

# Understanding bereavement, grief, and mourning: implications for donation and transplant professionals

This article surveys recent literature on bereavement, grief, and mourning. It offers a review of the state of the art of current understandings of those topics to assist professionals who work in the field of organ and tissue donation and transplantation. The article's goal is to provide well-developed and up-to-date education and knowledge about bereavement, grief, and mourning to supplement the natural skills and experience of donation and transplant professionals in their work with bereaved persons. (*Progress in Transplantation*. 2010;20:169-177)

**Charles A. Corr, PhD, CT,  
Margaret B. Coolican, RN,  
MS, FT**

National Donor Family Council, St. Pete Beach, Florida (CAC), Donor Family Services, Musculoskeletal Transplant Foundation, Edison, New Jersey (MBC)

Corresponding author: Margaret B. Coolican, RN, MS, FT, 18 West Lane, East Hampton, CT 06424-1410 (e-mail: maggie\_coolican@mtf.org)

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Professionals who work in the field of organ and tissue donation and transplantation inevitably also work in the larger arena of bereavement. They interact in situations with families who have lost a member and are approached concerning donation, with living donors whose gift may be rejected, with recipients who may die waiting for or after a transplant, and with the family members of those recipients. They may also experience their own professional and personal losses. As a result, professionals who work in this field can benefit from sound education about loss and grief to supplement their own natural skills and experience.

To engage effectively with bereaved individuals and to cope with situations involving grief and mourning, donation and transplantation professionals have a responsibility to strive for the best available understanding and appreciation of what they and the individuals they serve are experiencing. Just as education and knowledge are critical in the technical aspects of the work of these professionals, it is equally critical that their education and knowledge about bereavement, grief, and mourning be as well-developed and up to date as possible. For this reason, the International

Work Group on Death, Dying, and Bereavement has stated that, "Education about death, dying, and bereavement should be a required, distinct, and substantive part of the core education of all health care and human services professionals."<sup>1</sup>(pp235,236)

As a contribution to that education, this article reviews selected recent literature on bereavement, grief, and mourning with the goal of providing a current account of what researchers and scholars are reporting about these subjects. We offer this review in full recognition of Carl Jung's comment that "Theories in psychology are the very devil."<sup>2</sup>(p7) But Jung did not stop with that assertion. He went on to add in the very next sentence: "It is true that we need certain points of view for their orienting and heuristic value; but they should always be regarded as mere auxiliary concepts that can be laid aside at any time." Jung's observation has 2 key aspects for all professionals who work with bereaved persons: (1) education is a resource that provides us with auxiliary concepts or tools that are not ends in themselves but should be applied judiciously when professionals seek to help bereaved persons, and (2) good intentions alone are not sufficient because interventions

that are not guided by sound education are often haphazard, difficult, and unlikely to be truly helpful. Accurate and up-to-date information about recent developments in bereavement, grief, and mourning is indispensable for its “orienting and heuristic value” for professionals in the field of organ and tissue donation and transplantation.

### Kübler-Ross’s Stages

Perhaps the best known theory in the field of death and dying, one still appearing in many professional education programs, is the model of 5 stages proposed by Kübler-Ross.<sup>3</sup> Although these 5 stages—denial, anger, bargaining, depression, and acceptance—have been widely applied to many populations and many types of loss, they have not found support in the scholarly literature as a theory of coping with dying.<sup>4,7</sup> Further, these 5 stages were not originally offered as a theory of postdeath bereavement, although they have often been assumed to serve that function. A review of recent literature can help to explain current understandings of bereavement, grief, and mourning.

### Bereavement

There is little disagreement in the literature about the term that underlies all discussions of grief and mourning. “Bereavement is the term used to denote the objective situation of having lost someone significant through death.”<sup>8(p4)</sup> The noun “bereavement” and the adjective “bereaved” derive from a now-unfamiliar verb, *reave*, which means “to despoil, rob, or forcibly deprive.”<sup>9(vol 13,p295)</sup> The implication is that death-related losses always entail a more-or-less brutal plundering or stripping away of someone valued by the bereaved person. Encounters with bereavement always occur in deceased donation and may occur in living donation and transplantation.

