WHAT IS IT LIKE TO EXPERIENCE THE LOSS OF AN ADULT CHILD IN OLD AGE?

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In this study I relate some events around my father's death that were difficult for my whole family. The perspectives and beliefs represented here are my own, and may be different to those of other family members involved, whom I have decided not to mention but who, as individuals, were very supportive to me throughout that time.

If I could spare his life
If I could trade his life for mine
He'd be standing here right now
And you would smile, and that would be enough

Lin-Manuel Miranda*, Hamilton The Musical*

Death, there's no need to ask:
A mother will always lift a child
As a rhizome
Must lift up a flower

Helen Dunmore, *Inside the Wave*

Her last words to me were,
'I'm so sorry Mum',
and I didn't know what that was about.
And I didn't know what to say.
I should have just said, 'I love you'.

Ann, Participant 3

Abstract

Being bereaved of a child is one of the worst life events that can happen to a person. When the death happens as that person approaches very old age, at a time of life when other losses are common, the risks of mental and physical health problems, and even dying, increase. Despite this, relatively little else is known about the experience of losing a child in old age and of how older people understand and cope with their experience.

As part of this narrative inquiry, three stories were produced which stand on their own to represent different experiences of bereaved older parents. The participants were UK-based and 79-82 years of age. All had lost their middle-aged son or daughter less than two years previously. Their stories are analysed in the light of the silencing effect of society's preference for redemption and restoration narratives (Frank, 2010; McAdams, 2013) which act to deny the possibility of death. They are also examined in terms of the unique motivational perspective of an older parent heading into very old age.

According to Stroebe and Schut's (1999) Dual Process Model of Coping with Bereavement (DPM), people divide their attention between loss-oriented and restoration-oriented stressors (as well as having time off from both) in a process called oscillation. In recent years, the DPM has been modified to recognise the importance of both interpersonal factors (Stroebe and Schut, 2015) and overload (Stroebe and Schut, 2016) in bereavement. Despite the popular notion of old age as a time of quiet contemplation, these stories could in this regard be read as cries for help.

Suggestions are made for further research.

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Prologue

This is a study about the loss of a child in very old age, inspired by events surrounding the death of my middle-aged father when I was 23. For my family his death changed the world forever. But the cruelest aspect of it seemed to be that his two elderly parents (who had no other children) were left behind.

A fortnight after he died, and a few days after the funeral, my grandfather died too, of heart failure. I cannot know what he was thinking about my father’s death, or the emotions surrounding it. I remember him being very quiet. My grandmother lived another 10 years, struggling with loneliness and frequent tearfulness, but speaking very little about their deaths. She had a history of losses - her mother when she was 16, her younger brother in World War 2 – but as she grew older her story became one of bettering herself, broadening her horizons and raising a son who excelled at school and university, moving into Britain’s middle class. She was very proud of him for doing so: these upward trajectories were based on the implicit cultural narratives of self-improvement and self-realisation by which I believe, like many of us, she had come to measure success.

I remember her during the 10 years after my father and grandfather died as becoming tearful every time I left after a visit. What was she to make of this reversal of fortune, if there was any sense to be made of it? She was a widow, along with many of her friends and acquaintances. But what happened to her identity as a mother? She mentioned once that she felt guilty – for what? I wish I had encouraged her to say more, to speak openly. Perhaps I was scared to stir up feelings she might not be able to cope with. Did she miss out on emotional support because people like me feared she might be too old and fragile to benefit from it? And if so, were such judgements based on any evidence, or on assumptions borne of cultural narratives around ageing, that cast her as a powerless victim of circumstances, instead of a thinking, breathing agent in her own life, with as much right as anyone else to rewrite her story? Did we all suffer from a kind of narrative foreshortening – the assumption that this was the end of her story?

I wonder what she might have made of her story had she been able to tell it in psychological therapy. Would she have developed a greater sense of her own resilience in having survived such enormous losses?

Given that she never had this chance, this is a depressingly bleak start to a research study. So I want to balance it with another picture of old age – one I saw manifest in my other grandmother, who worked into her 80s and lived into her late 90s, remaining intellectually curious and active, and only becoming physically frail in her last few years. She had never had much money, and had worked exceptionally hard all her life (both a day and an evening job for several decades) but genetics was on her side, and she had a curiosity and mental energy that was barely diminished even at the very end. This 'vital engagement' (Laceulle, 2018) strikes me as the marker of a good life at any age.

It is the contrast between these two that impresses me.   Much of the difference can be put down to luck and bad, or good, timing. Nevertheless, having known and enjoyed the company of an individual who enjoyed her old age, I am impressed by the opportunities for reflection and growth towards the end of life, which deserve to be recognized, acknowledged and, as far as possible, enjoyed by all of us.

Chapter 1: Introduction

Our population is ageing (Office for National Statistics, 2018). According to John Beard, Director of the Department of Ageing and Life Course at the World Health Organisation, ‘for the first time in human history, it is becoming normal to experience ‘old’ old age’ (Age UK, 2013). The 85+ age group – sometimes known as the ‘oldest old’ or the ‘fourth age’ – is the fastest growing section of the population in the UK. Currently 1.6 million, it is expected to more than double to 3.6 million by 2039 (Office for National Statistics, 2014, 2018), with a corresponding increase in mental health issues including depression (McCrone et al, 2008). The very oldest members of the population have traditionally been excluded from research for reasons of convenience: they are perceived to be harder to research because of their physical limitations and slower thinking. But it is now widely recognised that older people’s mental health is under-recognised and under-treated. Older people struggle to access parity of support with other age groups. They are more likely to be given drug therapies and less likely to receive talking therapies than other age groups. Fewer than one in six older people with depression ever discuss it with their GP (NHS Older People’s Mental Health and Dementia, 2017). We urgently need to understand better the factors affecting wellbeing in older age.

Old age used to start at retirement but, with increasing life expectancy and better health status, there is now a delay and old age proper seems to start around the age of 75, being widely regarded as the ‘end of the story’ in human lives. Even when 20 years are still to be lived, the ‘action’ is regarded as happening amongst younger people, with older people often seen as extraneous to society. We need to shine the spotlight on old age if it is to be given some value. One place to start could be to find ways of countering the idea that nothing much happens in old age, and that it is just a quiet descent into decrepitude.

The theme of loss is prominent in the stories of many therapy clients but the loss of a child in particular has been described as one of the worst things that can happen to parents of any age, placing them at increased risk of a range of psychological symptoms for the rest of their lives (Arnold et al, 2005). Losses in general are more common in old age with direct consequences for health: people over 75 show a greater susceptibility to infection in response to a loss, as measured by their levels of neutrophils and stress hormones (Vitlic et al, 2014), while the loss of a son or daughter in old age is a neglected area of research, despite being included as a general risk factor for complicated grief or Persistent Complex Bereavement Disorder in the DSM-5 (American Psychiatric Association, 2013). In addition, the loss of a child has different practical consequences from, say, the loss of a spouse. For example, statistically, age 80 is a turning point in terms of dependency: it is the age at which, on average, people start to receive more practical help from their children than they are able to give in return (Centre for Policy on Ageing, 2014). For those on the brink of such a change when their child dies, their sense of the future may be profoundly shaken.

Some of the barriers to researching older people's experience, and this type of loss in particular, are reflected in discussions I have had with colleagues over the past few years: One of them warned me off trying to research this age group, because illness and memory problems would mean they could not keep appointments. Others have pointed out that age should make no difference to how we understand or treat a person so there is no reason to study it separately (I agree somewhat with the first point, but argue that studying it separately is important for challenging assumptions). One senior colleague called my interest 'niche' – an interesting description given the growing concern about how we are going to look after our population of older people in future. In addition, on the loss of a child, it has been suggested to me that losing a middle-aged child in old age must surely be less painful than losing a younger one. Whether or not you agreed with the merits of trying to construct a hierarchy of loss in this way, on what can we base this last assumption? There is empirical evidence (Wijngaards-de Meiij et al, 2005) as well as anecdotal evidence which contradicts it: I have my own experience of my grandfather dying within days of my father, and many of us remember the 84 year-old actor Debbie Reynolds dying just a day after her daughter Carrie Fisher in 2016.

To be fair, underlying some of these concerns may be a resistance to treating older people differently and therefore perpetuating stereotypes about old age – arguably the very reason older people's needs get missed in the first place. Baars (2012) says, 'It may seem useful to generalize about 60 or 65 year-olds for certain policy purposes, but such "aged" persons are very different; not only as unique persons but even on major empirical indicators such as income, life expectancy and health'. Precise measurements of somebody's chronometric age are not very informative about that person's ageing process.

Nevertheless, understanding ageing remains vital for policy makers, and all of us, because of the demographic changes that are happening now. Older people need to be properly integrated into society as individuals who have simply lived a long time, rather than being labeled solely on the basis of a group identity, the boundaries of which are unclear. Changing attitudes means changing minds. At present older people are not only portrayed in the media as a future burden: It is frequently suggested they are living in luxury compared to their younger counterparts, when in fact a large proportion of over 80s are living below the poverty line (Independent Age, 2016).

My research aims to give voice to individuals themselves, faced with bereavement, as they enter this last phase of life. It will also offer a nuanced picture of their experience, increasing our knowledge and presenting an opportunity to look at the important issue of adaptation to change in old age (Wortman and Boerner, 2011).

Chapter 2: Literature review

In this chapter, I will review the literature related to my question, focusing firstly on old age, and then looking at work which sheds light on the experience of bereavement in general, on bereavement of a child, and then on the more specific loss of an adult child. In each case I will first examine my possible assumptions.

2.1 Old age:

2.1.1 Possible assumptions

The treatment of older people is an emotive topic, and relates to my sense of every person deserving attention and justice, irrespective of creed, colour, gender, sexuality or age. I take for granted that it is good for society to be inclusive and egalitarian, and I have chosen a methodological approach which allows me to offer an openly-expressed normative philosophical attitude: Old age can and should be a good and rewarding time of life and this is something we as a society and as individuals (of all ages) need to strive for.

As a white, middle-aged, heterosexual woman I have so far escaped a lot of society's prejudices. Some deservedly garner a lot of attention, less so ageism, and I feel strongly that this leads to injustice, not least because I have seen it perpetrated against members of my own family. These incidents happened in a hospital context where any prejudice manifests itself more obviously because the stakes are so high: for example, I have witnessed hallucinatory symptoms being dismissed as a geriatric reaction to drugs without any further examination (it later turned out to be septicemia), and a man dying of heart failure (my grandfather, mentioned earlier) after his symptoms were dismissed as a stomach bug, even though he was unable to walk. Admittedly these incidents happened in the 1990s, and there is now more awareness of age discrimination in the NHS (Clark, 2009). However, we cannot afford to be complacent. A recent report (Cooper et al, 2018) found evidence of abuse and neglect in all but one of 92 carehomes. According to historian Mary Beard our dangerous and dehumanizing attitudes will eventually be seen as such:

> My guess is that in a few hundred years time, the treatment of the frail old in 21st century Britain will be seen as much of a blot on our culture as Bedlam and the madhouses were on the culture of the 18th century. There will be many books and PhD theses written on how, and why, we got it so wrong. (Beard, 2014)

All this is not to deny that increasing age brings mental and physical changes, and the challenges associated with these. But in order to look at these changes in a nuanced way we have to negotiate ‘the moral and psychological implications of the narrative ideas we have been inserting into our heads since we were very young indeed’ (Gulette, 2004, p11) and open our minds to other possibilities. We need to make room for the *advantages* and inherent strengths of older people, and unearth new narratives around ageing (Laceuelle, 2018) through a more experience-focussed approach to research, closer to existing biographical or autobiographical literature, so we can begin to build a more balanced picture of old age with the stories we find there. By way of example, the writer Diana Athill, writing in her 90s, relates how in her mid 70s she ceased to think about herself as a sexual being, and after a ‘short period of shock’, found a new sort of freedom:

> This realization was extraordinary. It was like coming out onto a high plateau, into clear, fresh air, far above the antlike bustle going on down below me … In the course of the ninety-seven years through which I have lived I have collected many more images of beautiful places and things than I realized, and now it seems as though they are jostling to float into my mind. (Athill, 2016, p2)

2.1.2 Literature about old age

The characteristics of people in their 80s upwards tend to have been under-researched in all areas – medical, social and psychological – with their automatic exclusion from surveys being because ‘they are likely to be frail, cognitively impaired and generally harder to contact than younger age groups’ (Age UK, 2013). However, this situation has altered radically in the last 10-15 years, as evidenced by the increased number of studies being undertaken in this area, uncovering a greater than expected level of robustness in older people. For example, the Newcastle 85+ study (which focuses largely on medical issues) recruited over 1000 individuals to their longitudinal study starting in 2006. At the start of the study a full eighty percent of this group of 1042 people aged 85+ needed little care and rated their quality of life as good or excellent (Collerton et al, 2009), suggesting that age should not be an automatic barrier to participation in research.

However, the reality seems to be that most of us are vulnerable to prejudices about old age. Such thoughts might be self-protective. Ageing seems to tap into our deepest unconscious about the end of life and we therefore do our best to minimise our identification with the oldest people. For example, Terry (2008) has discussed how projective processes — which result in infantilisation of older clients in care homes, for example — may operate to protect carers or relatives from the reality of their own sense of helplessness and fear of old age. A darker interpretation of ageism might be that society balks at the potential expense of an ageing population, and unconsciously and conveniently forgets they exist.

While there is a reality to some physical and mental changes before death, it is hard to disentangle these from the impact of society's attitudes and from the attitudes of older people themselves, who may have lifelong prejudices about their worth in old age. Athill (2016, p108), arriving in an institution in her 90s, unashamedly reveals her prejudice about a fellow resident when she writes: 'I'd been surprised to discover how interesting one very old resident, who looked as though she was almost past communication, turned out to be'. Such attitudes are far from harmless: It seems they may even be implicated in the development of depression (Laidlaw, 2010). The concept of internalized prejudice or oppression applies to older people in a particularly interesting way because their attitudes were originally formed in younger versions of themselves: this may make attitudes particularly resistant to change.

More worryingly it seems that age prejudice itself is in danger of being overlooked. Murphy's (2017) textbook on Counselling Psychology has a section on socio-cultural issues including chapters on sexualities, social class, race and ethnicity, and gender, but nothing about age. If ageing people in general are at risk of being sidelined then the current generation of older people may be particularly at risk. Britain's oldest people are part of the so-called 'Silent Generation' born before 1946 – a termed widely believed to have been coined on Nov 1951 by Time Magazine in an article called 'People: The Younger Generation'. The term referred to this generation's tendency to work hard and stick to the rules, instead of speaking out to bring about social change. They have lived through World War II and the struggles of families to reintegrate after it ended, when the men came home. On the other hand they have seen dramatic scientific and medical advances, and have gradually transferred their faith in the church to a faith in other institutions including science, the modern family as an enduring unit (as it became in the 1950s) and the NHS (established in 1948). They have also seen their babyboomer and Generation X children grow up richer than themselves. A striking 2016 report, “The overlooked over-75s: Poverty among the ‘Silent Generation’ who lived through the Second World War” (Independent Age, 2016) characterises them as the ‘make do and mend’ generation who are reluctant to ask for help and avoid making a fuss.

These characteristics and the narratives associated with them sit in stark contrast to popular societal narratives of individualism and progress. It seems quantitative psychological and social research reported in the press is playing its part in distorting progress narratives to accommodate old age and perpetuate the idea that life just gets better and better (albeit in an attempt to replace the cliché of the crotchety old man). Headlines such as ‘Emotional Fitness in Aging: Older is Happier’ (American Psychological Association, 2005) and ‘Emotional Stability and Happiness increase with Age’ (PsychCentral, 2019) give the impression that individuals can enjoy a steadily trajectory upwards in this regard. The outcome of one counselling psychology study characterized the central process of therapy for older people as ‘finding equanimity’ (McIntosh, M. and Sykes, C., 2016). A strengths-based approach which reconnects counselling psychology with positive psychology may be valuable (Steffan, Vossler and Joseph, 2015) but there seems no reason to suspect older people have any more or less need to find equanimity than younger people.

Laceulle (2018) has written about the dominance and popularity of the narrative of self-realisation in modern times, which tends to exclude older people, whose narrative resources are either of decline (Gullette, 2004) or of defying age altogether (for example, going parachuting or having rejuvenating plastic surgery). For Laceulle, it is our failure to integrate the notion of *existential vulnerability* with self-realisation that contributes to giving ageing its association with decline and decay. She asks:

> How does the typical late modern discourse on self-realization, with its emphasis on autonomous choice and authentic fulfillment of one's aspirations and capacities, relate to the existential reality of ageing, in particular the fundamental fragility of the human condition and the growing vulnerability one is confronted with in later life? (Laceulle, 2018, p17)

Her work distinguishes between progress narratives, and what Laceulle calls 'narratives of becoming' which involve developing an optimal attitude to whatever we may encounter in life, and using these experiences in the service of a continuing process of moral self-development. In other words, there is a *continuing* (and therefore lifelong) process of working on ourselves to actualize our best potentialities, whilst not denying the reality that life can be very difficult. Quoted by Laceulle, Cruikshank (2003, p7) says, "Learning to be old may be the last emotional and spiritual challenge we can agree to take on".

It is time we put the views of this age group at the centre of our understanding, to develop a new narrative around the fourth age (Bazalgette et al, 2011). John Beard from the World Health Organisation (quoted in Age UK, 2013) suggests we may all need to shed some of the preconceptions we hold about this fourth age if we are to create the sort of world we would all want to live in as 90-year-olds. This project aims to explore and give voice to the experience of having to adapt to extreme and unexpected loss in old age.

Baars (2012) has distinguished three different discourses about old age – senescence, older people as a social category and ageing as a social-existential process of living in time. It is the third category to which I hope this project will contribute, by enriching our knowledge of life in older age, thereby suggesting how we might live well as older people. As Erikson (1997, p114) wrote, 'Lacking a culturally viable ideal of old age, our civilization does not really harbor a concept of the whole of life'.

2.2 Bereavement:

2.2.1 Possible assumptions

When I first became interested in this research topic many years ago, it was because I wondered, how does somebody so close to the end of their own life survive such a painful event — the death of their child?

Wortman and Boerner (2011) have identified five assumptions about bereavement which form a useful checklist against which to examine my own. The first is that bereaved people exhibit significant distress, and the 'failure' to exhibit such distress indicates a problem (for example, it may forecast a delayed grief reaction). A related second assumption is that positive emotions after a bereavement imply people are covering up or denying their distress. And a third assumption is that the bereaved must confront and 'work through' their feelings about the loss. I am aware, perhaps due to my training as a psychotherapist and my beliefs about the benefits of 'exploration', that I share these first three assumptions to some degree, without necessarily having good reason to do so, particularly given the growing literature on the interaction between the bereavement response and characteristics of both the bereaved individual and his or her relationship with the deceased person (Jerga et al, 2011). On reflection, I have seen a wide range of reactions to loss; it would be surprising if a bereaved person did not have their own, idiosyncratic coping mechanisms. Wortman and Boerner's fourth identified assumption is that bereaved people must break down their attachment to the deceased. Starting with Freud (1917), several writers suggested it was necessary to disengage with the deceased to go forward with normal life, but the last 25 years have seen a growing recognition of the importance of a continuing relationship with the deceased person. Klass et al (1996) in their groundbreaking book 'Continuing Bonds' wrote that their training as therapists had led them to expect grief resolution to involve the breaking of attachment bonds to the dead person. Instead they found memories of the dead person and a continuing relationship with them provided comfort and support to the bereaved. The fifth assumption is that within a year or two after the death, the bereaved person will have recovered and be able to resume their previous level of functioning. Evidence shows the length of grief reactions are in fact extremely variable, and highly dependent on the context in which the death occurs. For example, caregivers who experience the most difficulty whilst caring for a dying person often quickly rebound to high levels of functioning after the loss (Schulz et al, 2003), whereas the majority of parents whose child dies suddenly still show symptoms of PTSD five years after the event (Murphy et al, 2002). Generalisations are therefore difficult, and it is impossible to judge how well a person may or may not have adjusted to a loss purely on the basis of the time which has elapsed since the death.

A further possible assumption (borne of my own experience) is that a bereavement is necessarily negative. In fact, as Schulz et al's study (mentioned above) suggests, it may be that a death brings relief, perhaps ending years of suffering for the person who has died, or bringing to a close a relationship fraught with difficulties.

2.2.2 Theories of bereavement

> 'Moving on, as a concept, is for stupid people, because any sensible person knows grief is a long-term project. I refuse to rush. The pain that is thrust upon us let no man slow or speed or fix.'
>
> Max Porter, *Grief is the Thing with Feathers*

I originally entitled this section 'Theories of Grief'. However, the term 'grief' seems to me to imply sadness and not necessarily to capture the range of emotions bereaved people experience in response to a loss. The writer Virginia Ironside (1996, pg xii) condemns attempts to make generalisations about this deeply personal process, calling the idea that bereavements can be worked through a 'pernicious fantasy' leading only to disappointment 'when things don't work out like the fairy stories we've been fed'. Nevertheless, theory can be useful in guiding expectations and increasing the range of possible futures, particularly in grief, when clients may present with strong feelings of anxiety or hopelessness about the future. In my experience of bereavement counselling in a hospice, a frequent but unanswerable question is, 'How long will this last?'.

Historically, grief has been described as a series of stages. For example, Freud, writing a hundred years ago, wrote about a passage through stages during which ties to the lost person were gradually broken. Later Kubler-Ross (1969) identified a series of five stages: the first shock and denial, the second anger, resentment and guilt, the third bargaining, the fourth depression and the fifth acceptance. It was necessary to pass through all of these stages, and if any were missed, then pathology would result. Useful as this stage theory was in normalizing the huge range of emotional responses to grief, it left limited room for individual differences, and did not seem to be borne out by research evidence, although worryingly many health professionals still subscribe to it (Stroebe et al, 2017).

