

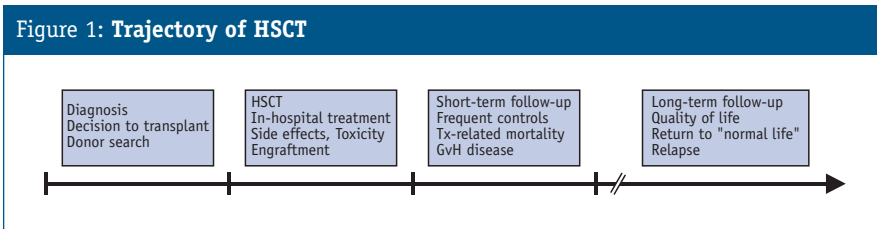
* CHAPTER 16

Psychosocial aspects of HSCT

A. Kiss, M. Kainz

1. Introduction

HSCT has moved from an experimental treatment to become an accepted therapy. At the same time, the primary focus on increasing survival in previously lethal diseases has been enlarged to encompass psychosocial issues such as quality of life. In this Chapter, specific psychosocial aspects of the patient, the donor, the family, and the transplant team will be discussed in relation to the time trajectory of HSCT shown in Figure 1.



2. Psychosocial aspects - the patient

2.1. Psychosocial morbidity

The diagnosis of a deadly disease and the option of a treatment that may cure but which also has potentially lethal side effects puts the patient under heavy pressure and adjustment is difficult. Psychosocial morbidity is frequent, particularly adjustment disorders with symptoms of depression and anxiety. Approximately one third of patients report significant symptoms of intrusive and avoidance stress responses (1). The search for a suitable related or UD in allo-HSCT is a hard time for patients, for fear of not finding a donor. Coping mechanisms vary according to individual patients from fighting spirit to hopelessness and helplessness. Psychosocial evaluation systems such as the Transplant Evaluation Rating Scale (TERS) (2) have been proposed for assessing the psychosocial functioning of HSCT recipients, which could then allow early intervention in case of poor functioning. Psychiatric morbidity prolongs hospital stay independently of in-hospital somatic risk factors (1) and pre-transplant physical and mental functioning is strongly associated with self-reported recovery from stem cell transplantation (3). The greatest emotional distress occurs after admission to hospital and before the transplantation. Anxiety and depression decrease one week after the transplant. Psychosocial well-being after the transplant is heavily influenced by mucositis, toxicity, and other side effects, but conversely psychological factors such as anxiety, BMT-related distress, and social support also have a significant impact

on how severely patients experience their mouth pain. Beside the usual medical treatments, psychosocial interventions such as hypnosis and muscle relaxation can substantially reduce nausea and pain. After discharge, many patients are disappointed by their low energy level (fatigue), high susceptibility to infections and the very slow return to normal life. In the first year after transplant psychological distress declines (4). However, elevated levels of anxiety and depression prior to transplantation predict more anxiety and depression in the follow-up period (4).

Somatic risk factors for outcome after HSCT are well described, and include factors relating to the patient, the donor and the type of transplant. However coping strategies assessed pre-transplant such as emotional support, acceptance, taking control, and compensation also seem to have an influence. Compensation is reported to be associated with shorter, the other strategies with longer survival. Replication of the data is essential before clinical recommendations can be made (5). Patients suffering from cGvHD have lower QoL and may therefore be more vulnerable to depression and anxiety disorders.

At long-term follow-up, some survivors still have to cope with a low energy level, some with fear of losing their job, and all have to deal with infertility and the fear of relapse and secondary malignancies. At 3 yrs post transplantation 80% of women and 29% of men report sexual problems (6).

2.2. Quality of life (QoL)

Good QoL in HSCT has been reported repeatedly. However, it should be kept in mind that QoL is a poorly defined concept and instruments professing to measure QoL measure different things. The approaches that are most frequently used are shown in [Table 1](#).