Any bereavement, involves 3 key elements: (1) an attachment, (2) a loss, and (3) an individual who is deprived of the valued person by the loss.

The term attachment identifies a special type of relationship, one that satisfies an individual’s basic need for safety and security. The prototype of all attachments is the relationship of a child to its mother. In donation and transplant situations, attachments may be most prominent among family members of a potential or actual donor, and family members of a recipient, as well as among care providers who have become close to a recipient and family. A donor family and transplant recipient who communicate and may even meet may also form a significant attachment.

The term loss points to the termination of an attachment or a separation from the valued person. Humans encounter many types of losses, but the death of a family member or significant other is perhaps one of the most difficult. In addition to the nature of the

attachment, how any loss will be experienced depends on several critical variables:

- The way the death occurred (Suddenly? Unexpectedly? Traumatically?)
- The contemporary circumstances surrounding the person experiencing the loss (Is life going well or has the person recently encountered other significant deaths and difficult challenges? Is this death one of many losses occurring at the same time?)
- The coping strategies the person has learned to use in dealing with previous losses (Are those strategies productive ways of managing stressors or not?)
- The developmental situation of the person (Is the individual person who is coping a child, an adolescent, an adult, an elderly person, or a handicapped person?)
- The nature of the support available to the person at the time of and after the loss (Is it helpful or unhelpful? When and for how long is it available?)

Any or all of these loss variables may be significant in donation and transplantation contexts.

Each death or primary loss is likely to be associated with multiple secondary losses, either tangible or intangible/symbolic in character.<sup>10</sup> For example, the death of a family member who becomes a donor may also involve the loss of the family’s main source of income or the person who was its emotional center binding members together, while the death of a transplant recipient may cut a family off from the support they had been receiving from the transplant center staff.

Finally, bereaved individuals are often described as survivors because they remain alive after the death of another person. However, what family members most need after the death of a donor or recipient is to find effective ways to cope with the death of their loved one and to adapt to the new world without the physical presence of the person who died. That is, they are challenged not only to survive the death, but also to survive the losses they have experienced.

### Grief

Grief is the term that indicates one’s reactions to loss.<sup>10,11</sup> Grief is experienced when one encounters a significant loss, which may or may not be a loss that is related to death. Not to react in any manner would suggest that (1) there was no real attachment before the loss, (2) the relationship was complicated in ways that set it apart from the ordinary, or (3) the individual is somehow suppressing or hiding his or her reactions to the loss.

The word “grief” is often equated with emotional reactions to loss or explained simply in terms of feelings. In fact, however, grief reactions may be physical, psychological (emotional, cognitive), behavioral, social, and/or spiritual in nature.<sup>12,13</sup>

- Physical reactions to loss can include hollowness in the stomach, a lump in the throat, tightness in the chest, aching arms, oversensitivity to noise, shortness of breath, lack of energy, muscle weakness, dry mouth, heart palpitations, or loss of coordination
- Emotional reactions to loss or feelings typically are experienced as sadness, anger, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning or pining, relief, numbness, or a sense of depersonalization
- Thoughts or cognitions as part of grief can involve disbelief, confusion, preoccupation, difficulties in focusing or concentrating, a sense of presence of the deceased, paranormal (“hallucinatory”) experiences, or dreams of the deceased
- Behaviors often experienced in grief include sleep or appetite disturbances, crying, absent-mindedness, loss of interest in activities that formerly were sources of satisfaction, avoiding reminders of the deceased, searching and calling out, sighing, restless overactivity, or visiting places and cherishing objects that remind one of the deceased
- Social reactions to loss can be seen in difficulties with interpersonal relationships, social withdrawal, or problems in functioning within an organization
- Spiritual dimensions in grief frequently involve searching for a sense of meaning, hostility toward God or a higher power, calling upon one’s religious or value framework to buffer or incorporate the loss, or perhaps realizing that previously held beliefs are inadequate to cope with this particular loss

To confine grief solely to matters of feelings or emotion risks ignoring or neglecting the full range of an individual’s grief reactions that are recognized and supported.<sup>14</sup> In working with the bereaved individuals they serve, donation and transplant professionals should recognize the full range of the grief reactions noted here.

