Exploring Issues of Grief and Loss in Individuals with Dementia or Other Cognitive Impairment

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Introduction

About the presenter

Why this topic?

Outline of presentation:
  - Review of research
  - Discuss issues and challenges in providing grief support
  - Discuss interventions that may be helpful
  - Present suggested best practice for hospice organizations
  - Questions and further discussion
Articles/Research on Dementia & Grief

- Often focus on caregiver grief and ambiguous loss
- Discussion of how topic is under researched
- Small sample size, qualitative research & focus groups
- Case Studies
- Discussion of how to support people & interventions; ‘how/if to tell’
- A call for new model of grief to guide carers
- Crossover areas - developmental disabilities & grief, attachment theory & dementia
Grief and mourning from the perspective of the person with a dementing illness, beginning the dialogue. Rentz, Krikorian, Grief. (2005)

- cognitive processes and how may dysfunction may affect grief
- discussion of different types of dementia and how grief may differ
- Non-cognitive processing abilities may remain available which process information and influence behaviors.
- Important to note the behavioral changes to know if simply the disease progression or grief reaction.

- Describes a symposium about the clinical challenges of care to patients with dementia with a plenary focused on bereavement
- Small group sessions to discuss several questions about prevalence of working with grief and dementia and responses/resources
- The issue of ‘telling’ came up, including guilt described by family who chose not to tell. Also retraumatizing
- The caregivers felt that specific interventions for bereaved with dementia were essential including; repetition, manicures, hand massage, play, singing, clergy visit, hymns, life review, photos, memory books, education to family, ‘emotionally oriented activities’, doll therapy (based on attachment theory).
- Reported that lack of knowledge on grief and dementia was a barrier.
A Survey of Grief and Bereavement in Nursing Homes: The Importance of Hospice Grief and Bereavement for the End-Stage Alzheimer’s Disease Patient and Family. Murphy, Hanrehan, Luchins (1997)

- Conducted a telephone survey of 121 nursing homes to assess what bereavement support was provided by facility
- Minimal support was offered and the researchers stated that particularly persons with dementia and their families need this support and that use of hospice would be one way to increase that support.

- Researchers looked at 2 case studies with bereaved who had extended delusions of their spouses’ being alive after death.
- They both had similar right frontal lobe dysfunction that researchers propose could be influencing this specific bereavement reaction.
- A discussion of different functions of parts of the brain and how dysfunction may related to grief response.
The right to mourn in dementia: To tell or not to tell when someone dies in dementia day care. Berenbaum, Tziraki & Cohen-Mansfield (2017)

- Qualitative study of semi-structured interviews of 52 staff members at day centers in Israel.
- Discussion of brain processes and how it may affect grief
- Disenfranchised grief for persons w/ dementia?
- Respondents felt the loss of a group member does affect group dynamics & that the participants were able to grieve/feel loss, though perhaps differently
- Two thirds responded ‘always tell’, several ‘never tell’, rest ‘it depends’
- Effect of death and grief on staff/caregivers, need support for staff too
- Staff felt they needed more guidance & information on informing and support the day program participants around grief

- The authors discuss 5 case studies and the phenomenology of bereavement distress; constant or recurrent, locus of distress, awareness of the death, psychosis present, and level of cognitive impairment.

- Present a discussion of barriers to normal grieving:
  - Prevent assimilation and incorporation of new information
  - Unable to access treatment modalities helpful for bereaved, i.e. groups
  - Unable to recall content are subject to traumatization
  - Psychotherapeutic interventions may be harmful or impossible w/ lack of insight
  - Physical, cognitive & social deficits may prevent family/peer support

- Currently not enough data to provide evidence based guidelines

- 16 family members & 6 professionals in focus group discussions, themes emerged of three responses to loss of loved one:
  - Self-Threat: a heightened sense of need and worry about their wellbeing & care
  - Substitution: having a hard time grasping the death the person believes someone else has died
  - Metaphone: ‘when a metaphorical loss changes from being the loss of a spouse to the loss of an object’.

- Discussion of whether or not to tell, and a need for guidelines around sharing the news of a death and participation in death rituals, the moral and ethical implications.

