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Psychological Impact of Bone Marrow Transplantation: Current Perspectives

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Despite advances in bone marrow transplant technology, major psychological stresses remain. Donor selection has become psychologically more complex with the option of seeking an unrelated donor. Family dislocation continues to be necessary for many families despite the proliferation of transplant centers. The range of choices between treatment options, level of room sterility, and the like can leave families open to guilt about their choices. Unpredictability of the transplant course, difficulty for patients in assessing the seriousness of symptoms, and the need to rely on a changing roster of teaching hospital physicians contribute to patient anxiety. Contrary to patient expectations, post-discharge recovery is often longer and more complicated, physically and psychologically, than expected. Follow-up studies on BMT patients show that a majority have a return to a satisfactory level of activity, although some physical symptoms may remain. Behavioral symptoms did increase, with estimates ranging from 15-35 percent of the survivors showing symptoms a year or more post-transplant. Staff impact is briefly addressed. The need for more research on psychosocial follow-up is stressed.

Despite advances in bone marrow transplant (BMT) technology over the past 15 years [1,2], the psychological stresses of transplant remain. In some cases, the stress may even be compounded by the expansion of opportunities which the new technology has made possible.

PRE-TRANSPLANT

The potential for bone marrow transplantation in itself changes the nature of treatment for hematological and other diseases. What was once simply a question of the availability of useful chemotherapy and/or radiation protocols is transformed into a family drama where genetics assigns (or disqualifies) family members to the role of potential savior for a sibling or a child. Even if no family donor is found, the process of tissue typing has raised the possibility for guilt. Some families have conceived children for the purpose of having a matched donor [3]. If a donor is found, family rivalries may surface, some family members wishing they were the donor and feeling unimportant if not chosen. The compatible sibling may wish he or she had not been chosen. And the patient or parents have to confront the reality that they must choose for or against having the transplant. This decision in itself raises the potential for guilt and family disunity should the transplant fail [4,5,6].

With the advent of bone marrow registries in this country and abroad, the family with no donor may have to decide whether to try to find an unrelated donor from among various donor pools [7,8]. While the medical condition of some patients may preclude waiting the minimum of two to three months necessary to search donor banks, the

option for other patients and families to do so again raises the question of how far one needs to go to feel that everything possible has been done. For some patients, this need has meant organizing tissue-typing drives among ethnic populations in major American cities, including television appeals by the patient and the family. While such appeals may provide a useful focus for the helplessness families feel in the wake of life-threatening illness, if no donor is found there may remain the uneasy feeling of not having searched far enough. And, if a donor is found, the euphoria which results may obscure awareness of the heavy physical and emotional costs which the transplant may exact on the way to an uncertain outcome.

The question of where the transplant can be done remains, in some cases, a difficult one [9]. As transplant centers have proliferated, families may be more likely to have a nearby facility available, thus avoiding the necessity for major geographic disruption. In some cases, however, insurance companies are now specifying certain hospitals where they will pay for BMT care, thus forcing some families to bypass a local transplant center for a distant one (often in another state), where the transplant will be paid for. In other cases, the highly specialized nature of certain transplant protocols means that patients have no transplant option other than travel to a distant center. If a transplant fails, it is often the psychological distance necessitated by geographic distance (i.e., not seeing friends, siblings, grandparents, and so on) which patients and families regret the most.

THE TRANSPLANT HOSPITALIZATION

Depending on the transplant center chosen, the physical restrictions imposed on the patient may vary considerably. While many centers continue to use laminar air flow rooms, others transplant patients in clean hospital rooms, and some centers maintain several levels of sterile rooms. Again the choice or range of options may leave patients or families wondering about the rationale and necessity for restrictions. From the patient's point of view, however, the loss of freedom to leave a room at will is still the major consideration. It has been amazing how compliant even very young children are in heeding the restrictions of life in a sterile environment, but the loss of control is often acted out by both children and adults in attempts at over-controlling other areas of their lives (e.g., food, visitors, schedules, and so forth). To the extent possible, maximizing choices in non-restricted areas may help to compensate for lack of physical freedom. When patients are well enough, physical therapy programs, including weight-lifting and riding a stationary bicycle, help them to regain physical strength [10]. Other patients have used binoculars or telescopes to enlarge their mental boundaries. Interestingly, follow-up studies of young children who spent extended periods in isolation show no lasting developmental deficits due to the isolation [11,12].

