Update of Grief Reactions in the Palliative Care and Hospice Setting

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Grief and Bereavement in the Adult Palliative Care Setting

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The Helping Professional’s Guide to End-of-Life Care

Practical Tools for Emotional, Social, & Spiritual Support for the Dying

by E. Alessandra Strada, PhD, FT, MSCP
Goals of this Lecture

• Update on grief and bereavement models

• Preparatory Grief aka Anticipatory

• Complicated Grief aka Prolonged Grief Disorder

• Grief and the DSM-5
Relevance

• “Love and grief have been with me from the beginning and are with me now that I am close to the end”

• Mandate for palliative care clinicians
• Denial of grief?
• Symptom overlap makes diagnosis difficult
• Diagnosis drives treatment
• Adequate treatment approach makes a significant difference in quality of life
Psychosocial Support for Patients with Advanced Illness and their Caregivers

CREATE EMOTIONAL AND EXISTENTIAL SAFETY IN LIVING WITH ADVANCED ILLNESS AND DURING THE DYING PROCESS
Palliative Care

Diagnosis of serious illness

Life Prolonging Therapy

Palliative Care

Medicare Hospice Benefit

Death

Normal Grief

Preparatory Grief

Bereavement
Triggers for Normal Grief

- Death of someone close
- Diagnosis of serious illness
- Diagnosis of advanced illness
- Worsening of illness
Grief

Anticipatory
AKA Preparatory

Complicated
AKA Prolonged Grief Disorder

Normal

Bereavement

Mourning
Grief Reactions

• PATIENTS
  – Anticipatory (Preparatory grief) : to approaching death
  – Complicated Grief : pathological /griever “stuck” unable to integrate

• CAREGIVERS
  – Anticipatory Grief
  – Bereavement : death of someone close
  – Complicated Grief
Additional Terms

• **DISENFRANCHISED GRIEF** – Doka, 2002
  – Not sanctioned by society

• **CHRONIC SORROW**- Eekes et al, 1998
  – Ongoing progressive losses

• **AMBIGUOUS LOSSES**- Boss, 2006
  – Unresolved
    – Lack of closure
Conceptualizations of Grief and Bereavement

• Early Models - “Grieving the right way and moving on”
  – Importance of “detaching” from the deceased
  – Freud: Mourning and Melancholia
  – “Absent grief” (Deutsch, 1937)
  – Importance of intense “grief work”
  – Phases or stages (Kubler-Ross, 1969)
  – Importance of exhibiting strong affect
Conceptualizations of Grief and Bereavement

• **Recent Models - Uniqueness**
  - Grieving Styles (Martin and Doka, 2000)
  - Maintaining a connection with the deceased (Klass et al, 1996)
  - Resilience (Bonanno, 2004)
  - Complicated grief and pathology (Prigerson, 2001; Shear, 2005)
  - Dual Model (loss-restoration) (Stroebe, 1999)
  - Two-Tracks Model (Rubin, 1981)
“No one told me grief felt so much like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing. At other times it feels like being mildly drunk, or concussed. There is a sort of invisible blanket between the world and me. I find it hard to take in what anyone says. Or perhaps, hard to want to take it in. It is so uninteresting. Yet I want others to be about me...

And no one told me about the laziness of grief...I loathe the slightest effort. Not only writing but even reading a letter is too much. Even shaving...It’s easy to see why the lonely become untidy, dirty, and disgusting”

C.S. Lewis “A Grief Observed”
Physical Reactions

- SOB
- Tightness in the throat
- Body aches, muscle tension
- Dizziness, nausea, GI problems
- Anxiety, panic attacks, heart palpitations
- Weight gain or loss
- Physical numbness

Zisook et al., 1982; Clieren, 1993; Raphael, 2000
Psychological Reactions

- Numbness, shock, disbelief, hysteria, euphoria, sadness, yearning, anxiety, anger, guilt, confusion, loneliness, irritability, anguish, and relief

- Disorganized thinking, auditory and visual hallucinations, impaired memory, lowered self-esteem, constant worry. Greater risk for destructive behavior and disruption in familiar relationships
Spiritual Reactions

• Hopelessness,
• Anger at God or Higher Power
• Conflicts in faith beliefs
• Loss of meaning
Anticipatory Grief in Patients (Preparatory)

- “The grief the terminally ill patient has to undergo to prepare himself for his final separation from this world” - KR

- NOT pathology

- Different from Depression, but could be comorbid

- Mood fluctuation and generally lack of worthlessness or irrational guilt — Mistakidou et al., 2008
Challenges of Preparatory Grief

- Awareness of prognosis

- Death Awareness (Glaser and Strauss, 1967)

- Transitions of care

- Negotiating levels of engagement with loved ones
The Dimensions of Preparatory Grief

Awareness

Suffering

Energy Management

Peace
The Awareness Dimension: “Is this really happening? What is really happening?”

Death Awareness (Glaser and Strauss, 1965)

• Closed Awareness
• Suspected Awareness
• Mutual Pretense
• Open Awareness

• Self-Directed Acceptance? DENIAL? (Strada, 2013)
“Acceptance should not be mistaken for a happy stage. It is almost void of feelings”

Elisabeth Kubler-Ross
The Suffering Dimension “How can I deal with this pain?

