

**Exploring Parental Death in Adulthood Through Life History Research: A
Representation of Five Women's Experience of Loss and Grieving**

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I, Maria Eleonora Ramsby Herrera confirm that the work presented in this thesis is my own.

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Abstract

A considerable body of knowledge exists regarding the role of meaning reconstruction in bereavement. Yet the loss and grieving associated with losing a parent in adulthood, and their related meanings, remains an understudied area. In this context, bereaved adult children remain notably overlooked. This life history research was conducted in London, the United Kingdom. The study set out to explore five women's experiences of parental death in adulthood, to gain an understanding of their loss and grieving and what it meant to them. In-depth semi-structured interviews were conducted, followed by a life history analysis, which sequenced the research participants' narratives chronologically and composed a rich life history unique to each person. Through a critical engagement with the meaning reconstruction model originally developed by Neimeyer and colleagues, the discussion identifies four meaning activities within the women's life histories: (i) sense making, (ii) benefit finding, (iii) identity change, and (iv) assigning importance. Each activity presents a range of constructed meaning outcomes that reflect the women's bereavement experiences up close. The insights brought forth by these meanings demonstrate that losing a parent in adulthood, even when it has been anticipated and/or made sense of, is a significant life event that can have adverse consequences for the adult child and should therefore not be underestimated. This study supports and expands the scope of postmodern bereavement theories. It further demonstrates the usefulness of life history methodology as a means of exploring loss and grieving, with particular regard to how family history and the parent-child relationship shape these experiences. These findings enrich emerging understandings from the fields of thanatology and psychology, and can be harnessed to inform the general public, researchers, and bereavement professionals about the struggles and needs of the bereaved adult child, as well as how to provide them with compassionate and appropriate support.

Impact Statement

This study demonstrates that losing a parent in adulthood can be a significant and impactful life event that should neither be underestimated nor go unrecognised. The theoretical contribution of this study to existing academic research is its extension of knowledge in the understudied areas of loss and grief, and their related meanings in relation to parental death in adulthood. The study also demonstrates the benefits of using life history methodology in bereavement research, as it can offer a more in-depth picture of loss and grieving that considers the family history and the parent-child relationship across time. The study highlights the usefulness of Neimeyer and colleagues' meaning reconstruction model (see Gillies & Neimeyer, 2006; Neimeyer, 2019; Neimeyer & Anderson, 2002), as it helped identify and reflect on the meanings within the participants' life histories. More so, this study offers a critical evaluation of and some revisions to the model with the intention to improve its usage in future bereavement research. The combination of life history methodology and a theoretical meaning-centred framework strongly supports postmodern bereavement theories, as it shifts the focus from a clinically pathological perspective to viewing grief and loss within a wider context. This study therefore contributes to the incremental theoretical developments and paradigm shifts within bereavement research, which can be applied in future studies.

The insights presented in this thesis also offer potential benefits to contexts outside academia, as they can inform training programmes for health professionals in hospitals who deal directly with bereaved adult children. An improved understanding and application of bereavement care in hospitals can provide better support for patients and families who anticipate and/or experience death. This is important as hospitals are often clinically focused on treatments with little accommodation of grieving families (Caswell et al., 2015). Such educational development amongst health professionals ought therefore to be part of private

and public hospitals' clinical policy to ensure the provision of consistent and well-rounded care to patients and their families. This can help to improve the effectiveness of workplace practices and to define best practice for bereavement care in healthcare settings.

This study can further inform public engagement and interventions, which can help to dismantle disenfranchised grief within communities. Indeed, the disenfranchised grief seen amongst some adult children in this study showed the importance of enhancing a social understanding of this issue. This can be achieved by organising public events like festivals and exhibitions, as well as establishing public memorials which recognise adult children's loss and ancestry. Such activities can be arranged through local councils, bereavement activists and other stakeholders at local, regional, national, or international levels. These research-driven measures can inform social attitudes and values on loss and grieving, while challenging established norms and conventional wisdoms that risk disenfranchising grievers. Thus, this study has generated theoretical knowledge which can be utilised to inform public engagement, interventions, and debates that enhance the social understanding of parental death in adulthood. This, in turn, can promote the social inclusion necessary to prevent those grieving from suffering in silence.

Dedication

I dedicate my doctoral thesis to my parents.

Acknowledgments

I wish to thank the five women who participated in my study. Your life stories form the core of this thesis, and your unique voices shine light on the experience of losing a parent in adulthood.

A heartfelt thank you to my PhD supervisors, Professor John Vorhaus and Professor Eleanore Hargreaves, for guiding the way. And to my family and friends, for your unwavering support.

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Glossary

Adult: The Children Act 1989 states that a legal adult in England and Wales constitutes anyone aged 18 years of age or above. The United Nations' (United Nations, n.d.), guidelines for what constitutes adulthood, consider people aged 25 years and upwards to be adults.

Adult Child: The adult who is also their parents' child up until and beyond their death (Moss & Moss, 1984).

Bereavement: The experience of a significant loss whereby the bereaved person feels deprived of their loved one in some way (Corr, 2002). I will use the terms *loss* and *bereavement* interchangeably throughout this thesis.

Disenfranchised Grief: Grief that is not recognised as legitimate within society as it does not fit with certain societal expectations around dealing with death and grief (Thompson & Doka, 2017).

Grief: The response to bereavement. Grief comprises different expressions depending on the circumstances (Weiss, 2008). Such expressions are not limited to emotions, but can also include behavioural, cognitive, and physical expressions (Corr, 2002).

Grieving: The active process of experiencing and coping with bereavement over time. Grieving can be intra and interpersonal, and it includes, amongst other things, grief as a reaction to loss (Attig, 2011), meaningful rituals (Barboza et al., 2021) and the establishment of continuing bonds with the deceased (Klass et al., 1996). Although Attig (2011) makes a clear distinction between grief and grieving, these two terms are often used interchangeably within bereavement research and understandably so. When writing and speaking about grief, it is difficult to discern where the line can

be drawn between the two terms as they seem to be two sides of the same coin.

Therefore, the current study will refer to grief and grieving interchangeably.

Grief Symptoms: Features that indicate grief, for example depression, distress, and anxiety. The term *symptom* is problematic due to its pathologising connotations. In accordance with Corr's (2002) recommendation, I will avoid using this word (unless I am referring to an author who does). Instead, I will refer to "signs, manifestations, or expressions" (Corr, 2002, p. 46) of grief.

Loss Adaptation: Concerns how the bereaved person adapts to their bereavement.

This is a wide-ranging term that includes many things, and it can be approached narrowly or broadly, depending on the focus. A narrow approach often considers loss adaptation as something finite and limits it to the regulation of grief symptomatology. In its broader sense, it can concern cognitive, behavioural, physical, social, structural, and spiritual adaptations that occur post-loss. I will make distinctions between such adaptations to loss throughout this thesis.

Mourning: A social and public form of prescribed ways of expressing grief within societies and cultures (Attig, 2011; Stroebe, Hansson, Stroebe, & Schut, 2001).

Mourning can thus be seen as a distinct interpersonal aspect of a person's grieving experience.

Psychopathology: The study of mental disorders and dysfunctional, unusual, or maladaptive behaviours, and their symptomatic manifestations (Britannica, 2017). A psychopathological approach to bereavement usually focuses on grief symptomatology and how it can be regulated.

Chapter 1: Introduction

Personal Statement

It was my father's death in 2014 that led me to explore the topic of loss and grieving in a western society. My experience of being faced with a significant loss for the first time at the age of 24 led me to reflect on how we approach death and grief individually and within our social networks. While living in London, the United Kingdom, I soon realised that I had hardly ever spoken of, or heard other people discuss, bereavement and grieving. I felt unable to express my sorrow, mainly due to my perception that I would not be understood by others and that there seemed to be little room in my social environment for my experience to be voiced.

Occasionally, people would say things to me in an attempt to help me feel better, but this often exacerbated the pain I was experiencing. More so, I felt frustrated when some people would, unintentionally, normalise my loss by attributing my father's death to his age, as he was 79 when he died; yet to me it felt anything but normal. Such normalising often felt like a belittling of my experience, which resonates with Smith's (2003) assertion that the death of an elderly parent is often disenfranchised within western societies, since losing a parent in adulthood is so common that it often goes unrecognised.

Within only a few months, it felt as if my father's death was nothing more than a distant memory. People would no longer ask about my loss, and life continued on as though little had changed. Due to this, I felt the implicit expectations both within my social surroundings and within myself that life would get easier and that my grieving would begin to subside. These views were not helpful and seemed to only exacerbate the sadness I was feeling. Related to this is my experience of working at a senior level as a yoga and meditation teacher in the wellness industry since 2008. Being part of an industry where much emphasis is placed on positive psychology and well-being added to this pressure. Of course, there is

nothing wrong with feeling good, but the constant striving for happiness places an additional burden on a society already filled with stressful obligations, and this was not pleasant to encounter while being ridden with grief. Considering this, the words of Edith Weisskopf-Joelson (1955, as cited in Frankl, 2008) resonate deeply with me:

Our current mental-hygiene philosophy stresses the idea that people ought to be happy, that unhappiness is a symptom of maladjustment. Such a value system might be responsible for the fact that the burden of unavoidable unhappiness is increased by unhappiness about being unhappy. (p. 118)

Devine (2017) similarly highlights how western societies' obsession with positive psychology has produced a "grief-illiterate culture" (p. 32), whereby people are incapable of speaking about grief but rather seek to silence it or fix it as rapidly as possible, so they can move on to more important things. Such grief illiteracy resonates with me as I can see how it has shaped my own grieving experience, one that I learned to keep quietly to myself. Indeed, grieving my father's death was and still remains a lonely experience.

Given my personal background, it is beyond doubt that the loss of my father has influenced my positionality as a researcher, thus contributing to the shaping of this study. It partly explains why my primary focus is not on post-loss recovery, rather my study approaches loss and grieving with a view to understanding them better and accepting them as part of life. Perhaps such an understanding can help to address the grief illiteracy discussed by Devine (2017). I therefore conducted this study in the hope that it would generate insights that could spark compassionate conversations amongst those grieving the loss of a loved one, particularly adult children who have lost a parent later in life, as well as bereavement professionals and researchers in the field.

Research Aims

The present study aims to explore the experience of loss and grieving, as told by five women who have lost a parent in adulthood. It seeks to capture and contextualise the experience of loss and grieving, and the related meanings, of each research participant through their own interpretations. Thus, this study seeks to ensure that the narratives and voices of these five women are heard and acknowledged in a research field where adult children have too often been overlooked. The aim is to contribute to the much-needed conversation about what it is like to lose a parent in adulthood, and although the current study is lacking male perspectives, I hope it can lay the groundwork for male adult children to share their experiences in future life history research¹.

Research Approach

My approach is firmly situated in life history research. It draws on the collection of rich qualitative data, which is useful for investigating and contextualising lived experiences, including their personal meanings, nuances, and contradictions, to offer thick descriptions and deep insights into aspects of human life (Lanford, 2019; Pistrang & Barker, 2012). Data collection is achieved through in-depth life history interviews followed by a life history analysis that attends to the time lapses within the bereavement processes and any social, cultural, and historical contexts that are relevant to each woman's story (Cole & Knowles, 2001; Goodson & Sikes, 2001; Plummer, 2001). Additionally, guided by Neimeyer and colleagues' meaning reconstruction model as my theoretical framework (see Gillies & Neimeyer, 2006; Neimeyer, 2019; Neimeyer & Anderson, 2002), an emphasis is placed on

¹ An in-depth reflection on research participant selection and demographics is provided in the methodology chapter (see pp. 97-102).

identifying and exploring the meanings included within each woman's narrative to gain a fuller understanding of their loss and grieving experience and what it means to their lives.

Background

Losing a Parent in Adulthood Warrants Further Attention

In today's modern industrialised societies where people live longer, it is expected that a child's parents can remain alive until the child reaches middle age (Leopold & Lechner, 2015). Parents are expected to live long enough to see their child enter adulthood, increasingly take care of themselves, and rely less on parental support. Naturally, as the child grows older, the risk of losing an ageing parent increases. Indeed, figures suggest that this is one of the most predictable and major life events for people aged between 35 and 60 (Umberson, 2003). For example, a large-scale nationally representative survey conducted across approximately 30,000 households in the United States showed that 26% of adult children between 45 to 49 have lost a mother, and 45% have lost a father. For those aged 60 to 64, approximately 70% have lost a mother and 87% have lost a father (Scherer & Kreider, 2019). These statistics can explain why losing a parent during adulthood is considered an "on-time" event (Leopold & Lechner, 2015, p. 747), which is often anticipated and normalised by society as something that will happen to most, if not all, people (Umberson, 2003). In light of this, it is ironic that although many have lost or will experience the loss of a parent in adulthood, there still exists a significant lack of empirical studies on the subject in comparison to other types of bereavement.

The public view that losing a parent in adulthood is a common event is reflected in the large number of studies that engage with childhood loss of a parent, with a notable absence of studies examining adult children's loss. There exists a large body of research that explores parental loss in childhood by focusing on the psychopathology associated with bereavement

(Berg et al., 2016; Brewer & Sparkes, 2011; Christ et al., 2002; Gray et al., 2011; Kaplow et al., 2010; McCarthy, 2007; Rolls & Payne, 2007; Silverman & Worden, 1993). Additionally, several studies have explored how parental death in childhood later affects the mental health of the bereaved person once they reach adulthood (Agid et al., 1999; Hoeg et al., 2017, 2018; Hollingshaus & Smith, 2015; Stikkelbroek et al., 2012; Tuazon & Gressard, 2021). Yet only a limited range of empirical studies have dealt with loss of a parent during adulthood (Carver et al., 2014; Hayslip et al., 2015; Leopold & Lechner, 2015; Moss & Moss, 2013; Nickerson et al., 2013). This lack risks overlooking adult children's experience of loss and grieving, thereby excluding them from receiving the appropriate attention, care, and support that they may need.

Adult children's loss and grief risks being minimised within their social circles in western societies. Parental death in adulthood is often not thought to cause serious adverse effects in adult children (Moss & Moss, 1984; Umberson, 2003). Friends, colleagues, and family members may expect the bereaved adult child to rapidly recover and to resume their usual roles and responsibilities, emerging out of their loss as an unchanged person. However, adult children may experience pervasive changes in response to their loss, which may permeate their relationships, behaviours, social roles, and their perceptions about themselves (Anderson, 1980). Indeed, losing a parent in adulthood may be an ordinary event but it can bring about extraordinary change specific to the adult child, which warrants further attention (Umberson, 2003).

Alongside this, the impact that adult children experience in response to their parent's death is often surprising to them, and at times they think that they are responding to their bereavement in ways that are unusually strong or inappropriate. These feelings sometimes cause them to invalidate and suppress their own process, which may result in further distress (Umberson, 2003). Thus, raising awareness of this subgroup of people in bereavement

research can inform bereavement professionals and the general public on how to approach and engage with bereaved adult children in ways that acknowledge and validate their experience. Furthermore, this increased awareness may also help to inform and support the grievors themselves throughout their grieving process.

In response to this being an understudied area, a growing albeit small number of quantitative- and qualitative data research studies are emerging in the field of bereavement studies (see Hayslip et al., 2015; Leopold & Lechner, 2015; Rostila & Saarela, 2011; Umberson & Chen, 1994; Umberson, 2003). These studies have primarily investigated the impact that parental death has on adult children's psychological well-being. Yet there is a need to conduct additional qualitative data research to offer further insights into the dynamic, everyday loss and grieving experience of adult children within the context of their family history, which is what this study aims to achieve.

Supporting Developments in Postmodern Bereavement Research

Bereavement research has developed substantially since western traditionalist grieving theories were first introduced in modern psychology during the early 20th century and were further elaborated upon up until the late 1980s. At this time, the modernist paradigm considered grieving to be experienced through stages and comprised of universal symptoms. Emphasis was placed on detaching from the deceased and confronting grief head on, with the aim of recovering from grieving and returning to a normal pre-loss functioning (Neimeyer, 1998). However, such theories did not account for context and overlooked key aspects such as individuals' life histories and sense of personal agency, cultural and social circumstances, cause of death, age, gender, and relationship with the deceased. Furthermore, these approaches tended to generalise and pathologise grieving through a dominant focus on

symptomatology and resolution. Such a modernist approach has been described by Stroebe et al. (1992) as follows:

[it] suggests that people need to recover from their state of intense emotionality and return to normal functioning and effectiveness as quickly and efficiently as possible. Modernist theories of grief and related therapeutic interventions encourage people who have experienced loss to respond in just this way. Grieving, a debilitating emotional response, is seen as a troublesome interference with daily routines, and should be “worked through”. Such grief work typically consists of a number of tasks that have to be confronted and systematically attended to before normality is reinstated. Reducing attention to the loss is critical, and good adjustment is often viewed as breaking of ties between the bereaved and the dead. (p. 1206)

Some argue that the modernist paradigm is still relevant to how grieving is approached today (Doka, 1999; Granek, 2017; Thompson & Doka, 2017). Yet, alongside this, a “counterculture” (Granek, 2017, p. 264) has gradually grown stronger, which offers alternative postmodern bereavement theories. An example of such a postmodern shift concerns the search for meaning in bereavement (Neimeyer, 1998; Neimeyer & Anderson, 2002). This approach is founded on the view that people live by certain beliefs and assumptions – so-called assumptive worlds – which help them relate to and navigate the world they live in (Janoff-Bulman, 1992). However, a significant loss can disrupt this assumptive world and the individual’s place within it, leading them to search for meaning in their loss to “reaffirm or reconstruct a world of meaning that has been challenged by loss” (Neimeyer, 2019, p. 80). Such reaffirmation can be referred to as meaning *finding*, whereas reconstruction refers to meaning *making* (Attig, 2001). Thus, finding and making meaning of

one's loss experience has now come into focus and is seen as a central process in grieving, which stands in stark contrast to the modernist emphasis on grief symptomatology and resolution (Neimeyer, 1998, 2019).

Psychologist Robert Neimeyer (1998, 2000, 2016, 2019) is a leading researcher and theorist on this topic who has, together with colleagues in the field, developed the meaning reconstruction model in bereavement (Gillies & Neimeyer, 2006; Neimeyer, 2019; Neimeyer & Anderson, 2002). This model will be critically discussed in detail in the literature review (see pp. 48-67); however, in short, the meaning reconstruction model consists of three meaning-making and -finding activities: (i) sense making, (ii) benefit finding, and (iii) identity change (see table 1). The bereaved individual engages with these activities to either find or make meaning of their loss and grieving experience. This engagement is dynamic and personal rather than consisting of generalisable traits and, when approached holistically, it can occur across different dimensions of a person's lifeworld, which includes the physical, social, personal, and spiritual (Steffen, 2019).

Table 1

My own summary of meaning-making and -finding activities as seen in Neimeyer and colleagues' meaning reconstruction model of bereavement.

Sense making	An attempt to understand the loss, or experiences related to the loss, by asking why and how something came to be. It also explores the overall effect of loss in the life of the bereaved, for example, through metaphor or storytelling.
Benefit finding	Finding benefits from a negative event through the pursuit of a silver lining, i.e. finding something positive in an adverse event.
Identity change	A sense of personal change within oneself. One feels different in the aftermath of loss. For example, one may experience a changed life role or newly developed values. Identity change can also be likened to post-traumatic growth.

The meaning reconstruction model in bereavement is relatively new; yet, it has acquired a strong grounding in empirical evidence. Over the years, studies have investigated the role of meaning-finding and meaning-making in psychological loss adaptation for people who have lost a spouse (Coleman & Neimeyer, 2010), a family member or a friend (Currier et al., 2006; Rolbiecki, Washington, & Bitsicas, 2021), parents who have lost a child (Keesee et al., 2008; Lichtenthal et al., 2010; Rolbiecki et al., 2017); and people who have lost a sibling (Flesner, 2015). Results from these studies suggest that the processes of finding and making meaning support people's loss adaptation, whereas not being able to find or make meaning is linked to bereavement complications. Such empirical support has resulted in the development of new strategies for facilitating people's loss adaptation and has added significant value to the meaning reconstruction model, establishing it as a key theory within current bereavement research.

As part of this postmodern development, the emphasis on finding and making meaning in bereavement has provided a broader, and yet more personal, focus for the grieving experience. The meaning reconstruction model has proposed alternative approaches to coping with grief, which can facilitate loss adaptation in ways that are different from the traditional approaches of detachment, catharsis, and linear stages/phases that are seen as uniform to all grievers. Furthermore, it offers a dynamic and personal process that is continuously influenced by the person's existing meaning structures, as well as their life history within a socio-cultural environment. Considering this, one can learn more about differences in how loss and grieving is experienced, including the different meanings assigned to this by people across various contexts. Such insights can provide a better understanding of the diversity of grieving processes and associated meanings, in ways that are not limited to the perspective of one group of people or one theory. This can have enriching implications for the modelling and assumptions of future research, including

theories related to the meaning and nature of loss and grieving in general. Moreover, this progress increases the possibility that the bereaved will be better understood and cared for, which is why this study seeks to support such postmodern theories. This is particularly the case in the context of losing a parent in adulthood, as little research has been carried out to explore this experience within the framework of a meaning-centred model.

Disciplinary and Theoretical Framework

The current study is located within the academic discipline of thanatology, which concerns the study of dying, bereavement, and grieving (Meagher & Balk, 2013).

Thanatology is strongly linked to, yet distinct from, the discipline of psychology, and much of its bereavement research and theoretical developments overlap with this discipline and its many branches. Therefore, most of the literature I draw upon in this thesis, including my theoretical framework, is grounded in the discipline of psychology.

I chose Neimeyer and colleagues' meaning reconstruction model (see Gillies & Neimeyer, 2006; Neimeyer, 2019; Neimeyer & Anderson, 2002) as my theoretical framework for three main reasons: (i) it was relevant to my research questions; (ii) it was developed through a constructivist lens within postmodern psychology, thus making it suitable for my research approach; and (iii) it is a well-established bereavement theory that has been applied across both thanatology and psychology.

Most empirical research on the meaning reconstruction model has so far been concerned with its effectiveness for loss adaptation. My focus expands on this knowledge in two ways. Firstly, this study will use the model as a theoretical framework to identify and gain insights into the meanings the women make from their experiences of loss and grieving within their narratives. Learning about these meanings can allow for a more in-depth understanding of bereavement that adds to, and expands beyond, knowledge of whether

meaning reconstruction supports loss adaptation. Secondly, I will approach the meaning reconstruction model with a critical eye by exploring how the model and my data are related. I explore insights into my data as revealed by the model, whilst also exploring how the model might be refined and improved so as to make the best sense of my data (and potentially others' data of a similar kind in future research). This will enable the use of the model in the widest possible context of adult child bereavement.

Thesis and Research Questions

Neither grieving nor meaning-making/-finding happen in isolation. Rather, these processes are closely interlinked with a person's life history, including the personal and social relationships, cultural and religious beliefs, and other circumstances that permeate their history (Flesner, 2015; Neimeyer, 2000; Rosenblatt, 2008, 2017; Shapiro, 1996). Thus, exploring grieving and its attached meanings through the lens of life history research can help to take such contextual factors into account across time. Additionally, life history research can encompass the time prior to the loss, which portrays a fuller experience of a person's grieving process, rather than solely focusing on the grieving and loss adaptation that follow bereavement (as most studies have done). It is from this basis, of exploring the dynamic experience of grieving over time and its attached meanings within a life history context, that I approach my study. Therefore, in this thesis I pursue two connected inquiries: *the influence of a woman's life history experiences, particularly the parent-child relationship across time, on their experience of parental death in adulthood; and how the meanings included in their narratives, as related to loss and grieving, yield insights into this experience.* The thesis will be pursued through investigating the following research questions:

Principal Research Question

(i) How are loss and grieving experienced across time by five women in relation to parental death in adulthood?

Supplementary Questions

(ii) What is the significance of the parent-child relationship across time for the women's loss and grieving?

(iii) What meanings can be identified from their loss and grieving experiences?

(iv) What insights do these meanings bring to our understandings of loss and grieving?

Significance of the Study

The insights my study aims to promote can inform researchers, bereavement professionals, and the general public about an understudied area of bereavement studies that warrants further attention. In doing so, my aim is that we can learn how to approach the loss and grieving of a parent – our own and that of others – with an attitude of increased understanding, compassion, and acceptance. This can allow for conversations around losing a parent in adulthood to be increasingly voiced, thereby addressing grief illiteracies and grief disenfranchisement, which are embedded within our social environments, particularly those that may be experienced by adult children. I will not approach grieving as a problem to be solved, as I think this risks contributing towards its pathologisation and disenfranchisement. Yet, paradoxically, the acceptance and inclusion of grievers' experience within society may in turn facilitate their grieving process and support them in adapting to their loss in beneficial ways.

Structure of the Thesis

My dissertation consists of 4 further chapters. *Chapter 2* includes a literature review that outlines western theories and studies of loss and grieving in psychology from the early 20th century onwards. The literature review is divided into 3 parts. The first part, *Traditional Modernist Perspectives on Grieving*, broadly outlines psychological theories and studies which have laid the groundwork for grieving in western psychology and have had a strong influence on how it has been understood by clinicians, researchers, and the general public, from the early 20th century to the mid-1990s. The second part, *A Critical Postmodern Perspective on Grieving*, narrows the focus to the work of scholars in the field of postmodern psychology from the last three decades, all of whom have critiqued and expanded on earlier psychological theories on the basis that they pathologise, generalise, and fail to sufficiently acknowledge the complexity of grieving. The third part, *Critical Aspects of Losing a Parent in Adulthood*, zooms in further to discuss the significance of the parent-child relationship and challenges related to loss and grieving that are specific to adult children. It also presents an overview of key empirical research on parental death in adulthood. The three parts are followed by a concluding analytical summary where I state my stance as a researcher in relation to the presented literature.

Chapter 3 is the methodology chapter. The chapter includes a detailed description of the development and conduct of my research study and presents my research design and its qualitative life history approach. I describe and justify my theoretical framework and disciplinary and epistemological stance. Methods of participant invitation, data collection in the form of in-depth life history interviews, secure data storage, and life history analysis are explained and reasons for my choices are given. I discuss anticipated risks and limitations and how I prepared for them, including the ethical protocols and guidelines that were central to the study.

Chapter 4 includes the findings from my interviews with the five research participants of this study. Using life history analysis, I have constructed each woman's shared narrative into their own life history. Each life history is presented separately in alphabetical order and includes long passages of transcribed speech from each woman's narratives.

Chapter 5 includes a final discussion and conclusions, which elaborate on my findings in relation to previous literature and my theoretical framework. Limitations and recommendations for future research are discussed, followed by my conclusions on the study's main contributions to knowledge.

Selection of Literature

The literature discussed in this thesis was primarily acquired through the UCL library database. I conducted my search using subject keywords such as *adult children, adult grievers, bereavement, death, filial bereavement, grief, grieving, loss of a parent, meaning, meaning reconstruction, mourning, and thanatology*. These keywords generated a vast number of sources, so to narrow the material down I looked at relevant empirical research published in established peer-reviewed journals with high impact factors, such as *Death Studies* and *OMEGA Journal of Death and Dying*, as well as academic handbooks on bereavement and grief. My literature review dates back to Freud's (1917) publication of *Mourning and Melancholia*, which laid the groundwork for subsequent theories to come. I included relevant literature and research leading up until the 21st century. This provided a comprehensive historical overview of the bereavement literature and its theoretical development over time.

As I familiarised myself with the literature, I learned about key theorists and researchers in the field whose work I decided to explore further. I also looked at the literature they referred to, to discover additional relevant sources to draw from. This ensured that I was

selecting and referencing authoritative and established voices in the field of bereavement research. If I could not find certain literature and empirical research in the UCL library, I would then search for the authors' publications through relevant websites. This included searching on sites like Google Scholar and the professional websites of specific authors.

Chapter 2: Literature Review

A Brief Discussion of My Choice of Literature

By focusing on the most influential western theories and studies of loss and grieving in psychology from the early 20th century onwards, I am aware that my literature review only captures a limited aspect of bereavement studies that is particular to a certain time and place, both historically and culturally, and to a certain academic disciplinary perspective. Indeed, my literary content would be quite different if I had approached bereavement through an anthropological or sociological lens as it could have offered a broader contextual and cross-cultural picture of loss and grief. However, this was not of particular relevance for the current study, since it sought to focus on the participants' individual and personal experiences of loss and grief. Indeed, there is a fine balance to be struck between what to include and what to leave out when conducting a literature review. To manage this, I made sure to be guided by my research questions when making those selective decisions. That said, I will briefly discuss some of the areas of literature that I chose not to include in my thesis, to point the reader towards additional references that they can explore further on their own initiative.

People's grieving experiences are shaped by historical context and entangled in cultural practices (Jacobsen & Petersen, 2020). In England alone, grieving practices have shifted significantly from Victorian times – when grieving was visibly expressed, often through ritual practices, and shared to a high degree in public – to the period after the Great War – when Victorian grieving practices now seemed inappropriate and inadequate due to the mass deaths and absence of deceased bodies, which were lost and buried in the battlefields. In the latter context, grieving transformed into a private and suppressed matter that one had to suffer through in silence (Jalland, 2020). For example, from 1915, grieving families were prohibited from burying their deceased family members who had fought and died in the war. Furthermore, soldiers did not wish for their family to grieve over them if they died, as doing

so could have been seen as unpatriotic. Although this did not stop people from experiencing loss, nevertheless, a major shift occurred whereby grieving was now done in private rather than shared within the community. This so-called privatised grieving was intensified after World War II, where “personal grief was sacrificed in the midst of so much death and with such minimal ritual” (Jalland, 2020, p. 53). Instead, people who had lost family members in the war were expected to show courage and stoicism as an “emotional ‘breakdown’ amounted to cowardice” (Jalland, 2020, p. 57). Thus, as these examples show, grieving is a dynamic process that is shaped by historical events and the societal expectations of a particular time and place.

From the 1960s onwards, largely due to the growth of grief studies as an area of study and war widows’ need for support, expressions of grieving were gradually emphasised again. Personal and social mourning rituals now came to be welcomed once more in English society, particularly amongst women and the middle and upper classes (Jalland, 2020). Examples of this can be seen in Margaret Torrie’s establishment of *The Cruse Bereavement Care Organisation* for widows in 1959, and Peter Marris’s sociological study *Widows and Their Families* (1958). That said, the privatisation and suppression of grieving remains present amongst grievers in England, as well as other western societies, to this day (see Devine, 2017; Granek, 2017; Jalland, 2020). Evidently, history has had a big impact on societal norms and how individuals operate within those structures.

Cross-cultural studies lend further complexity and nuance to grief studies, as indeed one must also recognise the diversity of loss and grief beyond one culture. As Rosenblatt (2020) points out: “It is arguably unkind and harmful to impose the standards of one culture on people from other cultures” (p. 38). This is particularly the case when generalising about what constitutes healthy grief. Culturally diverse views of grief can be considered unhealthy and strange within the framework of western psychology. For example, according to the

Diagnostic and Statistical Manual of Mental Disorders (DSM-5) standards, as set out by the American Psychiatric Association (2013), if one is not grieving enough, one is considered to have complicated grief. However, mothers in Lusaka, Zambia, who have lost a child, are encouraged to grieve in silence and to not talk about the child, as it is not considered in the best interest of the deceased child's spirit (Smørholm, 2016). Thus, in this context, it is not a pathological sign, but rather a common cultural practice. Another example concerns the length and intensity of grieving. Again, according to DSM-5 standards, if one is considered to be grieving for too long, or too intensely, this too can be characterised as unhealthy grief. Yet, in Cairo, Egypt, grieving can carry on for years and is considered perfectly normal (Wikan, 1980). Other practices such as loud wailing, singing, and dramatic embodied expressions of grieving are common among non-western cultures (Akunna, 2015; Haram, 2021; Otaegui, 2021), which fall far outside the norms of western societies and the standards of DSM-5. It is therefore misleading and wrong to apply one culture's assumptions to another, as this limits the various expressions of grieving that exist cross-culturally.

Related to my previous point, although grieving is intimately connected with and shaped by social, cultural, and historical factors (Silverman et al., 2021), it is at the same time a deeply personal experience, which varies in emotional, spiritual and cognitive responses, and influences the bereaved person's daily life in various ways (Rosenblatt, 2020). Additionally, as well as possessing a social history, grief is also shaped by one's personal history (Jacobsen & Petersen, 2020), and the individual's needs, behaviours, and preferences. This can at times create a conflict in which the personal and societal expectations and practices surrounding loss and grief do not always harmonise with each other (Silverman et al., 2021). For example, Hochschild (2012) speaks of the intersection between a society's "feeling rules" (p. 56) and how the individual manages and navigates their feelings in relation to such rules. This is often done by asking oneself the question of *what do I feel?* and *what*

should I feel? At times, individuals consciously choose to disregard such rules, but often they must learn to manage their emotions in relation to what their social network considers to be appropriate. Hochschild (2012) also highlights the “inappropriate affect” (p. 59) seen within institutions, which refers to “the absence of expected affect” (p. 59). As Hochschild (2012) points out: “We can offend against a feeling rule when we grieve too much or too little” (p. 64). This seems to parallel the standards of DSM-5 and what the American Psychiatric Association deems to be healthy versus unhealthy grief.