Grief reactions to loss, whether experienced inwardly or outwardly, expressed privately or publicly, are typically healthy, normal, and appropriate. Grief reactions may be unusual for those who have not experienced significant losses in their lives, but they are not abnormal as such. They are signs or manifestations of the distress associated with loss, not symptoms of disease. Grief is a “dis-ease,” a discomforting disturbance of everyday equilibrium, but it is not a “disease” in the sense of a sickness or morbid (unhealthy) condition of mind or body. Any human reaction can, of course, be carried to an unhealthy extreme, but ordinary, uncomplicated grief is an understandable and fitting reaction to the severing of an attachment to a significant person in one’s life.

Grief reactions are also unique to each particular loss and bereaved person. The same individual may react in different ways to different losses; different individuals may react in different ways to the same loss. Therefore, apart from extreme grief reactions that cause direct harm to oneself or others, one person’s grief should not be taken as a standard by which others should evaluate themselves or be evaluated.

## Mourning

Mourning is difficult to define precisely because it is used in different, overlapping, and sometimes conflicting ways both in everyday speech and in the professional literature. Thus, Rando<sup>15(p592)</sup> has written that, “The term mourning is probably the single most inconsistently used term in thanatology.” Worden<sup>13(p37)</sup> has noted, “In this book I am using the term ‘mourning’ to indicate the process that occurs after a loss, while ‘grief’ refers to the personal experience of the loss.”

Part of the confusion arises because the word “mourning” is sometimes applied to the public or social rituals that are involved in bereavement (eg, funeral and memorial rituals), while at other times it is used to indicate the internal or private processes that individuals use to try to manage the aftermath of their losses and their reactions to those losses. In the professional literature, these alternatives may reflect differences between sociological or anthropological and psychological or psychoanalytic perspectives.

A constructive way of understanding mourning is to think of it as involving 2 related processes: (1) coping with both the losses one has encountered and the grief reactions associated with those losses, and (2) adapting to the new world into which the bereaved person has been thrust while also developing healthful ways of living in that new world.<sup>10,12</sup> If so, mourning has 2 complementary forms or aspects: it looks both backward and forward. In addition, mourning is both an internal, private, or intrapersonal process and an external, public, or interpersonal process.

A further linguistic complication has to do with how one understands the term grieving. Some writers (eg, Attig<sup>16</sup> and Neimeyer<sup>17</sup>) and members of the public employ an unspoken distinction between the term “grieving,” by which they mean the internal or intrapersonal dimension of coping with loss, and “mourning,” which they use to designate the interpersonal aspects or social expressions of grief. But frequently, the terms “grieving” and “mourning” are used almost interchangeably with little distinction.

The important point is to focus not just on grief reactions, but on the broader processes of mourning because, as Shneidman<sup>18(p179)</sup> once wrote:

Mourning is one of the most profound human experiences that it is possible to have. . . . The

deep capacity to weep for the loss of a loved one and to continue to treasure the memory of that loss is one of our noblest human traits.

Donation and transplantation professionals can foster constructive mourning by offering the opportunity of donation and by providing follow-up support to families. Organ transplant recipients waiting for a lifesaving organ should be supported as they face their potential death. When receiving an organ, they should be helped to understand that the donor did not die so that they could live but that in fact the donation may be helpful to the donor family and the best thanks to offer may be in living fully with the new organ.

### **Theoretical Interpretations of Mourning Grief Work**

Freud<sup>19</sup> explained mourning in terms of grief work and distinguished it from “melancholia” or depression. Freud thought bereaved persons needed to work through their grief, which he saw as emotional reactions to loss, in order to detach or withdraw their psychic bonds to the deceased in a process he called *decathexis*, resolve and recover from the loss, and reinvest in life. Wortman and Silver<sup>20,21</sup> have argued that the evidential base for this view is weak.

### **Phases in Mourning**

In the 1960s and 1970s, two British psychiatrists offered an important account of mourning. Bowlby<sup>22,23</sup> developed the basic theory that attachments involve strong affectional bonds arising from a need for security and safety; Parkes<sup>24,26</sup> supplemented that work by drawing on his involvement in hospice programs in England and his studies of widows. Their account involved 4 phases: (1) shock and numbness, (2) yearning and searching, (3) disorganization and despair, and (4) reorganization.

