

AgeingWellPublicTalkSeries21-22

Disenfranchised grief in later life

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What are we talking about today?

- Grief
- Disenfranchised grief
- Five pillars of ageing well and the importance of attending to each when bereaved:
- Nutrition
- Hydration
- Physical activity
- Cognitive activity and engagement
- Social simulation

Why think about grief in an ageing context?

- The number of bereaved people aged 16 and above is set to increase by more than 100,000 people in the next 20 years, from 192,000 in 2014 to 294,000 newly bereaved people every year by 2039
- There is evidence that people over the age of 65 benefit more than working age adults from psychological therapies, but they are less likely to be referred for bereavement support.
- In fact, fewer than 1 in 5 people aged 65 and over have received bereavement counselling. (Independent Age, 2018)
- People who have experienced the death of a partner are up to four times more likely to experience depression than older people who haven't been bereaved
- More likely to have worse mental health as a result of bereavement than working age adults.
- Despite this, they are less likely to be referred for bereavement support than bereaved people who are younger. (Independent Age, 2018)

Some working definitions

- Bereavement is the period after the loss of a loved one.
- Grief refers to the psychological components of bereavement: the feelings evoked when that person dies (Huggard, 2011).

So...

- Bereavement is a state of having suffered a loss, whereas grief is a natural response to loss.
- Elizabeth Kubler-Ross proposed that grief follows a sequence of phases that includes initial shock or denial followed by anger. Subsequently, acceptance occurs prior to resolution of grief.
- However, in some cases, grief persists long after resolution should have occurred and therefore becomes abnormal.
- That is a whole other debate which is ongoing and rife...

Western society and grief

- In western society, when we talk about grief in the long term, we tend to refer to the adjustment that the bereaved person must make following their loss.
- *Usually involves developing:*
 - *A new routine,*
 - *Making new connections*
 - *Envisaging a new future and even adopting a new sense of identity.*
- *Each person has an individual response to their loss.*
- *No one way of grieving is better than another.*
- *Some people are more emotional and will explore their feelings.*
- *Others may seek distraction as a way of coping.*
- *Cultural, as well as circumstantial, factors contribute to how people express and cope with it.*

Anticipatory grief

- The grief reaction that occurs before an expected loss.
- Often experienced by those with caring responsibilities, especially carers of people with dementia.
- Diagnosis of terminal or progressive illness
- Grief has no set end point

Acute grief

- The initial response to loss
- usually intense and disruptive to the individual's life.

More on types of grief

Integrated grief

- The permanent response to grief that is long-lasting
- Often for the rest of the individual's life
- Reaching this stage of grief is dependent on the individual finding pleasure and satisfaction in life again.

Complicated grief

- A prolonged period of acute grief, which occurs when the 'normal'
- grieving process is interrupted.
- It is associated with reduced ability for coping. In some countries (not the UK) it is recognised as a distinct mental health condition.

Understanding grief has changed

- An understanding of grief has changed over time and a different interpretations can be found in the literature.
- Central to our understanding of loss emanates from Freud's seminal works on Grief and Melancholia (2017) in which grief was a process to be worked through to detach themselves from the deceased.
- The understanding of grief as a detachment process pervaded up until the 1990's.
- Then Klass et al (1996) proposed a new understanding that of continuing bonds.
- That is that the bereaved individual is restructuring the representation of the deceased in order to get on with life.
- They may talk about or refer to memories or wear an item the deceased wore.

A further understanding...

- A revised **dual process model** was then developed by **Stroebe and Schut**(1999) in which they defined two stressors that are experienced by an individual as they go through loss and restoration oriented stressors
- Oscillating between the two where they undergo the task of grieving and at other times avoids them.
- So this model argues for a small dose of grieving that is the need to take a break from grief as an essential part of adapting and coping.

The current focus...

- Much of research focuses is on grief as a response to the death of a loved one
- BUT we know that grief can be a reaction to all kinds of losses:
- loss of opportunities
- health
- identity (Bowlby, 1998).
- Partners can experience a variety of losses during the process of adapting to a life as a caregiving partner to someone with a health or life limiting condition. (Scmidt and Glintborg, 2021).

On bereaved individuals: some facts (Seymour et al, 2018)

- People over the age of 65 are more likely to experience bereavement than any other age group
- Increasing in life expectancy in the UK
- We are most likely to die in our 80s and 90s and the partners we leave behind will be of a similar age.
- More than 200,000 people will lose their partner this year.
- People aged over 65 report that losing their (often lifelong) partner, the person they would turn to for solace and support, is one of the hardest of life's transitions.