These are just a few examples of how loss and grieving are shaped by a multidimensional range of factors, and due to my research focus I can only point the reader towards literature in which they can explore some of these perspectives in greater depth. Such references include the books *Exploring Grief: Towards a Sociology of Sorrow* (Jacobsen & Petersen, 2020), *The Handbook of the Sociology of Death, Grief and Bereavement: A Guide to Theory and Practice* (Thompson & Cox, 2017), and a recent special issue on Anthropology and Grief in *Death Studies* (see Silverman et al., 2021), which focuses on ethnographic perspectives, including both psychological and anthropological studies across different cultures. Such work is incredibly important to show the historical, social and cultural influences of grieving on larger communities, whereas my study will zoom in on individuals’ experiences: the particular contexts in which they are embedded and their personal life histories.

Part 1: Traditional Modernist Perspectives on Grieving

Sigmund Freud’s Mourning and Melancholia

The publication of Freud’s *Mourning and Melancholia* in 1917 laid much of the foundation for the understanding of bereavement and grieving in the discipline of psychology (Neimeyer, 2014; Parkes, 2001; Stroebe, Hansson, Stroebe, & Schut, 2001). An influential

contribution of this paper was Freud's definition of grief, which emphasised the importance of working through grief. Freud considered grief to be a part of mourning,² and he used the terms interchangeably throughout the paper. According to Freud, grief is the reaction one has when faced with bereavement. He describes it as follows:

Feeling of pain, loss of interest in the outside world – in so far as it does not recall the dead one – loss of capacity to adopt any new object of love, which would mean a replacing of the one mourned, the same turning from every active effort that is not connected with thoughts of the dead. (p. 153)

Freud proposed that, in attempting to reach a state of resolution, the bereaved person had to actively confront their grief through a process of catharsis. Catharsis is a term derived from Ancient Greek, meaning to purge, and it was initially used in psychoanalysis, specifically in the work of Freud and Breuer, from the late 19th century (Freud & Breuer, 1955). Catharsis concerns a curative breakthrough where patients can “release from the results of traumatic experiences earlier in the course of life” (Illeris, 2014, p. 16). Freud's colleague, Breuer, was the first to draw on the term in the context of psychotherapy, by using hypnosis techniques to treat those suffering from intense hysteria. Catharsis subsequently became a hallmark of Freud's psychoanalysis, being associated with the release of emotional conflicts by confronting them directly, and he applied this to bereavement as well, as seen in *Mourning and Melancholia* (1917).

² Freud makes the distinction between mourning and melancholia. The mental features of melancholia are the same as in grief, with one exception: the “fall in self-esteem is absent in grief” (Freud, 1917, p. 153). Additionally, Freud considers melancholia to be a morbid condition, whereas mourning is not. Freud uses mourning and grief interchangeably, yet later researchers distinguish between the two. Stroebe, Hansson, Stroebe, & Schut (2001) consider grief to be a person's reaction to bereavement, whereas mourning refers to “social expressions or acts expressive of grief” (p. 6) within a society or cultural group.

In addition to grief confrontation and catharsis, Freud's (1917) approach required the bereaved person to sever the attachment bond to the deceased, "which bound the libido to the object" (p. 154), and to attach their libido to someone or something else. This detachment implies that one should no longer remain connected to the deceased and should instead shift one's attention to other people or activities. When this "work" (p. 154) was successfully completed, then the bereaved person's ego would become "free and uninhibited again" (p. 154), implying that they would then return to a pre-loss functioning state.

Freud's *Mourning and Melancholia* offered a significant contribution to the field of bereavement studies and informed the development of further theories on loss and grieving. An example of this can be seen in the influential work of Eric Lindemann (1944) who coined the term "grief work" (p. 143) based on Freud's perspectives. Lindemann's work will be discussed next.

Eric Lindemann and the Symptomatology of Grief

Another influential theory, which drew on Freud's (1917) notion of working through grief, was Eric Lindemann's (1944) *Symptomatology and Management of Acute Grief*. This study was the first of its kind to offer a descriptive view of what could be regarded as normal versus morbid grief, including its symptoms and how it could be treated with the support of a psychiatrist.

Lindemann undertook his study during World War II and argued that "the enormous increase in grief reactions due to war casualties [...] demands an evaluation of their probable effect on the mental and physical health of our population" (p. 141). Lindemann drew on the data of 101 patients who had experienced bereavement due to a variety of causes and had sought psychiatric support. He investigated their grief reactions, drawing descriptive conclusions on what could be regarded as normal and morbid grief. Based on his sample, he

considered grief symptomatology to be “remarkably uniform” (p. 141) for all people and he concluded that five aspects are indicative of normal grief and are common to all who experience it. These include: (i) somatic distress i.e. “feeling of tightness in the throat, choking with shortness of breath, need for sighing, and an empty feeling in the abdomen, lack of muscular power, and an intense subjective distress described as tension or mental pain” (pp. 141-142); (ii) preoccupation with the image of the deceased where the bereaved person believes, to some degree, that the deceased person is still with them, and the bereaved person continues some kind of interaction with them through talking and/or visualisation; (iii) guilt that the bereaved person is feeling towards him/herself, whereby he/she “accuses himself [herself] of negligence and exaggerates minor omissions” (p. 142); (iv) hostile reactions where there is a loss of warmth towards and connection with other people and “a tendency to respond with irritability and anger” (p. 142); and (v) loss of patterns of conduct, which includes restlessness and a lack of capacity to maintain organised patterns of activities and social interactions. Lindemann suggested that when these five aspects become amplified for a long period of time, the bereaved no longer experiences what is regarded as normal grief, but rather a condition of morbid grief, which is a pathological variation of normal grief patterns. Morbid grief included, for example, a delayed grief response to one’s loss, and alteration in one’s conduct and relationships with friends and family. He further described it in the following terms: “agitated depression with tension, agitation, insomnia, feelings of worthlessness, bitter self-accusation and obvious need for punishment. Such patients may be dangerously suicidal” (p. 146). Lindemann thus also became the first to introduce a timeframe for grief whereby he assumed that it would take no longer than 4 to 6 weeks to “settle an uncomplicated and distorted grief reaction” (p. 144) with the guidance of a psychiatrist. Lindemann further leaned on Freud’s methods of working through grief to overcome it, and he coined this process “grief work” (p. 143), i.e. “emancipation from the

bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships” (p. 143).

The concept of grief work is associated primarily with the views of Freud (1917) and Lindemann (1944) and was adopted by clinical theorists in the fields of psychology and psychoanalytic studies of bereavement (Belitsky & Jacobs, 1986; Deutsch, 1937; Kübler-Ross, 1969; Parkes & Bowlby, 1970; Stroebe & Stroebe, 1991). This resulted in a literature on bereavement that placed the notion of grief work at its core, which remained historically dominant over the span of decades. This view stressed the “importance of working through the thoughts and emotions associated with the lost relationship, with particular emphasis on negative material and on relinquishing the attachment bond to the deceased” (Bonanno & Kaltman, 1999, p. 761). A failure to do so, or a delayed response to this requirement, was initially assumed to lead to pathological and destructive grieving patterns, i.e. “morbid grief” (Lindemann, 1944, p. 144). However, such views were later criticised for lacking empirical support (Bonanno et al., 1995; Stroebe & Stroebe, 1991; Wortman & Silver, 1989). What follows is an overview of such criticism and the developments that emerged in the aftermath.

Questioning the Usefulness of Grief Work

Later developments in bereavement research brought many contemporary researchers to question the uniform assumptions and usefulness of Freud’s (1917) and Lindemann’s (1944) approaches, as their theories might not be appropriate to everyone at a given time. Indeed, empirical research and the disclosed data on their effects amongst bereaved individuals has yielded mixed results (Bonanno & Kaltman, 1999; Pennebaker et al., 2001; Stroebe et al., 2005). Three key aspects of grief work have been criticised: (i) the need to confront one’s grief reactions, (ii) the need to detach from the deceased, and (iii) grieving as a means to an end, whereby once an endpoint has been reached the griever returns to normal. I

will discuss each of these aspects and will present findings from grief theorists and studies that question these assumptions.

The Need to Confront Grief. The longstanding notion that grief work is a necessary aspect of the bereavement process was increasingly questioned from the early 1990s. Stroebe and Stroebe's (1991) study focused on the aspect of grief work that concerned confronting the loss and grief reaction. They assessed whether confrontation through grief work versus grief avoidance had any influence on the psychological adjustment to bereavement. The sample consisted of 30 widows and 30 widowers whose spouses had died 4 to 6 months previously. Data were collected over an 18-month period and included structured interviews and self-reported questionnaires that measured levels of depression using the *Beck Depression Inventory*. Results showed that for widows, the performance of grief work was irrelevant to the outcome 2 years post-loss. However, for widowers, research demonstrated that grief work was associated with better psychological adjustment, showing lower levels of depressive symptomatology. These findings led the authors to question the role of gender in grieving and how men and women may process avoidance and confrontation differently due to social upbringing and cultural influences. They partially confirmed the grief work hypothesis by concluding that the extreme avoidance of grief work can be detrimental to the psychological adjustment for some, while simultaneously pointing out that the "absence of a relationship between grief work and outcome on depression for widows suggests that the view 'Everyone needs to do grief work' is an oversimplification" (p. 481). In a later publication, Stroebe et al. (1994) supported this notion further, stating that the benefits of grief work have not received sufficient empirical confirmation and that "it is not always necessary to work through grief" (p. 195). These findings align with other studies. For example, Bonanno et al. (1995) tested the view that emotional avoidance post-loss would lead to delayed grief, prolonged grief, and/or somatic symptoms. Their study induced

emotional disclosure in 42 participants within 6 months of the loss of a spouse, by asking them to talk about the deceased. Results showed that emotional avoidance served the adaptive functions of the bereaved and did not lead to any of the three hypothesised consequences. Additional studies have continued to question how useful confrontation is for the psychological loss adaptation of the bereaved, and their findings demonstrate that it does not always benefit such adaptation. Inducing grief work by eliciting strong emotional reactions through confrontation risks causing greater distress, and it does not guarantee that there will be any less distress in the future (Lister et al., 2008; Range et al., 2000; Stroebe et al., 2002, 2005; Wortman & Silver, 1989). Given these developments, the strongly held belief that one must always confront grief was no longer considered a go-to-approach for all griever.

Although many studies have suggested that confronting one's loss and grief is not necessarily beneficial nor useful for all people, there have been other contradictory findings. Some studies have shown that emotional disclosure through written or spoken word, as part of confronting one's loss, has offered some positive effects on the psychological adaptation of bereaved research participants (Kovac & Range, 2000; Segal et al., 1999). Furthermore, as Pennebaker et al. (2001) pointed out, when people experience a strong emotion or emotional event, in most cases they feel compelled to share it. Additionally, although the sharing of emotions may not always aid a person's psychological loss adaptation by reducing emotional distress and can at times evoke negative aspects associated with their loss, it may still contribute to other benefits such as the development and maintenance of close relationships (Pennebaker et al., 2001).

There are several reasons why some studies on the usefulness of grief confrontation contradict each other. Firstly, grieving is not as uniform as Freud (1917) and Lindemann (1944) made it out to be. Indeed, different griever have different needs and ways of expressing themselves. Secondly, as Stroebe et al. (2002) posited, when investigating the

usefulness of confrontation in grief work, one needs to be clear about what grief work entails and to not confuse it with rumination. Stroebe et al. (2002) defined grief work as follows:

We have always emphasized the importance of distinguishing ruminations from actual grief work in the study of the grief work hypothesis [...]. Grief work implies a process of confronting a loss—an active, ongoing, effortful attempt to come to terms emotionally with the loss. In contrast, ruminations reflect a passive repetition of events without any active attempts at coming to terms with the loss and all its personal implications. (p. 172)

Thirdly, studies that explore whether the aspect of grief work concerning confrontation is beneficial to the bereaved person's loss adaptation, may struggle with the fact that what is emotionally disclosed, as well as how, when and to whom, will influence the bereaved and the various ways that they adapt to their loss. Thus, Stroebe et al. (2002) suggested that grief work, depending on how and when it is defined and measured, appears to be supportive of some people's loss adaptation but not others. This would seem to apply also to how one defines and measures loss adaptation, as this too can take various forms, such as the development of certain relationships, as seen in Pennebaker et al.'s (2001) study. These aspects are important to consider as they add further nuance to the discussion on loss and grieving while challenging prescriptive methods.

The studies questioning the notion of working through grief through loss confrontation offer a valuable addition to developments in bereavement research. Such developments have contributed towards a broader perspective of grieving, which recognises that griever's have different needs and that their grieving can take different forms. As a result, other possibilities for how grieving can be approached have emerged in the field of

bereavement studies, and these will be introduced and discussed further throughout this chapter.

The Need to Detach From the Deceased. The second assumption of Freud (1917) and Lindemann (1944) concerned the requirement of detachment from the deceased, and this too has been put into question. Bowlby's (1961) attachment theory proposes that, from the time of infancy, children develop certain attachment behaviours towards their primary caregivers. The child's sense of security, especially in stressful circumstances, is dependent on the physical proximity to their caregiver, as well as the psychological proximity, which refers to having their emotional needs met (Field et al., 2005). The child's sense of security is contingent upon these attachment bonds. The attachment bonds are part of the "human evolutionary heritage" (Bonanno & Kaltman, 1999, p. 764) that ensures our development and survival as humans. Bowlby's (1961) attachment theory has been extended into studies on adult relationships and has been applied in bereavement theory (Bonanno & Kaltman, 1999; Field et al., 2005). When experiencing loss, the bereaved person can experience a rupture of their meaningful and secure bonds, which are attached to the deceased (Attig, 2001, 2011). Consequently, this rupture can cause psychological disorganisation whereby the bereaved person can experience grief reactions in various forms, for example through distress, sadness, anguish, insecurity, and a lack of meaning (Field et al., 2005). Thus, attachment bonds are important as they provide safety and comfort in people's lives, and this contradicts Freud's and Lindemann's views on detachment as a required response to loss.

More recent grief theorists and researchers have dismissed the view that successful mourning requires a relinquishment of one's emotional attachment to the deceased. Instead, later research has offered support towards maintaining some form of attachment with the deceased. For example, Klass et al. (1996) consider the importance of maintaining a connection with the deceased through *continuing bonds*. Such continuing bonds offer a way

to internalise “the deceased as an inner comforting presence” (Field et al., 2005, p. 282), whereby the bereaved person can remain “emotionally sustained by the mental representation of the deceased with less need for the physical presence of the other” (p. 284). In addition, empirical findings suggest that the establishment of continuing bonds is a natural and healthy response to loss, which can provide the bereaved with comfort and security while also helping the bereaved to preserve and/or restore part of their identity and meaningful connection to the past (Bonanno & Kaltman, 1999; Klass et al., 1996; Neimeyer, 2014; Steffen, 2019). Even Freud, at a later stage in his career, seemed to change his stance around the necessity and possibility of a complete detachment. In his letter to Ludwig Binswagner of April 11, 1929, Freud (1960) wrote,

Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish. (p. 386)

This quote contrasts with Freud’s (1917) earlier views in *Mourning and Melancholia*, as there is no longer any expectation of letting go of the deceased to move on with life. This seems a more reasonable response to loss, since the meaningfulness that a person has in one’s life, and the love felt for them, does not cease to exist after their death. Instead, as Attig (2001) suggests, the loss can serve as a transition from loving the deceased person “in presence” (p. 34), to loving them “in absence” (p. 34), and this too can be seen as a form of loss adaptation. However, the form of continuing attachment to the deceased, and the extent to which one expresses it, can also influence whether it supports the adaptation of the

bereaved (Field et al., 1999, 2003, 2005; Field & Friedrichs, 2004). Indeed, such factors ought to be considered when discerning whether continuing bonds are useful or not for the bereaved person. Nevertheless, the theory of continuing bonds brings an important nuance to the concept of grief work that otherwise oversimplifies a multi-faceted human experience.

Grieving as a Means to an End. The third assumption concerns the notion that grieving is a means to an end and that once a resolution is achieved, the bereaved person returns to pre-loss functioning. Freud (1917) spoke of resolution and the bereaved becoming “free and uninhibited again” (p. 154) and Lindemann (1944) assumed that it would take no longer than 4 to 6 weeks to resolve most grief reactions. However, later findings show that most people need more time (Lehman et al., 1987; Stroebe et al., 2017), and some may not even achieve a resolution of their loss (Wortman & Silver, 1989). Lehman et al. (1987) investigated the long-term impact of losing a spouse or child in a motor vehicle accident. The results demonstrated that even after 4 to 7 years, a significant amount of the respondents had not reached resolution. Rather, they still relived painful memories of their loved ones, continued to ruminate about the accident, and appeared to be unable to accept or resolve the loss, suggesting that a timely resolution or a full adaptation to their loss did not apply to them. These findings led the authors to question the notion of grief work and its focus on the detachment from the affective bond to the deceased. However, their sample involved bereaved people who had experienced traumatic and sudden losses. Responses may have been different if the deceased had died under less traumatic circumstances. Such consideration has been discussed in recent studies, which have demonstrated that a person’s ability and the time taken to adapt to a loss can be highly dependent on context. For example, parents who have lost a child tend to experience stronger grief reactions, which can remain to some degree throughout the duration of their life (compared to other bereaved populations) (Malkinson & Bar-Tur, 1999, 2005). This suggests that grieving is not just a means to an end

where the bereaved automatically returns to a state of pre-loss function; rather, grieving is context dependent and may not always be resolved.

Parkes, Bowlby, and Kübler-Ross: Grieving in Phases and Stages

Following Freud's and Lindemann's work, models with similar underlying assumptions, such as the phase/stage models of grief articulated by Kübler-Ross (1969) and Parkes and Bowlby (1970), gained popularity. The phases/stages conception approached grieving as a sequential and linear process, which emerged out of longitudinal studies where grieving was now investigated over extended periods. Parkes (1970) undertook a longitudinal study of 22 widows in London, where he investigated their grief³ and how it changed over a 13-month period, following the death of their husbands. Parkes concluded that grieving was a complex phasic process, which corresponded with Bowlby's (1961) theory of the phases of grief. Subsequently, Parkes and Bowlby (1970) developed a composite and descriptive classification of the phases of grief. Four phases were identified: (i) numbness, (ii) yearning and searching, (iii) disorganisation and despair, and (iv) reorganisation. *Numbness* involves the person feeling unable to register or accept the news of the loss. The ability to feel or respond emotionally is thwarted, as one feels stunned. *Yearning and searching* are characterised by an intense preoccupation with the lost person and an urge to reunite with them. *Disorganisation and despair* represent a state of apathy, hopelessness, and aimlessness. Life has no purpose, and one is not interested in looking towards the future. Lastly, *reorganisation* refers to how the bereaved have adapted themselves in a world without the deceased person, and the development of a new identity and a new set of assumptions about life.

³ Parkes (1970) refers to grief as a process that is a reaction to bereavement. For this study, Parkes uses the term grief and grieving interchangeably.

The four phases of grief, as outlined by Parkes and Bowlby (Bowlby, 1961; Parkes, 1970, 2001; Parkes & Bowlby, 1970) can be associated with Elisabeth Kübler-Ross's (1969) stage theory of grief: a model for the needs of the dying and those who are grieving the death of their loved ones. The model involves moving through five stages of grief. The first is *denial* and is considered a temporary defence mechanism, whereby the person who is dying or the person who has just lost someone rejects the notion of either terminal illness or loss. The second stage is *anger* and includes feelings of anger, rage, envy, and resentment, where the bereaved or the dying person asks him/herself *why me?* The third stage is *bargaining*, whereby one enters into made-up agreements, which creates the illusion of postponing the inevitable. The fourth stage is *depression*, which is a deep sorrow, often accompanied by shame, guilt and concerns about the future. The final stage is *acceptance*, which occurs once the other stages have been worked through. Kübler-Ross (1969) stated that "acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over" (p. 110).

These linear phase/stage models have dominated the field of bereavement and have been widely accepted by clinicians and the public (Flesner, 2015; Maciejewski et al., 2007; Prigerson & Maciejewski, 2008). The models' appeal lies in their ability to simplify the grieving experience, by categorising it into a series of predictable stages that lead towards a resolution (Prigerson & Maciejewski, 2008). However, the model has been strongly criticised. For example, Corr (1993) questioned Kübler-Ross's methods as her entire theory was based on her experience of working with "a particular social population dying in particular ways and in a particular time and location" (p. 72). Thus, Corr considered it a mistake to make such sweeping assumptions about grieving based on such a narrow sample. More so, several researchers later contended that there is limited empirical support to validate these models (Bonanno, 2009; Holland & Neimeyer, 2010; Maciejewski et al., 2007).

Maciejewski et al. (2007) conducted what appears to be the first empirical study of the Kübler-Ross (1969) stage theory. This was a longitudinal cohort study of 233 individuals in Connecticut, the United States, who had lost a family member or a loved one to natural causes (not to traumatic deaths). Quantitative data were collected over a 24-month period, between January 2000 and January 2003, using single-item questionnaires. Findings demonstrated that the temporal order in which the five stages occurred, during these 24 months, was quite different from how it had been chronologically outlined by Kübler-Ross (1969). It was found that the most common response was acceptance, thus contradicting Kübler-Ross's stage theory which suggested that denial would be the initial and dominant grief indicator and acceptance the final stage of adaptation. In response to their findings, Maciejewski et al. (2007) suggested that instead of considering stages of grief, they could be approached as emotional states. This was subsequently reinforced by Prigerson and Maciejewski (2008) who argued that "rather than distinct, sequential stages of grief, it may be more accurate to conceptualise proposed stages as multidimensional grief states that evolve and diminish in intensity over time" (p. 436). Indeed, taking that approach would be more helpful as it identifies different manifestations of grieving, which can occur in a person at different times, without fixing them in any order or assuming that they are experienced in the same way by everyone. In that sense, phase/stage models have been useful for capturing some of these manifestations. Nevertheless, given the lack of empirical support and the dynamic nature of grieving, it would be misleading to assume that phase/stage models capture the grieving process in a sufficiently accurate way. Consequently, a critical evaluation of the traditionalist models of grieving sparked new theoretical developments, which will be introduced in the next section.

Part 2: A Critical Postmodern Perspective on Grieving

The Dual Process Model of Stroebe and Schut

Through a critical engagement with grief work and stage/phase models, Stroebe and Schut (1999) developed a theory on grieving called the dual process model, which has gained a strong footing in bereavement studies. Stroebe and Schut supported Freud's (1917) and Lindemann's (1944) notion that grief must be worked through to some extent. Yet, they had concerns regarding some aspects of grief work and the stage/phase models. For example, Stroebe and Schut (1999, 2010) highlighted that these previous theories and models did not acknowledge practical aspects of grieving, such as dealing with material and financial circumstances that may change because of the loss. Additionally, they emphasised the need to acknowledge different kind of losses that accompany bereavement. Such losses can be additional sources of distress, e.g. the loss of identity, financial security, emotional support, social circles, and so on. Stroebe and Schut (1999, 2010) also considered that previous theories did not address alternative ways of coming to terms with bereavement. Instead, they argued that "the types of confrontation involved in grief work are not universal, nor is non-confrontation systematically linked with mal-adaptation" (Stroebe & Schut, 2010, p. 275). Furthermore, Stroebe and Schut (2010) suggested that stage-like models are somewhat passive in nature as they imply that the griever is being "put through, rather than actively dealing with" (p. 275) grieving. Such models can therefore fail to accurately recognise that grieving requires the active struggle and participation of the bereaved. Based on these shortcomings, Stroebe and Schut developed the dual process model with the aim of providing a broader framework that diversifies grieving and considers individual differences.

Contrary to earlier traditionalist models, the dual process model presents grieving as a dynamic continuous process where the bereaved person oscillates between two categories of stressors: *loss orientation* and *restoration orientation* (Stroebe & Schut, 1999). *Loss*

orientation refers to “the concentration on, and dealing with, processing of some aspect of the loss experience itself, most particularly, with respect to the deceased person” (Stroebe & Schut, 1999, p. 212). It is a state in which the bereaved engages in moments of intense grief, which can include “experiences of rumination, replaying the circumstances of the death, yearning, and emotional responses such as crying” (Lister et al., 2008, p. 246). This overlaps with some of Freud’s (1917) grief work, whereby the bereaved person processes aspects of the loss through confrontation. However, in the dual process model, the emotional reactions that arise in response to loss are not necessarily considered as symptoms to be overcome. Rather, they are sometimes approached as coping mechanisms that can help express and process the loss (Stroebe & Schut, 1999). *Restoration orientation* refers to a person’s adaptation to the external consequences of bereavement by accounting for any practical aspects that arise. Stroebe and Schut (1999) defined this as: “focusing on what needs to be dealt with (e.g., social loneliness), and how it is dealt with (e.g., by avoiding solitariness)” (p. 214). The restoration orientation does not refer to an outcome variable; rather, it is part of the grieving process itself. Seen together, the oscillation between the loss- and restoration orientation is what characterises the dual process model, as a dynamic process that stands out from earlier models.

The oscillation between the loss and restoration orientation depends on the bereaved person’s needs and motivations. Stroebe and Schut (2010) stated that grief work can be “arduous and exhausting” (p. 275); thus, it could sometimes be recuperative to take a rest from the loss orientation by engaging with the restoration orientation. Additionally, implicit in the dual process model is the notion that the search for meaning is what motivates the bereaved person to undergo certain loss-oriented or restoration-oriented tasks (Stroebe & Schut, 2001). For example, the bereaved can search for meaning by reflecting on the loss experience and the impact and purpose it has had on their lives by engaging in loss-orientated

actions. Additionally, they can search for meaning by actively rebuilding their lives through restoration-oriented actions. This suggests that the search for meaning can serve as a strong motivating factor when engaging in grieving. Furthermore, this search can lead the bereaved person to find or make new meanings from the loss, which in turn may support their adaptation (Stroebe & Schut, 2001; Thompson, 2002).

The dual process model acknowledges a more dynamic approach to grieving that includes emotional reactions and practical adaptations as part of the grieving process. It represents a significant shift away from generalising peoples' grief response towards recognising that grieving is subject to one's personal search for meaning, as well as other individual differences. Additionally, the model describes grieving as an oscillating cyclical process rather than something linear that happens in phases or stages, while accounting for outcomes that reach beyond grief symptomatology (Neimeyer, 2014; Stroebe & Schut, 2010). Considering this, the dual process model has offered a rich contribution towards broadening the view of what grieving entails.

Meaning and its Role in Bereavement and Grieving

The role of meaning in relation to loss and grieving was largely absent in earlier grief theories. However, as part of the "new wave" (Currier et al., 2006, p. 420) of grieving theories that emerged since the 1990s, the search for meaning has increasingly been brought to light in contemporary bereavement research. The dual process model lightly touched on this (Stroebe & Schut, 1999, 2001), and it has been simultaneously explored in parallel trajectories by other theorists in the field of bereavement (Park, 2008; Steffen, 2019; Thompson, 2002). However, most significant to this development is the meaning reconstruction model put forth by Neimeyer and colleagues, and it is within this theoretical framework that my thesis is located. A detailed description of the theory will be presented

next, followed by its application in empirical research, and a critical evaluation of its strengths and weaknesses.

The meaning reconstruction model assumes that people rely on meaning structures, or so-called orienting systems which are made up of: beliefs and perceptions about the self and the world (including spiritual and/or religious beliefs), subjective feelings of meaningfulness and purpose, and desired goals (Gillies & Neimeyer, 2006). These types of meaning structures or orienting systems can “guide one’s perceptions of the self, the world, and the interactions between the two” (Gillies et al., 2014, p. 208). In the event of a significant loss, these structures can become damaged in that losing a loved one can rupture the very foundation upon which the bereaved person has built their understanding of life. In response to such a rupture, the bereaved can attempt to adapt their meaning systems that have been challenged by the loss to reorient themselves in the world and to integrate the loss into their life history in ways that support a positive loss adaptation (Neimeyer, Prigerson & Davies, 2002). According to the meaning reconstruction model, this can be done through the active attempt to *find* or *make* meanings in the life of the bereaved, as well as in the loss of the deceased.

Finding meaning implies that the individual finds a meaning that already exists from before, i.e. one cannot find something which does not already exist. Thus, finding meaning is the reaffirmation of one’s pre-existing meaning structures through a process of assimilation (Attig, 2001). If the experienced loss can be fitted well into the pre-existing meaning structures of the bereaved person, then they can “assimilate the loss experience into their pre-loss beliefs and self-narratives, in effect maintaining consistency with who they previously were” (Neimeyer et al., 2010, p. 74). For example, if one’s pre-existing belief (which is part of one’s meaning structures) is that healthy people live long lives, then this is reaffirmed should someone die from an illness (Lichtenthal et al., 2010). In other words, we “return to or

encounter something already established [...] we find our way home within surroundings filled with well-established meanings” (Attig, 2001, p. 34).

In contrast, *making meaning* implies that a meaning is created. If something is created, then it cannot previously have existed within the individual’s meaning structures (Attig, 2001). Thus, making meaning involves the active process of accommodation whereby the bereaved person needs to reorganise and expand their previous meaning structures to create a new sense of meaning, which embraces a new post-loss reality. For example, if a parent’s pre-existing belief is that the parent dies before the child, then they may struggle to make sense of the death if their child dies before them (Lichtenthal et al., 2013; Rosenblatt, 2000). Thus, what was once a familiar and comprehensible meaning structure to the bereaved parent is no longer sufficient because it conflicts with the reality of their loss. Park (2010) referred to this conflict as a discrepancy between one’s current meaning structures and the meaning that one has attached to the death. Similarly, Janoff-Bulman (1992) explained it as a situation in which “internal and external worlds are suddenly unfamiliar and threatening” (p. 63). In this circumstance, the bereaved parent may attempt to *make new meanings* through accommodation to make sense of the loss of their child, e.g. death can happen to anyone at any time. In this sense, meaning-making requires that “we are self-consciously active, take deliberate initiative, and bring new meanings into existence as we grieve” (Attig, 2001, p. 34). These two processes of finding and making meaning⁴ are what Neimeyer (1998, 2016, 2019) refers to as meaning reconstruction, and he considers this to be a central feature of grieving.

Against this background, the meaning reconstruction model describes three meaning-finding and -making activities that the bereaved person engages with in order to find or make

⁴ These two processes can be likened to how Piaget talked about learning, i.e. through *assimilation*, whereby we use our existing schemata, and through *accommodation*, whereby we have to create new ones (Moore, 2012).

meanings. These activities include: (i) sense making, (ii) benefit finding, and (iii) identity change (Gillies & Neimeyer, 2006). The process of finding and making meaning through these three activities is dynamic and personal, as it is influenced by factors such as one's life history, the circumstances of the loss, and one's socio-cultural environment. In turn, the meaning outcome of these activities (meanings made or found) can provide a meaning structure that the bereaved person can lean on for solace, reassurance, and orientation, thereby supporting them in navigating a post-loss world. What follows is a description of each of these meaning activities, as identified by Neimeyer and colleagues, including some examples that present the outcomes of these activities.

Sense Making. Sense making is the most comprehensive of the three meaning-finding and -making activities as it covers multiple approaches. However, these approaches have not been sufficiently marked within the extant literature on meaning reconstruction, thus risking some confusion to the reader. Thus, the subsequent descriptions of these sense making activities aim to provide further clarity by distinguishing between them in a more explicit way. One example of sense making involves searching for an understanding post-loss by asking: *Why did this happen? Why me? Why them?* Answers can include a causal explanation of the loss, as well as assigning blame or responsibility to oneself or others (Coleman & Neimeyer, 2010), e.g. "constructing an explanation of a loss based on one's beliefs/worldviews, such as the death being God's will or due to unhealthy behaviours" (Lichtenthal et al., 2010, p. 3). The answers to these questions are shaped by different influences, e.g. spiritual beliefs, personality traits, cause of death, racism, and personal relationships (Davis et al., 1998; Richards & Folkman, 1997; Rosenblatt, 2017; Rosenblatt & Wallace, 2005). Such answers either fit with a previous worldview (meaning found through assimilation) or lead to the construction of a new worldview (meaning made through

accommodation). In turn, these answers often help people make better sense of their loss (Barboza et al., 2021; Flesner, 2015).

Sense making can be seen through the narration of a story which connects separate parts into a meaningful whole, just like a life history narrative seeks to do. This narration is sometimes referred to as narrative meaning-making, or narrative creation (Hartog et al., 2020). In other words, by creating a story about a particular experience or event, the bereaved person can better make sense of their experience, as indeed “a coherent narrative, by definition, must make sense” (Rolbiecki, Washington, Bitsicas, Teti et al., 2021). An example of this can be seen through digital storytelling, a multi-media narrative approach whereby the bereaved creates personal digital stories to make sense of their loss and grieving (Rolbiecki et al., 2019).

