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*Information needs of the patients undergoing
bone marrow transplantation*

About 25 years ago, bone marrow transplantation (BMT) was an experimental procedure carried out as a last chance in terminally ill patients. Successful reports of Thomas et al. (14) from Seattle encouraged many centers to go ahead. The number of allogenic and autologous bone marrow transplantations (BMT) and the number of centers which perform these procedures have increased dramatically over the last 10 years. This increase can be attributed to the progress in supportive care which caused a significant decrease in transplant related mortality.

By the early 1990's, peripheral blood stem cell (PBSC) mobilized into the blood by growth factor and chemotherapy had largely replaced bone marrow as a source of stem cells for autologous transplantation. BMT is no longer an investigational procedure for most patients with hematological malignancies and solid tumors. More and more patients achieve long-term disease free survival. During last decade more than 115,000 patients were transplanted in Europe. The last report of EBMT (European Group for Blood and Marrow Transplantation) informs that BMT increased from 4,234 in 1990 to 18,720 in 1999. These data were collected from 580 centers of EBMT in 35 European countries. However, managing patients and families through transplant and associated stressors remains a challenge for oncology nurses and doctors (2, 9, 10).

Many authors were studying the art of the psychosocial support needed for patients and their families. Brown and Kelly (3) presented one of the earliest reports on the psychosocial impact of BMT. They described eight characteristic stages of BMT with associated psychological reactions as the patient progressed through the medical treatment. The initial decision-making process to proceed with transplantation involved significant

pretransplant issues, including reviewing and understanding informed consent for the protocol and actual admission to the hospital for the conditioning treatment. Stressors for patients during these initial stages included significant anxiety, fear of dying and psychiatric symptoms caused by prescribed medications (e.g. antiemetics, steroids, cytotoxic agents). The actual day of marrow infusion was described by the authors as uneventful, with many expressing gratitude for the donor.

There is another prospective study (11) which indicated a 54% incidence of psychosocial morbidity. The findings suggested that the pre-BMT assessment may predict post-transplant psychological outcomes. In the view of the studied patients who had previous experience with cancer treatment showed less anxiety and post-transplant depression. The study results emphasized that medical staff must view their patients in a holistic way and recognize that patients undergoing BMT find meaning in their experiences in different ways.

For children undergoing BMT, the transplant hospitalization is a necessary but difficult disruption in their young lives. Children's ability to cope with the psychosocial aspects of BMT depends on child's age, developmental stage, intellectual ability, personality, and support system available. Nursing care throughout each phase of transplant should reflect age-specific needs. Play therapy, parental involvement, attention to daily routines, and age-appropriate environment contribute to a happier child during the transplant hospitalization. The realization that a child's behavior is often indicative of feelings related to fear and anxiety may help the nurse to plan care that is responsive to behavioural cues (1). Loss of control is a common experience for patients of all ages during transplantation. However, allowing children appropriate choices within their daily routine can be beneficial to their psychological response and coping (1).

PSYCHOSOCIAL IMPACT OF BMT ON THE FAMILY

The holistic approach to the patients means that the family is an integral subject to the professional oncology care. Patenaude et al. (13) described BMT's impact on the family, and they identified several key factors that affected the family with a child undergoing transplantation: previous illness (e.g., the length of time that the family member had been ill, siblings' previous illness or death, especially when dealing with genetic diseases), geographic dislocation of the patient from his or her home and family, and other serious family emotional problems, such as marital conflict, separation or divorce, financial concerns, and concerns about other children in the family. Patenaude et al. also emphasized the value of including a psychologist or psychiatrist as an integral part of the BMT team to provide needed support to both the patient and the family. Heiney, Neuberger, Myers and Bergman (8) identified that parental support and involvement is a key to the psychosocial well-being of a child undergoing BMT. However, parents may experience considerable distress (e.g.: feelings of helplessness, loss of control,

fear of the unknown, anger, guilt, fear of death) during the transplant process. The feelings may result in post-traumatic stress disorder (PTSD) in parents of children undergoing BMT. Parental perceptions of the degree of life threat (for the child), duration of the trauma (length of transplant recovery), bereavement (other children on the unit dying), displacement from home and community, potential for recurrence, role of the parent in the trauma (caregiving activities), and exposure to death and destruction (side effects) were key risk factors for developing PTSD. Other authors – Futterman and Wellisch (6) described the psychosocial impact of BMT on the recipient's family members. Because spouses or partners are often the key support people, they are confronted with the demands from the patients, the rest of the family, and their own jobs or role responsibilities. Changes in roles and responsibilities between the patient and the spouse may add to the already significant stress of transplantation. The findings show that family members of some BMT survivors, who initially were supportive after transplant, also became blaming, overprotective, and generally unsupportive as time went on (7). The issue of financial burden for the patient undergoing BMT and the family is an important problem that may affect psychosocial recovery. The total costs of the BMT might be personal expenses for the family, including lodging, transportation, child care, housekeeping, special foods, and home modification. The family may also suffer from the loss of income from the patient or spouse or both.

