People with Intellectual Disabilities: Bereavement & Grief

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Overview of Presentation

- Intellectual Disability Research Group
- Grief/Bereavement General Population
- Grief/Bereavement I.D.
- IDRG Research
- Future

Applied Research in Disability (ARD) Group

- Made up of practitioners and academics commited to promoting and conducting research in the area of ID
- Real world and applied research topics are central to the work of the group

- Members:
  - Dr John Hillery (Psychiatry)
  - Dr Philip Dodd (Psychiatry)
  - Dr Suzanne Guerin (Psychology)
  - Dr John McEvoy (Psychology)
  - Dr Sarah Buckley (Psychiatry)
  - Dr Karen Ryan (Palliative medicine)
  - Dr Gemma Kiernan (Psychology)

ARD Group: Current & Recent Projects

- ADHD in children/adults with ID
- Service needs of older adults
- Death, dying and bereavement in ID are key topics
  - Palliative care needs of children with ID
  - Palliative care provision for adults with ID
  - Developing training resources for staff in ID settings
  - Complicated grief symptoms in adults who have experienced a parental bereavement
  - Prospective study of grief in adults who have experienced a parental bereavement

Bereavement and Intellectual Disability

- Complex!
- Life Events
- Intellectual Disabilities
  - Cognitive: Understanding of death, difficulty assessing self-reported needs and wishes
  - Social: Perceived as vulnerable, which can result in family members 'protecting' them from distressing experiences

Key Concepts

- Attachment
- Resilience
- People with I.D. are ageing
- Lack of research

Grief

- Response to a bereavement
- Life events (Brown & Harris, 1978)
- Kubler-Ross (1969)
- C.M. Parkes

  London Study(1970): ‘Normal Grief’

  Bethlam Study (1965): ‘Atypical Grief’
- Stage Theory of Grief

Stage Theory of Grief

Stage 1 Hours to days

- Denial, disbelief, 'numbness'

Stage 2 Weeks to months

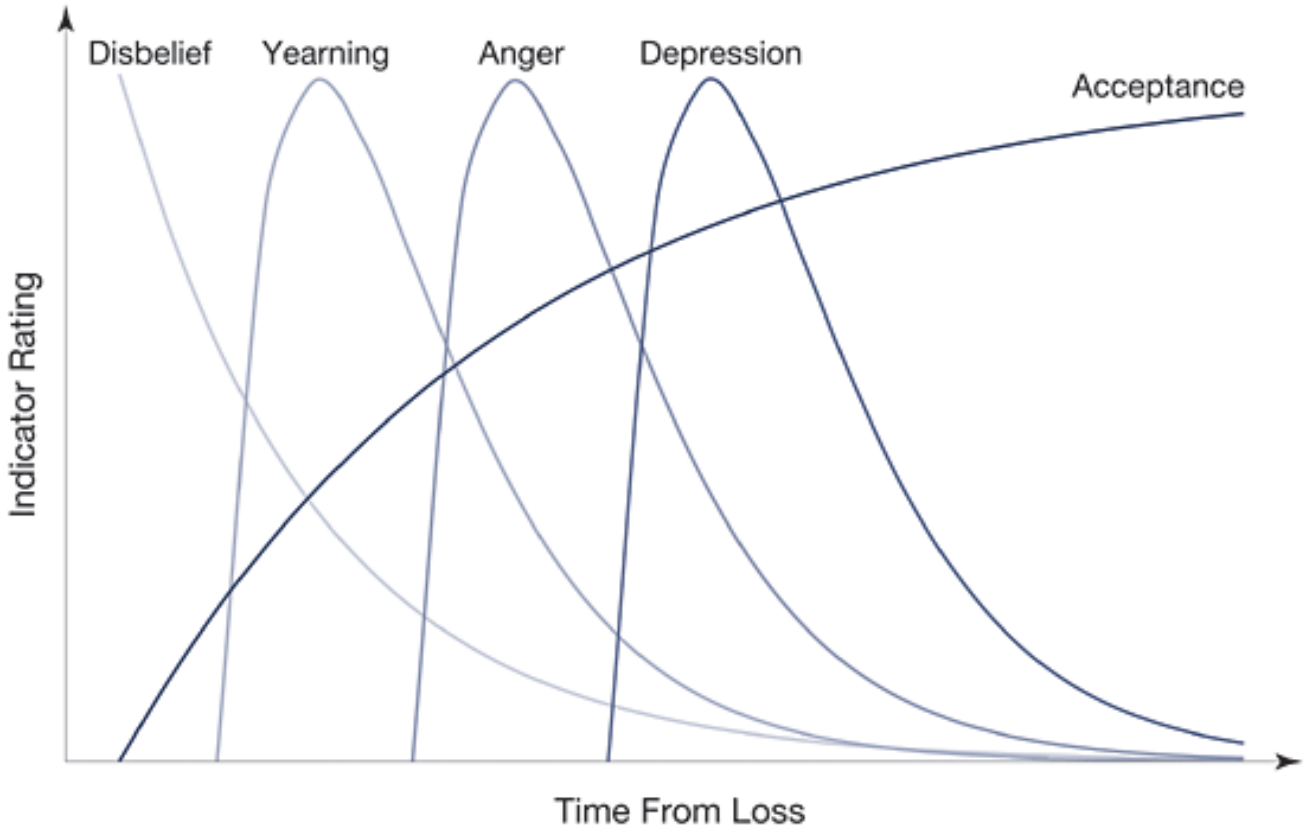
- Sadness, weeping, waves of grief,
- Somatic symptoms of anxiety
- Restlessness and poor sleep
- Reduced appetite
- Guilt, blame of others
- Illusions, vivid imagery
- Hallucinations of dead persons voice
- Preoccupation with memories of the deceased
- Social withdrawal

