A Family Perspective on a Program for Bone Marrow Transplantation of Adults

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Background:

This paper discusses a family impact analysis of an adult bone marrow transplant program in the Midwest. Bone marrow transplantation is an intervention for a variety of life threatening diseases. The transplant experience is itself life threatening, with an overall survival rate six years post transplant ranging from 20-80%, with a mean of 45% [International Bone Marrow Transplant Registry/Autologous Blood & Marrow Transplant Registry (IBMTR/ABMTR), 2002]. Bone marrow transplants (BMT) are conducted in hospitals across the United States, with hospitalization lasting 50-90 days or longer (Grimm, Zawacki, Mock, Krumm & Frink, 2000). Even though patients may be discharged after 50 days, many are required to remain near the center for a period of time thereafter.

Given the financial, emotional and time commitment of the transplant process, the implications for relatives of a BMT recipient are significant. Many centers now require a significant other, usually a family member, to be available to the patient while hospitalized. Caregiving extends beyond the hospital stay, however, as some programs also require the family member to stay with the patient upon discharge from the hospital, and reside with the patient near the hospital. This means that often two adult family members are relocated: one into the hospital and one staying near the hospital if it is not located near the family residence. This relocation alone can cause major disruption in family life.

Three quarters (75%) of individuals receiving transplants are between the ages of 21-50 (IBMTR/ABMTR, 2002). In a study by Boyle et al., (2000), more than three quarters (77%) of the patients were married and eight out of ten (80%) had children. The main source of support for patients is often their immediate family (Molassiotis, van den Akker & Boughton, 1997). Having access to this support is important for patient outcomes, but the family also needs support. Research shows that families need education and psychosocial intervention before and after BMT, as well as financial support (Zabora, Smith, Baker, Wingard & Curbow, 1992).

Family members can be affected by all stages of the transplant process: from pre-transplant anxiety to post-transplant caregiving stress. In a study by Futterman, Wellisch, Zighelboim, Luna-Raines and Weiner (1996), spouses of BMT patients were more susceptible to illness and psychological symptoms prior to the transplant. Clearly, the impact of this serious medical procedure can extend beyond the affected individual to the entire family network.

What's more, the effects of the BMT process on the family do not end at the time of discharge. Research indicates that families do not return to pre-illness functioning post-transplant, if indeed physical recovery of the patient occurs. Caregivers feel exhausted, and report stress and anxiety. They too experience health concerns, but often put the partner's health needs before their own (Case, 1999). Some families report deficient family support, and at times family caregivers find themselves faced with problems for which they feel unprepared (Invernizzi, Broich, Bressi, Guggeri, Caparreli & Lambertenghi, 1999; Boyle et al., 2000).

With the extensive financial, emotional, and time commitments required, bone marrow transplants inevitably affect family relationships. One study found that following BMT, patients and their spouses are likely to experience marital dissatisfaction and sexual dysfunction (Case, 1999). In terms of effects on children, another study found that at three months post-transplant, children under five responded to the loss of the hospitalized parent with a grief reaction; children older than five, but not adolescent, were puzzled and confused by the experience. Adolescents experienced stress in assuming new roles in the family and were frustrated and angry about these changes.

Because the bone marrow transplant process has such a demonstrated impact on both individuals and families alike, it is worth considering more closely how the program seeks to support family functioning and stability. The following section examines one BMT program in light of the six principles of family supportiveness outlined in the "Checklist for Assessing the Impact of Policies and Programs on Families," an instrument originally developed by the Consortium of Family Organizations (COFO).

Family Impact

Principle #1: Family Stability

- Policies and programs should aim to support and supplement family functioning and provide substitute services only as a last resort.

Juggling the multiple demands required to care for a family member who undergoes BMT can take a serious toll on the family unit's strength and stability. However, the program offers support services to aid the family during this difficult time. Family members and significant others are provided with contact information for a Patient Relations Specialist. This person is a source for handling concerns about lodging, transportation and other non-medical services. Services offered include van transportation, long-term housing, and specialty housing allotted specifically for BMT families. All of these services, along with the service coordinator, can help to support family stability. However, the responsibility for contacting support services falls on the family, which may prove an additional burden. Providing contact information for service coordination does not necessarily mean that all families in need of this service will receive it.

In addition to the Patient Relations Specialist, patients are paired with a social worker. The social worker can assist patients to apply for benefits to which they are entitled, however, the social worker's efforts do not guarantee complete financial coverage of the transplantation experience. Additionally, the social worker assists families in evaluating which programs would best meet the patient’s needs, and in making the transition to care outside the home. The program states that ‘together with family members, applications can be made for short-term nursing home care, for longer term nursing home stays, or for a variety of hospice care options (p.33)”. Thus, the social worker may serve as a key figure in supporting families’ ability to carry out some of their responsibilities.