Sense making also includes the use of metaphor to make sense of loss and grief. In their book *Metaphors We Live By*, Lakoff and Johnson (1980) defined metaphor as “understanding and experiencing one kind of thing in terms of another” (p. 5). They asserted that a metaphor is more than a description of something in that it can reveal, to some degree, how someone perceives, thinks, and feels about a certain experience. This “symbolization process” (Steffen, 2019, p. 132) can evolve from an internal felt state, which then shifts and transforms to an explicit logical verbal construction. In turn, this can illustrate an experience in ways that regular narratives cannot always do (Nadeau, 2006). Indeed, Neimeyer (2000) pointed out that simple verbal formulations do not always suffice when attempting to make sense of things, as some meanings are “too embedded in our lives, too embodied in our actions” (p. 554). Hence, when regular narratives are insufficient, Neimeyer (2000) encourages the use of metaphors to symbolically make sense of the deeper meanings of one’s life experiences. An example of such metaphors can be seen in the story of Peggy, a 35-year-old woman whose father committed suicide: “The image I have is of our family clinging to a

life raft” (Nadeau, 2006, p. 214). In this case, the meaning of the life raft represents a safe place amidst turbulent waters, where the family can be together and support each other in the aftermath of their loss.

Another example of sense making is seen through rituals. Rituals can reaffirm pre-existing meanings (meaning finding) surrounding death, thereby offering a consoling structure to the existential and emotional chaos brought by loss. Such acts can further strengthen connections between family members and communities, which facilitates their grieving in collectivist ways (Hooghe & Neimeyer, 2013). An example of this can be seen in the African Igbo mourning dances in the Igbo communities of South-Eastern Nigeria (Akunna, 2015). The taxonomy of the word mourning in the Igbo language does not carry the same definition as it does in the west (for a definition, see the glossary on p. 11). Instead, mourning in the Igbo sense is interpreted as “coming full circle” (Akunna, 2015, p. 41). This metaphorical view is integrated into their funerals, which consist of ritualistic mourning rites. These rites include dancing, singing, and masquerade displays that honour the cycle of life – birth, life, death, and reincarnation – thereby reaffirming pre-existing meaning structures within the community and helping the bereaved people make sense of their loss. This also suggests that sense making does not only occur within an individual, or a single local network of relationships, but it can also take place within a larger socio-cultural network. Hence, the ritualistic sense making that occurs within a person is also grounded in the discourses of the social and cultural traditions in which they live.

Benefit Finding. Benefit finding concerns the positive reframing of a bereavement through positive appraisal, whereby one extracts positive elements and valuable life lessons from what has happened (Barboza et al., 2021; Gillies & Neimeyer, 2006). These types of benefits can be spiritual, existential, or personal in nature (Neimeyer & Anderson, 2002). Examples include experiencing an enhanced sense of personal strength, increased

appreciation of life, improved relationships, and increased motivation to help others (Hooghe et al., 2013; Lichtenthal et al., 2010, 2013). However, the notion of benefit finding is not always welcomed amongst all bereaved people. When asking bereaved parents whether they had found any benefit in losing their child, some stated that there were no benefits while others reacted negatively to the question, as seen in one mother's reply: "Benefits – of course there are no benefits when your child dies!" (Lichtenthal et al., 2010, p. 11). Although finding positive elements can be helpful to some people who are coping with loss, it should not be assumed that there is always something positive to be taken from a bereavement. The impact may be so painful that a person is rendered unable or unwilling to search for any benefit. Death does not always come with a silver lining.

Identity Change. Prior to defining identity change as a meaning-making activity, I will provide a brief discussion of identity theory in general and how it has developed within the field of psychology throughout the 20th century. The concept of identity has been explored through various lenses, which can be traced all the way back to William James' theory of self, and its two components: the self as a subjective "I" and an objective "me" (for further details, see James, 1890). Since then, many identity theories have sought to describe what constitutes a person's identity and how one's representation of selfhood is organised. In this section, I will briefly touch on a selection of these developments that are relevant to this study. I hope this will offer some broader insights into identity as a concept, and will exemplify how identity can be approached in relation to loss and grief.

In simple terms, Neimeyer (2009) summarises the concept of identity as: "(it) is what makes you, a self both distinguishable from others and recognizable, with meaningful variations and developments, across time" (p. 19). However, aside from his own definition, Neimeyer (2009) points out the distinctions between modernist discourses of self – whereby the self is often viewed as a stable, singular, and individualistic entity, independent from its

environment and its relationships – and postmodern psychology, which follows a more constructivist approach – whereby the self is seen as dynamic, co-constructed and shifting in time and space. Examples that fall under the modernist spectrum include Cartesian dualism (Descartes, 1641/1990), which separated self from body, as well as self from other (Hermans & Kempen, 1993), and had a strong influence in the early development of psychology as a scientific discipline (Fancher, 2017); and Freud's (1923) tripartite system of the id, ego and superego and the five psychosexual developmental stages, which were solely driven by the individual's psychosexual energy. However, later theorists in psychoanalysis (Klein, 1932; Winnicott, 1971), developmental psychology (Ainsworth, 1989; Bowlby, 1969), and constructive psychotherapy (Neimeyer, 2004, 2006, 2009) came to question and expand on these views by considering the role of context – social relationships and narratives – and their impact on the development of identity. Indeed, Neimeyer accounted for these considerations when approaching identity in his meaning reconstruction theory.

A significant change within identity theory, particularly within psychoanalysis and in response to Freud's work, was brought by the concept of object relations. Melanie Klein (1932), a former student of Freud, developed a method of child analysis which presented children with toys to play with. By observing children's play, Klein argued that the toys represented key people and conflicts in the children's lives, and she spoke of this in terms of object relations, which refers to the relationships between persons (Abram & Hinshelwood, 2018). However, unlike Klein, who believed that children's object relations (whereby the object almost exclusively represented the mother) was motivated by food dependency (i.e., the mother's breast) and the reduction of anxiety, Klein's student and colleague, Winnicott (1971), adopted a different approach by saying that it was the relationships themselves that were the motivating force behind a child's personal development, as the child needs love and support from its main caregiver to progress healthily in life (this aligns with Kohut's (1971)

emphasis on the importance of an empathic parent in preventing the development of narcissistic personality disorders in their children). Thus, unlike Klein, Winnicott's focus extended to how an individual's experience of the environment came to shape their sense of self (Abram & Hinshelwood, 2018). Klein's and Winnicott's contrasting theories were central to the development of object relations theory and shifted identity theory from a one-person psychology to an interrelational approach. This later came to have a significant influence on the subsequent development of Bowlby's (1969) attachment theory.

The object relations tradition in psychoanalysis laid the ground for the development of much of Bowlby's attachment theory, with Bowlby (1988) himself categorising his theory as a variant of objects relations theory. Further inspired by evolutionary theory, cognitive psychology, and the research of Lorenz (1935) and Harlow and Zimmerman (1959) on primate species' instinctual connections to their birth mother, Bowlby (1988) postulated that forming close affectional bonds to one's main caregiver is a universal human need, whereby the experience of feeling safe and protected is the main purpose of the attachment system. The child engages in certain attachment behaviours (crying, clinging, smiling) to maintain proximity to its mother, and the mother's reciprocity to these behaviours (soothing, holding, feeding) helps to satisfy the child's need for comfort and safety. Depending on the parent's sensitivity towards and support for their child's needs, different attachment styles (from secure to insecure attachment) can take shape in the child. The work of Mary Ainsworth (1989), a close colleague of Bowlby and another pioneer of attachment theory, in particular her laboratory-based research on the Strange Situation (see Bretherton & Ainsworth, 1974), expanded on Bowlby's attachment theory by considering the individual differences of children who developed different attachment styles with their parents (for a more detailed insight into these attachment styles, see Ainsworth et al., 1978; van Wielink et al., 2020). These attachment styles, which become integrated into a person's identity as they transition

into adulthood, demonstrate that a child's upbringing has a strong impact on how they view themselves, their development of social relationships, and their relation to the world.

According to Bowlby (1988), during early infancy, the development of attachment bonds occurs parallel to the child developing so-called working models, which hold internal representations that the child develops based on their experiences with their caregivers. These models represent how the child perceives the outside world (beliefs concerning people's values, feelings, and reactions), and their internal world (self-beliefs and self-worth), and serve as a map for understanding the world, and their place within it (see van Wielink et al., 2020). Bowlby's working models are similar to Fonagy et al.'s (2004) concept of mentalisation, which refers to one's capacity to understand one's own mental states, as well as to understand and imagine what other people might be feeling. According to Fonagy et al. (2004), there is a strong link between the quality of an attachment relationship and the child's capacity for mentalisation. In other words, a secure base, whereby the caregiver can offer consistent psychological and physical proximity to a child in need, can help the infant to understand themselves and the people around them, i.e., "As the self exists only in the context of the other, the development of the self is tantamount to the aggregation of experiences of self in relationships" (Fonagy et al., 2004, p. 40). Thus, one's attachment history, including one's working models and the ability to mentalise, serve as a foundation for identity formation (Pittman et al., 2011).

Relevant to my doctoral research, these attachment relationships continue from infancy into adulthood. As children mature into adults and gain increased autonomy and independence, they nevertheless maintain some level of attachment to their parents (Ainsworth, 1989). Ainsworth (1989) highlighted that the mourning an adult child feels for their deceased parent "demonstrates that the attachment bond has endured" and that "even after mourning has been resolved, internal models of the lost figure continue to be an

influence” (p. 711). This demonstrates that the parental relationship can remain significant throughout a person’s life and identity development – including after the parent’s death. Therefore, it is only reasonable to say that the loss of an attachment figure to death can have a significant impact on the bereaved self. Indeed, Bowlby is considered the first theorist to have acknowledged that grief was a healthy reaction to the loss of an attachment (van Wielink et al., 2020), and he later went on to outline a grief model together with his colleague Collin Murray Parkes (see Parkes & Bowlby, 1970; and pp. 41-43 in the literature review).

Bowlby’s view on the loss of an attachment leading to a grief response can be likened to Attig’s (2011) ruptured web metaphor, which is derived from his grief theory on relearning the world. Attig referred to the world as a network of co-existing webs. Each person constructs their own web and every thread that emanates from that web represents a specific attachment that they have to the world. In this web, there are many threads that connect a person to people, locations, and events that are of value to them to varying degrees. Through these threads, a person forms bonds that pervade many aspects of their life and the lives of others. Thus, the web symbolises a person’s unique identity and life history, including the world as they perceive it, and it co-exists with and is co-constructed in a network of other people’s webs. However, losing a loved one to death brings a significant change in shape to the web as it ruptures the threads that are attached to the deceased. This rupture dislodges parts of the web structure that the relationship in question provided, leaving the bereaved person with a broken web (i.e., a broken self). As Attig (2011) described: “when a particular relationship holds a prominent place in our lives, a death strikes a severe blow to our personal integrity by dislodging an even broader wedge of the web” (p. 141). Consequently, the bereaved person can find themselves in what they perceive to be a changed world. This sudden change, and the impossibility of reversing it, can leave the bereaved in a state of deep agony and confusion, since they are attached to the past while having to adapt to a new reality

in the present. A bereavement of such significance can shake the very foundation upon which the bereaved person has built their sense of identity and place in the world. It is in response to this that the bereaved can attempt to reweave their web by reconstructing the meaning systems that have been challenged by the loss to reorient themselves in the world and thereby experience a change in identity (Neimeyer, Prigerson & Davies, 2002).

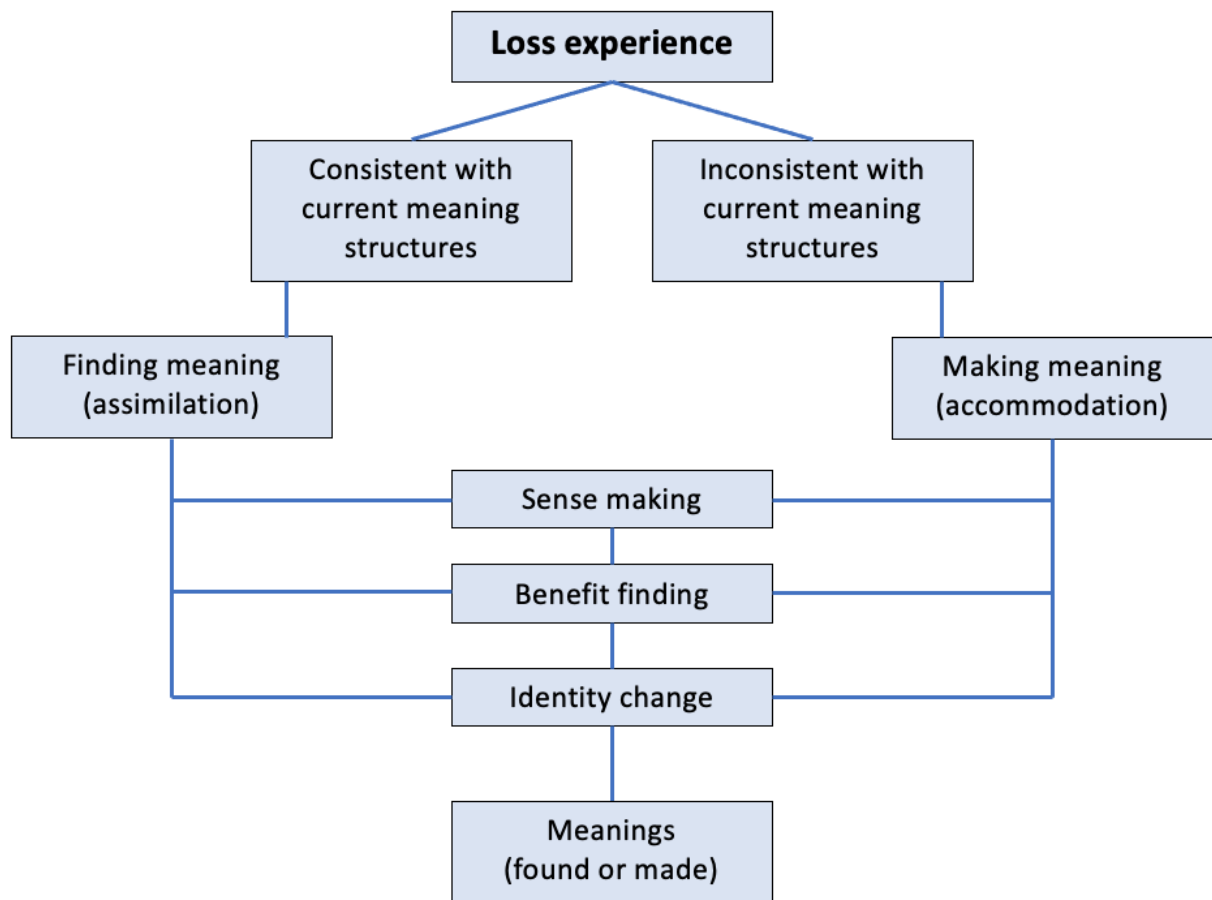
Within the framework of the meaning reconstruction model, identity is approached through a postmodern constructivist lens and seen as “multiplistic, shifting, and interpenetrated by the social world” (Neimeyer, 2006, p. 106) – a view that aligns with the aforementioned theorists. Specific to the model (see Neimeyer, 2004; Neimeyer, Botella, Herrero et al., 2002; Neimeyer et al., 2010) is the emphasis on the construction of life narratives, and its meaning structures, whereby identity is considered a continuously shaped narrative achievement - similar to Stern’s concept of a “narrative self” (Stern, 1985, p. xxiii & p. 174). In Neimeyer’s own words: “our sense of self is established through the stories that we tell about ourselves, the stories that relevant others tell about us, and the stories we enact in their presence” (Neimeyer, 2004, p. 54). This identity construction takes place within, and is shaped by, a sociocultural environment whereby social relationships play a crucial part in constructing one’s identity: how one views the world and one’s place within it. Thus, identity is not only something we solely create within and for ourselves, but rather is a co-constructed concept that is shaped in relation to context and social influences, and changes over time (see also Stern, 1985).

As reflected in these theories, social relationships are significant to one’s identity formation. Thus, it is understandable that losing a loved one can have a major impact on one’s self-perception and relationship with the world, leading to an identity change (Attig, 2011; Neimeyer, 2000). For example, the death of a family member can change the family structure and thereby change the family members’ roles and how they identify themselves

within that structure (Nadeau, 1998). Additionally, if a person's pre-existing meaning structures have been ruptured by the loss, then the act of making new meanings can result in the bereaved experiencing a change within themselves and their outlook on life. In other words, when a loss is of great significance, it can trigger a "re-authorship" of a new life narrative that integrates the loss into the plot structure of our biography" (Neimeyer & Anderson, 2002, p. 51). To contribute a personal example of my own, as I was grieving the death of my father, I gradually began to view my mother as an individual with an identity of her own. She was no longer part of the unit that used to be *her and Dad*. Thus, my own identity changed through an internal shift in perspective as the identity of my mother (as I perceived it) shifted from being the wife of my father, to being an independent woman of her own accord – who is also my mother. This influenced how I related to and acted towards my mum, and our relationship matured into what to this day feels like a more equal and respectful relationship. Metaphorically speaking, it was as if a new chapter in our lives – as mother and daughter – had begun, and it was being written by both of us as our relationship evolved.

Lastly, Gillies and Neimeyer (2006) mention that identity changes in the bereaved can also include becoming more independent, resilient and/or empathetic, as well as taking on new roles, learning new skills, and growing emotionally closer in current relationships. Additionally, Neimeyer and Anderson (2002) liken identity change to post-traumatic growth, referring to the possibility of personal growth that may arise from one's suffering related to a trauma, crisis, or struggle (Lawrence & Tedeschi, 2006; Tedeschi & Calhoun, 1995).

Figure 1.

The Meaning Reconstruction Model in Bereavement

Note: The figure depicts my own summary of the meaning reconstruction model as explained in publications by Neimeyer and colleagues (see Barboza et al., 2021; Gillies & Neimeyer, 2006; Neimeyer, 2019; Neimeyer & Anderson, 2002; Neimeyer et al., 2010).

Applying the Meaning Reconstruction Model to Empirical Research

The meaning reconstruction model has primarily been applied when investigating whether the bereaved person has found or made meaning from their loss and the subsequent influence that this has had on their loss adaptation. Adaptation has mostly been concerned with measuring psychological adjustments in response to meaning reconstruction, using questionnaires such as the Inventory of Complicated Grief (Prigerson & Jacobs, 2001),

Bereavement Index (Jacobs et al., 1986), Present Feelings About Loss Scale (Singh & Raphael, 1981), Texas Revised Inventory of Grief (Zisook et al., 1982), Center for Epidemiologic Studies – Depression Scale (Radloff, 1977), and the Positive Affect subscale (Bradburn, 1969). In addition to measuring psychological adjustment, studies have included questions such as: “How much sense would you say you have made of the loss? [...] Have you been able to find any benefit from your experience of loss? [...] Do you feel that you are any different, that your sense of identity has changed, as a result of this loss?” (Gillies et al., 2014, p. 210). Some studies include all three meaning-finding and -making activities (sense finding, benefit finding, identity change), whereas other studies only consider one or two of these. A selection of these empirical research studies will be discussed next.

Findings from empirical research show a statistically significant connection between meaning reconstruction and loss adaptation. For example, a correlational study by Neimeyer et al. (2006) assessed sense making, benefit finding and identity change in the prediction of complicated grief symptomatology in 506 young adults who had lost a loved one (family members, friends, or partners/spouses). High levels of these meaning reconstruction activities predicted better grief outcomes, demonstrating lower levels of traumatic and separation distress in the first 2 years post-loss. However, the correlational nature of the study cannot imply causation. Additionally, although the study included a high number of participants, they were all college students, which makes it difficult to generalise these findings to other groups of people. Indeed, college students may be confronted with challenges specific to this developmental stage in their life and due to the study’s quantitative nature, the collected data could not reveal such insights.

A cross-sectional study by Currier et al. (2006) investigated the role of sense making and whether this could be associated with the grieving outcome that follows a violent loss such as homicide, suicide, and accidents. Their sample included 1,056 undergraduate students

studying psychology. Findings suggested that sense making seems to be more difficult for people who have experienced violent losses, and the inability to make sense of a violent loss was a significant mediating factor in grief symptomatology. However, due to the study's cross-sectional approach, it is difficult to determine whether sense making influences grief over time. Additionally, the associations made cannot determine the cause. Indeed, the reverse may be the case, i.e. the bereavement may cause distress, which subsequently influences cognitive processes in ways that make it difficult for the bereaved to engage in any sense making activity.

Coleman and Neimeyer (2010) explored the role of sense making in late life spousal bereavement using data from a prospective longitudinal study (Changing Lives of Older Couples Project), which included 250 research participants. Findings demonstrated that successful sense making at 6 months and 18 months predicted reduced grief and depressive symptoms and an increased sense of subjective well-being, 4 years following the death of a spouse. Although these findings suggest that sense making can support loss adaptation, the authors pointed towards a need to clarify the definition of meaning making, including the necessity to distinguish between meaning-making processes versus meaning outcomes.

Flesner (2015) explored bereaved siblings' meaning reconstruction through a qualitative narrative research design by interviewing seven young adults who had lost a sibling in adolescence. Flesner identified the meaning reconstruction activities of identity change, sense making, and benefit finding and highlighted the importance of these activities as it helped the bereaved siblings to better organise and understand their loss experience. Flesner's (2015) study also contributed towards distinguishing between the *processes/strategies* of finding and making meaning, and the meaning *outcomes* of these processes/strategies. Flesner concluded that by examining meaning reconstruction as a process/strategy rather than an outcome, bereavement therapists can become more adept at

developing processes/strategies that can support bereaved people in finding and/or making meanings that can lead to improved adaptation post-loss. Additionally, by examining the meaning outcomes of the meaning reconstruction process, one can further identify how these outcomes can differ between people, why these differences exist, and the influence these meaning outcomes may have on loss adaptation. According to Flesner (2015), these developments can help clarify which elements of the processes/strategies and meaning outcomes are associated with improved loss adaptation. Flesner's study is rich in qualitative data, which is a valuable addition to the field of empirical bereavement research. However, the sample is small and only concerns a particular type of loss. Thus, more qualitative research with a greater number of people who have experienced different types of loss would be beneficial to gain additional insights and diverse perspectives on loss and grieving.

Meaning-centred interventions grounded in the meaning reconstruction model have also been explored in studies led by interdisciplinary teams consisting of researchers, clinicians, and artists. One of these interventions concerns digital storytelling, whereby bereaved individuals get to use artefacts like photos, videos and music to put together a digital story about their loss (Rolbiecki et al., 2019). Rolbiecki et al. (2017) explored the influence of such interventions in families who have lost a child, and findings suggested that it provided families with an opportunity to make sense of their loss and to communicate this outward to the world, thus helping them to “reconstruct global beliefs and move forward as a family” (Rolbiecki et al., 2017, p. 248). Although a largely unresearched topic, a later study by Rolbiecki, Washington and Bitsicas (2021) lends support to earlier findings, demonstrating that digital storytelling helped to facilitate personal growth and meaning making amongst bereaved family members.

Most of the empirical research on meaning reconstruction in bereavement focuses on the importance of meaning reconstruction for grievers. However, a study by Davis et al.

(2000) took a more provocative stance by focusing on the significant minority of bereaved people, i.e. the group who had not sought out meaning or who had sought out meaning but failed to find it. Note that meaning in Davis et al.'s (2000) study is defined as follows:

We define meaning as an explanation for an event that renders it consistent with one's assumptions or understanding of the nature of the social world. That is, an event "makes sense" or "has meaning" when it does not contradict fundamental beliefs about justice, order, and the distribution of outcomes. By this definition, one may make sense of an event by interpreting the event as consistent with existing views of the self and world or by changing self- or worldviews to be consistent with the interpretation of the loss. (p. 498)

Davis et al. (2000) discussed meaning in relation to two studies. The first was the sudden infant death study (SIDS), which included 124 bereaved parents who had experienced the sudden death of their baby (McIntosh et al., 1993). The second study included people who had lost loved ones in motor vehicle accidents (Lehman et al., 1987). Davis et al.'s (2000) analysis of these studies questioned three assumptions: "(a) people confronting such losses inevitably search for meaning, (b) over time most are able to find meaning and put the issue aside, and (c) finding meaning is critical for adjustment or healing" (p. 497). When analysing the SIDS, Davis et al. (2000) pointed out that 14% of the parents had not sought out any meaning in their loss. Another 18% had searched for meaning and 59% of this 18% had not been able to find it. The remaining 68% of the participants were still actively searching for meaning as they thought that it was important. The SIDS indicated that those who were not concerned with searching for meaning were doing better than those who searched for meaning but had been incapable of finding it. Those who had searched for meaning and

found it reported a better psychological adaptation than those who had not sought out meaning, but the difference was not statistically significant. Regarding the Lehman et al. (1987) study on motor vehicle accidents, findings showed that even 4 to 7 years after the loss, 30% of those who had lost a spouse and 21% of those who had lost a child, reported that they had never been concerned with making sense of their loss, thus presenting similar findings to the SIDS. Furthermore, the bereaved who had never searched for meaning experienced far less distress than those who had been searching for meaning but not found it.

Taken together, these two studies, as analysed by Davis et al. (2000) showed that most people from both studies had searched for meaning. The people who had found meaning or not sought it adapted better psychologically than those who had sought meaning and not found it. Davis et al. (2000) highlighted that although the quest for meaning plays a central role for many bereaved people, there is still a large minority who do not find it relevant to their loss adaptation. Neimeyer (2000) pointed out that the findings from Davis et al.'s (2000) study "serve as a useful corrective to the glib assumption that meaning must be sought in death and must be found if the loss is to be resolved" (Neimeyer, 2000, p. 548). These findings suggest that meaning making and finding is not relevant for all grievers' loss adaptation, nor may it be a central feature of their grieving process, thus challenging such claims.

A Critical Evaluation of the Meaning Reconstruction Model

The meaning reconstruction model has indeed played a significant role in the development of contemporary bereavement theories by offering new perspectives on grieving that extend beyond grief symptomatology (Neimeyer & Anderson, 2002). Neimeyer asserts that by focusing on meaning reconstruction post-loss, one makes a significant shift "away from a medical model emphasizing the control of disruptive symptomatology" (Neimeyer,

2000, p. 548). However, Neimeyer's work is itself part of an empirical research programme that continues primarily to focus on whether meaning reconstruction supports loss adaptation by reducing disruptive symptomatology. This is largely measured by looking at what is often referred to as grief symptoms, i.e. levels of depression, anxiety and distress in relation to subjective well-being. In these instances, a positive adaptation refers to lowered levels of grief symptomatology along with heightened well-being and personal growth. Thus, the primary focus remains how to stop any grieving, return to normal functioning, and to emerge a stronger person than before. These studies also use language that often refers to the grieving experience in terms of *symptoms* and *recovery*. These words suggest an association between grief and illness whereby grief is seen as a "disorder that needs to be treated" (Granek, 2017, p. 275). These views risk pathologising what could otherwise be seen as a normal and healthy response to bereavement, while presenting a flawed view of what grieving should look and feel like, and how long it should last for (Corr, 2002; Granek, 2017). Moreover, if the bereaved person's experience does not fit into these unrealistic expectations, they may experience feelings of shame or embarrassment, causing them to withdraw and to grieve in isolation. This can lead to some grief disenfranchisement, thereby worsening the bereavement experience while also leaving someone without adequate support (Doka, 2002). In this context, the meaning reconstruction model goes only some distance towards a departure from the medical model endorsed by traditionalist grief theories. There is scope for further research on the contribution of the meaning reconstruction model to the study of bereavement in ways that are not limited to measuring its impact on psychopathology.

Another limitation which calls for further theoretical development concerns the usage of the term meaning reconstruction. Meaning reconstruction is often interchangeably used with meaning finding and/or meaning making (Gillies et al., 2014; Keese et al., 2008; Neimeyer, 2019). Although the terms are used interchangeably, it must be noted that

reconstruction, finding, and making are not synonyms. *Reconstruction* implies the process of rearranging or building upon something which already exists; *finding* implies the discovery of something which already exists; whilst *making*, as understood here, comprises the creation of something new.⁵ These are significant distinctions, and their conflation can only cause confusion. To avoid this, I suggest clarifying the distinction between the model's title and the processes that the model consists of. Therefore, I shall instead refer to it as a *meaning-centred bereavement model* when discussing it in relation to my data and overall study (as seen in the Methodology, Discussion and Conclusions). As the name suggests, the model centres around the meanings attached to a person's loss experience; meanings which are developed through the process of finding and making meaning.

There is a second point of clarification that must be made, which concerns the definition of the meaning activities *benefit finding* and *identity change*. These activities sometimes overlap with each other and sometimes seem to be taken to be the same thing (see Gillies & Neimeyer, 2006; Holland et al., 2006; Lichtenthal et al., 2010; Lichtenthal, Neimeyer, Currier et al., 2013). This can cause confusion and inconsistencies with regards to how the terminology is being used and measured. For example, at times, enhanced compassion or empathy in the bereaved falls under the category of benefit finding, and other times it is considered an identity change, thus making it difficult to apply the theory to data. I will therefore emphasise the following distinction that was initially outlined by Neimeyer and Anderson (2002): identity change, when favourable, expresses itself as a form of post-traumatic growth, where the bereaved person experiences profound positive personal changes in the aftermath of great adversity. Benefit finding concerns the pursuit of a silver lining, in other words extracting any type of benefit from a negative experience. However, what makes

⁵ These distinctions are not straightforward, and there are numerous complexities that should be acknowledged: to give just one example, we might *make* a new meaning by *reconstructing* previous meanings which we had *found* or made use of before rearranging or reconceiving them. Cases of this kind require more attention than I can provide here, but the distinctions offered in the text will suffice for my purposes.

this slightly complicated is that post-traumatic growth can indeed be seen as a benefit, but it is something more intrinsic and personal compared to other benefits such as the seizing of a loved one's suffering, or the strengthening of family bonds in the aftermath of loss.

Therefore, these two meaning activities ought to remain separate, and I will continue to relate to them as such while maintaining a clear distinction between the two.

It is also important to further consider the influence of social, historical, and cultural contexts, which can contribute towards shaping the meaning-finding and meaning-making process and its meaning outcomes for a particular person (Neimeyer, 2000; Neimeyer, Prigerson & Davies, 2002). This includes studies that foreground the impact of class, gender and ethnicity on the experience and expression of loss. More empirical research is needed that considers the meaning reconstruction model in relation to such contexts, as well as the griever's life environment and life history (as the current study seeks to do). Indeed, such considerations can better the understanding of what loss and grieving means, and the reasons for those meanings, for different people across various contexts.

Additional Postmodern Theoretical Concepts of Grieving

The modern and postmodern theories presented so far are primarily concerned with grieving in response to bereavement – that is, they focus on the time post-loss. However, recent research has begun exploring the time pre-loss and the grieving associated with it, leading to further postmodern theoretical developments in bereavement, which I will briefly discuss next.

Anticipatory Grief and Dementia Grief

Anticipatory grief concerns the pre-loss grieving process, as it encompasses grief in anticipation of the future loss (Cheung et al., 2018; Holley & Mast, 2010). One example of anticipatory grief has been studied in the context of dementia family caregivers and refers to caregivers' experience of "pre-death grief in response to compound serial losses in the dementia process" (Cheung et al., 2018, p. 2). Holley and Mast (2010) investigated what aspects of caregiving would lead family caregivers to experience grief prior to the care recipient's death. Results suggested that the behavioural changes exhibited by the care recipient were the most likely predictor of anticipatory grief in the caregiver, i.e. the person that the caregiver used to know was no longer the same as the person they know now. A study by Cheung et al. (2018) suggested that the level of anticipatory grief may be higher in people caring for a person with profound dementia in its later stages, due to the complete loss of communication and the recognition that there is no hope of improvement in their condition as they are approaching the end of life.

Blandin and Pepin (2017) coined the term "dementia grief" (p. 67) as a variant of anticipatory grief. They made the distinction between general anticipatory grief and dementia grief by pointing out that dementia caregivers experience several unexpected losses during the time of their caregiving, rather than simply anticipating a death that is about to happen. Examples of losses include loss of freedom and time, loss of shared activities and communication with the person living with dementia, loss of the person they used to know and meaningful interactions (Blandin & Pepin, 2017; Large & Slinger, 2015). Sikes and Hall (2017) point out that such losses can be a "source of grief leading to significant stress and emotional, mental, psychosocial and physical ill health" (p. 324).

Seen together, these recent theoretical concepts and their empirical findings suggest that grieving must also be considered in the time pre-loss, particularly amongst populations who are caregivers to ill or dying family members. This can inform communities about

support systems that can be made available when an individual or a family is struggling whilst a family member is dying. Such considerations may be especially relevant to the adult child, as they are more likely to lose an elderly parent compared to their younger counterparts (Scherer & Kreider, 2019; Umberson, 2003).