Table 1: Different approaches to the measurement of QoL in HSCT

Approach	Examples
Generic	SF-36 (Medical Outcomes Survey - Short Form 36; EORTC QLQ-C30 (European Organisation for Research and Treatment of Cancer Core Quality of Life questionnaire), FACT (Functional Assessment of Cancer Therapy)
Disease-specific	Leukaemia/BMT module of EORTC QLQ-C30, FACT-BMT (Bone Marrow Transplantation)
Utilitarian	TTO (Time Trade-Off)
Individualised	SEIQoL-DW (Schedule for the Evaluation of Individual QoL - Direct Weighting)

A standardised multidimensional questionnaire (physical, psychological, functional and social dimensions) is often used in combination with a disease-specific module (7). Recently, a high-dose chemotherapy questionnaire module to supplement the European Organisation for Research and Treatment of Cancer Core Questionnaire (EORTC QLQ-C30) has been developed (8). The advantage of a generic approach is to obtain a numeric figure for a specific item, which can be used to assess the impact on QoL across different diseases or to assess changes in the same patient over time. However, the individual perception of a given symptom is neglected by these questionnaires: e.g. not being able to climb two flights of stairs may represent a substantial impairment for one patient but may have no impact on another patient. The utilitarian approach has only been used in solid organ transplantation but not for HSCT, as far we know. In this approach it is left to the patient to decide the areas in which the health-related QoL is compromised, as well as the severity of impairment. However, no information about the characteristics of the compromised dimension is given.

An individualised approach not only lets the patient define the specific domains which are most important for his or her QoL, but also allows the patient to weight the importance of these domains individually (9). Such areas included positive aspects, e.g. a changed view of life and oneself (10). Cancer-related fatigue is one of the biggest constraints of QoL after HSCT.

The majority of studies are cross-sectional and restricted to short follow-up. Compared to normal controls, HSCT survivors at a mean of 7 years after transplantation reported poorer physical, psychological, and social functioning but, conversely, more psychological and interpersonal growth, differences that appeared to persist many years after HSCT (11).

In a study in survivors 10 years after HSCT, health problems were not focused on specific diseases or limited to survivors with readily identifiable risk factors. Musculoskeletal problems were frequent. Survivors require screening for sexual problems, urinary frequency, mood and need for antidepressants or benzodiazepines (12).

However, it should be kept in mind even if QoL is measured more frequently nowadays, the data are often not understandable for the physician involved and therefore not used in the decision-making process with the patient (13).

2.3. Neglected issues

2.3.1. The patient with delirium

Half of patients who undergo HSCT experience an episode of delirium during the 4 weeks post transplantation. Symptoms of delirium are poorly recognised by professionals because of the variability in the symptoms of confusion over the 24-

hour period and also the patients' tendency to dissimulate, as they do not want to be identified as "mad". If symptoms are recognised there is a tendency to label them as difficulty in coping with an unbearable situation rather than a diagnosis of delirium. Transplant physicians are often inexperienced in the treatment of delirium, which can be successfully managed with a low dose of narcoleptics. Compared to patients without delirium, patients who experience delirium during myeloablative HSCT showed impaired neurocognitive abilities and persistent distress 80 days after transplantation (14). The long-term effect of delirium post HSCT remains to be determined.

2.3.2. The dying patient

A substantial number of patients die despite HSCT and they represent the primary sources of stress in nurses and doctors working on a transplant unit (15). In a recent study about Advanced Care Planning (ACP) in HSCT patients, those patients least likely to have planned for poor outcomes were the ones most likely to face them (16).

2.3.3. The non-compliant patient

Non-compliance in patients transplanted for solid organs is one the main factors of transplant failure. The prevalence of non-compliance in HSCT recipients is unknown (17). Given the complex medical regimen and the strict dietary and behavioural rules after transplantation, the medical team may incorrectly ascribe poor therapeutic outcomes to inadequacies in the regimen instead of non-compliance of the patients. They may prescribe more potent medicine with the potential for greater adverse reactions (17).

Poverty is a potential factor in non-compliance that is often neglected: In the US underinsured/poor HSCT recipients have the same mortality during inpatient treatment as the non-poor, but a significantly higher mortality in the following 100 days. The authors hypothesise that the higher mortality is due to the poor patients' inability to comply with or seek medical care because of deficient socioeconomic resources (18).

3. Psychosocial aspects - the donor

3.1. Related donor

In contrast to living solid organ donors little is known about the decision-making process of HSC donors. Most donors do not even recognise a decision-making process, they have "no choice", they just want to help the recipient (19). They believe the psychological aspects of the procedure outweighs the physical aspects of

donation (19).

Siblings of unsuccessful transplant recipients may feel guilty for their “bad marrow”, some donors have problems in coping, and difficulties within the affected families are not uncommon.