IMPACT..

- Independent Age: Good grief report by Seymour and colleagues(2018)
- Loneliness and isolation
- Mental and physical health
- Financial and practical considerations
- Feelings and grief
- Other impacts

Impact: Loneliness and isolation. (Seymour et al, 2018)

Nearly a third of bereaved people over 65 consider themselves very lonely, compared to just 5% of people of the same age who have not lost their partner.

More than 1 in 5 people said that loneliness was the hardest thing to cope with after the death of their partner.

Older people who are carers for their dying partner are at greater risk of feeling lonely both before and after their partner dies.

Family and friends are usually the route to alleviating loneliness, but for those without family, it can be difficult to know how to cope.

Impact on Mental and physical health. (Seymour et al, (2018) Good Grief Report)

Older people are more likely to have worse mental health as a result of bereavement than younger people

Older bereaved people are up to four times more likely to experience depression than non-bereaved people.

An older person whose partner has died is more likely to die in the three months following their partner's death than someone who hasn't been bereaved.

Older people's health also worsens prior to bereavement, while caring for a dying partner. Getting help can be a lottery: GPs have no standard training in assisting their patients to cope. NICE has no pathways to guide GPs.

Financial and practical considerations

- A person's ability to manage the essentials of day to day living typically decreases following their partner's death.
- Many people feel overwhelmed by the burden of dealing with multiple systems following their partner's death
- Struggle with funeral and estate costs.
- Women's household incomes fall after the death of their partner, while men tend to see their incomes increase. (Seymour et al, 2018)

Impact: Feelings and grief

- Grief more than sadness:
- Feelings of relief or release
- Anger, altered identity, confusion
- Guilt or a sense of hopelessness
- Important note! are all common and normal.

A good death means a better bereavement. (Seymour et al, 2018)

- Family members of people who plan ahead and have their wishes enacted, had fewer symptoms of:
- post-traumatic stress
- depression and anxiety after their loved one's death.
- Fewer than 1 in 5 people aged over 60 have received counselling following a death
- More than half said it was not something of interest to them.
- Nearly half of older people said that their preferred way of remembering their loved one was by talking about them.

Other reported facts... Good Grief Project

- People aged 65 > are less likely to seek help than younger bereaved people
- Organisations that provide support to people struggling with bereavement - least likely to be contacted by people aged 65 and over (unless the service specifically targets older people).
- This is despite nearly three quarters of bereaved people in England being 65 and above

WHY??

- Over a quarter of older people don't seek support even from family and friends they didn't seek any help or support at all with their bereavement, even from family or friends.
- Bereavement counsellor: people don't ask for help because they "*don't want to be a burden*" or they don't feel entitled to special help because, at a certain age, this is "*just how life goes*".
- Also less likely to be referred for bereavement support than younger people.

Yet..

- NHS England states that 56% of over 65s showed “reliable recovery” after receiving psychological therapies compared with 42% of working-age adults.

AND...

- People’s mental health needs go unrecognised (possibly because older people are less likely to recognise their own needs).
- Common assumption that people aged 65 > have the resilience to cope with loss as a “normal” part of later life.
- Also less likely to receive end-of-life care, especially in the early stages of their illness

Meet Ron..

Ron 62, from Kent,

His wife recently died after developing dementia, says, *“The dementia nurse used to come and visit every two weeks to help me understand what dementia was and see if I was alright, but the day my wife died, that stopped, and then I had no-one at all. You need someone to talk to who understands and has all the knowledge of what is available to help you.”* (Hashim et al, 2013).

- Ron’s exemplifies the impact of the severance of support
- A way of coping is to talk about things
- Access to knowledge about help erased
- Supporting Ron: think five pillars

Five pillars: Ron

- **Nutrition:** grief may decrease appetite
 - good meals even ones which can be cooked in batches
- **Hydration:** grief may lead to decreased hydration
 - think of favourite drinks (not alcohol) juice with water
- **Physical activity:**
 - Accessing green and blue spaces (parks, lakes, canals, sea) to keep supple and to increase well-being and mood. Endorphinate! Doesn't have to be a marathon
- **Cognitive:**

keeping this supple – accessing blogs, reading about similar experiences to combat isolation
- **Social simulation:**

Meeting others (support groups, walking groups, classes, forums dedicated to carers/ older people/bereaved)

