Grief and Complicated Grief

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BILD Conference, Dublin, November 2013.
Presentation

- Grief/Complicated Grief
- Grief in Intellectual Disabilities
- Complicated Grief in Intellectual Disabilities
Grief

- Response to a bereavement

- Kubler-Ross (1969)
- Bowlby, 1980/1981
- C.M. Parkes
  - London Study (1970): ‘Normal Grief’
  - Bethlam Study (1965): ‘Atypical Grief’

Stage Theory of Grief
“Normal Grief”

- Acute Stress response
- Broken attachment
Stage Theory of Grief

Stage 1 Hours to days
• Denial, disbelief, ‘numbness’

Stage 2 Weeks to months
• Sadness, weeping, waves of grief,
• Somatic symptoms of anxiety
• Restlessness and poor sleep
• Reduced appetite
• Guilt, blame of others
• Illusions, vivid imagery
• Hallucinations of dead persons’ voice
• Preoccupation with memories of the deceased
• Social withdrawal

Stage 3 Weeks to months
• Symptoms resolve, with return to social activities
  (Parkes, 1983)
Stage Theory of Grief

Disbelief  Yearning  Anger  Depression

Acceptance

Time From Loss

Indicator Rating
‘State’ Theory of Grief (Maciejewski, 2007).
Attachment Theory

- Biologically programmed to seek, form & maintain attachment relationships
- Interrelated Behaviours
  - Attachment
  - Exploration
  - Caregiving (Feeney, B.J.Soc.Pers.Rel, 2010)

(Carmichael & Reis, 2003; Roisman 2005; Kim, 2008; Mukulincer, 2002)
Contain Cognitive & Affective memories

• Explicit (in awareness), including episodic/narrative; semantic/rules

• Implicit (out of awareness) includes motor/procedural/emotional memories

• Loved ones in each kind of memory
Attachment: Disruption of restorative emotional & physiological processes (sleep, appetite, activity, energy)

Exploration: Loss of sense of wellbeing, confidence

Caregiving: self-blame, loss of well-being.

Acute grief symptoms = disruption of these systems

Resolution & Resilience-helped by other attachments in adulthood
Bereavement 'raises risk of dangerous heart changes'

Recently-bereaved people have heart rhythm changes which may make some of them more vulnerable to health problems, say researchers.

The University of Sydney study, released at a US heart conference, monitored the hearts of 78 bereaved spouses and parents.

They beat faster on average than unaffected volunteers, with more common periods of very rapid heart rates.
'The grief hath crazed my wits....'

(Gloucester)

Act 3, scene 4; King Lear. William Shakespeare
'Grief is not a mental illness that should be treated with pills': Doctors hit back at creeping medicalisation of life events

- Treatment of grief with antidepressants is 'dangerously simplistic', experts say
- Backlash follows the American Psychiatric Association's reclassification of grief as a mental illness

By LAUREN PAXMAN
UPDATED: 15:54 GMT, 17 February 2012
Grief and Psychiatric Disorder

Complicated Grief
‘Pathological’ Grief

- **Mourning/Melancholia** (Freud, 1917)
- **Absent** (Deutsch, 1937)
- **Distorted** (Brown & Stoudemire, 1983)
- **Abnormal** (Pasnau, Fawney & Fawney, 1987)
- **Morbid** (Sireling, Cohan & Marks, 1988)
- **Truncated** (Widdison & Salisbury, 1990)
- **Atypical** (Jacobs & Douglas, 1979)
- **Traumatic** (Prigerson, 1999)
- **Complicated** (Shear, 2011)
- **Prolonged grief disorder** (Prigerson 2008...)
Complicated Grief/Prolonged Grief Disorder
Diagnostic Criteria (Prigerson, 1999; 2009)

A. Separation Distress
- Yearning
  - Intrusive thoughts
  - Searching/Preoccupation

C. 6 months duration

D. Social etc. Impairment

E. Not MDD/GAD/PTSD

B. Cognitive/Emotional/Behavioural Symptoms (Traumatic Distress) (5/9)
- Purposelessness
- Disbelief
- Avoidance
- Shattered world view/Distrust
- Irritability, bitterness, anger
- Stagnation in life
- Sense of numbness
- Emptiness
- Stunned, dazed, shock
Prolonged/Complicated Grief: Distinct Diagnostic entity

Risk Factors

- Dependent relationships (Cleiren, 1994; Johnson, 2000; Bonanno, 2002)
- Parental loss, abuse, neglect in childhood (Silverman, 2001)
- Insecure attachment styles (Van Doorn, 1998; Carr, 2000)
- Separation anxiety in childhood (Vanderwerker, 2006)
- Preference for lifestyle regularity (Cleiren, 1994)
- Lack of preparation for the death (Berry, 2001; Hebert, 2006)
Distinct clinical syndrome
Prevalence 10% (Barry, 2001; Latham, 2004)

