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When Does the Responsibility of Our Care End: Bereavement

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ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital, founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

Two vignettes are presented of a caregiver’s response to the death of a patient, contrasting the extremes of involved compassion for the family and fractured relationships. Grief for loss is an inevitable part of life and a common part of cancer care. Support of the bereaved may be one of the hardest tasks for cancer care professionals, who are confronted with the limits of modern medicine. There is a responsibility to provide grieving families with support and care; care that goes beyond the death. A compassionate response helps both those who suffer and those who care. Complicated and uncomplicated bereavement, grief reactions, resources for bereavement counseling, and the role of condolence letters are reviewed. The Oncologist 2002;7:251-258

LEARNING OBJECTIVES

After completing this course, the reader will be able to:

1. Understand the effect of grief on the bereaved and on staff.
2. Understand the responsibilities of compassionate cancer care.
3. Recognize the resources available for uncomplicated and complicated grief.

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PRESENTATION

Vignette #1

Social Worker: I wanted to talk about Joey who was a three-year-old very bouncy little Mexican jumping bean kind of a boy. He came in a little stroller with his baby sister and once in a while with his older sister who was 9 at the time. Everybody cared a great deal about him. He developed strong relationships, both in Radiation Oncology and on the Pediatric floor where he got his chemotherapy.
As time went on, he became more and more ill. There were some difficult issues. As he came closer to death, he was transferred to a local hospital and then went home and died at home. The parents came from two different religious backgrounds and the question arose, “Where was Joey going to be buried?” The father wanted one place and the mom wanted another. Because it was very important to the mom that Joey be buried where she was going to be buried, they found a rabbi and he was buried in a Jewish cemetery. It was a huge loss for the family, for the parents, for the grandparents, and for staff as well. I am still close to the mom and a few months ago, after Joey died, she came in with her older daughter who said, “Tell her, tell her.” Mom was pregnant and it was very exciting for everyone. She has subsequently had a healthy baby boy. Ms. S says he is a lot like Joey. Mom did a number of things with dad to help her move on and to say goodbye to Joey. In fact, she was close to Mike Gollivan of the television program Chronicles. He was a good friend and asked permission from the parents to put Joey’s story on television, and it aired on Channel 5. The parents were very open. The father especially wept copiously. They were very honest about how hard it is to live with the loss of such a special kid. Joey loved the play corner up on the pediatric floor, so they donated this really beautiful, well-constructed wooden kitchen with a sink and a fridge and a stove. There is a little plaque that has Joey’s name on it. I continued to talk with Ms. S. They came to the pediatric memorial service that is held annually. Everyone is invited. People come, they write poems, they speak, they draw pictures, and they put up photos. It’s a wonderfully healing ceremony. Ms. S. and I have an appointment for coffee very soon. They are going to be okay, but I think it’s a loss that they will always have. There is a gap that is always going to be there. There have been letters and phone calls from the doctors and nurses and all of this has been enormously meaningful.

Vignette #2

Oncologist: Mr. A is a 47-year-old man whom we took care of for approximately 4 years with non-small cell lung cancer and who participated in approximately seven different chemotherapy regimens, most recently having a beautiful response to Iressa®. Many of the fellows have seen pictures of Mr A’s tumor response. He really had a wonderful response to Iressa. The reason to present him in this venue, is that he was someone who became very close with me, with his nurse, his infusion room nurse, with the clinic coordinator, and with many others on the floor. He had a very rough clinical course, and toward the end was coming in very, very frequently. There were lots of phone calls. He talked to us probably once every day or two and was seeing me at least weekly for the last 3 months of his life (pause); and then he died two months ago. I called his wife to offer my condolences and we really hadn’t talked since, nor have other people from the team talked to the family. We were talking yesterday about how hollow that feels. An intense personal relationship suddenly ends when the patient dies. We talked about what role bereavement care has, not just for the patient and family, but also for the staff themselves; and if we made a better commitment, what a difference that would make to our care. Yet we understand the need to balance that commitment with the extraordinary responsibilities we face, making the time to take care of our current patients.