Now that we have talked about grief..Disenfranchised Grief

- Disenfranchised grief is defined as “ the grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported (Doka, 2002)
- This refers to circumstances where an individual’s loss cannot or is not recognised by the person’s social group or society. There are three key elements to this form of grief:
 - There is a lack of recognition given by others to the relationship
 - There is a lack of recognition of the loss
 - There is a lack of recognition of the person suffering the loss.(Huggard, 2011: 70)

Disenfranchisement of expression

- Societies and communities establish rules that govern the extent to which we experience and express our grief.
- There are gendered rules such that men may be tasked with being stoic while women tasked with being expressing emotion.
- An expectation on time such that there is scale by which people should be over it.
- But we know that while grief may abate there are triggers such as anniversaries.
- Some deaths and relationships attract disenfranchisement such as:
 - Carer – assumed sense of relief
 - and of certain deaths such as suicide.
- There is also disenfranchisement attached to a care giving role such as an assumed sense of relief following a death that was attributable to dementia or cancer for example (Doka, 2002).
- The consequence of this is that grieving response are restricted they cannot be grieved for publicly or limited to certain individuals or groups or shut down (Thøgersen, and Glinborg ,2021)

Disenfranchise grief caregiving (MacCourt et al, 2016)

- The intensity of grief changes throughout a caregiving journey
- Grief intensifies as the disease progresses.
- While the bereavement is experienced as the death of the person that was, the losses are not always appreciated by others
- We know that if this grief is not validated or acknowledged it can become disenfranchised grief and its impact on the care giver can be debilitating and on carer burden.

Dementia care giving: the issues. (MacCourt et al, 2016).

- While care givers may be provided with practical support such as information and education that accompany care
- Emotional needs receive relatively little attention by health care services.
- In turn a lack of knowledge and identification of grief in dementia care giving further disenfranchises the carer's grief
- There also remains an absence of policies and practices which detail best practice for supporting care givers.

Canadian study: Coaching intervention

- MacCourt et al (2016) undertook research in Canada in which they developed a coaching intervention to provide support in face-to-face, online and telephone six week support sessions. Session content included
- Introduction to transitions
- Dimensions of grief
- Living with grief
- Honouring grief
- Marinating self
- Enhancing resilience (in two back up sessions)

Findings... what can we learn

- Findings indicate that coaching resulted in increased coping and resilience and less grief for those who received the coaching.
- But...participants who reported increased coping tended to be less distressed before the coaching
- This means they would have more strength to bring to the coaching sessions when exploring their grief.
- Limit in using this elsewhere..
- The coaching sessions were led by a clinician who was skilled and experienced in dementia care, grieving and coaching.
- A further limit....
- The study lacked diversity in terms of people who took part lacking in recruitment from different ethnic and socio economic background which can influence caregivers resilience and empowerment.

Asking for help...

- Survey conducted by Davies et al, August 2021
- Grieving people tend to find it difficult to ask for help, even from close family members.
- Not wanting to be a burden
- Tendency of families to dismiss psychological symptoms
- Underestimate the severity of distress or diminishing signs (unkempt appearance, loss of weight)

- Regularly check on older people and associated distress

Davies et al, 2021

- Just 4% of people aged 65 and over who had been bereaved in the past five years sought extra support, compared with 9% of adults aged under 65
- Only 20% of over 65s who had been bereaved in the past five years were given information about emotional support after the bereavement
- Of the 8% of adults of all ages who sought extra support following a bereavement, just over half (57%) went on to receive it in a reasonable timeframe.
- Just over a tenth (12%) were not able to access support at all
- 7% said that they were still waiting for support at the time

Meet Zainab

Zainab lives in the north west of England. She was married to Ayshir for 20 years. Ayshir had Motor Neurone Disease which led to many trips in and out of hospital and eventually to a hospice where he later died. This caused Zainab an enormous sense of guilt as she had vowed to care for Ayshir in his final days.

Zainab experienced a traumatic bereavement as she tried to negotiate a life without him. The loneliness was overwhelming as she had centred on Ayshir's care and was now at a loss about how to spend her time.

While family were supportive, she was desperate to hear his Ayshir's voice as well as to have a presence around her as she had never lived on her own. She continued to feel guilt, sadness, regret and loneliness and she felt the need to talk.

While her family were very supportive in the few weeks that followed Ayshir's death, they were beginning to find Zainab's grief overwhelming and would be dismissive of her feelings or when she talked about how she felt instead trying to instil positive comments such as : "it is still early days."

While well meaning Zainab didn't feel like she could express how she felt and was left feeling as though how she was, was somehow abnormal.