Newer theories of grief tend to portray bereaved people as *active agents*, working towards regaining a normal life, rather than just passing through stages. They also recognize a distinction between recovering from the pain of the loss, and adjusting to life without the person. In Worden's (2009) Task-based model a grieving person is engaged in four tasks: accepting the reality of the loss, processing the pain of the grief, adjusting to a world without the deceased and finding an enduring connection with the deceased in the midst of embarking on a new life.

While Worden's model implicitly assumes that grieving people move between different tasks as part of the process of grieving, the Dual-Process Model of Stroebe and Schut (1997, 2010) gives a central role to the regulation of this process as part of a return to normal functioning. This model describe the grieving person as *oscillating* between two different modes of functioning – 'loss orientation' (usually but not necessarily involving emotion-focused coping, for example planting a tree in someone's memory) and 'restoration orientation' in which there is mainly problem-focused coping and attention to life's ongoing demands. It is clear that this latter demand will vary widely in the context of an older peson losing a middle-aged child: life for someone who was living with that child will very likely be radically altered by the death, whereas someone used to a daily phone call may not find their routine as disrupted by the loss. This appears to render the Dual-Process Model's distinction between loss- and restoration-focused activity less immediately relevant for people who do not live with or have prolonged daily involvement with the person who has died. In this case, both loss- and restoration-focused activity may be around the loss of the practical and emotional 'safety net' a son or daughter can provide.

Stroebe and Schut's model moves grieving away from a medical model of healing a wound, and towards the idea of a person gradually adjusting to life without the physical presence of the deceased person, in whatever form they find helpful. In other words, an ongoing relationship with the person who has died is normal, and its development is an important aspect of healthy grieving. This relationship is captured by the concept of Continuing Bonds, which has spurred a considerable literature since it was first discussed (Klass, Silverman and Nickman, 1996; Klass and Steffen, 2018). In the DPM model, Continuing Bonds are the result of work done in the loss-orientation phase of the oscillation (Stroebe, Schut and Boerner, 2010).

A further model is the Two Track Model of Bereavement (Rubin, 1981; Rubin et al, 2012) which sets out an adaptive process mediated by two interactive sets of variables – the first representing biopsychosocial functioning (physical and mental health, employment status) and the second the nature of the ongoing emotional attachment and relationship to the person who has died (continuing bonds). This model emphasises the nature of the prior relationship with the deceased person as being the key to understanding variations in people’s response to bereavement. As Kosminsky (2018) emphasises, ‘Given the considerable variations in the quality of people’s attachments to the deceased … the question .. is not whether CB are helpful or unhelpful in adaption to loss, but rather when and how they are helpful or unhelpful’.

2.2.3 Complicated grief

Normal grief has been described as, ‘a bewildering mixture and wide range of painful feelings that rise and fall in waves, like a rollercoaster …’, diminishing in intensity after about six months, in contrast to complicated grief, when you ‘fall apart and remain broken. There is little or no respite.’ (Davis, 2012.) Such complicated grief occurs when a person remains stuck in their grief and preoccupied by thoughts and images of the deceased, almost as if the loss has just happened. The distinction between normal and pathological grieving has prompted a great deal of controversy over the years, particularly in relation to changes to the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), which both removes the bereavement exclusion from the diagnosis of major depression (even shortly after a death), and includes a new diagnosis under ‘conditions for further study’ called ‘Persistent Complex Bereavement Disorder’ (widely regarded as equivalent to Complicated Grief). Said to occur in up to 5% of bereaved adults, this is defined as a combination of separation distress and cognitive, emotional and behavioural symptoms that develop after a death and continue for more than 12 months, including longing for the diseased, preoccupation with the circumstances of the death, bitterness or anger related to the loss, a sense of diminished identity, and a difficulty or reluctance in planning for the future. The controversy over diagnoses has arisen partly because of concern that diagnosed individuals might be over-medicated, disturbing a ‘normal’ process of adjustment and reengagement with life, and that they might also suffer prejudice because of being labelled with a mental illness. On the other hand, these diagnoses recognise that depression and complicated grief are not just ‘normal’ phenomena that will ameliorate with time. Shear et al (2011) observe that many of their research participants had spent years on ‘treatment odysseys’ being told by clinicians that ‘they were coping as well as could be expected because their loss was very difficult’. In a case study which demonstrated the value of a diagnosis focusing on bereavement (written prior to its inclusion in DSM-5), Woerner (2010) emphasized the delicate intrapersonal dynamics which may unconsciously motivate someone to continue grieving: their perceived continuing bond with the deceased, self-punishment because of guilt at the death, and the gaining of sympathy which they fear will dissipate if they improve. Similarly to this identification of Persistent Complex Bereavement Disorder in the DSM-V, a condition called Prolonged Grief Disorder is included in the 11th edition of the International Classification of Diseases (World Health Organisation, 2019).

Research into Complicated Grief has provided some interesting insights into the psychology of loss and subsequent failure to readjust to life, suggesting that it is a disorder separate from others like PTSD and depression, and even suggesting possible links to addiction and reward. For example, one research team (O’Connor et al, 2008) scanned the brains of people who had lost a relative to breast cancer, and found complicated grief was associated with persistent activity in the nucleus accumbens (the ‘reward centre’ of the brain) as if the individual was continually seeking the reward of contact with loved ones, whereas more ‘normal’ grievers had activity in the emotional and memory areas of the brain.

The concept of Complicated Grief is still relatively new, but evidence is accruing for the usefulness of screening tools which can highlight established risk factors like multiple losses (Delaney et al, 2017). In a review of the empirical literature on risk factors for complicated grief, Burke and Neimeyer (2013) point out that some of the research in this area confounds causes with correlates and consequences of complicated grief. In a review focusing only on studies using prospective designs, they identified 14 predictive factors, including being a spouse or parent of the deceased, low social support, lack of family cohesion, having an insecure attachment style, scoring high on neuroticism, and being unable to make sense of the loss. It is likely these factors may vary across age groups and some researchers have addressed these issues. For example, in a study of elderly spouses, Bonnano et al (2002) showed no link between neuroticism and grieving.

2.2.4 Meaning making and continuing bonds

As Worden's (2009) fourth stage emphasizes, theories of grief have gradually moved away from an emphasis on detachment from the deceased, and towards an acceptance of the importance of establishing continuing bonds with the dead person. At the same time, there has been great interest in meaning-making after a death and in particular two processes in the wake of loss: *sense-making,* which is the thinking processes engaged in to understand the loss and integrate it into a personal worldview, for example, to understand the cause of death, and *benefit-finding*, which involves discovering positive consequences, like increased compassion (eg Neimeyer, 2011). While sense-making involves finding consistency between the bereaved person's perspective of life and the loss, for example coming to understand why the person became ill, benefit-finding involves understanding the more positive consequences of the loss such as new perspectives and a strengthening of remaining relationships.

What is less clear is the impact of these meaning-making activities on the trajectory of the grief response, and the bereaved person's ability to adapt to normal life again. It seems that for some people, but perhaps not all, finding meaning is extremely important, and failure to do so can lead to a pathological grief reaction (Neimeyer, 2011). While establishing causality is not the goal of qualitative research, further qualitative exploration of the way recovery and adaptation unfold in the context of individual lives may contribute to producing a more nuanced understanding of the concepts of meaning-making, sense-making and benefit-finding.

2.3 The death of a child:

> ‘A child evokes a connection with the past, an investment in the future, and an extension of self. To say it another way, a child is a concrete expression of hope in the future, and when a child dies, much of a person’s hope dies as well.’ Bush (2018, p59)

2.3.1 Possible assumptions

My grandmother was mother to a single child, who died aged 50. I am also the mother of a single child. I therefore identify in particular with accounts of parents who lose an only child, and the severe challenge this seems to pose to their identity (Talbot, 1997). In fact, none of my participants lost their only child; all three (and my two pilot participants) had other living children. If my assumption before I started this work was that their pain might be less extreme as a result, I would say now that such generalisations become meaningless in the face of the myriad other factors that play into a person’s response to the death of their child.

As I remember, I became used to my grandmother being sad after my father and grandfather died, and we regarded this as the inevitable consequence of her double loss. At no time, as far as I know, was she offered any counselling or medication to help her. I suspect many older people in similar circumstances are offered little or no support because the impact of their loss is underestimated.

2.3.2 Literature

Many studies have confirmed the stressfulness of losing a child and the consequent suicide risk (Agerbo, 2005). Bush (2018, p58), himself a bereaved parent, writes, ‘I now firmly believe that a true accounting of this subject must begin with .. the sheer torture of losing a child, and a view of life to come as hopeless and horrible’.

When a child dies, parents can feel a part of themselves has died as well (Malkinson & Bar-Tur, 2005). Indeed a common theme in the research is that after a child’s death, a parent’s own death is viewed by that parent as a potential ‘release’ (eg Harper et al, 2011). In this way bereavement may throw individuals into an intensive and difficult search for meaning. In line with findings about bereavement in general, several authors have found that the inability to find meaning in the loss is associated with distress and complicated grief (eg Bonanno et al, 2007; Currier, Holland and Neimeyer, 2006). Keesee et al (2008) quote one of their participants, a mother whose 34 year old son was killed almost eight years earlier:

> ‘My son’s murder was a bizarre, random event that occurred on Christmas Eve morning … He was accosted by a carjacker who shot him at point-blank range. My son died all alone, without ever having an opportunity to see his family. I have never been able to make sense of this event. The fact that one can make no sense of it makes the death very difficult to bear.’

Conversely successful positive meaning-making may be linked to post-traumatic growth. Bogensperger and Lueger-Schuster (2014) found the number of sense-making and benefit-finding themes expressed in qualitative interviews with parents who had lost a child up to 10 years before correlated with post-traumatic growth (as assessed using a standardized questionnaire). Sense-making by parents included a child having given a parent the skills to work with other disabled children in the future, biological explanations for the death and ideas about the afterlife. Benefit themes included being more tolerant and having a greater trust in and appreciation for life, with 10% mentioning they had more time and freedom. The authors suggest extensive qualitative research is needed to develop a way of assessing meaning-construction, to allow for a causal interpretation of the findings. As Keesee et al (2008) point out with regard to their own study, which found a connection between sense-making and adjustment to the loss of a child, it is possible that some third factor, for example attachment security or emotional regulation, may underlie the relationship between meaning-making and the intensity of grief. Meaning-making has been referred to as the ‘complement of affect regulation’ (Kosminsky and Jordan, 2016) and also implies a link with the concept of epistemic trust (defined as an individual’s willingness to consider social information as trustworthy and relevant, Fonagy, 2014).

While establishing causal links between meaning-making and recovery may eventually guide the direction of therapeutic work, what may be more useful to a psychotherapist is to better understand the individual experience of losing a child. In one study, ‘Mothers Now Childless’ (Talbot, 1997) the author spoke to 80 mothers whose only child had died five or more years previously, with the aim of ‘illuminating the life worlds of bereaved parents’. In a subsequent book (Talbot, 2002) she broadened her focus to look at adaptation to child bereavement in general. She found those mothers who considered themselves to have ‘survived’ the loss had not given up parenthood but found meaningful ways to continue the relationship with the child, often involving volunteering and career changes to helping professions. Interestingly, most could remember the moment when they made the decision to survive. Meanwhile, another group of mothers considered that they had *not* survived, and seemed to remain in a state of perpetual bereavement, only going through ‘the motions of living, remaining physically alive’ yet emotionally and spiritually dead (2002, pg xvi).

One interpretation of Talbot’s findings is that if — through a continuing bond — a child’s death has redemptive value, if for example it leads to good being done for others or leads to political change, then it can be concluded that the child did not die in vain (and even in some sense survived death). Such redemptive narratives run strongly through the Western psyche (McAdams, 2013). For Bush (2018, p 61), ‘The perception of a continuing bond with the dead child has often been one of the most inspiring motivations for the surviving parents, and thus a key manifestation of a redemptive view of the survivor’s experience of grief.’ He regards both Mark Twain’s and Abraham Lincoln’s losses of children as being motivators of their subsequent creative output; this allows their losses to be seen as redemptive by others, but whether either of them had a sense of this redemption is another matter. In writing about them, and being a bereaved parent himself, Bush (p62) says, ‘I hope to inspire further biographical story-telling that will help light the way forward for those who find themselves, sadly, on the same path in future’, suggesting that perhaps this perspective offers consolation, or some promise of consolation, in his own life.

2.4 Older parents who lose a child:

> There is .. the thought quite common amongst us who are old:
> ‘Well, thank god I shan’t be here to see that’.
>
> Diana Athill, *Somewhere Towards the End*

2.4.1 Possible assumptions

There is an awful upside-downness or cruel reversal of the expected order if a child dies before a parent in the UK. Sadly, elsewhere in the world or in war zones, adult children die all too frequently, leaving elderly parents behind. On reflection, for my grandmother — whose mother had died suddenly when she was 16 and her younger brother in World War II some years later — her son's loss may have brought a sense of dreadful recognition, but one which fitted more readily into her more established understanding of life as a painful and challenging journey.

Jenny Jones, who with her husband runs a support group for older bereaved parents in East Sussex, says members of her group find solace in talking about the lives of their children, without any pressure to 'get over it' or recover. Mostly, they continue to wish they could change places with their child, and to feel the 'wrongness' of their own good health: 'Our children were robbed of their lives and denied a future.' (Personal communication, June 2019.)

2.4.2 Literature

Most literature on bereavement in old age focuses on the loss of a spouse or partner, and not on the loss of other relationships. Even Hansson and Stroebe's (2007) book focusing specifically on bereavement in late life whilst including discussions of many types of loss, largely cites research about the loss of a husband or wife.

However, research carried out as part of wider studies of ageing populations has given a broad picture of the impact of the death of an adult child. In one longitudinal population-based study of older bereaved parents (Maccallum et al, 2015) a proportion of individuals (mean age 70) become depressed or fell into prolonged grief after the death, but the majority (64%) demonstrated what the study labelled 'resilience', at least after the first two years. Statistical analysis identified three other trajectories of grief: parents who were already chronically depressed and remained so (10.7%), those who become 'stuck' in chronic grief after a bereavement (14%), and those who became depressed but then improved (11.1%) (the same trajectories, with strikingly similar proportions in each category, were observed for the loss of a spouse, with fewer respondents suffering chronic grief compared to the loss of a child). Interestingly, older age was not predictive of grief trajectory class, and nor was the age of the child at the time of their death. The authors point out the usefulness of taking a prospective design, which can identify bereaved parents who were already depressed before their child's death. The (perhaps unsurprising) implication for psychotherapists and counsellors working with grieving clients is that they may be seeking help for an underlying depressive illness as well as for a bereavement.

Other studies have painted a bleaker picture of recovery from bereavement of a child in old age when compared to younger populations, perhaps because participants are often recruited from populations who are seeking support to help deal with their grief. De Vries at al (1997) found that being bereaved of an adult child leads to a strong and lasting increase in depression. And Van Humbeeck et al (2013) in a review of the literature, identified 19 studies looking at the impact of the death of an adult child. They concluded that the death of a child may be *hardest* to cope with in old age, when there are fewer opportunities to invest in other relationships and fewer distractions. Their study also found an increased probability of admission to a nursing home, lower self-esteem, guilt with searching for what they had done wrong to cause the tragedy, higher death anxiety and a 'lasting decline in morale'. Rubin (1993, p299) reported that older parents seemed to fare worse than younger parents in adapting to the loss of a child:

> Developmentally, older parents appear less resilient and less able to emerge from the severe dislocation of the loss of a child. Physiologically and psychologically, consciously and unconsciously, older parents often experience the death of an adult child as one of the most dominant themes and preoccupations of their later life.

However, it is hard to draw conclusions from these studies without knowing more about the participants' lives, and the cohort effects that may have driven these results (for example, these older adults may have been more fully exposed to the traumas of World War II). For this and other reasons, it seems to me that age per se may therefore be a poor proxy for vulnerability in the face of bereavement (Hansson and Stroebe, 2007) and that age comparisons may therefore be very hard to interpret.

The extent of the struggle to contain and live with grief in old age is highlighted by another study which explores the phenomenology of child bereavement and includes some 'oldest old' participants. Weed (2007) in the United States carried out phenomenological research with nine individuals aged between 63 and 95 years (mean age 67) who had lost a child after the age of 60, and were mentally well and living independently in the community. Nearly all the sons or daughters had died suddenly. The predominant theme was ‘lifelong hurt’ and the intense agony participants reported on hearing about their child’s death. Another theme was ‘just not real’: It was as if some participants refused to really believe their child was dead. Older parents in particular feared losing memories of their child as they aged.

As I said above, the meaning of a loss is likely to vary across cultures. Most of the literature cited in this proposal relates to studies carried out in the US and Europe. One exception is a study carried out using data from the Taiwanese Longitudinal Study of Aging which looked at how the death of a son or daughter differentially affects the wellbeing of older parents (Lee et al, 2014). They concluded that a son’s death caused an increase in depression and lower self-rated health for mothers, but not for fathers. And there was little evidence that the death of a daughter had any negative effect on either parent’s wellbeing. They interpret their findings through the lens of a cultural ‘son preference’ and the consequent inequality which means both mothers and daughters are less able to earn well and support themselves and their parents financially.

2.5 Bereavement and Counselling Psychology

Because of the growing literature on the topic of grief, you might expect trainee Counselling Psychologists to want to familiarize themselves with the literature in this area, not least so they do not fall into the trap of subscribing to the older stage-models of grief (Stroebe et al, 2017). The 4th edition of the Handbook of Counselling Psychology includes a useful couple of pages on working with death (Douglas et al, 2016). But headed ‘the final journey’, its inclusion at the very end of a chapter on physical ill health makes it look like an afterthought. Perhaps this relatively new profession is still influenced by the historical idea that grief is a natural process which should not be disturbed unless it becomes disabling - in which case it should be addressed by specialist bereavement counsellors (Stroebe et al, 2005). Another textbook (Murphy, 2017) deals with bereavement more extensively, although in relation to other topics such as trauma and not as a topic in itself.

I would like to see Counselling Psychologists staking out their territory in this field. With their broad understanding of culture, context and narrative they seem ideally placed to make new connections between bereavement research and the broader experience of loss, including trauma and post-traumatic growth. In particular, at the intersection of bereavement and more general distress lies the slippery concept of disenfranchised (or unrecognized) loss , for example, immigrants' loss of their native culture (Henry et al, 2018). This may also encompass, for example, an elderly step parent not being being recognized as a mourner after the death of their step child. Death is a part of life, and specialist knowledge of grief is worth having in any area of client work.

As far as I know, no *qualitative* research exists which focuses specifically on the loss of a child and the evolving experience of grief in people in this older age group (79+). This study aims to explore this experience. I considered focusing on individuals like my grandmother who had lost their only child. However, this seemed in itself to be making assumptions about the impact of other children on bereaved parents' experience of grief

Chapter 3: Methodology

3.1 My relationship with quantitative versus qualitative research

As a psychotherapist with a mixed caseload who consults the literature at least every few days, I find it is the real-life, contextualized examples of individual experience that are most useful to inform my work. This is the territory of qualitative research. But what of my perspective as a researcher? In 1988, Polkinghorne drew attention to the gulf between the experiences of doing quantitative research versus psychotherapy in his counselling psychology trainees. This happens to be the very year I started a PhD in experimental psychology, so I have some idea of the strength of the stranglehold of quantitative thinking on psychology.

I have all but turned my back on my research training in the late 1980s and early 1990s, which relied entirely on positivism and the hypothetico-deductive method. But even then, as a researcher of text comprehension who sat people in front of screens and asked them to read sentences repeatedly (sometimes wearing equipment which monitored their eye movements), I was concerned I was not getting to the heart of what was usually going on when people read, and consoled myself with the idea that Artificial Intelligence might eventually have some use for my research. In fact, the thesis I wrote as an outcome of that research was critical of my methods, suggesting that my subjects were adopting strategies that did not reflect the way they would read language in real life. And although there is a chance I may have been unconsciously picking up elements of postmodern thinking, which were being talked about by some of my colleagues, I assumed the solution would be to look for better experiments, not different philosophies.

That is not to say I did not enjoy my experience with positivist research: dipping once again into experimental psychology papers for this project, I was reminded of the thrill and satisfaction of designing a clever experiment in order to ‘nail’ a particular phenomenon by attempting to isolate it from all other influences. Alongside the difficulties of trying to negotiate early adulthood, nothing much beat plugging data into a t-test and waiting for a positive result, then running to tell my supervisor. It was fun!

But time passes, and I am now a psychotherapist who spends her days enjoying - on the whole - the richness of other people's *individual* experience, and drawing on these experiences as she dips a toe into psychological research once again. In this project, I have found myself unexpectedly straddling the two worlds, shamelessly drawing on psychological research that is based on positivist methods, not because this work gives me hard-and-fast answers (I do not suppose any researcher or scientist would say it does) but because, in engaging with the often brilliant minds of the people who carry it out, I hope to open up different possibilities for my clients – that is, different ways they might think, feel or understand themselves. So, for example, as a psychotherapist I do not need to know (necessarily) the latest research on whether a husband's state of mind with regard to a recent loss affects his wife. I just need to think of that possibility and consider raising it with his wife, who is my client, and if it fits she will tell me. Maybe I am being naïve in saying that, generally speaking, this seems to work well.

I do not want to sound as if including quantitative research in this project needs an apology but perhaps I am catching myself feeling that way. If I am, this may be a reflection of the difficulties involved in building bridges between these different approaches, and my sense of how easy it is for them to undermine one another.

3.2 Research philosophy

In doing this research and using narrative inquiry as a research method, I am identifying myself primarily with a social constructionist philosophy of science. In doing so, I make assumptions about ontology, epistemology and the relationship between the researcher and the research participants, as well as axiology, and rhetorical structure (Ponterotto, 2005).