As the model of care for patients undergoing BMT changes, so do the needs of caregivers. Overall, the findings showed that caregivers face considerable personal and interpersonal stress as the patient moves through transplantation. A consistent theme demonstrated by the family was the difficulty in seeking effective communication with the healthcare team. It was also clear that the caregiver's need for information was significant and related to such areas as learning complex skills (e.g., managing ambulatory pumps, obtaining supplies, identifying and reporting symptoms). Families reported many challenges by developing their own self-care strategies and identified those members of the system who could facilitate their needs. Finally, the families also identified positive feelings of personal growth and closeness among family members (4, 5, 6, 7). There are numerous side-effects, probable infertility, fear of relapse, decrements in strength/stamina and limitations in work and other important activities.

IMPLICATIONS FOR PROFESSIONAL PRACTICE

Another way to assess the information needs of the patient and family as well as to facilitate early recognition of patients at risk for psychosocial morbidity, is to conduct interviews with them at home pretransplant. The homecare nurse's involvement at this early stage is often underused, but it does provide him or her with an opportunity to assess family dynamics and interactions, as well as to assess potential caregiver needs. The home health nurse can assess the home environment for safety and infection preven-

tion, which is relevant for the early discharge transplant patient. Problems identified during this assessment, whether they are related to the actual physical environment or caregiver issues, afford the patient and family, along with the healthcare team, time to resolve the problems prior to BMT Pretransplant support and may be also available to patients and families through support groups or by meeting other patients who have experienced BMT. In fact, the availability of support groups for patients and families was cited as a need in Ferrel and others' (5) interviews with survivors.

Special programs may provide patients and their families with other valuable resources. Identification of additional community resources is important information that the patient and family can use throughout the transplant process. During the hospitalization phase of transplantation, regular support for the patient and the family has been identified as an important component of care (2). Use of other professionals, such as psychiatrists and psychiatric liaison nurses, chaplains, or social workers, is appropriate. Ersek (4) identified the importance of maintaining hope during transplantation and hope as an effective coping strategy for patients. She cautioned clinicians that patients must be able to deal with negative information or events in such a way that allows them to maintain hope. She also recommended that healthcare professionals create an interactive environment that enables patients to manage information in the way that allows them to cope effectively. Physical symptoms related to the conditioning regimen and the transplant process, such as nausea, vomiting, anorexia, mucositis, diarrhea, fatigue, and skin breakdown, are subject to discussion, since they are burdening and depressing. The study results suggest that preparation of BMT nurses and doctors should include education in specific psychosocial strategies, documentation, and coping with personal implications of practice in this unique setting (2, 3, 4, 5).

WHAT EDUCATIONAL AND SUPPORT RESOURCES ARE AVAILABLE TO PATIENTS AND THEIR FAMILIES TO HELP COPE WITH THE STRESSES OF BMT?

BMT programs often have extensive patient education and support resources. Books, monographs, and videos, for patients, are now available. The topics range from description of the procedure to specific care practices (e.g. Hickman catheter) and a long-term effects and care. Active newsletters are sent out by some centers, and one patient-developed newsletter has a regular subscription list. Support and survivors groups can be contacted through the larger BMT programs as well as the Internet. Many programs offer formalized psychosocial consultation with social workers, nurses, or psychologists to all patients.

HOW LONG DOES IT TAKE FOR PATIENTS TO RETURN TO NORMAL AFTER BMT?

HOW DOES BMT AFFECT A PERSON'S QUALITY OF LIFE?

The trauma of undergoing transplant usually affects all aspects of well-being: physical, psychological, social and spiritual. The first year after transplant is often characterized by great emotional intensity and fear of the patients to cope with continued treatment of transplant-related complications, including GVHD and infections. Many of the physical effects lessen over time, and most patients can resume a normal function within 1 year after the procedure. A minority of the patients (5-15%) experience lasting physical effects that may not improve and require permanent adaptation or significant rehabilitation. Chronic GVHD, pulmonary problems, reproductive effects, and second malignancies are among the most devastating complications (9,10). Many patients do not experience a linear recovery from the psychological, social, and existential effects of transplant. Most BMT survivors report only mild-to-moderate psychological distress. Survivor guilt, changed relationships with family and friends, and changes in employability and insurability are unpredictable nonphysical effects. Some beneficial effects are also reported by patients, including renewed sense of purpose and meaning in life and reprioritizing what is important. Most report they are "glad to be alive" or to have a "second chance" at life. With regard to social functioning, the ability for patients to resume their pre-BMT role has a positive impact. The influence of these factors on recovery has been studied only recently.

Early conclusions suggest that follow-up services and resources that allow patients and outlet to talk about their stories and to share long-term emotional challenges are important aspects of the nurse's task. Because some BMT patients encounter difficulties in returning to work, vocational retraining may be an important component to full recovery.

HOW DOES A PATIENT CHOOSE A TRANSPLANT CENTER?

Depending on the type of the disease and treatment, nurses can advocate for patients to be knowledgeable consumers regarding the quality of the program in which they seek treatment.