Grief and Intergenerational Trauma

Another aspect of grief that warrants further exploration is the effect of intergenerational trauma and the subsequent grief reactions within families. A definition of trauma is provided by Herman (1992):

Psychological trauma is an affliction of the powerless. At the moment of trauma, the victim is rendered helpless by overwhelming force. When the force is that of nature, we speak of disasters. Where the force is that of other human beings, we speak of atrocities. Traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning. (p. 33)

Bereavement can be traumatic when death is the result of a traumatic event like an accident, disaster, or violence (Heeke et al., 2017; Newman, 2002). Irrespective of the cause of death, bereavement can itself be a traumatic event as it can shatter the bereaved person's assumptive world (Janoff-Bulman, 1992), akin to the ordinary systems of care that is referred to by Herman.

The grief felt as a response to a traumatic life event can have an effect over several generations and express itself in various ways. Gajdos (2002) suggests that if trauma and the grief that follows it are not tended to in one generation, it can have deleterious effects, including dysfunctionality, across subsequent generations. This is just one example of the

historical roots of loss and grief and of how it can be passed on from one generation to another. Dashorst et al's (2019) systematic review of the intergenerational consequences of the Holocaust on the offspring of Holocaust survivors suggested that survivors who have experienced loss or maltreatment can experience an impact on their parenting and attachment bonds to their child. The caregiving of some Holocaust survivor parents has in some cases been characterised by an inability to provide physical and emotional care. Other characteristics include emotional neglect and a tendency to push a child to achieve and to satisfy the needs of their parents (Dashorst et al., 2019). These consequences can be likened to intergenerational trauma, which refers to "the ways in which trauma experienced in one generation affects the health and well-being of descendants of future generations" (Sangalang & Vang, 2017, p. 2). Such an influence can further affect how one responds to a family bereavement, as exemplified in the experience of survivor's guilt among bereaved people who have lost a loved one to a traumatic and tragic death. "Survivor's guilt" (Niederland, 1961, p. 238) is a term which describes a feeling of guilt accompanied by a fear of punishment for having survived a disaster, such as the Holocaust, in which loved ones have been lost. This guilt can manifest itself as part of one's grief reactions (see also Juni, 2016).

When considering loss and grief in relation to intergenerational trauma, a diverse and inclusive picture can evolve, which accounts for historical contexts that cover the time pre-loss and across generations. This in turn can shed light on experiences that might influence a person's grieving, besides the bereavement itself, which might otherwise go unnoticed. This is of relevance to my study, as I seek to explore loss and grieving in relation to my participants' life histories and the parent-child relationship, stretching across a broad span of time, taking account of events included within, but not confined to, the experience of bereavement and the grieving process.

Part 3: Critical Aspects of Losing a Parent in Adulthood

The Significance of the Parent-Child Relationship

The parent-child relationship can be considered the most important relational connection of all, and this intergenerational bond plays a critical role, particularly in the child's early social and psychological development (Umberson, 2006; Umberson & Chen, 1994). The parent usually serves as the primary attachment figure who provides safety and comfort to their child to ensure their survival. It is one of the few relationships that lasts from birth and remains throughout life, albeit in different ways, as the adult child progresses into adulthood and towards their own death (Hayslip et al., 2015; Stokes, 2016; Umberson, 2006). The parent-child relationship is dynamic, as it develops over time. According to Rostila and Saarela (2011), a parent's role as a caregiver and the attachment bond between parent and child grows weaker as the child matures into an independent adult. As the adult child develops their own relationships and structural resources (financial, professional, residential, etc.), they no longer depend on their parents as much as before. Nevertheless, the parent-child relationship can continue to develop positively and strengthen over time, even as the child becomes increasingly self-reliant with age (Carver et al., 2014). For example, the adult child may continue to rely on their parents for love, advice and support. The relationship can also improve further when the child is old enough to understand and appreciate the value of their parents' care, and/or when they become a parent themselves (Umberson, 2006). Thus, given the significance of the parent-child relationship over time, losing a parent can be highly disruptive to the adult child, irrespective of their age.

Adult Children are Underrepresented in Bereavement Studies

Most research on parental death has been conducted with younger children, with a notable lack of studies exploring the experience of adult children. Moss and Moss (1984) were among the first to address this deficit, with particular regards to losing a parent in

adulthood. They argued that this type of bereavement was often considered less important than the death of someone younger because adult children were not seen to exhibit the same intense grief reactions as other grievers. A similar point was raised by Osterweis et al. (1984) who claimed that the expectation in western society is often that parental death is not thought to have adverse effects on adult children. Parallels can be drawn between these earlier discussions and recent studies, which demonstrate that younger people are more negatively impacted by losing a parent and experience poorer mental health outcomes in comparison to middle-aged adults (Hayslip et al., 2015; Leopold & Lechner, 2015; Nickerson et al., 2013; Rostila & Saarela, 2011). For example, Rostila and Saarela (2011) observed how parental death influenced the mortality risk of the bereaved child compared to non-bereaved children. They measured the impact on children aged between 10 and 59 years old, using data from the Swedish Work and Mortality Database. The study included over three million people and each person was observed over a 10-year period. Findings revealed that younger children had higher mortality risks soon after bereavement compared to their adult counterparts. This led the authors to assume that a parental death in young age is an unexpected event, and therefore it has a stronger impact on their grief reactions. Conversely, adult children showed a lower mortality risk post-loss, as parental death was more anticipated due to their parent's old age and deteriorating health. Based on this, the authors concluded that "older offspring have greater acceptance of parental death and are better prepared mentally to cope with the bereavement process" (Rostila & Saarela, 2011, p. 243). However, the study did not reveal any explicit links between parental death and subsequent child mortality; therefore, such assumptions should be viewed with caution as they are based on correlational associations. Nonetheless, additional empirical findings offer support toward the conclusions offered by Rostila and Saarela (2011). Leopold and Lechner (2015) demonstrated that younger adult children experienced a higher decline in life satisfaction compared to middle-aged children

who had lost a parent. If a death happened when the child was younger, it was considered “off-time” (p. 747) and resulted in a stronger decline in life satisfaction. Conversely, if it happened due to the parent’s old age and was anticipated by the adult child, it was considered an “on-time” (p. 747) transition and therefore the decline was less. This was supported by Hayslip et al. (2015) who confirmed that the younger people in their study suffered parental death more intensely than their middle-aged counterparts, thereby concluding that “the death of a parent is a normative experience for many middle-aged adults” (p. 13). However, both studies used the same measures to compare the impact of bereavement on two distinct groups of people. Doing so assumes that young people and adults experience grief in the same way, which overlooks challenges and responses that are particular to each group. Furthermore, it can be problematic to describe losing a parent in adulthood as an on-time or normative event and to assume that adult children suffer less because of it. Such views risk overlooking the seriousness of parental death in adulthood, while fostering a societal expectation that adult children are less affected by their loss. However, the adult child’s experience may be quite different, and far more complex, than this supposition.

Although losing a parent in adulthood can be seen as a normative and anticipated event, it does not necessarily make it easier to bear. This is discussed by Smith (2003), who shared the frustration that followed his mother’s death:

After my mother’s funeral, I frequently felt as though I had run a gauntlet of questions: “How old was your mother?” When I answered eighty-three, the frequent response was, “Oh, then she lived a good long life”. “Oh” felt like a slap to my face. Grief particularly for an aged mother, is disenfranchised. [...] Though the loss may be deeply felt by the [adult] child, society does not accept or support profound or extended mourning in this situation. This may leave the adult child in the position of

outwardly denying the impact of the loss, while inwardly he or she may be grieving.

(p. 2)

Smith's words reflect the tension that can exist at the intersection of a person's grief and the norms of society. Although his view concerns his personal experience as one individual, his description puts words to the experience of disenfranchised grief that some adult children may face when burdened with such norms. Disenfranchised grief⁶ is a concept first introduced by Doka (1989, 1999), which refers to the lack of recognition of the significance of a person's loss. It involves a degree of invalidation whereby the bereaved person perceives their grieving as unrecognised within society, which in turn risks aggravating their grieving. Against this background, the lack of bereavement research on losing a parent in adulthood places adult children at risk of such disenfranchisement. This is problematic as bereaved adult children are faced with challenges that warrant appropriate care and support. Thus, they should not be left to fend for themselves as this can make matters worse.

Challenges of Losing a Parent in Adulthood

Losing a parent in adulthood can present many challenges unique to the adult child. Examples of these challenges are illustrated by Anderson (1980), who points out that losing a parent can be a "role-loss" (p. 154), resulting in an experience of abandonment and a loss of identity. This is particularly painful if the adult child has continued to identify themselves as primarily being their mother's or father's child and has relied on their parents when it comes

⁶ This term has been criticised by Robson and Walter (2013), who argue that it implies that grieving is binary, i.e. either your grief is disenfranchised or not. Thompson and Doka (2017) responded to this critique by pointing out that the term "disenfranchised grief" is used in a metaphorical sense; therefore, such literal interpretations of the word do not apply. Rather, their concept "involves a degree of invalidation, rather than an all-or-nothing approach" (Thompson & Doka, 2017, p. 178).

to asking for advice and feeling a sense of safety. Losing that parental support can lead to a sense of increased autonomy where the bereaved adult child develops self-assertion and a “greater valuing of one’s own opinions, insights and plans” (p. 157). Thus, a parental death can also represent a transition from childhood to adulthood, which can be seen as a conflicting experience due to one simultaneously feeling orphaned (Anderson, 1980). Furthermore, losing a parent in adulthood can intensify the adult child’s sense of finitude. Such a loss can have a profound impact on a person’s life, as it challenges the illusion of immortality. Once one or both parents have died, the adult child is next in line and therefore “death seems closer” (p. 151). This risks complicating the conflicting emotional crises of mid-life, especially if it happens in tandem with other adult responsibilities like trying to raise a child of one’s own. Anderson’s (1980) observations were documented over 40 years ago and are founded on a small number of individual case studies. Nevertheless, these observations offer valuable insights that remain relevant today, as similar challenges have been seen in more recent studies (Marks et al., 2007; Umberson, 2003; Umberson & Chen, 1994).

Losing a parent in adulthood can result in significant psychological distress. Umberson and Chen (1994) conducted the first quantitative study that sought to measure the impact of parental death on adult children’s psychological well-being, physical health, and alcohol intake. Data were collected from adults between the age of 24 and 96 through a large two-wave national survey in the United States. Survey interviews were conducted in 1986 (3,617 adults) and again in 1989 (2,867 adults). During these 3 years, a total of 207 survey respondents had lost a parent. Psychological distress, self-reported physical health factors, and alcohol consumption were measured. The survey questions also asked about the nature of the parent-child relationship pre-loss by assessing emotional support from the parent, relationship strain, the parent’s impairment prior to their death, frequency of contact between

parent-child, and childhood memories related to drinking, mental health problems, marital problems, and domestic violence within the family. These questions offered some insight into the parent-child relationship pre-loss, and how this may have affected the adult children's reaction to bereavement. Findings showed that when compared to non-bereaved respondents, most bereaved adult children reported an increase in psychological distress, a decline in physical health and an increase in alcohol consumption post-loss. Findings also revealed that the gender of the deceased parent and the adult child was a strong influential factor on how the parent's death affected the adult child. The loss of a mother led to increased psychological distress in daughters, whereas loss of a father resulted in increased alcohol consumption in sons. Additionally, adult children's coping mechanisms in relation to their loss and grief was either similar to those of the deceased parent, or reflected prior parent-child relationship quality and gender influences. For example, bereaved sons demonstrated an increased alcohol consumption post-loss when losing a father who had drinking problems. In contrast, daughters exhibited relief, which could be due to perceiving her father's alcohol problems as threatening. The data also showed that a small but significant group of adult children exhibited improved functioning post-loss, consuming less alcohol, and reporting improved physical health. The authors assumed that this was due to a desire to take better care of their own health, as they had become increasingly sensitive to their own mortality. However, such causal inferences were based on statistical associations made by the researchers. The researchers' data did not provide qualitative insights into what the actual experience was like for the bereaved adults, nor could they know for certain why their research participants responded to their loss the way they did. Given these limitations, the authors recommended that additional qualitative data research should be undertaken to gain a deeper insight into adult children's loss and grieving experience.

Drawing from the Umberson and Chen study in 1994, Umberson (2003) proceeded to publish the book *Death of a Parent: Transitions to a New Adult Identity*. Umberson included the data from her 1994 study with Chen and complemented it with new qualitative data from interviews with 73 adults who had recently lost a parent. She also shared excerpts of their narratives throughout the book. The combination of the two separate data collections was useful since much of the quantitative data collected in the earlier 1994 study supported some of the narratives offered by the participants in the later study and vice versa, thus yielding further insights into the matter and strengthening the credibility of these studies. For example, Umberson's (2003) qualitative data revealed that unresolved issues with the parent can complicate the loss and grieving experienced by the adult child. Umberson also highlighted that some adults may experience positive effects such as relief, physical improvements, or a decrease in stress post-loss. This is more common when the adult has had a complicated and dysfunctional relationship with their parent, or if the time pre-loss has created a burden and involved informal caretaking where the child needed to care for their parent. Umberson's (2003) findings further showed that a parent-child bond may be strong, but it can also be riddled with conflicts. Some adults spend their lives yearning for a more loving parent, but when the parent dies this yearning can intensify, given that there is no hope of improving or repairing the relationship. The death can also evoke a degree of guilt in some bereaved adult children who feel that they have not been there enough for their parent. This suggests that past conflicts can have a significant impact on how the adult child responds to their parent's death. Furthermore, the data suggested that parental death is unique in the sense that it initiates a "rite of passage" (p. 100) for many adults. Similar to Anderson's (1980) views, this passage transitions the bereaved adult child from childhood to adulthood, while also leading them to re-evaluate their lives as they grow more aware of their own mortality. More so, due to their strong relational bond, a parent's death can symbolise the death of a part of oneself,

and in particular, the death of one's childhood. In other words, one has lost the main link to being a child, which can elicit earlier childhood emotions that are fundamental to child development, such as the fear of separation or abandonment. Thus, the loss of a parent can make one's childhood fears become a reality, while simultaneously being faced with one's own mortality as an adult (Umberson, 2003).

Losing a parent in adulthood can also bring relational challenges. Umberson's (2003) findings revealed that a parent's death can influence the marital quality of the bereaved adult child. Most married participants reported a negative decline in marital quality, with an increase in marital strain, conflicts, and disappointment. Women expressed greater disappointment in the lack of empathy and support received by their spouses, who often seemed uncomfortable with their wife's strong emotional responses post-loss. Umberson argued that this could be due to the social conditioning of gender roles, whereby men and women are treated differently and encouraged to behave in ways according to gender stereotypes. Emotional expression is commonly encouraged in women, whereas men are often socially conditioned to avoid and suppress their feelings through distracting themselves, for example by increasing workload or alcohol consumption. Women also use avoidance strategies but balance these with other coping strategies that include expressing their emotions overtly, engaging in conversations, and asking for help from their social network (Umberson, 2003). Thus, these data suggest that men's and women's different coping skills and needs can sometimes make it difficult for a husband and wife to provide each other with necessary support post-loss.

Umberson's (2003) book, and Umberson and Chen's (1994) earlier study are significant contributions to bereavement research as they present a well-rounded picture of loss and grieving unique to adult children, through both quantitative and qualitative data. Findings from these studies suggest that the severe impact of parental death on adult

children's lives should not be underestimated. They further highlight the importance of the parent-child relationship and how this impacts the time post-loss in various ways. Therefore, adult children's loss and grieving experience, including any challenges that may be seen as more particular to their group merit increased attention within the field of bereavement studies. Further studies are necessary to gain an increased understanding of the loss and grieving of adult children as a basis for enhancing support for a group of people whose potentially traumatic experiences too often go unrecognised. Such an understanding and acknowledgement, if shared among researchers, bereavement professionals, and the general public, can contribute towards developing essential and appropriate support, which facilitates adult children's grieving process, thereby lessening any grief disenfranchisement they may be experiencing.

Concluding Summary of Literature Review

The literature review has provided an overview of key developments in the field of bereavement studies throughout the 20th century and leading into the 21st century. *Part one* introduced modernist theories and research in psychology that shaped perspectives on grieving in the west through most of the 20th century. The key characteristic of modernist psychological perspectives on grieving was its individualistic lens, whereby it was considered an intrapersonal process with little concern for social and cultural influences. The focus was primarily on uniform grief symptoms and psychopathology, which assumed that grieving was experienced in the same way by all people. Grieving was mostly considered a means to an end, leading towards resolution in a linear progression, and often through a process of grief confrontation and detachment from the deceased. However, the current study does not favour these views, as empirical research offers limited support and findings suggest that they can do more harm than good. Consequently, this has encouraged scholars and researchers – myself

included – to question and develop alternative approaches. Nevertheless, there are some elements from earlier theories that are worth preserving. Freud's (1917) notion of confrontation and detachment may sometimes be necessary for some people, but not always and not for everyone. Furthermore, these terms are not all-or-nothing but can rather be applied on a scale. For example, it may be that one needs to confront a certain aspect of one's grief, whereas other aspects are left alone. Similarly, one may feel the need to detach from some elements of a relationship and not others, therefore maintaining some degree of connection with the deceased. Lindemann's (1944) description of what constitutes grief is useful to describe how grief can manifest within the griever; yet at the same time, one must refrain from assuming that this is uniform to all grievers or that it follows a fixed timeframe. The phase/stage theories of Kübler-Ross (1969) and Parkes and Bowlby (1970) are too prescriptive in their linear chronology, yet there is value in the idea that the intensity and expression of grief can change and subside over time for some people, even if not necessarily as proposed by these theories. Elements from traditionalist theories will be considered later, when analysing my data.

Part two presented significant contemporary developments that emerged from a critical engagement with traditional perspectives. A “new wave” (Currier et al., 2006, p. 420) of theories and models of grieving arose in postmodern psychology in the late 20th century and has gained traction during the first two decades of the 21st century. Instead of solely focusing on grieving as a set of symptoms in one individual, it is now viewed as a multifaceted human experience that is seen within a larger context – a view which the current study supports. Grieving is no longer considered a linear process of predictable stages/phases that happen in isolation from one's environment. Nor are loss confrontation, catharsis, and detachment from the deceased seen as inevitable necessities. Instead, grieving is approached as a dynamic, cyclical, and interactive process that is shaped by the interplay of influential

factors that arise from within (intrapersonal) and that arise in relation to one's outside world (interactive/interpersonal). Central to these developments is Neimeyer and colleagues' meaning reconstruction model. This model proposes that the bereaved person engages in meaning finding or making to help them adapt to a different reality post-loss (Neimeyer & Anderson, 2002). In light of these recent developments, the most illuminating aspect is that they lend themselves to an increased sensitivity to the different manifestations of grieving, while disregarding one-size-fits-all models where grieving is a means to an end. Instead, grieving is approached as a dynamic and purposeful process that is entrenched in meaning – an experience that is deeply personal, as well as intimately connected with one's life history and social relationships. Indeed, postmodern developments in bereavement show that there is no single theory that is particularly useful in all situations or applicable to all grievers; rather, the best view allows for complexity, plurality, and differences. In that sense, theories can be best used as background knowledge to inform one's understanding of grieving and to acknowledge and affirm others' experience. It is important to take this into account since a misinformed bereavement professional (or other) could misuse theories and generate unrealistic expectations that are damaging for the grieving person and may only exacerbate their sense of loss. Given these postmodern developments, earlier modernist theories are not adequate for understanding how people experience loss and grieving, and more should be done to support and add to the momentum of the new wave of multi-dimensional perspectives, along with challenging outdated models and myths relating to loss and grieving. It is from this stance that I will position myself as a researcher and approach my research questions.

Part three narrowed the focus further by discussing critical aspects related to parental death in adulthood. Although empirical research shows that younger children can be more vulnerable to bereavement than adults, adults too experience challenges that are particular to

their circumstances and different to those experienced by children. These challenges are brought forth in the small sample of existing empirical research on adults' experience of parental death. These studies and their findings offer valuable contributions to an understudied area, demonstrating that parental death can lead to heightened psychological distress, weakened physical health, and increased alcohol intake among adult children. Additionally, losing a parent in adulthood is seen as a turning point for most adults, leading to a heightened awareness of their own mortality, and a re-evaluation of their life choices, relationships, and actions. Findings also suggest that the history and quality of relationship between parent and child are significant to the grieving process, highlighting the importance of considering family history in bereavement studies. Seen together, these findings support the rationale of my study, as they show that adult children's experiences of parental death are a significant and impactful life event, and children across all ages deserve to be heard in order to provide the appropriate support and care that answers to their specific needs and facilitates their grieving process.

By surveying the literary landscape of bereavement studies, I have been able to show my positionality in relation to these developments and the approach I am taking in the current study. Concurrent to this, the review of theories and empirical research concerning the grieving process, meaning reconstruction, and adult children's experiences of parental death demonstrates room for further development, as this study seeks to address. Additional exploration is required in regards to: (i) the loss, grieving, and meaning reconstruction that occurs in adult children who have lost a parent during adulthood; (ii) using the meaning reconstruction model in bereavement research as a means to better understand the significance of grieving for the bereaved person, rather than as a sole means to regulate psychopathology; (iii) taking into consideration the time pre-loss, particularly in regards to family life and the individual's history. Most research on grieving and meaning

reconstruction solely focuses on the time post-loss, which overlooks important parts of the bereaved person's pre-loss life narrative and history that can be of significance to their grieving. Indeed, qualitative data show that the parent-child relationship pre-loss plays a significant role in adult children's post-loss grieving response, suggesting that it ought to be taken into account; (iv) most research on adult children's loss of a parent consists of quantitative data that primarily measures the impact of the bereavement on adult children's psychological and physical well-being. More engagement is needed with the meanings held within those stories, to better capture the dynamic and personal process of loss and grieving located within the context of their life history. This present life history research seeks to address these points. In the process, it seeks to contribute to the new-wave developments in bereavement literature, and to acknowledge more substantially and enhance knowledge of the experience of adult children who have lost a parent in adulthood. Additional qualitative research is therefore necessary to present narratives told by adult children, which can provide rich descriptive and explanatory accounts and capture the loss and grieving process, including its meaning outcomes, across time spans, thus allowing for a more compassionate response to the griever's experience. This offers a strong justification for the current study, as my methodological approach is well-suited to capture such insights.

Chapter 3: Methodology

Development of Research Inquiry

The primary research question for this thesis was: *How are loss and grieving experienced across time by five women in relation to parental death in adulthood?* Based on a thorough engagement with the literature, I adopted the viewpoint that loss and grieving are distinct experiences, yet are closely connected. Additionally, I assumed that grieving could be experienced differently by each person, despite certain similarities. Thus, I sought to explore each research participant's loss and grieving experience in an open-ended manner.

I developed three supplementary questions to narrow my focus further. The first question was: *What is the significance of the parent-child relationship across time for the women's loss and grieving?* This question was shaped by the view that loss and grieving take place within a social and historical context. Thus, the question considered the family history of the bereaved person, with particular regards to their pre-loss relationship with the deceased parent.

The second and third supplementary questions were: *What meanings can be identified from their loss and grieving experiences?* and *What insights do these meanings bring to our understandings of loss and grieving?* These two questions arose from recent theoretical developments on the role of meaning in bereavement. Most research on the role of meaning reconstruction in bereavement approaches it as a means of regulating psychological loss adaptation. This was not my primary focus; rather, I used Neimeyer and colleagues' meaning reconstruction model to identify meanings included in the women's narratives to gain further insight into how bereaved adult children experience their loss and grieving and what this means to them.

These research questions linked together all the other components of the methodology, research design and methods, permeating the different processes involved in the research and influencing every aspect of it.

Choice of Methodology

Life History Research

Given my research inquiry, life history research offered an appropriate methodological approach for exploring loss and grieving in a contextualised manner. This methodology seeks to explore in depth a particular aspect of a person's lived experience across time within a socio-cultural and historical context. Life history is founded on the principle of "gaining insights into the broader human condition by coming to know and understand the experiences of other humans" (Cole & Knowles, 2001, p. 11). According to Goodson and Sikes (2001), the primary aim of life history research is to: "explore how individuals or groups of people who share specific characteristics, personally and subjectively, make sense of, and account for the things that happen to them" (p. 39). Additionally, life history research aims to not only tell the story of the person but to also put that story into a broader context, for the purpose of gaining a deeper understanding of questions such as "'why', 'how', 'what it's like' and 'what does it mean to you?'" (Goodson & Sikes, 2016, p. 74). These aims resonated well with my theoretical framework of a meaning-centred bereavement model and how I sought to approach loss and grieving. Thus, by engaging with this methodology, I would be able to provide rich insights into each participant's lived experience of loss and grieving in a way that could best answer my research questions.

The Development of Life History Research

Historically, life history research has its roots in anthropology. In the early 1900s, life history interviews were conducted with members of Aboriginal and Native American groups, as a way of keeping their history alive, as it was otherwise mainly passed on through oral tradition (Barrett, 1906; Radin & Blowsnake, 1926). Life history research was later adopted in the social sciences from the 1920s onwards in publications such as Thomas and Znaniecki's (1918) *The Polish Peasant in Europe and America* and studies of city life in Chicago, conducted by members of the Chicago School of Sociology under Robert Park, such as *The Gang* (Thrasher, 1928), *The Gold Coast and the Slum* (Zorbaugh, 1929), *The Hobo* (Anderson, 1923), and *The Ghetto* (Wirth, 1928).

Life history peaked in the 1930s and then declined in popularity amongst social scientists up until the 1980s. This was mainly due to an increasing interest in the application of statistical methods and a declining interest in (auto)biographical narratives. Statistical methods were quicker, required less labour, and could be applied across a larger population (Goodson & Sikes, 2001). With the advent of modernism,⁷ generalisable facts and objectivity were viewed as the hallmarks of truthful and accurate research. The goal of such research was to acquire a "fixed immutable truth about whatever it is that is being investigated" (Goodson & Sikes, 2001, p. 39). However, life history researchers do not make claims that represent an unchanging reality. Rather, they offer a subjective interpretation and representation of a person's lived experience as told by that person. Thus, life history does not provide generalisable facts, clear-cut measurements, and fixed immutable truths. According to

⁷ It is difficult to put forward a precise timeline for the era of modernism, since it has developed over time, across multiple disciplines and in various ways. Some consider it a concept, others an era, which makes it challenging to position it in time (Barnes et al., 2014). There is no exact beginning or end to this development, yet it has been roughly estimated to have taken place from the renaissance until the end of the 19th or mid 20th century (Raskin, 2002). The name postmodernism implies that it came after modernism, which suggests that the modern era has ended, yet this is debatable since aspects of modernist views still exist today across various disciplines.

Goodson and Sikes (2001), it was for this reason that life history research “failed its membership test” (p. 14) and was not regarded as a valid social science research method at the time.

The shift towards postmodernism in the social sciences around the 1980s challenged the objective and finite truth of modernism. Views began to favour the “multiple, disrupted notions of subjectivity” (Goodson & Sikes, 2001, p. 15), which acknowledged the subjective variety of human experience and multiple realities. Life history, as a means of “getting close to living human beings” (Plummer, 2001, p. 2), was brought to light again in Plummer’s (1983) *Documents of Life*, where he critiqued anti-humanist methodologies and instead encouraged “creative, interpretive story tellings of lives – with all the ethical, political and self-reflexive engagements that this will bring” (Plummer, 2001, p. 1). Plummer (1983) offered a comprehensive introduction to the field of qualitative biographical research and suggested that life history research needed to be made prominent and developed in the social sciences. Postmodernism contributed towards the gradual revival of life history, where “its lack of representativeness and its subjective nature” (Goodson & Sikes, 2001, p. 15) now became its greatest strength within sociology. Since then, sociology has seen a significant development regarding biographical and narrative studies, including life history research (Plummer, 2001).

Life History Captures a Life Story

A life history sets out to capture a life story as told by the research participant. Considering this, Goodson and Sikes (2001) make the distinction between a *life story* and a *life history*. The research participant is considered the informant or the storyteller for their lives and shares a part of their *life story* in narrative form with the life history researcher. Subsequently, *life history* happens when the researcher takes historical context into account,

as they represent the *life stories* told to them by the informant, covering the social histories in which these stories are embedded. A *life history* thus offers a contextual element of time and space and is often presented through a chronological sequence. Such contextualisation is important as Cole and Knowles (2001) argue that “lives are never lived in vacuums (...) in complete isolation from social contexts” (p. 22). Thus, according to Cole and Knowles (2001), what distinguishes life history from narrative and autobiographical research is that the person’s *life story* is placed — by the researcher — within a larger social, cultural, and/or historical context. In turn, life history research explores how the storyteller’s experiences may have been influenced by such factors to gain a fuller understanding of their experiences within a particular time and place. As a life history researcher, I followed Goodson and Sikes’ (2001) distinction between *life stories* and *life histories* when discussing my research. I did so to distinguish between what was told by the research participant (their *life story* as told by them to me) and my construction and interpretation of their story (*life history* as my representation of their *life story*).

The Characteristics of Life History Research

Life history research is not limited to a singular prescriptive way of working, but rather encourages a flexible approach (Cole & Knowles, 2001; Goodson & Sikes, 2001; Plummer, 2001). Goodson and Sikes (2001) highlight that:

We do not believe that there is only one, ‘proper’ way of doing life history research. Different projects will have their own features and requirements and each researcher is likely to have their own personal style and a unique emotional engagement with any particular project. (p. 19)

Although there is not one prescribed way of conducting life history research, there are some common characteristics. For example, life history research typically focuses on one or a small number of individuals and explores, in detail, a particular aspect of their life experience. This is usually achieved through a naturalistic inquiry in which the researcher collects qualitative data through multiple methods such as interview conversations, group work, journals, photographs, and artefacts (Cole & Knowles, 2001; Goodson & Sikes, 2001, 2016; Plummer, 2001). Data collection is comprehensive and is usually carried out over an extended time period to generate insights into a particular aspect of a person's life story. Alongside this, life history analysis organises relevant data into a rich life history account that stands in relation to a particular topic of inquiry. This account often follows a chronological sequence (even though chronological order is not a requirement during data collection), in the form of a historical timeline of a person's life (or aspects of it) (Goodson & Sikes, 2001). According to Goodson and Sikes (2001), the timeline usually begins with place and date of birth, and chronologically follows the life course of the research participant until the time of the interviews. It can also capture some of the participant's future aspirations. This timeline can be likened to Plummer's (2001) metaphorical guideline for "living a life like a book" (p. 124). The book's chapters represent significant moments/stages of one's life in a chronological order, i.e. chapter one represents birth, and so on. Plummer (2001) states that a life history locates a person's life on a "historical time line" (p. 128), where shared generational and historical experiences play a key role in the story that is being told. The chronological pattern, which is co-constructed by the storyteller and the researcher, thus becomes a way to map out a life trajectory, and within this trajectory the researcher can identify critical life events that are relevant to their research enquiry (Plummer, 2001). This makes life history methodology particularly valuable for exploring parental death in adulthood and its development across time, as such life trajectories can provide knowledge of

the time pre-loss as well as post-loss. This can present a broader picture of what the loss and grieving experience is like and important influences that may shape this experience, such as family history and the parent-child relationship. If one only focuses on the time post-loss, as much bereavement research to date has done, then one can only see part of the story.

Epistemological Stance

In this section, I shall briefly summarise the epistemological stance that I took in this research study. Epistemology is the name given to the theory of knowledge, and it concerns questions about what we know and how we know what we know (Denzin & Lincoln, 2018). Epistemology is a large and technically complicated domain of philosophy, and I can only indicate, in the broadest terms, what my position is and why I adopted it.

Rooted in my choice of methodology, my epistemological paradigm followed a constructivist view. According to Denzin and Lincoln (2018), constructivism, in its most general sense, is interpretivist in nature, whereby one gains “understanding by interpreting subject perceptions” (p.114). It concerns how persons and societies construct and interpret what they believe to be true about their reality and recognises that truth is a matter of perspective. Maxwell (2012) takes this same assumption to mean that reality cannot be fully known, but nonetheless exists, and people can have their own interpretation of it.

Life historians commonly subscribe to such epistemological considerations, whereby life history researchers and research participants are each engaged in “interpreting the world from their own various perspectives” (Goodson & Sikes, 2001, p. 39). A central assumption in life history research is that “different interpreters who have had different life experiences are likely to make different interpretations which will, therefore, result in the description of different realities” (Goodson & Sikes, 2001, p. 39). For each individual, knowledge is constructed through their own experience and interpretation of social reality. This knowledge

is grounded in: (i) how they interpret their experience and (ii) how they then construct, using that interpretation, their own meaningful reality. This is explained further by Goodson and Sikes (2001): “We hold to the opinion that it is through the construction, telling and retelling of our personal stories, to ourselves and to others, that we attempt to make sense of our lives and give them meaning” (p. 40).