Stage 3 Weeks to months

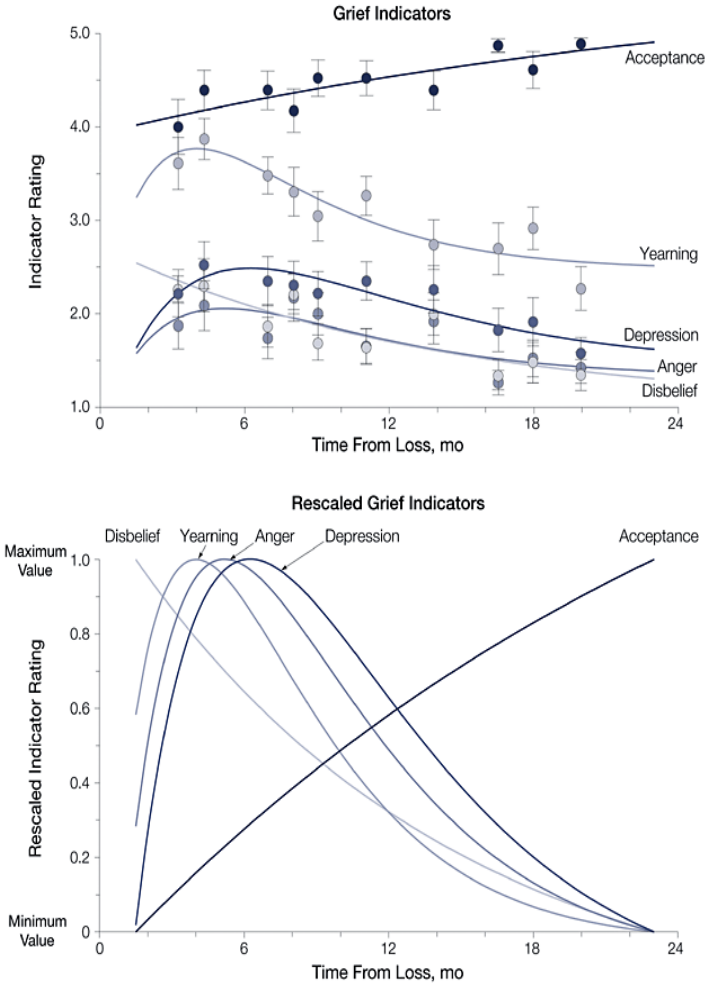
- Symptoms resolve, with return to social activities

(Parkes, 1983)

Stage Theory of Grief



State Theory of Grief (Maciejewski, 2007).



‘Pathological’ Grief

- 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 (Prigerson,2000)
- Prolonged grief disorder (2008…)

‘Pathological’ Grief

Pathological Grief Reaction

- Freud
  - Mourning (“normal” grief)
  - Melancholia (“abnormal” grief)
- Klein
- Bowlby
- Parkes
  - Inhibited Grief
  - Delayed Grief
  - Chronic Grief

Complicated Grief:

Consensus Diagnostic Criteria (Prigerson, 1999)

Separation Distress (1/3)

- Intrusive thoughts
- Yearning
- Searching
- Excessive loneliness

- *6 months duration*
- *Social Impairment*

Traumatic Distress (5/9)

- Purposelessness
- Disbelief
- Avoidance
- Shattered world view/Distrust
- Irritability, bitterness, anger
- Sense of numbness
- Emptiness
- Stunned, dazed, shock

Complicated Grief: Distinct Diagnostic entity

Risk Factors

- Controlling parents/Dependent relationships (Cleiren, 1994)
- Parental loss, abuse, neglect in childhood (Silverman, 2001)
- Poor parental bonding (Carr, 2000)
- Separation anxiety in childhood (Vanderwerker, 2006)
- Preference for lifestyle regularity (Cleiren, 1994)
- Lack of preparation for the death (Berry, 2001)

Complicated Grief: Distinct Diagnostic entity

Distinct clinical syndrome

Prevalence 11%

- Different to depression/anxiety (Boelan, 2003)
- Poor response to TCA (Reynolds, 1999) and IPT
- Different to PTSD (Prigerson, 2000)
- Distinctive sleep E.E.G (Mc Dermott, 1997)

