

3.4 Grief and Bereavement

Key Points

1. Grief is a universal response to any kind of loss.
The grief response is emotional, cognitive, and behavioral. Examples of losses occasioning grief include loss of job, loss of friendship, loss of child departing for college, and loss of physical ability.
2. The experience of grief and loss is particularly complex and intense at Life's End.
Everyone involved experiences grief: the dying person, the family and significant others, and caregivers and medical providers—including the physician.
3. Some persons may require intervention for complicated or pathological grief.
Complicated grief is more intense, prolonged, and disabling and may endanger the bereaved person by becoming self-destructive. Manifestations include self-neglect, substance abuse or other harmful coping behaviors, depression, and suicidality. The Palliative Response to grief uses a multidisciplinary approach including pastoral care, counseling, and medical assessment to monitor the bereavement progress and to intervene in complicated grief.
4. We now know that the stages of loss described by Kubler-Ross are neither predictable nor neatly progressive.
Manifestation of grief may oscillate back and forth between stages, and elements of different stages may occur simultaneously. “Getting stuck” in one stage of grief is a sign of complicated bereavement.
5. Normal grief includes an initial sense of disintegration—a period of feeling less whole and complete—followed by reintegration that incorporates the loss into one's sense of self.
6. Discussing honestly what is happening and what is likely to happen avoids mixed messages and allows the patient and family time for preparation.
Patients need time to review their lives. Loved ones need to plan for a future without the patient. Honesty allows everyone to expect, understand, and prepare for losses and to attend to needs in all domains of suffering.

Grief and Bereavement



The Palliative Response

Grief Is Universal

- Grief is a response to loss
 - Emotional response*
 - Cognitive response*
 - Behavioral response*
- Grief is experienced with many kinds of losses
 - Loss of job*
 - Loss of friendship following disagreement*
 - Loss of child departing for college*
 - Loss of physical ability*

Grief and Loss at Life's End

- Particularly complex and intense
- Experienced by everyone involved
 - Dying person*
 - Family*
 - Significant others*
 - Caregivers and medical providers, including physicians*

Anticipatory Grief

- Who?
 - Dying patient*
 - Loved ones*
- When?
 - Prior to death*
- Why?
 - In anticipation of the impending loss*

Bereavement

- What?
 - Grief*
 - Mourning*
- Who?
 - Family, friends, personal caregivers*
 - Medical professionals*
- When?
 - After the death of the patient/loved one*

Complicated or Pathological Grief

Indications and manifestations

- More intense and prolonged
- Disabling (depression, self-neglect)
- Endangering (substance abuse, other harmful coping behaviors, suicidal)

Intervention

- Monitor progress of grief process
- Multidisciplinary approach usually indicated (*medical assessment, counseling, pastoral care*)

Dimensions of Grief

Presentation

- Sadness over loss
- Distinguished from depression (which is marked by lack of self-worth)
- Often comes in waves
- Triggers may or may not be predictable

Course

- Often very intense at first
- Intensity/frequency usually diminish over time

Stages of Grief

Interpretation of stages of grief
(described by Kubler-Ross)

- Stages are not predictable
- Manifestation may oscillate between stages
- Progression varies from person to person
- Elements of stages may occur simultaneously

Complicated grief

- Failure to progress through grief
- “Getting stuck” in one stage of grief

Effect of Grief on Sense of Self

Initial sense of disintegration

- Loss of any sort can affect sense of self
- Period of feeling less whole and complete
- Initial sense of disintegration

Process of reintegration

- Fostered by normal grief work
- Fashion a newly integrated self
- Experienced loss finds its place in one’s sense of self

The Physician’s Role

Honesty at Life’s End

Truth-telling in diagnosis and prognosis

- Avoids mixed messages by discussing without ambiguity what is happening and likely to happen
- Allows patients to review their lives
- Assists loved ones to plan for a future that necessarily will be very different
- Allows everyone to expect, understand, prepare for loss
- Helps identify and attend to needs/suffering

Honesty Fosters Communication

Five things everyone needs to say at Life’s End:

Forgive me
I forgive you
Thank you
I love you
Good bye

The Physician’s Role Open Communication

Fostering communication

- Open the door to discussion
- Then listen!

Conversation starters

- “Things have been changing. How are you and your family coping with the changes?”
- “Are you feeling afraid or overwhelmed?”

The Physician's Role

Assess/Treat

- What?
Symptoms

- Why?

Foster comfort for patient

Free energy, and often more time, for patient and family to work through their grief and prepare for the loss of death

- How?
Aggressively!

The Physician's Role

Familiarity with Resources

- Pastoral care
- Community support groups
- Communities of faith
- Counseling
- Grief and survivor's groups
- Social Work services
- Community mental-health providers

The Physician's Role

At Time of Death

- Respond empathically
"I am sorry for your loss"

Offer to call someone

- Be available

Answer questions

Give family and friends time to process

Welcome contact with the family for future questions and needs

- Check back in

The Physician's Role

After the Death

- Offer emotional support
Consider sending cards
Offer to maintain dialogue with the family
- Offer practical support
Write necessary letters
Sign necessary forms
Reassure family you will be helpful
- Offer availability
Often nagging questions come up later

Bereavement

Follow-up Programs

- Who?
Medicare hospice programs
Palliative-care programs
- Why?
Help facilitate grief work
Monitor for complicated grief
- How long?
Up to one year

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The Palliative Response

Honesty at Life's End allows patient, family, friends, and medical caregivers to expect, understand, and prepare for the loss of death.

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Selected Readings

Dying as a Process

Wade, D. T. "The Disintegration of Death." *The Lancet* 360 (2002): 425–426.

Family Experience

Billings, J. A. and E. Kolton. "Family Satisfaction and Bereavement Care Following Death in the Hospital." *Journal of Palliative Medicine* 2 (1999): 33–49.

Morita, T., S. Chihara, and T. Kashiwagi. "Quality Audit Committee of the Japanese Association of Hospice and Palliative Care Units: A Scale to Measure Satisfaction of Bereaved Family Receiving Inpatient Palliative Care." *Palliative Medicine* 16 (2002): 141–150.

Silverman, P. R. "Living with Grief, Rebuilding a World." *Journal of Palliative Medicine* 5 (2002): 449–454.

Teno, J. M., V. A. Casey, L. C. Welch, and S. Edgman-Levitan. "Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members." *Journal of Pain and Symptom Management* 22 (2001): 738–751.

Medical Provider Experience

Rosenblum, J. L. "Why I Still Cry. Share a Young Internist's Reflections on the Death of a Patient at the End of a Long Day." *Medical Economics Magazine* 79 (2002): 65–66.