HELPING WITH GRIEF AND LOSS: IT'S NOT JUST FOR FUNERALS ANYMORE

Dr. Jennifer Hill
April 5, 2013

Overview
• Stages of Grief
  • Losing something that is yours
• Tasks of Mourning
  • Losing someone else to death
• Grief and Mourning in People with Intellectual Disability
• Helping our Clients
• Case Applications

STAGES OF GRIEF

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

...
Grief

• Losing something that is yours
  • Relationship
  • Home
  • Community
  • Possession(s)
  • Ability or capacity
  • Your own life

Kübler-Ross Stages of Grief (1969)

• Feelings associated with losing something that is yours
• Conceived to help and understand people’s preparation for their own deaths from chronic illness
• Never meant to be understood as a step-wise progression
• Kübler-Ross thought people would experience at least two of the stages
  • Denial, Anger, Bargaining, Depression, Acceptance

• Mixed research support
• Very practically useful

Kübler-Ross Stage of Denial

• “I feel fine.” “This can’t be happening; not to me.”
• “I can’t think about this right now.”
• Throwing self into a distraction

• Denial is usually only a temporary defense for the individual.

• This feeling is generally replaced with heightened awareness of positions and individuals that will be left behind after death or the shifts that will happen after the loss.
Kübler-Ross Stage of Anger

• “Why me? It’s not fair!”
• “How can this happen to me?”
• “Who is to blame?”

• Because of anger, the person is very difficult to care for due to misplaced feelings of rage and envy.
• Any individual that symbolizes life or energy or vitality is subject to projected resentment and jealousy.

Kübler-Ross Stage of Bargaining

• “Just let me live to see ________.”
• “I’ll do anything if ________.”
• “I will give my life savings if ________.”

• Bargaining involves the hope that the individual can somehow postpone or delay death or loss.
• Usually, the negotiations are made with a higher power in exchange for a reformed lifestyle.
• Psychologically, the individual is saying, “I understand I will have this loss, but if I could just delay it...”

Kübler-Ross Stage of Depression

• “I’m so sad, why bother with anything?”
• “I’m going to experience this loss... What’s the point?”
• During the depression stage, the person begins to truly face the certainty of loss.
• Because of this, the individual may become silent, refuse visitors and spend much of the time crying and grieving.
• This process allows the person to disconnect oneself from things of love and affection.
• Do not attempt to cheer up or distract a person in the depression stage.
• It is an important time for processing the feelings of grief.
Kübler-Ross Stage of Acceptance

• "It's going to be okay."
• "I can't fight it, so I may as well prepare for it."
• Individual begins to come to terms with his or her mortality or the inevitability of loss
• Quiet knowing that loss will come
• Still sad, but accepting

Polling Question

• People with or without intellectual disability have grief reactions when they lose something or someone important. Pick out the word that is NOT a stage of grief according to Elizabeth Kübler-Ross.

A. Denial
B. Anger
C. Bargaining
D. Coping
E. Depression
F. Acceptance
Tasks of Mourning (Worden, 2009)

- Mourning is associated with losing someone to death
- Task I: To accept the reality of the death
- Task II: To experience the pain of the death
- Task III: To adjust to an environment in which the deceased is missing
- Task IV: To withdraw emotional energy and reinvest it

Task I: Accept the reality of the loss

- Usually follows a period of denial
- Realize that the death actually occurred
- The loved one is gone and will not be coming back

Task II: To experience the pain of grief

- We instinctively attempt to avoid or escape pain
- Culturally, we are encouraged to not show emotional pain
- The above strategies prolong the inevitable rather than avoid unpleasantness
- Gently and safely encourage people to express what they are feeling
- Respect cultural and gender differences
Task III: To adjust to an environment in which the deceased is missing

- Most need to adjust to the loss of companionship and emotional support

- Adjustment to the loss of activities the person performed
  - Meals, lawn care, transportation, finances, making appointments

- Change is inevitable
  - Learn new skills
  - Assistance with life activities
  - New ways to meet emotional and social needs

Task IV: Withdraw emotional energy & reinvest it

- “Moving on with your life”

- Some feel like this is disloyal to the deceased

- Task completion involves a balance between
  - Calm understanding that they will never forget the loved one
  - Channeling energy into activities and other relationships

Polling Question

- No right or wrong answers on this one. In your opinion, which task of mourning do you think is most difficult for your clients?
  