Complicated Grief: Distinct Diagnostic entity

Associated with adverse outcomes

- Suicidality (6/12) (Latham, 2004)
- M.D.D.(6/12) & Anxiety Disorders (12-18/12) (Boelan, 2003)
- Cancer, Hypertension, M.I.,(Prigerson, 1997)
- Poor service utilization
- Persistent symptoms

Complicated Grief: Promising Treatments

- Medication: SSRI: need an RCT for C.G.
- Pre-loss preparation for the death, and survivor's aftercare
- Psychotherapies
  - CBT focusing on CG symptoms (RCT, Shear et. al., 2005)
  - Brief Integrated Psychodynamic (Horowitz, 1984)

Complicated Grief

- ICD 11 ?
- DSM V ?

- No research to date has charted the experience of grief (normal or complicated) among adults with intellectual disabilities

Grief in People with Intellectual Disabilities

- Disenfranchised Grief (Doka, 2002)
- Ability to Grieve (Lipe-Goodson, 1983; Mc Evoy, 1983, 2004)
  - Formation of Concept of death
    - Universality
    - Irreversibility
    - Inevitability
  - Influenced by life experience (MacHale, 2009)
  - Attachment behaviours
  - Bereavement Ritual Involvement (Dodd, 2005;2008)

Grief in People with Intellectual Disabilities

- The Effects of Grief (Dodd, 2005)
  - Psychiatric Illness
    - Day, 1985
    - McLaughlin, 1987,
    - Stoddart, 2002;
    - Hollins & Esterhuyzen, 1997
  - Behaviour & Emotion
    - Emerson, 1977
    - Harper & Wadsworth,1993
    - Hollins & Esterhuyzen,1997
    - Bonell-Pascual, 1999

Grief in Intellectual Disabilities: Staff

- Death brings a number of challenges that can be a stressful for healthcare professionals
  - Coping with the death of a service user
  - Supporting relatives through the bereavement process
  - Supporting service users who have been bereaved
  - (Payne, Dean & Kalus, 1998; Georges & Grypdonck, 2002)
- Can also generate personal and emotional challenges, including anxiety about one's own death
  - (O'Gorman, 1998; Dowling, Hubert & Hollins, 2003)

Grief in Intellectual Disabilities: Staff*

- Research conducted with staff in one ID service to explore training needs.
- Need for **formal information on bereavement and ID**
  - *"I think it'd be important to emphasise to people that just because somebody had an ID doesn't mean they don't understand death and dying and bereavement."*
  - *"I think bereavement awareness is the big key in this, its actually having [staff] talk about it … help them [to] feel comfortable talking about bereavement with one of the service users."*

*McEvoy, Guerin, Dodd & Hillery 2010

Grief in Intellectual Disabilities: Staff

- Desire for training in **practical skills and strategies**
  - "*... there are going to be different scenarios for different areas ... parents, service users in the community who are supposed to be verbal, service users in some of the residential areas who would be nonverbal, so the types of strategies you'd use with them would obviously be very different*"
- Should draw on and build on the **existing experience of staff**.
  - "*... these are skills; these are human skills we're going to be trying to develop in staff. Like, most staff have them, it's just a matter of finding them and developing them.*"

Control Study of Complicated Grief Symptoms*

- 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

*Dodd, Guerin, McEvoy, Buckley, Tyrrell, Hillery, 2008

Study of Complicated Grief Symptoms (Dodd et al., 2008)

- Retrospective study
- Sample
  - Carers of 2 Groups of Individuals
- Group A:
  - Mild/Moderate I.D. (verbal)
  - Parent bereavement in last 2 years
- Group B:
  - Matched Comparison

- Procedure
  - Bereavement History Questionnaire (Adapted from Hollins & Esterhuyzen, 1997)
  - Complicated Grief Questionnaire (Modified form): Administered to 2 Carers
  - Index of Social Competence (McConkey & Walsh, 1982)

Key Findings

- Adapted CGQ-ID valid and reliable with this sample
- Bereaved group did show symptoms of Complicated Grief, with separation distress more evident than traumatic grief
- Possible positive relationship between involvement and difficulty, at odds with current practice
- BUT may need to consider Quality of involvement rather than Quantity
  - Implication of involvement without preparation?

Grief in People with Intellectual Disabilities*

- Research has considered a group that are specifically at risk
  - Over 30 (so parents over 50)
  - Moderate or higher disability
  - Living at home with parents
  - Lack of engagement with service
- Represent approx 7.5% of individuals on the NIDD
- Evidence of poor assessment practices e.g. significant periods of time between contacts with the individual and limited contact regarding service planning.

* Dodd, Guerin, Mulvaney, Tyrell & Hillery, 2009

What next?

- Study experience of bereavement
  - life events
  - complicated
- Develop risk factors/resilience pointers
- Evidence based therapeutic interventions
- Staff: Screening
  - Psycho-education
  - Training

Questions/Comments?