Ontology

Constructivists believe that reality is not 'out there' but constructed in the minds of individuals. Social constructionism is similar, but further implies that this work of construction is always done in a social context, that we are always drawing on narratives from our social past or present. Thus social constructionism sees individuals as richly embedded in their context, and not separable from it. This increasingly aligns with my philosophy, particularly as a psychotherapist, that there is no one truth.

Epistemology

Epistemology relates to the question of how we come to know. Positivism is based on the assumptions that research participant and topic are independent of one another, and that it is possible to exclude researcher bias (hence the notion of a controlled trial). Postpositivism, on which some quantitative methods are based, acknowledges the importance of context and researcher influence, but pursues objectivity by recognizing the effects of such biases. In social constructionism, by contrast, there is no pretence that the researchers can somehow remain neutral and divorced from the research process (Ponterotto, 2005) or that they have access to knowledge about the participant untainted by their own presence. On the contrary, dialogic interaction between the researcher and researched is central to the process of knowledge creation in social constructionism.

Axiology

All qualitative researchers acknowledge that they bring their own value system and biases with them into any research setting. They cannot hope to do more than ‘bracket’ these – a commonly-used but ambiguous term in the context of narrative research, because it also carries a slightly different meaning of this word in connection with Husserl’s phenomenology and phenomenological analysis. In narrative research bracketing is more of a relative term, the result of a reflexive process of holding in mind one’s own position and its possible impact on the encounter with the participant. This aspect of narrative research leaves me free to disclose aspects of my experience to my participants, and also to use them reflexively to interpret my findings.

Rhetorical structure

Quantitative reports tend to use formal, unemotional language. In contrast qualitative research openly includes a personal perspective, with the emotional and intellectual life of the researcher being detailed openly to a greater or lesser degree. There is no pretence to objectivity, and therefore language may be more emotionally-laden and also used to further certain arguments or highlight certain aspects of the findings. At the same time (and I say this somewhat ruefully), I have a feeling that I as a writer need to be aware of the impact of my developing persona on my audience, and consider whether a too-emotive style of writing could lessen my trustworthiness as a researcher (this might be different if my report was explicitly and primarily autoethnographic or critical realist, which this one is not, although I believe there are elements of both here). I hope I have struck an appropriate balance.

Caveat – critical realism

Having set out my philosophy I want to add a caveat. Relatively little work has been done on the experience of the loss of an adult child in old age, and some observations are likely to emerge from my findings which seemed to speak to the positivist psychological literature on ageing and bereavement. When necessary, I have flexibly adopted a critical reality philosophical stance, addressing the relevant research and commenting on the possible relevance of these findings, whilst knowing that in doing so I am seeking to influence a story which is no more ‘real’ than any other, but which may be enriched by what positivist researchers might call new data, and what I would call new stories.

3.3 Choosing a methodology

Qualitative methods such as Interpretative Phenomenological Analysis acknowledge the social constructionist nature of a participant’s contribution but have an underlying realist orientation, requiring an in-depth exploration and elaboration of feelings and reactions in an ‘experience-near’ way, and a more sustained focus on specific emotional experiences. I did not want to go into this study with any prior assumptions about what I might find, nor very specific recruitment requirements (particularly since I suspected recruitment might be difficult), nor a requirement to elicit themes. More than anything I wanted to leave participants and myself free to include, or leave out, whatever we wanted, including any details around the death itself and their immediate feelings afterwards.

Grounded theory is another popular qualitiative methodology, with a number of well-worked out protocols (Glaser, 1992; Strauss and Corbin, 1990). This method is often used for exploring new areas where there is a lack of theoretical knowledge (Flick, 2014). But my question seemed too wide-ranging and exploratory to be approached with any theory in mind. I was also interested in participants' experience of sharing their stories of loss.

Other mixed-method research has used creative combinations of different methodologies. Hubble and Tew (2015) use a bricolage of narratives (personal diaries), reflections on group encounters and responses to fiction to reveal the experiences of older people that would normally remain hidden from pubic view. I hesitate to compare my study to theirs, which is an impressively large-scale and longitudinal undertaking which draws on data sources like the Mass Observation Project set up in 1937 to study ordinary lives. I note that their reason for avoiding one-to-one interview methods was to minimize researcher influence and expectations, and arguably, as a psychotherapist, I am better placed that most researchers to bracket and reflect on these.

3.4 Why stories?

When starting to think about this research I set out with a number of questions. How do older individuals who lose an adult child understand what has happened to them? How do they make sense of the death? Did they, like some of the participants in Talbot's (2002) study of parents who had lost a child, make a conscious decision to survive the death? And how has their continuing relationship with their dead child changed over time?

Narrative Inquiry is an approach which foregrounds individuals' stories and wider narratives, allowing them to 'speak for themselves', with the material often structured as a journey through time (Owton, 2012). In Narrative Inquiry, co-constructed stories stand on their own merits, rather than leaving the researcher trying to 'discover' the truth of what really happened. McLeod (1997), charting the decline of narrative knowing, points out that we have all been 'socialised into a realm of abstract propositional knowledge' which excludes context and social influence. In doing so we are missing an opportunity. I assume narrative knowing is valid and useful and that people's stories often represent knowledge that other forms of representation do not. Downey and Clandinin (2010) emphasise the importance in narrative inquiry of thinking *with* rather than *about* stories in order to gain a deeper understand of how participants live. As Frank (2010, p2) says,

> The study of stories .. is less about finding themes and more about asking what stories do, which is to inform human life .. stories give form — temporal and spatial orientation, coherence, meaning, intention and especially boundaries — to lives that inherently lack form. How stories inform lives can be a gift or a danger.

3.4.1 Narrative inquiry and old age

Narrative inquiry is particularly appropriate to a study about older people because of its focus on and appreciation of cultural factors. According to Reissman (2008, p8), 'Storytelling occurs at a historical moment with its circulating discourses and power relations … a story is designed for particular recipients – an audience who receives the story, and may interpret it differently'.

People over 75 today are a growing minority in this country, with a shared history of World War 2 and its aftermath, including the birth of the NHS, the post-war emphasis on the nuclear family and an extended period of rising standards of living. Individuals are unique, but their stories often draw on the some of these shared cultural narratives, together with family-based or localized narratives. According to Frank (2010, p14), 'No one ever thinks a story that is wholly original to that person, and no one ever thinks a story alone'.

In addition, a good story can move us emotionally through imagined identification, "mobilize others into action for progressive social change" and get certain facts out into the public arena, perhaps highlighting discrimination (Reissman, 2008). Existing cultural narratives tend to cast the older person as a passive victim of life circumstances but narrative research gives the participant an active role in telling and constructing their story. This research will illuminate the extent to which their stories evolve in the retelling (if at all) and attempt to uncover aspects of the story which may have remained implicit until then.

Another reason for my choice of Narrative Inquiry concerns the nature of stories themselves. Flick (2014) describes how narrators become entangled in certain constraints of storytelling, which encourage a richness not present in some other forms of research. These are the constraint of ‘closing gestalt’, which means that narratives have to come to an end, the constraint of ‘condensing’, which means only what is necessary for understanding is told, and the constraint of ‘detailing’, according to which details are given of personal motives and relationships that might not otherwise be included so that the listener can understand the story. Stories may also include knowledge that has not been integrated into participants’ theories of themselves and their lives – thus this information is available at the narrative level of knowing, but not at the level of ‘theories’ (Hermanns, 1995), and its relevance may become apparent as the research develops.

3.4.2 Narrative inquiry and grief

Narrative inquiry seems to honour the lack of homogeneity in people’s experience of grief. In narrative inquiry phenomena are inextricably tied to an individual, and can only be understood in their context, which can vary on different dimensions and be described in terms of time, sociality and place (Clandinin, 2013). Thinking narratively about a phenomenon challenges the dominant story of a phenomenon as fixed and unchanging through the research process.

In addition, narrative takes a wide view of lives and is not prescriptive about what can be included. An unexpected event such as the death of child causes a kind of biographical disruption or ‘narrative crisis’ to occur (Frank, 2010). This tends to foreground the diverse narratives on which a person bases their identity (and through which they may enjoy a certain peace of mind), requiring them to engage in narrative work to understand and make sense of both the disturbance and the rest of their lives (Neimeyer, 2001).

Because of my personal connection to this research study and my questions around it, it is important to me that there is no assumption that I will be able to bracket my involvement in the service of objectivity. Narrative Inquiry, which is grounded in a social constructionist philosophy, recognizes this. The story would not look the same if told at another time and place, or to a different person.

3.5 Contribution to the field

I aim to give confidence and knowledge to therapists who may be reluctant to work with this age group because of their lack of familiarity with older clients and this type of loss. Through my chosen methodology (narrative inquiry), I hope to challenge prejudices and give value to this period of life by presenting individuals as thinking and developing human beings who may benefit from telling their stories of loss whether in psychological therapy or elsewhere. A more general aim is to increase the literature on bereavement in counselling psychology and psychotherapy, to suggest forms of therapy which may benefit elderly bereaved parents and to inform carers.

3.6 Method and analysis

I will explain my method in terms of four key areas: ethical considerations, recruitment, conversations and analysis. I completed a pilot study involving two participants before I carried out the main research. I will give a brief account of this pilot study and also detail some findings at the end of this chapter. Pilot studies and recruitment were carried out over a time period of approximately a year, with another five months for interviewing and writing up.

3.6.1 Ethical considerations

My intention in doing this research has been to give voice to participants who might otherwise remain silent and, in doing so, attempt to counter prejudice and exclusion. When older parents are grieving for an adult child, the nuclear family tends to be foregrounded, with a lack of social awareness of the possible impact on parents. I have expressed my openness to different accounts of the experience of losing an adult child, and my wish to represent the uniqueness of individuals. However, I have an ethical duty to protect the privacy and dignity of those whose lives I study (Josselson, 2007). Here this meant assessing participants as suitable for the study, guarding both their free right to participate and withdraw and their privacy, and protecting them from harm. The participants were briefly and minimally assessed with a few simple questions before the first interview, because I wanted their stories to be fresh. These questions covered when their son or daughter had died, why they had decided to contact me, and whether they had had counselling before. I also asked them what sort of emotional support they had around them if needed. I told participants about their ongoing free right to withdraw from participation (this was also included in their information sheet, see Appendix 2), but I did not remind of this again because I thought it might lead them to feel anxious or unwanted. According to Josselson (2007), ‘there is something oxymoronic about the idea of ‘informed consent’ in narrative research, when participants cannot fully understand what they are consenting to at the outset. Josselson’s ‘ethics of relational care’ includes the idea of informed consent as being part of the relational process, rather than just an agreement at the outset.

To maintain anonymity as far as possible, the identity of participants was disguised, with name changes and distinguishing personal details altered. However, a participant’s contribution could not be guaranteed to remain completely confidential. In particular the participant’s spouse and any siblings of the deceased son or daughter may come to learn something new at any time, and it is possible this could influence their relationship with the participant. As Bold (2017, p58) points out, ‘some subtle influences may still exert themselves when their narratives become public. Nobody can prevent this happening or judge what the impact might be.’ For this reason I decided to remove sections of material that could be perceived as very critical of any living family member or their behaviour. Any comments about the deceased child’s behaviour which the participants wanted included would be portrayed with as much sensitivity and context as possible.

Bold (2012) says that narrative can be an intrusive style of research which may draw on emotional reserves more than expected. Talking about the bereavement or events of the past might retraumatise or upset the participant. Recognising this, Neimeyer (2012) suggests that direct exploration or retelling of the experience of the death itself should be preceded by interventions that stabilize the bereaved. However, a detailed account of the death itself was not required for this work to be meaningful, although I expected that it might well be offered by participants, and I hoped that I would be able to draw on my skills as a psychotherapist to help the participant if needed. I also considered making some form of writing exercise part of the research protocol, in order to prepare participants for the interviews. Holtslander (2012) describes a ‘Finding Balance Writing Intervention’ for elderly people who have recently lost a spouse, in which writing exercises are used to encourage reflection, expression of emotions, sources of support and the identification of personal and creative ways to find balance. However, including this intervention would have required a different methodology because for narrative research I needed the participants’ stories to be fresh for the first interview.

Impact on researchers

This study involves listening to and reading potentially upsetting material and might have triggered the need for some psychological support for anyone involved, including any colleagues helping me. We all have our own stories in relation to this topic. Fortunately, we knew each other well and could therefore provide secondary checks on how we were responding to it.

3.6.2 Recruitment

I intended to recruit three to four individuals who could be regarded as belonging to the so-called ‘oldest old’ and who have been bereaved of an adult child in the past 10 years. Studying the ‘oldest old’ seemed to me to provide a rationale for the project, given the intense interest in this age group amongst researchers and policy makers. The definition of the ‘oldest old’ varies however: it has sometimes been taken to be 80, but it was 85 for one major study in the UK (eg Collerton et al, 2009, and the Newcastle 85+ Study) and a recent project in the United States took the entry point to be as old as 90 (eg Kawas, 2008, and the 90+ study). Balancing the need to maximize the possibility of finding what Morse (1998, p73) called ‘good informants’ with the need to represent accurately this final phase of life, I decided to take 79 (my grandmother’s age at the time of my father’s death) as the minimum age of participants. Because the study focused on adaptation to loss in old age, it was important that the death had happened within the past few years, so one criterion was that any participant’s son or daughter should have died between 18 months and 10 years ago. The rationale for the minimum time since the loss being 18 months was to allow sufficient time to have past for the participant to have gained some perspective, and the beginnings of a sense of the impact of the death on their lives.

Because of the need for a degree of homogeneity, particularly in terms of shared cultural narratives, participants needed to have lived or been based in the UK all their lives. They would therefore have lived through World War II, and the opening of the National Health Service, with the expectation of good health and long term survival that that may imply. Limiting the study to UK-based individuals made possible richer comparisons of individual responses within this group (Flick, 2014). These limitations were not intended to preclude ethnic diversity, but made it more difficult to achieve.

All contact was responded to with an introductory email and phone call. Two people did not fit the age critieria, three did. During a phone call, I introduced myself, briefly asking for their story, and arranging a first face-to-face interview. Before the interview, participants were sent details of the project and the permission form they would be asked to sign (see Appendix 1).

3.6.3 Conversations

Kvale and Brinkmann (2009) emphasise that qualitative interviewing is a *craft* involving personal skills. For them, what is of primary importance is the *experience* of the interviewer because many of these skills are implicit, context-bound and a matter of personal judgement and sensitivity (this idea is in striking contrast to the concept of method in positivist research which has come to mean the application of a fixed set of rules, although from the original Greek the term method can be understood in the broadest sense as 'the way to a goal'). Kvale and Brinkman refer to what they call an 'antimethod' to social research in general, which tends to characterize the person of the researcher as the research instrument. They quote the anthropologist Jean Lave:

> I think it is complete nonsense to say that we have a method. First of all I don't think that anyone should have a method. But in the sense that there are 'instruments' that characterize the 'methods' of different disciplines – sociological surveys, questionnaire methods, in psychology various kinds of tests and also experiments .. Anthropologists refuse to take those as proper ways of studying human beings .. And so what you use is your own life and your own experience in the world. (Lave and Kvale, 1995, p220)

The skills I bring from psychotherapeutic work including being sensitized to people's willingness to talk at any particular point, and their non-verbal responses. As Kvale and Brinkman say, skills may be implicit, hence the importance of experience. But perhaps more importantly, I am used to listening closely and constructing my own picture of what people are saying as I am talking to them, integrating new information as they say more. This directs and informs my non-verbal interventions, and also any further questions, allowing me to keep people engaged and comfortable.

Conversations took place in the participants' homes. In each case the participant and I had privacy and were not in danger of being overheard. Each recording continued for around an hour (and for a maximum of 1.5 hours). During the first conversation, participants were encouraged to tell the main story with as little verbal interruption from me as possible (Jovchelovtich and Bauer, 2000). When I interrupted, it tended to be to encourage the participant to continue, or to reassure them that they were providing relevant information (sometime they would express doubt, for example, 'I don't know if this is what you want ..'). Sometimes this initial storytelling took up the whole of the first visit, or if not, there was time for some questions and reflections. The second conversation took place 3-4 weeks later, by which time I had transcribed the first interviews, and read the transcripts. During this conversation I mainly collected information about participants' family history, memories of childhood, and work history as context for the main interview, but I also asked any questions that may have arisen from my reading of the transcript. If sensitive information had been omitted (such as details of the death itself) I tended not to ask, but noted its omission to be included in my reflections and analysis.

3.6.4 Analysis

My analysis was both collaborative and interpretative. Participants were closely involved in constructing the stories presented here, but not in their interpretation. For each interview, the analysis was carried out in phases:

1. I listened back to the conversations as soon as possible, sometimes on the journey home, making notes by hand in a research journal.
2. I fully transcribed the material up to two weeks later. At this point my understanding of the participant's story was already forming as a result of my notetaking in the previous phase. The transcription was written into the first column of a 3-column table (see Appendix 3).
3. During several further readings of the material, I made notes in the second column of any points of interests, noting any broader themes (as they occurred to me) in the third column. I then attempted to further immerse myself

in the material by frequent re-reading of the transcript and the addition of further notes. During this time the second conversations took place and these were also transcribed and annotated, as above.

4. I selected the sections of the text to be used in the analysis. I held in mind that I needed to look for the stories (Kim Etherington, personal communication, October 2018). Other text was selected on the basis of whether it made chronological links between stories, but also if it was particularly meaningful or emotion-laden (if for example, it conveyed deep sadness at the loss), or novel (if it surprised me) or seemed to have psychological or psychodynamic significance (in terms of attachment or trauma for example).

5. Assuming the rest of the participant’s story was told in historic chronological order, I reordered those sections which were not, as long as on balance this added to rather than detracted from the meaning (one of the three participants did not sequence her story chronologically — I talk more about this later). Stories that didn’t seem to fit easily into the chronology but seemed to warrant inclusion were positioned with material that had a related meaning, based on my second/third column notes (this produced a text which would eventually be returned to participants for checking, see stage 9).

6. I then removed all content directly relating to the behaviour of individuals who were not part of the research but who might eventually read or see it — for example, another son or daughter — unless I considered it to be a vital part of the story, in which case I considered how I might disguise these details as necessary. I replaced the missing sections of the narrative with commentary to keep the narrative flow.

7. I excluded anecdotes that I regarded as so unique or distinctive that they might identify the person.

8. For the most part, I didn’t include my questions unless they were necessary to convey meaning.

9. At this point, I had a third meeting with participants to show them the sections of text I intended to use from their interviews. I removed anything they did not want included.

10. I then looked again for chronological and causal links so that there was some element of narrative smoothing, in order to make the story more

comprehensible to the reader. (As I discuss later I reversed some of chronological reordering in the case of one participant, and retained instead the chronology of the interview itself, highlighting the regularity and meaning of her frequent time shifts. What is sacrificed in retaining these might be the ease of understanding for a reader who is more comfortable with the narrative convention of chronological order.)

11. To present the longer stories, I used a technique popular in narrative inquiry, in which the material is presented like a poem in stanzas, highlighting ‘idea units’ on each line. Reissman (2008) has highlighted the difference between including a verbatim interview or a tidied up transcript which focuses more attention on the participant and reduces the apparent presence of the researcher. There is a place for both in this research, but my priority has been to allow participants to tell their stories, whilst acknowledging the significance of my role as interviewer in other parts of my report.
12. To provide an element of triangulation, a colleague who is a counselling psychologist read the transcripts from my first participant and went through a similar note-making process to me, making notes on what they considered to be the most important ideas and themes. We compared notes. On the basis of our discussion I included one story element that had previously been excluded.
13. Each story was analysed, highlighting aspects of story structure and content (Reissman, 2008) and, where relevant, commenting on these.
14. On the basis of a comparison between the analyses of my stories (including my own commentary) I identified a number of emergent themes which I address in my discussion.
15. A function for each story in the interpersonal context of the conversation was suggested for each narrative.

3.6.5 Judging the quality of qualitative research

Qualitative research cannot be judged by the same standards as quantitative research. As Yardley (2000) points out, for quantitative research there is a set of well-established and widely acknowledge conventions, methods and terminology, whereas in qualitative research most people reject the idea that there could ever be a fixed code of universal practice. I have borrowed from Yardley a set of flexible criteria by which this study could be judged by others:

1. **Sensitivity to context:** There should be a cultural and philosophical understanding of the background to the work and relevant literature, an awareness of the socio-cultural setting of the study and the social context of the relationship. There should also be an awareness of how context influences the balance of power, which I address in my discussion.
2. **Commitment, rigour, transparency and coherence:** Commitment encompasses prolonged engagement with the topic, the development of relevant skills and immersion in the relevant data. Rigour refers to the completeness of the data collection and analysis, including triangulation of data (in this case the use of my colleague to check transcripts, and the involvement of my participants in constructing their own stories). Transparency and coherence relate to clarity and the power of the argumentation, involving detailing all methods, creating a construction of reality which readers recognise as meaningful to them and using reflexivity to consider how aspects of the research context affect the findings. Coherence also refers more broadly to the fit between the research question and the philosophical perspective adopted.
3. **Impact and importance:** This can be assessed in terms of novelty, socio-cultural impact, and impact on practice, issues which I consider in my discussion.

To add to these here is one of my own: the idea of generalisability in qualitative research is a controversial one, particularly in research of this type which focuses on the particular circumstances of individuals without claiming to produce widely applicable ‘facts’. According to McLeod (2010, p35), generalisability can be understood to lie in the intersection of the individual stories with the reader’s pre-existing schemas of understanding, in this case in relation to older people and bereavement. Such intersection may allow the reader to generate new working hypotheses and spark further research.

3.6.6 Pilot participants

As part of this research, as I have mentioned in my methodology section, I carried out two sets of pilot conversations done a year before the main research. Both were recruited through my own friends and relatives, and in this way they differed from those included in the final study. Their contributions are very different from the main participants, but seemed too precious to exclude entirely. I have taken some short extracts, with their permission, to illustrate the development of my method and thinking at this stage in my research.