Getting help

- Eventually, Zainab sought help through grief counselling. Ayshir had received care from a hospice where Zainab was aware counselling was offered. She contacted them and found that she was able to talk without judgement which enabled her to explore all her feelings.
- Zainab felt listened to and had her feelings acknowledged. Zainab was reassured that what she was experiencing was normal and that what works for one person may not be suitable for another.

- Zainab's case demonstrates the importance of being acknowledged. Her grief was harder to deal with when she wasn't able to talk about it with family. Zainab's situation also serves as a reminder that bereavement can take time and can be a long process of gradual adaptation.

Why is it difficult to talk about grief?

- Independent Age: Dealing with Difficult Conversations (2016)
- People feel they lack the knowledge and confidence to begin a conversation.
- They worry about the reaction of family members.
- People want to avoid facing undesirable possibilities.
- They feel the time is not right.
- Attempts are hindered by distance or a lack of time for discussion.

Meet Jenny

Jenny is 66 and lives in South West England. Her sister, Julie died of a heart attack this year aged 60. Jenny had been her carer for the last five years. While Julie had a number of long term health conditions, her death was unexpected and was felt as a shock.

Jenny struggled with feelings of guilt as she had not been able to check in on her sister as she was working night shifts in a local nursing home. She felt especially guilty as her sister had died on her own. Jenny was someone who wanted to seek out help as there were no family members to draw on support from. As she was involved with her local church she decided to join the support group which met once a fortnight. She found being surrounded by other people's grief overwhelming and turned to online support forums that were specifically supported sibling grief. She found reading and posting on the forum helpful as others expressed similar feelings.

So what support is out there???

Getting help: a lottery

- While the GP is often the first port of call when grief feels unmanageable
- GP's receive no standard training
- No NICE Pathways for grief for GPs to refer
- Some GP's signpost/others don't (Seymour et al, 2018).
- Feelings not taken seriously
- Lack of options despite suicidal thoughts

What helps? Death Cafes

- The purpose of a death café is “to increase awareness of death with a view to helping people make the most of their (finite) lives”.
- Thousands of death café events have taken place across 48 countries (mostly in Europe and America).
- Death cafés give “permission” for people to talk about what can be considered a taboo topic in a relaxed setting.
- Conversations can range from living wills and power of attorney to funerals, last words of loved ones and being around dead bodies. (Davies et al, 2021)

Again, what helps...

- Hobbies and interests to combat loneliness
- Volunteering (sense of routine and social contact)
- Walking in nature
- Friendship services (Independent Age, Age Concern)
- Mindfulness (more to come)

Recommendations (Seymour et al, 2018)

- **Everyone** in later life to access informal and formal types of support they need to help them cope with a bereavement.
- To do this...
- **Improved leadership** and coordination at multiple levels to improve access to bereavement support
- **Government led** strategy for the whole system of bereavement support that outlines responsibilities and sets out a plan for how more investment will be secured.
- A named bereavement lead within **each integrated care system** (ICS) structure
- A named bereavement lead within **NHS England**.
- Improved **signposting** to support options,
- Health and care professionals to **play a key role** in this signposting
- HCP **awareness** of the factors that may make an individual likely to need extra support after a bereavement
- Especially those **socially isolated** or having had **caring responsibilities** for the person who died.

Beyond professionals...

- Information about bereavement support should be readily available in all those places:
 - supermarkets
 - libraries
 - hairdressers
 - faith centres.
- A bigger focus on tackling loneliness as one way to support people bereaved in later life
- Activities that reconnect people and build up their social contact are a key part of an effective response to the challenge of bereavement for some people in later life.

Key messages

- Not one size fits all
- People grieve differently
- Seek support that best suits your needs
- Seek out like mind others to share experiences
- Keep well, active, stimulated, hydrated

Thank you for joining today!

We will be in touch to get your feedback Kerry.jones@open.ac.uk [DR Kerry Jones](#)

The next talk will be on: 'Nutritional needs while ageing' 23rd February 2022.

Venue: online webinars via Microsoft Teams, talks held 11AM-1PM

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Podcasts

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- [Vseteckova J & Broad E \(2020\) Keep Me Walking - researching with people living with dementia and their carers - Podcast – Open University in collaboration with The Parks Trust](#)
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- [Broad E & Methley A & Vseteckova J \(2021\) Podcast OU & The Parks Trust & Northamptonshire Healthcare NHS Foundation Trust - Spotter sheet and mindful walking.](#)
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