Quality of Patient Care in Bone Marrow Transplantation

Bone marrow transplantation (BMT) is an established therapeutic technology, which has been employed since the early 1960s for chronic benign conditions, such as sickle cell anemia and polycythemia vera and for malignant diseases, such as leukemia, myeloma, lymphoma, and myelodysplastic syndromes (1). In essence, it is a procedure comprising several stages of providing the patient with a normal hematopoietic system when his or hers has been rendered defective due to a disease or therapy. First, an intensive course of high-dose chemotherapy and total body irradiation, known as the conditioning regimen, prepares the patient for the transplant. Its purpose is the destruction of the patient’s defective marrow or any residual malignant cells and the suppressing of the immune system sufficient to allow the donor marrow to engraft. In the next stage, a healthy marrow (usually from a donor – allogeneic BMT, different from autologous BMT, in which it is derived from the patient himself or herself) is infused to engraft over a period of weeks to permit a gradual return of the system to independence as optimal hematopoiesis is re-established (2). Until the donor marrow is successfully engrafted, the individual is at risk of debilitating side effects and a range of potentially fatal infections. During the past two decades there have been significant advances in the refinement of the bone marrow transplantation process, resulting in reduced mortality and morbidity (3). The procedure has seen rapid expansion during the last decade, including hematopoietic stem cells transplantation (HSCT) for acquired or congenital disorders of the hematopoietic system or chemosensitive, radiosensitive, and immunosensitive malignancies (4,5).

Biomedical research is well established in this field and has focused predominantly on improving survival rates as well as on achieving a more effective control of toxic effects. The evolution of clinical supportive care to prevent and successfully control dangerous complications resulting from the blood and immune system suppression accompanying BMT has contributed significantly to this scientific progress. However, less emphasis has been placed on the patients undergoing the procedure, most of whom have a disease, which, if left untreated, is generally fatal after several months. Living under pressure of a life-threatening disease and complications that result from the therapeutic procedure have both a physical and psychological effect (6,7). It is therefore essential to adopt a broad view of the patients’ needs and concerns during the various stages of the procedure and to ensure that high quality, patient centered, timely and effective patient care, consistent with current professional knowledge is available whenever indicated (8). The European Group for Blood and Marrow Transplantation has introduced an annual activity survey which covers 95% of all HSCT centers in Europe. The survey permits detailed observation of changes in technologies and may serve as a tool for external quality review (4) as an accreditation that would probably focus on technological issues and address mainly efficacy and safety. I am, however, not aware of any report that relates to the quality of patient care delivered in the highly technological BMT settings, with possibly varying standards of their own. The increase in the number of BMT survivors and concern for their quality of life as well as long-term complications, inevitably begin to involve medical practitioners outside the specialized settings such as oncologists, hematologists, and primary care physicians. Therefore, it may be indicated to address the issue of the quality of care rendered to those who undergo BMT and to review the appropriate medical and nursing intervention for problems occurring in various stages of the procedure.

Conditioning Regimen

During this stage, the main problems are:

- Severe nausea and vomiting requiring the administration of high doses of antiemetics, assessment of their effectiveness and monitoring for potential side effects. Fluid and electrolyte status also needs ongoing assessment.

- Painful mucositis demands daily oral assessment, teaching the patient to practice frequent oral care in order to minimize superimposed infection, as well as the use of topical anesthetics or parenteral narcotics for pain control.

- Hemorrhagic cystitis due to sloughing of bladder epithelium with subsequent bleeding, requiring prevention by vigorous intravenous hydration combined with bladder irrigation, accompanied by fluid and electrolyte assessment.
Early Post Transplant Stage

Problems, mainly due to consequences of the conditioning regimen, which may arise during the first few weeks after the transplantation are:
- Acute renal failure (due to regimen related toxicity).
- Profound neutropenia and thrombocytopenia requiring blood and platelet transfusions and prophylactic antimicrobial treatment.
- Veno-occlusive disease, a liver disease manifested by sudden weight gain, hepatomegaly, right upper quadrant abdominal pain, ascites, jaundice, encephalopathy.
- Graft versus host disease, unique to allogeneic transplantation, occurs when the donated marrow recognizes the recipient tissue as foreign, and is manifested by rash, diarrhea, and liver dysfunction.
- Infections requiring prompt treatment with broad-spectrum intravenous antibiotics or antiviral and antifungal preparations.
- Interstitial pneumonitis, with a complex etiology, manifested by cough and fever, has the potentiality for rapid progression to respiratory failure with mortality of 80%.
- Marrow graft failure.
- Immunodeficiency: reconstitution of the donor marrow generally begins 3-4 weeks after BMT, but patients remain immunosuppressed for many months, even once blood counts have recovered (probably due to lymphocyte subset imbalance and impaired mucosal defense).

In addition to physical problems, there is also psychological distress, which is less severe in the presence of adaptability and family cohesion (9). Family relationships are important determinants of physical and psychological recovery (10) and therefore families need education before the transplant, as well as psychological intervention afterwards (11).

Until normal hematopoiesis is achieved, protective isolation is a common requirement that may have psychological impact on the patients’ adaptation, coping, and emotional responses (12). During the experience of isolation, intensive caring relationships are likely to be established between patients, their families, and staff, occasionally causing problems. Such emotionally intense work may be expected to result in a certain level of stress among staff, which may lead to burn out and ultimately to decreased levels of motivation, declining sense of role satisfaction and an inflexible approach to care (13).

