Complicated Grief: New Understandings and Implications
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Overview: Complicated Grief
- Current Context
- Theoretical: Evolution of the Concept
- Clinical: Mental Health Classification
- Practical: Considerations for Hospice and Bereavement Support Programs

Grief: A Normal, Natural Process
- Normal, natural reaction to loss
- Biologically adaptive
- Process of accommodating and integrating life change
  - Behavioral, cognitive, emotional, physical, social and spiritual adaptation
  - Variable course, intensity and length
  - Influenced by many factors (individual, social, historical, cultural, contextual)

Grief: The Course it Takes
- Commonalities exist
- Unique experiences expected
- Grief is non-linear: Cycles, waves, and rollercoasters typical
- Stages and phases can be revisited, timeline unpredictable
- “There is a wide range of normal”

“What is impressive about mourning is not only the number and variety of response systems that are engaged but the way in which they tend to conflict with one another. Loss of a loved person gives rise not only to an intense desire for reunion but to anger at his departure... not only to a cry for help but sometimes also to a rejection of those who respond. No wonder it is painful to experience and difficult to understand.”

Bowlby, 1980, p. 31

“It is not the grief that people experience that is abnormal. Their experience of grief is their experience of grief. The difficulty lies in the mourning process. There is something impeding the mourning process and not allowing it to move forward toward a good adaptation to the loss.”

Worden, 2009, pp. 137-138
Current Context

**Complicated Grief (CG)**

**Question 1**

Is "Complicated Grief" a recognized disorder in the current version of the DSM?

**Question 2**

- Complicated Grief is estimated to be experienced by what percentage of bereaved persons?

Current Context: CG

- Concept widely available in professional, pedagogical, and layperson settings
- Definitions and descriptions vary
- Estimates of 10-20% bereaved affected*
- No agreed upon diagnostic criteria, not a specified disorder

*Bonanno, 2009; Holland, Neimeyer, Boelen, & Prigerson, 2009; Shear, Field, Mauck, & Reynolds, 2005; Zhang, El-Jawahri, & Prigerson, 2006

Complicated Grief Online

Complicated Grief Online

- Some proportion of bereaved family members impacted
- Hospice bereavement programs tasked with identifying those at risk
- Meaning of concept varies among IDT members
- What does hospice "do" with CG?
CG in Hospice Bereavement
- Clarify the scope of bereavement services for our staff and our families
- Consider how we structure bereavement assessment and careplanning for CG
- Identify and utilize alternative and community resources for bereaved clients with CG as appropriate

Evolution of the Concept
Theoretical Understanding of Complicated Grief

Question 3
- The concept of complications in grief has existed for what length of time?

Early Conceptions of Grief
- Discussions emerge in psychoanalytic writings, particularly in Attachment Theory
- Distinctions between normal and pathological mourning made from outset

Early Conceptions
- Freud (1917)
  - ‘Decathect’ libido from ‘lost loved object’
  - Distinguished mourning from melancholia
- Lindemann (1944)
  - Identified typical and ‘morbid’ bereavement reactions
  - Wrote about loss resolution as ‘grief work’, including accepting pain of the loss, working through fears, expressing sorrow

“...although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition....”
Freud, 1917, pp. 263-264
Early Conceptions
  - Trilogy on “Attachment and Loss”
  - Integral role of attachment bonds in human development/well-being across lifespan
  - Revolutionary conceptualization of social ties
  - Breaking of these bonds gives rise to grief
  - Identified phases of mourning
  - Discussed role of defensive processes in “disordered variants”

Bowlby (1980)
- Phases of Mourning
  - Numbing
  - Yearning/Searching
  - Disorganization/Despair
  - Reorganization

  - Yearning/searching — anxiety/anger
  - Disorganization/despair — pain/grief
  - Reorganization — resolution

  “On how he achieves this turns the outcome of his mourning - either progress towards a recognition of his changed circumstances, a revision of his representational models, and a redefinition of his goals in life, or else a state of suspended growth in which he is held prisoner by a dilemma he cannot solve.”
  - Bowlby, 1980, p. 139