Grounded in this epistemological paradigm, life history researchers seek to interpret, contextualise, and represent a particular aspect of the world, through narratives they have been given by their research participants, and to explore the meanings the participants have attached to this aspect through their interpretations and constructions. As a life history researcher, I assumed that the participants’ interpretations and constructions of their loss and grieving experience would only capture some aspects of their lived reality as they knew and remembered it at the time of our interviews. I was also aware that what they constructed was “a version of their story and of their life” (Goodson & Sikes, 2001, p. 46). I further allowed for the possibility that the participant may fail to remember something accurately and might therefore be mistaken in some parts of their account. There could also be elements they chose to leave out, or aspects of their experience that were exaggerated, understated, or misunderstood. In turn, my own interpretation, construction, and representation of each person’s life story only reflected some aspects of these stories and the experiences that they represented. In light of this, I could not aspire to fully capture and depict the experience exactly as it appeared to the research participants. My representation of their life stories would never altogether exactly replicate their life experience, and this would not be a realistic expectation. Pertinent, too, is the fact that when the women spoke about themselves and their experiences, they did so as, and in the context of, the “life story teller —the informant” (Goodson & Sikes, 2001, p. 40). Their life story was constructed (by them) for the purpose of (my) life history research; yet, if it had been shared for a different purpose and in a different

circumstance, i.e. with a family member, at a job interview or at a doctor's clinic, then the narrative would most likely have been constructed differently. This suggests that their interpretation and constructs of their life experience were being negotiated, constructed, and reconstructed, during a particular time and place, and within a particular social context. Additionally, not only did I, as the life history researcher, retell what I had been told, but I did so "within the context of their [my] own frames of reference and the particular stories that they [I] wish to tell via their [my] use of what informants say" (Goodson & Sikes, 2001, p. 51). In other words, how the women shared their stories was shaped by their life experiences, choice of language, education, culture, gender, history, societal structures and so on – and my interpretation as a researcher was shaped by but was not limited to this, as I brought my own perspectives and contexts to bear on the data. Thus, my life history research was a co-constructed process between myself (researcher) and the research participants, whereby the context had a bearing on what was told and how it was told (in both our cases).

Against this background, my aim throughout this process was to pursue a common meeting ground where my interpretation and the interpretations of the participants could come together to offer a rigorous, trustworthy, and coherent representation of their life stories. Indeed, as Goodson and Sikes (2016) highlight: "life history work is always co-constructed and is not the singular product of the external researcher" (p. 75). As part of this co-construction, I endeavoured to present a faithful and trustworthy version of the research participants' testimonies, in so far as this represented their experiences of loss and grieving in relation to parental death, which manifested themselves at particular moments in their lives.

Disciplinary and Theoretical Framework

Disciplinary Framework: Thanatology

Bereavement and grieving can be considered multi-dimensional experiences in an individual's life (Attig, 2011), and they have been explored across numerous academic disciplines, such as psychology, psychiatry, anthropology, and sociology (Neimeyer, Prigerson & Davies, 2002; Rosenblatt, 2001; Silverman et al., 2021; Souza, 2017). However, the study of bereavement and grieving, including its various disciplinary aspects usually falls within the scientific discipline of thanatology. Thanatology is a standalone scientific discipline that concerns the study of dying, bereavement and grieving, and it is strongly linked to but also distinct from psychology as an academic discipline (Meagher & Balk, 2013). Similar to studies situated within the field of thanatology, my study relies heavily on psychology, as I have primarily drawn from theoretical and empirical perspectives in this field. Indeed, as Souza (2017) makes clear, "the literature on bereavement has been dominated by psychology" (p. 61). This is understandable because psychology, in simple terms, is the scientific study of human experiences in relation to behaviours, emotions, and mental activities (Gazzaniga, 2018), aspects which cannot be separated from loss and grieving, and hence its close relationship to thanatology.

Theoretical Framework: Meaning-Centred Model

My choice of theoretical framework was influenced by my disciplinary stance, as well as my methodological and epistemological approach. Bereavement theories have often been developed within psychology and have informed the field of thanatology. Traditional bereavement theories stem from modern psychology and have often been guided by a modernist worldview (Neimeyer, 1998), in favour of empirical realism, and logical positivism, which supports a universal truth, generalisability, predictability, and the notion

that knowledge is independent of the knower (Gergen, 1985, 1990). Such theories of grieving within modern psychology can be recognised through their emphasis on grief symptomatology and the assumptions that grieving follows a universal pattern that can be seen across time, people, and cultures (Neimeyer, 1998). In contrast, during the “postmodern turn” (Gergen, 1990, p. 26) in psychology, which emerged throughout the mid to late 20th century, an increasingly constructivist view began to emerge amongst critical psychologists. Truth was now considered by some to be a social construct and a matter of perspective; hence, there could exist multiple subjective truths around a particular event, all constructed by the individual in relation to their culture, history, and relationships (Gergen, 1990). It was from these postmodern perspectives and constructivist epistemologies that a postmodern “new wave” (Currier et al., 2006, p. 420) of grief theories emerged, which informed the field of thanatology. Significant to this was the development of the meaning reconstruction model, which was constructivist in nature and shaped out of a postmodern psychological approach (Neimeyer et al., 2010). The current study aims to support this development and its expanding perspectives by providing researchers, bereavement professionals, and the general public with a deeper insight into the meanings embedded within the research participants’ narratives on loss and grieving, as a means of learning more about and gaining a better understanding of their experiences. Indeed, the meaning reconstruction model resonated with and illuminated what this research study sought to explore within a life history context, and it fitted well within my chosen epistemological paradigm. Therefore, I decided to draw on this theoretical framework as something to refer my findings back to through a critical lens, while remaining open to new theoretical insights. I will refer to this framework as the *meaning-centred model* when discussing it in relation to my study (see pp. 62-66) for an explanation of the name change).

Influential Research Design Framework

The research design framework is loosely based on that developed by Sikes and Halls (2017) and the general guidelines for conducting life history research provided by Cole and Knowles (2001), Goodson and Sikes (2001) and Plummer (2001). I say loosely since each piece of life history research, including my own, is a unique process, which is not restricted to one definite framework or set of rules (Goodson & Sikes, 2001; Plummer, 2001). Therefore, it was important for me to remain open and flexible to how my research process would develop.

Sikes and Hall (2017) referred to their study as a narrative life history study, which aimed to “gain a sense of how individuals with different biographies go through similar social experiences” (p. 326). They explored the concept of grief with 22 children and young people who had a parent with dementia. I will describe this study briefly and will also offer a description of two elements that I chose to integrate into my own study. These elements specifically concerned: (i) interview techniques and (ii) the inclusion of long quotations from the participants when presenting the data.

Interview Techniques

Sikes and Hall (2017) included at least two interviews with each research participant, with interviews each lasting on average 1.5 hours. Interviews invited the participants to freely tell their stories of parental dementia, whereby the researchers did not ask any pre-determined questions. The aim of this approach was to gain an insight into the participants’ lived experiences, by centring the study around the experiences of the participants themselves. The intention was to “elicit detailed accounts which are considered in light of the particular social, cultural, historical and other contexts in which they are lived” (Sikes & Hall, 2017, p. 326). Their findings were analysed thematically and divided into five themes. Each theme was

presented through lengthy quotations from different participants, to provide further insights into their experience.

I decided to follow a similar interview approach, although my interviews were more semi-structured in the sense that I asked some predetermined questions, while leaving room for the participant to speak freely around the topic in question when necessary. My questions were open-ended, which offered the participants a space to shape and tell their narratives in the way they wanted to, thereby centring the interviews around them and their experiences.

Including Long Quotations

Seeing as the topic explored by Sikes and Hall (2017) was of a highly sensitive and personal nature and seeing as the participants often shared what Sikes and Hall (2017) regarded as “painful reflections” (p. 329), they presented their collected data through longer participant quotations with minimal researcher commentary, while leaving their analysis and commentary for the discussion at the end. Sikes and Hall (2017) felt it would be more appropriate to give the participants room to share what needed to be said without interfering with their stories too much. I adopted a similar approach when constructing the participants’ life histories, whereby I included longer quotations from them to place their voice at the centre of their narrative. This is a common method when presenting life history data, since it is the voice of the storyteller that is to be brought forth (Goodson & Sikes, 2001). Similar to Sikes and Hall (2017), I left all my commentary to my discussion chapter.

Inviting Research Participants

Pre-Invitation: Applying for Ethical Approval

Prior to inviting research participants, I applied for ethical approval at the UCL Institute of Education. As part of my ethical approval application, I completed the mandatory

Information Security Awareness training, Freedom of Information training, and the GDPR training course. I strictly followed and committed to these regulations throughout the research process. I submitted an ethics application form to UCL, which went through a two-step process: (i) the application form was reviewed to obtain a mandatory data protection number for my research, and (ii) my ethics application was reviewed by my supervisor and another academic member of staff (see Appendix A for the ethics application form). My ethical approval was granted on September 2, 2019, and after that I began the process of inviting participants.

Selecting Participants

My aim was to work with five research participants. Five was a good number as it allowed me to explore the participants' stories in-depth, while providing enough breadth to demonstrate some variety of experience. It further enabled me to develop a closer research relationship with each participant where I could spend more time focusing on each person and explore their life story in more detail to ensure research rigour (Cole & Knowles, 2001; Goodson & Sikes, 2001). If I had had more participants for my study, then it would have been more difficult to achieve such depth and detail. Yet, a larger sample could indeed have yielded additional insights into loss and grieving, beyond the scope of my current study, thus demonstrating that there are advantages to each scenario. However, there were also practical implications to consider, as collecting, transcribing, and analysing large amounts of qualitative data takes time and resources, which extend beyond what a single life history researcher can manage (Goodson & Sikes, 2001). Hence, five participants seemed like a reasonable number to maintain a manageable workload.

I initially considered inviting research participants through bereavement support services. These organisations serve as a trusted source, and if they chose to present my

research project to their audiences then this would also have provided wider dissemination for my work. Additionally, through these services I would have been reaching out to people with whom I had no previous contact. This type of relational distance could be seen as a positive factor as no pre-existing relational dynamics would influence our research relationship. However, three factors led me to reconsider this possible approach.

Firstly, I was wary about relying on other organisations' efficiency in accepting my project and supporting participant invitation. I was concerned about the additional workload and time pressures that this could potentially involve. Therefore, I preferred to work independently, as it gave me more control over time and task management. Secondly, by reaching out to people outside bereavement services, I could reach those who may not normally use such services. Bereavement researchers should not solely access research participants through bereavement services, as many studies have done, as this risks overlooking people who do not seek such support but still have a lot to say. Thirdly, by contacting people within my social network, there would already exist a level of established trust, which could support the relationship between researcher and participant (McConnell-Henry et al., 2010). Such connections can be seen as advantageous in life history research, since the existing trust can support both parties in feeling comfortable enough to embark on a research journey together, thus allowing for a deeper exploration of personal stories (Goodson & Sikes, 2001). Taking these factors into consideration, and given the sensitive nature of my research topic, I decided to search for participants in more informal and personal settings, which were already part of, or had some connection to, my social network.

Purposive Participant Selection

My approach to participant selection was "purposive" (Maxwell, 2013, p. 97), as I deliberately searched for "information rich" participants (Plummer, 2001, p. 133) who could

provide the insights needed to answer my research questions (Etikan et al., 2016; Maxwell, 2013). My purposeful selection process was underpinned by the following criteria:

- The participant had to have lost either one or two parents (to any cause of death) during adulthood, and the parent's death needed to be considered a significant event in the participant's life.
- The participant had to have the ability to commit to three to four interviews with me "for the purpose of gaining in-depth insights into an area of mutual interest" (Cole & Knowles, 2001, p. 65). The interviews would take place between September 2019 and March 2020.
- The participant had to have fluency in English and the ability to articulate themselves clearly about the topic in question and talk about it for extended periods in great depth (Goodson & Sikes, 2001).
- The participant had to be based in, or nearby, London, the United Kingdom. The practical aspects of geographical location and time availability were crucial in ensuring that we could easily commit to the required meetings.

With these requirements as my guide, I identified three potential research participants, with whom I was already acquainted. They were aware of my PhD studies and had expressed interest in partaking in the study. Parallel to this process, I was also contacted by two women who expressed their interest after having heard of my study through a mutual contact. I spoke with each of the five women (either in person or over the phone) about the research, and I provided them with a proposed information sheet and consent form. I asked them to read it in private and to take some time before making their decision. They were welcome to contact me if they had further questions. Thankfully, all five of them accepted my invitation.

Reflection on Participant Demographics

At the outset, it was not my aim to have an all-women group of research participants. Instead, this was the result of several chance encounters through a sequence of serendipitous events (Cole & Knowles, 2001; Plummer, 2001). On the one hand, I knew what I was looking for in terms of requirements; yet, on the other, I was open to whoever would emerge. I did not actively look for a certain number of women or men; rather, I thought that if I spread the word about my study and put forth an open invitation then whoever wished to share their stories with me would eventually show up – and indeed they did.

I was aware that working with an all-women group would bring some implications. An underrepresentation of men is common in bereavement studies (Coleman & Neimeyer, 2010), and this applied to my study as well. Due to this, I was unable to present any male narratives to offer their perspective on loss and grieving. Indeed, loss and grieving can be experienced differently by men and women (Umberson, 2003; Umberson & Chen, 1994). Although the intention of my study was not to compare gender differences (for such comparisons see Stroebe, Stroebe & Schut, 2001 and Stelzer et al., 2019), I realise that if I had included male participants' narratives, I would have been able to present additional perspectives that could have contributed towards a richer and more diverse discussion. Because of this, future life history research on loss and grieving ought to include participants of different genders (that also exceed the common two-gender binary). Hearing from different genders may also help to debunk potential gender stereotyping and to elicit important differences, including explanations as to why such differences exist, thus resonating with Butler's (1990) work on gender performativity⁸.

⁸ Gender performativity refers to “the repeated stylization of the body, a set of repeated acts within a highly rigid regulatory frame that congeal over time to produce the appearance of substance, of a natural sort of being” (Butler, 1990, p. 45).

The five women in my study were between the ages of 38 and 58. They had at minimum an undergraduate degree and their socio-economic status was either middle- or upper-class. They identified as heterosexual, three women were married, and two women were single. Two women were brown: Amara (aged 57) had migrated with her mother from India at a young age, while Rania (aged 38) had Sri Lankan parents but was born in London, the United Kingdom. Three women were white: two of them, Sophie (aged 58) and Kim (aged 40), were born in London, the United Kingdom, and Rachel (aged 55) was born in the United States. The women had different religious backgrounds. Amara was secular, but her parents were practising Hindus, and as a family they would sometimes perform Hindu rituals; Rania was a practising Buddhist; Sophie and Rachel identified as Jewish; and Kim's mother was a Catholic and her father was Jewish, but she did not identify with any religious practice. None of the five women had participated in a bereavement research study before.

Informed by Crenshaw's (1989) concept of intersectionality, an analytic tool that examines how one's social and political identities, such as race, class, gender and sexuality, combine to influence various modes of privilege or discrimination, I was acutely aware of the importance of having a diverse group of research participants comprised of women from varied socio-cultural backgrounds. This would contribute a cross-cultural element, where their different backgrounds could shape their stories, enriching the research by offering diverse views on loss, grieving, and meaning outcomes. Admittedly, my groups of participants could have been more diverse in terms of race, gender, sexual orientation, levels of education, socio-economic status, and nationality, which would have afforded a more diverse sample of perspectives. Yet, due to the small-scale nature of this study and the sampling strategy used, this was not completely possible.

Although the women were of different nationalities, the majority (three out of five) were white, and two were brown. All had grown up in and were well-adapted to a typical

western society, i.e. the United Kingdom or the United States. An overrepresentation of white women is common in bereavement research and most bereavement studies are conducted in western societies (Flesner, 2015; Report on Bereavement and Grief Research, 2004). This is problematic, as it is not sufficiently representative of people of different genders, races, ethnicities, or from other parts of the world. Furthermore, the women were middle- to upper-class, and they were educated to at least undergraduate degree level. Their language and vocabulary reflected this, as they articulated their experiences critically and with fluency and sophistication. The women's capacity to express themselves well contributed to a richness of data, which is advantageous for life history research. However, although these women were good storytellers, one must consider that people's social, economic, and cultural position affect the language they have access to. As Usher (1998, cited in Goodson & Sikes, 2001, p. 47) asserts, "we are constituted in language and positioned differently depending on the discursive practices of gender, race, class, ethnicity and other marks of difference". Furthermore, these positions also have an impact on the experience of loss and grieving itself, e.g. understanding how to negotiate the healthcare system requires a certain level of education, as well as having the financial means to make funeral arrangements and to take time off work, and so on. For this reason, future bereavement research needs to diversify the choice of research participants to support a more equal representation of their experience. Such diverse representation should include, but not be limited to, characteristics such as race, nationality, ethnicity, culture, socioeconomic positioning, religion, gender identity and sexual orientation.

Information Sheet and Consent Form

Prior to commencing my data collection, I ensured that each research participant had read the information sheet and signed the consent form. I based my information sheet and

consent form on the British Sociological Association's ethical codes (BSA, 2017). The BSA (2017) guidelines highlight the importance of maintaining professional integrity, while ensuring that the rights, privacy, and boundaries (such as anonymity and confidentiality) of the participants are being respected. The code emphasises the importance of building a trusting relationship between researcher and participants, thus also ensuring that the participants' well-being is not harmfully affected. The roles and rights of everyone involved are clarified and safeguarding measures are taken for everybody involved. The code also refers to appropriate measures that should be taken in relation to data storage, archiving, distribution, and the publication of research (see Appendix B for a copy of my information sheet and Appendix C for a copy of my consent form).

After they had familiarised themselves with the proposed information sheet and consent form, I asked each woman if she had any questions, or if she wanted to amend anything in these documents to suit her needs further. None of them thought that was necessary, and they were content with the information provided. However, if someone had wanted to make alterations, then I would have arranged a conversation with that person to clarify any questions and to mutually agree on amending the terms accordingly and in writing. Once each woman had agreed on the information provided, then they signed the consent form as a paper copy. I digitally scanned their consent form and saved it as an encrypted file on my encrypted laptop. I also backed it up on my encrypted hard drive. Additionally, I kept one signed paper copy of the consent form and one was also given to the research participant. I have safely archived all copies in a place that only I have access to.

The Importance of Ongoing Consent

The procedural ethical protocol of consent does not solely occur at the beginning of the research. Maintaining an ethical research practice requires an ongoing sensitivity by

means of mutuality and reflexivity throughout the research project (Hertz, 1996; Sieber, 2013). This includes the importance of ongoing consent. With regards to bereavement research, Rosenblatt (1995) stresses that there is only so much information that the researcher can provide in advance. Neither the research participants nor I could completely anticipate what the research would involve, and we could not specify in advance what exactly would arise, i.e. perhaps the research project would turn out to cause more distress than either of us had initially anticipated. For that reason, the informed consent that each participant gave in advance was indeed offered without a full awareness of possible developments during the research process. Therefore, it was important for me to continuously remind each research participant that their consent was ongoing. The research participants were informed that they were free to withdraw from the study at any stage of the research up until the publication of the thesis. If they were to withdraw, I would not publish their data. I understood that leaving the option for withdrawal open until the publication of my thesis was a risk that I took from my end. It could mean that I would lose work effort and time that had been invested in collecting, analysing, and representing their data. However, seeing as my research topic was of a highly sensitive and personal nature, I chose to put the research participants' needs first. Thankfully, none of the five participants withdrew. Therefore, the data that I collected from them could be included in the published thesis.

Data Collection

Life History Interviews

Having obtained ethical approval from UCL, sent participant invitation forms, and received back signed consent forms, I commenced my data collection with the research participants. I collected my data through in-depth life history interviews. The participants were continuously informed prior to, and sometimes during, each interview that all our

interviews would be kept strictly confidential and would only be used for the purpose of this study. With consent from the participants, all interviews were audio recorded to ensure the women's narratives were fully captured. The interviews took place in the participant's home or workplace. The locations were mutually agreed upon, and we both ensured that these locations felt safe, quiet, and private enough for us to conduct our interviews uninterrupted. There was one instance with each of three different women when I had to schedule one of our interviews over a video call on Skype, due to a participant or myself being abroad. However, this did not seem to have any major impact on the quality of the interview, as we both felt accustomed to the interview process by this stage. I transcribed the audio recordings myself. Minor editing was required at times during the transcription when leaving out repetitive sounds like "ehm", but apart from that, I kept the transcripts as close to the original conversations as possible. If there was a pause in the speaking, then I would make a note of that in the transcript through brackets. I also noted down emotional responses such as laughter or crying (see Appendix D for an example of a raw transcript).

Life history interviews can take many hours, with conversations varying from 45 minutes to 4 hours each (Goodson & Sikes, 2001). Due to the flexible nature of the work, it was not easy to estimate exactly how much time was needed per interview. However, to structure my time and achieve a standardised approach, I aimed to conduct three to four interviews per person, each interview ranging from one to two hours. The number of interviews depended on whether the participant felt willing to continue and was able to commit with their time, as well as the amount of data that had been shared. Once the conversations had answered my research questions in sufficient depth and both parties mutually felt that we had said what we wanted to say, then I brought the data collection to a close. The number of interviews, the time it took per person, and the time passed since their most recent loss are summarised below in alphabetical order:

Amara	3 interviews	Total: 3.5 hours	15 months post-loss
Kim	4 interviews	Total: 4.5 hours	17 months post-loss
Rachel	4 interviews	Total: 5 hours	4 years 10 months post-loss
Rania	3 interviews	Total: 4 hours	10 months post-loss
Sophie	2 interviews ⁹	Total: 2.5 hours	11 months post-loss

As with Sikes and Hall's (2017) narrative life history research study, I aimed to take, as far as possible, an informal and unstructured approach when conducting my interviews. The participants were invited to share their experiences and to take the lead in shaping their story the way they wanted. Before our first interview, I made it clear to each participant that I was interested in her words and perspectives on the topic in question. However, I found myself having to be flexible in adapting my interview style depending on who I was interviewing. Some of the women seemed comfortable to lead the way and talk in an uninterrupted flow, whereas others seemed to prefer me leading the way by asking them questions or giving them prompts. This required me to be responsive to the needs and preferences of the interviewee and to keep an open mind towards how the interviews could develop and what I could do to support this process. Our interviews could thus be viewed as an inter-relational process between the interviewer and the research participant (Beer, 1997). I think that this process is appropriate for a life history researcher dealing with a sensitive topic, rather than approaching the interview as a series of questions and answers. According to Beer (1997), interviews are multi-layered conversations between the interviewer and the participant, "in which both the interviewer and the respondent have voice and effect" (p.

⁹ I only conducted two interviews with Sophie, as it was quite an emotionally intense experience for her. Thanks to her generous narratives, I was able to gather enough data to write up her life history. Although I may have benefitted from having some more time with her to collect additional data, we both felt it was best to not continue with more interviews, as it could potentially have caused her unnecessary distress. We both felt that two interviews were sufficient to fulfil the research purpose.

113). Indeed, it is highly unlikely that the interviewer can separate themselves completely from the interview because their presence and their purpose will have an impact on what is being shared. Beer (1997) further describes interviews as:

Full-blown human interactions, unique speech events with affective experience, cognitive struggle, verbal and non-verbal messages, in which human beings strive to construct together, understand together explanations, stories, definitions, descriptions, and ideas about the world. That is why we send human beings, rather than robots, to conduct them. (p. 114)

As an interviewer, it was my role to facilitate this process. Although the interviews with each participant were unique, there were some common aspects to the approach taken. I kept the first interview relatively open-ended and unstructured by handing it over to the research participant, as much as it was possible, to speak about what they wanted to share in this first instance. After each interview, I listened through the audio recording and took note of any follow-up questions that arose. The second interview explored some preconceived themes or questions that had arisen in the first interview, while leaving plenty of room for the participant to speak freely about the topic at hand. If I still had questions left to explore, I would return with these in the subsequent interview. For the final interview, I came full circle by leaving it open to the research participant to talk about anything that had been left unexplored and to further revisit any previously shared topics if necessary.

I sometimes took notes during the interviews to help me keep track of what was said and any emerging themes, questions, or reflections that I perceived at the time. However, I kept my note-taking to a minimum, since it felt like an overly formal thing to do in front of someone who is sharing a personal story, and I was also aware that it could be distracting for

the interviewee and myself. Instead, I would listen to what was being said and leave most of my note-taking until the interview had finished. Furthermore, after each interview, I did a brief informal check-in over e-mail with the participant where I thanked them for their time and let them know that I was available, should they wish to contact me. This was a way for me to acknowledge the effort that they had invested in the interviews and to assure them that they could reach out to me with questions or concerns. Although the space had been created, none of the participants reached out to me regarding this.

Interview Questions Explored

Maxwell (2013) makes the distinction between research questions and interview questions, i.e. “your interview questions should be judged not by whether they can be logically derived from your research questions, but by whether they provide the data that will contribute to answering these questions” (p. 26). Thus, my interview questions needed to be more focused and context-specific in comparison to my broader overall research questions.

For example:

- Can you broadly describe your life along a chronological timeline leading up to the loss of your parent and to this moment in time?
- Where did you grow up? What was your upbringing like? What part did your parents play in that?
- Tell me about your relationship with your mother/father. How did it influence you as a person?
- How did your parent die? What were your first reactions?
- What does grief/grieving mean to you? What does your grief/grieving feel like today?
- Have you noticed any external social or cultural influences on your experience of losing a parent?

- How would you describe the experience of losing a parent during adulthood?
- How do you view yourself now in the absence of your mother/father?
- Does your parent's presence continue to live on in your life? If so, in what way?
- What changes, if any, have you experienced in your life since your loss?
- Has your parent's death had any effect on your relationships (various), job/career, outlook on life etc.?
- How have other people responded to your loss?
- Have you perceived any expectations, your own or others, of how you should deal with your loss? If so, what are they, how did you respond to them, and why do you think they exist?

Data Storage

All the collected audio records and written transcripts, including my own personal notes, were organised chronologically, and stored digitally in an encrypted file on my encrypted computer. I was the only one with direct access. I also stored a backup on an encrypted hard drive. As suggested by Plummer (2001), the core files of transcripts that existed in their pure unedited form were kept separate from the changing analytic files that I worked with when editing, analysing, and organising my data into life histories. The data were only accessible to myself, the research participant in question, and my supervisors at UCL. Any sharing between us was made digitally through a secure server and through my UCL school e-mail. In accordance with the UCL Code of Conduct for Research, all my collected and stored data will be kept for 10 years from the date of publication of my thesis and the "data which has been stored should be checked periodically to ensure that it remains accessible should it be necessary to consult this data" (University College London, n.d.).

Data Analysis

In life history research, the analysis is considered to begin as soon as the life history researcher starts working with the research participant. In other words, the analysis does not only happen after the data collection; rather, it also occurs during the interviews as ideas and themes take shape in the perception of the researcher. The researcher can then decide whether to explore these ideas and themes further, and this continues throughout the research process (Goodson & Sikes, 2001). I planned this to be the case in my study, as I approached my analysis as an ongoing process that occurred throughout the duration of my data collection and beyond.

During the interviews, I would perceive certain information and themes to be of relevance to what I sought to explore. I documented this through personal notes after each interview, which gave me an overview of certain aspects of my findings that I wanted to focus on more specifically. This work continued throughout the transcription of my audio recorded interviews. Although the transcription was a lengthy process, it served as a useful way for me to get to know my data better, which was of central importance to my ongoing analysis. In line with Plummer's (2001) guidance for transcribing life history research interviews, I would make notes about specific sections of the transcripts that I thought were of relevance to my study. I compared my notes from the transcripts with my interview notes, while also listening to the audio recordings and reading through the transcripts multiple times, bearing in mind my research questions, methodology and theoretical framework. This procedure helped me to identify content from the data that I deemed essential for my research inquiry, while also discovering and creating links between the data, my methodology and theoretical framework.

Subsequently, I followed Goodson and Sikes' (2001) and Plummer's (2001) suggestions concerning how to construct life histories. Typical to life history research, this

included searching for and constructing a linear order of events (through chronological sequencing), i.e. a “historical time line” (Plummer, 2001, p. 128) that situated the storyteller’s life trajectory within particular contexts, and within that life trajectory certain critical life events were identified and brought forth. When engaging in this process, my focus circulated around the critical event of parental death and any events and experiences related to this loss that I deemed relevant to my research questions. Eventually, through my ongoing familiarisation with the collected data, I was able to select and organise relevant data in such a way that a story began “to appear” (Plummer, 2001, p. 149). However, this appearance was not something passive in that the story was out there just waiting to be found. Instead, I actively constructed each woman’s life story into a life history, with the pieces of data that I had perceived to be of importance, through the back and forth process of rigorous analysis. Throughout this construction, I took extra care to ensure that the participants’ stories were presented in a way that would faithfully capture the essence of their narrated experience in relation to my research inquiry (Cole & Knowles, 2001). As I did this, I included long quotations from the research participants and provided synthesised descriptions (which I constructed) of their experiences and events in between their quotations, while carefully maintaining contextual relationships and contiguity. In this way, sections of the data were not taken out of context.

The timeline structure helped me to organise and construct the life history, and it created a sense of consistency across all five life histories, while maintaining the uniqueness of each life history. I ensured that the woman who told her *life story* remained at the centre of the *life history*, which I constructed. I further shaped each woman’s story according to a sense of causality, as elaborated upon by each woman, where one thing led to another, i.e. “if this, then that” (Plummer, 2001, p. 196). The timeline helped to capture these connections and accounted for the time pre- and post-loss. This structure is important because it can help the

reader to see the bereaved women and their grieving and meaning outcomes within the context of their whole lives, the lives of their parents, and their combined family history. Against this background, the women's stories were contextualised primarily within their family history, and when relevant I would locate their family history within a broader historical, social, and cultural context. However, this was entirely dependent on what emerged from the data. The women spoke in great depth about their family history and family relationships, as related to their loss and grieving experience. Cultural factors were not explored to the same extent, as all but one participant spoke of this (and only a little) during the interviews. Hence, although cultural contexts are of central importance in bereavement research, these ended up being a minor focus in this study.

My theoretical framework, where I identified the meaning activities of sense making, benefit finding, and identity change, and the meaning outcomes that derived from these activities, guided my search for meanings within the women's narratives. This search occurred both through my deep reading and engagement with the raw data, and through further observations of the constructed life histories. At this point, however, I noticed that the model's three meaning activities only captured to a certain extent the meaning outcomes I had identified in the data. I therefore decided to include a fourth meaning activity, which I titled: *assigning importance*. Assigning importance refers to meaning as personal significance in that something is either important (or not) to the bereaved. This is distinct from benefit finding, as it is not about finding the silver lining of a negative event. Rather, it refers to giving importance to certain actions and events, as these may fulfil particular needs or purposes for the bereaved, i.e. *this is important to me because (...)*. The added category was useful as it captured additional meanings embedded in the participants' narratives, which would otherwise have fallen outside the scope of the initial three meaning activities. As a result, this helped me to make the best sense of my data, as I was able to relate the life

histories to an expanded theoretical framework, which was more suitable to encompass my findings.

Oscillating Between an Inductive and Deductive Approach

My data analysis did not follow an inductive approach to qualitative data analysis in the purest sense. An inductive approach is solely data driven, meaning that the findings are strongly linked to the data themselves, and it is not led (or imposed on) by the researcher's chosen methodology or theoretical interest in the topic (Braun & Clarke, 2006; Thomas, 2006). Simply stated: "Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis" (Patton, 1980, p. 306). Conversely, a deductive approach is driven by theory and aims to "test whether data are consistent with prior assumptions, theories, or hypotheses" (Thomas, 2006, p. 238).

Although my engagement with the data led me to identify themes and meanings that I perceived to be relevant to my thesis and research questions, which constitutes an inductive approach, I was not completely free from my theoretical and methodological commitments, as my data was closely related to these aspects throughout my analysis. Indeed, part of my analysis was driven by methodology in the sense that I was analysing and organising my data to form a life history account, and part of my analysis was guided by my (extended) theoretical framework, whereby I searched for the meanings included within the participants' narratives. This undoubtedly limited the scope of possible interpretations and outcomes more than a purely inductive approach would have done. However, it was useful to be guided by my methodology and theory, as it helped me to maintain a sharp focus on what I set out to explore in a way that supported me in answering my research questions. Thus, it can be said that I continuously oscillated between an inductive and a deductive approach, as I engaged

interactively with the data, theory, and methodology, in such a way that they informed each other, contributed towards my construction of the life history accounts, and shaped the discussion of my findings.

Summarising my own Approach to Data Analysis: A Principle-Based Approach

My experience of conducting this data analysis has led me to appreciate it as a very personal process which can look different, and certainly generate different outcomes, depending on who is doing the analysis. I did not follow any pre-set rules, nor did I follow a linear trajectory when analysing my data; rather, the process felt much more intuitive, dynamic and creative. At the same time, the analytic process was contained within the structure of the life history, in that I wanted to create a chronological account. This helped me to structure my ideas in an orderly manner. Thus, there was a balance to be struck between spontaneous discovery and creativity, and a more structured approach that was in line with my research endeavours and kept an end goal in sight: to produce a life history account. Considering this, in this section I will further expand on how I dealt with my analysis by presenting my own principle-based approach which has formed the backbone of my analysis. I have consolidated this into four principles that approach analysis as: (i) a continuous process, (ii) a process of personal and active discovery, (iii) the co-creation of a story, and (iv) a creative and intuitive craft. These principles, which are described in further detail below, do not follow a certain order and are by no means finite in their description. I would invite anybody who draws from these to add their own signature and remove or add whatever is of relevance to them and their study.