However, while social workers assist families in obtaining benefits for BMT patients, this is a not a guarantee that all associated costs will be covered. In addition to the financial commitments for surgery and care, many families will incur additional related costs. Loss of income of the ill family member, cost of additional childcare, and loss of income of the significant other in charge of caregiving are a few examples of potential family costs not considered in the program. The expense of lodging, food and transportation for the family member(s) during the stay may also pose a significant burden.

Once BMT patients return from the hospital, program materials outline specific procedures for home preparation and routine cleaning (p. B-49). If the family caregiver is employed full-time, it may be unrealistic to expect him or her to do the level of cleaning needed on a daily basis in addition to other caregiving activities. The program guidelines do not discuss resources to help with cleaning. Thus, taken together, the program may have unrealistic expectations for families to assume both caregiving and financial responsibilities for their seriously ill family member.

Principle #2: Family support and Responsibilities

- Whenever possible, policies and programs should encourage and reinforce marital, parental, and family commitment and stability, especially when children are involved. Intervention in family membership and living arrangements is usually justified only to protect family members from serious harm or at the request of the family itself.

The bone marrow transplant program literature supports parental and marital commitment by addressing the importance of personal feelings and relationships. Guidelines in program materials state explicitly that the BMT process may make “maintaining some type of family involvement seem very difficult” (p. B-33), and that both parental and spousal relationships will likely be strained. To address this situation, the program literature encourages patients to keep their families informed of their progress, as well as to solicit similar updates from family members so as to stay connected to the family unit.

For married or partnered spouses, the program provides guidelines regarding sexual activity and a discussion regarding changes in sexual desire (B-60). This may ease communication on this sometimes difficult subject, and thereby enhance the strength and stability of spousal commitment. The program also recognizes the likelihood of permanent infertility as an outcome of BMT (B-36). Freezing of sperm and eggs prior to transplant is offered, but not stated in the written program.

One of the main stressors on families of BMT patients is separation from the ill family member. Long-term housing is one resource available to out-of-town patients and families to keep the family together. The program does not state, however, if children are able to stay in these facilities. Additionally, flexible visiting hours are available to family members of BMT patients, and 24-hour access is available if the patient's condition allows. However, for children under age 14, patients and/or their families must obtain special permission for visitation from a physician. While program materials explain that young children often are carriers of different types of illnesses that would put the patient at risk, lack of visitation can put stress on all family members involved. Additionally, some families may not be comfortable asking their physician for special considerations or permissions, lest it seem that they question the judgment of the 'expert' in charge.

Another indicator of family supportiveness is whether or not the program offers incentives for someone other than a family member to take over family responsibilities. While this program does not offer incentives in this regard, if both adult family members need to relocate, it is up to the family to find coverage for their children. The program provides no resources to address this concern.

Principle #3: Family involvement and interdependence

- Policies and programs must recognize the interdependence of family relationships, the strength and persistence of family ties and obligations, and the wealth of resources that families can mobilize to help their members.

The BMT program requires the participation and support of at least one family member. Patients are encouraged to bring this family member with them when meeting with the physician and other health team members prior to transplant. This is intended to help both patient and family understand what lies ahead and to be able to validate with each other information shared. The degree to which all family perspectives are represented in this process will likely vary with different families and physicians.

Many of the program's services target both the BMT patient and her or his family, thus acknowledging the interdependence of family and individual needs. Social services seek to support the patient and family through the emotional challenges and adjustments to changing roles. Program materials indicate patients can access individual counseling, family conferences, and support groups. Additionally, the program also supports early and effective pain management. The literature in the program points out that "even low intensity pain can tax your ability to communicate effectively with your family and friends and alter your quality of life (p. 4)". The program makes clear from a relationship perspective why early pain management is recommended.

As part of preparing families for the complexity of caring for an ill family member, patients are encouraged to leave the hospital for a few hours at a time before discharge to help acclimate them to their new freedom and to help caregivers get ready for the homecoming. The program also emphasizes the importance of including family in discussions regarding various discharge instructions and medications.

Decisions about the involvement of extended family in the caregiving and support of BMT patients are left up to the families themselves. While this supports families' ability to decide who is best prepared to assume caregiving responsibilities, it does not necessarily ensure that all family members' perspectives are represented. Additionally, the program sets limits on the number of family members visiting the patient at any one point in time. While program materials point out that frequency of visits and number of people visiting is dependent on the patient's condition, much more could be done to provide the opportunity to all family members for some level of involvement. Clear information regarding a trajectory of times when family assistance is needed for the patient's physical and emotional support could help families plan their involvement and thereby limit negative impact on family resources.

