Bereavement in Older Age

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Loss

(Kissane and Zaider 2010)

- Bereavement is the state of loss resulting from death
- Grief is the emotional response associated with loss
- Mourning is the process of adaptation , including the social and cultural rituals prescribed as accompaniments.

Theoretical models - what we thought we knew

- Freud and psychodynamic theories - early relationships lay down a template that guides future relationships
- Bowlby and attachment theories - the bonds of close relationships are severed by loss and the nature of the attachments influences the impact of loss
- Murray Parkes' and transition theories - responding to loss of assumptive world. Acceptance of change is implicit.
- Prigerson and the traumatic model - DSM V
- These are medical models with the implication that there is a price to pay for not grieving/confronting the experience of loss.

Colin Murray Parkes

Phases of grief (1972)

- Numbness
- Pining
- Disorganisation
- Re-organisation

William Worden

Tasks of mourning (1983)

- Accept reality of loss
- Experience pain of grief
- Adjust to new environment
- Withdraw emotional energy/relocate the deceased

Importance of continuing bonds (Klass and Silverman 1996, Rubin 1999).
Death ends a life, not necessarily a relationship.

Emerging challenges
(Wortman and Silver 1989)

- There had been little research on actual course of grieving over time and still less on efficacy of interventions
- Models criticised as rigid and culture bound
- Is griefwork essential? Most had believed major emotional expression necessary for grief to be “resolved”

- High > low distress
- Never high
- Always high

- Bias through those we help

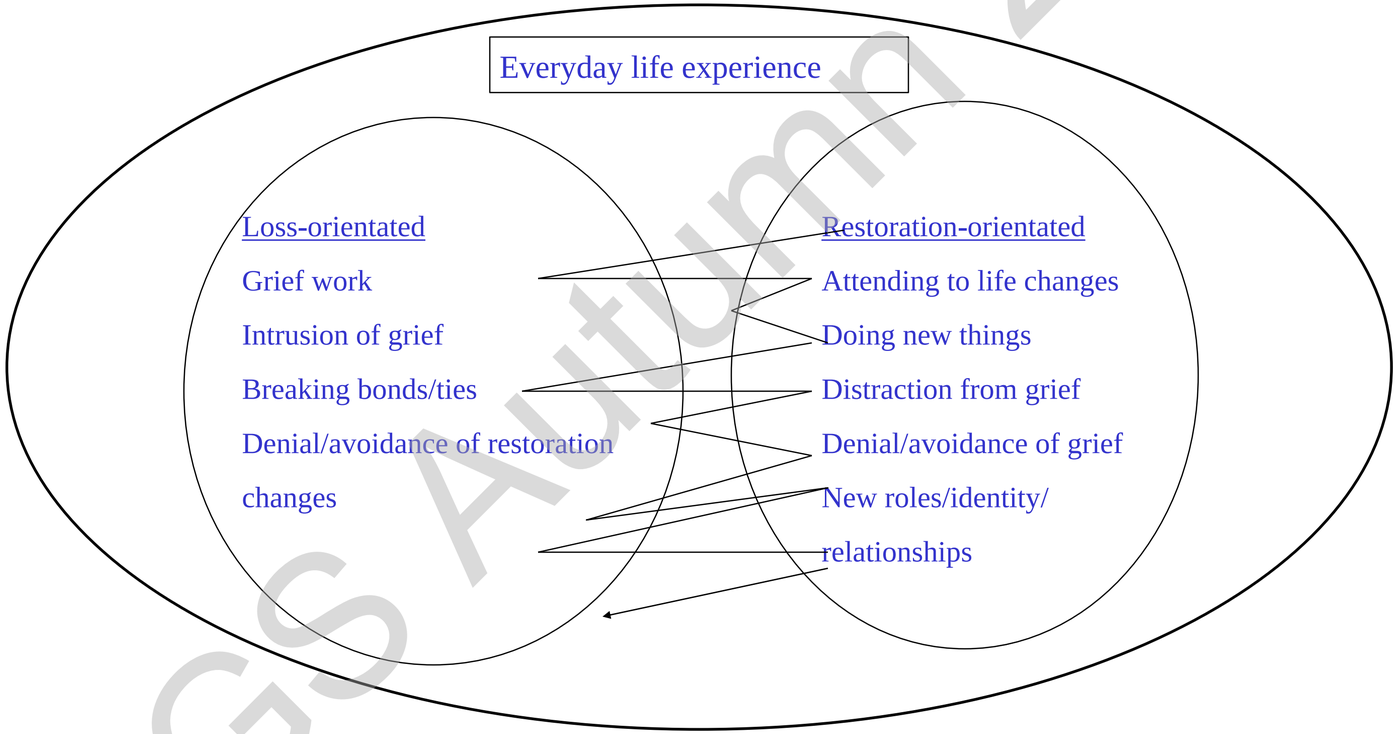
Revisions (1) Cognitive stress/ coping theory models

- Stroebe and Schut (1995,1999) Two categories of stressor in bereavement: coping with loss experience itself and with the other changes and adjustments that result from it. Dual process model accounts for vacillation in emotional responses seen in the bereaved. No suggestion of progression or stages. Both activities involve negative and positive emotions

- Machin (2001) -Adult Attitude to Grief Scale - coping responses fall into three categories: overwhelmed, controlled, resilient.