Patients should be encouraged to ask some or all of the following questions: 1) What types of diseases are treated and what types of transplants are performed? 2) Are nurses and doctors specially trained to perform transplants? 3) How long has the program been in existence, and how many BMTs have been performed? 4) What are the outcomes of their patients treated for the same disease? 5) Does the center perform investigational treatments and report results to a national organization? 6) Can the patient talk to previous patients at the center? 7) What support resources and housing are available for the patient and the family?

WHAT ISOLATION PRECAUTIONS ARE NEEDED DURING BMT?

Different degrees of immunosuppression are associated with autologous and allogenic transplants; suppression is less with autologous BMT. Isolation procedures vary from center to center, but patients who have undergone autologous BMT are usually treated in a private room. Ill visitors are restricted, and all visitors must wash their hands before coming in contact with the patient. Fresh flowers are not allowed in the patient's room, and patients are given a low microbial diet (no fresh fruits or vegetables). The level of isolation is difficult for patients to cope with. Contact with caregivers and visitors is limited, and all persons must gown, glove, and mask before entering the patient's room. Because several studies examining the benefits of protective isolation in BMT centers have not supported the use of strict protective isolation, many centers have relaxed their restrictions and allow patients to leave their rooms without masks, relying on handwashing as the main protective technique (5,7).

THE ALTERNATIVE & COMPLEMENTARY MEDICINE

Many of the interventions, such as hypnosis, relaxation techniques, biofeedback, and music therapy, have been used successfully with patients with cancer and are relevant for patients undergoing high-dose chemotherapy pre-BMT. In addition, a pretransplant psychosocial assessment done by a psychologist, advanced practice nurse, or social worker may help to identify preexisting problems that could affect a patient's recovery (5, 7).

CONCLUSIONS

Care of the patient undergoing bone marrow and blood cell transplantation represents a challenge for physicians and oncology nurses both from technical and psychosocial perspective. It is important to base our daily practice on the scientific research and implement the findings. As the medical staff continue to evaluate the clinical outcomes and QOL of patients undergoing transplantation and their families, the need to cautiously and actively identify the impact of medical advancements in this setting.

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SUMMARY

The number of allogenic and autologous bone marrow transplantation (BMT) and the number of centers which perform these procedures have increased dramatically over the last 10 years. This increase can be attributed to the progress in supportive care which caused a significant decrease of transplant related mortality. Hematopoietic stem cell transplantation (HSCT) is now established therapy for many hematological malignancies, solid tumors and autoimmune disease. In spite of the great progress made, BMT is still a drastic procedure that may make patients suffer very much and can be even fatal. Careful exploration of the social and psychological situation of the patient is a very important factor which may prevent future difficulties. Many patients suffer psychological difficulties related to bone marrow transplantation from inadequate psycho-social preparation and support. It is important to prepare an information document about the newly diagnosed hematological malignancies. It must be a clear language and must answer the initial questions the patient will ask after diagnosis is made. The information leaflet distributed to the patients suffering from hematological malignancies can play an important role in the recovery of the immune system, thereby promoting a return to health.

Zapotrzebowanie na wsparcie informacyjne wśród pacjentów leczonych metodą przeszczepu szpiku kostnego

Pierwsze próby przeszczepiania szpiku kostnego podejmowane były już we wczesnych latach pięćdziesiątych. Niestety, ich rezultaty nie były zbyt pomyślne. Wszyscy pacjenci znajdowali się w zaawansowanym stadium choroby i po przeszczepie następował nawrót choroby; nie umiano sobie również radzić z chorobą przeszczepu przeciwko gospodarzowi (GVHD). Pod koniec lat siedemdziesiątych, wraz z udoskonaleniem opieki wspomagającej, a więc pojawieniem się nowoczesnych antybiotyków czy żywienia pozajelitowego, oraz rozwojem nauki umożliwiającym na przykład typowanie tkankowe, transplantacja szpiku kostnego zaczęła przynosić znacznie lepsze rezultaty. Transplantacja szpiku kostnego, będąc początkowo metodą stosowaną jedynie w leczeniu eksperymentalnym, stała się obecnie standardową metodą leczenia niektórych chorób. Na całym świecie istnieje dziś więcej niż 200 ośrodków transplantacji, wykonano ich dotychczas ponad kilkadziesiąt tysięcy.

Procedura związana z transplantacją szpiku kostnego wymaga od pacjentów oraz ich rodzin dużego zaangażowania zarówno emocjonalnego, jak i ekonomicznego. Ponieważ nie istnieje zbyt wiele ośrodków transplantacji, pacjenci wraz z niektórymi członkami rodziny mogą być zmuszeni do przeprowadzenia się na jakiś czas do miejsca, gdzie ma być wykonany przeszczep. W tak trudnych dla nich chwilach znajdują się oni w obcym otoczeniu, a jedynym oparciem, jakie mają, jest nieznan im personel medyczny. Metoda ta jest dość drastyczna i powoduje u chorych pojawienie się wielu problemów natury psychospołecznej i duchowej. Dlatego też większość ośrodków transplantacji sponsoruje grupy wsparcia, jak również zapewnia regularne formy poradnictwa dla pacjentów oraz ich rodzin.