Another key indicator of family friendliness is whether the program builds on informal social support networks such as community, neighborhood or religious organizations. For both individuals and families dealing with the strain of the BMT process, access to support groups for those in similar situations could provide an important outlet. While program materials list the names of support groups for families to contact, they do not make any explicit effort to connect families with informal networks of this kind.

Lastly, family supportive programs protect the rights and safety of families. The BMT program considered here discusses patients' rights, which include that "every patient may designate persons who are permitted to visit the patient during the patient's stay in the hospital (p. 6)". However, family rights and role as partners in care are not articulated in the program.

Principle #4: Family Partnership and Empowerment

- Policies and programs must encourage individuals and their close family members to collaborate as partners with program professionals in delivery of services to an individual. In addition, parent and family representatives are an essential resource in policy development, program planning, and evaluation.

Individual and families considering bone marrow transplant need access to complete, accurate information and a range of choices. The program addresses this by encouraging patients and their families to seek second opinions regarding transplantation. Resources available to facilitate this are provided in the program materials. However, it is the patient's responsibility to share program information with the family. Nothing has been developed specifically for the family and their informational needs regarding their role in the experience and what they are expected to do in seeking second opinions.

Should individuals elect to go through the BMT process, collaboration of families and program professionals can be essential. Families are encouraged to be part of the BMT process as "valuable member[s] of the team" but are not identified as partners in care. One guideline directed at family well being identifies sleep and rest needs as being important for family (B-14). All other suggestions are focused on protecting the patient. The program supports the patient staying in contact with the family but does not discuss family staying in contact with the patient.

While families are encouraged to communicate with program professionals, this does not necessarily mean that these communications will be effective. For example, families are encouraged to inform the nurse of any changes noticed in the BMT family member's physical or mental status during and after the BMT experience. However, specific physical and mental status variables that are relevant to communicate are not provided to families.

Communication difficulties can occur in the other direction as well. Zabora et al. (1992) found that families could not recall specific statistics after meeting with the physician, yet perceived the patient's chance of survival as high pre-BMT, even though chances of survival can vary between 20-80%. Families also did not perceive the decision to go ahead with a BMT as a decision, which indicates that families' involvement in planning and decision-making may not be given sufficient attention.

Another important contribution families can make to programs' effectiveness is to participate in development, planning, and evaluation. By soliciting and considering families' input, programs can be made to be more supportive of both the needs of the individual and the family unit. The BMT program considered here does not involve families in macro-level planning or evaluation.

Principle #5: Family Diversity

- Families come in many forms and configurations, and policies and programs must take into account their different effects on different types of families. Policies and programs should not discriminate against or penalize families solely for reasons of structure, roles, heritage/values, or life stage.

Family is not defined in program materials, however, terms such as immediate family, family member, spouse, children, parental role, legally authorized representative and persons identified by patient as having a role in care are terms used in the program. The patients' rights published in the program state "a patient may not be denied appropriate hospital care because of the patient's race, creed, color, national origin, ancestry, religion, sex, sexual orientation, marital status, or new born status, disability or source of payment (p.5)". However, "family" is not identified in the program as having rights, nor do program materials discuss family-related criteria upon which care can be denied.

To address support for diverse family needs, the program has chaplains available from a variety of faith backgrounds, as well as persons with no denominational connections (p. 35). Ethnic and religious dietary considerations are incorporated into the program. The patient rights statement also states "patients shall be treated with consideration, respect and recognition of their individuality and personal needs, including the need for privacy in treatment and consideration of psychosocial, spiritual and cultural variables (p. 5)". This information is not discussed in relation to family.

Although translators are available through the hospital, the program materials are not offered in languages other than English. This may prove a significant barrier for families who may not be literate in English. Because the program literature is such a key source of information for patients and families, this is a serious oversight. Additionally, the reading level of program materials may be too advanced for some families. Because of the discomfort and stigma attached to reading difficulties, families may be unwilling to admit that they need assistance in understanding program guidelines. Without such assistance, these families are at serious risk of going without the support services they need to care for themselves and for their ill family member.

Principle #6: Targeting Vulnerable Families

- Families in greatest economic and social need, and those determined to be most vulnerable to breakdown, should have first priority in government policies and programs.

The program is not specifically directed toward low-income families, nor should it be. The program makes it clear that it is open to individuals from all socioeconomic levels of society. While social workers are connected with the family before the transplantation takes place, they may or may not see it as their role to identify and target families who are the most vulnerable. Emphasis is on the patient in the written program, however, and not the family. Program priorities may benefit from clarifications regarding if and how vulnerable families are identified and targeted.

In some states, the cost of bone marrow transplantation is not covered by state insurance policies. In the state where this program takes place, however, Medicaid is an option for those who qualify. Program materials point out that the pharmacy accepts payment methods inclusive of both private and public health care providers and assistance. The consequence of not having financial coverage through these resources is not indicated in the program.

