

The Long Goodbye: Grief and Caregiver Stress in End-of-Life Care

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A Buddhist Parable



In this Webinar

- What is grief?
 - Theories of grief
- Grief and caregiving
 - Impact
 - Culture
 - Process
- Ways to help

Definitions



- ☞ Grief: deep sorrow, especially that caused by someone's death:
 - ☞ synonyms: sorrow · misery · sadness · anguish · pain · distress
- ☞ Mourning: a period and/or show of sadness at somebody's death
- ☞ Bereavement: the state or fact of being bereaved or deprived of something or someone

Theories of Grief



- 1 • Shock and Numbness
- 2 • Yearning and Searching
- 3 • Despair and Disorganization
- 4 • Reorganization and Recovery

Bowlby, 1961

Theories of Grief



Kubler-Ross, 1969

7 Stages of Grief

(Modified Kubler-Ross Model)

Shock*	• Initial paralysis at hearing the bad news.
Denial	• Trying to avoid the inevitable.
Anger	• Frustrated outpouring of bottled-up emotion.
Bargaining	• Seeking in vain for a way out.
Depression	• Final realization of the inevitable.
Testing*	• Seeking realistic solutions.
Acceptance	• Finally finding the way forward.

*This model is extended slightly from the original Kubler-Ross model, which does not explicitly include the Shock and Testing stages. These stages however are often useful to understand and to facilitate change.

Graphic from Schaffer, 2013. <http://thesnapper.com/2013/04/24/moving-on-from-tragedy-how-to-cope/>

Theories of Grief

Ω

Outcry Denial and Intrusion Working Through Completion

Horowitz, 1990

Worzen's Tasks of Mourning

Task #1 To Accept the Reality of the Loss	Task #2 To Work Through the Pain of Grief
Task #3 To Adjust to an Environment in Which the Deceased is Missing	Task #4 To Find an Enduring Connection with the Deceased While Embarking on a New Life

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Piktochart

Summary



- ☞ Emphasize finality
- ☞ Suggest "linear" relationship
- ☞ Allow for a fixed transition





☞ *"The happiness of most people is not ruined by great catastrophes or fatal errors, but by the repetition of slowly destructive little things." - Ernest Dimnet*

What's missing?



- ☞ The nature of loss
 - ☞ Permanent
 - ☞ Death
 - ☞ Progressive
 - ☞ Physical
 - ☞ Social
 - ☞ Emotional



Mortality and Grief



- ☞ Perceived high caregiver strain (mental, physical, and/or emotional) is correlated with increased mortality
- ☞ Schulz and Beach (1999) found that elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age
- ☞ Widow(er)hood is associated with higher mortality for both sexes, but the risk is much greater for men
 - ☞ Women report more ailments; men have higher death rates

Stepanenko, 2014

Caregiving perceptions



- ☞ Caregiving studies have emphasized both negative and positive feelings associated with caregiving
- ☞ Negative
- ☞ Positive

Cultural Considerations



- ☞ Nature of relationship between the caregiver and receiver
- ☞ Attitudes toward death
- ☞ Concepts of the afterlife
- ☞ Where the caregiving is taking place

Models of Caregiver Grief



- ☞ The Relief Model



- ☞ The Complicated Model



WaUrop, 2007

Process



- ☞ "Anticipatory" grief is an ongoing process
- ☞ Caregivers must process the stages of grief at each loss
 - ☞ Roles
 - ☞ Memories
 - ☞ Companionship

What can we do?



- ☞ Assess
 - ☞ Beliefs, values, fears, concerns, needs
 - ☞ Ask questions about how the caregiver is feeling:
 - ☞ Physically
 - ☞ Emotionally
 - ☞ Socially
- ☞ Educate
 - ☞ Symptoms and experience of grief
 - ☞ Grief as a process

What can we do?



- ☞ Normalize
 - ☞ Feelings of anger, guilt, frustration
 - ☞ Physical feelings of fatigue, aches, difficulty sleeping
- ☞ Validate
 - ☞ Never underestimate the impact of bearing witness
- ☞ Alleviate

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☞ *"Everything is smaller when it's out."* – Old AA Saying

What can we do?

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☞ Encourage process

- ☞ Most problems come from getting "stuck" upside down on the grief roller coaster.

☞ Aid with coordination of services

Resources

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☞ Caregiver Support/Education

- ☞ Focus heavily on behavioral changes that make caregiving easier
 - ☞ <http://www.caregiveraction.org>
 - ☞ <http://www.caregiver.va.gov>
- ☞ National Family Caregiver Support Program (OAA Title III-E)
http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx
- ☞ Medicare
<http://www.medicare.gov/campaigns/caregiver/caregiver.html>

Resources



- ☞ Grief support groups
 - ☞ Local Hospitals, Universities, Churches
 - ☞ Provide for that peer support/mutual validation experience
- ☞ Peer Support
 - ☞ Can be arranged through many organizations
 - ☞ Phone calls, in person meetings
- ☞ Foster communication with counselors, pastors, friends, family

A note on the care receiver



- ☞ Loss of independence is one of the 4 most significant fears of all older adults
- ☞ Care receivers grieve their losses at the time they also experience guilt, sadness, frustration with the "burden" they place on caregivers
 - ☞ The stages of grief are prevalent here too: denial, anger, depression etc.

A note on the CSA



- ☞ *"Who can listen to a story of loneliness and despair without taking the risk of experiencing similar pains in his own heart and even losing his precious peace of mind? In short: "Who can take away suffering without entering it?"*
- Henri J.M. Nouwen, *The Wounded Healer: Ministry in Contemporary Society*
- ☞ Vicarious Trauma
- ☞ "Self-care"

☞ *"Only people who are capable of loving strongly can also suffer great sorrow, but this same necessity of loving serves to counteract their grief and heals them." ~ Leo Tolstoy*

References

☞ Bowlby (1961) Processes of Mourning.
☞ Horowitz MJ (1990). A model of mourning: change in schemas of self and other.
☞ Kübler-Ross, E. (1969) On Death and Dying, Routledge
☞ Stepanenko, A (2014). Death and Grief
☞ Waldrop, D (2007). Caregiver Grief in Terminal Illness and Bereavement
☞ Worden, W. (2009). Grief Counseling and Grief Therapy, Fourth Edition

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