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*Communication with patients and the family
undergoing the Bone Marrow Transplant*

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.

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 the last decade more than 115,000 patients were transplanted in Europe. 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 (1).

Hematopoietic stem cell transplantation (HSCT) is now an 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 and can be even fatal. Careful exploration of the patient's social and psychological situation is a very important factor, which may prevent future difficulties.

COMMUNICATIONS WITH THE PATIENTS AND FAMILIES

Proper communications with patients and families is crucial for the quality care. Many patients suffer psychological difficulties related to bone marrow transplantation from inadequate psychosocial preparation, proper communication and support available. The nurses and doctors are the best source of information and should have in mind the areas of interest for the subject of their care. That includes: educational and support resources to patients and their families to help cope with the stresses of BMT, patients return journey to normal life after BMT, the BMT effect on person's quality of life, making the best choice of the transplant center, isolation precautions needed during BMT, and the alternative & complementary medicine issues.

There are areas which need to be discussed and questions that should get adequate answers. The process of initial decision-making to proceed with transplant procedure involved significant pretransplant issues, including reviewing and understanding consent for the protocol and actual admission to the hospital for the conditioning treatment. The most prevalent stressors

for patients during these initial stages included significant anxiety, fear of death and psychiatric symptoms caused by prescribed medications (e.g. antiemetics, steroids, cytotoxic agents). Most of BMT programs offer extensive education and support resources. Books, monographs, and videos, are now available for patients. The topics range from description of the procedure to specific care practices (e.g. Hickman catheter, mouth care, diet etc.) also a long-term effects and care. Some centers send out newsletters. The larger BMT programs as well as the Internet offer contacts with support and survivors groups. The formalized psychosocial consultation with social workers, nurses or psychologists to all patients is often included in many programs.

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. BMT impact on the family was described, several key factors were identified that affected the family with a child undergoing transplantation. Patenaude et al. also emphasized the value of including a psychologist or psychiatrist as an integral part of the BMT team to provide support to both the patient and the family. It was found out that parental support and involvement is the key to the psychosocial well being of a child undergoing BMT (7).

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 the children undergoing BMT. Parental perceptions of the degree of life threat (for the child), duration of the trauma (length of transplant recovery), bereavement (dying children on the unit), displacement from home and community, potential for recurrence, role of the parent in the trauma (care giving activities), and exposure to death and destruction (side effects) were key risk factors for developing PTSD.

Other authors 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. Often, they take a leave of absence from work or from child-rearing responsibilities and suffer from fatigue as they remain at the patient's bedside for long hours. As the patient progresses through transplant, the feelings of fear, anger, and ambivalence frequently occurs. Little support is available to the spouse as other friends and family members may be at home, away from the transplant center. Changes in roles and responsibilities between the patient and the spouse may add to the already significant stress of transplantation (10, 11). The findings show that family members of some BMT survivors who were initially supportive after transplant also became blaming, overprotective, and generally unsupportive as time goes.

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. It was shown in the findings that caregivers face considerable personal and interpersonal stress as the patient moves through transplantation. The issue repeated by the family was the difficulty in seeking effective communication with the healthcare team (6). 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 to many challenges by developing their own self-care strategies and identified those members of the system who could facilitate their needs. The positive feelings of personal growth and closeness among family members were also identified.

Ferrel demonstrated that BMT survivors identified eight dimensions of Quality of Life (QL): family/relationships; independence; physical, mental and spiritual health; ability to work

and experience no financial distress, heightened appreciation of life and being "normal" (described as what QL actually is like compared to what the individual wants it to be).

The side effects associated with probable infertility, fear of relapse, decrements in strength and limitations in work and other activities, were also identified as important (4,5).

IMPLICATIONS FOR PROFESSIONAL PRACTICE

Another way to assess the psychosocial needs of the patient and family as well as to facilitate early recognition of patients at risk for psychosocial morbidity, is to conduct pretransplant interviews with them in the home. The home-health nurse can assess the home environment for safety and infection prevention, which is relevant for the early discharge of 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 (8). Pretransplant support may also be 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 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 the family can use throughout the transplant process (12).

During the hospitalization phase of transplantation, regular support for the patient and the family has been identified as an important component of care. The presence of other professionals, such as psychiatrists and psychiatric liaison nurses, chaplains, or social workers, is appropriate. The importance of maintaining hope during transplantation and the use of hope as an effective coping strategy for patients are important. Clinicians that patients must be able to deal with negative information or events in such a way that allows them to maintain hope. Healthcare professionals should create an interactive environment that enables patients to manage information in ways that allow 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 clearly associated with distress for the patient. It is essential that the nurses assess the patient's perception of his or her experience and that they work collaboratively to achieve maximum relief. The nurse's ability to anticipate symptoms and to act accordingly to relieve perceived distress is one of the many challenges in BMT nursing. The study results suggest that preparation of BMT nurses should include education in specific psychosocial strategies, documentation, and coping with personal implications of practice in this unique setting (9,13).