- *Analysis as a continuous process:* My analysis did not begin once the data collection was complete. Rather, it was already in full bloom by the time I started conducting my interviews. As I was listening to the women share their story, there were things

that stood out to me in what they said that I found particularly powerful, and that offered some real insights into their experience, which I wanted to capture. There were little pearls of wisdom throughout their narratives, and I kept these in mind when writing the thesis. I am aware that what stood out to me might not stand out to another researcher, and that this might be due to my own experience of loss, how I related to the women's stories, and what I felt was important as someone who had also lost a parent. Additionally, as our conversations went along, sometimes what the women said generated questions which I had neither anticipated, nor reflected upon in relation to my research and to my own loss experience. These were insightful moments akin to opening little windows of discovery. As I completed the data collection, I already felt like I had a good idea of where I wanted to take these stories. That said, my analytic process continued through my transcriptions, and my construction of the life histories. It was an oscillating process that moved between these phases, took different shapes and turns, and was comprised of different parts, until I constructed what felt like a whole and coherent life history that did justice to the women's narratives and my research endeavour.

- *Analysis as a process of personal and active discovery:* As I was engaging with my data over time, I began to develop my own personal relationship with them. The data were seen through my eyes and life experiences, and my analysis was also influenced by my direct encounters with the women. To me, my data were not just transcribed words on a piece of paper, or a mere audio recorded voice. Rather, they were also the face-to-face encounters that I was privileged enough to share with each woman, which left a significant impression on me. All these aspects combined led me to interpret the data, ask follow-up questions and reflect upon the women's stories in what felt like an ongoing process of discovery, traversing the known and the

unknown. I could not have known in advance how the data would unfold, nor how exactly I would end up analysing and constructing the material, or what route I would be taken down next. Thus, this also required a sense of curiosity and openness to the process as it happened. As I was gathering more data, I was able to create something like an internal image within my mind. As this image grew bigger – an image which I was both discovering and creating within me – I was able to crystallise it in writing through a back and forth process between the internal reflections and imaginaries within me, and the external story which was beginning to take shape. Considering this, my analysis was not a process of passive discovery by any means, but rather a creative one that I actively took part in while following its natural flow.

- *Analysis as the co-creation of a story:* As I was constructing the women's life stories into a life history, I had to frequently reflect on who the *storyteller* was. It was neither just the woman who was the telling her story, nor was it just me. In that sense it was a co-creative story-making process where we both had a significant part to play in co-constructing the life history. Yet, I considered myself to be the main actor in building the so-called story plot. For example, when I transcribed my data, I transcribed them by following the sequencing of information in the interviews. But what was said in the interviews did not always follow a chronological order, so I was looking for a chronology as I was transcribing the interviews. I could see patterns within each woman's story which I tried to put together in a coherent way (my internal monologue often sounded like: *this part goes well here, this part belongs to this section*, and so on), and I tried to make sure the whole time that I was faithful to the context in which things were being said. Additionally, I handpicked aspects of the women's accounts that related to my theory and methodology, while also creating a narrative that built a certain amount of tension. In this way, whoever was reading the life history would be

taken on an intimate journey into the world of these women that could spark the reader's interest and leave them wanting to know more. Thus, I was also taking the reader into account when conducting my analysis. At the root of this however, I had to remain faithful to the women's accounts and not warp the data for the sake of superficial entertainment. It was a privilege to take on this responsibility, and I committed myself fully to this throughout my analysis.

- *Analysis as a creative and intuitive craft*: I experienced the data analysis as a creative and intuitive process that developed over time. Plummer's (2001) description of the analysis of life history data captures aspects of my process:

In many ways this is the truly creative part of the work – it entails brooding and reflecting upon the mounds of data for long periods of time until it ‘makes sense’ and ‘feels right’, and key ideas and themes flow from it. It is also the hardest process to describe: the standard technique is to read and make notes, leave and ponder, re-read and so on. (p. 152)

One of the key words for me in Plummer's quote is ‘feels right’, as it refers to something so personal and intuitive that it is near impossible to instruct anyone as to how and when this is accomplished. Rather, it is something we need to find within ourselves, as an internal signal that we then choose to trust. For me, the best way to describe this feeling is like being in a state of flow (Csikszentmihalyi, 2009). The concept of flow refers to being fully immersed in an activity while experiencing enjoyment and a sense of control and success in what is being done. This, to me, is when I felt that aspects of the narrative “clicked”: where it all came together to make a coherent life history that made sense and felt right. This required a form of labour,

where my work with the data was very hands-on, almost like sculpting a shape where the material continuously responded back to me. This intuitive sculpting is what, to me, makes each researcher's analysis unique, whereby we leave our own mark on the work, and I believe that my own experience of loss played a significant part in this process.

Asking for Input from Research Participants

Once I completed a first draft of my life history analysis, I offered to share it with each research participant so they could, if they wanted to, provide their input to the analysis. This so-called "member checking" (Lanford, 2019, p. 502) was a way of maintaining a trusting relationship between myself and the research participants and ensuring that "an accurate representation would ultimately be presented" (p. 502). The women had the authority to decide what to disclose and to address potential inaccuracies in my analysis. If necessary, we could elaborate upon and discuss ways of clarifying or developing the analysis further. I was prepared to make any necessary adjustments to their life history until the participant and I felt mutually satisfied. However, this did not mean that I as a researcher had to always agree with my research participants' interpretations, nor that they had to agree fully with mine. If we disagreed or interpreted the data differently, then it would be acknowledged and discussed by both parties and taken into consideration when finalising their life history.

Only two out of the five women asked to read through her life history. Consequently, one participant asked me to make one alteration of removing a paragraph from one of her quotations, which disclosed sensitive information about her parent. I was aware of the delicate nature of this paragraph but had initially decided to include it as I thought it would help to further describe the problematic relationship that she had with her parent. At the same time, I understood her concern and respected her wishes. I removed the paragraph, and she

accepted her amended chapter. The second participant read her life history and chose not to make any changes to it.

Anticipating Limitations

Anticipating possible limitations in my study was important as it enabled me to become aware of and to be prepared for potential difficulties that could be experienced throughout the research process. These anticipations are crucial when designing and conducting a rigorous research study (Maxwell, 2013). The next section will present potential limitations that I had prepared for and how I approached these. These differ from the limitations that I had not anticipated, which I came across at different points throughout my research process. These additional limitations are presented and discussed in my discussion chapter.

Participant Withdrawal

Life history research can be time consuming for the research participant. Additionally, bereavement research can cause distress for research participants, the extent of which is difficult to anticipate beforehand. For these and other reasons, I was aware that participants could decide to withdraw from the study. As I was working with a group of only five women, the consequence of participant withdrawal could have had a strong impact on my study. For example, it could have impacted my time schedule, as I would have had to invite new participants and conduct additional data collection. Although I could not control the outcome of this, I did my best to avoid it happening. I did this by informing the women in advance about what the research collaboration entailed and how much time I anticipated it would take, so they could be as informed as possible before deciding whether to participate. I also strived

to make the participation convenient for everyone involved, particularly when it came to scheduling a time and place for the interviews.

Revealing Identities

I was aware of the risk that participants or their family members could be identifiable in my written representation of the data, thus indirectly revealing their identity in some ways. I addressed this by asking each participant to choose their own pseudonym to protect their anonymity. I protected the anonymity and privacy of third parties (e.g. family members and significant others) that were mentioned by all the five participants, and I used pseudonyms for them as well. The names of any geographical locations mentioned, with the exception of London, the United Kingdom, and the women's country of origin, were changed to minimise the risk of identification.

Time Management

Life history is a time-consuming research process for both researcher and research participant. I could not predict the exact amount of time each interview would take, or the amount of data that would be collected in each instance. With some advice from my supervisors, I was able to navigate this by estimating that I would need three to four interviews per person, each interview ranging between one to two hours. I prepared my interviews well and kept relevant questions at hand when needed. I aimed to collect necessary data during our scheduled interviews, to avoid returning for additional data collection at a later stage. The amount of data collected would impact the time it would take to transcribe and analyse it. If a research participant wanted to read through my analysis, then this too would require additional time. I took all of this into consideration when organising my time

schedule. Thanks to self-chosen deadlines, an organised schedule, and regular meetings with my supervisors, I was able to manage my time well and keep track of my progress.

Exploitation

There is a risk that data collection for the purpose of research can exploit the research participant. In a worst-case scenario, the researcher takes the information they need and then casts the participant aside once they have got what they came for. Exploitation is in that sense a misuse of power and responsibility, whereby the researcher cares more about their own interests than that of their research participants. To prevent this from happening, it was important to assure the research participants of their agency and to treat them with dignity. The suggested ethical guidelines of Cole and Knowles (2001) on *mutuality* and *care*, *sensitivity*, and *respect* served as a useful compass when interacting with the research participants, thus ensuring that no exploitation was taking place. I will explain each guideline next and how each related to my research practice.

“Mutuality” (Cole & Knowles, 2001, p. 28) occurs when the researcher and the research participant come together for the purpose of mutual inquiry and interest. Cole and Knowles (2001) assert that the researcher and the research participant can co-create a space of inquiry where they jointly make decisions on matters such as confidentiality, responsibilities, and data protection, in addition to using procedural ethical protocols. This was done prior to and throughout the interviews. The participants had received an information sheet and consent form, which we could together agree to amend if they wished to do so. However, the participants were satisfied with the information provided and did not request to make any changes. Furthermore, as stressed by McConnell-Henry et al. (2010), mutuality is also important when it comes to bringing the interview process to a close. The interviews that I conducted were part of a process that was followed through from beginning

to end. I would let each woman know where we were in the process and informed them once we were nearing the end. More so, I wanted the closing of the interviews to be, as much as possible, a mutual decision. I honoured this by asking each woman if she felt okay with having a final interview together. As we neared the end of our final interview, I asked if there was anything more that she wanted to share before the interviews were completed.

“Care, sensitivity, and respect” (Cole & Knowles, 2001, p. 43) refers to experiences between human beings. Cole and Knowles (2001) argue that these practices are qualities that must be integrated into the research relationship. Otherwise, one is not actually practising a genuine ethical approach. I practised care by showing the research participants that I was actively listening to, and engaged in, what they were saying. I reminded the participants that if they wanted to take breaks at any point during the interviews, they could do so. At times they would ask me for a break, and at times I suggested taking a break; thus, when we felt ready, we would continue with the interview. If the interview had been taxing in any way, then we would mutually agree to finish the interview sooner. I continuously reminded the participants about ongoing consent and withdrawal. I also informed them that they could withdraw from any future publications subsequent to the publication of the PhD thesis, should they wish to do so. Furthermore, if they ever felt like that they had overly disclosed something, then they reserved the right to withdraw this data. For me, sensitivity was about reading signals and knowing when to stop or start with questions, probes, and so on. It was knowing when to step in with a follow-up question, or when to be quiet and let them continue speaking. I showed the women respect by arriving on time for our interviews; keeping our commitments; and co-creating a space where they could have their experience, without me judging or imposing something upon them.

Pre-Existing Relationships and Conflicting Roles

A trusting and well-connected relationship between interviewer and interviewee can result in a richness of data (McConnell-Henry, 2010; Plummer, 2001). The sensitivity and attention paid by the researcher can result in the interviewee feeling listened to and understood, making them comfortable to share personal reflections and experiences. If the researcher and the research participant already have a pre-existing relationship, then the obtained data can become “very rich, both in depth and breadth, because time has not been ‘wasted’ establishing a forum in which the participant feels comfortable to open up” (McConnell-Henry, 2010, p. 3). However, McConnell-Henry et al. (2010) also point out the potential risks that come with a pre-existing relationship. For example, there is potential for mistrust to occur if the research participant feels that the researcher has a hidden agenda. It can also be difficult to set boundaries between the different roles within that relationship, and you might assume, as given, some knowledge that is necessary for the investigation.

I had a pre-existing relationship with three of the women, as we were acquainted through a mutual social network. Through my attention to detail, this did not pose a problem during our research collaboration. The positive aspect of this was that we already had a degree of established trust between us; yet, I made sure not to take their trust for granted. I maintained the same professionalism and transparency towards them as I did to the other two women, whom I had never met before. I was aware that the risk of boundaries between researcher/research participant and other pre-existing roles could become blurred, thus risking conflict or confusion in relational dynamics. Thus, establishing clear boundaries was key. I did this by being transparent about my role and responsibility as a researcher. I informed the research participants about the purpose of my research through the information sheet and consent form. I made it clear that anything discussed outside the interviews would not be included in the data collection. Even though our research relationship could feel informal and relaxed because of our pre-existing acquaintance, the structure around the

research process was adhered to. Professionalism in terms of committing to times, protocol procedures, and confidentiality, was consistent throughout.

Referrals

If necessary, I would suggest appropriate support to a research participant if she wished to speak to someone about their experience of the research process, or about their bereavement. I would then refer them to my supervisors, local bereavement support groups, and/or counselling services. This was not needed and did not end up happening.

My Positioning as a Researcher

I maintained integrity with regards to how I approached my research and its findings by continuously reflecting on my choice of literature, research inquiry, and interpretations of findings. Furthermore, I remained transparent about my motivations, stance, and the purpose of my research by being explicit about how my values and interests had influenced the study and my relationship to the data. Alongside this, I was mindful not to let my positioning as a researcher influence the data to the point of distortion. Indeed, my personal interest influenced the chosen topic of study, the aspects I decided to focus on, and the stance I actively took. However, I still did my best to keep an open mind to what the data presented me with, and I remained flexible enough to expand my focus, and to question my perceptions and interpretations to the best of my ability. This became evident in the learning that took place for me when listening to the women's stories. I heard about experiences that I had not considered before, which brought me to explore additional literature. I also cast a critical eye on my writing and how I related to the literature and my theoretical framework throughout the whole course of this study.

Generalisability

This study endorses Maxwell's (2013) assertion that the concept of transferability is more appropriate than generalisability, when working with qualitative in-depth data from a small number of participants. This means that the findings of this study cannot be extended to larger populations but new theories or insights might be developed in the process, which can be transferred to other bereavement contexts. Each participant's life history was a unique account of a personal experience, placed within a context relevant to them. I did not seek to generalise their experience; rather, I sought to provide insights into these particular accounts. I looked for certain elements in my findings for each research participant, which either did or did not relate to the other research participants in question. The purpose of this was to highlight any similarities or differences in the experiences of the five participants. Indeed, the grieving process, including the meanings that accompany it, can be felt and experienced differently between people. At the same time, there may be aspects of this process that are similar from person to person. I took these differences and similarities into account, while remaining aware that they could be relatable (or not) to other research findings and to people who have experienced loss themselves. Additionally, I linked relevant aspects of my findings with findings from other studies and existing literature on bereavement to demonstrate possible contradictions, or to identify similarities that offered support to findings from previous studies, as well as my own.

Ethical Considerations Unique to Bereavement Research

Ethical considerations need to be adapted to suit the study and the needs of the participants. Skinner Cook (2001) highlights that researchers need to be aware of the ethical issues unique to bereavement research, since it explores a sensitive topic that can cause distress to the bereaved research participants. Indeed, I was aware of the vulnerability

involved when researching such a personal and private matter as losing one's parent to death and the consequences of making this information public, through a published thesis.

Therefore, the safeguarding of the research participants was my ethical priority throughout the research process, and it required ongoing sensitivity from my side. In support of this, I applied ethical considerations unique to bereavement research, which I adhered to throughout my study. I will discuss these next.

Emotionality

An important point made by both Rowling (1999) and Valentine (2007) is that the bereavement research process can be highly emotional for both researcher and participant. One ought to acknowledge the emotional interchange between researchers and participants and recognise it as an interpersonal relationship. Rowling (1999) further suggested that the role of the researcher can be viewed as “being alongside” (p. 167) or “being with” (p. 167) the participant throughout the research process. However, I would query to what degree this can be sustained. After all, the roles of the researcher and the research participant are, in my view, still distinct.

Part of my role as a researcher was to listen to the participant. As much as I wished to immerse myself in the research interview, I still had to manage my emotional reactions so that these would not override or negatively impact what the participant was sharing or experiencing at the time. I did this by focusing on the participant's narrative, and I refrained from diverting attention away to focus on my own emotionality and associations with my own stories. Rowling refers to this as “empathic distance” (Rowling, 1999, p. 171). In that sense, I could be seen to be more *alongside* the participant, sharing a particular moment with them. Yet, I was not *with* them, as I would not share the same amount of information about

myself. Indeed, this was not the intention of my research, nor was it the purpose of my role as a researcher.

Regulating the Intensity of the Interviews

Reflecting on the risk of causing pain goes in tandem with the researcher's attempt to do no harm during interviews (Rosenblatt, 1995). The distress that can occur during interviews is not necessarily harmful. However, Rosenblatt (1995) points out that there can be instances where the participants might be brought to places during the interview where the pain, or so-called hurt, is wrong to cause. If so, Rosenblatt (1995) points out that he tries to "move the interview away from the painful matters while asking more 'benign' questions" (p. 145). He further asserts that, at times, it is not that clear whether one is causing harm. In those moments, it is key to reflect on how things evolve and to be sensitive enough to know when to stop, or to apologise if one did not anticipate the pain caused and thus did not stop in time. The women I interviewed were capable of managing their own experience and knowing their limits; yet, I would remain sensitive to their needs and at times de-escalate the intensity of the interviews by suggesting a break or shifting my questions towards more *benign* matters.

Timing

Another aspect that is related to harm prevention in bereavement research is the sensitivity of timing (Skinner Cook, 2001). Skinner Cook (2001) points out that the time passed between the death and the research process can influence the well-being of the participant and the topics that they address during the interviews. I was aware that speaking with the bereaved closer to the time of their loss could be a painful experience for them. From the time of the first interview, at least 10 months had passed since the participants' bereavement. Both the participants and I considered this to be enough time for them to speak

about their experience without it becoming too overwhelming for them. However, two participants (Sophie and Amara) experienced quite strong emotional reactions throughout the interviews. It seemed particularly difficult for Sophie, so we mutually decided to bring our interviews to a close after two sessions. Additionally, according to Skinner Cook (2001), one should take into account certain times of the year that may be difficult for the participants, i.e. birthdays, the anniversary of a death, significant holidays, and so on. I considered this for one of the participants (Amara), as the anniversary of her mother's death was approaching. We decided to schedule our first interview at a later stage, once the anniversary had taken place, as this was a particularly sensitive time for her.

Research, Not Therapy

Being clear of what one's responsibilities are as a researcher is important for the sake of maintaining clear boundaries when interacting with research participants. In the case of bereavement research, both Rosenblatt (1995) and Rowling (1999) make the distinction between the role of a therapist and the role of a researcher, as well as between "therapy and therapeutic experiences" (Rosenblatt, 1995, p. 151). The interaction between researcher and research participant in bereavement research is not focused on growth and healing; rather, the purpose is to elicit knowledge around a particular research inquiry. At the same time, this process can be perceived as a therapeutic experience, i.e. as Rosenblatt (1995) points out: "I think bereaved people may gain enormously from talking with someone who takes their stories seriously and witnesses and acknowledges their pain" (p. 144).

As some of the research participants expressed, talking about their experience during our interviews felt like a good thing to do. One research participant (Kim) mentioned that some of the things she was sharing at that point had not been spoken out loud before. She said that the interviews were a way for her to reflect openly about her loss experience, where

she remembered and/or talked about things that she had not thought about in a long time. She perceived this to be painful at times, but she said that it also came with a sense of relief and reflexivity. Taking this into account, I was aware that the interviews could indeed have a therapeutic effect for some of the research participants, even though they were not therapy sessions. As Skinner Cook (2001) points out:

The larger society often expects people to resolve their grief quickly and to “get on with their lives”, sending a message that their grief is not legitimate and that the depth of their loss is not fully recognized. Participating in a research study can, for some grievers, be an outlet for thoughts and feelings not previously shared with available support systems”. (p. 132)

Some of the research participants seemed to develop a further understanding of themselves or a situation during the interviews, by sharing, reflecting on, and answering questions about their experience of loss and grieving. However, I was explicit about the notion that the interview process was distinct from therapy, where the intention and methods are fundamentally different. Rowling (1999) elaborates on this distinction:

It appeared that being involved in research facilitated disclosure, disclosure some may not feel comfortable with in a counselling session where they perceive themselves as ‘needing help’. It is my belief that in the research interaction they were ‘powerful’, they were offering their experience so that it might help others. It was not a situation where they were exposing themselves as being unable to cope and needing counselling. They were also powerful because the iterative process of the repeated

interviews, involving the progressive building of ideas and themes, enabled them to see that their experiences were shaping the research findings. (p. 173)

Rosenblatt (1995) further points out that one does not have to be a therapist to draw on the key skills of “listening, acknowledging, avoiding being judgmental, bracketing personal reactions, supporting, knowing when to back off, and realising that something has been misunderstood” (p. 149). Although I am neither a therapist, nor do I see the need to be one when conducting this kind of research, I still agree, in accordance with Parkes (1995) and Rosenblatt (1995), with the usefulness and importance of having some form of training when interacting with bereaved people in the context of research. My educational and professional experience equipped me with the skills and confidence to embark on this research. For example, I have worked at a senior level as a yoga and mindfulness teacher with students in various contexts, including vulnerable groups of people in need of trauma-informed support. Furthermore, I have a Master of Science degree in Psychological Sciences, and I have worked as a mental health support worker at an acute psychiatric ward in London, United Kingdom. These experiences have taught me the important skills of paying attention to people’s needs, practising non-judgmental listening and compassionate communication, and applying these to the best of my ability when necessary. These skills served a valuable role in my research.

Interviews as a Two-Way (Non-Therapeutic) Intervention

I also wish to highlight that although it is quite straightforward to draw a line between therapy and therapeutic effects in theory, this boundary was less obvious in practice when sitting face-to-face with the women and discussing matters that were deeply personal and close to their heart. The emotional responses that arose in each woman during our interviews demonstrated that my presence and my questions were a form of intervention in each of their

lives. This intervention encouraged remembrance and reflection on the women's part, which seemed to influence how they felt in the moment of each interview – and perhaps also in the time that followed. This resonates with Valentine's (2007) observation in her bereavement research, whereby her interviews allowed for "the past to be recovered and the future to be considered via the present. Such reflections may have an impact on the future, suggesting that the research interview may be transformative" (p. 164). As my research intervened in the women's grieving process, it may also have had a transformative effect to some degree (without it being my aim). Considering this, my intentionality was a key guiding light. My role was that of a researcher, and my purpose was to facilitate these interviews within the framework of my research endeavour. At the same time, I could still sit with each woman as a fellow human being who could relate and show compassion with regards to what they were going through.

Adding to this, I was also intervening in a different manner whereby my own life story was playing a part in how I conducted my interviews and related to the data as the women were sharing their stories with me. Indeed, my own relationship with loss and grief played a part in the narrative constructions of the women, yet I was careful not to disclose too much of my own personal story, because this was not the focus. At the same time, my own experience of loss could not be left out of the study. For example, in my interviews with Amara there was a moment where I drew my own conclusions from what she was saying. These conclusions arose from my personal relatedness to her words based on how I had sometimes experienced my own loss:

Eleonora: There is something here that I'm picking up on, about not feeling understood, or not feeling appreciated for what is going on, or acknowledged that what is happening is painful and that you need support. Does that make sense?

Amara: Yeah, I think, I think you're probably right.

Amara continued to elaborate on her answer by relating it back to her own experience, and so one could say that my observation/question opened a window of insight which might have been bypassed otherwise (for her full answer, see pp. 154-155). By making this observation, I was careful that I was not imposing my own lived experience, agenda or preconceived idea on Amara's narrative. Rather, I acted on what felt to be a genuine thought, which came from a place of having listened to Amara's words and picked up on aspects of her story that I too related to. As people, we can connect with each other through stories, and I believe that my question came from this place of connectedness. In that sense, my presence, along with my own biographical disruption of losing a father, formed part of the fabric of this study and contributed to the co-construction of the women's life histories.

The interviews were not only an intervention in the research participants' lives, but also in my own life story as it relates to loss and grief. The transformative effect that interviews can have, as mentioned by Valentine (2007), was indeed something I experienced. I did not leave the interviews with the same base of knowledge that I had stepping into them, as the interactive field between me and the participants inspired new insights that I had not considered before. Just as Valentine (2007) discovered, sources of knowledge are constructed in the interaction between the self and other (see also Hockey, 1990). I may even go as far as to say that not only did it change what I knew, but it also changed me as a person. For example, Rachel spoke about the idealisation of the dead – questioning why people have a need to idealise the dead by only speaking of their achievements and good qualities. Rachel's words stuck with me, and I have come to realise over time that this is something I did with my dad's memory. Almost 9 years have passed since his death, and today I am able to embrace and talk about his good and bad sides, and to acknowledge his role as a father and

husband – the things I think he did well, and what I think he could have done better. Bringing Dad down from his pedestal has also brought me closer to my own mother. Prior to his death, my dad was the centre of our family, and my mother fell into the shadows of his loud character. As Daddy's girl, I was always in awe of him, and we were like hand in glove, but this did not leave much room for my mother's presence at times. After Dad died, I gradually began to see my mum as an individual with her own needs and story, separate from my father and her late husband. This also allowed for her own light to shine, and for me to see it clearer than before. For example, my father had always been the humorous and charismatic person in the family, but upon his absence I discovered what a great sense of humour and zest for life my mum has, and this got to take more "centre stage". Additionally, since my dad's death, I have developed a relationship with my mother that is more equal and understanding, and am appreciative of the role she played in my and my father's life. I realise the sacrifices she made to support him in his illnesses, while still running her own business and always being there for the rest of the family. Her strength was and still remains a silent presence, similar to how Kim described her own mother's commitment to her family. My heightened awareness of this has also increased my gratitude towards Mum. There is also a sense of mutual support that exists between us now, where we are offering love and support to each other: Mum contributing with her motherly wisdom, and me as an adult woman who is her daughter, but at the same time a steadfast companion that she can lean on if and when she needs to.

Chapter 4: Findings

This chapter includes five distinct life histories, which are organised in alphabetical order according to the women's names: Amara, Kim, Rachel, Rania, Sophie.

Amara's Life History

Amara's mother, Indira, had an unexpected fall that led to a severe head injury followed by death, after being hospitalised for 4 months. During these final months, Amara and her three sisters and father spent most of their time caring for Indira at the hospital, with the last few days being spent at Amara's sister's home. After this sudden and unfortunate turn of events, Amara lost her mother in October 2018, at the age of 56. What follows is an account that represents some aspects of Amara's relationship with her mother and a brief family background and description of the 4 months of caretaking, as well as the year following her mother's death.

Childhood and Family Background

In 1963, when Amara was 1 year old, her father decided to move from India to the United Kingdom. However, Amara's mother, Indira, wanted to stay on in India, and so Amara's father went on his own and left his wife and three daughters behind. In December 1964, when Amara was two and a half years old, her mother decided, of her own accord, to join her husband and to migrate to London with her daughters, who were all under the age of 5.

Amara: It was December, '64, and I'm told that when she arrived there had been miscommunication so my dad wasn't there at the airport. She was there with three kids and couldn't speak English and it was snowing apparently in Heathrow, and I don't know how she did it, but she came across an Asian taxi driver who then drove

her to Shepherd's Bush. And when she got to Shepherd's Bush, my dad was in this one rented room in Shepherd's Bush but my dad wasn't there, so the guy on the floor below was in and he took her in with us and waited for my dad to arrive. So, it was a shock to him when we arrived, apparently.

Shortly after they arrived in London, Indira got a job at an ice cream factory. Amara recalls that her parents had just enough money to get by at first. They had to work hard to build a life for their family in London and to get their daughters through university, in the face of financial hardship. As one of three, and later four, children, Amara therefore did not get to spend much time with her parents growing up.

As well as dealing with the heavy workload of being a full-time factory worker, Indira was the main caretaker for the children and family home. Amara describes her mother as the woman who held the family together, by offering security and consistency. At the same time, Amara perceives their mother-daughter relationship as both practical and complicated, and lacking in much emotion or warmth. Amara believes that the lack of affection and care that her mother experienced during her own upbringing in India contributed to her parenting style and personality, and that this also had an impact on the quality of their relationship.

Amara: I wouldn't say it was an easy relationship. It wasn't. It was difficult. She, I think we've all said it [sisters], we definitely said it while she was alive, all the sisters said she could be really difficult. My mum could be really difficult, but then when we've reflected on it, we've also, as we've grown up, reflected on how hard her life was. What we looked back on was how amazed we are at how she did this. My dad tells us that she used to get up at four or half past four to bathe us, to feed us, to get us ready for school, and then she would leave for work at half past six.

My mum would come home about half past five, and she'd had a really long day, and she would then have to cook, she'd have to clean, she'd have to bathe us, and I wonder because I haven't had that life [silent pause]. Life is tough when you have kids, but nothing like that. At that time there were no washing machines. There were no dishwashers, no nothing, and I'd reflect on that and we have all said that actually she did all the practical stuff, but she couldn't do the nurturing. She wouldn't have had time. She must've been exhausted most of the time, and that exhaustion would come out in different ways. So, she could sometimes be quite sharp, and she had a sharp tongue at times. I do remember her shouting a lot at us for not doing things, but I also remember, because we didn't have a lot of money, I do remember Mother's Day and we would collect some money and buy these simple things for her. So, I think there was affection there.

I do remember our parents always taking us out on picnics to far-away destinations in the car to Brighton, or Portsmouth, and one day we did a day trip to Blackpool. I mean, who would do a day trip to Blackpool? It was like 5 hours to get there. On those trips, my mother would always have done the most amazing picnics. It would've taken her a long time because it's Indian cooking from scratch. All our food was from scratch and you'd think: *Gosh!*. She'd gotten up really early to go to work, and then she would still come home and cook us fresh food. It was always fresh food. So, her energy was ensuring that we were properly clothed, fed, and that the house was tidy. There wasn't a lot of time for giving hugs and things like that, and I don't remember lots of hugs and kisses. Or me time. I don't remember any me time.

When we talk about my mum, the four sisters, we do recognise that we didn't have the kind of mothering that we have tried to give our own kids because you learn from the telly or whatever, that's what you're supposed to do. You're supposed to

give your kids hugs, you're supposed to talk to them and find out if they are ok. So, my mum didn't have that and that might be the same for other people from other cultures at that time, I don't know. But certainly my mum didn't have a mother role. All she was doing was what she had done in her upbringing, which is survive. So, she was doing all the practical stuff but not the emotional stuff.

During her adult years, Amara took on what she refers to as the *practical* (Amara's words) role in her family. Amara was always the one who would go and do things with or for her mother. Most of the family lived in London, but in 2016 Amara relocated with her husband and one of her two children to Seattle, which meant that she did not spend as much time in person caring for her mum as before. Yet, she remained as active as she possibly could in supporting her mum from afar, both financially and practically, whenever it was necessary and possible.

Although being away from her mother concerned Amara at the time, she accepted the situation for what it was. Amara knew that her family's move to Seattle was temporary and that she would eventually be back in London, better able to support her mother again. Despite her mother's health being fragile for the past 10 years, she was still in fairly good form and there were no immediate concerns about her life, as her health seemed stable. For that reason, nobody expected the sudden change in circumstances that occurred in June 2018, which came as a shock for the whole family.

Sudden Hospitalisation and the Time Leading Up to Death

One day, Amara received a call from London informing her that her mother had had a fall while she was shopping at Waitrose with her husband. The fall had inflicted a severe blow to her head, so she had to be hospitalised and put in intensive care. The doctors

informed Amara that her mother was not expected to survive the night, and so Amara immediately got on a plane back to London. Her mum remained alive for another 4 months while being cared for in the hospital during most of that time.

Amara: She was in the hospital for 4 months before she did die. But during those 4 months I have to say that it was life and death, and I always thought she was on the edge of death. So, it was a slow process. That process was so traumatising, that when it did happen, it [the death] was still quite a big impact. So, I was kind of prepping myself during those 4 months, that she was likely to die. But there is also that small hope that makes you think that she's not going to die. So, when she did die, it was difficult because I've got three sisters and when we talk about it now, I think the feeling is that had that 4 months of trauma not happened, it would have been easier to accept her death. It's really difficult to know because it's in retrospect, but I do wonder if you have someone who dies suddenly, that's it, they are dead. Or to see someone in pain for 4 months and they may die, I kind of think the earlier one is better. Because I think the trauma of the journey of death was as impactful as the loss at this stage. Maybe next year I will feel differently, but a year on from her death that is how I feel.

Eleonora: How did you spend those 4 months with your mother before she died?