- Different to depression/anxiety (Boelen, 2003; Prigerson, 2008)
- Poor response to TCA (Reynolds, 1999) and IPT (Shear, 2005)
- Different to PTSD (Prigerson, 2000)
- Distinctive sleep E.E.G (Mc Dermott, 1997)
- fMRI study: nucleus accumbens & yearning (O’Connor, 2008)
Associated with adverse outcomes

- **Suicidality** (6/12) (Latham, 2004)
- **M.D.D. (6/12) & Anxiety Disorders** (12-18/12) (Boelen, 2003)
- **Cancer, Hypertension, M.I.** (Prigerson, 1997)
- Poor service utilization
- Persistent symptoms
- Adverse Quality of Life
Medication: SSRI: need an RCT for C.G. (ongoing)

Pre-loss preparation for the death, and survivor’s aftercare (ongoing)

Psychotherapies

- CBT focusing on CG symptoms (RCT, Shear et. al., 2005)
- Brief Integrated Psychodynamic (Horowitz, 1984)
<table>
<thead>
<tr>
<th></th>
<th>DSM V: ‘Persistent Complex Bereavement-Related Disorder’ (Section 3) (<a href="http://www.dsm5.org">www.dsm5.org</a>)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>Death of close family member/friend at least 12 months ago</td>
</tr>
<tr>
<td>B.</td>
<td>(1/4) Yearning, Sorrow, Preoccupation-person, Preoccupation-death</td>
</tr>
<tr>
<td>C.</td>
<td>(6/12) Reactive distress to death (6 symptoms)</td>
</tr>
<tr>
<td></td>
<td>eg: Shocked/stunned/numb, difficulty with positive reminiscing</td>
</tr>
<tr>
<td></td>
<td>Social/Identity disruption (6 symptoms)</td>
</tr>
<tr>
<td></td>
<td>eg: Desire to die; feeling alone/detached from others</td>
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<tr>
<td>D.</td>
<td>Distress/Impairment of function</td>
</tr>
<tr>
<td>E.</td>
<td>Inconsistent with cultural, religious, age-appropriate norms</td>
</tr>
</tbody>
</table>
Diagnostic Overshadowing- with grief as well!

Higher risk
Grief and Intellectual Disabilities

- Unclear impact of Intellectual Disabilities
  - Attachment Theory-Role of implicit memory

- Ability to Grieve *(Lipe-Goodson, 1983; Mc Evoy, 1983, 2004)*
  - Concept of Death *(Mc Evoy, 2006)*
  - Influenced by life experience/psycho-education/Staff support *(McEvoy)*
  - Bereavement Ritual Involvement *(Dodd, 2005)*
  - Probably now accepted!
Intellectual Disability: An Ageing Population

![Bar chart showing the proportion of people with moderate, severe or profound intellectual disability (combined), by age group: 1974-2011.](chart)

**Figure 2.3** Proportion of people with moderate, severe or profound intellectual disability (combined), by age group: 1974-2011
Age of Parents with Service Users Living at Home

- Age Unknown: 216
- Age < 30 yrs: 47
- Age 31 - 40 yrs: 198
- Age 41 - 50 yrs: 410
- Age 51 - 60 yrs: 283
- Age 61 - 70 yrs: 263
- Age 71 - 80 yrs: 185
- Age > 80 yrs: 55
Complicated Grief: Risk Factors

ID Non Specific
- Dependent population
- Insecure attachment (De Schipper, 2006)

ID Specific
- Socially isolated (Dodd, Guerin, Mulvaney, Tyrell & Hillery, 2009)
- Loss of family home, associated losses (Hollins & Esterhuyzen, 1997)
Grief and Intellectual Disabilities

The Effects of Grief  (Dodd, et al. 2005; Dodd & Guerin, 2010; Blackman, 2012)

**Psychiatric Illness**  (Day, 1985; McLaughlin, 1987; Stoddart, 2002; Hollins & Esterhuyzen, 1997)

**Behaviour & Emotion**

(Emerson, 1977; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Bonell-Pascual, 1999)

*No specific link to Complicated Grief*
Study of Complicated Grief Symptoms
(Dodd et al., 2008;2011)

- Complicated grief symptoms in a sample of adults with ID, who have experienced a parental bereavement
- Assess bereavement preparation and ritual involvement
- Carer Based initially due to exploratory nature
Results

Occurrence of symptoms
(Sometimes to always)

• Loneliness: 73.7%
• Wishes deceased were here: 63.2%
• Gets upset thinking about deceased: 63.2%
• Hard to do activities: 39.5%

• 31.6% >10 symptoms
Results

Subscales Identified

• Prigerson (2006/2009) two subscales
  – Separation distress
  – Traumatic grief