Stroebe and Schut DUAL PROCESS MODEL (1995)

People need to confront <u>and</u> avoid



To face <u>or</u> avoid grief all the time can lead to serious mental health consequences.

Revisions (2) Sociological models - cultural influences shape the form and content of grief

- Doka (1989) Disenfanchised grief: relationship, loss or griever not recognised, creating additional problems of grief while removing or minimising sources of support
- Walter (1999) Biographical model: the need to tell and share the story
- Nadeau (1997), Neimeyer (2005) : the importance of narrative and meaning making
- Kissane and Bloch (2002) Family systems theory. Family are main source of support and family functioning determines outcome.

Risk in bereavement: before death - background factors

- Socio-economic deprivation. (Those in poorest neighbourhoods 3 times mortality rate of most affluent. Lancet 2017)
- Personality and coping style
- Past history of mental health problems
- Social support (Adults 65-74 without children will have doubled between 2012 and 2030 ONS 2017)
- Caring load and practical problems
- Overly dependent or ambivalent relationship
- Cumulative experience of losses
- Religious and spiritual beliefs and practices

Risk in bereavement: nature of death

(Neimeyer and Burke 2012)

- Untimely within life cycle (loss of adult child, Newson 2011)
- Sudden or unexpected
- Traumatic: accident, suicide, murder, finding body
- Stigmatised
- Guilt inducing: not present, not place of patient choice, poorly controlled symptoms
- Good quality end of life care can minimise carer burden and regrets
- Advance decision, ACP, PoAs - satisfaction of wishes followed. Compassion in Dying for free materials and support line.
- Benefits of shared record - twice as likely to die in place of choice and have other care wishes fulfilled, fewer emergency EoL admissions (You Gov/McMillan 2018).

Risk in bereavement: after death

- Nature and extent of family and community support network (family dysfunctional: high conflict, poor communication) - geographic dispersal
- Perceived lack of/poor social support - alienated
- Isolation: new migrant, moving house, retirement, friendship network predicated on deceased
- Practical problems and reduced material resources: financial, daily living; IT, bills, washing machine and cooking; ill health - can get worse. Increase in cardiovascular related deaths in 45-75s (Zisook et al 1994, increased mortality in general (Karam 1994). Changes in immune system in over 65s (Phillips 2014).
- Change of role - loss of caring role, loss of carer - personal care needs
- Acute loneliness and “cascade of events” more likely for oldest old. Some evidence older bereaved men are at greater risk (Byrne and Raphael 1994).
- In absolute terms the greatest risk is related to age and gender. Young and male. (Sanders 1993)