**DIALOGUE**  

**Bereavement**

Palliative Care Nurse: In the palliative care service, we have a built-in follow-up for patients and families following a death. However, we still struggle with what the right kind of follow-up should be. How much? How often? What should we be doing? How much can we help? We did a survey of caregivers’ bereavement care at MGH. It was wonderful to see that across the board individual caregivers are doing a tremendous amount; cards, letters, phone calls [1]. Everybody who answered felt they should be doing more, and felt that MGH should be doing more. I think that each one of us struggles with what we should do and how we make ourselves available. We’re always telling people, “Please call at any time, please let us know how you’re doing,” and if they actually take us up on it and call us, then what do we do? It’s important to...
know who is at risk of serious depression, who needs more support than others, and what a caregiver can do. I think there is also a personal comfort level. Some of us are more comfortable than others making that connection. These are personal and professional decisions. I got a phone call from a patient’s son recently. Apparently, we had sent a lot of cards and letters. I had probably sent a letter to this family at about the 2 or 3 month mark. He called up to thank me for that letter. I couldn’t place the person I was talking to. I think that it was the patient’s father who had died. To be honest, I couldn’t remember the patient. He said to me, “I just wanted to call and thank you and I wanted you all to know that our family will hold on to this letter forever.” The importance of these gestures really hit me.

**Social Worker:** The kind of closeness that the staff has with the person when he or she is terminally ill and going through treatment, is something that few others in the community really share with the family. Then the emptiness that’s left after a death is one of the toughest things to deal with. I think part of what makes continued contact so meaningful is the knowledge that you weren’t just doing your job. You’re acknowledging that you connected with the patient and the family in the struggle, and that the relationship still holds meaning for you. The medical team can become an extended family. The family or relative can feel very isolated.

**Infusion Nurse:** I find that there are a lot of patients who want to do everything they can to treat their cancer and so their referral to hospice is very late, often in the last 2 weeks of their lives. Family and friends of a patient that we form closer relationships with often come back to update us, but many fall through the cracks.

**Social Worker:** It worries me that the cranky patient doesn’t get the same follow-up.

**Oncologist:** Hospice programs have wonderful bereavement programs but their bereavement staff, for the most part, is not the staff that cared for the patient prior to the death. They are separate and they are separate for a lot of pretty good reasons. You can burnout caring too much. I would like to ask a question that I struggle with. I know we all feel that we want to be there and reach out to our families, we don’t want to be seen as not caring, and people are truly at risk for significant dysfunction. But what I struggle with is where do you draw the line? It has been a personal struggle for me trying to balance my clinical care with my own sanity.

### Condolence and Counseling

**Social Worker:** I think you can ask the question, “Who else is there for you?” and take more initiative. I have felt pretty comfortable reviewing that with the family, “What would be most helpful to you” or “What would you like right now?” Not to focus on their neediness, but to see this contact as part of the ongoing care. We’re not through just because the patient died. They need to know that. Certainly, they want to know we’re doing it out of our care for this particular person, but it also helps to know that’s the way the hospital feels. I think it makes them feel less needy.

**Oncologist:** The culture has changed radically. Ten years ago as a practicing oncologist I had never made a single hospice visit to a patient at home. There are a number of indications for referral to hospice, and while the care of your patients is obviously the priority, when the patient dies there are a greater number of suffering individuals. Hospice gives 1 year of bereavement counseling. I see counseling for the survivors as an indication for hospice much like symptom management or VNA (nursing) services for the patient.

**Social Worker:** Something that I’ve done when I’ve worked very closely with a family and I knew I couldn’t keep up with forever is to bring a community person or a bereavement counselor to a meeting with me to enable the transition. They could hear about our relationship, and our memories, and then they can go on from there, having already connected, via me, to the family.

**Pediatric Oncologist:** In pediatrics, the relatives often say staff had a better understanding of what the patient was really going through, compared to other members of the extended family or friends. We developed a practice where we sent cards at the crucial times that are the
hardest on the family, such as Christmas and birthdays and anniversaries, as well as the memorial service. The service is very hard for parents because they have to say their child’s name and acknowledge that the child really died.

**Pediatric Nurse:** We’ve recently started bereavement rounds for staff once a month and discuss every child who has died over the past month. We invite everyone involved in the patient’s care. We’re also starting to ask families to come back in if they wish. Not all families are interested in doing this, but we believe it is helpful to actually formalize the invitation so that every family is given the invitation to come back in and meet with staff and talk about the loss of their child. In pediatrics, many of us go to the wakes and funerals of our patients. There are some families we are really close to and we talk to them very frequently. But there are other families that no one has contact with at all. What we’re trying to develop is a program where everybody gets at least some minimum level of contact.