According to this theory, one is shocked or stunned by the impact of the loss, leading to a kind of “psychic numbing” or “psychic closing off.” As that defense against bad news and unwanted pain wears off (although those reactions may recur from time to time, eg, at anniversaries of the death), this theory notes that people are often unwilling to acknowledge the loss or relinquish the physical presence of the deceased. As a result, people yearn or pine for a time that is now gone and search for what it entailed. These activities are doomed to failure since the past is simply no longer available as it once was. Grasping that fact is to realize the depth, extent, and finality of the bereaved person’s loss. This realization can lead bereaved persons to experience a sense of disorganization and despair in the new world of the present with questions about personal identity and how to go on with everyday living. Much that was previously taken for granted is

now called into question in the struggle to find a way to go forward. Still, this theory argues that most bereaved people succeed in carrying through a process of realization by reorganizing their lives and developing “new normals” for future living. They make real in their inner, psychic worlds what is already real in the outer, objective world.

This phase-based model of mourning (and others that modify the theory in various ways) essentially offers broad generalizations about common elements in (some? most?) mourning. As such, one must be cautious in applying these generalizations to individual mourners. Critics of theories like this view them as describing a rigid, linear schema in which one phase is said to follow another in sequence. Perhaps that is one reason why so often we hear talk about how much time is appropriate for mourning and suggestions that mourners will “go through” these phases almost in a passive way to achieve some desired “completion,” “resolution,” “healing,” or “recovery.” In fact, mourning is a process quite different from an automatic car wash machine in which a dirty automobile is hooked up to a mechanical apparatus, dragged through the process without exerting any effort, and turned out clean at the end.

### **Tasks in Mourning**

In 1982, Worden was perhaps the first to move theories of mourning away from stages and phases by focusing on tasks. Worden<sup>27</sup> originally proposed that mourning involves 4 tasks: (1) to accept the reality of the loss, (2) to experience the pain of grief, (3) to adjust to an environment in which the deceased is missing, and (4) to withdraw emotional energy and reinvest it in another relationship. In 2009, Worden<sup>13</sup> modified some of these descriptions as follows: (1) to accept the reality of the loss, (2) to process the pain of grief, (3) to adjust to a world without the deceased, and (4) to find an enduring connection with the deceased in the midst of embarking on a new life.

Clearly, the most significant change appears in the fourth task, where Worden has moved away from a notion of mourning as involving separation or detachment from the deceased. The new version of Worden’s fourth task reflects an effort to restructure or revise, rather than relinquish, the relationship with the individual who has died. The point is to allow for the possibility of an ongoing connection with that individual in such a way that the mourner is not prevented from going forward with life.

However phrased, Worden’s tasks interpret mourning as, in principle, a proactive way of striving to manage one’s loss, grief, and new challenges. They depict this process as involving a set of interrelated tasks, not as a succession of stages or phases that one might move through in a more or less passive way. A task-based approach enables individuals to regain some

Table Examples of loss-oriented and restoration-oriented processes for donor families and transplant recipients

<b>Loss-oriented processes: Donor families</b>	<b>Restoration-oriented processes: Donor families</b>
Mourn losses associated with the death of their family member	Restructure relationships and establish continuing bonds with their deceased family member
Participate in remembrance ceremonies	Adjust to new family roles required by the absence of the deceased family member
Contribute squares to donor family quilts	Communicate with their recipients and/or other recipients
Establish memorials to loved ones	Advocate for donation
<b>Loss-oriented processes: Recipients</b>	<b>Restoration-oriented processes: Recipients</b>
Mourn the loss of their former healthy state	Accept the gifts they have received and the opportunities those gifts make available
Mourn the death of the donor	Communicate with their donor family and/or other donor families
Support donor families	Live healthy full lives

measure of control over their lives because they can choose when, how, or if they are ready to tackle any particular task.<sup>28</sup>

Worden does not view these 4 tasks as involving a fixed progression. On the contrary, his position is that, “Tasks can be revisited and worked through again and again over time. Various tasks can also be worked on at the same time.”<sup>13(p53)</sup> He also added an important reminder: “There is a sense in which mourning can be finished, when people regain an interest in life, feel more hopeful, experience gratification again, and adapt to new roles. There is also a sense in which mourning is never finished.”<sup>13(p77)</sup>