The unpredictability of the patient's course through transplant is responsible for the high levels of anxiety patients experience. The mucositis which follows pre-transplant radiation and the frequent infections which develop secondary to neutropenia cause patients a good deal of discomfort. Similarly, the diarrhea and pruritis of Graft-Versus-Host Disease (GVHD) can be very depressing for patients. It is impossible to predict accurately the time course for many of the symptoms. With GVHD, it may often take trials of several different drug regimens to achieve control and symptom reduction. Patients have a particularly difficult time assessing the threat to life posed by symptoms which are disfiguring or debilitating. They must rely heavily on trust placed in doctors to get some perspective on their status. This reliance may be complicated by

frequent changes of house staff and attending physicians in the teaching hospitals where many BMT centers are located. It is, in any case, often difficult for the staff to judge how long symptoms are likely to last or even how serious they may be. Ironic contrasts have been noted, where patients focus their anxiety on uncomfortable but relatively minor symptoms, like mucositis, when the staff focuses on silent but life-threatening problems evident in laboratory results.

Length of hospital stays now vary greatly among patients, with some autologous patients leaving within three weeks, while other patients stay two to three months. Extended stays are associated with depression and withdrawal in both pediatric and adult populations. Depression focuses on lost abilities and freedom and often leads to a questioning of the original goals of transplantation.

Non-compliance with the bowel prep or mouth-care regimens are common, with a wide range of behavioral interventions being attempted to coax patients to take the medicine.

BMT FOLLOW-UP

While success rates for many forms of BMT have improved over the past ten years, we are now realizing the long-term physical and psychological effects of transplantation. Contrary to many patients' expectations, the discharge from transplant hospitalization is only the beginning of what is likely to be a lengthy, gradual period of difficult readjustment. Up to a year of social isolation may be necessary, and rehospitalization occurs in about half the cases. Infections, chronic GVHD, kidney and liver problems, cataracts, growth delay, and relapse are just some of the serious problems which may occur post-transplant. Healthier patients will still face psychological issues of sexual adjustment, marital and family reintegration, possible work and/or school re-entry, and re-establishment of an identity not solely based on having been a transplant recipient [13,14].

A few follow-up studies of psychological status in post-BMT patients are to be found in the literature. Wolcott et al. [15] studied 26 adult recipients who were at least 12 months and an average of 42 months post-transplant. Seventy percent had good current health, though 25 percent continued to have adverse physical effects. All but 15 percent were employed. Fifteen to 25 percent seemed to have significant psychological distress and poor adaptation, but three-quarters of the patients indicated a high level of satisfaction with current relationships and activities. Most felt there was little change in the relationship with their donors. Of interest is the finding in the recipients that physical symptoms were negatively correlated with time since transplant, but that psychosocial variables did not correlate with time elapsed since transplant.

In the Netherlands, 17 patients aged 16–42 were interviewed 12 to 60 months post-transplant [16]. Fifty-nine percent were employed or in school, while 29 percent were disabled. Seventy-six percent were able to carry on normal activity. Patients wished they had been given more or better information about immunosuppression and total body radiation and about post-transplant complications, sexuality, and fertility post-transplant. At the time of the interviews, 52 percent continued to have physical symptoms related to transplant. Nearly 60 percent reported negative social experiences characterized by “feeling like a leper” after discharge.

The only published psychosocial follow-up study of pediatric BMT patients is that by Pot-Mees [17], in which she studied 44 English patients, who were observed and tested pre-transplant and both six and 12 months after transplant. She compared

transplant patients to matched cardiac surgery patients and normal controls. The post-transplant BMT patients showed no significant decline in cognitive function. In fact, scores at 12 months showed some improvement over pre-transplant scores, a difference attributable to pre-transplant anxiety. At 12 months post-transplant, however, the patients' academic abilities were below age expectation, although the relative effects of school absence and emotional disturbance could not be sorted out. At six months, behavioral symptoms, especially depression, were more prevalent than pre-transplant. Forty percent of the children showed behavior disturbance at six months, versus 15 percent pre-transplant. By 12 months out, 35 percent had behavior disturbance. Physically, 80 percent of the children had no limitations, four children had mild limitations, and one was limited by moderate Graft-Versus-Host Disease.

Much future work remains to be done in assessing the psychological impact of bone marrow transplantation on the cognitive abilities and emotional well-being of patients. Some studies are under way to try to follow patients who have received similar prior therapy so as to limit other confounding effects. Longitudinal studies are essential to follow patients through the extended stage of recovery from BMT.

STAFF

Briefly, it should be mentioned that the psychological impact of working in a BMT unit has also been observed and studied [18]. It is clear that this milieu is a challenging, often rewarding, but stressful environment where the potential for iatrogenic disaster can cause high levels of anxiety, over-involvement, and often irrational guilt. Psychological support for the transplant staff is strongly advised to minimize psychological distress [16,18,19,20].

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