3.2. Unrelated donors

Medical advances have made possible HSCT from UD. Many donor registries have been established in recent years. The motivations of UD donors may be different from related donors, as they do not know the recipients. Higher levels of ambivalence about BM donation are associated with joining during a recruitment drive for a specific patient, perceiving the recruitment staff as less informative, being discouraged from joining by others and not having an intrinsic commitment to donate (20). Unrelated female donors are mostly motivated by positive feelings, empathy and the desire to help someone.

4. Psychosocial aspects - the family

The most significant social support for HSCT recipients comes from their family. Family members experience the similar distress as do the patients and report more impairments in family relationship than patients (21). Physical and emotional recovery after HSCT depends on the quality of family relationships as perceived by the recipient. They seem to have the most important role as a filter for stress. In a recent study in HCT survivor/partner pairs (n=177) spouses/partners experience similar emotional and greater social long-term costs of cancer and HCT than survivors without the potential compensatory benefits of post-traumatic growth (22).

5. Psychosocial aspects - the transplant team

5.1. Present and future of the transplant team

There is great economic pressure for transplant teams to carry out more transplant procedures in less time with the same or even reduced staff. Earlier discharge and frequent unscheduled readmission may result.

5.2. Psychosocial well-being of team members

The very nature of HSCT is characterised by the dominance of technology and the rapidity of decision-making and practice. Death is considered as a failure and is often due to the toxicity of the procedure itself or infections (23). Both doctors and nurses consider regular work with dying patients as the primary source of stress, besides other stressors such as interpersonal staff conflicts, excessive responsibilities and

highly demanding patients and families (15). The death of a patient may be considered as a mismatch of high investment (high costs, time, emotional labour) and low returns (causing suffering without survival). Burnout in nursing and medical staff is high, half of them being emotionally exhausted, and 80% reporting feelings of low personal accomplishment (15). Doctors and nurses reported that the most frequent effects from prolonged stress were increased illness, reduced productivity and increased clinical errors.

5.3. Care for/of the team

As the care of the patient is the primary focus for transplant teams, their own needs for care are often denied and seldom addressed. Burnout must be considered as a permanent danger and not as an individual problem of the team member concerned. Time and resources have to be devoted to the care of the team as a prophylactic measure and not only after a team member has cracked under the pressure.

6. Personal conclusions and practical applications

Psychosocial issues in patients, donors, families and transplant teams are not "soft data" but have a substantial impact on the morbidity of all persons involved and probably on the survival of patients.

Communication and psychosocial skills are core competencies for doctors and nurses. They cannot be delegated to mental health professionals. Evidence-based training in these skills is available but seldom used by transplant teams.

"The availability of specialised psychosocial care is necessary and, as with medical treatment, it should be carried out by specially trained staff" (24, 25).

Every transplant unit must have a mental health professional who is a team member of the transplant team. A consulting psychiatrist coming solely on request as demanded by the present JACIE accreditation procedure is not sufficient. The tasks of a mental health professional regularly working in the transplant unit and its outpatient department is to care for individual patients and their families, and to support the transplant team.

References

1. Prieto JM, Blanch J, Atala J, et al. Psychiatric morbidity and impact on hospital length of stay among hematologic cancer patients receiving stem-cell transplantation. *J Clin Oncol* 2002; 20: 1907-1917.
2. Hoodin F, Kalbfleisch KR. Factor analysis and validity of the Transplant Evaluation Rating Scale in a large bone marrow transplant sample. *J Psychosom Res* 2003; 54: 465-473.
3. Andorsky DJ, Loberiza FR, Lee SJ. Pre-transplantation physical and mental functioning is strongly associated with self-reported recovery from stem cell transplantation. *Bone*