3.6.7 BARBARA – living with not knowing

Barbara agreed to act as a pilot participant for this study. Her son had died 3 years ago. I had met her once before, although she did not remember me. She was in her mid 80s, and a friend of a family member, which made the situation both easier because we immediately had a rapport, and harder because I was a little nervous about this first conversation, and would have liked to hide behind a 'professional researcher' façade. She knew my mother had died from cancer in 2013, and I was interested in whether she might mention this (I am not so sure whether she knew about my father, although I told her afterwards). The living room walls and piano were covered in photos of her family: her three children grew up in the house where she still lives.

I gained useful experience from doing this first pilot interview. I have worked as a journalist, so I was well practised in this use of the 'who, what, when, where, why and how' questions needed to elicit a story. However, in this situation I was no longer an interviewer as such, but a researcher, and I needed to leave lots of space for participants' stories (and not just those I was expecting to hear). When I showed my first transcript to the narrative researcher Kim Etherington, she pointed out that some of my interventions were more like therapeutic ones (like the example in paragraph 4, below). Instead my focus needed to be on eliciting the story. In practice of course, I never completely avoided these therapy-style interventions, partly because my other participants were at times more visibly distressed than Barbara, and I wanted to communicate my empathy.

> *(paragraph 1)*
>
> *He had two years of struggling, and we always thought he was going to get better. It's quite nice to go back into it, my daughter-in-law doesn't talk about it, and the children don't talk about it. But I would like to know more about when he was ill.*

> *(paragraph 2)*
>
> *At one stage my son sent a message, that he'd like to see me. And of course I wanted to see him. But I didn't realise that he'd want to see me. I never realized very much at all. I was always frightened of interfering.*
>
> *(paragraph 3)*
>
> *I did interfere to a certain extent with various names and addresses of people who helped. But if I mentioned it to him he tended to say we've done that or tried that. It wasn't any good me helping really. I just assumed they would do the best for him and I'm sure they did.*
>
> *(paragraph 4)*
>
> *I wish I'd been firmer with them. In those days we didn't interfere. We didn't get to know our children nearly as much as we do nowadays. My husband said have them, and love them, and leave them alone.*
>
> ***[me]** That's a sort of regret in a way?*
>
> *Well I don't suppose I could have altered anything. Cancer – well you know yourself – it can be so odd, so different.*

In paragraph 1, Barbara's language, 'he had two years of struggling and we always thought he was going to get better' suggests she is used to telling the story to others in a very summarized form. She then goes on to say she appreciates the opportunity to speak about her son's story in more depth, and there is some sense that in doing so, she might be able to find out more about him ('I would like to know more'). I was struck by her openness, and her wish to continue the conversation beyond the agreed time (we spoke for an hour and a quarter when I had expected to be talking for about 45 minutes). Of course, I would have stopped interviewing her if she had wanted to stop. I found Barbara did most of the talking. When I did interrupt, in what I may have misinterpreted as a pause, I often felt I had interrupted her train of thought.

In paragraph 2, I got an immediate sense of how cut off Barbara felt from her son when he was ill, and the tension she had felt between wanting to be involved, and not interfering. Her expression, 'I was frightened of interfering,' assumes my knowledge of the dangers of getting too closely involved in a son or daughter's family life, and how fraught the situation can get when values and expectations are different. Our culture of individualism seems to foster an expectation of emotional separation from parents or cutting bonds but this never quite happens, leaving ambiguity about how things are meant to be. Barbara clarifies in Paragraph 3 that she tended to feel that almost any kind of involvement initiated by her would be ‘interfering’ (‘I did interfere to a certain extent’) even when she is passing on information about people who might help her son. Interestingly there is no suggestion at any point that she received negative feedback when she did interfere; instead in paragraph 4 we learn that this attitude is reflected in the way she brought up her children and elsewhere in the conversation (not included here) she comments that her own upbringing was the same. In paragraph 4, she makes it clear that she has revised her thinking somewhat since and wonders if in fact she could have been a different, more involved mother. This apparent reworking of her identity as someone who might have ‘interfered’ a little more seems to have happened when she saw her daughter-in-law actively encouraging her grandson to be more outgoing, which she told me later. But these changes are coalescing as she thinks and speaks for this interview. My identity and unconscious reactions as a psychological researcher and psychotherapist may also be nudging her towards greater emotionality, which may have led her to question whether being someone who leaves her children ‘alone’ was acceptable. Parents nowadays are expected to be very involved, and she may feel (perhaps because she knows I am younger and a mother myself) that I am judging her for her hands-off approach.

I was surprised by how strongly she expressed a continuing wish to mother her son when he was ill and dying (and also the level of protectiveness she expressed towards her two living children). Not only was she a mother, she was a mother living with not knowing; not knowing what had really happened, not able to find out. She felt she had to respect other people’s need to stay silent, and wondered whether she would ever be able to ask questions in future.

What was perhaps most striking about Barbara, although this was largely conveyed non-verbally, was that she was clearly maintaining strong continuing bonds with her son in a variety of ways, mainly through photos and videos (for example of his wedding). At times, like Alice Herz-Sommer (Stoessinger, 2016), she told me she sometimes forgot he had had even died.

If trying to loosen bonds with the deceased is an out-dated 20th century concept, then Barbara was already enacting ideas set out in the continuing bonds literature (Klass et al, 1996). It is an interesting question to what extent these predominant psychological ideas, for example of breaking bonds with the deceased, actually influenced people outside the profession.

Her final comment (Paragraph 4) is interesting. Alluding to *my* mother's death, which she knew about, she says, 'Cancer – well you know yourself – it can be so odd, so different'. I did not pick her up on it. I was preoccupied with asking about the last time she saw her son before he died. It could be said that narrative interviewing requires even closer listening than psychotherapy, because (unless it is a factual detail you can return to) you might not get another chance to ask.

3.6.8 SARAH – relieved her daughter is safe

Sarah was an 84 year old mother of three children, the youngest of whom had died suddenly in hospital after an acute illness. She agreed to speak to me only five months later, through one of my colleagues who knew another member of the family. My colleague is extremely sensitive and professionally skilled, and I knew she would have asked the right questions, and established whether this recently-bereaved woman really felt able to be one of my pilot participants. In this situation I was more cautious than previously and I decided to start by asking her about her early life, so we could get to know each other a little better, before I asked about her daughter's death.

I used the transcript of this second pilot conversation as a way of thinking about the elements of a narrative that might be important. Kim Etherington (personal communication, October 2017) had told me to look for the stories, and this transcript seemed to show the role of stories in mediating the relationship between a person's understanding of themselves and their response to grief. Again, despite Sarah telling me a long and very moving story of her loss, I am not going to present the story I constructed here, because I did not involve her in that process, and for that reason it does not seem appropriate to include it.

This first extract is a classically structured story complete with setting, initiating event, the response of the protagonist, the consequences, and finally the moral of the tale

(Stein and Glenn, 1979). It takes on extra poignancy (although I think I was only dimly aware of this at the time) in the context of Sarah's daughter's death:

> *As a staff nurse, working in the 1960s, I worked with a surgeon. One day there was a very small child having an operation; and the child died on the table and the first person to leave the room was the surgeon, then the anaesthetist, then the person left was the little child and the senior theatre sister and me, and I couldn't stop crying and she took me to one side and she was really quite cross with me, she said, 'Now look, you've got to be able to hold your feelings back, you'll have student nurses learning from you and you can't let them see you're upset'. And I said, 'I can't help it! This little girl belongs to somebody!'. She was a soft hearted person, I knew her well by then – and she said, 'you've got to learn to control your feelings a bit'. I pulled myself together because we had to get on and do things, but I've never forgotten it'.*

The vividness of this story is remarkable, her language, 'then .. then .. then ..' evoking the rising tension as her senior colleagues left the room, until she could no longer contain herself. Then for a moment she is a child herself, as the nurse takes her to one side and tells her 'hold her feelings back', pushing her into a new role as a more senior professional, and helping her discover she can (after all) 'help it'. This demonstrates how stories are used in identity constructions (McAdams, 2001) and it is likely that Sarah has been drawing on this story, consciously and unconsciously, for the whole of her life.

Having interviewed my two pilot participants, I looked across the narratives for shared themes. Both participants had a faith in God, but this was expressed in different ways, in Sarah's case as a sense that she was still being taken care of, as Sarah had taken care of her while she was still alive:

> *My biggest worry was how she would manage when I was no longer around .. it's not applicable now. Mm .. in a way she's in the best place isn't she. You have to believe a little bit to get you through.*

I think her slightly tentative caveat at the end could be seen as an acknowledgement that I might not share her beliefs, rather than a genuine expression of doubt. These insights were co-creations, in a way that was beyond my control, and letting go and immersing myself in this process would be nothing short of my own leap of faith.

Chapter 4: Findings

Having lived with these stories for a few months, it is easy to forget how it felt embarking on the interviews for these projects. My own experience, although many years ago and from the perspective of a 23-year-old, still has a traumatic quality, and it was important to me to be able to open myself up to whatever participants had to say without my own memories intruding. But I did not anticipate how hard it would be for me to listen to these stories of pain, confusion and contradiction, and to what extent they would disorganise my own thoughts. After the first two conversations, I re-entered personal therapy with the aim of minimising the impact of this on participants. But a sense of chaos is also part of the meaning of these narratives. I hope I have struck a balance between leaving some of it visible and producing, in collaboration with my participants, stories which are readable and interesting.

I have related each participant's story in turn. Each one is followed by my comments on their story. Some quotes, generally those gathered during the second or third conversation, are presented after the main narrative because they seem better placed there, rather than in the story itself. As you will see, I have not included very much of my speech in these narratives; not only did I want the participants' contributions to stand on their own but (without exception) they all poured out of their narrators with very little prompting. I believe this sense is best conveyed by excluding my occasional prompts and short questions. Reissman comments that presentations such as these can be compelling but are also highly interpretive. If it appears that these stories 'arose, full blown, from within 'the self of the speaker' (Reissman, 2008, p35), then that is pretty close to my experience, except that I had a strong sense of my presence and my impact on the participants.

4.1 ALEX and JACK, a married couple

I went to see Alex and Jack in the small seaside town where they had met, married and lived all their lives. They had contacted me after a charity posted details of my research on their Facebook page, and I had subsequently phoned them to arrange a visIt. They had lost their son Andrew to cancer nearly two years ago.

Arriving by taxi somewhere totally unfamiliar, it was disconcerting to enter a three-bedroomed house so similar to the one in which my paternal grandparents had lived – the size and layout were almost identical (the small dog was a nice addition). The garden was beautifully kept and tended, as my grandparents' had been. If I had hoped to get some insight into my grandparents' experience via this project, then this was an uncannily appropriate start.

I am not sure to what extent it was these parallels that led me to feel a bit nervous about speaking to Jack whom, Alex had told me, did not tend to say much. In this, he was similar to my grandfather, who was almost silent during the fortnight by which he survived my father's death. Perhaps as a result I projected a fragility onto Jack, and being tired after my long journey (in retrospect I realise I should have made the journey the previous day), I wondered how I would be able to clear my head to speak to this man without causing him — or myself — too much distress. In contrast to Jack, his wife Alex seemed eager to talk, though I am aware this may also have been a projection, based on my own experience of my talkative, sociable grandmother.

Alex and Jack had decided that Alex would be interviewed first and I sat down beside her on the sofa in their front room, where photographs of family members lined the mantelpiece and walls. I was interested to what extent they would tell different stories and was conscious that their experiences might be quite different.

I have analysed their narratives separately, whilst avoiding too much repetition. Later I compare their stories.

4.1.1 ALEX: ’The cement that keeps the family together’

Having recently celebrated her 80th birthday, Alex had an aura of energy and purpose about her. She was well-dressed, warm and welcoming.

Like all the participants in this project, Alex had been born at the start of World War 2 and had always lived in the same town. Family closeness was important from the very start of her life. She explained how, when she was a young child during the war, she and her mother had uprooted temporarily and moved hundreds of miles to live where her father was stationed. After the war, home was a safe place for her and her younger brother: her mother was ‘gentle, but strong’. Her father had ‘a bit of temper’, which she says she has inherited, but was kind and forgiving. She was never slapped or severely chastised, and always encouraged by her father to stand up for herself, especially during one short period of bullying by another girl. In adulthood, Alex married Jack and they had their two children — Andrew, who had recently died, and his younger sister Sharon, who still lived a few miles away.

Alex is a natural storyteller, linking events together causally to make sense of them. I have therefore decided to tell most of her story in her own words, interspersed with bits of explanation from me. I decided to use a layout for her transcript similar to some used by Reissman (2008). My own reason for doing this was because I think it conveys the liveliness and pace of her speech better than the sometimes meandering quality of ordinary prose (some narrative inquiries use even shorter, even one-word, lines). I chose to leave most of the punctuation out (except where I wanted to emphasise repetition). Where Alex moves into obvious commentary on the action, I have indented those lines to highlight their slightly different function. Alex sets the scene by describing her son and his involvement in their lives ..

Andrew

(L1) *he was exceptionally good to us*
(L2) *he was a really good son, he was very, very good*
(L3) *I mean you know Jack and him used to go to football matches*
(L4) *he would come up and take him somewhere for the match*
(L5) *because they're both into football*
(L6) *and he was really, really healthy, really well*
(L7) *superfit, superfit*

(L8) *Andrew used to treat me as an equal*
(L9) *We always laugh about this*
(L10) *I was helping him in the garden one day*
(L11) *And he was holding a branch*
(L12) *And he sawed it off and I fell over*
(L13) *And I fell on my bottom*
(L14) *And we were hysterical laughing*
(L15) *He always treated me more like a friend*
(L16) *We had a really good friendship*

Andrew had originally got married in the 1990s to a woman young, Sharon, who quickly became a member of the family.

(L17) *she was young when I first met her*
(L18) *she was more like a daughter to me*
(L19) *he and his wife came and lived here for a long time*
(L20) *so we're all very very close*

The couple went on to have two children, a boy and a girl, whom Alex and Jack adore.

It all went wrong

However, after this really good start, things seemed to deteriorate sharply.

(L21) *It all went hideously wrong*
(L22) *we've had a lot of stress in the last 20 years —*
(L23) *I had cancer*
(L24) *then I had a knee operation that went disastrously wrong.*

Although Alex recovered from cancer, her operation left her unable to walk properly. This was a major loss as long walks were a hobby she had previously enjoyed. A few years later, things seemed to deteriorate further.

(L25) *and then — sad to say —*
(L26) *Andrew had an affair with his second wife*
(L27) *who was his first wife's best friend*
(L28) *which wasn't done but never mind …*

Andrew moved out of the family home, but Alex still very much hoped he and his wife would work things out. But it didn't happen. His new partner Lucy and her children soon moved in with Andrew.

(L29) *I told him he was wrong*
(L30) *and we had never fallen out in our lives, ever*

(L31) *I know he was wrong*
(L32) *so I was annoyed at him at the time, very annoyed*
(L33) *but I felt sorry for him as well*

(L34) *but I still don't want to blame him*
(L35) *I should do but I can't, I can't blame him, I couldn't*
(L36) *I think he should have been stronger*
(L37) *he didn't really want to get divorced*

(L38) *Well I know I should have said something*
(L39) *I didn't want to stir things up*
(L40) *I wanted him to be happy*
(L41) *For her to leave him alone*
(L42) *And let him get on*

Don't rock the boat

The new arrangement meant that Andrew's two children (Alex's grandchildren) spent half their time with their mother, and half with Andrew, his new partner and her own children. But the arrangement didn't go smoothly, particularly for Andrew's daughter Amy. Eventually, she developed a severe anxiety disorder and had to be hospitalized.

(L43) *and to be truthful we've always blamed Lucy*
(L44) *but we didn't want to rock the boat*
(L45) *so we didn't say anything*
(L46) *I've always been brought up to get on with things*
(L47) *and that's what I did*

(L48) *a**nd** Amy was so ill she nearly died*
(L49) *we were going*
(L50) *up and down, up and down*
(L51) *Amy was in hospital*
(L52) *and we were going down there every week to see her*
(L53) *it's just been an awful, awful lot of years*

Then came Andrew's cancer diagnosis.

I couldn't do anything

(L54) then he got a pain and that was it
(L55) it was awful, just keep going
(L56) cry, cry, cry at night
(L57) and just keep going through the day

(L58) I just felt like — when he was ill
(L59) it's hard for me cos I was his Mum
(L60) but we had to ask to go into the bedroom to see him
(L61) 'Oh no .. It's not suitable at the minute'
(L62) and this sort of thing.
(L63) she kept everything to herself
(L64) even in the hospital ..
(L65) I was just crying all the time
(L66) we were never left alone with him
(L67) ever, never

(L68) if you lose a child
(L69) it doesn't matter what age
(L70) I'd always been there for him
(L71) and I couldn't do anything
(L72) it's a horrible feeling

A nightmare

(L73) he was stage 4, he was dying
(L74) we were back and forwards again
(L75) we went to the hospital
(L76) backwards and forwards, backwards and forwards
(L77) I was a nervous wreck
(L78) and the hospital was a horrible, horrible place
(L79) it was like out of the ark

(L80) and that's what I sort of mean about grieving
(L81) we were grieving before he died
(L82) we knew what was happening
(L83) I think Jack always thought he would get better
(L84) but I knew he would not

(L85) it's been very awkward
(L86) round about when he was dying
(L87) there were some awful things said
(L88) a lot of arguing
(L89) it's been a nightmare

(L90) *and then when he died, when he was ill in hospital*
(L91) *we were allowed to sleep in the relatives' room*
(L92) *you can't believe the state of that room —*
(L93) *it was dirty*
(L94) *and we were sleeping in there*
(L95) *cos we were called down*
(L96) *they said he wouldn't get over that night*

(L97) *and then we'd just got home*
(L98) *and we were called back down again*
(L99) *that's when it happened*

(L100) *I just wanted to run away, I just wanted to run away ….*
(L101) *I could have just gone to sleep quite easily —*
(L102) *then I thought about the family*
(L103) *what's going to happen to them*
(L104) *and you've just got to pull yourself together*
(L105) *which I did*

It's changed my personality

(L106) *but after he died I was in a really bad state*
(L107) *and I was so frightened — scared —*
(L108) *I was frightened that anything would happen to Sharon*
(L109) *and my grandchildren*
(L110) *I thought what are they going to do?*
(L111) *I was more worried about the kids than I was about me*
(L112) *Jack's taken it really badly*
(L113) *I go out and talk*
(L114) *Jack's not a big talker but they were very close*

(L115) *it's not just a normal bereavement*
(L116) *it's all that went on before*
(L117) *this bad feeling*
(L118) *which we'd never had in our lives before*

(L119) *it sort of changed my personality*
(L120) *cos I used to see the best in everyone*
(L121) *and try and keep everyone happy — this one and that one —*
(L122) *and then when all this was over*
(L123) *I thought right, that's it*
(L124) *I'm just going to be friendly*
(L125) *with the ones I want to be friendly with.*
(L126) *I've sort of cut out a lot of people.*
(L127) *so it has changed my personality*
(L128) *without a doubt*

(L129) *little things upset me —*
(L130) *like my friend — she didn't mean anything —*
(L131) *but she rang me yesterday*
(L132) *and they've been away for the weekend*

(L133) *it was her wedding anniversary*
(L134) *and she said 'the whole family's been together*
(L135) *it was fantastic having the whole family together'*
(L136) *and I said 'lovely' — and I thought fancy saying that to me!*
(L137) *she didn't mean anything though*

(L138) *I got a lovely message for my birthday*
(L139) *it said 'you are the cement that keeps the family together'*
(L140) *and that meant a lot*
(L141) *but a big chunk has now gone, a big chunk*

(L142) *and I'm just sort of putting myself together*
(L143) *we've lost a whole way of life*
(L144) *we used to go out places*
(L145) *and he used to take us all over the place*
(L146) *and we've lost all that*
(L147) *and the family's scattered now*

(L148) *I don't want to go anywhere.*
(L149) *I can't see us going abroad again*
(L150) *it's what I mean when I say*
(L151) *it's changed my personality*

A future without Andrew

(L152) *we just always thought*
(L153) *both Andrew and Sharon would be there for us*
(L154) *when we got really old*
(L155) *and Andrew was always the one who dealt with things*
(L156) *Sharon never had to think about much*
(L157) *but she does now*

(L158) *but Andrew always had a sensible head on him*
(L159) *and I thought I could rely on him when we get old and ill*
(L160) *and he's not there and that's a shock*
(L161) *but I worry for Sharon*
(L162) *she's sort of taken over and*
(L163) *she worries all the time about us*

(L164) *I do a lot of gardening*
(L165) *and I think that's what keeps me going*
(L166) *we've planted a tree for him*
(L167) *and put it where he used to play when he was little*
(L168) *so I sit there quite a bit*
(L169) *I'm coping better*
(L170) *I obviously think about him every single day*
(L171) *but I don't dwell on it*
(L172) *I just try and get on with the life through the day*
(L173) *and do things that I normally did*
(L174) *I'm not normally like this [crying]*

One of the difficulties has been disagreements between Alex’s grandchildren and Lucy’s children. Alex wishes relations between them could get better.