- Professional caregivers respond to survey assessing 17 individuals in Sweden with dementia and their grief responses
- Asked to observe and report on responses such as seeking for deceased, changes in mood & behavior, physical and mental changes. Responses included all these and were varied.
- The burdens of behavior changes with grief on professional caregivers was discussed and presented as a concern and area for future inquiry.
Delusional Double Mourning: a complication of bereavement in dementia. Herrmann & Grek (1988)

- Two case studies in which bereaved with dementia experiencing a loss also believed that a previous loss, a parent’s death, had happened simultaneously, rather than many years prior.
- Did these people have a dependent relationship on their spouse and felt like loss of a parent or simply triggering old memories with difficulty integrating the new memory?
The mourning process of older people with dementia who lost their spouse. Watanabe & Suwa 2017

- A look at reaction to bereavement in a small sample size (13) in Japan by interview with family or professional caregivers
- Focus on bereaved remembering or not that the spouse had died, and relating to FAST score.
- The authors call for a new model of grief tailored to bereaved with dementia.
Counseling older adults with dementia who are dealing with death: innovative interventions for practitioners
Lewis & Trzinski 2006

- Authors look at how two interventions Space Retrieval and Group Buddies (using stuffed animals) may help bereaved with mild-moderate dementia
- A case study is presented for each intervention
- Spaced retrieval: repeating and testing for information with validation is used to help bereaved remember the fact of the death
- Group buddies for comfort and support, including using the buddies outside of the group to carry over coping skills from the group.
Specific Foci in ITP: Grief, role, transition, role dispute, interpersonal deficits; in Clinicians guide to interpersonal therapy in late life. Miller (2009)

- Lists complications of grief such as:
  - difficulty with emotional aspect of mourning due to executive dysfunction
  - depression risk
  - secondary health risks
  - deficits more apparent if deceased was compensating their deficits as their caregiver
  - risks of poor judgement in post-death decision making.

- A case study is presented in which a bereaved lost her spouse and concurrently had somatic pain complaints which was ultimately resolved with antipsychotic medication after which the client had more insight and able to reflect on anger at her deceased husband.
Informal Survey of Hospice Grief Counselors

- Yes, we do provide grief support
- Most receive referrals for bereaved with dementia
- Varied considerations for appropriateness for grief counseling
- Family is key factor in requesting and/or educating
- Interventions often focused on emotions, listening, reminiscing, education to family
- Question of ‘telling’ and retraumatization, ‘more harm then good’
- Wishing for best practice and more guidelines
Challenges to providing support

- Current theories assume cognitively intact; tasks, ‘grief work’
- No guidelines for caregivers and practitioners on how to approach grief
- Every grief is different, every person is different, every dementia is different
- Ethical and moral implications of ‘telling’ about the death
- Disenfranchised grief
- Complicated grief
- Person may have not only lost someone they love, but primary caregiver
Possible grief reactions

- Changes in mood
- Increase in depression and anxiety
- Delusions and hallucinations
- Aggression, irritability
- Seeking for deceased
- Sleeping and eating changes

- Bodily complaints
- Decrease in activity
- More time in bed
- Confusing deceased with another person
- Distress at being reminded of loss
- Self-isolation
Interventions & Ideas

- Observe emotional & behavioral responses
- Look for patterns in routine/time of day and distress
- Respond to emotions
- Validation therapy
- Speak in past tense about deceased
- Supportive therapies; art, music, massage, play
- Comfort; pet therapy, reminiscence, volunteer companionship
- Education to family
- Memory books, photos, life review
- Medications
Best practice in a hospice organization

- Prepare educational handout
- Bereavement staff to provide education to hospice staff
- Bereavement to educate facility staff and family
- Pre-death
  - Care team to identify early families that have a bereaved with dementia
  - Support & information to family members via discussion and informational sheet
  - If the griever is a patient, consult with bereavement for best support plan
- Post-death
  - Bereavement remain sensitive to death discussion to identify bereaved with dementia
  - Send family member information sheet with first mailing or condolence card
  - Education to the family via phone or in-person counseling
  - Bereavement to provide 1:1 counseling to bereaved with dementia 1-2x to assess ability to engage in counseling (develop considerations/criteria for participation)
  - If counseling assessed not to be effective, referrals to other supports when available such as music therapy, volunteers, family support, facility programs & support
Future Research Areas

- Useful interventions
- Stages of disease & process of grief
- Attachment theory as related to grief and dementia
- Guidelines on how/when/if to tell people about a death and what grief rituals they should participate in
- Reducing burden on staff
- Delusions/hallucinations in typical bereavement vs dementia
Discussion & Questions

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References

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References


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