family member or friend who was 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 flowers were allowed, the bed linen used by the patients had to be laundered three times a week, and the patient's home had to be within one to two hours' driving distance from our unit. During conditioning, information was given concerning when and where to ask for help, what the patient was allowed to eat, and regarding outdoor activities. Visitors were allowed but had to be free from overt infections. During the acute post-transplantation phase,