• Correlation with bereavement ritual involvement
Key Findings

- Bereaved group did show symptoms of Complicated Grief, with separation distress more than traumatic grief
- Positive relationship between ritual involvement and complicated grief symptoms, at odds with practice
- Evidence of poor previous ritual involvement
- Involvement without understanding/preparation?
Self Report Study: Complicated Grief Symptoms (ongoing)

- Bereaved & Non Bereaved Group – Matched Sample (Self-Report)
- Staff Report (By-Proxy)
- Mild/ Moderate ID
Sample Question on the CGQ-ID

<table>
<thead>
<tr>
<th>CGQ-ID Questions</th>
<th>Sample Visual Prompts</th>
<th>Frequency question/Additional notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Some people get very upset when they think about the person that died. Do you</td>
<td><img src="upset_b.png" alt="Image" /></td>
<td>Does this happen</td>
</tr>
<tr>
<td>get upset when you think about _________?</td>
<td><img src="think.png" alt="Image" /></td>
<td>some of the time □</td>
</tr>
<tr>
<td>Yes □ No □ I don’t know □</td>
<td></td>
<td>a lot of the time □</td>
</tr>
<tr>
<td></td>
<td></td>
<td>or all of the time □?</td>
</tr>
</tbody>
</table>

- Initially assesses acquiescent responding and conceptual understanding of frequency.
- Assesses through subscales of Separation Distress, Traumatic Grief and Social/Occupational Distress
- Focus on symptoms that occur frequently (a lot/all of the time or often/always)
## Preliminary Analysis – Separation Distress Subscale Items

<table>
<thead>
<tr>
<th>Separation Distress Items</th>
<th>Self Report</th>
<th>Proxy Report</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Freq</td>
</tr>
<tr>
<td>Gets upset when thinking about the deceased (Q1)</td>
<td>100%</td>
<td>71.2%</td>
</tr>
<tr>
<td>Misses the deceased so much they cannot tolerate it</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Wishes the deceased were here (Q4)</td>
<td>71.4%</td>
<td>52.3%</td>
</tr>
<tr>
<td>Likes/Wants to revisit places they used to go to with deceased (Q5)</td>
<td>76.2%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Feels lonely since the death (Q17)</td>
<td>81.0%</td>
<td>52.4%</td>
</tr>
<tr>
<td>Thinks about the deceased when wanting to think about other things (Tries to stop thinking – Q20)</td>
<td>61.9%</td>
<td>38%</td>
</tr>
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</table>
## Preliminary Analysis – Other Items

<table>
<thead>
<tr>
<th>Other Items</th>
<th>Self Report</th>
<th>Proxy Report</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Freq</td>
</tr>
<tr>
<td>Has the feeling that _____ will come through the door (Q2)</td>
<td>52.4%</td>
<td>52.4%</td>
</tr>
<tr>
<td>Feels angry because mum/dad died (Q7)</td>
<td>61.9%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Does not believe (Finds it hard to believe) they are gone forever (Q8)</td>
<td>38.1%</td>
<td>23.8%</td>
</tr>
<tr>
<td>Finds it unfair that they are still alive and mum/dad is not (Q15)</td>
<td>76.2%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Do they talk to _____ and does _____ talk back? (Q12)</td>
<td>52.4%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Do they see _____ in front of them when they are awake? (Q13)</td>
<td>52.4%</td>
<td>23.8%</td>
</tr>
<tr>
<td>Envious (jealous) of people who have not lost mum/dad (Q16)</td>
<td>52.4%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Feels guilty that the death was their own fault</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Key Findings

- More symptoms reported on self-report compared to proxy report
- More Separation distress symptoms compared to traumatic grief symptoms
- Similar to Proxy study
- Supported by attachment/bio-behavioural theory
- Prolonged Grief Disorder (DSM V)-relevant to people with ID?
What have we learnt from our research?
People with Intellectual Disabilities ...

- Do grieve
- Have some understanding of death
- Display a variety and range of reactions
- Can experience significant ‘Separation anxiety’
Frontline staff ...

- Agree that PWID should be taught about death
- May fail to recognise or report dysfunctional behaviour
- Are an important source of support but ...
  - Lack confidence in providing bereavement support
  - May disagree about support needs
  - Are emotionally attached
Families and relatives ...

• Agree that PWID should be taught about death
  • but not if relative has challenging behaviour

• Often confused about what to say, what to do.
  • May ‘disenfranchise’ relatives grief

• Are an important source of support
Implications for Clinical practice?
Organising Clinical Support

- Pre-bereavement work
- Ongoing support during illness and death
- Post-bereavement support
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Frasier, Season 6, Episode 1 “Good Grief”

http://www.youtube.com/watch?v=xjs7gJ6MS2Q

(3 parts)