Revisions (3) Who needs help? The public health model

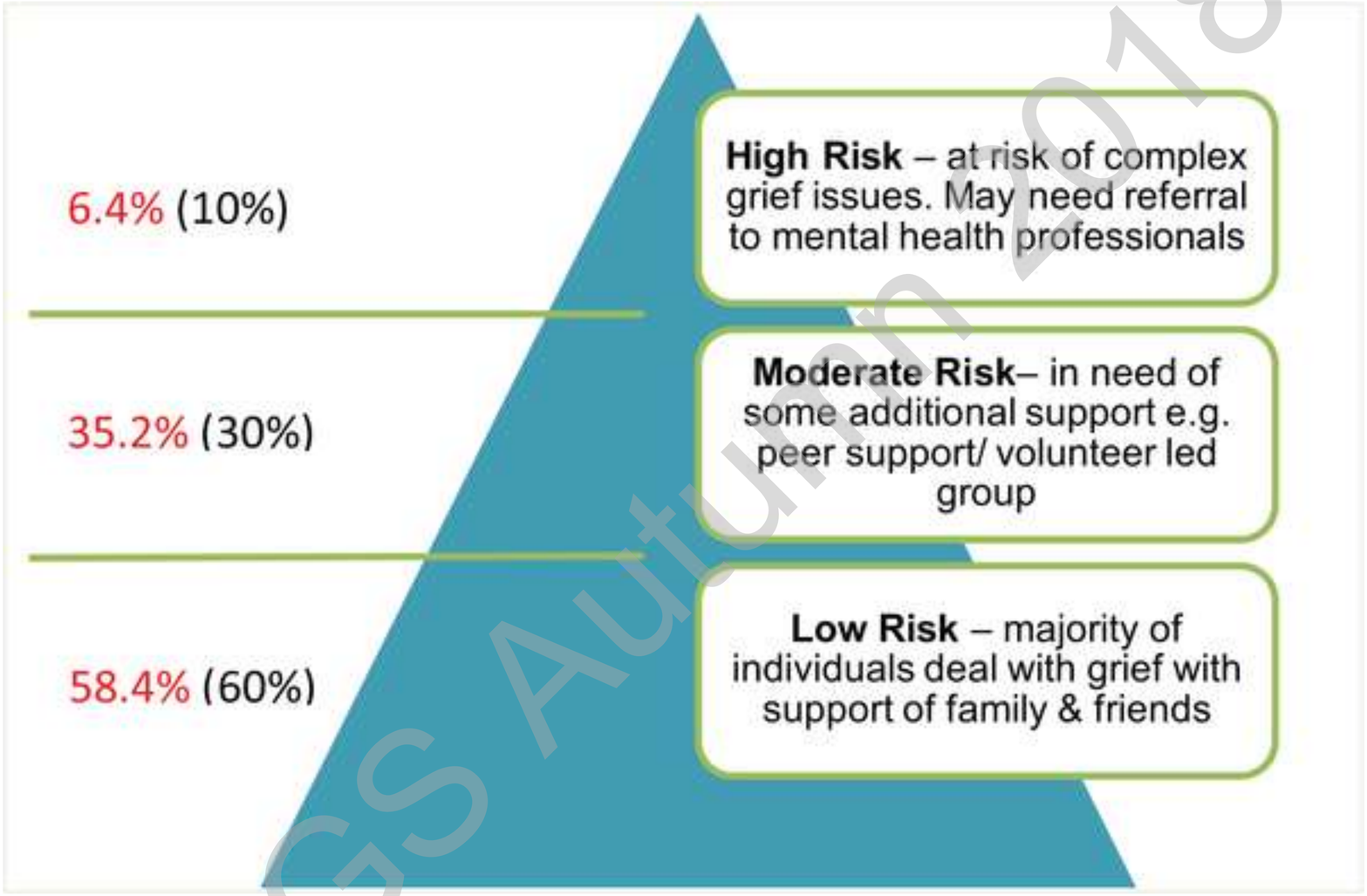
- NICE Guidance 2004 recommends three tier model: information, volunteer/self support, specialist interventions

- Almost everyone in society has experience of finding ways to live with loss. Professionals should not interrupt too soon and prevent individuals from providing their own solutions

- Most individuals and communities have a reservoir of relevant bereavement experiences and strategies to draw upon (they may need potentiating). Dangers of the professionalisation of services once performed by citizens for each other. The risk of care becoming a commodity that makes people doubt their ability to help others. (Coping repertoires of widowed can be expanded in mutual help groups. Silverman 2004)

- Counselling as a normative professional response discounts or ignores resources in existing local networks.

Fig 2. The Public Health Model: Predicted (in brackets) and Actual Proportions for the three risk groups.



Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, et al. (2015) Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need. PLOS ONE 10(3): e0121101. https://doi.org/10.1371/journal.pone.0121101
https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0121101

What can professionals do to help?

- Early proactive follow up contact (Practice Death Registry)
- Listen, acknowledge unfamiliar thoughts and emotions, share a personal memory, recognise and reinforce achievements in caring - did what could. Consider support needs and point to sources of help. Leave written information.
- Prompt and answer questions (death certificates). “I am wondering if you have any questions about...” “What is the hardest thing at the moment?” “What is important to you?”
- Be direct “Who is around for you at the moment?” If necessary get permission to help engage family, friends, neighbours
- Follow up the follow up! Consider community supports, remembering talking is not the only form of support e.g. Choir, walking group, Silverline, runners to visit housebound
- Remember there is ageism in all our services. Reassure individuals that they matter and have legitimate needs. See Independent Age
- Significance of an engaged grandparental death for children; role as memory guardians and translators in parental death
- Take self referral seriously
- If you are very concerned at any point discuss a referral, but particularly look out for prolonged disturbance of functioning

Cognitive impairment and frailty

- Number with dementia and two other conditions will double by 2030. More than 1 million over 65s will need intensive social care by 2035. Number of over 85s needing round the clock care doubles in 20 years. Spending on social care shrunk by £7billion since 2010. Social care on point of collapse in poorer areas(Lancet Public Health 2018). Individuals may have urgent care needs which need assessment and referral.