Donation coordinators will be familiar with how difficult it is for family members who are called to a hospital emergency department or intensive care unit to accept or even acknowledge that their loved one has died and how challenging it can be for them to process the pain of their loss as Worden’s tasks propose. Bereavement aftercare specialists supporting donor or recipient families will know that the ongoing work of adjusting to a world without the deceased and restructuring a relationship with that individual so as to enable the healthy ongoing living that Worden describes can be a life-long journey.

### Six “R” Processes

Rando<sup>10</sup> also emphasized what mourners can do, at least potentially, in responding to loss and developing a new way of living in the future. Rando’s interpretation proposed 6 “R” processes: (1) recognize the loss by acknowledging and understanding the death; (2) react to the separation by experiencing the pain, by feeling, identifying, accepting, and giving some form of expression to all the psychological reactions to the loss, and by identifying and mourning secondary losses; (3) recollect and reexperience the deceased and the

relationship by reviewing and remembering realistically and by reviving and reexperiencing the feelings; (4) relinquish old attachments to the deceased and the old assumptive world; (5) readjust to move adaptively into the new world without forgetting the old by revising one’s assumptive world, developing a new relationship with the deceased, adopting new ways of being in the world, and forming a new identity; and (6) reinvest emotional energies. These 6 processes differ in some respects from Worden’s 4 tasks, but here they serve mainly to offer different ways of describing what is involved in mourning and its twin faces highlighted in the next theory we consider.

### The Dual Process Model

The dual process model describes mourners as involved in a dialectic that oscillates between 2 different types of processes: loss-oriented processes and restoration-oriented processes.<sup>29</sup> This model depicts bereaved persons as shifting back and forth between experiencing their loss and intrusions of grief, on the one hand, and finding ways to attend to life changes and to integrate the death into their “new” life, on the other hand. In this account, coping with loss and grief does not move on a straight line in a single direction; on the contrary, it ebbs and flows according to the specific challenges an individual is responding to at a given time. As a result, this model emphasizes the effort that coping requires of bereaved persons, the potentially active nature of their mourning, and the complexity of the interplay and interaction between their coping processes.

From this point of view, one can see how the first 2 of Worden’s tasks and the first 2 of Rando’s processes focus on coping with loss, while the remaining tasks and processes look more directly to what is here called “restoration.” The Table provides an example of how

some of these processes might apply to donor families and to transplant recipients. Similar processes are likely to apply to living donors and to the families of transplant recipients after the death of their recipients.

### Meaning Reconstruction

Neimeyer<sup>17(p110)</sup> has been a leading proponent of the view that “meaning reconstruction in response to a loss is the central process in grieving.” Here, “reaffirming or reconstructing a world of meaning that has been challenged by loss” is critical and redefining ongoing connections with the deceased is essential.<sup>30(p195)</sup> According to Neimeyer,<sup>17(p92)</sup> “Grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by loss.” Many factors affect that process, including culture, family, personal experiences, relationships, and support. A central activity in reconstructing the lives of bereaved persons involves redefining themselves psychologically, socially, and spiritually, most often accomplished through narrative or story-telling processes. These processes can include what Attig<sup>16,31</sup> has called “relearning the world” in which the bereaved move from “loving in presence” to “loving in separation.” There is no timetable for when or how this might occur.

Donation professionals are well positioned to appreciate the initial efforts at meaning making represented by the act of authorizing donation. Those who follow and support donor families can observe the extended processes through which they strive to reconstruct their lives. Also, transplant professionals are familiar with the complex ways in which transplant recipients find joy in the gifts they have received, often feel unworthy of those gifts, and determine to make new meaning in their future lives.

### Continuing Bonds

One other account of what is involved in mourning focuses on continuing bonds in bereavement. This focus has been implicit in more than 1 of the theories discussed thus far. It is also clearly present in the activities of many donor families, living donors, transplant recipients, and the families of recipients who died waiting for or after the transplant.