Late Post Transplant Stage

Even if cured of the disease, patients who have undergone BMT are prone to a series of long-term complications. During this stage the following problems may arise:
- Gonadal and/or endocrine dysfunction, with 25-50% of patients having difficulties in sexual function, as well as experiencing induction of menopause and infertility (14).
- Cataract (from radiotherapy).
- Immunodeficiency.
- Chronic graft versus host disease may affect 25-50% of long-term survivors of allogeneic BMT; it is manifested by skin changes (dryness, thickness, changes in pigmentation), abnormal liver function, dryness of eyes and mouth, contractures, and esophagitis.

Social support and strong family relationships are associated in BMT patients with better long-term adjustment concerning their domestic, extended family, or social environment and psychological distress, the main aspects of contributing to higher levels of their quality of life (15).

The relative 5-year survival for all treated leukemia patients is still around 25%, implying that a significant number of those who receive treatment, including the patients with multiple myeloma and lymphoma, primarily BMT, will die.

Variations in BMT practice may mean that some specialized settings already incorporate an effective palliative care philosophy throughout the treatment experience while in others such intervention is introduced late in the disease trajectory and in some palliative care may not be perceived as relevant at all. As the case may be, staff in the BMT settings has to daily deal with issues of dying, death, and bereavement (16).

Patients and families need support throughout the procedure and the recovery phase, monitoring changes in their condition and providing a range of therapeutic interventions. Bone marrow transplantation is a protracted and painful event for all those involved, a uniquely challenging procedure, which places considerable demands on both patients and caregivers. It requires appropriate, complicated, and technically excellent care delivered with the required skill. It further demands excellent interaction between the provider and patient in communication, in the ability of the provider to maintain the patient’s trust, and to treat him or her with concern, empathy, honesty, tact, and sensitivity while also giving emotional support to patients and families.

As bone marrow transplantation becomes a standard treatment for certain malignancies and the number of long-term survivors increases, more attention needs to be paid to the delayed psychosocial aspects of the transplant process. This will enable the medical and nursing staff to monitor the long-term outcomes of the procedure more effectively, which could in turn lead to an increased quality of life for long-term survivors (17). Quality of life in these patients has been a research focus over the past 30 years with assessments commonly addressing a variety of objectives and quantifiable dimensions such as the functional status, social role and independence (18) but there is also a need to capture the more qualitative, subjective elements of patients’ experiences, such as well-being, self-esteem, and general life satisfaction.

References
1. Kessinger A, Armitage JO. The evolving role of autologous peripheral stem cell transplantation following...
2 Duncombe A. ABC of clinical hematology. Bone mar-
row and stem cell transplantation. BMJ. 1997;314:
1179-82.
3 Hansen F. Hemopoietic growth and inhibitory factors
1995;34:453-68.
4 Gratwohl A, Baldomero H, Horisberger B, Schmid C,
Passweg J, Urbano-Ispizua A. Current trends in hemat-
opoietic stem cell transplantation in Europe. Blood.
2002;100:2374-86.
5 Gratwohl A, Baldomero H, Labar B, Apperley J,
Urbano-Ispizua A. Evolution of hematopoietic stem cell
transplantation (HSCT) in eastern and western Europe
from 1990 to 2003. A report from the EBMT activity sur-
6 Soutar RL, King DJ. Bone marrow transplantation. BMJ.
7 Lennard AL, Jackson GH. Stem cell transplantation.
8 Lohr KN, Schroeder SA. A strategy for quality assurance
9 Lesko LM. Surviving hematological malignancies: stress
responses and predicting psychological adjustment.
10 Syrjala KL, Chapko MK, Vitaliano PP, Cummings C,
Sullivan KM. Recovery after allogeneic marrow trans-
plantation: prospective study of predictors of long-term
physical and psychosocial functioning. Bone Marrow
11 Zabora JR, Smith ED, Baker F, Wingard JR, Curbow B.
The family: the other side of bone marrow transplanta-
tion. Journal of Psychosocial Oncology. 1992;10:
35-40.
12 Andrykowski MA. Psychosocial factors in bone marrow
transplantation: a review and recommendations for re-
13 Molassiotis A, Haberman M. Evaluation of burnout and
job satisfaction in marrow transplant nurses. Cancer
14 Andrykowski MA, Henslee PJ, Barnett RL. Longitudinal
assessment of psychosocial functioning of adult survi-
ors of allogeneic bone marrow transplantation. Bone
15 Molassiotis A, van den Akker OB, Boughton BJ. Per-
ceived social support, family environment and psycho-
social recovery in bone marrow transplant long-term
16 Kelly D, Ross S, Gray B, Smith P. Death, dying and emo-
tional labor: problematic dimensions of the bone mar-
row transplant nursing role? J Adv Nurs. 2000;32:
952-60.
17 Molassiotis A. Late psychosocial effects of conditioning
18 Baker F, Wingard JR, Curbow B, Zabora J, Jodrey D,
Fogarty L, et al. Quality of life of bone marrow trans-
plant long-term survivors. Bone Marrow Transplant.