- Marrow Transplantation 2006; 37: 889-895.
4. Hjermsstad MJ, Loge JH, Evensen SA, et al. The course of anxiety and depression during the first year after allogeneic or autologous stem cell transplantation. *Bone Marrow Transplantation* 1999; 24: 1219-1228.
 5. Grulke N, Bailer H, Hertenstein B, et al. Coping and survival in patients with leukemia undergoing allogeneic bone marrow transplantation - long term follow-up of a prospective study. *J Psychosom Res* 2005; 59: 337-346.
 6. Syrjala KL, Roth-Roemer SL, Abrams JR, et al. Prevalence and predictors of sexual dysfunction in long-term survivors of marrow transplantation. *J Clin Oncol* 1998; 16: 3148-3157.
 7. Kopp M, Schweigkofler H, Holzner B, et al. EORTC QLQ-C30 and FACT-BMT for the measurement of quality of life in bone marrow transplant recipients: a comparison. *Eur J Haematol* 2000; 65: 97-103.
 8. Velikova G, Weis J, Hjermsstad MJ, et al. The EORTC QLQ-HDC29: a supplementary module assessing the quality of life during and after high-dose chemotherapy and stem cell transplantation. *Eur J Cancer* 2007; 43: 87-94.
 9. Frick E, Borasio GD, Zehentner H, et al. Individual quality of life of patients undergoing autologous peripheral blood stem cell transplantation. *Psychooncology* 2004; 13: 116-124.
 10. Wettergren L, Sprangers M, Bjorkholm M, Langius-Eklöf A. Quality of life before and one year following stem cell transplantation using an individualized and a standardized instrument. *Psychooncology* 2007 Jul 5 [Epub ahead of print].
 11. Andrykowski MA, Bishop MM, Hahn EA, et al. Long-term health-related quality of life, growth, and spiritual well-being after hematopoietic stem-cell transplantation. *J Clin Oncol* 2005; 23: 599-608.
 12. Syrjala KL, Langer SL, Abrams JR, et al. Late effects of hematopoietic cell transplantation among 10-year adult survivors compared with case-matched controls. *J Clin Oncol* 2005; 23: 6596-6606.
 13. Lee SJ, Joffe S, Kim HT, et al. Physicians' attitudes about quality-of-life issues in hematopoietic stem cell transplantation. *Blood* 2004; 104: 2194-2200.
 14. Fann JR, Alfano CM, Roth-Roemer S, et al. Impact of delirium on cognition, distress, and health-related quality of life after hematopoietic stem-cell transplantation. *J Clin Oncol* 2007; 25: 1223-1231.
 15. Molassiotis A, van den Akker OB, Boughton BJ. Psychological stress in nursing and medical staff on bone marrow transplant units [published erratum appears in *Bone Marrow Transplant* 1995 Aug; 16: 328]. *Bone Marrow Transplantation* 1995; 15: 449-454.
 16. Ganti AK, Lee SJ, Vose JM, et al. Outcomes after hematopoietic stem-cell transplantation for hematologic malignancies in patients with or without advance care planning. *J Clin Oncol* 2007; 25: 5643-5648.
 17. Bishop MM, Rodrigue JR, Wingard JR. Mismanaging the gift of life: Noncompliance in the context of adult stem cell transplantation. *Bone Marrow Transplantation* 2002; 29: 875-880.
 18. Selby GB, Ali LI, Carter TH, et al. The influence of health insurance on outcomes of related-donor hematopoietic stem cell transplantation for AML and CML. *Biol Blood Marrow*

Transplant 2001; 7: 576.

19. MacLeod KD, Whitsett SF, Mash EJ, Pelletier W. Pediatric sibling donors of successful and unsuccessful hematopoietic stem cell transplants (HSCT): A qualitative study of their psychosocial experience. *J Pediatr Psychol* 2003; 28: 223-230.
20. Switzer GE, Myaskovsky L, Goycoolea JM, et al. Factors associated with ambivalence about bone marrow donation among newly recruited unrelated potential donors. *Transplantation* 2003; 75: 1517-1523.
21. Siston AK, List MA, Daugherty CK, et al. Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplantation* 2001; 27: 1181-1188.
22. Bishop MM, Beaumont JL, Hahn EA, et al. Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *J Clin Oncol* 2007; 25: 1403-1411.
23. Futterman AD, Wellisch DK. Psychodynamic themes of bone marrow transplantation. When I becomes thou. *Hematol Oncol Clin North Am* 1990; 4: 699-709.
24. Fallowfield L, Jenkins V, Farewell V, et al. Efficacy of a Cancer Research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet* 2002; 359: 650-656.
25. Gratwohl A, Apperley JF, Gluckman E, (eds). *The EBMT Handbook. Blood and Marrow Transplantation. European School of Haematology; European Blood and Marrow Transplantation, 2000.*

NOTES