

Understanding bereavement, grief, and mourning

There is much to praise in an article that recently appeared in this journal (Family, Friends, and Faith: How Organ Donor Families Heal. December 2009;19: 358-361). We commend the authors for their efforts “to better understand the needs of donors’ families,” for their awareness that “[f]ew studies address the grief process of organ donors’ families,” and for their concern about “over-diagnosing mental illnesses” in such families, that is, treating normal grief processes as psychiatric disorders.

We also join with these authors in highlighting “the importance of having qualified organ procurement organization (OPO) staff on site to evaluate . . . the needs of the patient’s family . . .” In addition, we agree that “[i]t is very important that OPOs recognize the role of customer service to donor families beyond the consent process” and that “[a] team approach to caring for the family is vital and should include hospital-based resources (such as social workers and chaplains) as well as OPO-based family service coordinators.”

Nevertheless, we feel obliged to note that none of this will go well if OPO staff and all of the other professionals who have contact with potential and actual donor families before, during, and after donation are not well informed about current literature on bereavement, grief, and mourning. For example, Stouder et al¹ repeatedly mention what donor families need to “recover from their grief,” but that language is generally avoided by bereavement specialists because it may suggest “either that grief is an illness or that people who ‘recover’ are unchanged by the loss, neither of which is correct.”^{2(p52)} Other authors note that bereaved people (in Western culture) “do not simply recover or ‘get over’ their loss and return to normal; there is no resolution or completion per se; instead, they adapt, adjust, and are to some degree changed forever.”^{3(p10)}

Except in rare instances, donor family members are ordinary people experiencing a broad range of normal, healthy, and appropriate reactions and responses to the death of a significant person in their lives. None of this is captured in linear stage models or fixed end points for grief and mourning. There are not just 5 ways to react to loss, there are no “stages” that any bereaved person must or needs to “go through,” and when asked when their grief ends, bereaved persons usually say “never,” although they acknowledge that it may change as they learn to live with their losses.

Recent literature from researchers and scholarly writers on bereavement emphasizes a number of key points, including the potential complexity of loss experiences; the typical breadth of grief reactions; the value of framing grief experiences in terms of tasks and

processes, not stage- or phase-based theories; the potentially active nature of grieving and mourning; attention to challenges from both loss and adaptation to new normals; the value of restructuring the relationship with the person who died; the potential value for many of maintaining ongoing and dynamic continuing bonds with the deceased; and the importance of meaning making.^{4,8} The same literature favors appreciation of individual differences in grieving styles and the influence of a wide variety of religious, social, cultural, personal, or other variables on individual grief journeys.

Donation experiences mirror all of this. Offering the opportunity of donation and giving follow-up support can provide solace together with opportunities for significant growth and transformation as members of donor families struggle to adapt to a life without the deceased.

What might be needed to qualify OPO staff and other professionals to offer real assistance to potential and actual donor families and to create a true team approach to caring for the family are large subjects beyond the scope of this brief note, but clearly there is a need to go beyond mere disciplinary backgrounds, training on technical matters associated with donation, and the fund of experience that individual professionals might have amassed over time to include a major focus on current understandings of bereavement, grief, and mourning, and on what is involved in true bereavement-centered care.

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Defining high risk in adult kidney transplantation: reflections from the Belgian perspective

We commend the multidisciplinary task force for addressing both medical and psychosocial screening in the article, "Defining High Risk in Adult Kidney Transplantation" (September 2009;19:252-258). Because only professionals from the United States were involved in this study, we would like to highlight the Belgian perspective on screening of high-risk patients.

The screening guidelines for medical and immunological risk factors resemble the protocols applied at our hospital. Cytomegalovirus and polyomavirus occur frequently after transplant, affecting patients' quality of life and long-term graft function. We wonder which strategies the authors recommend to treat these viruses, and what nurses can do to optimize the patients' quality of life. Another problem we encounter is that people are sometimes on the waiting list for several years. Screening for cardiac diseases is not always repeated during this period.

Interestingly, the authors advised all patients to stop smoking; we believe nurses should assist patients more actively in smoking cessation, instead of merely recommending to quit. Perhaps we should consider implementing more objective measures (eg, cotinine or carbon dioxide measures) to check smoking status. How do other centers check smoking status and what they do if smoking is discovered?

We are uncertain if the criterion on financial resources is applicable to Europe. Belgium has a compulsory health insurance that is paid through social

security, granting access to transplantation and fully or partly reimbursed medications. Our system guarantees equal access to health care for everyone irrespective of financial means.

Also, we disagree with the statement that patients living alone show more nonadherence because of poor social support. We are sometimes surprised how many patients living alone have good support, and how many married patients are poorly surrounded. It is our task to help patients develop a social network that may help them to take care of themselves.

We are not convinced that presence of psychopathology is always a predictor of poor outcomes. Patients may feel depressed or anxious given the impact of dialysis on their lives. We probably picture transplantation as the "holy grail" too much, which may contribute to patients' posttransplant symptoms. Even if psychopathology is detected, the appropriate interventions are not always prescribed. Many transplant centers, including ours, have no direct access to a psychologist who is part of the team.

Nurses at the dialysis centers and peripheral referral centers must have a basic understanding about how to take care of kidney transplant candidates and recipients. They need to be trained in screening for risk factors and reporting the results to the transplant centers. Pretransplant screening is often a single event but, ideally, it should be a continuous process, not to punish patients and remove them from the waiting list, but to provide them with the best care possible. By doing so, risk factors are no longer barriers but opportunities to optimize the patient's transplant trajectory. And who is better positioned to make this happen than nurses?!

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