Because the program focuses more on the individual undergoing bone marrow transplantation, there is little explicit effort to target resources toward preventing family problems before they become serious crises or chronic situations. The focus is prevention in terms of patient complications and not in terms of family coping and adaptation.

Policy Considerations

As this paper has shown, bone marrow transplantation programs would benefit from a family perspective. The impact of transplantation of an adult member on the family is great, as are the resources needed by the family during transplant and recovery. The bone marrow transplant program examined here shows some evidence of supporting family stability and acknowledging family support and responsibility. For example, the program provides patients with information on what to do when separated from the family, identifies resources available for housing when the patient and family member/significant other need to relocate, provides immediate family visiting hours, helps family members with discharge planning, and offers sexual activity guidelines for recovering patients and their spouses. This is a good beginning, but more needs to be included from the family perspective. Following are recommendations based on results of the analysis.

1. *Develop a written resource manual for family, similar to the patient's resource manual.* The information in the present program is written for the patient. It would be helpful to provide information specifically written for the family about transplantation and suggested interventions families could participate in to foster family stability. Included in this might be a listing of resources available to families that would support their stability and functioning.

2. *Complete a family assessment prior to transplant.* Because families differ, an assessment of each family is recommended. It is unclear in the present program if families are assessed pre-transplant in terms of their well-being and the potential impact of transplant. Research has indicated that families are lacking in support, yet their support to the patient is critical in the transplantation process (Invernizzi, Brocih, Bressi, Guggeri, Caparreli & Lambertenghi, 1999; Boyle, Blodgett, Gnesdiloff, White, Bamford, Sheridan & Beveridge, 2000). Lack of family support, which may ultimately impact patient support, may have dire consequences for future family and patient functioning. Support resources could be identified for the family and an ongoing assessment of their need for, access to and utilization of support could be implemented. Making explicit efforts to connect new families experiencing BMT with families that have successfully navigated a similar journey might also be of help. Offering Internet and e-mail access might help patients and family stay connected with other family members during hospitalization and while recovering in an outpatient residence. Other family-supportive activities might include audio-taping of patient/family conferences with the medical staff, as it can be difficult for family members to take in all of the relevant information in one sitting. Providing parents/family with information geared to children about transplantation that helps explain what will be happening to their relative might help to minimize some of the stress children experience at this difficult time.

3. *Identify expectations of family and anticipated impact on family at the beginning of the BMT process.* The role expectations of the adult family member identified as caregiver need to be made clear at the beginning of this program. Specific information on how family can carry out these roles in the inpatient and outpatient settings would facilitate family members transitioning to and assuming these roles (Zabora, Smith, Baker, Wingard & Curbow, 1992). Use of an informed consent for the family member/significant other who commits to care taking throughout transplantation and recovery may help to get families talking about the implications of this process for the family unit.

4. *Develop a policy regarding advanced directive discussions that include a family member.* Given the vulnerability of the patient with this procedure and the impact on family of the patient's state of illness, open discussion inclusive of a patient-selected adult family member(s) would make clear the decisions the patient would want the family to uphold. This anticipatory planning, communicated to family, would ultimately support family stability.

5. *Assess couple relationships prior to transplant and provide psychosocial support and education post transplant.* Research informs us that couples experience low martial satisfaction post-transplant, sexual dysfunction is a major concern, and infertility often is the result of going through this intervention (Case, 1999). Assessment and interventions are needed to support the couple in this stressful and uncertain experience.

6. *Evaluate if expectations of the family are realistic.* The program needs to be evaluated regarding realistic expectations made of the bone marrow transplant recipient's family. From the obligation for a family member to be present during hospitalization to the assumption that a family member assumes caregiving responsibilities, families of BMT patients face major commitments. The adult family member is usually already taking on additional roles in the absence of the patient. Careful monitoring of family in terms of realistic expectations is recommended, as are targeted support services for families overwhelmed by their responsibilities and at risk of breakdown.

7. *Target vulnerable families.* Targeting vulnerable families would be critical early in the decision to transplant so that the family is made aware of resources available to them and they go into the experience with full realization of the financial and emotional burden ahead. Additionally, program materials should be available in languages other than English, and should be evaluated to ensure that they are written at an accessible level.
8. *Work with legislators to facilitate a paid family leave policy.* The family member caregiver would benefit from paid family leave for at least 90 days and at times up to a year, depending on the progress of the patient. Availability of unpaid family leave also needs to be communicated to family members.

As stated early in the paper, bone marrow transplantation is a life and death decision in many instances. The decision to proceed with transplantation is a family affair. Investment in strengthening the family perspective in the present program would not only benefit the patient but the whole of the family on their uncertain journey.

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