Best Practices in Bereavement Care

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Disclosure

• I receive author royalties for two books: Overcoming grief and An Introduction to Coping with Grief

Aims

• To review the nature of grief from a psychological perspective
• To outline guidelines and practical strategies for providing bereavement follow-up
• To describe risk factors for poor bereavement outcomes and outline interventions that might help mitigate a complicated grief reaction
My Approach

- My background
  - Clinical psychology
  - Informed by cognitive-behavior therapy model

- I learned very early on that I could not ‘fix’ a bereaved person’s problem

- My aim is to help the bereaved take control of their grief rather than letting their grief take control of them

Introductions

- You
- Where from?
- Role

My Conclusions Up Front

- Bereavement care falls within the purview of prevention

- Palliative Care clinicians can play an active role in assessing and managing the bereaved before and after the death of the patient

- Hospital-based bereavement programs should be a standard of care consistent with the guidelines from the National Consensus Project for Quality Palliative Care
Your Role

- Palliative care clinicians are in a unique position to:
  - help families prepare for the death of the patient ahead of time
  - help families prepare for their bereavement ahead of time
  - identify risk factors and provide early support that can help mitigate a difficult grief reaction

Bereavement in Context

- Death of a loved one is believed to be the most powerful stressor in everyday life (Holmes & Rahe, 1967)
- Each year in USA, approximately 2.5 million deaths (CDC)
- Bereaved individuals are at increased risk of:
  - depression, suicide, cardiovascular problems, and substance abuse (Stroebe, et al. 2007)
- 10-20% bereaved estimated to experience suffering requiring professional intervention (Prigerson, 2004)

Bereavement in Context

- Approximately 45% of people die in hospitals (CDC)
- Research findings indicate that:
  - bereaved family members of cancer patients who die in hospitals are more likely to suffer from PGD than bereaved family members of patients who die at home with hospice (Wright, et al. 2010)
  - bereaved family members of cancer patients who die in the ICU are more likely to suffer from PTSD than bereaved family members of patients who die at home with hospice (Wright, et al. 2010)
Understanding Grief

• Grief is defined as the anguish experienced after the death of a significant loved one (APA, 2007)
• Grief is a normal response to loss – it is not an illness with a prescribed cure
• Intense physical and emotional reactions
  – often described as paralyzing
  – sense of being on automatic pilot in first weeks
• Initial support from others is quickly withdrawn and bereaved often state that they ‘feel worse’ 4-6 weeks after as reality sets in

Understanding Grief

• Characterized by a deep sadness and an intense yearning to be with their loved one again
• One of the hardest things for bereaved individuals is ‘not knowing’ what to expect
• While 80-90% of bereaved individuals cope without professional intervention, grief remains an intensely painful experience

Understanding Grief

• Grief occurs within the context of our society which is:
  – technology driven
  – fast paced
  – sense of control

I thought I’d be better by now
Central Psychological Factors

- Attachment
  - nature and strength of attachment bond
- Loss
  - many losses ranging from practical roles to hopes and dreams for the future
- Change
  - the more change, the greater the adjustment
- Control
  - regarding the death itself and the grieving process
- Expectations
  - how we think things will be – larger the gap between what expected and reality, the greater the adjustment

Navigating a Different Path
Normal Bereavement

- Intense emotional and physical reaction characterized by deep sadness and yearning for the deceased
- Period of adjustment
- Wave-like pattern
- Intensity slowly subsides usually by six months with triggers that result in an intensification of emotion – from research focusing largely on spousal loss

Maciejewski et al (2007). *JAMA*

Prolonged Grief Disorder

- Characterized by yearning for the deceased and at least 5 out of 9 disabling symptoms including: difficulty accepting the loss, numbness, and avoidance of reminders of the reality of the loss
- Symptoms cause clinical impairment in social and occupational functioning
- Diagnosis not made until 6 months post-death though PGD did not make DSM-5 (Prigerson, et al 2009)
- New category for further study in DSM-5 is ‘Persistent Complex Bereavement Disorder’
Depression
- Characterized by depressed mood and loss of interest or pleasure, feelings of worthlessness, guilt, and hopelessness etc, whereas in bereavement focus is more on the loss
- Symptoms cause clinically significant distress or impairment in functioning
- DSM-5 – removal of the ‘bereavement exclusion’ where previously, clinicians were advised to refrain from diagnosing major depression with the first two months following the death of a loved one