(L175) *I said to Sharon the other day*
(L176) *‘if the two sets of children would just get friendly*
(L177) *and speak to each other!’*
(L178) *she said Mum you’re living in a dream world*
(L179) *which I am*
(L180) *however they’re doing alright*
(L181) *so that’s the main thing*

No silver lining

(L182) *when he first got it people were saying you got better*
(L183) *but .. mmm .. not that one*
(L184) *you see every cloud has a silver lining*
(L185) *I made friends, I made friends*
(L186) *with a whole load of lovely people*
(L187) *who’d also had cancer*
(L188) *and we still have coffee every week*
(L189) *but you see*
(L190) *there is no silver lining with Andrew*

4.1.2 Further analysis of Alex’s story

Alex was articulate in putting her story across. At times I felt her openness and warmth, at other times her indignation at the ordeal to which she and her family had been subjected. As she spoke about so many difficult years, and despite my recording equipment and arrival in her house as a relative stranger, I felt like a friend or relation being taken into her confidence to mirror her distress at what had happened. Following the conventions and constraints of story structure (Flick, 2014), she set the scene, related the events around the death, and then reflected on the impact of the loss. In one set of procedures for analyzing narratives (Schutze, 1983, described in Jovchelovitch and Bauer, 2000) so-called non-indexical statements (description) are separated from the rest of the story. I used this idea when presenting the material, by indenting any pure commentary to demarcate it from the rest of the text and highlight such ‘asides’. For me as the interviewer, these were moments of connection during our conversation, one woman to another, when Alex briefly came out of her story to let me know what she thought.

Tragedy

The content of Alex’s story was devastating — in her eyes, her family was torn apart by an affair, from which it never recovered. Structurally, her account can be compared to a Greek tragedy, with Alex taking the role of the chorus and commenting on the action, and a man’s ‘fatal flaw’ (his attraction to someone other than the person he is married to) leading to the family’s undoing. A causal chain of events seems to gather momentum, with turning points highlighted, preparing the reader for the next difficult development (L26 ‘*and then — sad to say — Andrew had an affair*’) including the near death of Amy, and then the death of Andrew. There is hardly time to get over one thing when another thing happens and the repetition in the language mirrors the sense of repeating difficulties over many years (L54, ‘*then he got pain*’; L50 ‘*up and down, up and down*’; L56 ‘*cry, cry,cry*’). So strong was my sense of the causal links driving this story and perhaps my inevitable engagement with the positivist paradigm that runs through our culture and drives a search for concrete understanding, that after the conversation I asked Alex whether she thought this chain of events had caused Andrew’s illness. She replied: ‘I do wonder if all the upheaval and everything had anything to do with it but it couldn’t have done .. I’ve read up a lot about cancer and no, it couldn't have done'. One of the advantages of narrative research is that it can reveal or suggest implicit meanings.

Alex's blame of Lucy becomes understandable because of the apparent impact of the divorce on Amy, who became ill. Alex found herself in a truly impossible situation with contradicting family narratives about what she should do next: She had been taught by her father to stand up to bullies (not that she necessarily saw Lucy in quite this way), but in standing up to her, she was also deepening a split in the family. We are left to infer and imagine this huge moral dilemma which is embedded in the story and not made explicit, although she mentions her reluctance to '*stir things up'* (L39) which hints at it. Alex knows I know about the unacceptability of someone having an affair with their friend's husband. When she talks about Andrew's affair and says it *'wasn't done'* (L28), she knows I will know what she means (and I do). In this way, her assumption of our shared knowledge is related to the way the story is presented by Alex: At another time and place, and to someone else, she may have said something different.

Idealisation

Going back to the start of her narrative, Alex sets the scene by describing her son. Not only was Andrew an attentive son and physically very fit (L1-7 *'he was exceptionally good to us ….*'), he was also a successful businessperson. It has become quite common for parents who have lost a child to compare their children to angels in recent years, but Alex seems to have found a more modern (and possibly gendered) alternative: Andrew is portrayed more like a superhero (a not uncommon comparison for both sportspeople and entrepreneurs, eg Nazar 2012). Neimeyer describes the backstory of the relationship as providing attachment security as the narrator reconstructs their continuing bond with the deceased ('*we had a really good friendship'*, L8-16) .

Her narrative functions to eulogise and idealise Andrew. It is expected that we not 'speak ill of the dead' but there is something more poignant about a mother's idealization of her child (and Alex is quite explicit about this process in L35: '*I couldn't blame him, I couldn't*'). The holocaust survivor Alice Herz-Sommer wrote of her own son: 'The only time my son gave me pain was when he died' (Stoessinger, 2016, p152). Hayes (2016), in seeking to explain our tendency to idealise the dead, found that the mere thought of a person's dying is enough to prompt more positive appraisal of them, and in further investigations found that when the imagined person was someone the experimental subject knew well, such idealization reduced their level of death anxiety. On the basis of her findings, she concluded that the idealization of the dead has become embedded in culture as a way of emotionally supporting the close family and friends of the deceased. It seems possible that idealization might continue to function as a way of regulating emotion, which might be one of the reasons Alex began her account in the way she did.

However, there might be other strong reasons why a parent might want to idealise or protect the image of their child. According to Terror Management Theory (Pyszczynski et al, 2010) we developed culture as a way of overcoming the conflict between the goal of continuing life and the knowledge of inevitable death. Through culture we can potentially become immortalized by the next generation, through things that are said about us for example. But such death transcendence must be earned and it seems likely that parents might attempt to earn it on behalf of their offspring, given that the child is not able to do this for themselves. This motivation could be seen as an expression of Bowlby's caregiving system (Bowlby, 1979; Kosminsky and Jordan, 2016) which like the attachment system continues to be stimulated after a loss (I discuss this further below, p65).

In order to fulfill this need to idealise, Alex must remove Andrew from his role as protagonist of this sad story. From L43 onwards ('*and to be truthful we've always blamed* ..'), Andrew is not portrayed as an active agent but as a victim of events beyond his control. Alex's comment, *'he didn't really want to get divorced*'' (L37) has the effect of explaining the contradiction between Andrew's central role in the family and his actions in starting an affair.

Holding the family together

Of my participants, it is Alex who is perhaps the strongest storyteller. Strawson (2004) distinguishes between 'diachronic' and 'episodic' self experience, with the former applied to those who see their lives as a continuous story and have a narrative outlook on life (as opposed to those who do not see their life in narrative terms). Not only does Alex seem to think in stories – she is also embedded (at least in this telling) in her *family*'s story, rather than in the story of herself as an individual. Whereas McAdams (2013) distinguishes between 'agency' and 'communion' in relation to narrative identity, with agency respecting the 'expansion and assertion of the self' and the other affirming 'love, friendship, family and the expressions of communion', it is as if here they merged into one, with Alex trying to assert and defend the family's agency. But Alex was uncertain as to her actual power in all this: Could she have done anything, could she have changed the course of events and preserved the original family? She has been living with competing cultural narratives. As part of the so-called 'silent generation' who were born before or at the start of World War II, she learnt not to rock the boat (L44) and to just keep going (L55). But Alex is also the '*cement that holds the family together'* (L139) – the assumption of family togetherness having been firmly established in the post-war period of the 1950s, when it formed the bedrock of the welfare state. It is possible there are also elements of older family narratives. Alex told me in a later conversation that her mother's family had been refugees from Russia to France during the early part of the 20th century: stories of family unity and stoicism might have helped them make the difficult transition to a new life. As if identifying directly with the family, she adds of Andrew's death (L141), '*A big chunk has now gone. A big chunk*.'. Her identification with the whole family is also reflected in the underlying metaphor of a battle between Andrew's original family and his new partner. Alex so closely identifies with the family system and in particular Andrew's original family ('*we're all very very close'*), that their loss is also hers. But to tell several people's story in one inevitably results in a certain amount of over-simplication. Frank (2010) says that stories making dangerous companions when they reduce too much complexity, and Sartwell (2000), observes how narratives can become domineering and controlling: '*a kind of deadening prison, designed to tame and hold back, seclude us from the noisy clamor of experience'.* This may be particularly true in bereavement, which involves such extreme pain and sadness that the story itself may constitute a defence against other realisations and feelings.

As I will show later, too strong a story can affect relationships between people who are grieving. Thus the softening of the story may allow a whole family to move forward. As psychological therapists that may be one of our jobs: to catch the softening when it happens. Despite Alex's tears, which were many during this telling, she appeared resolute with regard to her story until at a certain point, when, apparently feeling heard and perhaps safer in my company, she seemed to soften her position somewhat, becoming touchingly wistful and reflective, expressing a wish that *‘the two sets of children would just get friendly’* (L176).

Motherhood

The most poignant part of Alex’s story as she told it to me that day was her account of her feelings as a mother (L59-72 *‘It’s hard for me* ..’). As an expression of her attachment to her child, these lines convey an almost unbearable sense of regret that she could not ‘mother’ her son. Such a strong sense of wanting to care is common when people we are close to are ill, but it may be uniquely strong in a parent towards a sick child. The caregiving system, the reciprocal of attachment behaviour in a child, was originally discussed by Bowlby (1979, p296) as being vital to protect helpless human offspring until the child got older:

> Imperceptibly this transitional phase passes into a final phase in which mother increasingly leaves maintenance of proximity almost entirely to the growing juvenile. Thenceforward, *except in conditions of emergency* [emphasis added], she plays only a minor role.

An inability to help may therefore result in very strong feelings of guilt, failure, and even shame. It appears that a lack of recognition from other people of the strength and validity of these instinctive feelings (eg ‘*We were never left alone with him’*, L66) can hamper an individual’s struggle both to manage them and to give them meaning, deepening the traumatic nature of their experience.

Repairing the narrative

In general, relating the narrative of a loss is considered a useful part of grief work and can lead to change. According to Neimeyer (2012) integrating the reality of a loved one’s loss involves the event story of the death gradually being woven into the larger story of a bereaved person’s life. Alex’s work in this regard could be understood in terms of Frank’s (2012) illness narratives, in which the purpose of the narrator is to fit the disease, or in the case of this research the *death*, into the narrative trajectory of a life. Medical explanations may be of only marginal interest. The effect is to repair the biographical disruption brought about by the illness by making sense of and giving meaning to what has happened (for example L115-117 ‘It’s not just a normal bereavement …'). According to Frank, 'What begins as disruption is thus reconstructed into continuity' (Frank, 2010, p115). I suggest that Alex may be seeking to repair not only her own but other narratives (for example, of the deceased person and of the family as a whole) by projecting responsibility for what has happened onto a relative outsider (Lucy). This is obviously something we as human beings do all the time. Here it could be seen as a way of providing continuity with the more distant past, and keeping that person alive in the minds of those who love him. Furthermore, it is even possible that the resistance with which this narrative is embued (for example, L37, 'he didn't want to get divorced') may unconsciously evoke some imagined future in which the divorce never happened. Several forms of therapy include idealised scenarios developed in imagination to encourage a greater sense of security in the world and this might be functioning in a similar way (eg Pesso, 2013).

Alex's assumptive world has been overturned by an event for which she can find '*no silver lining*' (L190). The notion that good can come out of tragic circumstances (the redemption narrative) has been identified by Dan McAdams (2013) as being intrinsic to the American construction of self and has identified various clichés to sum up this concept, for example, 'it's always darkest before dawn', 'turning lemons into lemonade' and 'finding the silver lining of a dark cloud'. It has also emerged in the UK, through various means, not least through the World War I songs that my grandmother used to sing me ('there's a silver lining in the sky-ee ..'). How does a redemption narrative fit with the perspective of people on the verge of entering the 'fourth age', who have lost a child? The lack of an answer to this question bothers me, because it feels similar to the 'dead end' feeling I experience when I think about my grandmother's loss of my father and grandfather.

It was interesting that during the course of Alex's narrative her anger seems to dissipate, and turn into a sort of longing for a different outcome. The stuckness of the narrative dissolves somewhat, and a gentler, sadder part of her emerges, albeit one in which she has been told she is 'living in a dream world' (L178) for hoping things might eventually be different. What also emerges is a vague hope that relationships can heal. However, she remains bound to defend her grandchildren. This highlights the extreme complexity presented by the opposing pull of different family loyalties on some older people when their son or daughter dies.

4.1.3 JACK: Wanting to be where *he* was

Despite my concerns about speaking to Jack, he appeared very ready to tell his story. On the whole he spoke naturally and unselfconsciously, with only a few moments of discomfort when his emotions seemed briefly to overwhelm him. Jack's family has been local to the area where he lives for several previous generations, and, at the risk of muddling the actual chronology of the telling in favour of a life history chronology, I will start with some details of Jack's family background. I did not hear about these until after the main story, but in my view these quotes may be psychologically illuminating so I will put them first. Jack's manner of speaking was gentle, clear and steady. I decided an ordinary prose presentation best reflected this.

Jack's parents were cousins who married in the 1930s. He was born during World War 2 and, with his father conscripted as a skilled worker, Jack does not remember meeting him until he was 5 years old, when there was a knock on the door and this 'stranger' walking in. In the years that followed, his parents went on to have more children (both boys), and Jack remembers a happy childhood. Jack's adult life included meeting Alex through the local youth club and a long career as a lecturer, which he found increasingly frustrating as the job became more and more administrative. He lived close to both his parents until they died, his mother in her late 60s. He thinks his mother had been depressed since the children had left home:

> (quote 1)
> *She enjoyed the young times when we were toddlers and then right through to teenage years, but after we left – I think it was a bit of a cliff edge for her, she was left sort of looking round – what am I going to do now? She never said that but that's just my interpretation of what she must have felt like.*

After his mother's death, Jack spent the next 25 years visiting his father daily:

> (quote 2)
> *After she died I used to go every day to look after my Dad because he wasn't in the best of health then. He was a very quiet man, he never had a lot to say for himself but in many ways I'm a bit like that as well. He would never slag anyone off, he would be quiet rather than get into any sort of discussion or argument.*

As I said, he told me this family history later. For our first conversation, I asked him to start the story of his recent bereavement wherever he liked, and he started by talking about how he was now.

It was me living through him

> (quote 3*)*
> *It's nearly two years since we lost Andrew. People say time heals – I'm not finding that.   I can't get any enthusiasm for anything. I sort of go through the motions really …*

When Andrew died, Jack lost a close companion and (particularly as he got older) a man who facilitated his engagement with the wider world.

> (quote 4)
> *We were very close Andrew and I, and over the years there were very few months when we didn't go down or he came up, and we used to share a lot of things together.   We've always watched football a lot, and he got into cycling and he loved that.   He got very, very competitive and we used to follow him all over.   And we used to holiday together as family – we went all over, France, Italy, America. Before we lost Andrew the tables were turned really, I used to rely on him for a lot and he would take the initiative and it was a kind of reversal of roles really in later life.*
>
> ***[me]*** *Was there a point when that reversal happened?*
>
> *Well it was probably when he started his business. Looking back there was a lack of confidence really and I thought he was taking on things he wouldn't be able to do. I often said to Alex, 'do you know, he's done things I wish I could have done'. In a way I suppose it was me living through him.*

Maybe I should have noticed things

> (quote 5)
> *It's just as if when Andrew died, everything's sort of fallen down like a pack of cards. It doesn't seem there's any way I can change the situation. All the problems started when Andrew and [his first wife] split up .. he was under a great deal of strain at work at the time, and well .. she lost a baby. We knew very little at the time, but I knew Andrew was badly affected, it was obviously the worst stress on him .. she had problems as well. That was when Lucy stepped in. It was just a classic case — he was vulnerable and he decided that he loved her.   She was quite determined.*

After Lucy moved in with her children, things appeared to work at first, but then relations between Lucy and Jack's granddaughter Amy deteriorated, and Amy subsequently developed a very serious anxiety disorder. Jack wonders whether he could have done anything to prevent it:

> (quote 6)
> *If we had quizzed Lucy more deeply about the relationship between her and Amy I think it may have made a difference, I don't know. Maybe I should have noticed things .. we just thought it was best to keep things on an even keel, so you just wish you had the benefit of hindsight. She's still recovering at the moment but she's busy and all the rest of it ..*

Lucy's illness was a great worry for Alex and Jack. But Andrew's cancer diagnosis and death a few years later was unthinkable.

> (quote 7)
> *We were by his bedside when he died, but right through, all the time, he kept convincing us that he was going to get better. At the funeral, I couldn't believe the people that were there. The church was absolutely full.*

Some things I don't want to tell

> (quote 8)
> *I was a wreck at the time, I was meeting people going into shops and I could hardly speak .. it took me a while to get over that stage. I'm ok now. If someone asks "how is the family?" I can have a conversation. But I never know whether I should say, "well Andrew died" because it seems a lot to drop on somebody.*
>
> ***[me]*** *You're worried about how they might feel?*
>
> *Yes, I had an experience a while ago, probably left it's mark on me really. When I was at school there was a lad who was in the year group and after we left I didn't hear from him for a long long time and I bumped into his brother three to four years ago out for a drink at a pub and I got in conversation and I said how is Mark getting on, and he said oh he died, he ki- he committed suicide .. (coughs) .. my heart just sank and I think of that occasion when I'm talking to somebody. There are some things I don't want to tell Alex, same with my daughter, I don't want to sort of .. for want of a better expression, you don't want to upset the cart .. you just sort of keep it in .. We just found out that [another relative] has got the same thing [as Andrew]. It's difficult when you know something, when you've experienced something like that. When you talk to somebody who's actually going through the same thing again - cancer - you finish up just saying nothing. You know you could say, "I've experienced all this so don't worry". But the end of Andrew's story was that he's died .. there's a good chance that it might happen to him*

Being in places where Andrew was

(quote 9)
I think it would just help if I could continue being in places where Andrew was. Ideally it would have been best if after he died Alex and me and Sharon we could have gone down there and stayed at the house with Lucy .. I would like to have done that, I would have liked to have been part of what used to be. But Alex won't go - she won't go back to the house - Sharon felt the same. The result is I'm stuck between … I'm neither here nor there really .. I'd like to visit the house, we've only once been able to go to the churchyard and that's not far, it just seems stupid to me that I can't do that.

[me] And you talk to Alex about this?

It's partly my fault because I don't. I think it's a kind of betrayal really because she feels so strongly about it. But sometimes she thinks I get short tempered and that's probably a lot to do with it. Because I think of him all the time. I think of Andrew all the time. I still don't sleep very well. I said at the hospital when he died I don't know what I'm going to do because everything revolves around Andrew ..

***[me]** That was your focus really?*

Mmm, so it's devastating .. I don't know really .. just .. nothing's going to work out the way I thought it was going to work out after Andrew died .. I can't see .. I think if I stopped having contact with Lucy, I think I would just fade away .. but that's, that's the reason I have kept in contact with her because I just thought if I did that well it might keep what's left of any relationship

***[me]** Any relationship with Andrew?*

Yes

***[me]** So you feel almost in contact with <u>him</u>?*

Yes – I've just got to be happy with what's left really.

4.1.4 Further analysis of Jack's story

Is there something unique about the loss of a child – does it involve pain we can never prepare for? (indeed if we were prepared we might not have children in the first place). Jack is finding that time does *not* heal as most of us have been promised from childhood. Bush (2018) comments that there is clinical evidence that the old adage 'Time heals all wounds' does not easily fit parental bereavement (Florian, 1989). He suggests that in fact the opposite is true; there may be an intensification of pain, especially in the third or fourth year after the loss, and Jack's experience bears this out: '*People say time heals. I'm not finding that*' (section 3).

As I said before, I found myself concerned about speaking to Jack, who had lost his 53 year old son less than 2 years before. On first meeting, this robust-looking 79-year-old man was less forthcoming than his wife. I asked myself whether he would be able to speak, and was unexpectedly nervous I might harm him in some way, whilst recognizing that my feelings might have more to do with the fate of my grandfather who had died (apparently of shock) so soon after my father. At the same time, I reminded myself that just as narrative inquiry gives voice to silenced minorities, it can give voice to silenced individuals who, for whatever reason, have not yet been able to tell their story.

Chaos is anti-narrative

Jack's account is full of language which suggests that Andrew's loss, and the difficult years which preceded it, has deprived him of a developing narrative: '*I really just stopped'* (paragraph 3), '*Everything's sort of fallen down like a pack of cards'*, '*I'm stuck between'* (paragraph 9) and *'I'm neither here nor there really'*. Frank (2013, pg xv), writing from the perspective of someone with a chronic illness, notes the 'anti-narrative' effects of chaos: 'Life is reduced to a series of present-tense assaults. If a narrative involves temporal progression, chaos is anti-narrative.'

The expectation of a recovery

Even though Andrew had been diagnosed with a serious form of cancer, Jack had held onto the idea that Andrew might get better. Over the course of the 20th century, improvements in sanitation and housing have vastly increased life expectancy, as did the opening of the NHS in 1948, with the result that nowadays people do not generally expect their children to die before them. According to Frank (2013, p77), ‘Contemporary culture treats health as a normal condition that people ought to have restored. Thus the ill person’s own desire for restitution is compounded by the expectation that other people want to hear restitution stories.’ People who are either terminally ill themselves or who are close to someone who is ill have probably experienced other people’s refusal to face up to it (for example, being told they need to ‘think positive’). As if to forecast Jack’s state of narrative paralysis, Frank (p94) says, ‘When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real.’

So what are the narratives Jack can draw on to understand what is happening now? How is he to make meaning of his own life when ‘Everything revolves around Andrew’? His family history includes stories of people being left on their own. There are parallels between Jack’s description of his mother’s reaction to the children leaving – ‘I think it was a bit of a cliff edge for her. She was left sort of looking round …’ (paragraph 1) - and his own reaction to Andrew’s loss. In addition he told me in a later conversation that both his mother and father had been separated from their parents at an early age, his mother before she reached her teens, when she was sent away from the family home, and his father by the age of 19, when both his parents had died.

Grieving, attachment and complicated grief

There are certain aspects of Jack’s narrative which link to the psychological literature on bereavement and show the complexity of trying to use attachment theory in any straightforward way to understand patterns of grief (I will return to this in the discussion). In his narrative Jack describes himself as having managed his mother’s death in her late 60s and his father’s at the age of 93 without difficulty, which hints at an avoidant personality style. In Stroebe and Schut’s (1999) DPM model of bereavement, avoidance as a personality style tends to result in an overfocus on restoration-oriented activity. But Jack’s narrative tells us he longs to visit the places where Andrew used to be, and that he believes visiting his grave would help him feel better (paragraph 9), which would fit better with a loss-oriented way of coping. He also seems to long for a sense of Andrew’s presence (Dennis and Kunkel, 2018), a form of continuing bonds also associated with loss-oriented coping. The same study found relationship strength positively predicted later prolonged grief, of which Jack's presentation has many features.