The new emphasis on continuing bonds differs from theories that encouraged the bereaved to “let go of” or “forget” the deceased. From this perspective, continuing an internal relationship with a representation of the deceased or keeping close an object that links bereaved persons to the individual who died is an important way to learn to live with the death of a loved one. Klass et al<sup>32</sup> in 1996 broke new ground by arguing on behalf of the importance of “continuing bonds” or “ongoing connections,” especially among bereaved parents and parentally bereaved children. They suggested that it is okay for many bereaved

persons to have a connection or constructive relationship with the deceased person as a powerful support in their mourning. As Anderson<sup>33(p5)</sup> wrote much earlier, “Death ends a life, but it does not end a relationship.” Cantor<sup>34</sup> suggested that a constructive mourning process can lead to “enriched remembrance.” This point of view recommends restructuring the relationship with the individual who has died in order to carry forward the legacy of that relationship into new modes of living. In this way, effective mourning can free the bereaved to live meaningful lives in their new situation without wholly abandoning what they have lost.

### Grieving Styles

It has long been thought that the “conventional,” normative, or right way to cope with loss requires emotional expression of grief and being willing to reach out and accept help. Thus, Staudacher<sup>35(p3)</sup> argued that “there is only one way to grieve. That way is to go through the core of grief. Only by experiencing the necessary emotional effects of your loved one’s death is it possible for you to eventually resolve the loss.” If this is correct, bereaved males are disadvantaged because they are seen as ignoring their feelings, hiding from their grief, being unwilling to share their emotions, and refusing offers of help.

Martin and Doka<sup>36</sup> rejected this view and focused, instead, on what they called grieving styles. According to these authors, grieving styles are influenced but not determined by gender. Further, Martin and Doka proposed a continuum of adaptive grieving styles ranging from the intuitive to the instrumental. Intuitive grievers experience grief as strong waves of emotion, find it important to express their feelings, and adapt to grief in strongly affective ways. Instrumental grievers, by contrast, primarily experience their grief cognitively or physically by thinking through the loss and doing things in response to its consequences. Apart from anger, instrumental grievers are likely to experience muted affective reactions to loss.

Martin and Doka suggested that many individuals may employ a combination of these grieving styles in adapting to the death of a loved one. Also, individuals may change their grieving style throughout their life course. This research challenges the grief work hypothesis that only through expression of inner feelings can someone effectively cope with grief. It also clearly favors individual pathways in coping with loss and grief, a point that is of special importance for donation and transplantation professionals as they take care not to approach and support bereaved individuals through the distortions of gender stereotypes.

### One Exception

There has been, however, one exception to recent trends in understanding bereavement. A report on

retrospective interviews with a selected population of 233 subjects bereaved through natural causes—largely older white women who most often had experienced the death of a spouse—identified a series of sequential responses to loss by death.<sup>37</sup> These responses were acceptance, disbelief, yearning, anger, and depression. Acceptance was the dominant initial reaction. Subsequently,

[D]isbelief decreased from an initial high at 1 month postloss, yearning peaked at 4 months postloss, anger peaked at 5 months postloss, and depression peaked at 6 months postloss. Acceptance increased through the study observation period.<sup>37(p297)</sup>

The researchers concluded that, “The 5 grief indicators achieved their respective maximum values in the sequence (disbelief, yearning, anger, depression, and acceptance) predicted by the stage theory of grief,”<sup>37(p297)</sup> and therefore these “stages” and this period of time describe the “normal” course of grief. These are, however, not the Kübler-Ross stages, and critics have suggested concerns about the limitations, methods, assumptions, conclusions, and generalizability of this research.<sup>38</sup> For these reasons, donation and transplantation professionals would do well to be cautious about this and other stage theories of grief and mourning, especially since the bulk of the mainstream literature in this field has moved away from staging grief.

