Responding to Grieving Families

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Understanding Grief

In a conference session entitled "Understanding Grieving Families,"[1] bereavement professional Paul V. Johnson, MA, HealthPartners, Hospice of the Lakes, Minneapolis, Minnesota, highlighted both the individual and relational nature of grief as it occurs within a familial context: "Grief within the family consists of the interplay of individual family members grieving in the social and relational context of the family, with each family member affecting and being affected by the others."

Families sometimes erroneously believe that each member's grief will be similar to the others' because they have experienced the death of a specific person within their family system. In reality, however, each family member's grief is unique. The specific nature of the relationship between each family member and the deceased varies, as will the particular history and social context of their relationship. Further, to fully understand grieving families, it is important to recognize that their grief is also affected by the relationships they have with each other and the "emotional legacies" they have created as a family and with the one who died.

These differing grieving patterns are also affected by the degree to which family members are willing or able to anticipate and prepare for loss, as well as such factors as the gender, age, and maturity or developmental level of each person within the "system." Understanding family grief, therefore, is a task with multiple layers and interplays.

Assessing Family Grief

A critical component of responding to grieving families involves making a thorough assessment of their grief, including the stresses/challenges before them as well as the strengths they exhibit. The goal of the assessment process is to ascertain how much at risk family members are for negative outcomes in bereavement. Such outcomes include long-term distress and poor coping, depression and anxiety, and other symptoms of complicated grief. As described by Cordt T. Kassner, PhD, Colorado Hospice Organization, Colorado Springs, Colorado, and Julie Thomas, MA, LPC, HospiceCare of Boulder and Broomfield Counties, Colorado, in their presentation titled, "The Colorado Hospice Bereavement Project and Software,"[2] an assessment provides "the ground work for bereavement care services and should address family and significant others' grief and bereavement responses and needs on physical, emotional, social and spiritual levels."[3] In addition, Dr. Kassner and Ms. Thomas asserted that it is important to also identify family strengths and stressors (see Table), and their Colorado Bereavement Assessment was proposed as a model assessment tool.

Table. Grief: Strengths and Stressors

Physical	Psychological	Spiritual	Strengths and Stressors
Preexisting health concerns	Emotional concerns	Involvement in faith community	Access to support
Increased visits to physicians	Obvious mental health problems	Importance of beliefs, faith	Satisfaction with social interaction
Health insurance coverage	History of mental health concerns	Sense of spirituality, meaning	Experience of disenfranchised grief
Change in health status	Suicide ideation, plans	Satisfaction with funeral, memorial ritual	Adequate financial resources
Change in energy level	Extreme dependency	Signs of spiritual strength	Change in activity level
Exhaustion	Extreme anger	Signs of spiritual distress	Legal concerns
Sleep changes	Extreme fearfulness		Employment status
Appetite changes	Extreme guilt		Day-to-day living concerns
Weight gain/loss	Attitude (optimism vs pessimism)		Advance preparation for death
Neglect of appearance	Current therapeutic interventions receiving		Circumstances of death
Recent accidents			
Alcohol/substance abuse			

In addition to individual factors, determining how the family interacts and how each member works to support the family system in times of significant stress and change are important components of the assessment process.

Helping Families Cope and Adapt

John Schneider's work on Transformative Grief[4] was cited by Dr. Johnson as providing a helpful structure for both understanding grieving families and providing appropriate intervention to help them cope and adapt to the loss within their system. Schneider poses important questions for consideration, underscoring that the questions must both be asked and answered in order to effectively cope with and adapt to loss.

Questions to be Asked and Answered

1. What have we lost?
2. What do we have left?
3. What may still be possible for us?

As families work to address these questions, they begin to recognize that they must be "reorganized" and that it will be necessary, over time, for the members to "reinvest" in a "new" family configuration and system that will be created without the deceased.

Essential to this adaptation process is communication, which Dr. Johnson identified as the most important element in a family's ability to adapt. Acknowledging the reality of the loss and experiencing it collectively requires that family members be both willing and able to communicate with each other. Communication that respects family members' thoughts as well as feelings enables members to identify and share their beliefs and determine the meaning of the loss in their lives, both individually and collectively.

Much of families' work of coping with loss and adapting to the changes that accompany it will occur well outside the boundaries of the healthcare environment with which they have been associated during the illness/death of a member. There are, however, important and desirable roles that healthcare professionals can play at the time of, and immediately following, death.

Healthcare Professionals' Roles

Clinicians working in the end-of-life care arena play a number of roles in supporting patients and families in the last weeks and days of life, but their involvement generally comes to an abrupt end with the death of a patient for whom they have cared. Christian Sinclair, MD,[5] Kansas City Hospice, Kansas City, Missouri, in his talk on "The Clinician's Letter of Condolence," posited that there are a number of very appropriate roles for healthcare professionals at the time of death and immediately afterward. He asserted that medical professionals have not taken advantage of the many opportunities they have for helping and supporting families grieving the loss of one of their members. Generally, healthcare professionals' training has not included the development of skills to assist them in caring for families at these difficult and vulnerable times.