  A. Task 1: Accept the Reality of the Loss
  
  B. Task 2: Fully Experience the Pain
  
  C. Task 3: Adjust to the Environment in which they were used to having the deceased
  
  D. Task 4: Reinvest Energy by Getting Needs Met Another Way
GRIEF, LOSS, AND MOURNING IN PEOPLE WITH INTELLECTUAL DISABILITY

Grief, Loss, and Mourning for People with ID

• There is growing evidence that many people with intellectual disabilities experience atypical and prolonged grief following the death of a family member or close friend (Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Bonelli-Pascual et al., 1999).

• 50% of persons with MR who live in residential settings with sudden onset of verbal aggression, physical aggression, or extreme withdrawal experienced a death or loss of someone close to them in the preceding year (Emerson, 1977).

Grief and Mourning Reactions (Lindemann, 1944; Rando, 1993; Worden, 1991, 2009)

• Sadness – with or without crying
• Anger – at self or others, difficulty controlling intensity or direction
• Guilt – about behavior toward deceased, ‘survivor’ guilt
• Somatic distress – fatigue, tightness in chest, dry mouth, headaches, stomachaches
• Restless over-activity – activities, pacing, exercise
• Feeling “different” – apart, unconnected
• Regression
• Experiencing the image of the deceased
• Loss of daily routine
Difficulties in Learning or Understanding

- Ability to understand the concept of death varies.
- Even people who do not fully understand death experience loss.
- Give a full explanation, even if full understanding might not be possible.
- Tell the truth even if it's sad.
- Encourage and offer communication.

Polling Question

- Which is the best way to tell a client with ID that a staff member named Sally was killed in a car accident over the weekend?
  A. Sally passed away.
  B. Sally is in heaven.
  C. Sally got hurt in an accident and she can't work here any more.
  D. Sally is dead. She was in a car accident that killed her.

Tendency to Respond in a Positive Manner

- Agree to whatever question is asked
- Answer “positively” to open-ended question
  - How do you feel?
- Desire to please
- “Negative” emotions and behaviors have real consequences for folks with ID.
  - More professionals, more pills, more behavior management, perhaps a move
Behavior (not words) Indicates True Feelings

- Look for behavior change:
  - Sleeping more or less, disturbed sleep pattern
  - Eating habits
  - Productivity
  - Withdrawal from social activities
  - Physical symptoms
  - Personality change

Others Act as Reporters or Interpreters

- Family members and staff often fulfill these roles
  - Can be very helpful
- Can add to difficulties with bereavement, loss, and grief
  - We don't always interpret accurately
  - We sometimes assume we know what is happening for the person with ID
- Describe what has been said about the death or loss
- Describe how the person has responded (words and behaviors)
- Describe any changes in behavior

Lack of Social Support

- Fewer opportunities to make friends
- High residential staff turn-over
- Less likely to have children

- Not uncommon for people with ID to talk about (or otherwise express) a parental loss for TEN years.
- Lack of “mainstream” supports often means that bereavement for people with ID entails more time, effort, and support.
Connections that are not Obvious

• Smaller social circles
• Connections valued more by people with ID
• Connection not apparent
  • Don’t have the same “give and take” as general population
  • Fear of being “alone in the world”

History of Multiple Losses

• Numerous residential transitions
  • Social support of those residential settings
  • Staff turnover
  • Changes in jobs and vocational settings
• Effects add up over time OR
  • Often concurrent with a familial death

Lack of Resources

• Fewer skills, less knowledge to deal with grief, loss, and bereavement
• Don’t have driver’s license & car to quickly drop by the cemetery
• Little money and opportunity to go on vacation or “get away from it all”
Uncertain Future

• Death and other losses increase the person’s fears about the future.

• The world becomes unpredictable, out of control, unsafe.