PSYCHOSOCIAL PREPARATIONS OF CHILD AND FAMILY

It is important for the medical staff to remember who the child is. The child is a little person, a little human being. It must be treated with the dignity and respect. At many well recognized hospitals there are special programs which are designated to meet the requirements quality care for the child, and are created to ease the stress connected with BMT procedure by proper education. The day before the stem collection, the nurse performing the procedure explains what will happen to a child. A book containing photographs of a child undergoing a stem cell collection is used to aid explanation. The parents and child are taken to the hemodialysis unit where the collection takes place. This enables the child and family to view the cell separator and see other children undergoing hemodialysis and attached to machines similar to the cell separator. The family is given written information in the form of a leaflet detailing the stem cell collection. Parents are warned the child will be connected to the cell separator for

up to 4 hours and encouraged to bring favorite videos or toys, games or books with them. The actual collection process is painless, however, the child may feel some discomfort as the newly inserted apheresis catheter is attached to the cell separator lines.

The procedure of BMT does affect a person's quality of life in a very serious way. 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 the fear of coping with continued treatment of transplant-related complications, including GVHD and infections. Many of the physical effects lessen over time, and most patients can resume their normal functions within 1 year after the procedure. The 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. Many patients do not experience 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 a 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 patients' ability 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 an 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 (13).

The knowledgeable medical staff is able to help patients choose a transplant center. Depending on the type of the disease and treatment, nurses can support the patients in being 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: What types of diseases are treated and what types of transplants are preformed? Are nurses and doctors specially trained to perform transplants? How long has the program been in existence, and how many BMTs have been performed? What are the outcomes of their patients treated for the same disease? Does the center perform investigational treatments and report results to a national organization? Can the patient talk to previous patients at the center? What support resources and housing are available for the patient and the family?

The precautions needed during BMT are often seen as unavoidable, as a great threat and may contribute in a great sense of lowering the patient's quality of life. Different degrees of immunosuppression are associated with autologous and allogenic transplants; suppression is with autologous BMT. Isolation procedures vary from center to center, but patients who have undergone autologous BMT are usually treated in a private room. Sicks 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 fruit or vegetables) – 14.

The level of isolation is difficult for patients to cope with. The contact with caregivers and visitors is limited, and all persons must wear a gown, gloves, and a 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 hand washing as the main protective technique. Patients and their families are often interested in alternative and complementary medicine and care. Many of the interventions, such as hypnosis, relaxation techniques, biofeedback, and music therapy, have been successfully used with patients with cancer and are relevant for patients undergoing high-dose chemotherapy pre BMT (2).

CONCLUSION

Care of the patient undergoing bone marrow and blood cell transplantation represents a challenge for professional caregivers, doctors and oncology nurses both from the technical and psychosocial perspectives. As the staff members continue to evaluate the clinical outcomes and QOL of patients undergoing transplantation and their families, the need to cautiously and proactively identify the impact of medical advancements in this setting. The 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. The daily practice and care should be based on the scientific research and it should implement the findings.

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SUMMARY

Bone marrow transplantation (BMT) is a widely accepted treatment for malignant and nonmalignant diseases. With advances such as autologous and allogenic stem cell transplant, umbilical cord blood transplant, and improved biomedical support therapies, the need to evaluate the impact technology on the patient and the family continues to be an important aspect of medical and nursing research. BMT has been described as a procedure associated with isolation of the patient, prolonged hospitalizations, rapid fluctuations in medical conditions, frequent and often life-threatening infections, and graft-versus-host disease (GVHD). Although some patients encounter such difficult experiences during recovery and a significant mortality rate is associated with the procedure, other patients experience rapid recovery with minimum risk of serious complications and a shortened hospital length of stay. Issues related to the caregiver availability and caregiver burden become more important in these aggressive outpatient settings. The paper discusses the psychosocial impact of BMT on the patient as well as on the family. The psychosocial nursing care during BMT is discussed. The cultural influence is recognized and stressed. Quality-of-life dimensions and the impact of BMT as well as implications for nursing are stressed. Also, the experience of donating bone marrow to a relative will be discussed and the implications for a nursing practice will be described.

Komunikacja z chorym i jego rodziną podczas przeszczepu szpiku kostnego

Przeszczep szpiku kostnego (BMT) jest obecnie szeroko stosowaną metodą leczniczą w hematologii. Opieka świadczona przez personel medyczny koncentruje się wokół zabezpieczenia jakości w ramach biopsychospołecznego funkcjonowania pacjenta i jego rodziny. Procedura przeszczepu niesie ze sobą znaczący negatywny ładunek emocjonalny, głównie ze względu na użycie zaawansowanej technologii, przedłużającą się hospitalizację, wymaganą izolację, możliwość gwałtownych zmian w stanie zdrowia oraz realne niebezpieczeństwo poważnych powikłań. Tak więc niezmiernie ważne dla całokształtu świadczeń i jakości sprawowanej opieki, a szczególnie dla jakości życia, staje się umiejętne komunikowanie się z osobą chorą i jej rodziną, oparte z jednej strony na wiedzy związanej z psychospołecznymi reakcjami, jakie wywołuje ta specjalistyczna metoda lecznicza, a jednocześnie na właściwym zastosowaniu umiejętności profesjonalnego komunikowania się.