The nature of Jack's close relationship with Andrew also implies a common parental reaction to losing a child, which is for a parent to feel they have lost a part of themselves or their identity (Hayes and Steffen, 2018). His wishing to be where Andrew was reminds me of the 'magical thinking' described in Joan Didion's (2005) memoir in which she tried to create conditions which would restore her husband to life. We do not necessarily need to label Jack's (or Didion's) longings as delusional though – so-called 'ontological flexibility' is part and parcel of entering into an individual's world, whether as a researcher of therapist. This may be particularly important in bereavement (Hayes and Steffen, 2018).

Quietness and relationship

Even in our modern age of individualization, we are all haunted by ghosts from the past. Christopher Bollas writes about psychic life as a 'kind of haunting', full of encounters with people from the past but whose impact we cannot fully know (Roseneil, 2009). Jack's father was apparently a very quiet man, and Jack is the same. He may never have felt the need to be anything else, having enjoyed his relationships with both his father and Andrew through shared interest in sport and other activities (for example, his father was very good at woodwork, and Jack told me in a later conversation that he remembers being in the garden with him when he built things). In particular enjoying football together was something he did with both his father and his son, bringing to mind the Kohut's (1984) concept of twinship transference and the need we all have throughout live to find people who are similar to ourselves. Notably Kohut (1984) said that verbal communication is not necessary for a twinship tie to another person; in fact, he said, 'being together with the twin in silent communication is often the most satisfactory state'. The quiet contentment of such a state also seems to be reflected in Jack's memories of his environment as a child:

> *You were totally unaware of bad things that went on. You lived in your own little world, and you had your friends to play with, there was no busy traffic, there was no people round the streets, it was a completely different world.*

Strong relationships based on a comfort with silence may however be a risk factor when that relationship is gone, and might make it harder to build new connections to others. This seems to be reflected in Jack's perception of his current environment:

> *Nowadays if you walk down the street it's very seldom that people say hello or how are you. If I'm walking up to the paper shop, people will speak to the dog and totally ignore you.*

Narrative as a means of communicating the unspeakable

Jack's longings for closer contact with places and people he associates with Andrew have been blocked (paragraph 9). His loyalty to the living means that he feels unable to voice this need. In some cultures men are expected to be strong and emotionless (Doka, 2016), behaviour which in Jack's case was modelled by his own father. It seems possible that Jack has found in the invitation to tell his story a way of voicing his frustration ('*I'd like to visit the house, we've only once been able to go to the churchyard where his ashes are buried and that's not far, it just seems stupid to me that I can't do that',* paragraph 9*)*. Valentine (2018) emphasizes the importance of helping mourners find creative ways to develop continuing bonds. This research has at least given him a context in which he feels free to speak, without having to protect or betray anyone. Before my third meeting with the couple, I supplied them each with a document containing the quotes I wanted to use to construct their stories, knowing that they would read each other's. I reflect on this decision in my discussion (section 5.4).

4.2 ANN: Finding Alison

When I first spoke to Ann on the phone, she had just moved from a house she had shared until a few years before with her daughter Alison, who died in 2017. She was now living in a retirement flat on the outskirts of town. Like the previous two participants she had responded to a notice about this research on a charity's facebook page. When I phoned her, she told me her relationship with her daughter had sometimes been difficult, and she felt guilty about this now she had died. She was still reasonably well supported, having two living children with whom she was in contact, and also some occasional involvement with a bereavement group. She seemed keen to talk to me.

I took a train a few hours out of London to meet her. Her new home was a block of retirement flats, quiet but not deserted, with a warden and people working in the garden outside. From the reception, I was directed through to Ann's one-bedroom flat. Ann had a stroke nearly 10 years ago, which affects her mobility, but if she has occasional word-finding difficulties, she is still extremely articulate. We sat down on two armchairs in her living room to begin what turned out to be a ninety minute interview (with a short break).

I think it might help to understand why I have presented her story in the way I have. At my first reading (of the transcript), I could not see how Ann's account fitted into any sort of chronology and, sensitive to this apparent disorganisation, I set about editing and then reordering it. However, as I struggled (unsuccessfuly) to do this I wondered if the order of these thoughts and reflection, which seemed to move so rapidly between past and present, might not be important both to me and to other people reading it. Perhaps this postmodern, apparently fragmented, text was to be embraced in all its apparent contradiction and confusion! So I went back to the original transcript to see what I might possibly do with it and I noticed that Ann, rather than being disorganised in her delivery, seemed to be systematically sweeping between past and present, as if scanning the terrain for connections. I hope this remains visible in the narrative presented here. I have presented her narrative in stanzas using minimal punctuation.

Relationship

(LL1) *I'm sad now when I think of her,*
(LL2) *and I will be looking back – but at the time*
(LL3) *it was just pure anger, rage, shock –*
(LL4) *how could this happen to her?*
(LL5) *just disbelief.*

(LL6) *and I've thought since how*
(LL7) *I could have been a kinder and rather nicer mother.*
(LL8) *I just can't believe it, I almost can't admit –*
(LL9) *She used to send me*
(LL10) *the most fantastic over-the-top birthday and Christmas cards*
(LL11) *full of how much I love you*
(LL12) *and you've done so much for me*
(LL13) *and I used to go, oh god all this stuff ..*
(LL14) *I just used to look at it with a sort of disbelief*
(LL15) *because that wasn't the person I knew.*

(LL16) *she wasn't all over me*
(LL17) *we're both very – what's the word?*
(LL18) *undemonstrative.*
(LL19) *And I thought yes, she probably got that from me,*
(LL20) *she doesn't sing about what she thinks of you,*
(LL21) *she makes our life bloody difficult,*
(LL22) *but she was always there, was there for me,*
(LL23) *was there for anybody that needed her*
(LL24) *or appreciated her.*
(LL25) *And I think since she died,*
(LL26) *I realized what a different person she was*
(LL27) *to the one I knew.*

(LL28) *And I mean we didn't fight*
(LL29) *but it's just all the things she liked*
(LL30) *and all the things I like –*
(LL31) *were almost total opposites – music-wise, everything.*
(LL32) *She got a huge collection of CDs –*
(LL33) *the Bruce Springsteens, the Dolly Partons,*
(LL34) *I think she got every single record that was ever produced*
(LL35) *dozens of them and boxed sets of favourite films*
(LL36) *she was obsessional about that –*
(LL37) *but it was just a sign of the sort of love she felt for everything.*
(LL38) *She didn't just like things, she loved things.*

(LL39) *And I had this naughty little daughter*
(LL40) *that gave me lots of grief, argued with me,*
(LL41) *but I thought the world of her.*
(LL42) *But I don't know if I did think the world of her,*
(LL43) *she wasn't that sort, she wasn't what I expected.*
(LL44) *I wanted a little girl I could dress up in pink*
(LL45) *and send to ballet lessons*

(LL46) *and she was a tomboy, total tomboy.*
(LL47) *until she got to middle age,*
(LL48) *and she took an interest in clothes*
(LL49) *and started being a very blingy person ..*
(LL50) *I think she always was fairly extrovert.*
(LL51) *She liked a crowd, she didn't like my preference for quiet things.*
(LL52) *and thoughtful things.*
(LL53) *And when I say thoughtful –*
(LL54) *I mean sort of philosophical,*
(LL55) *talking about what might be, what's not real.*
(LL56) *So lots of my ideas we argued about when she was young.*

(LL57) *I'm going on, there's so much of her, there's so much of her.*
(LL58) *I don't know where it's come from.*

(LL59) *I didn't, I didn't want her.*
(LL60) *And I think I probably didn't bond with her.*
(LL61) *But then .. aaah .. I suppose that made her the person*
(LL62) *I couldn't really get close to,*
(LL63) *well I was close in a mother-daughter sort of way.*
(LL64) *She was always wanting to involve me in things*
(LL65) *and I was always resisting.*
(LL66) *'Oh Mum come and hear this'*
(LL67) *'No I haven't got time I'm too busy'*
(LL68) *'Come and hear this it's good' ..*
(LL69) *I rejected all those things about her.*
(LL70) *'Oh I haven't got time for that.'*
(LL71) *But then when she was a child*
(LL72) *and I was trying to involve her in things I thought she'd enjoy,*
(LL73) *'Oh I don't want to, I want to go out!'*
(LL74) *So I had this child who was always resisting.*

(LL75) *She could wind me round her little finger!*
(LL76) *I think she was very manipulative.*
(LL77) *Well I thought so at the time. I wonder now.*
(LL78) *I felt she'd got this power over me.*
(LL79) *That she could get whatever she wanted from me.*
(LL80) *Yes, a lot of the time I felt she had me where she wanted me.*
(LL81) *That's the growing up person, not the grown up person.*

(LL82) *I so felt we weren't on the same wavelength,*
(LL83) *different sorts of people,*
(LL84) *and something I loved,*
(LL85) *whether it was music, a book, a television programme or place,*
(LL86) *she wouldn't.*
(LL87) *Now I think it was just a way of being different*
(LL88) *from her dominant mother.*

(LL89) *Dad she wanted,*
(LL90) *it was her Dad's show of affection that she wanted,*
(LL91) *And as she got older, that was really troubling to her,*
(LL92) *because he was so critical*
(LL93) *and that mattered to her.*
(LL94) *He'd say something negative about the way she looked,*
(LL95) *'What have you got that different haircut for?'*
(LL96) *'Why did you choose that colour?'*
(LL97) *Mmm. He didn't realise what he was doing*
(LL98) *but she spent a long time*
(LL99) *trying to get people to love her that didn't love her*
(LL100) *– a big part of her life.*

(LL101) *Shall I tell you about the happy things or the bad things?*
(LL102) *The bad things are just that*
(LL103) *I didn't give her enough time or attention or value.*
(LL104) *I used to make it quite clear to other people –*
(LL105) *'I don't know where she came from – she's not mine!'*
(LL106) *It was quite light-hearted - 'It's not me!'*
(LL107) *She could be outrageous, she could shock you,*
(LL108) *she was funny .. she could be very funny.*

(LL109) *And she's a much more sensitive person than I ever thought.*
(LL110) *She must have known about all the marriage problems.*
(LL112) *My husband and I split up and she came and lived with me.*
(LL113) *She was 14, I've heard since it's the worst time.*
(LL114) *God knows what sort of legacy that left her with,*
(LL115) *and dictated the rest of her life.*
(LL116) *And that's the sort of thing I torture myself with.*
(LL117) *She was such a lovely person, and loving,*
(LL118) *but she got such a rotten deal.*

(LL119) *I think she would talk to anybody, she's one of those kids.*
(LL120) *I had a neighbour brought her back –*
(LL121) *I was always listening to the radio –*
(LL122) *and a neighbour up the road brought her back.*
(LL123) *And she said, 'Oh Alison came to see me!'*
(LL124) *Why did I not take any notice of her?*
(LL125) *I don't know what I thought about her.*
(LL126) *I thought when she was older,*
(LL127) *'She's sensible, she can look after herself.*
(LL128) *I didn't wait up when she was a teenager going out*
(LL129) *Cos I said, 'I know you'll come back, I know you're ok,'*
(LL130) *and she said, 'You don't know what we got up to Mum'.*

Death

(LL131) She didn’t deserve it, poor old Alison.
(LL132) And everybody said that.
(LL133) And everybody wrote eulogies about her.
(LL134) She had a lovely funeral, horrible death,
(LL136) When they eventually gave her something
(LL137) cause they thought it was the right time –
(LL138) all along she thought ‘I’ve got a terminal diagnosis –
(LL139) why the hell won’t they put me down when they do it to a pet?’
(LL140) The hospice couldn’t get the pain under control
(LL141) and they can’t for all of them.

(LL142) She was still smiling, still making jokes from a bed,
(LL143) because - she explained it to me –
(LL141) she wanted to be surrounded like Julius Caesar
(LL142) by people who laugh and smile
(LL143) she didn’t want me around in the beginning.
(LL141) People said, ‘she’s protecting you’, and I thought
(LL142) maybe she is protecting me, but it’s awful.
(LL143) and she explained it eventually –
(LL144) ‘It’s because all the time I have my friends around me
(LL145) they make me laugh, we joke and we chat, and I forget it,
(LL146) and when I see you I see your face your pain reminds me’.

(LL147) She desperately didn’t want to die, but she wanted it over.
(LL148) She was frightened of the pain I suppose,
(LL149) and the loss of control of every organ.
(LL150) Her face was just bones and skin, there was nothing of her.
(LL151) But quiet and peaceful I guess –
(LL152) and that’s what I’ve managed to get rid of,
(LL153) I don’t want to remember it,
(LL154) I’ve got to remember the happy times, the good things.
(LL155) We weren’t all hugs.
(LL156) We did hug towards the end and she’d go ‘eugh’.

(LL157) I think when I first heard it,
(LL158) Mark came into the house
(LL159) and he stood in the hall and said,
(LL160) ‘I’ve got some bad news for you Mum’.
(LL161) And he told me .. I don’t know how he told me ..
(LL162) ‘It’s Alison, she’s got cancer’.
(LL163) I don’t know if he went into ‘She hasn’t got long to live’.
(LL164) I just screamed, ‘She can’t, it’s not possible’,
(LL165) and I yelled and shouted,
(LL166) ‘How can bloody God do such things?’

(LL167) And the NHS – cos they didn’t diagnose her,
(LL168) but they don’t diagnose everybody,
(LL169) you only hear about the good things.
(LL170) I’ve met several people who know of others
(LL171) with misdiagnosis or lousy ends,

(LL172) *but it’s hard to diagnose .. I can’t balance the two.*
(LL173) *I mean she was always in the doctor’s with her symptoms*
(LL174) *that’s what makes me so angry,*
(LL175) *constant bleeding, constant backache,*
(LL176) *I suppose it was assumed that it was the menopause.*
(LL177) *Whether she didn’t make it clear enough to the doctor’s,*
(LL178) *whether she made light, ‘Oh it’s just this backache again’.*
(LL179) *But that was shock! I was in shock from then on,*
(LL180) *and that’s what I feel is the only thing I ever want to do,*
(LL181) *shout about and be angry.*
(LL182) *Tears aren’t enough.*

Recovery

(LL183) *She lived in a village - she’d only been there three years -*
(LL184) *her own little cottage which she loved.*
(LL185) *And she made it a beautiful home cos she’d got lovely taste.*
(LL186) *And a garden, she loved the garden,*
(LL187) *and everything she touched, she made fun and beautiful.*
(LL188) *She was quirky and arty in her taste.*
(LL189) *She only had it three years!*
(LL190) *Her first proper house in the country,*
(LL191) *with birds and horses across the way!*

(LL192) *She became an alcoholic*
(LL193) *and had a drinking binge for many years.*
(LL194) *This was in the 2000s, and it was terrible,*
(LL195) *she was living at home for most of the time.*
(LL196) *It was a roller coaster, life was a roller coaster,*
(LL197) *you never knew where you were.*
(LL198) *You’re living on eggshells,*
(LL199) *totally unable to keep arrangements.*
(LL200) *There came a point when I said,*
(LL201) *‘much as I love you Alison,*
(LL202) *you’re going to have to find somewhere else to live’.*
(LL203) *She retold it as, ‘Mum threw me out’ but ..*
(LL204) *I can’t! I will end up in the loony bin,*
(LL205) *I don’t know what reality is anymore because*
(LL206) *she’s just this crazy person.*
(LL207) *She was in hospital lots of times.*

(LL208) *She went to AA, became a devotee of AA,*
(LL209) *and the irony of that, the wickedness of that,*
(LL210) *was that she’d been going round saying,*
(LL211) *‘I’ve been dry for 6 years!’*
(LL212) *and then she got her diagnosis.*
(LL213) *And you think how did anybody get to be so unlucky?*

(LL214) And that’s what gets to me most
(LL215) and I have a great deal of difficulty getting rid of,
(LL216) and it’ll come back to me again now –
(LL217) I don’t know how anybody comes to terms -
(LL218) And I think of all the horrible things that happen in the world,
(LL219) like the 1st World War mothers that lost all their sons,
(LL220) and I think they must be as angry and bitter,
(LL221) it’s the innocence and the surprise.

(LL222) I play some of her music and records,
(LL223) I go aaaah, that makes me feel very emotional
(LL224) cos I don’t do it very often,
(LL225) but it would be good for me
(LL226) if I could release it and cry.

(LL227) Coming here, my anxiety had gone mad.
(LL228) And I realized when I’d had that when I was younger,
(LL229) I went to a doctor and they put me on pills.
(LL230) I didn’t go to a doctor this time, but I went through it.
(LL231) Moving from your home after so many years with Alison ..
(LL232) and I thought, that’s partly why I moved I expect,
(LL233) full of this idea of starting a new life.

(LL234) My old age is my third chapter and I’m giving in to it –
(LL235) I always thought, I’ve come up here, cut off from anywhere,
(LL236) apart from a rare busy day,
(LL237) and quite happy wanting a lot of time on my own.
(LL238) Though I recognize you’ve got to have a social life
(LL239) and I go and chat to people sometimes.

(LL240) But I’ve dropped off groups I can’t be bothered to go to.
(LL241) Classes I can’t be bothered.
(LL242) I don’t know if that’s depression, or old age, or what,
(LL243) or just a natural feeling.
(LL244) I was always a very adventurous person.
(LL245) I think I’m just resting and getting over it, don’t you?
(LL246) I’m just taking time to chill out,
(LL247) and I’ll take as long as I need.

When I went back to interview Ann for the second time, we talked about her childhood during the war, and her relationship with her mother which deteriorated when she was about 7, around the time her father came home from the war. Then her mother started beating her for bad behaviour. After that, she says, she didn’t like her anymore (‘I loved her, but I didn’t like her’). During our third conversation in person, she told me something she did as Alison was dying:

Her last words to me were, ‘I’m so sorry Mum’, and I didn’t know what that was about. And I didn’t know what to say. I should have just said, ‘I love you’. I kissed her when she was dying – they’re incredibly soft aren’t they, lips?’

4.2.1 Further analysis of Ann's story

'From the complications of loving you
I think there is no end or return.
No answer, no coming out of it.'

From 'A Pretty Song', by Mary Oliver

Arthur Frank writes about storytellers' 'varying levels of willingness to let their stories loose', and Ann seems to give her story like a gift for us to do as we will with (Frank, 2010, p35). She goes to one place, then another, seemingly contradicting herself. There is pain and regret, but she is also enjoying playing with the thoughts and memories.

At our third meeting, I took the text I planned to use for her story and read it out to her. I was struck by her pleasure at hearing her own words. She mainly nodded in recognition and smiled at various turns of phrase she had used. As we read it we decided certain sections were best left out. One sensitive area (Alison's alcoholism) she decided needed to be kept in, because, as she said, it was important to the story. I agreed. There was little anxiety about getting the story 'right', other than to protect her daughter's privacy sufficiently. Her perspective was aligned with my social constructionist one: her story was not a fixed entity, but a snapshot of her ever-evolving understanding of her daughter.

Relationship

Broadly this is a narrative about Ann trying to make sense of her relationship with Alison. Her descriptions are colourful and full of energy and extremes: words like '*over the top'* (LL10), '*obsessional*' (LL36), and '*fantastic*' (LL10). There are lots of material objects too – birthday and christmas cards (LL10), '*blingy*' jewellery, a huge collection of CDs (LL32). It is as if she is trying to conjure Alison into life, her colourful existence reflecting the energy of youth and the increasing noisiness and materialism of the 1980s onwards. Then the pace slows as she remembers her own preference for '*quiet things and thoughtful things'* (LL53) and becomes aware of all the images flooding her mind, '*I'm going on, there's just so much of her, I don't know where it's come from'*.

Ann has knowledge of psychological ideas: she describes how she '*didn't bond with her*' (LL60) and gives a picture of their ambivalent relationship (LL59-LL74). Then '*She's a much more sensitive person than I ever thought'* (LL108). Her reworking of the story of the relationship, in an atmosphere of self blame, is almost like a tormented lover rebuking herself for what went wrong. What can have prompted Ann to be so questioning of herself? As Klass and Steffan (2018) point out, meaning-making is not an individual process, but is created and sustained within communities. My guess is that it is not just losing Alison that has prompted this reappraisal, but conversations with Alison's friends and carers around the time of her death, who all talked about the best in Alison.

She uses popular expressions to describe her relationship with Alison as a child which reveal how idioms can become part of the narrative of a relationship: '*she could wind me round her little finger'* (LL75) and *'we weren't on the same wavelength'* (LL82). These seem to come from a less reflective part of her. But she adds, as if to acknowledge the confusion of identities, '*Now I think it was just a way of being different from her dominant mother'* (LL87-88).

In LL103, the confessions continue, '*I didn't give her enough time or attention or value'*. Then, mirroring her light-heartedness with her tone, she says, '*I was quite light-hearted, it's not me!*' (LL106). There is a sort of wanton mimicking of her former self, and then she goes on to say of Alison, *'she could be outrageous, she could shock you,'* (LL107) as if it is herself she's talking about. Fragments of identity are shifting and changing not just through time, but even between mother and daughter.

In LL119-LL130, she tells the stories of little Alison going off down the road by herself and being brought back, and later not waiting up for the teenage Alison. No allowances are made for the fact that times have changed somewhat and parents are now expected to be much more watchful of their children, with the result that she seems quite self-critical.