**Palliative Care Physician:** Following people through bereavement is very important. Isaac Bashevis Singer said in one of his short stories, “Grief is silent and therein lies its uncanny power.” They just aren’t reaching out for help. When we did our bereavement survey, the interviewers didn’t really like it. They were calling the family at 3, 6, and 9 months. Families weren’t talking about things and they weren’t in bereavement programs. They were not getting services and were just suffering quietly in all of the terrible sadness they are living with on their own. There is real morbidity associated with it and intervention is helpful. Bereavement care always ends up on the bottom of the list of things to do. It can always be put off until tomorrow. If you want to get it done, there needs to be someone assigned to take care of these people.

**Psychologist:** Doing focus group research on bereavement was incredibly painful for the staff because of the stories that we heard. At the same time it was also a wonderful example of God being in the details, because very small gestures like receiving a sympathy card were tremendously powerful and very important to the families.

**Social Worker:** Bereavement care is also painful because it brings up the difficult issue that what we were trying to do for a patient didn’t work.

**Oncologist:** I guess it also comes down to how much do we embrace the concept that most of oncology is palliative care to some degree. We should therefore look at death not as failure, but natural.

**Palliative Care Physician:** I always feel guilty when somebody dies and I think of all the things that could have been done better. Although calling a widow is terribly sad, it is also incredibly gratifying for us to see that we have made a difference in people’s lives. Maybe we judge ourselves too harshly.

**Oncologist:** I’ve found that it’s very helpful to reinforce three things in phone calls to people who’ve recently been bereaved. First, that we’ve valued their loved one. Second, that we did everything we could do and equally important, is, third, to state that they did everything that one could do. I’ve been impressed at how often the family member is initially surprised when you say that, then clearly reassured that they did do everything that they could do to help their loved one.

**Psychologist:** Both cure and healing fall within the responsibility of the health care profession. I think doctors and nurses offer the most powerful kind of healing possible when they really care about someone. You weren’t just a pro doing what you had to do. You went beyond being technically competent.

**Closure**

**Psychologist:** I think we should separate the needs of families to grieve from our need to say goodbye to these people when the patient dies. Many times, I think staff reach out to families because they just felt connected to them while the patient was alive and they need some closure for themselves, acknowledging the personal contact. That is to be respected. We should honor the personal relationship by saying
goodbye before the patient dies and then to the family or friends afterward. A phone call or condolence note isn’t quite the same as doing bereavement work for the family. To an extent it’s part of “finishing up” for us and I think there are two needs here and that we sometimes only think in terms of the patient’s needs as survivors; we also need to realize we have to sacrifice.

Oncologist: In response to that, I very often ask myself the question, “Am I doing this for me or am I doing this for them?” I have sometimes been reluctant to do that follow-up because I did not want to put the family in the situation where they were consoling me for my loss.

Social Worker: For me one of the most powerful Schwartz Rounds was when the mother of a young man who died said, (I can’t say this without weeping. I was so moved) “It means so much to me to know what my son meant to you. My mother died 35 years ago. The doctor never spoke to me after her death. You have just healed 35 years of suffering” [2]. So I think when we can sincerely say how we feel, that really does make a huge impact on the family, even if we think that it’s coming from our own need.

DISCUSSION

Introduction

More than 2 million people die each year in the U.S. The death of a loved one is widely acknowledged to be one of the most traumatic of life events [3]. Bereavement is associated with declines in health, inappropriate health service use, increased risk of depression, sleep disruption, increased consumption of tobacco, alcohol, and tranquilizers, increased suicide and death [4, 5]. Yet many individuals receive little or no support from health care professionals during the bereavement period. A telephone interview study of 53 English speaking relatives or close companions of adults who had died in the proceeding year at MGH reported high satisfaction. However, there were complaints about the lack of privacy, dignity, and comfort, poor communication, excessive waiting for care, little attention to advanced directives, and little bereavement support. Over one-third of relatives reported no contact with hospital health professionals after the death and of the 19% who sought professional help, none had been referred by their own, or the deceased’s, physician [6]. Larger studies corroborate these findings [7]. Even in areas well served by palliative care, family’s needs for additional information and emotional support continue to be great [8].