- Meaning-Centered Interventions
- Dignity Therapy
- Life Review
- Transpersonal psychotherapy
- Psycho-spiritual approaches
- Medication when needed
“I must let this pain flow through me and pass on. If I resist or try to stop it, it will detonate inside me, shatter me, splatter my pieces against every wall and person that I touch.”

Audre Lorde, “The Cancer Journal”
The Energy Management Dimension: “How can I be part of the world, and yet detach from it?”

- Concerns about family members and other loved ones
- Internal work Vs. engagement
- What will the world be like without me?
- Legacy
  - Make sure it is the patient’s agenda
  - Worry they will not be ok
  - Worry they will be ok
The Peace Dimension: “What’s next?”

- Begin a parallel existence
- Changes in consciousness as death approaches
- Transcendence
- Natural withdrawal
- Doing the best we can without idealized fantasies
Preparatory Grief

- Mood fluctuates
- Self-esteem is generally intact
- Patient able to enjoy seeing and interacting with friends and family
- Able to experience pleasure in various activities
- Able to look forward to special occasions

Depression

- The patient feels sad or low most of the time
- Feelings of worthlessness and guilt
- Patient withdraws from friends and family
- Less talkative, not engaging
- Anhedonia
- Inability to make decisions
Anticipatory Grief in Caregivers

• Could be worst than bereavement
• Requires ongoing monitoring
• Identify concerning behaviors
• Respect cultural expressions
• Possible risk factor for complicated grief

Reynolds & Botha., 2006; Holley & Mast, 2009
Complicated Grief

- The bereaved individual is frozen or stuck in a chronic/constant state of mourning.

- Much of the individual mental anguish stems from their psychological protest against the reality of the loss and a general reluctance to make adaptation to life in the absence of the loved one (Prigerson et al, 2001; Shear et al., 2005, 2011)

- Symptoms experienced for at least six months
  - Consider cultural differences
Complicated Grief

- Separation distress with intense longing and yearning
- Anger and bitterness
- Shock and disbelief
- Hallucinations
- Behavior change

- Different from depression — Jacobsen et al., 2010

- Caregivers
  - Identify risk factors during palliative care
Risk Factor for CG

- Relationship and attachment style
- Personal vulnerability
- Circumstances of the death
- Psychosocial context of the death

Shear et al., 2005; Simon et al., 2011
Grief and the DSM-5

1. Persistent Complex Bereavement Disorder as a condition for further study
2. Elimination of bereavement exclusion criterion in diagnosis of Major Depression

- **DSM-IV**: Other conditions that may be a focus of clinical attention”

- Major depressive episode:
  - 29% to 58% after first year
  - 50% of widows and widowers in first year of bereavement
Pharmacological Approaches

• Complications of grief reactions: major depression, anxiety disorders, and complicated grief
• Some support for use of antidepressants
• Combined therapy $\rightarrow$ best results
• Concern that medication interferes with mourning process not supported by evidence
Psychotropic Medication During Acute grief

• Use of benzodiazepines
• Prescribing practices
• Not immediately after bereavement

(Woods and Winger, 1995; Warner and Metcalf, 2001; Cook et al, 2007 a; Cook et al., 2007b)
Bereavement-Related Depression

- Safe and moderately effective
- Better for depression than grief symptoms
- Desipramine (Jacobs et al., 1987) n=10
- Nortriptyline (Pasternak et al., 1991) n=13
- Nortriptyline and Interpersonal therapy (Reynolds et al., 1999) n=80
- Bupropion (Zisook et al., 2001) n=22
- Antidepressants and ADLs in older patients (Oakley et al., 2002) n=10
- Sertraline for disturbing dreams (Ishida et al., 2010)
Complicated Grief

- Antidepressants some efficacy
- Depressive symptoms improve earlier
- Comorbid with depression
- Paroxetine and therapy for traumatic grief (Zygmont et al. 1998) n=15
- Escitalopram (Simon et al., 2007; Hensley et al., 2009) n=4
- Concurrent naturalistic pharmacotherapy and Complicated Grief Therapy (Simon et al.)
Psychosocial Approaches

- Supportive Education
  - By each member of PC team
  - Clarify and normalize
  - Grieving style

- Counseling
  - Facilitate normal grieving
  - Here and now

- Psychotherapy
  - Complex grieving process
  - Pathological grief

Strada, 2013; Worden, 2009
Evidence-Based Interventions

• Time-Limited Psychodynamic psychotherapy – Horowitz et al. 1981
• Family-Focused grief Therapy – Kissane et al., 2006
• Complicated Grief Treatment – Shear et al., 2005
• Internet-based Interventions – Wagner et al., 2008
“...no human being can be reduced to what we see, or think we see. Any person is infinitely larger, and deeper, than our narrow judgment can discern...He or she can never be considered to have uttered the final word on anything, is always developing, always has the power of self-fulfillment, and a capacity for self-transformation through all the crises and trials of life”

Marie de Hennezel