The Experience of Grief
- Janet’s Story

The Experience of Grief
- Overwhelmed
- Little control
- Am I going crazy?
- Uncertain about what to expect
- Conflicting advice
- Society’s awkwardness
The Experience of Grief

• Barriers to healthy grieving:
  – distressing feelings
  – unanswered questions
  – unresolved differences or conflict
  – avoiding certain people or places
  – difficulty making decisions

Risk Factors

• Hx of psychiatric disorders
• Poor social support
• Hx of abuse or neglect in childhood
• Concurrent stresses
• Previous losses
• High initial distress
• Lack of preparation for death
• Unexpected Dx and unanticipated death
• Death of a child
• Highly dependent relationship with the deceased
• Conflict with the deceased/unresolved issues
• Witnessing a difficult death (Wright 2010)
Caring for the Bereaved

The National Consensus Project for Palliative Care (NCP, 2013) outlines bereavement services as a clinical practice guideline where:

- Bereavement services are recognized as a core component of the palliative care program
- Bereavement risk assessment is routine
- Information and support are readily available

Caring for the Bereaved

Before death

- Help family members prepare for their loved one’s death
- Provide clear and accurate information about the dying process to facilitate decision-making
- Make a referral to a community-based mental health clinician for individuals with risk factors for complicated grief
- Facilitate opportunities to say goodbye and to participate in providing EOL care

Caring for the Bereaved

Before death

- Involve palliative care clinicians to assure good symptom control as the quality of the dying process impacts the caregiver’s bereavement
- Hospice use has been shown to reduce major depressive disorder and mortality among patients’ spouses
Caring for the Bereaved

• After death
  – physician to contact those family members not present at the death of the patient to inform them, to offer condolences and to answer any immediate questions
  – offer the opportunity to view the body
  – send a letter of condolence - an essential component of quality EOL care that should be incorporated into routine practice
  – bereavement calls – check-in & say goodbye

Condolence Guidelines

• use simple language
• refer to the deceased as you knew them
• avoid euphemisms
• articulate how you have been affected
• if possible, emphasize good job family did
• if you knew the deceased well, write something that reflects his/her personality
• don’t promise anything you can’t deliver

What does a Grieving Person Need?

• To be able to tell their story
• To express their thoughts and feelings
• To try to make sense of what has happened
• To increase their sense of control
• To build a new life without the deceased physically present
Psychological Strategies

• Education about grief and what to expect
  – Wave-like pattern, path diagram

• Maintaining a routine
  – Helps by limiting change

• Self-care activities
  – Often neglected when care-giving
  – Includes medical appointments, hobbies, exercise

• Social connections
  – Often hardest as bereaved often avoid
  – Use graded hierarchy approach – easiest situations and friends first

Psychological Strategies

• Opportunities to acknowledge the death and express their loss
  – Support groups
  – Counseling
  – Empathic friends who don’t want to ‘fix’ problem

• Facing new or difficult situations
  – Graded hierarchy approach
  – Challenging unhelpful or unrealistic self-talk

• Tackling barriers
  – Identify barriers and unhelpful thinking
  – Graded hierarchy approach
  – Challenging unhelpful or unrealistic self-talk

Psychological Strategies

• Maintaining a connection with the deceased
  – Telling and recording their loved one’s story using technology
    • Photo books using online applications
    • Invite others to contribute stories that can be compiled into a book
  – Legacy exercises
    • Especially helpful for the death of a parent
    • Support a significant cause in their memory
    • Create new traditions e.g. celebrating their birthday, Holidays
Essential Components of a Bereavement Program

- Acknowledgment of death
- Information about grief
- Support services
- Memorial activities
- Staff support and education
- Evaluation and research

Revisiting My Conclusions

- Think about bereavement care as a preventive model of care
- Palliative Care clinicians are in unique position to help the bereaved before and after the death of the patient
- Hospital-based bereavement programs should be a standard of care consistent with the National Consensus Project for Quality Palliative Care

Discussion
References