Clinicians' involvement and support at this critical time can have a very positive effect on the family's experience, and may help prevent some of problems that are associated with poor coping (decline in health; inappropriate usage of healthcare; increased risk of depression; sleep disruption; increased consumption of tobacco, alcohol, and sedatives; increased suicide risk; and death).[6,7] In addition to clinicians' common roles of delivering bad news (at the time of death) and immediately consoling the family, healthcare professionals can be helpful to families by providing short-term contact after death. Such contact facilitates the healthy adaptation process of families, provides an appropriate and definitive closure to the relationship between the family and healthcare providers, and creates an opportunity for clinicians to encourage the family to contact

appropriate community resources for bereavement follow-up. In addition, this intentional contact can provide an outlet for healthcare professionals and helps to support the "human" side of medicine.

Dr. Sinclair suggested that a primary reason clinicians do not routinely engage in such follow-up after death is that they do not know what to say (or, in correspondence, what to write). He also suggested that healthcare professionals believe that they lack the time to complete the contact. He encouraged them to seriously consider devoting the small amount of time that is necessary to complete such follow-up contacts, and argued that the family, healthcare providers, and the healthcare system will all benefit from the effort.

Does Contact After Death Make a Difference?

Very little has been documented about the importance and value of providing contact to families after death, and Dr. Sinclair cited sources that indicated that such follow-up was indeed a rare occurrence. While over 60% of physicians surveyed provided a call to family members after death, personal contact by letter (34% to 46%), visit (8% to 15%), or attendance at memorial events (27% to 35%) was less likely.[8]

Another survey about clinicians' attitudes and practices at the time of death showed that less than 10% provided contact following death.[9] Billings and Koulton[10] found that a note was the most common form of contact (44%). Subjective comments by family members in their study indicated that they appreciated clinicians' "extra effort" to contact them after death. Conversely, family members commented that they felt "insulted" when they did not hear from their physician, and were even more upset when contact they initiated did not receive a reply. Dr. Sinclair's own work with residents who wrote to family members after death (pending publication) indicates positive results not only for family members who receive the contact, but also for the clinicians themselves.

Responding at the Time of Death

Although it is clear that family members appreciate and can benefit from follow-up contact, Dr. Sinclair encouraged the creation of a written expression of condolence as well. A primary advantage for this form of contact is that it is tangible, can be reread to extend support and care to the family over time, and can be shared with multiple family members. Written expressions of condolence are more effective than the routine telephone call, and family members report treasuring and appreciating the written expressions of their healthcare team. Still other healthcare professionals may be able to meet family members in person and provide more direct, in-person contact. Indeed, it is not unusual for family members to return to healthcare facilities after death as a way of "connecting" to their deceased loved ones and to acknowledge their appreciation for the care they received.

Expressions of Condolence

Responding in Writing

An effective condolence letter takes a number of important variables into consideration. The following guidelines, taken from a source devoted to condolences,[11] are offered to assist the clinician in crafting a meaningful correspondence to grieving families:

- Identify the deceased by name and acknowledge his/her death;
- Express sympathy to the family;
- Note special qualities of the deceased, recall a memory, or identify a legacy left by the deceased;
- Extend support and care, noting community resources where the family can access bereavement care services; and
- Share an appropriate, meaningful quote or reading, a life philosophy, or personal perspective.

Responding in Person

Personal contact with family members after death, when they are experiencing acute grief, requires special skill and patience. It is important that clinicians be aware that the most significant aspect of the contact (from the family's perspective) will be their "presence." Another skill that cannot be overestimated is the ability of healthcare professionals to engage in active listening. It is less important for family members to hear professionals' verbal expressions of sympathy than it is for professionals to be "present" with them, sometimes in silence, while acknowledging their grief. These are foundation principles for responding to grieving families, with additional guidelines for professionals as follows:

- Identify the deceased by name and acknowledge his/her death;
- Acknowledge the importance of grieving and give the family "permission" to do so;
- Offer, as appropriate, concrete suggestions for families to remember and honor the life of the deceased (activities, memorials, rituals, etc.);
- Encourage the family to access community bereavement support programs and groups; and
- Consider the needs of, and ask about, all members of the extended family, especially children.

Summary

Responding to grieving families at the time of death and immediately afterward is an important and meaningful contribution that healthcare professionals can make; one that can facilitate the adaptation process for families. It is important that healthcare professionals recognize the complexity of the family system and how it impacts the grief and bereavement experience. Likewise, it is helpful for healthcare professionals to have an understanding of the components of a bereavement assessment, the potential of negative outcomes in bereavement, and indications of poor coping in bereavement. Given the complexity of the multiple layers of a family system's grief and bereavement experience, healthcare professionals are challenged to take advantage of the opportunities

they have to positively impact families after death. Families benefit from appropriate follow-up and meaningful contact after death, and healthcare professionals are encouraged to make this an intentional part of their care.

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