Bowlby (1980)
- Disordered Mourning
  - Chronic Mourning — intense prolonged emotions with anger, self-reproach, depression and anxiety
  - Prolonged Absence of Conscious Grieving — lack of expected grief response, vague physical and psychological symptoms, may precede later breakdown
  - Scope, intensity, and persistence of defensive processes distinguish pathology

More Recent Conceptualizations
  - Accept reality of the loss
  - Process the pain of grief
  - Adjust to a world without the deceased
  - Find an enduring connection with the deceased in the midst of embarking on a new life

More Recent Conceptualizations
  - Recognize the loss
  - React to the separation
  - Recollect and re-experience deceased and the relationship
  - Relinquish old attachments to deceased and old assumptive world
  - Readjust to move adaptively into new world without forgetting the old
  - Reinvest
Complications with Tasks

- Current theorists describe complications in terms of undone/unfinished tasks:
  
  "...a generic term indicating that given the amount of time since the death, there is some compromise, distortion, or failure in select processes of mourning."  
  
  Rando, 1993, p. 12

- "...the demarcation between uncomplicated and complicated mourning is hazy at best and constantly changing...Reactions to loss can only be interpreted within the context of those factors that circumscribe the particular loss for the particular mourner in the particular circumstances in which the loss took place."

  Rando, 1993, p. 12

Question 4

- Bereaved who had previously been highly dependent on the deceased are more likely to experience Complicated Grief.

Factors Associated with Complicated Grief

- Deeply ambivalent/hostile relationship
- Markedly dependent relationship
- Compulsive caregiving or self-reliance
- History of unresolved loss
- History of depression, mental health difficulties
- Concurrent life crises
- Traumatic, violent, multiple losses
- Perceived lack of social support

Bowlby, 1980; Ledermann, 1944; Parkes, 1987; Rando, 1993; Worden, 2009

Normal Grief

- Uncomplicated bereavement viewed as expected, even adaptive, response to loss
- Bereaved proceed through painful mourning experience, re-emerge reinvested in life and relationships
- Phases or tasks of mourning successfully completed, grief finds "resolution"
Complicated Grief

- Terminology implies disturbance in loss engagement and/or resolution processes
- Bereaved fail to experience expected grief disruption (intensity, timing)
- Bereaved persist for too long with too much intensity and functional impairment
- Processes of mourning remain incomplete, may precede pathology

Mental Health Classification

Clinical Conceptualization of Complicated Grief

DSM and Bereavement

- DSM-III recognized “Uncomplicated Bereavement” as a V-code
- “Uncomplicated Bereavement” became “Bereavement” in DSM-IV
- Both editions recognized a “Bereavement Exclusion” for Major Depression (2-3 mos.)

Classification Efforts

- Delineation of diagnostic criteria/category for Complicated Grief has been subject of much debate
- Decades of psychiatric research
- Differing schools of thought
- Revision to proposed new DSM-V category as recently as 6 weeks ago

Two Approaches

- Mardi Horowitz’s work - Stress response syndrome akin to PTSD
  - Intrusive symptoms
  - Signs of avoidance and failure to adapt
- Holly Prigerson’s work - Grief-specific disorder distinct from major depression and anxiety

Prolonged Grief Disorder*

- Extended impairment of daily functioning following loss
- Inclusive of separation and traumatic distress
- Studied since the mid-1990’s largely in widowed persons
- Features identified from existing literature and clinician expertise
- Prior iterations as “Complicated Grief” and “Traumatic Grief”

* Also known as “where we thought we were heading until just recently...”

**PGD - Most Recent Criteria:**
5 symptoms over 6 months
- Yearning*
- Avoidance of Reminders of Deceased
- Disbelief/Trouble Accepting Death
- Perception that Life is Meaningless
- Bitterness or Anger about Death
- Detachment from Others
- Feeling Stunned about Death
- Feeling Part of Oneself Died with Deceased
- Difficulty Trusting Others
- Difficulty Moving On with Life

* Required symptom

**Question 5**
- PGD most closely resembles which "Disordered Variant of Mourning"?

**PGD Associations**

**Historical Precedents**
- Childhood maltreatment
- Insecure attachment
- Lack of preparation
- Kinship relationship

**Antecedent Outcomes**
- MDD/GAS/PTSD
- Poor health status
- Sleep disturbance
- Suicidal ideation
- Functional impairment