Amara: She was in hospital for actually all that time, and she was having procedures done to her, so, those 4 months you know, I've thought about it because she had a traumatic brain injury. She had a fall. By the time I got to her, she'd had the injury and I wasn't convinced she was the same person. My sister says there were times when she was lucid and other times where she was very confused. She didn't

recognise people. There was this one time, you know, you can laugh at it, but you know, my father came through the door to her hospital room and she said: *Who's he?* I was never quite convinced that she was the [same] mother [as] before her fall, and because I had been away, and I hadn't seen her in a few months, I think that the idea that she was alive for 4 months, and that those 4 months allowed me to prepare myself to say whatever I wanted to her, it didn't really arise. Because I didn't feel that she was lucid enough, most of the time, for me to be having a conversation about: *I'm really grateful for everything you've done.* I didn't feel I had that. So, it was really just looking after her and reassuring her, because I think she was scared of death at the beginning. I think by the end she wanted to go, but at the beginning it was, I think it was a shock for her, finding herself where she was.

Caring for her mother had a traumatising impact on Amara, for multiple reasons. One reason was that she witnessed her mother go from being what Amara knew as her normal self, to not really being the mother she knew anymore, due to the rapid deterioration of her health. As Amara recalls, her mother was, most of the time, not lucid enough to be able to participate in conversations. From the time of her mother's fall, Amara was no longer able to communicate with her mum in the way that she was used to, and their relationship was now revolving around fulfilling the practical duties of acute caretaking within a hospital environment.

The family did not want Indira to be alone in a hospital bed, so they were taking turns to make sure that someone was always there with her, 24 hours a day. They would work in 8-hour shifts, which Amara described as being physically exhausting and emotionally stressful. She speaks of this as a time of *just existing* [Amara's words]. Caring for her mother became her main priority and everything else had to take second place, including Amara's own

immediate family, comprised of her husband and her two sons. The long shifts at the hospital and commuting times became very tiring. Additionally, the emotional shock and distress that came with seeing her mother hang on to life by a thread while trying everything they could to keep her alive was putting the family under a lot of pressure. Amara thinks this is the reason why she struggles to remember much of this time in detail. Looking back, most of it seems like a big blur to her that left a mark of pain and many unanswered questions.

Amara: One of my regrets is I never remembered those things that my mum said to me in the hospital, because my sisters tell me that she was lucid at times, and they are quite clear about that. And in my mind I can't remember those lucid times, and that actually really upsets me because I mean, well, if she was lucid, what did I say to her? I can't remember. You know, did I say: *I'm really happy you're my mum?* Did I thank her? I'm not sure.

Amara's time spent in the hospital also reminded her of a previous lived trauma: when she had given birth to one of her sons prematurely and had almost lost him to death. Reliving this memory created an additional emotional burden for Amara, which she had to navigate while simultaneously caring for her mother.

Amara: So, those expectations during those 4 months that she could die anytime, it was really difficult for me because I was reliving my son's trauma as I was having to deal with another one. I was used to being in a situation where you are in an ICU unit with lots of machines keeping someone alive and for a lot of the time my mum was in that same situation. So, for me there was a double trauma. I'd experienced something years earlier, and now it's coming back. One was a newborn baby, and one was an

elderly parent. One was coming into life, and the other one was exiting, but that was a trauma that I was experiencing again as I was going through grief. So actually, it had a huge impact on me.

The trauma of my son's near death has never left me. I don't think it has ever left any parent whose child has been prematurely born. And I was surrounded at that time, for 6 months, with machines, noises, jabs of the needles going into someone, and you can see that they were experiencing pain. When you're in the hospital and you're having intensive procedures being done to you, I always thought you're being tortured, and I always believed that with my son, my baby. With my mum it was the same thing. I actually believed she was [being tortured]. She frequently, not frequently but sometimes, her saturated levels went down, so she needed an intervention, and had she not had that intervention she would have died. There were times during those 4 months where I was on my own and there was a crash team there, and I was talking to her as she was about to die. So, that trauma reminded me of what had happened with my son because he had also gone through apnoea episodes where had he not been bagged, he would have died.

The Process Post-Loss

After 4 months, Amara's mother died, in the home of one of her daughters, who is a medical doctor. Indira was 77 years old at the time of her death. The whole family had gathered around her bedside, while Amara's father shared a story of his wife's life. Amara described it as a heartfelt moment that was a mixture of joy and sadness. The family shared it together. Shortly after Amara's father had finished telling his story, Indira died.

Amara describes the day of her mother's death as peaceful, although the months leading up to it had been very hard on all the family members involved. Amara stayed in

London after her mother's death to help with the organisation of the funeral. She and another sister were also made the executors of the will, which meant Amara couldn't go back home to Seattle straight away. Instead, she remained in her London home for the next couple of months.

Amara: After her death, we all coped in our different ways. For the first few months, we were dealing with the burial. So, my mother, there was a funeral in London, but we also had to, because she's religious, quite religious, we had to perform the rituals in India as well, and that meant scattering her ashes in the river Ganges. I would say, she died at the end of the year, she died in October [2018], beginning of October. The rest of that year was taken up with organising things. The funeral in England, all our time was devoted to that and then arranging an India trip to carry out what we believed would be her wishes. So, it was only in January [2019], well not even in January, when that side had finished.

You know, I, everyone has their role in the family, don't they. There is the person who is more emotional, there is the person who is more practical. I'm the practical one, so I am the one who is usually left to deal with, with things like paperwork. After my mum's death, that responsibility, again, fell on me, and perhaps my sister just below me. She did step up, but you know we all had our different roles, and we fell into a, sort of, our normal roles, where one of my sisters lives in Spain. So, after the religious things were done she kind of, she took refuge by going back to Spain and not having to deal with anything else. And I stayed in London, even though I was meant to be going back to Seattle. I stayed in London because my mum had made me and my older sister the executors. But my older sister went off to Spain, and

so it was all left to me, as it would be. We didn't really as four sisters come together and talk about that.

Amara recalls taking on her usual family role of being the practical one, which resulted in additional responsibilities for her. In addition to this, Amara also experienced an emotionally painful and difficult period of grieving, which she did not share openly with her family. Instead, she perceived that each family member kept to themselves and undertook their own grieving process.

A central aspect of Amara's grieving was the feeling of not having gained closure with her mother and the guilt that arose from this. Amara voices several reasons for these feelings. An expression of love, care, and appreciation for her mother had never been particularly explicit in their relationship, and Amara describes their relationship as practical, rather than affectionate. However, although Amara's relationship with her mother lacked emotional intimacy, it was still meaningful and important to her. Indeed, Amara loved her mother very much, and this love was expressed by offering her mother practical and financial support. Amara also points out that even though she knew her mother was going to die one day, she did not quite grasp that her death was going to happen so soon. Neither did she expect that it was going to happen the way it happened. The feeling of it being too late to share and do things with her mother in a more loving and affectionate way, manifested itself as another feeling of loss. The loss was, in this sense, a loss of an opportunity to say what she wanted to say to her mother. With this loss came a sense of guilt for not having spent more time with her mum or doing enough to help her while she was still alive, especially after Amara's move to Seattle.

Amara: I think closure would be where you have said things that you want to say and that you've left on peaceful terms. I think, one of the difficulties is, that if you're not there for your mum, and I wasn't because I had been in Seattle for most of the last 5 years, I was very aware that my not being there, at the back of my mind I wondered, I didn't think she'd die. I knew there was always going to be that possibility, but I thought it was going to be a slow process, and it was a slow process, but I didn't think that it was going to be a brain injury that would mean that you couldn't talk to her: a conversation-ending relationship. So, I think it was made more difficult because I was away from her the last 5 years, so I don't think there has been closure.

We [sisters] often wondered whether she had a sense that her time was coming to an end. When I look back to some of the things she said, I think she did know. In my last visit to London, and it was a few months before her fall, and she'd always be saying things like: *Oh, I'm going to give you this or that or the other*, and I'd really just ignore her. But on this particular day she insisted, she got out [interrupts herself], she used to have her jewellery in this suitcase, and she said to me: *I want you to look at this jewellery, and I want you to choose something* [crying]. Sorry [silent pause]. Anyway, she got out the jewellery, and she said: *You've got to choose something*. Most of her jewellery is gold and for whatever reason, I don't like gold, and she knew I didn't like gold, and I regret saying that to her now, but I said: *Mum, I don't like gold. You know I don't like gold. I don't really need anything. I don't want anything*. But she really wanted me to have something, and so I was going through that suitcase with her jewellery, and these were things that she had acquired through her life, and I chose a bracelet, a bangle. I could tell it was a very old bangle. I think it must've been probably 50 years old or something because the decoration and style of it was very, very nice. So, I said, oh you know: *I'll take this*. But I wish [silent pause], now

looking back [silent pause], it was her way of saying: *I think I'm coming to the end of my life*, and I didn't really appreciate it then [crying]. So, I was dismissing that conversation, and in a way, I was dismissing her when she was doing all that. I think: *Gosh! Why didn't I just pay more attention?*

Another reason for Amara's felt lack of closure was that it never became completely clear to Amara and her family what the reason for Indira's fall actually was. The doctors could not determine whether Indira had slipped and hit her head, which subsequently led to her stroke and brain injury, or whether she had had a stroke, which had caused her to fall, hit her head, and injure her brain. Being able to make sense of her mother's fall by gaining clear answers about its circumstances was important for Amara because it would have helped her to determine whether she could have done more to prevent it from happening. If her mother had had an accidental fall, Amara thinks she or someone else could have been there to prevent it, thus adding to her feelings of guilt. However, if the reason for her fall was the stroke, then not much could have been done on the part of any of the family members, and the guilt might have been less acute, as it would have been beyond Amara's control.

Guilt and regret assumed a central role in Amara's grieving experience and left her with many unanswered questions such as: *Why didn't I? What if I had just? Could her fall have been prevented?* [Amara's words]. With time, Amara has been able to reflect upon the answers to some of these questions and to come to terms with the reality that she will never have any definite answers. Simultaneously, at the time of the interviews, Amara still felt that she had not gained closure. Despite this, she states that she has found other ways of living with her loss and grief, namely through honouring her mother and expressing gratitude for her, post-loss. For example, Amara committed to climbing Kilimanjaro in late February 2019, as a means of honouring her mother and the hard work that she had done in raising and

providing for her family. This was a way for Amara to give back and to repent for the guilt that she was feeling in relation to her mum. It was also a time for Amara to test her own strength, to appreciate herself and to put her needs before those of her husband and children. She describes the climb as a cathartic experience, which reshaped her grieving moving forward.

Amara: One thing I reflected upon was: *Gosh, I'm always there for my family!* When I had kids, it was me that gave up my career to look after our kids. When I moved to Seattle, I gave up my career to be there for my husband's career, and I thought: *Gosh, the number of times I've done things for all of them*, and then, when it came to actually being there for me, they weren't there for me. You know, they were there in different ways of, they keep saying: *They were there for me*, but well [silent pause]. And I do have this strong feeling about equality, so it made me think: *Well hang on, I'm just as important as them, and why were my needs ignored?*

I then started thinking more about me, and I remember saying to each of them: the next year is about me, and I'm putting me first, and I'm not going to put you first. And I made that clear to each of them. And then what I did, was I made a decision with a girlfriend, a friend I met in Seattle actually, who had been talking about wanting to go mountain climbing in Kilimanjaro, and I think it was in January. She mentioned it again and I said: *Yeah, I want to do it and I want to do it now*, because I was in this haze of grief, really quite lost, with really strong feelings and I needed an out. I needed something to [silent pause], cleanse isn't the right word, but I needed something to get rid of those intense feelings. So, we agreed that we were going to climb Kilimanjaro at the end of February, so then my focus became on that climb. I

thought that I need to get away, I need to do something that is almost like punishing me. But you know, a challenge, that is a real physical challenge and to cleanse myself.

I do remember that thought go through my mind, that I needed to do something to move on. It had to be something really significant, something really hard. It couldn't be easy. So that's why I said: *Yeah, I'm doing this!* I don't think I thought it through properly, but I do remember going to the airport. I was on my own. This was my trip and a real feeling of relief actually. This is me, I am on my own. In some ways it was nice that this was about me. This is the first time that it is just me and my feelings about everything, about my mum and everything.

I will always associate that climb with losing my mum. So, you know, on day 3 I started doing mini [audio] recordings. And, on the day, when we were climbing up to the summit, it was getting progressively harder as we got up because of the loss of oxygen. My mum was on my mind the whole time, and what I did do, because I knew it was going to be cathartic like for me, that is how I saw it, I had a notebook. In fact, I had bought one. My sister gave me one as well. She said: *You know, I want you to write your thoughts down on this.* And I knew I was going to do that anyway because I had bought my own notebook, but she gave me one, and every day at night-time, when we were in our tent, I would write in it about feelings related to my mum. And so it was meant to be a cleansing trip and that was its purpose. I knew I had to do it, and I was pushing myself because I knew what the climb was for. It was for my mum.

That climb was also about: *You know what? You could do this, Mum. You just didn't have the opportunity but I'm doing it, and it's for you.* So that climb, it was definitely about me, but it was also about her. I did feel when I got back down, and when I got back to London, I did feel a sense of calm. I remember I wasn't crying every night, and that was a big difference. So, prior to going, I would break down

every night. It would be in the shower or whatever, unexpectedly. I wasn't doing that. I would still cry at odd times, but not nearly as much as I had been, and there was a period when I didn't cry at all, that I thought: *Wow!* I could see that something had changed, that there had been a change. So, that grief that had been there prior to Kilimanjaro, it was coming out in a different way after I did that climb.

After her mother's death, Amara made a critical assessment of what her role was within the family and how she had lived this part of her life. She began to reflect on and to question some of her previous assumptions, thoughts and actions concerning her role within her immediate family, as a mother and as a wife. A change in perspective, which saw Amara put herself first for a change, led Amara to rearrange her life, to shift priorities, and to make different choices. She changed a part of her behaviour by taking more decisions on her own, independent of her family's needs, i.e. she decided to focus on her needs, as she did not want to make the same sacrifices as her mother had had to make.

Amara spoke of how her grieving gradually transformed from a series of acute emotional reactions into a process of reflection and acceptance. The pain is still there, and if she thinks about it, it hurts. However, at the time of the interviews, Amara describes her grief reactions as being much less intense than in the immediate aftermath of her mother's death. For a long time, she has been ruminating about things that make her feel guilty, regretting past actions, and wishing things would have been different. Although the guilt and regret still persist, she perceives herself to be ruminating less, and she is learning to accept the situation for what it is.

Amara: One of the things I've reflected on [is] when I look at my mum's life is that actually it was her time to go. She had been in pain. She had had very bad illnesses.

So, it was her time to go. You also do learn that there is no point in having or continuing to dwell on regrets. It is not going to change anything. You know, there are these huge feelings of guilt, and there isn't a day that goes by where I don't think about her. I don't know at what point it becomes less difficult to talk about it, or less painful. On a day-to-day level, there is not a day that goes by that I don't think about my mum, but on a day-to-day level, I think the extreme feelings of loss have got easier. They are not as extreme. The loss is there, and if I think about it, then the pain is there.

Amara developed an interest in her family history after her mother's death. She learned about her mother's family history and upbringing, and the hard work invested by her mother in the upbringing of her daughters while supporting the family. This led Amara to appreciate and acknowledge her mother's efforts in a way that she had not done while her mother was alive. It also resulted in Amara becoming more understanding of who her mum was, why she was the way she was, and how this influenced their mother-daughter relationship. Furthermore, Amara spoke of a sense of heightened importance in capturing and appreciating what is left of her family. This has, for example, led Amara to re-evaluate the relationship she has with her father, who is still alive.

At the time of the interviews, Amara expressed the importance of fostering an understanding and forgiving relationship with her father, instead of holding on to resentments that she had towards him from the past. Amara has sought to gain closure with her father, in a way that she was unable to with her mother. She has spoken to him about death, what he wants for his own burial when his time comes, as well as other personal matters. The family even arranged for a filmmaker to make a documentary about her father's life, resulting in a 90-minute film where he speaks about his life and upbringing. Learning about her family

history has enabled Amara to understand her parents better, their origins, as well as her own cultural roots, something which she has come to appreciate more now, in the aftermath of her mother's death.

The loss has also had an influence on how Amara interacts with her sons. For example, she informs her sons about their family history, so that they have an idea about their ancestry, as the possibility to learn about her family history through her mother was lost when she died. She does not want the same for her sons.

Navigating Social Support, Both Pre- and Post-Loss

The trauma of Indira's fall, her 4 months in hospital, her death, and the effect that this had on all her daughters, made it difficult for the family to support each other emotionally during this time. Indira's daughters have not come together much to process the loss of their mother as a group of sisters. Their father has also been quite absent during this time, as he has decided to spend more time in India, his home country. Amara points out that the family's lack of contact is partly circumstantial, due to living in different countries and having separate lives, as well as each family member needing their own personal space to process their loss and grieving individually.

Amara: We [sisters] haven't really come together to support each other. In fact, we've been quite bad at it really. Because, you know, a year on, when we had her 1-year anniversary, her bedroom is almost the same as it was. We haven't really come together emotionally, even pragmatically we haven't, because we all think different things. So when they say: *I'm not ready to deal with Mum's clothes or jewellery*, or whatever, and so we've let it go. But I said to them last time: *You said you're not ready to deal with it, but I'm not ready to let it carry on*. So, emotionally, we haven't

really sat down to discuss it, and I'm not sure we're ready to do that because it's really difficult to explain to others just how intense those 4 months were. And we're only still traumatised by it. So, that memorial, it was actually quite nice that 1-year anniversary, that was the time, a year since her death, when we did get together. We did a small prayer for her in the place where she used to pray in her own house, and that house is my mum. So, we're praying and remembering her in her little prayer section. It was just the four sisters and my dad. And then in the evening we invited all the grandkids, there were eight of them and they all came, and we basically were sharing happy memories of my mum, fun ones. That is probably the time when we've only gotten together to kind of half discuss it, but we haven't really come around to find out: *Well, what was it like for you?*

Amara's mother was the lynchpin that held the family together, and when she died, there was no longer a central figure in the family. This has taken some time to adjust to. Despite the family's lack of connectedness with each other, Amara thinks it is only a matter of time before they will all sit down again and share their part of their grieving process together as a family. This is something that she looks forward to, when the time is right, especially now that she has moved back to London. Amara thinks this is important, as there are things that some of the sisters know from conversations and memories of their mother that Amara does not know, and vice versa. Amara wants to be able to speak about their mother and share information about her that may otherwise be lost. The few times when the family did get together, during the funeral and the 1-year anniversary of Indira's death, it served as a nourishing and meaningful ceremony, where they could honour and remember their mother in various ways. For instance, they shared memories, recited Hindi prayers,

performed poetry, and showed each other photography, all of which supported a sense of connection between the family members and the deceased mother.

Amara is understanding of the fact that there has not been much support from or connection with her sisters and father. However, she feels differently regarding her husband and her youngest son. During the interviews, Amara expressed her disappointment in her husband, as he was not as supportive as she would have wanted him to be, both during and after her mother's death. Amara's husband stayed in Seattle for most of that time and did not offer much practical or emotional support. Neither did she experience support from her youngest son who was at university in Seattle at the time. Amara attributes her husband's avoidant behaviour and lack of care to his generation, as well as his gender and his own upbringing, which did not consist of much parental affection. She also suspects that her husband's behaviour has rubbed off on their youngest son. In contrast to this, Amara points out that her eldest son, who was living in the United Kingdom and in the fourth year of studying for his degree in medicine, was a consistent source of support during and after her mother's illness. For example, Amara did not want to sleep alone in the London flat in the time after her mother's death, so she asked her son to move in next door, which he did. She recognises his efforts to be there for her; simultaneously, she reflects on whether the amount she leant on him was appropriate to their mother-son relationship. In hindsight, she questions how much a son can really be expected to support his mother, because after all, that is not the expected social norm when it comes to parent-child relationships. It is a common assumption that a parent is supposed to be there for their children, but Amara did not live by that assumption during this time, when she was the one who needed help and support and he was one of the few people in her life who could offer it. Amara pointed out that he was an adult, after all, and that is what families are supposed to do. They are supposed to be there for each other and to help each other in times of need.

Amara: I was very disappointed, very hurt, even more so retrospectively, I think, because at the time my energy was elsewhere. I feel very disappointed. It's a difficult one because it is also embarrassing to have to share. Well actually, the one person that you've spent the most of your life with is not really there when you need them. What does that say about anything? I'm really angry towards my husband. Yeah. His lack of empathy was shocking. I told him so. It's not something I've come to terms with still. I don't understand it, so yeah real anger there. I didn't have nice thoughts towards him, and it has still impacted our relationship to this day. There is a lack of trust there. And I said to him, well you showed me that when push comes to shove, you're not gonna be there. So yeah [silent pause], it was very difficult talking to him, very, very difficult. Whether that is his character or whether that is his maleness I don't know, but [silent pause], it hasn't been resolved really. Because I still say to him until this day, and I said it to him recently: *I don't understand how you couldn't be there when my mum died.*

With my younger son, I don't want him to follow [in] his father's footsteps and not be empathetic to others. And then when I did reflect on that with my youngest son after my mum had died, I told him I felt that he should've done more, and I hoped that if he went through a similar experience that he would be there for someone else next time around. I think it was important for me to have that conversation because I kind of think that he was young enough to change and perhaps empathise a bit more in the future. I wanted him to understand that you can really feel let down when the person you think is going to be there just isn't there. Sometimes you need to put someone else first. So, that conversation that I had with my youngest son, was designed for him not to behave in the same way in the future. To be fair, you know, what he said to me was: *Well why didn't you ask? You say you needed support.* And I

said: *Well, you don't think about those things, and actually you shouldn't have to ask. You should know that somebody is going through trauma and that you need to be there. It is not something you ask someone: Do you need help? It is something you know: that that person would need help.*

Eleonora: There is something here that I'm picking up on, about not feeling understood, or not feeling appreciated for what is going on, or acknowledged that what is happening is painful and that you need support. Does that make sense?

Amara: Yeah, I think, I think you're probably right. Maybe that is some of the differences between losing a parent when you're younger because the expectation is that a young person would need support. The expectation is that when you're an adult, you're going to cope better, so maybe the support isn't needed quite so much. And I think that's quite right, and it's only probably since losing my mum that I can see that actually it's quite devastating, that brought home to me just how big that loss was because I didn't expect the loss to be felt quite as much as it has been felt with me. My mum was not in great health for the last 10 years of her life, so the expectation was there that at some point she was going to die. I just didn't expect it to be then, and I didn't expect it to be sudden. For me it was sudden because even though she lived for 4 months, I didn't feel that she was my mum for those 4 months, and I didn't have that closure. So yeah, I think the support, the understanding wasn't there, and maybe I wouldn't have understood how devastating it was until I had that loss, so yeah [silent pause]. I think it's a feeling in society that you should be able to cope with that pain when you're an adult.

I think there is the pressure on you, because you're an adult, you're not supposed to cry quite so much. It's more acceptable to show emotions as a child because you're needy. You know, children are vulnerable, whereas adults are not

expected to be so vulnerable. Actually, an elderly person is expected to be vulnerable. So, you know there are two stages in your life – when you're very young and when you're very old – when you are vulnerable, and then there is this stage in the middle where you are expected to be steadfast and independent and able to cope with things. Yeah, those expectations when there is a loss [silent pause], I think when a parent loses a child I think there is a good understanding there. So, when a parent loses a young child, then people are very sympathetic because they understand how huge that loss is. But I suppose it's the expectations as you get older, your parents are going to get older, and they will die. It's the expectation that you've prepared yourself for it a little bit, and actually it's difficult to prepare. I think it was unexpected. I hadn't really thought about it, so [silent pause], I haven't thought about losing a parent. I didn't know what to expect.

Kim's Life History

Kim was born in 1979 and was raised in East London where she grew up with both her parents and her older sister. She had lived in her family home for most of her life and had a close relationship with her immediate family. In May 2014, Kim found out that her father had oesophageal cancer, and what followed were 2 intensive years of caring for him until his death in April 2016. Shortly after, Kim's mother was diagnosed with lung cancer, and she died in May 2018.

Having both parents diagnosed with cancer in quick succession was a life-changing event for Kim, which brought with it a new set of circumstances, responsibilities, and priorities as she became their main caregiver. Kim describes putting the rest of her life on hold while committing herself to supporting her parents throughout their illness, ensuring that they both received the proper care and treatment they needed until their deaths.

What follows is a representation of some of Kim's life story of losing her parents to cancer and the impact this had on her, both in the time leading up to and following their passing. This chapter captures, to some extent, the history and relationship that Kim had with each parent: the time she had spent caring for them, her grieving process both while her parents were alive and after their death, and the feelings and thoughts she was experiencing at the time of our interviews.

A Tumultuous Childhood

Kim remembers her childhood as quite tumultuous, although she still perceives it to have been a safe upbringing. She describes her family home as a non-traditional place and attributes this to the dynamics between the immediate family members residing there, alongside the spatial arrangements of the house itself. Her parents, who remained married until the end, lived separately in the same house and did not speak to each other. Kim has a

sister who moved out at the age of 21 years old, when Kim was 11. Following this, Kim and her mother each had their own bedroom. Years prior to this, Kim's father had laid claim to the living room lounge. The living room was the public space for both family and guests to spend time in; yet, next to the sofa, there was also a bed installed specifically for Kim's father. Kim speaks of her father as being the centre of attention and the centre of the house. She points out the difference in personalities and roles between her parents: her father was the centrepiece of the house and her mother was the glue that quietly but determinedly kept everything and everyone together.

Kim remembers their house as lively, decorated with heated arguments, as well as joy and laughter. The family consisted of strong characters, and when they clashed, they did so with intensity. Kim perceived that despite the resentful and broken relationship between her parents, what her mother and father shared was their love and support for Kim. Kim always felt that her parents believed in her and stood by her unconditionally.

Family life played a major role for Kim, and she lived with her parents for most of her life. After having lived nearby her family house with a boyfriend for 5 years between 2006 and 2010, at the age of 31, Kim decided to move back in with her parents. While living at home again, she had the freedom and opportunity to develop her career and embark upon various job ventures, which would have been difficult to do without the financial stability of that home environment. The family bonds were thick and strong, and although the relationships seemed to be — in varying degrees — complicated, damaged, and unusual, they still stuck together as a family.

Kim: We lived in East London first of all, when I was born. We lived in Chingford, in a flat. As well as Daddy doing his acting, they ran market stalls selling ladies' underwear, so that was always a family business that we all sort of participated in. We

used to go to South London, Elephant and Castle, to a market called East Street Market, which is really cosmopolitan. It's always been really cosmopolitan and growing up working on the stall was such a life experience. You learn a lot working on a market stall in South East London [laughter]!

So, yeah, so during the 80s, Daddy was busy as an actor, often working, which meant that he was often drinking too, after his jobs, and it was part of the acting scene to be seen and to be mingling with all walks of life in Soho. So, when I was born, Mum said she didn't see him for 2 years basically. She would only see him drunk, and he'd be standing over my bed crying, *It's my little girl, it's my little girl*. So, you could imagine, he was a bit of a nightmare [laughing]. He was self-indulgent! Poor Mum, she's juggling all the plates, looking after her baby, looking after my sister, yeah Mum just kept everything going, she was solid.

So, if he'd been drinking locally and he'd run out of money he'd come home and we'd all be like, the family would be in the living room, and he'd be at Mummy: *Have you got a tenner? Have you, have you got some money?* And she would have to really keep holding on to the purse because he would just spend it. He was too casual with everything, immature, you know [silent pause], and obviously they would argue, they would argue, and [silent pause] yeah, it could be volatile, not in a [physically] violent way, but it was just that they both had strong characters and they both had different ideas about how things should go. He just wanted to do his own thing. He never cheated, as far as I know. It wasn't about other women, it was just about him being the actor and going from pub to pub, and holding court in the house as well.

He had his bed in the living room! He slept in the living room, because Mum said, *Well he would fall asleep on the sofa!* He would never go to bed with her and join her in bed, so it just ended up with him having a bed in the living room. And

people would come around, and I'd be sitting with friends with him in the living room [imitating her dad's words]: *I worked in the RSC [Royal Shakespeare Company] with Michael Gamber, and when I worked with Sir Trevor Nunn, he kept me waiting because he was having dinner with the Queen!* These kinds of stories, in jest, but it's all about him, bless him.

So, their relationship [Kim's parents] just got a lot more distant as time went on, and we did all live separately in this two-bedroom house. My sister moved out when she was 21, so I would've been 11, and at that point I've got my own room, and Mummy stayed in her room, and Daddy stayed downstairs. So, we were individuals but as a family, it functioned somehow because Mummy kept it going, kept the household going, she kept us all together. And he would say, *Well I've only stayed for you!* He would say to me, *I've only stayed for you! Your mother is damaged. I've only stayed for you!* And I would say, *Ah that's nice! Don't make me feel guilty about that. I'd rather you didn't! I'd rather you hadn't stayed because I'd rather there had been no arguing.*

Kim's Relationship with Her Father

Despite the regular arguments that took place at home, Kim points out that there was plenty of laughter in the house as well and that this was what brought the family together, regardless of the animosity that existed between them. In spite of the turmoil, upset and resentment that resulted from her father's drinking and partying, Kim consistently felt the security that her father would always be there for her. She described her relationship with her father as one in which she could not have felt more love. Even though he was the centre of attention and would take pride in his daughter for his own glory, and even though he always put himself before everyone else, she still never questioned his love.

Kim: Oh my God. It used to annoy me. He used to annoy me how proud he was: *Oh shut up!* [Kim telling her dad]. And if anyone came around to the house: *Kiiiiim!* *Play them that tune on the piano* [imitating her father]. *NO!!! Not in the mood* [Kim replies]. *Come on!* [imitating her father]. But then if I went to practise the piano he would say: *I'm just watching this programme. Or: Can you do this another time? Or: Can you play one that you know?!* [laughter]

They always gave me the encouragement and confidence to be big, my parents, but at the same time, Daddy was the biggest. So [silent pause], yeah [silent pause], and things like, when we had the market stall, so I would go to work with him on the Saturday and Sunday, he'd set the stall up for like 8 o'clock in the morning, but as soon as the pub opened at 10 a.m. he'd leave you, and you'd be on your own. I was like 14-15 [years old] and he would be in the pub until like 2 o'clock [2pm], and you would've held the fort, and it was busy those days as well. It was a busy market and then he'd come back, after having a few [drinks], and completely destroy your stall. He'd open all the packages and throw out [the underwear]: *Come on girls, come on girls, see what we've got here!!* You've got everything in order, what sizes you've got here and dadadada, you know where everything is, and Daddy would come in and [silent pause]. Yeah, so complicated, but the overriding thing is that I couldn't have been loved more, you know, and even in the silly thing of him saying, *Well I only stayed for you. I only stayed for you!*, he was saying it to make me feel more loved, but obviously it wasn't the right thing to say.

The Father's Time Living With Cancer

Kim's father lived with a condition called Ankylosing Spondylitis, a form of arthritis of the spine where his spine was fused straight. Kim describes this as a reason for her father

experiencing a great deal of physical pain and discomfort throughout his life and his need for regular heavy doses of painkillers. In hindsight, she thinks that perhaps his frequent heavy drinking also became a way of self-medicating. While he was still alive and before he was diagnosed with cancer, Kim said that although there was love there, they [Kim, her mother and sister] would not take him seriously, and they did not pay particular attention to the discomfort he claimed to be experiencing. Instead, Kim recalls that they would brush off his behaviour and go on with their day without stopping to wonder why he was behaving the way he was. In that sense, Kim did not think they had a lot of compassion for him, and this dynamic continued to some degree while he was living with cancer.

Kim: He was on a lot of drugs, painkillers, his whole life. And I didn't realise how much those drugs made him sleep and would have changed his mood, and obviously he was drinking as well, so we were just thinking: *Oh it's him, it's Dad, he's lazy, he's hungover etc.* But I think that possibly, he was self-medicating with liquor a lot of the time. I mean, he liked it, don't get me wrong. It was part of his culture, so yeah, the combination of the illness, and he had high blood pressure, so he took tablets for that and sleep apnoea, and I mean, the snoring, it's legendary. Anyone who's visited the house [silent pause], it was actually sleep apnoea. I mean, he would hold his breath for maybe a minute and then go: *Hrrrrraarrh* [imitating her father's snoring intensely]. It was legendary [laughter], it was comical. But to think about his health now, it wasn't good for years and years and years.

So, in 2014, I went on holiday with my friend to the South of France. I think it was the month of May. And Dad was always saying, he was always moaning about the doctor: *Well she doesn't know what she's talking about! I've told her there is something wrong here!* But it was a habit of his to moan about the doctor, so you

wouldn't take any notice. He was always having a row with someone at the doctor's, so you'd just think: *Oh it's just Daddy*. And he had mentioned to me that he was having some test, and this cancer word was mentioned but just in passing though. He'd always said: *Our family don't get cancer, our family don't get cancer*. And then he phoned me on the way home from the hospital and said: *I've got cancer*. I said: *That's not right! They've got it wrong, or you've got it wrong, or something is not right*.