Redemption

The final section of the narrative, ‘Recovery’, is so-called because it is about Alison’s recovery and also about Ann’s. Alison’s recovery is from alcoholism: the story of her hitting rock bottom and then recovering so spectacularly that she is able to act as a mentor to others (which Ann told me Alison did) is the classic story of a recovering member of Alcoholics Anonymous (McAdams, 2013). According to McAdams (p201-2), in AA stories, ‘the downward spiral is viewed as having been necessary. The suffering had to occur; it was all part of some master plan. He or she eventually moved past fear and shame to acceptance and serenity’. McAdams’ interest is on the story as an example of Erikson’s mid-life generativity, with generativity in this case being the performance of one’s own narrative identity: ‘By ‘re-storying’ their lives as redemptive talks, recovering alcoholics are able to wrench meaning and hope out of a most difficult course of events’. So it is that Alison, through this redemptive narrative of her mother’s, becomes a fundamentally very good person who has suffered a series of contaminating episodes (since childhood). The idea of basic goodness is also part of humanistic thinking (Rogers, 2004). These ideas are now firmly embedded in our culture, but they have left Ann wondering where she went wrong.

Mother blaming

As I discuss later, Ann’s story has a very psychological and moral flavor and I think this emphasis might be partly to please me. Overall, her story plays into the cultural narrative of mother-blaming, which according to Harrington (2016), began during the 1930s, with a growing belief in deviance and mental disorder having their roots in the environment, but became more prevalent after World War 2, when there was a new idealization of domesticity and the monogamous nuclear family: ‘In the postwar era, however, it took an increasingly punitive and accusatory edge .. the failure of the mothers to love their children in the right way came to be seen as the witting or unwitting pernicious force behind virtually every form of deviant citizenship within society.’ So Ann both grew up and became a mother herself in this climate, which continued right through to the 1980s when the dominant cultural understanding finally started to shift.

Continuing presence and ontological flexibility

Ann has no hesitation in thinking and speaking in spiritual or religious terms. Life is not about concrete realities but ideas (she likes 'talking about what might be, what's not real', LL55). There are various ways that Ann's text implies Alison's continued existence in her life, from 'there's so much of her, there's so much of her' (LL57) to 'I play some of her music and records, I go aaaah, that makes me feel very emotional' (LL23). At our third meeting I spotted some glasses tucked behind a coffee table, which she was delighted to have back having lost them a week ago. I wrote down her delighted response:

> *'I think children you love might live in a cell in your brain somewhere – that's comforting – to think they're there – and that's why things go well sometimes – and I thought somebody's behind that! [finding the glasses] Maybe she hid the glasses!'*

Even here, the contradictions of her relationship with Alison are apparent – on the one hand she is a comforting companion, and on the other she is the naughty child who might have hidden the glasses as a deliberate ploy. She may also have been saying something about her relationship with me, a woman almost exactly her daughter's age, who is manipulating her (as Alison did, LL76) into producing this long story, but also keeping her company.

It was at my third interview with Ann that she spoke so movingly about kissing Alison goodbye (p82). As if describing her very first kiss, she looked at me wide-eyed for a moment as she said, *'they're incredibly soft aren't they, lips?'* The intensity of this moment seemed to have heralded some new awareness, a sort of awakening which hinted at post-traumatic growth, and may have played its part in triggering the reworking of the past in which Ann was now engaged.

Chapter 5: Discussion

I will now discuss the implications of this narrative research, talking first about what these stories do or how they act in the world. Then I will revisit my methodology, before looking at the issue of power in this project. I will then consider ethical issues and finally look at themes that emerged when I look across the different analyses.

5.1 What do their stories do?

Alex's fast-paced story took me on an exhausting journey to show me the devastating effects of the past 20 years of her life. McLeod (1997, p4) might call this a story of someone (or rather a family) 'moving steadily towards their fate'. In a follow up phone call after the first interview, she said she had felt better for telling it – but, as I wrote in my research journal (29 April 2019), she was also wondering whether 'a load of personal stuff' was really relevant. Her stuff *was* relevant in my view, but only as part of the story. Perhaps when she tried to dissect it later, the sense of causality was missing and it made no sense; the story and its meaning were inextricably linked. Jack used his story to speak out too. He told his story of staying silent and, in the process, broke that silence. What happened? Perhaps it was the need to fulfill the demands of storytelling (Flick, 2014) that led him to articulate thoughts previously forbidden to him. And Ann presented me with a time-shifting, ever-evolving story which refused to settle down into traditional narrative form, and demanded our joint effort to weave the contradictory threads of her stories together. This is the story of a relationship with her daughter, its structure embodying their ambiguous relationship.

I understand Alex's storytelling as an appeal to me as a fellow human being to acknowledge and recognize the psychological strain she has been under. Stroebe and Schut's (1999) Dual Process Model of bereavement has recently been updated to recognize the importance of 'overload' (Stroebe and Schut, 2016), an accumulation of stressful events which complicates a bereavement. Alex shared her experience of overload with me. Sitting alongside her on the sofa, I am another woman, listening closely to what she has to say and empathizing (visually if not verbally) with her story. It is not a 'true' version of events (in my social constructionist philosophy there is no underlying true version) but one co-constructed in relation with me.

Jack's storytelling is also help-seeking: Men remaining silent in the face of loss may have been beahviourally modeled by his father, who was also a quiet man and had lost both parents before he was 19. There is also a more general cultural expectation in the UK that men do not show their emotions (McQueen, 2017). Jack used the story to articulate his distress in a way that could potentially be shared with others. I did not feel like a counsellor or psychotherapist as he told his story; because of the arrangement of the room we were sitting alongside one another in an arrangement that seemed to evoke the sense of twinship (Kohut, 1984) he shared with his father and grandfather. At times his story flowed out of him so easily that I felt a little extraneous to his story, not ignored exactly but a channel for his thoughts and reflections, a guardian of the recording device. By speaking to me about his grief, he was abiding by the constraint of detailing in story-telling (Flick, 2014) and providing me with information he might not otherwise share. This was not, by the way, the only way I experienced Jack; outside of this particular conversation, I found him talkative and engaging, particularly during our second conversation which was mostly about his childhood and his family's history in the town where they lived. This took place on video call but was face-to-face, so may have encouraged a different kind of interaction, but the subject matter was also less emotive.

My third participant, Ann, was highly aware of my training as a psychotherapist and knew what psychotherapists and counsellors do. Her story in its psychological focus may have been unconsciously fashioned to draw me in, to please me, to forge a relationship or enjoy her connection with me, perhaps because she was missing her daughter who was my age. She was familiar with counselling which she had had after her mother died. Her story includes references to mother-child bonding, child-rearing practices, mental health, addiction, the impact of divorce on her daughter, and so on. This provides an interesting perspective on what it is like to live through decades of different psychological fashions. She also uses the term 'loony bin' (*LL204*), reflecting the perjorative way mental hospitals were talked about in this country until deinstitutionalization in the 1980s. The words themselves seem to imply that mental breakdown marks a point of no return to the normal world, and this is offered as the reason she could not help her daughter further (although of course in reality she continued to support her). Thus the content of this story redeems Alison, but the function of the story may be to seek understanding and redemption for Ann herself as a mother.

5.2 Methodology revisited

Recruitment for this project was not easy. Initially I tried to find a residential home or homes from which to recruit participants but seemed to experience a ‘gatekeeping’ effect by staff, which I imagine could be a serious barrier to research of this kind being done in future. For example, after being accepted to do research at a retirement village, recruitment was then attempted through the staff by word-of-mouth. No participants were forthcoming. Eventually, having decided to source participants from the community instead, a staff member at one charity suggested she could place a request on their Facebook page. I had thought about using social media before, but was concerned that I might receive such a sea of replies that I would not feel able to choose amongst them without leaving some volunteers feeing rejected. I no longer felt so concerned about this, given my struggles to recruit. The recruitment advert used the text of an email from me to the charity, which included my designation as a psychotherapist This had not necessarily been planned, and its implications are considered below. Nonetheless I was delighted that in this way I was able to recruit three participants.

After this, the ethical considerations and dilemmas involved in the research were mainly focused around ensuring the wellbeing of participants and myself throughout the process and afterwards. This meant doing my best to limit any emotional distress that might be caused by the research process itself, protecting the identity of participants, and protecting relationships between participants and members of their families, given there was always a chance they might hear about and read the contributions.

When I phoned participants after my first research conversation with each of them, none reported feeling distressed afterwards, and two out of three spontaneously expressed relief at having been able to talk. I had made it very clear from the start that they could withdraw at any time, but no participant ever mentioned wanting to do so. However, at times I wondered what would happen to my research project if they did, particularly given the small number of participants, and I wonder if this anxiety ever conveyed itself to them. I just had to tell myself that if all the participants withdrew, then my submission was not meant to be! As regards my own self care, I did find the material quite overwhelming and I entered personal therapy for four months to minimize the effects of this on the participants and research.

After transcribing the first interviews, I decided not to show participants the raw transcripts of our conversations, out of consideration for their wellbeing. All three of my main participants seemed to lose any inhibition during their storytelling, despite knowing I was a researcher. So for example there were comments like, ‘I’d only say this to you, Hannah’. McLeod (1997) observes,

> It is as though the human capacity for reflexivity, of being not only able to experience something but to monitor that experience and reflect on what it might mean, is largely suspended when a story is being told.

I suspect that had I shown them full transcripts, there was a risk that one or two of the participants might have been very upset or even withdrawn. There is a great difference between relating a story in conversation to an attentive other, and seeing that story written down to be recorded in perpetuity, particularly because a transcripted text, in written form, does not include emotional tone, crying, volume and emphasis. One participant nevertheless described themselves as sounding ‘embittered’ when they read my first version of their story. That participant’s response could also be interpreted in another way: that I had produced a stronger not a gentler version of the story, which made it more powerful.

Anonymising the participants’ contributions was more complex than I had anticipated. I made a decision early on in the development of this research that I could not ask any participant to keep their involvement a secret from their family or friends. Instead I suggested that they might be thoughtful about whom they told they were taking part. All participants told at least two family members about their participation, and it is hard to say how many more family members would eventually find out. I was therefore mindful that the accounts would have to be constructed so as to minimize the chance of damaging family relationships in future. This was one reason I edited the material very extensively after the first interviews, which meant the process of choosing which parts of the text to include was driven as much by a process of exclusion as inclusion.

The apparently more straightforward process of anonymising the text from the wider world also led to fairly extensive discussion with the participants, because for them, such changes risked making their story (or a character within it) unrecognizable to themselves. So in general I ended up omitting details about a person or a place (for example the geographical location of an event) rather than changing it, which may have resulted in the stories being less easy to read.

My own 'further analyses' or commentaries on the narratives (in which the participants were not involved) was also written with the participants' well-being in mind. Josselson (2007) compares reading about oneself to hearing one's voice on tape, which most people do not particularly enjoy. If any of the participants read and object to something I have written in future, I want to emphasise that these are just my interpretations: many others are possible.

Was this therapy as well as research? I had been advised by the narrative researcher Kim Etherington (personal communication, October 2018) to present myself as a researcher, not a therapist, but the participants in this study already knew I was a psychotherapist when they were recruited because it was mentioned in my recruitment advert. This may have reassured my potential participants as they read the advert, and encouraged them to contact me (it may of course have put other participants off). It may also have led them to believe they would be receiving some sort of treatment. I told them I 'had my researcher hat on' for the purposes of this research, and yet I myself struggled not to slip into my therapist persona at times. For example, during my first conversation, and once the main story had been told, we started to have more of a back-and-forth exchange, in which I sometimes found myself 'reframing' what they said, especially when they were being self-critical. I think in the circumstances this was probably appropriate, but it required my constant monitoring and judgement. There were also times during the interviews that it was definitely appropriate for me to use my therapeutic skiils, for example to convey empathy when the participants were crying (which all of them did, fairly openly). As Josselson (2007, p546) says,

> If we are good interviewers and the interview is intensive and extensive, people will often take the opportunity to articulate the most sensitive areas of their lives .. this interpersonal dynamic requires that we be good containers, that we can listen empathically but nonjudgmentally, feeling from the participant's emotional space … rather than the locus of our own emotional reactions.

5.3 Power

Social constructionism and its associated values suggests that in narrative research there should be an equal distribution of power between the researcher and her participants. Power nevertheless affects all interviews and conversations, and is constantly being negotiated and constructed. Power can be determined by 'socioeconomic status, educational or professional background, and gender or ethnic diversity of the parties involved' (Anyan, 2013).

In relation to this study, the researcher (me) is female, white and middle class. My participants were also white, middle class and British so there were no striking issues around race, culture or class. My position as a student researcher gave them power: I was delighted to have recruited these participants, and therefore keen to please. I had travelled several hours to see them, and I knew they could stop the interview at any time, and withdraw from the study if they wanted to. They also held power in relation to the location of the interview, which was in their home. I could only stay for as long as they were willing to have me.

On the other hand, I had a professional identity as a researcher and psychotherapist, and I had a recording device which I would be taking away from the visit with their voice on it. I was an experienced interviewer (and I also work as a therapist so I am very used to one-to-one conversations about intimate topics in a professional setting), whereas as far as I knew they had rarely been interviewed before and may have felt nervous. It was likely I was going to be the one deciding what we talked about, and having control of the material afterwards, so in that sense I held a very powerful role. I tried to maintain a friendly, open manner which is likely to have reduced any perceived power imbalance. Their age may also have created a power imbalance, given public perceptions about older people being helpless and dependent.

During the analysis phase, when I immersed myself in the interviews and spent long periods of time thinking about their stories, I had somewhat more control than the participants, although I knew any version of their story would be subject to their approval, and that if they did not like it, they might withdraw. For this reason I gave participants complete control to remove any part of their story if they wanted to. Participants were very different in this regard: one made lots of changes, another made very few, and another engaged me in a collaborative discussion until we reached a consensus. This collaboration seemed to work well and participants were more engaged that I expected them to be.

5.4 Ethics and other thoughts regarding working with a couple

I had decided before the study that I would not ask the two married participants to keep any information from one another at any point. Quite apart from my not wanting to appear manipulative, such a request would have been based on a positivist expectation that this might give me better or truer results. However I had not considered that a participant might share significant information with me that he had been reluctant to share with his wife [Section 4.1.3, Paragraph 9]. After much thought, and trusting in my clinical judgement that this might be a helpful intervention, I sent the quotes to the couple by email, one document for each. As I expected, they then shared them with each other. I do not know the details of their discussion in regards to this, but when I spoke to them sometime later they told me that doing the research had been a very positive experience.

Alex and Jack's positioning in relation to their stories were quite different. Alex seemed to speak from an authoritative place, as head of the family, and Jack from an outsider position, as someone not in control of what was happening. Similarly their grieving styles seemed to be somewhat different, with Jack very quiet and withdrawn whereas Alex was able to talk about her loss. Hansson and Stroebe (2007) noted how models of bereavement coping have over-focussed on intrapersonal processes of grieving and neglected important interpersonal dynamics that could affect outcome. However, there is limited research on how couples influence one another during coping with the bereavement of a child. For example, Dijkstra et al (1999) showed that perceived discordance in terms of loss- versus restoration-orientation in the DPM was negatively related to mental health in bereaved parents, whereas Wijngaards-de Meij et al (2008) found that men whose partner was more restoration-oriented had less severe grief intensity. Further Albuquerque et al (2017) have looked at the interaction between couples' coping responses and an outcome variable of successful meaning-making and benefit-finding — 'meaning-made' (Park, 2010). They identified a possible contagion effect of grief intensity within a couple, leading to lower meaning-made.   Given the concept of 'overload' recently integrated into the DPM by Stroebe and Schut (2016), it is not hard to imagine how two people whose coping systems are overloaded could heighten one another's distress. The importance of understanding the expression of grief as embedded in a system is further shown by a study suggesting that partners who avoid talking about the loss and try to stay strong with the aim of protecting the partner inadvertently increase the intensity of their partner's grief (Stroebe at al, 2013).

5.5 Discussion of themes

When I look across the contributions of my participants, I notice how very different they are. As Frank (2012, p110) says, 'each person's story can remain unique while being representative in that uniqueness'. I will now discuss what seem to me to be shared themes.

5.5.1 Feeling excluded

Most of my participants felt sidelined at some point.   This was particularly strong in relation to their experience of enacting parenting roles, leaving them with overwhelming regret that they were not able to 'mother' their children. In Alex's case, she wanted more access to her son when he was seriously ill, but was usurped in her role by another family member. Ann would have liked closer contact with her dying daughter, but her daughter wanted her friends around her, so she could briefly forget she was dying.   And my pilot participant Barbara would simply have liked to know more about what happened to her son, but was reluctant to ask questions. These varied experiences are relatively unexplored in the literature, because of the focus on spousal loss in the bereavement literature on old age.

It seems apparent that Jack even felt excluded from former parts of himself (*'I think if I stopped having contact with Lucy, I think I would just fade away ..'* paragraph 9). There is evidence for the popular idea that parents who feel regret and disappointment over their own lost opportunities may vicariously resolve their unfulfilled ambitions through their children (Brummelman, 2013), in particular if the parent sees their child as part of themselves, experiencing a sense of oneness with them (Aron et al, 2004). If death is the end of Andrew's story ('the end of Andrew's story was that he died, paragraph 8), then Jack must feel a part of him has died too.

5.5.2 Role reversal

The experience of my participants speaks to the popular concept of role reversal in old age, in which the parent is compared to a child depending on the son or daughter (now taking the parent role) for support. It seems from the experience of these participants that the term 'role reversal' oversimplifies the situation, with the level and type of dependence varying across individuals. Whereas Alex was dependent on Andrew for her vision of a safe and supported future, Jack seemed to express more emotional dependency, wishing he could go on living life vicariously through Andrew. In contrast, one of my pilot participants, Sarah, expressed some relief that her daughter was now in a safe place. It would not be surprising to find a very mixed picture with regard to dependence at this particular time in life, since this is the age when people typically start to transition towards greater dependency (Centre for Policy on Ageing, 2014). A subtler and qualitative examination of this transition, separating out emotional and physical changes, would be an interesting addition to the literature.

5.5.3 Overload

This research highlights the activation of two motivational systems in relation to the loss of an adult child in later life: the Caregiving and Attachment drives (George and Solomon, 1999). Caregiving is the less well known of the two, but it has been operationalised not only behaviourally but also neurobiologically (Lenzi et al, 2015). The continuation of this bond is captured so well for me by Joan Didion's (2012, p97) refrain to her sick daughter and variations on it, 'You're safe, I'm here', and by my participants' urgent wish to be at the bedside when their children are ill.

It may be that child bereavement in later life constitutes a sort of ‘double whammy’ in which both attachment and caregiving drives are overstimulated. Hypothetically this might seem more likely around the age of 80, when typically the more practical element of any role reversal begins to happen (Centre for Policy on Ageing, 2014). In my view this makes the bereavement of a child towards the end of life an interesting focus of study in terms of its integration into existing models of bereavement, such as the R-DPM (Stroebe and Schut, 2015).

Stroebe and Schut (2016), in discussing the concept of ‘overload’ as an addition to the DPM, note that bereaved people may encounter more loss- or restoration-oriented stressors than they feel able to deal with, or experience a sense of conflict between dealing with stressors, resulting in emotional and/or physical exhaustion. Interpersonal difficulties may further contribute to a feeling of overload. They say little more about the specific symptoms of overload, but Kastenbaum’s (1969) slighty different concept of ‘bereavement overload’ (referring specifically to multiple bereavements) is linked to death anxiety, intrusive experiences and difficulty reconstructing a meaningful self-identity. Stroebe and Schut (2016), drawing on the concept of ‘openness’ (Dyregrov and Dyregrov, 2008), suggest the bereaved person should be encouraged to be frank, honest and direct about their needs, with supporters needing to listen, understand and respond appropriately. In practice, they admit, it may not always be so simple. I discuss the potential usefulness of this concept further in the context of this cohort of older people, in 5.5.5 below.

In terms of the implications of this work for psychological therapists or clinicians, it is suggested that a simple question which raises awareness of a bereaved adult’s recent history (what other losses or changes have you suffered in the past few years?) would raise overload as a risk factor for physical and mental health problems. Further research into the nature of overload in later life in particular seems warranted.

5.5.4 Continuing Bonds

We all find ways to remember people we love. The holocaust survivor and pianist Alice Herz-Sommer lost her only son when she was 98. Her biographer (Stoessinger, 2016) relates how she stopped playing the piano for several weeks, but then slowly started playing again. Later she reported feeling glad that he missed the sorrows and pain of old age, and says the many photographs displayed around her room remind her that he is dead, while videos of him working as conductor made her feel he was still alive: ‘Technology is amazing .. Who knows, someday, maybe with technology, there will be no more death’ (p152).   Like Barbara, my pilot participant, there were times when Herz-Sommer could bask in the illusion that her son was still alive.

The Continuing Bonds literature has generally tended to treat their development as an intrapersonal process, done alone, but Jack’s experience of feeling stymied in his wish to visit Andrew’s grave and house highlights the importance of a systemic perspective on Continuing Bonds (see 5.1.2). This may be particularly true in older age, if individuals become increasingly dependent on other family members. There seems to be a paucity of research on Continuing Bonds that are achieved or developed via relationships with other people. The DPM-R of Stroebe et al (2015) recognizes their importance, but Jack’s narrative illustrates how difficult they can be to achieve, especially when they are incompatible with other values such as spousal loyalty.

5.5.5 Asking for help

Members of the ‘Silent Generation’ are less likely as individuals to complain and ask for what they want (Independent Age, 2016).   In general, they have lived by stories of people enduring hardship without complaint during and after the Second World War, and were often taught not to ‘wash your dirty linen in public’. New societal narratives around the benefits of Openness (Dyregrov and Dyregrov, 2008) may encourage older people to speak out about what they need as a way of addressing difficulties. These could include those highlighting the benefits of psychological therapy for this age group.