### Disenfranchised Grief

One important development in this field that has been widely accepted is the concept of disenfranchised grief, defined as: “The grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported.”<sup>39(p4)</sup> According to its author, grief can be disenfranchised in 3 primary ways: (1) when some relationships (eg, unsuspected, past, or secret ones) are not granted social approval, (2) when the significance of some losses (eg, those involving elective abortion, perinatal death, or loss of body parts) is not recognized by society, or (3) when some bereaved persons (such as young children, the very old, or the mentally challenged, and even health professionals) are not seen as entitled to experience grief or have a need to mourn. As noted earlier, these 3 are the key structural elements of bereavement. Certain types of deaths (eg, those resulting from suicide or HIV/AIDS) were also said to be “disenfranchising deaths,” but the main point was to link disenfranchisement to relationships or attachments, losses, and bereaved persons or survivors. Treating people this way creates what has been called a paradoxical problem: “The very nature of disenfranchised grief creates additional problems

for grief, while removing or minimizing sources of support.”<sup>39(p7)</sup>

Corr<sup>40,41</sup> added that disenfranchisement can also extend to the 2 dynamic or functional elements of bereavement, including grief or the ways persons experience and express reactions to loss and mourning or the ways persons cope with their losses and grief reactions. Doka<sup>42(p14)</sup> acknowledged that the “ways individuals grieve also can contribute to disenfranchisement.” Examining disenfranchisement in this way draws attention to the 3 central concepts in this article: bereavement, grief, and mourning. It also points to the need for donation and transplantation professionals to be cautious in their interactions with bereaved persons so as not to unwittingly disenfranchise important aspects of the ways in which those individuals are living with their bereavement, grief, and mourning.

### Grief, Mourning, and Outcomes: A Brief Summary

In recent years, researchers and scholarly writers on bereavement have emphasized the potential complexity of loss experiences. They have also sought to avoid limiting grief reactions to feelings alone and have stressed the typical breadth of those reactions. In explaining mourning, recent writers have focused primarily on tasks and processes, not on stage- or phase-based theories.<sup>43-46</sup> That focus emphasizes the potentially active nature of grieving and mourning.<sup>47</sup> Details of the interpretations of mourning offered by recent writers differ somewhat, but they generally favor appreciation of individual differences, open-ended processes, and the influence of a wide variety of religious, social or cultural, personal, and other variables on individual grief journeys.

In addition, the long-standing rejection of fixed end points as outcomes of mourning (eg, recovery, completion, or resolution)<sup>48</sup> has been coupled with a new awareness of opportunities for growth and transformation in bereavement.<sup>49-51</sup> Evidence suggests that bereaved persons can achieve significant personal growth as they struggle to readapt to life without the deceased. Research on posttraumatic growth has led some to argue that even traumatic losses can be a source of growth.<sup>52-54</sup>

Some writers have sought to reinterpret and rehabilitate the notion of “recovery,”<sup>55</sup> but others have preferred to emphasize the importance of “resilience.”<sup>56-58</sup> In this view, many bereaved persons have been seen as finding that their lives can improve in some ways through their mourning processes. However, they most likely will remourn their losses as they move through their lives and age. Donation and transplantation professionals are likely to encounter all of these postdeath experiences in their work with bereaved persons.

## Some Lessons for Donation and Transplantation Professionals

There are many lessons that donation and transplantation professionals might take away from this review of current understandings of bereavement, grief, and mourning. Among these lessons, individuals will be best positioned to determine which apply most directly to their work and how they can integrate them into their professional practice. Here we can suggest only some general lessons that may be relevant.

- If each individual's experiences in bereavement are unique, then each bereaved person is the real expert in his or her bereavement, notwithstanding all of our education and knowledge.
- Professionals must listen closely to each bereaved person with whom they work to learn about what is involved in that person's bereavement.
- Professionals must take care to appreciate how each bereaved person's losses and grief are being experienced and expressed.
- Professionals must attend to how each bereaved person with whom they work is mourning or coping with his or her losses and grief.
- Professionals have important roles to play in helping bereaved persons by offering the opportunity of donation, fostering successful transplantations, and supporting donor families, living donors, and families of transplant recipients after a death occurs.
- Each donation and transplantation professional may not be able to witness the long journey of the bereavement and return to well being of the bereaved persons with whom they interact, but they can contribute important sources of solace for those they serve.
- It is a professional responsibility to learn as much as one can about current understandings of bereavement, grief, and mourning in order to help improve interactions with bereaved persons and optimize the donation and transplant experience for donors, recipients, their families, and professionals.

## Financial Disclosures

None reported.

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