Definitions

Grief is the psychological, behavioral, social, and physical reaction to the loss of someone or something that is closely tied to a person’s identity. Grief is a natural but intensely individual aspect of human experience. Mourning represents the process by which people adapt to loss. Bereavement is the period after a loss during which grief is experienced and mourning occurs [9-12].

There are a number of constructs that attempt to explain how individuals cope with grief. The task-based approach is the model most commonly used [13]. Kubler-Ross’ seminal model, with the stages of denial, anger, bargaining, depression, and acceptance, has been criticized as inflexible [14]. While all these behaviors are common in bereavement, not all individuals experience all stages, some skip stages, while others regress through stages or experience different reactions concurrently. Increasingly, the phases of grief are seen in relation to the conceptual framework of attachment theory (which describes the bonds that are formed early in life with parental figures and derived from the need to feel secure) and human information processing (the filtering of unwanted information). This then divides the bereavement process into four phases: A) shock and numbness: survivors have difficulty processing the loss and are stunned and numb; B) yearning and searching, intense separation anxiety and denial of the reality of the loss; C) disorganization and despair, depression and distraction lead to difficulty planning future activities, and D) reorganization and positive readjustment [15]. Though sorrow is intensely painful and psychologically draining, grief is a normal emotional response for all that experience a loss [16, 17].

Optimal End-of-Life Care: Anticipating Bereavement

The quality of care at the end of a patient’s life is very important to the family of the patient and can directly affect the way the family deals with the death of their loved one. In order to truly be effective in end-of-life care, the physician needs to be sure he or she addresses the pressing issues of the impending grief of the patient as well as that of the family and the caregivers [17].

Patients and family members define a “good” death based on physical comfort, the quality of personal relationships,
finding meaning in their life and death, feeling some sense of control in the situation, and active preparations for death [7].

Counseling

Grief counseling guides uncomplicated “normal” grief to healthy completion with insight and adjustment. The positive impact of counseling the bereaved was pioneered by Colin Murray Parkes with a study of the effects of a comprehensive bereavement program. Twenty close relatives of patients who had died in a palliative care unit were compared with a matched group of 20 relatives of patients who had died of cancer in other wards of the same hospital [18]. Interviewed by telephone 2 weeks and 1 year after bereavement, relatives of the palliative care unit patients reported significantly fewer psychological symptoms and less lasting grief and anger. Factors thought to have contributed to the better outcomes were successful relief of pain, awareness of the coming death of the patient, and support given to relatives after bereavement. A larger study also reported better outcomes for the bereaved of those who died in hospice [19]. However, other studies have reported few or no significant differences [20]. Notably Kane’s study used a longitudinal design and randomized participants to either hospice or traditional care [20].

Whatever the setting, proactively providing indicated counseling around the time of death appears to help shorten the period of distress after bereavement [21].

Immediately after the death, the bereaved need compassionate attention and validation of their loss, with time and permission to grieve. Over the first month, expression of grief should be encouraged and the person reassured that it is a normal human reaction. Assessment of the social support and coping strategies should identify practical or financial problems. Beyond a month, a physician should screen for depression, consider referral for counseling, or should consider pharmacologic intervention. A recent review helpfully summarized the assessment, recommendations for interventions, and indications for referral [10]. Data suggest that a variety of interventions, including individualized counseling by a trained volunteer, professional counseling, or group therapy may offer benefit [18, 22]. Physician competence in end-of-life care requires skill and relationship building. The carer needs to be prepared to establish what is known, negotiate how information should be handled, share bad news clearly and compassionately, respond to emotions, set goals, and agree to a plan [17]. A comprehensive assessment should include a screen of the psychosocial domains, with a view to optimizing control of symptoms, maintaining psychological integrity and finding meaning in the chaos [16]. What did the illness mean to them [23]? What are their coping styles [24-26]? What is the extent of the social network [27]? What are the strengths and weaknesses of major relationships with health care providers [28]? What are the major stressors [29]? What spiritual resources are available [30]? Are there psychiatric vulnerabilities (depression, anxiety, or drug dependence) [25, 31]? Are there financial issues [32]?