5.5.6 Faith and spirituality

There is conflicting evidence on the importance of faith in bereavement (Becker et al, 2007). All my participants but one mentioned the importance of their beliefs at some point during our discussions, and both Ann and my pilot participant Sarah seemed to draw particular comfort from religious beliefs and spiritual experiences. This was an area that could have been explored more deeply with participants during my questioning phase, but at the time it did not seem of particular interest to me. This may have been partly a reflection of my own experience of my father's death, because organized religion was not helpful to me. In addition I may have fallen into the trap of dismissing this area of experience, because I hold an expectation that this cohort of older people have grown up with organized religion and are therefore more likely to talk about God and hold spiritual beliefs. This expectation may have led me to overlook their individual experience.

The medicalization of grief, with its associated reliance on evidence grounded in a positivist philosophy, sits uneasily alongside spiritual experience. The DSM-5 (American Psychological Association, 2013) mentions hallucinations as being an associated feature supporting diagnosis of Persistent Complex Bereavement Disorder. It would be useful to be able to clarify how spiritual experiences and healthier forms of bereavement may incorporate a sense of presence or even hallucinatory experiences.

5.5.7 Moving into old age

Alex's narrative of the future reveals a sense of precariousness about the future, as she confronts the fears associated with very old age (L152-154, *'We just always thought / both Andrew and Sharon would be there for us / when we got really old'*). According to Higgs (2010), newer and more empowering narratives around disability, chronic illness and earlier old age (up to the age of about 75) have left the oldest old identified with a narrative of frailty, 'with frailty defined less by the identities of those who are deemed frail than by what frailty seems to augur in its direction of travel', and no validated identities or empowering self-narratives to draw on. Gilleard and Higgs (2015) call the fourth age a moral black hole, 'where human agency is no longer visible'. A clearer understanding of the relationships between aspects of very old age and their relationship with society would offer a more nuanced understanding of this period of life and reduce the danger of 'othering' older people. This point would seem to be supported by Hubble and Tew's (2015) research, which draws on longitudinal data sources (including the Mass Observation project set up in 1937 to study the lives of ordinary people) to creatively explore individual experience of old age. Their findings identify the emergence of an understanding which sees a process of continuation, rather than any sharp differentiation, in the transition from the newly retired years of the 60s and 70s into the older age of the 80s upwards, with the difference being understood as a product of historically-contextualized behaviour.

In contrast to Alex, who fears moving into old age, Jack seems unable to see a future at all (‘*I sort of go through the motions really. I really just stopped,’* paragraph 3.) According to McAdams (2001), when individuals describe their life story they spontaneously use temporarally extended periods, such as marriage, as chapters to create an overall structure. Kirkegaard Thomsen et al (2017) have talked in terms of the need for bereaved people to ‘give up a planned future’ in order to rewrite a different one. It might seem that these narrative-focussed researchers are taking on as their own the old 20th century idea of needing to relinquish bonds!

5.6 Implications for the practice of psychological therapy

This study demonstrates that because of the complexity of grief, psychological therapists (and others) risk missing important aspects of bereavement in old age if they focus too narrowly on the loss of a relationship. Didion (2012) says, ’We tell ourselves stories in order to live’. This study shows that gaining a narrative sense of the experience of the loss of a child in old age — whether it be the years of struggling with a daughter’s alcoholism, the endless journeys ‘up and down’ to different hospitals, or the fear of other relatives dying of the same disease — can give access to knowledge only implicitly held by the client. For example, self-blame, noted as a possible symptom of Persistent Complex Bereavement Disorder in the DSM 5, was present to some extent in all the participants’ contributions, but not only in relation to the events of their recent bereavement (so for example, they also questioned whether they had acted appropriately in their child’s early life or in relation to their divorce).

In addition, this study also shows the danger of over-reliance on chronological time and how this might limit our understanding of a person. Firstly, in relation to bereavement, we should not assume we know how long grieving will take, what it will involve, or how it will progress. And secondly, as therapists, we need to be wary of allowing the concept of age to dominate our thinking. The many cultural narratives favouring youth, and those that project frailty firmly onto old age, mean the term ‘old’ carries many associations. In order to keep an open mind about the individual concerned, it is better to think in terms of a person having lived for 80 years (with all the richness that implies) rather than use their age as a label.

Finally, like my participant Alex, I might be accused of '*living in a dream world*' (L178) for saying this, but I would love to see people like her routinely offered psychological therapy, not because she falls into any diagnostic category, but because she has suffered a wide-ranging and traumatic loss that deserves attention.

5.7 Limitations

These participants were self-selected via social media: there is no pretence that they are a representative sample of older people experiencing being bereaved of their child. All are white, heterosexual and middle class. Cohort effects need to be acknowledged which will make any findings less relevant to people of the same age in future. According to Baars (2012), this could be called the 'Heisenberg principle of uncertainty in aging': just as it seems to be impossible in quantum theory to determine the position and moment simultaneously, we cannot determine aging, or cohort independently of each: 'We can only hope to determine specific forms of aging in retrospect.' Also, grieving can be a lengthy process, and there is no longitudinal perspective in this study. These participants were still in the midst of their grief and trying to manage the early implications of their loss. A longitudinal perspective would give a better sense of how (and if) participants feel they have coped. The above limitations are to some extent built into the design of this small qualitative study.

Further, the need for anonymity limited the contextual detail that could be included here, but which would (if included) have further enriched my analysis. Similarly my own story could not be truly let loose in these pages because of the need to protect my family's privacy; had this been possible, there would have been more opportunities to reflect on how my participants' stories interacted with mine.

5.8 Future research

People tend to think of grief as becoming manageable after a year or so, but these participants were still seriously affected by the death of their child nearly two years later. Although some had been offered bereavement counselling soon after the death, it would be interesting to know more about the impact of interventions at this later stage post-loss. This might also encourage GPs to refer older people to IAPT (Improving Access to Psychological Therapies). Of people who use these services already, most are under 75 and very few are over 90 (NHS Older People's Mental Health and Dementia, 2017).

Enduring parental grief normally associated with the loss of younger children was seen in all these participants. An older parent's strong need to continue looking after their sick child seems to be under-recognised by society. Further research could have implications for policy in hospital, hospice and other settings, and also affect psychotherapists working with anticipatory grief as well as bereavement.

This research has opened up questions about the relationship between life story, identity (McAdams, 2001) and the loss of an adult child in old age. Further work could address how this type of loss might interact both with a person's life story and personality variables like attachment style or epistemic trust (Fonagy, 2014), giving insights into the process of change and adaptation in old age.

Other types of losses could also be explored by work similar to this, particularly those which tend to go unrecognized — so-called 'disenfranchised' losses. For example, the impact of family estrangement towards the end of life (Aglias, 2011) could be a fruitful and important area for exploration.

Chapter 6: Conclusion and reflections

According to Etherington (2016), ‘when we enable other people (and ourselves) to give voice to experience, those voices create a sense of power and authority’. Narratives of passivity and lack of involvement are countered by the contributions of these participants. They have told vivid and evocative stories about the death of their adult child. Importantly they were not just talking about the distant past, but their experiences over recent years. They were also speculating about their lives in the future. Baars (2012) contrasted ageing discourses about old age, senescence and the ‘social existential process of living in time’. This work shows lives do not just stop in old age. Narrative research brings individuals to life by giving them a voice. It is hard to think of anything less compatible with a peaceful and passive slowing-down, than the stories told here of experiencing the illness and death of an adult child.

Current narratives around old age concern the growing population of older people as a ‘burden’ – with the implication not only that they will cost a lot of money, but also that they might have little to give back to society. A recent report on ageing in Britain contrasted our atittudes with those of European countries where older people are valued. According to Lindemann (2014, pg x), the way in which we ‘hold people in their identities’ affects how they think of themselves:

> We are initiated into personhood by interactions with other persons, and we simultaneously develop and maintain personal identities through interactions with others who hold us in our identities. This holding can be done well or badly. Done well, it supports an individual in the creation and maintenance of a personal identity that allows her to flourish personally and in her interactions with others. Done badly, we hold people in invidious, destructive narratives. Some such narratives identity the social group to which someone belongs as socially and morally inferior, and in that way the stories uphold abusive power relations between ‘us’ and ‘them’.

We need to provide alternative narrative resources to ensure that the oldest people are integrated into our society as fully-fledged members. We need to give serious attention to the fact that while there have been many attempts to tackle other prejudices (for example, those based on gender, ethnicity, sexualty), age prejudice has not received the same attention. In future I hope we will find other language to talk about older people: ‘people who have lived a long time’ is rather wordy, but, unlike ‘old’ and ‘ageing’ at least carries with it the implication of a rich history.

Is narrative inquiry an appropriate way to do this job of changing the perception of the oldest people in society? The statistics produced by quantitative research simply are not going to change minds in the way that is needed. Much as they highlight the need for extra resources, they do not engage people’s minds in the way stories do. Reports on ageing such as those produced by government think-tanks use qualitative research alongside quantitative, but are illustrative of a theme, rather than portraying an individual in all his or her complexity and context. In contrast, narrative research shows ageing as just one facet of a person’s identity, and challenges unhelpful narratives. If by telling people’s stories of their experiences in old age, we can elicit empathy or partial identification with the narrator from readers, then we have begun the process of changing the way we hold older people in their identities (Lindemann, 2014), so that they become ‘one of us’ instead of ‘not us’. The more we can explore common or difficult experiences in older age, the more we build a web of meaningful connections between young, middle-aged and old.

The terminal illness and loss of a child in childhood or young adulthood draws huge sympathy for parents (and deservedly so). But when a child dies in middle age, it seems the role of parents gets lost: the nuclear family is the focus of attention and older parents can feel invisible. All my three participants felt pushed out and overlooked in different ways. In a conversation with Jenny Jones (9 July, 2019) who, with her husband, runs a support group for bereaved older parents in West Sussex, she told me how hard it was to find help. In her experience, internet searches bring up lots of advice about what to do if a child or teenager has died, but not an adult child. Members of her group feel forgotten by a large part of society.

My difficulty sourcing participants for this study suggests creative ways to access this population are needed, at least for independent researchers like myself.   This may become less of an issue as the use of social media amongst older people becomes even more widespread (neither of my pilot participants had access to email, for example). In this study the difficulty recruiting participants was overcome by using social media to contact potential participants directly. This method of recruitment and its potential pitfalls could benefit from more research. It would also be interesting to know how this might interact with the cautious ‘gatekeeping’ behaviour by carers which I encountered in my initial search.

Having been so deeply immersed in this work, I can now stand back a little and reflect on my own experiences. It has not been easy and there have been many reminders of my parents’ and grandparents’ deaths. But I am now so comfortable speaking to my psychotherapy clients about dying and death that they must sometimes wonder at my morbid fascination. It is no longer a cliché, death really has become a part of life. There is also in me a deepening existential awareness of life’s unpredictability, and an appreciation of meaning-making as an ongoing process, not a destination. I cannot know what my own old age will bring. As Watts (1987, p43) says:

> We think that making sense out of life is impossible unless the fix of events can somehow be fitted into a framework of rigid forms … But if this is what “making sense out of life” means, we have set ourselves the impossible task of making fixity out of flux.

The liberation and peace that we hope for in old age is fragile and susceptible to change. With luck we will continue to have an ongoing sense of purpose and meaning as we grow old (and sufficient narratives to draw on which support this) but we are all reliant on our good relationships, past and present, for our sense of security and this leaves us vulnerable, just as we have always been, not least in the face of the death of a child.

When my father and grandfather died so close together nearly 30 years ago, I could not imagine how my grandmother would survive. I have always wondered what she would have said if I had asked her about it. What have I learnt about her from this study? In one sense, quite a lot: it is as if I have got to know her again from the perspective of my middle age. But in another sense I have learnt nothing at all, because no individual’s story is like anyone else’s. It is not as if the story she might have told me is lying somewhere fully-formed but hidden from view: it has not yet been constructed (and it seems unlikely it ever will be). What has changed is that now, in my mind, her image is almost crowded out by context — her friends, her home, what I know of her life history, and her historical and cultural contexts. Reissman

(1990) wrote of the impact of working with narratives about divorce on the way she looked at the world:

> I could no longer view the interviews as objects, from whom data could be extracted and analyzed separate from the contexts in which they were created. I saw active and imaginative subjects, women and men who reflected on themselves … I began to see divorce as an interpretive process, not as a series of stages. I became intrigued with the imaginative enterprise itself – how individuals, through talk, construct meaning out of loss .. The subjects had changed the investigator, and thus, the research.

Through doing this research, I have become far, far more aware of context, and appreciate more deeply what Riessman (2015) meant about reflexivity when she compared it to ‘entering the hall of mirrors’. I started my life in the same place I live now and I feel very comfortable here. I have spent years amongst the changing local narratives which constantly shape my experience, and I have barely noticed them. Perhaps this is why it has taken me so long to acquire this unsettling and embodied appreciation of the impact of stories.

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Appendix 1. Consent form

Research project – 'What is it like to be bereaved of your adult child in old age?'

Consent form

I confirm that:

1. I have read and understood the information given to me about this project.

2. I have felt able to ask any questions about it.

3. I agree to participate in it.

4. I understand I can withdraw *at any time* without giving reasons, and that I will not be questioned on why I have withdrawn. Once I have completed my interviews and they have been written up by the researcher, I will be given the opportunity to read my contribution and to remove any material I do not wish to have included.

5. I understand my contribution will be anonymised so that it remains confidential (e.g. use of pseudonyms) and I cannot be recognised in either the completed research thesis or in any journal or magazine article published about this research.

6. I understand that a small number of other researchers may be given access to this data as part of the research process, but only if they agree to preserve the confidentiality of the data.

Name of participant:

Signature:

Date:

Name of researcher: Hannah Cruttenden

Signature:

Date:

Appendix 2. Research information sheet

PARTICIPANT INFORMATION SHEET

April 2019

Researcher
Hannah Cruttenden
Home address:
Phone:
Email:

This research is being conducted as part of a Doctorate in Integrative Psychotherapy and Counselling Psychology at Metanoia Institute, validated by Middlesex University. The research has been approved by the Research Ethics Committee at Metanoia Institute. It follows the research guidelines of the British Psychological Society.

The progress of my research will be discussed with my research supervisors Dr Vanja Orlans and Dr Jenifer Elton-Wilson and my research consultant Professor Kim Etherington. They are bound by confidentiality agreements in respect of the data I share with them.

Title
"What is like to be bereaved of your adult child in old age?"

Summary of the research
The purpose of this research is to see what I can learn about the experience of being bereaved of an adult child in older age (77 years plus).

My aim is to give all participants in the research an opportunity to tell their own unique story, from their own perspective and as they wish to tell it, without any pre-determined sense of what that experience might be.

Method
The research will involve an initial face-to-face interview which will last approximately 45 minutes. This will take place at an agreed location (probably at your home, if you are happy for me to visit) at a mutually agreed time. I will audio record our conversation, using a small portable dictation machine. The recording will later be transcribed by me.

At a subsequent meeting, either in person or via Skype, we can discuss any further information you or I think might add to your story.

A final version of your story will be forwarded to you for approval. You will be given an opportunity to discuss, change or delete any information you do not wish to be included in the project.

Audio recording will be stored electronically (with password protection) and deleted on completion of the research project.

All participants will be able to withdraw from the study at anytime, up until the submission of the project to Metanoia Institute.

The final project will be stored in the library of the Metanoia Institute and will be in the public domain. In addition I may use the outcome of this work in future publications, research and conference presentations.

Confidentiality

The identity of any participant will be known only to me, and I will ask you to choose a different name to be used in the project. Other names, places or details such as job descriptions may also be changed to protect your anonymity and those of other parties mentioned in your stories.

Self-care

My intention is that any participant will benefit from telling their story, but it is possible that you may also have strong feelings during or after the conversations we have.

Contacts

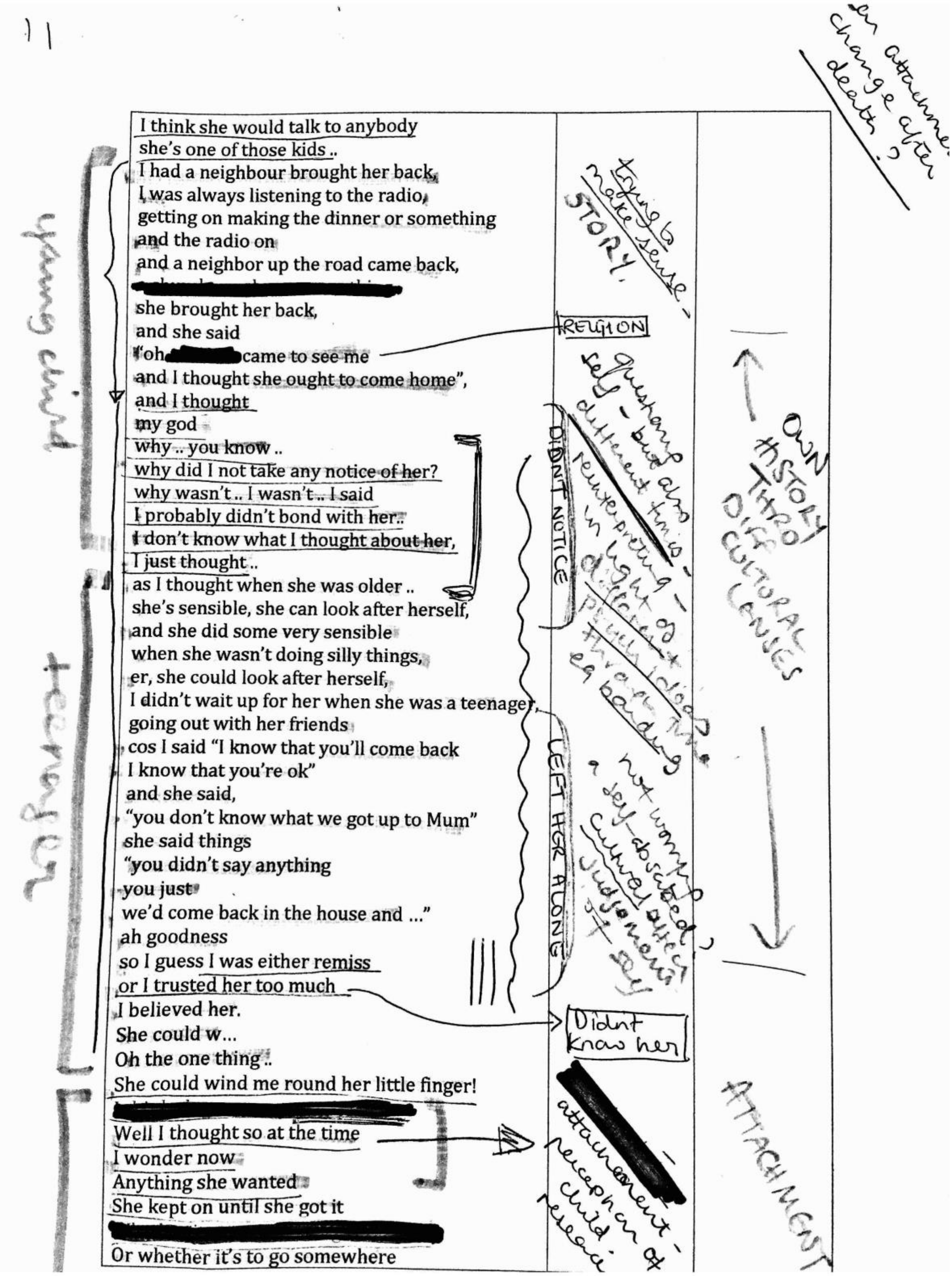
For any questions or concerns about this project please contact:

Dr Vanja Orlans
Email:

Or

Dr Sophie Bager-Charlson
Metanoia Institute
Email:

Appendix 3. Extract from my annotated transcript



11

I think she would talk to anybody
she's one of those kids ..
I had a neighbour brought her back,
I was always listening to the radio,
getting on making the dinner or something
and the radio on
and a neighbor up the road came back,
[redacted]
she brought her back,
and she said
"oh [redacted] came to see me
and I thought she ought to come home",
and I thought
my god
why .. you know ..
why did I not take any notice of her?
why wasn't .. I wasn't .. I said
I probably didn't bond with her..
I don't know what I thought about her,
I just thought ..
as I thought when she was older ..
she's sensible, she can look after herself,
and she did some very sensible
when she wasn't doing silly things,
er, she could look after herself,
I didn't wait up for her when she was a teenager,
going out with her friends
cos I said "I know that you'll come back
I know that you're ok"
and she said,
"you don't know what we got up to Mum"
she said things
"you didn't say anything
you just
we'd come back in the house and ..."
ah goodness
so I guess I was either remiss
or I trusted her too much
I believed her.
She could w...
Oh the one thing ..
She could wind me round her little finger!
[redacted]
Well I thought so at the time
I wonder now
Anything she wanted
She kept on until she got it
[redacted]
Or whether it's to go somewhere

young child

teenager

er attachme change after death ?

trying to make sense - STORY.

RELIGION

questioning self - but also different times - reinterpreting - in light of different present ideas? eg bonding

DIDNT NOTICE

LEFT HER ALONG

not worrying? a self-absorbed? cultural differences judgement of self

Didnt know her

[redacted]

attachment - perception of child research

OWN HISTORY THRO DIFF CULTURAL LENSES

ATTACHMENT

Appendix 4. Ethics approval letter

METANOIA
INSTITUTE

13 North Common Road
Ealing, London W5 2QB
Telephone: 020 8579 2505
Facsimile: 020 8832 3070
www.metanoia.ac.uk

Hannah Cruttenden
DCPsych programme
Metanoia Institute

4th May 2017

Ref: 18/16-17

Dear Hannah,

Re: What is it like to experience the death of your child in old age?

I am pleased to let you know that the above project has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please inform me as research ethics representative for the DCPsych programme.

Yours sincerely,

Prof Vanja Orlans
DCPsych Programme Leader & Faculty Head
Faculty of Applied Research and Clinical Practice

On behalf of Metanoia Research Ethics Committee

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