**PGD Treatments**
- Several authors have found favorable results for mixed psychoeducational and CBT (cognitive-behavioral therapy) approaches
- Confrontation of the loss
- Cognitive reappraisal
- Finishing incomplete business

Rosner, Pfoh, & Kotoucova, 2011; Shear et al, 2006; Wagner-Kranewied & Maercker, 2005

**Pros and Cons of PGD**
- Proponents note diagnosis permits treatment and insurance coverage
- Some study participants indicated diagnosis would offer relief
- Opponents concerned with pathologization, unnecessary classification, withdrawal of social support
- Pre-existing mental health disorder with compromised coping likely - grief is additive not causative
“...one wonders the extent to which the dysfunction is, at its root, bound up with the bereavement or merely triggered by it.”

Rubin, Malkinson, & Wittum, 2008, p. 190

“...it may be as important to accept that ‘normal’ grief includes severe suffering which, unless there is complication, cannot be accelerated or alleviated.”

Stroebe & Schut, 2005-2006, p. 67

Revisions to Revisions: DSM-V Draft (as of April 30, 2012)

- Recent proposed changes:
  - Footnote to Major Depression
  - Persistent Complex Bereavement-Related Disorder (Section III, recommended for further study)
  - Adjustment Disorder Related to Bereavement
  - No Inclusion of Prolonged Grief Disorder

http://www.dsm5.org/ProposedRevision/ProposedRevision.aspx?rid=44
http://www.dsm5.org/ProposedRevision/ProposedRevision.aspx?rid=577

Complicated Grief in Mental Health

- After 30+ years of consideration, diagnostic concept remains in flux.
- Widely referenced as if recognized disorder
- Looks unlikely to be resolved in DSM-V
- Duration of symptom impairment limits utility in hospice bereavement

Practical Application

Considerations for Complicated Grief in Hospice and Bereavement Support

CG in Hospice Bereavement

- Clarify the scope of bereavement services for our staff and our families
- Consider how we structure bereavement assessment and intervention for CG
- Identify and utilize alternative and community resources for bereaved clients with CG as appropriate
Scope of Bereavement Services

- Address and care plan for grief and loss needs from time of admission forward
- Assess strengths, issues, stressors, and coping skills of bereaved
- Identify individuals at risk for grief complications and appropriate interventions including need for additional support

NHPCO, 2008

Matching Services to Need

- Bereavement services exist along a continuum from least to most intensive
- Effective matching permits effective allocation of limited resources and optimal benefit for bereaved
- Enables provider to avoid difficulty in offering inadequate services that cannot meet complicated needs

Walsh-Burke, 2000

Grief Counseling and Grief Therapy

- "Grief counseling" facilitates adjustment to the loss; may incorporate emotional, psychosocial, and spiritual components
- "Grief therapy" focuses on identifying and resolving psychological conflicts that preclude successful mourning; utilizes specialized techniques

NHPCO, 2008; Rando, 1993; Walsh-Burke, 2000; Worden, 2009

Bereavement Assessment

- Identify risk factors likely associated with Complicated Grief
  - Ambivalent/conflicted/hostile relationship
  - Highly dependent relationship
  - Social isolation/Absence of support
  - Significant coping difficulties
  - Unprepared for the loss
  - Markedly unresolved prior loss
  - Concurrent mental health difficulties, including substance abuse and Axis II (i.e. Personality d/o)

NHPCO, 2008, p.8

Bereavement Assessment

- Consider protective factors unlikely to be associated with Complicated Grief
  - Positive or neutral relationship with deceased
  - Adequate social support
  - Effective/Resilient coping
  - Absence of mental health difficulty
  - Relatively prepared for the loss
  - Meaningful belief system
“Gut Instinct” Assessment
- Bereaved focus on complaints of longstanding (i.e., family conflict, social disappointments, financial distress)
- Grief appears secondary to the struggle
- Anger is predominant, may be ‘scary’
- Anxiety gets in way of support access
- Support efforts are unsatisfactory