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Complicated Grief

In 1944, Lindemann described “morbid grief reactions” [33]. Complicated or pathological grief occurs when normal bereavement is associated with psychiatric sequelae and overlaps with an adjustment disorder, major depression, substance abuse, or post-traumatic stress disorder. There is no clear definition and the cultural context has a profound influence on the interpretation of the intensity of loss and disruption caused by “excessive” grief. There is greater consensus about absent, inhibited, delayed, conflicted, or chronic grief [9, 34]. Identifying compounding grief from earlier losses, unfinished business, and secondary gain may be necessary to enable the grief to be working through. While some argue for early intervention for major depressive disorders irrespective of bereavement status [35], others advocate treatment be instituted only if symptoms persist beyond 1 year after the loss [36], yet other diagnostic algorithms for diagnosing complicated grief mandate significant “separation distress,” “traumatic distress,” and disrupted functioning extending beyond 6 months [37]. Obviously suicidal ideation should prompt urgent assessment.

Grieving Children

The National Cancer Institute estimates that 24% of adults with cancer are parenting children under 18 years [38]. Children are helped by a simple and age appropriate explanation of death. Questions should be addressed honestly and directly. Euphemisms that are open to misinterpretation should be avoided. Children benefit from being
involved in the planning of and participation in mourning rituals. Common concerns of bereaved children are: was it my fault, is it going to happen to me, and who is going to take care of me? These should be explicitly addressed. If the remaining parent is too distressed to be a support, other support should be mobilized [39]. Perhaps what children and adults most need is that we be “real” with them, as outlined in the *Velveteen Rabbit* by Marjorie Williams in which the new toy learns the rocking horse’s wisdom, earned in his dedication to love [40]. The MGH has a tremendous liaison psychiatric support service for families of patients with cancer, a review of which is to be published in the *Journal of Clinical Oncology* later this year [Paula K. Rauch; personal communication] [41].

**The Condolence Letter**

It is true. We are too busy. We may feel that we did not know the patient well enough to write a genuine letter of condolence, the responsibility for writing the letter may not be clearly assigned to one member of the team, or there may be no mechanism to collate information about recent deaths. Writing condolence letters requires that we overcome our own sense of loss, our sense of failure, and it is hard to know what to say when someone dies. Physicians rarely write letters of condolence [42].

A flurry of very positive correspondence followed a recent *New England Journal of Medicine* sounding board article “The doctor’s letter of condolence” [43]. A number of institutions have successfully instituted “task forces” or “bereavement coordinators” who coordinate letters, bereavement counseling, and have information about community resources, support groups, and the services of the hospital chaplains [44]. However, a personal letter communicates compassionate care. The article helpfully listed suggested elements to a letter of condolence: A) A direct expression of sorrow. This should not revisit clinical issues in order to avoid issues of legal liability; B) Detail of the extent and depth of the relationship between physician and patient; C) A specific personal memory; D) Reference to the patient’s work, courage, or character, and E) A statement that it was a privilege to have taken part in the patient’s care [43]. Superficial attempts to assuage grief, such as, “It was meant to be,” or “I know how you feel,” should be avoided.

**Resources**

www.cancer.gov/cancer_information has helpful information on loss, grief, and bereavement for both patients and health professionals. There is a list of bereavement services and support groups available in the U.S. at www.hospicefoundation.org. THEOS (They Help Each Other Spiritually) is an organization that helps widowed men and women cope with losing their spouse through monthly meetings (telephone: 412-471-7779). There are also a number of “local” grief support websites such as www.counselingforloss.com with excellent information and specific national organizations such as www.aarp.org/griefandloss or CRUSE (http://www.crusebereavementcare.org.uk) in the UK (telephone: 0870 1671677).

**Conclusion**

“Never does one feel oneself so utterly helpless as in trying to speak comfort for great bereavement.”

*Jane Welsh Carlyle*

Grief for loss is an inevitable part of everyone’s life. People cope, or fail to cope, in diverse ways. Bereavement may be one of the hardest tasks for health care professionals confronted with the limitations of our endeavors. Medical staff have a responsibility to provide grieving families with support and care; care that goes beyond the death. A compassionate response helps both those who suffer and those who care.

**References**


An erratum has been published regarding this article. Please see next page or:
http://theoncologist.alphamedpress.org/content/7/4/388.1.full.pdf
Erratum

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On page 252, in the first paragraph, the anchorman was misidentified for the television program Chronicles: the correct anchor was Ron Gollobin.