Polling Question

• Think of one client with ID who has experienced a major loss. How did he or she show grief behaviorally?
A. Sleeping more or less, disturbed sleep pattern
B. Eating habits changed
C. Withdrawal from social activities
D. Increased physical symptoms and complaints
E. Personality change
F. Something else
Actions to Take

- Clearly tell the person that a death or other loss has occurred
- Allow and encourage the person to share his or her feelings
  - Offer periodically for a long time
  - Provide reassurance that others are there to help
  - Offer support over time
- Remember that recovery takes time
- Don’t assume
- “Walk beside”

Supporting Those who are Grieving & Mourning

- Recognize and respect their vulnerability
- Support the person’s experience of their loss
- Support the person’s experience of themselves in the grieving process
- Know your own Grief Triggers
  - Emotions
  - Fears
  - History

Polling Question

- What is one of your grief triggers? By that, I mean, what is one thing related to grief & loss that makes your own wellness drop, makes your stomach turn, or makes a strong personal memory come back?
  A. Death of children
  B. Death of a parent
  C. People openly crying, wailing, or sobbing
  D. Loss of physical capacity
  E. Loss of mental capacity
  F. Something else
Death & Dying Basics, In Order

- Encourage, but do NOT force the person to attend the funeral/service
- Video or audio tape the funeral/service
- Support
  - Spend time
  - Encourage expression (words, sounds, hand movements, facial expressions, pictures)
- Consider books on death, dying, loss
- Consider spiritual traditions
- Observe
  - Reflect feeling
  - Find a Ritual

Common Rituals

- Drawing
  - Feeling, Deceased person
- Photograph
- Objects
- Write A Story
- Plant a Tree
- Use of Daily Objects (mug with picture)
- Use of Daily Memory (prescribe time to mention person/situation)
- Use of Pendant (purchased or modeling clay)
Chad

• Several years after the death of his Aunt Lois, Chad began compulsively saying he was going to visit her.

• What could be happening?

Polling Question

• What would you do if you supported Chad?

A. Reflect the feeling back to Chad. Tell him, “I guess you really miss Aunt Lois. I would feel sad if I were you. Are you sad?”

B. Explain that Aunt Lois is dead. Explain what dead is if Chad does not fully understand what dead means.

C. Offer to do a mourning ritual with Chad like maybe taking flowers to Aunt Lois’ gravesite.

D. Something else.

Jaime

• Jamie’s father had visited him weekly on Sundays. Then, after Thanksgiving weekend, he stopped showing up. There was no contact from Jamie’s family to tell him that his father had died. He was just gone, and a very dependable, predictable pattern of relationship and Sunday routine was broken. At Christmas, his family told him that his father was dead. His family and staff reported that Jamie was OK and seemed to barely miss his father. About a year later, Jamie began packing his bag, putting on his coat, and sitting the front door waiting for his father. Soon, he was doing this daily.
Polling Question
• Jaime’s behavior is telling us that something is likely happening related to mourning his dad. Which response is closest to your therapeutic style?
A. Silently sit with Jaime. Just be with him while he waits.
B. Ask a direct question like, “Are you waiting for your dad?”
C. Reflect feeling by telling him he seems sad or frustrated.
D. Share something personal with Jaime like that you are scared of people you love dying or that you miss people forever when they die.
E. Something else.

Sarah
• Sarah was sexually abused at a residential placement when she was 22 years old. Immediately after this, she returned to live at home with her parents. Sarah began to yell and scream at her mother and was generally despondent and non-verbal the rest of the time.
• Sarah’s grief could be about a number of things.
  • Sexual safety
  • Resident placement
  • Placement peers
  • Placement staff
  • Independence of living away from home

Polling Question
• What would you try first to help Sarah grieve?
A. Drawing—draw the feelings, draw what hurts, draw what happened
B. Use a daily memory—talk about all the changes every day at the same time
C. Use pictures—put up pictures of peers, staff, the residential placement building and gently offer to talk about Sarah’s experiences there
D. Something else
Q & A

References


Thank you!!!!!