Evaluate Appropriate Interventions
- Recall continuum of support services, evaluate where bereaved best fits
- Consider early initiation of services (pre-death)
- Individualize intervention plans for each client: bereaved with Complicated Grief may still benefit from program services

Questions to Consider
- Is the bereaved:
  - Appropriate for volunteer contact?
  - Able to navigate 1:1 counseling? Support group? Educational class?
  - Open to an agreement for concurrent mental health services?
  - Seek external/community referral as needed

Community Referrals
- Collaboration with community professionals and agencies necessary when complications present
- May include issues of mental health, substance abuse, financial assistance
- Network to develop relationships and establish reliable referral resources
- Prepare bereaved for this possibility

Case Example #1
- Suzanne
  - 58 y.o. female with husband (pancreatic CA) and son (suicide, hx schizophrenia) deaths
  - Angry that ‘system’ did not help her son
  - Employed FT by the state
  - Limited social support, recent loss of cat
  - Self-reports hx depression, suicide attempts*, family abuse*, volatile marriage*
  - Sees psychiatrist monthly for med mgmt., MD reports hx alcoholism*, eating d/o*, BPD*
  - Identifies significant spiritual belief*

  *Disclosed during bereavement counseling

Our Assessment, Approach, and Outcome
- Entire IDT recognized as Complicated
- Initial outreach by multiple staff, bereavement within day
- Seen in 1:1 sessions, 9 visits/7 mos.
- Many sessions focused on intense anger and deep sadness over son’s illness/death
- Required Mental Health agreement following suicide gesture directed “at” new boyfriend
- Client began day tx and DBT group
Case Example #2

- **Janet**
  - 50 y.o. female with mother death (CVA)
  - Lived with both parents and brother, father in ill health, long term advocate role
  - Unemployed, left prior job due to 'bullying'
  - Anger/blame at health care system
  - Limited social support
  - Strong spiritual belief, daily faith practice

Our Assessment, Approach, and Outcome

- MSW and PCC identified as Complicated
- Bereavement outreach within week
- Seen in 1:1 sessions, 5 sessions over 3 mos.
- Sessions focused on disappointment in care, self-blame and related sadness
- Client benefited from/able to accept redirection to grief-related discussion
- Transitioned to support group after 3 mos.

Coping with Challenges

- Dealing with client resistance
- Lacking necessary alternatives
- Being caught off guard
- Accessing support from management
- Establishing written practices/policies

An Alternative Idea: Complex Grief

Complex Grief

- Complicated Grief suggests protracted, pathologic/compromised response to loss
- Rooted in individual coping and capacity
- Grief added/secondary to existing struggle
- Complex Grief suggests additional stressors compounding response to loss
- Rooted in situational context
- Grief struggle largely due to circumstance

Some Complex Grief Factors

<table>
<thead>
<tr>
<th>Individual</th>
<th>Social</th>
<th>Situational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor health</td>
<td>Family conflict</td>
<td>Off-time loss (child, young parent)</td>
</tr>
<tr>
<td>Financial strain</td>
<td>Multiple losses</td>
<td>Short time from dx to death</td>
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<tr>
<td>Ongoing CG role</td>
<td>Limited social network</td>
<td>Cultural sanctions</td>
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<tr>
<td>Unresolved prior loss</td>
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</tbody>
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Case Example #3

- Michael
  - 39 y.o. with wife death (melanoma), father of 8 y.o. dau
  - Primary parent, not employed
  - High social support, close to immediate family, has school support
  - Prior involvement with cancer counseling
  - Keeps a blog of experience

Our Assessment, Approach, and Outcome

- IDT identified as Complicated, Bereavement assessed as Complex
- Husband initially interested in community peer group support for daughter
- Initiated monthly 1:1 when group ended
- Sessions focused on range of thoughts/feelings, strengths/challenges in being widowed single father
- May resume follow-up peer support group

Complex Grief: Increasing IDT Awareness

- IDT staff may be prone to confuse Complex Grief with Complicated Grief
- Increasing IDT awareness of the distinction will enable more efficient, effective matching of bereavement services to client need

Thank you!

Questions and Comments.....