- Anticipatory grief and guilt - offer reassurance. Suggestion it is particularly associated with severe behavioural problems and institutionalisation (Meuser 2001, Holley 2010, Chan et al 2012).

- Professionals have a role with over protective family and carers. Respect individual's right to know and to mourn. Loss of cognition does not mean loss of ability to express emotions (Rando 1993, Ling 2016).

- But balance with avoiding prolonged and multiple episodes of acute distress (retraumatisation). Suggest tactics: " No he isn't/ can't be here today. Let's look at the photo album..."

- Acknowledge carer distress when confusion occurs with previous losses

Evidence on risk and efficacy

- Grief is probably naturally self limiting. Suggestion some support may be detrimental not substantiated, but little difference in outcomes for majority between no intervention and unsolicited help based on routine referral and delivered shortly after loss. Providing universal bereavement support irrespective of need neither effective nor economical. (Schut and Stroebe 2001, 2005, Breen 2012, Aoun et al 2012).

- Large cohort study of death by natural causes: acceptance predominant response from earliest weeks. Denial and anger at low levels.(Holland 2010) Prospective studies of spousal bereavement. Resilience most common pattern. Many spouses cope well in a matter of weeks. For some - relief e.g. from oppressive relationship or caring burden leads to early improvement over baseline functioning (Bonano et al 2002, 2004).

- Estimates suggest 10-20% demonstrate significant and persistent psychiatric difficulties (Prigerson et al 2009, Lobb et al 2010). Lower end - or less - now looking more accurate

- Individuals experiencing such difficulties are the most likely to benefit from (targeted) grief interventions (Rosner et al 2010, Bryant et al 2014) e.g. CBT Boelen 2007, narrative therapy and meaning reconstruction Neimeyer 2009.

- Those who seek treatment are most likely to benefit (Currier, Neimeyer, Berman 2008). Bereaved caregivers with prolonged grief disorder are less likely to seek professional help (Lichtenthal 2011). Be proactive.

When to worry - complicated grief

Generally speaking wait six months to a year before instituting formal professional therapeutic intervention

- Grief so disabling it significantly interferes with ability to function
- Persistent disbelief and inability to accept death
- Still stunned by loss and bitter over death
- Preoccupied to point of distraction by thoughts of deceased
- Feeling life completely meaningless without deceased/urge to die to join them
- Distinguishing grief and depression: share many characteristics but depression has psychomotor retardation and pervasive disturbance of self esteem and hopelessness (Shear et al 2011). Bereavement related depression in older people linked to increased age, poverty, caregiver stress, poor social support (Hashim 2013).

Resilience and factors enhancing it

(WHO 2005)

Resilient individuals tend to:

- Draw on own and others' past experiences of surviving loss
- Connect with family/ community of care
- Draw on religious/spiritual beliefs
- Identify internal and external strengths and resources
- Actively reconstruct meaning and personal identity
- Have higher levels of practical support
- Believe in a just world and find a way of accepting the death
- Gain comfort from talking about deceased

Build on community resilience and networks

- Increased interest in the importance of social relationships for health and wellbeing. (Social relationships and mortality risk - a meta analytic study Holt-Lunstad 2010)

- Increased need and diminishing resource demand a new approach. Frome model of a Compassionate Community united with primary care. When isolated people with health problems are supported by community groups and trained volunteer “health connectors”, emergency admissions to hospital fall significantly. Whole of Somerset rose by 29% during study period, Frome fell by 17%. (Abel et al 2018)

- Bereavement is associated with increased physical symptoms and increased use of medical services (Stroebe and Schut 2007). Bereavement associated with longer hospital inpatient stays/ more GP consultations, adding to cost of healthcare services by an estimated £20m per year in Scotland(Stephen et al 2015).

- Some evidence targeted therapeutic bereavement support associated with reduced use of healthcare services (Connor 1996, Relf 2000, Christakis 2003)

- Training to transfer skills, knowledge and confidence: GPs, DNs, Care home staff, social carers, volunteers

- Importance of appropriate ritual. Value of more personal approach to funerals. Individuals helped by the approval, support and fit with wider networks. Disapproval is a source of risk - e.g. for some second generation immigrants

- Need political lobbying and legislation. e.g. paid leave for carers, benefits in illness and bereavement.

“A person’s story is back filled from the past but is lived out actively into a future set in communities, in families, in circles of friends and in workplaces.”

Orla Keegan 2014

Bereavement is an experience not an illness. As a result of it many learn new skills and experience personal growth.