It was like, out of the blue, which is what it is, so it was oesophagus and the next meeting we had at the hospital was to see if we could do anything, operate or, but there was no way they could operate. It had spread to the lymph nodes, which is, that's the thing with oesophagus cancer, the symptoms only arrive when it's too late and it was coughing, it was coughing, and he used to have this hacking cough, but we just thought it was him being overly dramatic.

So, I started going to the chemo appointments and he wanted the best treatment that he could possibly get, you know. He tried to get into Marsden, which was the top specialist cancer hospital in London, but they only take rare cases, so he couldn't get in there, and then I had a German friend who had had cancer, and he [Kim's father] believes in the Germans'... he really believes ... in Germans' discipline and logic, so we got all the files and sent them to Germany, but we never got to the blooming hospital and it was all this trying, trying, trying. Anyway, went through two lots of chemo, and all the time joking, laughing. I mean, it was a façade, but that's what he did. He loved to make people laugh; that was actually one of the biggest things I ever said about him. That was his joy, it was attention seeking, but it was his joy to make people laugh, so you can imagine the nurses in the hospital.

We [Kim and her dad] used to go to Euston Hospital. I'd go with him for all the treatments, and I bought him a sandwich. He'd been out drinking the night before the chemo, and I bought him a sandwich and I thought, he was like this [imitating someone sitting with their torso folded over their legs and hanging down], and I thought he was picking up his sandwich packet but he was having a reaction to the chemo, and then he started shaking. Now, this is an open plan chemo ward, it's huge and I had to shout: *Heeelp, heeelp!* and the whole team of people came on to him and the receptionist took me away. Thinking about it now, I don't think she should've taken me away because he might have gone then, it might have been the end, but they gave him adrenaline to bring him around, and what happened was [laughter], he's got the adrenaline [Kim gets up and starts dancing, imitating her father singing Tony Christie's *Is this the way to Amarillo?*]: *Is this the way to Amarillo?* Oh God, he was nearly dead a minute ago, and he got up and started [silent pause] — that's typical Daddy [silent pause]. He just wants to be happy, and I was like: *Dad, take something seriously. Just take one thing seriously!* Anyway, they kept him in, and he was all right after that, and they had to change the chemo because that chemo didn't work, and he's getting thinner, and you know he's not getting better. And it's a lot of anger associated with it as well. You're just angry at the situation. You feel helpless, and, so even as he was deteriorating, you kind of knew the last Christmas was going to be the Christmas of 2015. You just knew it.

Waiting for the End

Kim recalls that in early 2016, they were told by the hospital staff that there was nothing more that could be done for her father. Kim feels that, from that moment, whatever little hope they had been holding onto was now gone. She describes it as a dark and sad time

for everyone, where they were grieving in anticipation of his death and waiting for the end to come.

At this stage, Kim was taking care of her father full-time at home. They also had specialist Macmillan¹⁰ cancer nurses who came to their home on a regular basis, which Kim describes as a significant support. During this time, Kim describes her father as scared and agitated. She recalls that he neither wanted to speak of death, nor to write a will. For the last two weeks of his life, he withdrew and did not want to see anyone. To cope with the emotional and practical distress, Kim turned to smoking marijuana. She had done this since the age of 17, but during her father's illness, the smoking increased significantly. Towards the end of her father's life, she would lock herself up in her room and smoke for several hours a day to calm herself down, while simultaneously juggling her caregiving responsibilities.

Kim: In the final weeks, he smelt it, and it became this thing to fixate on. And the anger came out about me smoking dope. And he was angry at me, he was angry at me for smoking dope and for smoking in the house, but I think that his sense of smell, his senses were hyperalert, and everything made him feel sick, even the cooking smells. Because he'd always been a nightmare and driving everyone mad; we weren't very compassionate in some ways. Like Mummy cooked a roast lamb dinner and he was going: *It stinks, makes me feel sick. Makes me feel sick!* And she'd ignore him. But that's how we operated, so for anything to have changed at that point would've been weird, and she said she would've felt like a hypocrite to have been any different towards him. And she also said: *Well, he came up one night when you weren't here*

¹⁰ Macmillan Cancer Support is a registered charity and a limited company that is independent of the NHS. It is financially supported through donations (Macmillan Cancer Support, 2020).

and he was trying to get in here! [her bedroom] Trying to talk to me and get in here!
 She said: *I don't want it! I don't care and I don't want it!* She said: *Of course I will look after him, but I cannot go there.* There had been too much water under the bridge at that point. So, there wasn't any softening at the end.

During this time, Kim remembers feeling exhausted while being under severe stress and on constant high alert. She was up most nights caring for her father, and then she would wake up every morning, jump out of bed and run downstairs to check if he was still alive. In his final days, she had to deal with something called terminal agitation, where he would get spurts of energy and suddenly stand up in the middle of the room not knowing where he was or what was happening. Those episodes continued for 2 days straight, and when it happened Kim had to try and calm him down and get him back to bed.

In the days prior to her father's death, Kim recalls there being a sense of acceptance of and surrendering to death. She described how she could see her father's suffering and did not want him to keep struggling to stay alive anymore. With the support of their GP and the Macmillan nurses, her father was now made as comfortable as he could be at home. He was given morphine and did not seem to be in much pain while drifting in and out of consciousness. Kim also wished for him to know that she felt it was all right for him to die and pass on from his suffering. She did not want him to unnecessarily prolong a now difficult life and came to accept that it was time for her to let her father die.

Kim: It was about 8 o' clock in the evening and we hadn't eaten anything. Mummy went for a rest upstairs to shut her eyes, and my sister was making me a cheese sandwich, and I just thought: *I can't watch him, I can't watch him.* And so, I went over to him and stroked his hair and I said: *Daddy, if you want to go, I don't blame*

you. We love you very much, and we'll see you very soon. And with that he started to go, and I just called Mum and my sister and the three of us just held hands and told him we loved him. And then [crying], he slipped away. So, it was actually like a Hollywood ending in a way [laughter] because, you know [silent pause]: *If you wanna go it's all right. I don't blame you Dad, it's not fun is it?* I said, *It's not fun mate is it?* Yeah [silent pause].

Kim describes her parents' relationship as troubled, and she tells of how her mother had been ignoring her husband for years. During his illness, Kim recalls that her mother did not show him any affection and only helped to care for him with regards to the most basic necessities. However, in the moment right before his death, as Kim, her mother and sister came together to bid him goodbye, there seemed to be love and compassion: what Kim referred to as a *Hollywood ending*.

What Followed Post-Loss

Kim's aunt organised the funeral and cremation ceremony. Thanks to this, Kim, her sister and her mum could be relieved of some of the practical responsibilities. Kim remembers the day of the funeral as surreal, and she did not assign it much importance. Rather, she thought of it as something that just needed to be done. She perceived the funeral as something that fulfilled a social obligation rather than having much sentimental value for her, and she recalls it as something that she was quite indifferent towards at the time.

In the days after her father's death, Kim remembers feeling exhausted and in shock. The experience as a whole seemed strange to her. Accompanying this was a sense of relief. She describes feeling relieved that she no longer had to continue with her caregiving responsibilities and the hard work this entailed. She was also relieved that her father was no

longer suffering, as she knew that his illness could have dragged on much longer, and she was glad that it had not.

With the relief also came guilt. Kim felt guilty that, as a result of her father's death, she was less burdened. She also felt guilty about some of her behaviour towards her dad while he was still alive. Although Kim did spend a lot of time listening to her father talking about himself and sharing his anecdotes, she still feels that she did not listen to him enough when she had the chance. She did not think that she had taken him seriously enough, or that she had been compassionate enough towards him and his behaviour, especially during his illness. However, she points out that her level of compassion and desire to recognise her father's achievements grew stronger after he died. She became increasingly curious about his life history and wanted to learn more about it. For the first time in her life, she decided to search for her father on YouTube, and she was surprised to see so many video clips of him acting. Kim could see that many of the stories he had told had been true. Yet, while he was alive, she had not recognised this, nor realised how significant his work had been. Watching the clips online was a way for Kim to reconnect with her father, and she thinks that her search for him on YouTube grew from the central question of: *Where are you, Dad?* His absence seemed to have left her wondering about other ways that she could connect with him and feel his presence again post-loss. For Kim, watching these videos became a way to feel closer to her father and to remember him. She felt proud of her father and wanted to share his achievements by posting YouTube clips of him on her Facebook platform.

Kim: I wanted to be proud of him, whereas I hadn't been proud of him when he was here. I was aware that what he'd done with his career and his life was exceptional coming from his background, but [I was] not necessarily proud. I wasn't proud. This was my moment to be proud of him, yeah, yeah. And I really did become proud of

him, the realisation that actually, well, when somebody is telling you: *Well you know what I've done? Not many people have done what I've done!* So, if someone, you know, your dad is sitting there saying it to you, you go: *Oooh Dad!* [sighs and rolls her eyes]. It's hard to be proud of them because you think: *Shut up! Showing off! Don't spoil it. We all know what you've done!*

After her father died, Kim felt that there was a big piece missing in her life. She recalls that their family home felt emptier after his death, as he had been the centre of the house, both symbolically and literally.

Kim: Oh, it was strange. Just so strange. And that's the best word for it, strange. Because he was the centre. Really. He made himself the centre and he was such a huge character that everybody knew. Just a massive, I mean, he occupied the lounge. So, it was a small house and that was his room, so the heart of the house, the lounge, was desolate. Absolutely desolate.

We'd been living upstairs, Mummy and I, for years, for years! Probably 15 years, I reckon that the set-up was like that. So, we started using the lounge, we had to start using the lounge and reclaiming that part of the house and make it, not forgetting him but [silent pause], making it feel like home to be in that space without him there. I mean, such a big force of nature has been there, since the beginning, and that's all you've known, so your whole reality just changes. Your whole landscape changes.

There was always a single bed in that lounge, and it was infamous. The whole street, you know people would think it was odd, and Mum: *Oh we can't have people around. We can't have people around. We have nowhere to sit!* That would cause me anxiety growing up actually because I'd think, well, we can't have a normal social

family with [silent pause] [a bed in the living room]... It [the family] wasn't normal anyway but if people would come around, he'd be asleep on that bed in the corner. So, he'd be there in the corner, and then the sofa here and a sofa here [outlining the space with her hands], and he'd be sleeping and snoring so loud and the chatting would carry on regardless, but it was unusual and some people just thought it was crazy! Well, it was a bit crazy. Daddy was a bit crazy so [silent pause], so he was literally part of the furniture in that room.

Adapting to The New While Still Remembering

Kim speaks about reclaiming the lounge and making it hers and her mother's, as a means of adapting to their new circumstances post-loss. Kim points out that this was not about forgetting her father. Instead, she felt that she could honour his memory, remember him and love him while at the same time move forward with her life. For Kim, it was very important to keep going, and, in doing so, her focus was on being practical. In the months after his death, Kim and her mother renovated and refurbished the living room and turned their home into what now felt like a more normal and traditional household.

As a family, they carried on in a *business as usual* [Kim's words] kind of way, while everything still felt different in the absence of Kim's father. Despite her exhaustion, she was not ready to rest. Keeping the wheels turning became Kim's way of coping with her loss, and she did not want to confront her grief. She described how the main purpose of her daily life tasks was to distract herself from her grieving. It was not a time for self-reflection and giving space to her emotions. Rather, she describes it as doing what needed to be done to get through the day.

Kim: I just got on the train of being practical, being practical, being practical, what needs to be done, what needs to be done, and that is how I operate anyway, but I think that's usual when a death occurs. People just try and be practical, practical, practical. And you just think: *What can I do, what can I do, what can I do?* Rather than looking internally. Yeah, my head wasn't ready to rest. There was no way I was going to recover at that point; it was running around. It was looking to see what was going to make me feel better, but yeah [silent pause], it was chaos. Emotional chaos.

Neither Kim, her sister, or her mother seemed to express their grieving openly within the family. Instead, Kim perceives that each family member was quietly dealing with their own sadness, and they did not talk much about his death or him as a person, or their feelings surrounding either of these. She recalls that this was how the family had always been, and it was what they did best.

Kim: We didn't sit down and talk to each other about how we were feeling, how we missed him, we didn't. None of that happened as a family, none of that. I think it might be to do with my mum is from a generation where they don't necessarily talk about their emotions, you know. Well, she definitely wasn't one to talk about her emotions. Generally you knew she was upset, either sad or angry, if she was quiet, so yeah, we just catch each other every day, making dinner and whatever, going about everyday business, and something might trigger one of us, and we'd have a little cry but no discussion, no discussion.

Facing Cancer for the Second Time

After her father's death, Kim describes how her mother kept the home running as she had always done. They seemed to have found a new routine amongst themselves and were carrying on with everyday tasks. However, a few months later, Kim's mother began to show concerning symptoms, including shortness of breath. Her mother was taken to hospital for a check-up, and the doctors decided to scan her lungs. The scans came back showing a shadow on one of her lungs.

In October 2016, 6 months after losing her father, Kim's mother was, at 72 years old, diagnosed with lung cancer. Kim recalls that receiving the news came as a shock, and there was a sense of resignation as well: of giving in to the reality of things and carrying on with the verdict. Kim had just spent 2 years living through her father's cancer, so now it was just a matter of continuing the fight: of *getting on with it* [Kim's words]. There was a difference though, Kim points out. Kim knew that her father's diagnosis was terminal, but with her mother there was still hope that a treatment could help and that her mother could be cured. This was the main reason why Kim encouraged her mother to have surgery and chemotherapy, even though she did not want any medical interventions. Kim describes how her mother was afraid and resistant, but it was Kim that persuaded her to go through with it. She recognises that her mother had the treatments for her daughters. In hindsight, Kim feels guilty about having pushed her mother like that, knowing how much her mother had to suffer through the hospital procedures.

In January 2017, Kim's mother was admitted for a few days to Barts Cancer Institute, where she underwent surgery that removed half her lung. Shortly after that, she was sent home and had to follow up with six rounds of chemotherapy. Kim, who supported her mother throughout these treatments, described her mother as being both physically and mentally

strong. She never complained and kept her spirits up, even though the treatments had worn her out and weakened her body considerably.

A few months later, around March or April 2017, the doctors did another scan and her mother's test results came back clear. This came as good news for the family. However, Kim was conscious that the cancer could return, and even though she knew her mother was strong, she could also see that she had been weakened by the fight so far and that she would not return to how she was before. Six months later, after she had been cleared of cancer, Kim's mother returned to the hospital for another scan.

Kim: I think it was another 6 months for the next scan, and they said: *Well, there is something there but we don't think it's anything sinister. [We'll] call you back in 3 months.* And we kind of looked at each other and just thought: *How can they know it's not anything sinister if they don't know what it is?* You know, but you don't [silent pause]. We'd been through so much that we just didn't want to push it. We kind of had the attitude of it will be what it will be, and we can't control this. We didn't want to go more hospital, more hospital, more hospital. It would've meant more of that, more tests. I mean, she had to have a biopsy at some point to determine if it was cancer, and they put a needle in her, about this big [showing with her hands] and long, through the ribcage into the lung, and the doctor clipped her liver when he was going in, so she had some bad experiences with the medical procedures, and even with that second shadow there [in the lung] and them saying, *Ah we don't think it's anything sinister*, she was like: *Whatever.* You know [silent pause]. She was too tired to care. But then she started losing weight and it was obvious, she was getting weaker.

Come January 2018, the doctors could now confirm that the lung cancer was back and that nothing more could be done. So began, once again, the waiting for the end. During this time, the family were tired. Whatever hope there had been for her mother's recovery was now gone, and Kim recalls experiencing a strong sense of defeat and exhaustion. Her mother was done with the treatments and hospital visits, and she was no longer interested in carrying on with the battle. Instead, Kim describes how her mother had now accepted the road she was on, carrying on with her normal routine as much as she could.

Being on The Conveyor Belt

Alongside this process, Kim described feeling disappointed with the National Health Care's (NHS) hospital system and felt that neither her mother nor her father had received proper care or respect from the doctors. Having gone through similar processes with both parents, Kim viewed the patient experience of cancer treatment in hospitals as akin to being on a conveyor belt. She attributes this to the overwhelming number of cancer patients and the lack of personalised communication from the doctors.

Kim: The whole thing of the cancer treatment, talking about the process in general and now seeing it twice from two different cases, it's just a conveyor belt, the cancer programme of treatments in [United Kingdom] hospitals. And it has to be, because they are so overwhelmed with patients.

They try to personalise it. Every time we went to see that doctor with my mum, he asked the same questions every time: *Where are you from? Where's that accent from?* And we went through the same conversation every time. That she was from Newcastle, that he [the doctor] had studied in Newcastle, and we said: *Yeah we've had this conversation before.* It didn't give you faith that they are looking at

your case individually, like a person, and I don't blame them because wow, the amount of patients that they've got [silent pause], but it is, it's a conveyor belt of processes. They just have to get you into this bit: *Okay right!*, you know, pass you over to this department, get the chemo done, come back in a few months, have a scan etc. And that's it, and it's just back and forward, and I think personally if I get diagnosed, I wouldn't want any treatment; I wouldn't want to be part of the conveyor belt, and Mummy didn't, and I didn't really respect that. I just wanted to save her at all costs. I just wanted to save her.

Although Kim was grateful for the treatment and help that her parents received through the NHS, there were nevertheless several occasions during the process where she felt that the NHS had let her parents down and had failed to provide the necessary support. Kim understood that part of this was not due to the individual doctors and nurses themselves within the NHS, but to the fact that there was a lack of resources for meeting the demand, without compromising the care of each individual patient¹¹.

It hurts Kim to think about the process her mother had to go through and how her mother experienced more physical trauma during treatment than her father had done. Her father never had to undergo surgery, whereas her mother had several interventions carried out on her body, which wore her out. Towards the end of her life, Kim's mother was in a lot of

¹¹ Kim's experience demonstrates "the tension between the intended moral and ethical purpose of care and the inevitable day-to-day difficulties of retaining that purpose at the point of care" (Goodrich & Cornwell, 2008, p. 3) in hospitals. Goodrich and Cornwell (2008) write about the industrial scale of healthcare in the United Kingdom, and how the pressure that hospitals are under has resulted in the depersonalisation of both staff and patients. Thus, the amount of interaction time between individual patients and individual members of staff has decreased, at the same time as hospitals are struggling to keep up with increased costs, and the increase in volume of activities in both planned and emergency care. Additionally, in the United Kingdom, since 2009 the NHS has suffered from a reduced budget allocation, due to the austerity measures adopted in response to the economic crisis in 2008 (Robertson et al., 2017). This, along with increasing privatisation of the NHS, has today left the NHS facing even more pressures. It is undeniable that these circumstances have had a negative knock-on effect on patients' overall hospital experience and, at times, the health of patients in need of care.

pain, yet Kim does not remember her mother ever complaining. Instead, she perceived her mother as being calm and strong. This strength seems to be interpreted by Kim as her mother's determination to carry on with life, despite the adversity she faced.

Kim continued to care for her mother, but at this stage she was so tired of everything that she wanted to get away from her mother at every opportunity. Kim recalls how she wanted her mother to fall asleep early so that she could retreat to her room and smoke marijuana to cope with her stress and anxiety. Thinking back on that time, Kim felt that she had been selfish and not compassionate enough towards her mother and her needs. The feeling of not having done enough, similar to what she had experienced with her father, was present, and she felt guilty. She also felt guilty about her own struggle and complaints about the difficult situation she was going through, while knowing that her mother was the one who was suffering the most.

Kim's Role as the Caregiver

When supporting both her parents through their illnesses, Kim did her own study and learned about her caregiving responsibilities as she went through them. She took initiative to study how the hospital system worked and to learn about her parents' illnesses and needs, to ensure that they could receive the best possible care. Kim had appointed herself the main caregiver, mainly because she wanted to be in control of the situation and because she felt that nobody else would care as much as she did. At the same time, Kim felt that she was left to her own devices in that although she had chosen to be the main caregiver, the circumstances also did not give her much of a choice. Kim describes how her sister seemed to have found it emotionally difficult to offer regular help, something which Kim does not blame her for. Kim also mentions her aunt, her mother's sister, an elderly woman who could not offer much practical help either, although she did visit often. The lack of support through

their family and social network thus left Kim alone in her caregiving responsibilities, as she became the primary caregiver. The extended period of caring for both her parents took its toll on Kim, and she describes herself as being emotionally drained, stressed and exhausted due to the heavy workload at the time.

The last couple of days before her death, Kim's mother was in a lot of pain, and Kim had trouble sourcing morphine because several pharmacies were running low on stock. Thus, in between caring for her mother at home, while her mother was suffering from intense pain, Kim describes having to drive around London, frantically looking for morphine. Kim feels angry about the fact that it was her responsibility to source the medicine herself, and she thinks this should have been provided by the NHS. At the very end, Kim's mother was made comfortable, with the help of the Macmillan nurses and herself. Her mother had been given enough morphine for the pain to subside and was now drifting in and out of consciousness. At this stage, Kim, her sister and her aunt were in the house together with a nurse. In a similar way to her father, Kim wanted her mother to feel as if she could now let go and pass away. She did not want to hold on to her mother by urging her to stay. Instead, she wanted her mother to be free. Kim's mother died at home on May 15, 2018. Her two daughters and sister were next to her as she passed.

Accepting Death as Part of Life

Kim looks at her parents' illness in the context of the global community and not in terms of an individual or an individual family. Thus, she never stopped to ask why this had happened to her parents or why it had happened to her. She did not see much point in that. Instead, she accepts that illness and death are things that can happen to anyone at any time and that everybody is going to die at some point.

Kim: It's an acceptance of we're all going to die. Yeah, yeah. And endings are hardly ever happy, you know. Yeah, I do have, I think I do have a strong sense of acceptance that we've all got to go out some way, and when it's our time it's our time. Like Mummy would say: *When your number is up, your number is up!* And also, she used to say: *Tomorrow is never guaranteed, for anyone at any time, any day.* So, you know, that philosophy was always present.

The Time Post-Loss

Alongside Kim's acceptance of the death of her parents, she experienced strong episodes of sorrow and distress. She describes how she kept this to herself and mostly coped with her pain in private, as she did not want anyone else to interfere with her process. When Kim was alone, she would cry or she would turn towards smoking marijuana.

Kim and her sister remained close in the aftermath of both losses. However, according to Kim, they have not shared much of their grieving with one another. Kim points out that although they have a very loving sibling relationship, there were times when their relationship felt – and still feels – fragile due to their loss. For example, on the day before their mother's funeral, they ended up physically fighting with each other, and Kim gave her sister a black eye. This was not a common occurrence, but it was clearly a consequence of the amount of pain and stress that the family were under during this time.

After her mother's death, Kim says that she was focused on the practicalities of things, in the same way she had gone into *practical mode* [Kim's words] during her father's illness and after his death. Kim spoke of how she wanted to keep herself distracted by organising everything, from her mother's funeral, to selling the family house, to buying her own first home, and relocating to a new town just outside London. At this stage, Kim too was the one responsible for most matters. She said that nobody else in the family would have been

able to handle such practicalities in the way she would have wanted them to be handled, so it is an experience that she feels okay with and has accepted as part of the circumstances.

Kim spoke of being close to her mother and she experiences that closeness still to this day, even though her mother is not physically present. She talks to her mother and regularly hears her voice. Kim describes how much she values her mother's strength and integrity, and this is what inspires her to carry on with life's daily tasks, despite the exhaustion and pain that came with the consecutive losses of her parents. And that seems to persist, to some degree, at the time of our interviews. When asked what Kim missed about her mother, she said:

Kim: [Laughter] The hugs that would break your neck! She was just selfless, Mummy, she was selfless, and I think she was the stability in the chaos. She was the stability in all the chaos that Daddy created. There was still security in her, even though as ill as she was.

She was solid and she'd always give you sensible advice and empower you. She would empower us: *You can do whatever you want in this life. You put your mind into it, and you know you can!* And they shared that, Mum and Dad. They shared that, they were on the same page with that. And she never looked back. She wasn't one to look back. She was the one to look forward: *That was yesterday. There is nothing you can do about it. It's gone, so forget about it and move on now* [imitating her mother]. Very practical and pragmatic. Yeah [silent pause], I mean, don't get me wrong, she could be difficult. You know, if you pissed her off, you'd get the silent treatment [laughter].

In the period directly following her parents' deaths, Kim described the mornings as the worst time. She would wake up and then the realisation would hit her that they were not around anymore. The pain would then come at her in waves, which Kim described as short and intense episodes. Kim's overarching response to her grieving was to not ruminate on her pain for too long, so she would quickly put a stop to her emotional experience and push herself to get on with whatever needed to be done practically. She admits that, in doing so, she has left a lot of stones unturned. Kim senses that there is still more that needs to come out, but she is not letting it emerge just yet. She thinks that the reason for this is that the pain is too overwhelming. Furthermore, Kim feels it is a waste of time and that her parents would not want to see her in such a sad state. Instead, she prefers to move forwards and get on with her life, while at the same time acknowledging that whatever she is carrying inside will need to be brought to the fore before it can be let go. During one of our interviews, she acknowledges that she has been running from one thing to the other, and she thinks the reason for this has to do with her still being in shock and denial over what has happened.

Kim: I've run from one thing to the other. Started a new job at a new school last September, and that didn't work out, so I dropped that, then I started doing some more private lessons, and I'm just running from one thing to the other. And then I've sold the house, and yeah the shock, I think it is still just shock and denial maybe, it's still denial. Not like I'm logically sitting here and saying: *No of course they are still here*, but it's like your mind won't let you. It won't let you feel the true pain of it, in a way.

During our final interview, Kim describes her current experience as being in a state of shock. She experiences a confusion of emotions, whereby it is difficult for her to know how exactly she is feeling. At times, she does not feel anything at all.

Kim: Sometimes you're just numb, so you don't know what you're feeling. I don't know how long this state of shock lasts, and that puts you in a place where you're not feeling much.

A year after her mother's death, many things have changed in Kim's life. She and her sister sold the family house, and thanks to the money from the house sale, Kim was able to buy her own house in a new town just outside London. She is starting afresh and she is, for the first time, living in a house that solely belongs to her. She has a garden, and she is planning to spread some of her parents' ashes there, as she recalls that one of her father's final wishes was to live in her garden.

After both her parents had died, it was the first time in years that Kim could now focus on her own life. Although there were matters that needed to be attended to as a result of her parents' deaths, this was still a time where Kim also just got to be Kim. She could be there for herself and did not need to be there for anybody else. At the same time, her parents' deaths left a big hole in her life, one that she says she fails to fill with something else that is just as meaningful. In an attempt to cope with this sense of a void in her life, Kim started a relationship with a man. Her need for human connection had grown stronger, as her parents were no longer around to provide her with a sense of comfort and love. She said that in an attempt to *fix the hole* [Kim's words], she looked elsewhere for connection in what she describes as a short-lived destructive attempt to try and cope with her loss. Kim refers to this relationship as a distraction, since she perceives it to have been a way to distract herself from the pain she was experiencing within herself. She realised early on in the relationship that the feeling of something missing in her life was still present and that it was not helpful for her to try and replace or paint over that feeling with a partner. Hence, she broke off the relationship

after a short period, as she thought that she needed to give herself grieving space, without diverting her emotions in ways she deemed destructive.

Kim pointed out that the overwhelming sorrow has lessened, and the frequency of episodes involving crying and emotional breakdowns has decreased. Yet the pain is still there, and it is when she speaks of her parents' deaths that the pain becomes more present. She says she may not cry as much, but she is experiencing what she refers to as an *existential crisis* [Kim's words], whereby she feels lost. She also speaks of experiencing a plethora of emotions, from numbness, shock, sadness and helplessness, to utter exhaustion, relief, freedom and emptiness.

When asked if her parents' deaths have led to a change in her identity, she replied that she does not think so. Her parents' deaths were life-changing events, but she does not feel as if her identity and sense of self have changed. She said that *Kim is still Kim*, even though her feelings are different and even though she is experiencing something that she had not experienced before her parents' illnesses and deaths. The changes she felt concerned the feelings she held towards her parents and people in general. Kim perceived herself to have become more understanding, compassionate and accepting.

Kim: I've gotten a bit more compassionate and more kind, all the time, all the time. Yeah, because of the way we related as a family, and there was shouting, and everyone niggling each other. That way of communication carried on even throughout the illnesses, but that's just how we communicated, because we did resent each other and get on each other's nerves [laughing]. But once they've gone [silent pause], they only did that because they were trying to do that for me, or they did that because [silent pause], you see the reasons behind things and you think: *Ok, well I need not to be so judgmental. I need to be more compassionate. I need to be kind in every*

circumstance really. Because I wish I'd been kinder at times. And maybe I'm skewed, maybe that's skewed but [silent pause], you know, there were times where I left her to watch the TV downstairs, and I'd go upstairs and wanna smoke, you know. And I said: *I'm going to bed Mum. Will you be alright? Yeah, yeah, I'll be alright* [imitating her mother's voice], and I knew she didn't really want to be on her own. I just don't think she wanted to be on her own. I don't think she wanted to be alone.

Rachel's Life History

In September 2014, Rachel received a phone call from her father informing her that her mother had died from cancer. The call came as a surprise, as Rachel had not spoken to her family for several years, and she had little contact with her parents. Rachel had left her country of birth, the United States, and moved to London, the United Kingdom, in 1985. Since then, she had only seen her parents in person on three occasions. Rachel's mother had been ill with cancer since Rachel was a child, but she kept her illness private and carried on with her life as best she could. Despite the cancer, Rachel's mother had been able to live a functional life for decades until her death in 2014. Rachel cannot recall the exact date of her mother's passing but clearly remembers the moment the death was announced and the response that followed.

Eleonora: Let's start from when you found out that your mother died and how that evolved.

Rachel: How weird, I didn't think I'd cry [laughing surprisingly with eyes tearing up]. That's revealing. I found out that my mother died when my father called to say that she had passed and asked for the codes to her bank account [laughing and drying her tears]. My father hasn't been in touch for years, but when my mother died, he got in touch right away and wanted the codes for her bank accounts. Which says a lot about my family. And I didn't have the codes. But that's not what you meant. When I found out that my mother died, the knee-jerk reaction, straight from the gut, from the heart, was relief. And I know that sounds horrible. That's not what you're supposed to feel when your mother is dying, but it was a relief because she was not a very nice woman.

Rachel's life history tells a story that depicts a painful and complicated mother-daughter relationship that was absent of love. Her account provocatively displays an eye-opening dimension of loss and grieving that can emerge in light of difficult family relationships, a dimension which has too rarely been discussed in bereavement studies. Indeed, a life story like Rachel's would perhaps, for some, be too uncomfortable to share in public. Yet, Rachel's blunt and raw testimony can be seen as a refreshing and sobering account, reminding the reader that grieving can take many forms and can occur at different times in one's life.

Rachel's life history covers aspects of her upbringing between Chicago, New Orleans and Washington D.C., and her move to London, the United Kingdom, where she sought to break free from what she perceived to be a destructive and toxic family environment. This life history covers the period leading up to her mother's death and the time leading up to our interviews in September 2019.

A Childhood out of the Ordinary

Rachel is an only child. She was born in 1964, in Chicago, the United States. Her mother, who is of Jewish descent, was born in the early 1940s [no exact date and year] in Bergen-Belsen, a Nazi concentration camp in Northern Germany. She was born shortly after her parents [Rachel's grandparents] were transferred from Auschwitz. After the Second World War, Rachel's maternal grandparents were eventually able to migrate to the United States with their daughter. As they settled into their new lives, they went on to build what Rachel refers to as a *business empire* [Rachel's words]. The wealth that the family acquired offered Rachel's mother a comfortable upbringing, and she developed into a successful businesswoman herself.

Rachel grew up in a wealthy household with servants and a full-time nanny, Vanilla, who was Rachel's primary carer during her childhood years. Vanilla got her name because she was *black as a Nilla bean* [Rachel's words]. She was one of many female African American helpers that worked as a helper for white families in the United States, reflecting a racially oppressed society and a highly segregated workforce. With hindsight, Rachel understands the sensitive position that Vanilla held within their household in that Rachel had a closer relationship with Vanilla than with her own mother. This required Vanilla to navigate her way carefully within the family system while managing her job responsibilities. At the same time, Rachel remembers Vanilla as the only person in her family who showed affection and care towards her during her childhood and teenage years, and she considers Vanilla to be the closest that she has ever had to a mother figure.

The main people in the family household were Rachel's parents and her three maternal uncles. At the time of our interviews, Rachel had not spoken to her uncles since her mother's passing in 2014, and she did not know if her father was still alive. Rachel's overriding memory of her father during her childhood is that of a distant figure. On the rare occasions that he was home, he and Rachel would sometimes spend brief moments together.

Rachel: Sometimes when my father was home, I won't say that we were close, but we had quite a fun relationship. My mother didn't allow us to eat in the kitchen. The kitchen was for servants, and we were supposed to eat in the dining room. And my father and I would stay in the kitchen at night eating ice cream, having fun knowing it would drive her crazy. We could do, I mean, it wasn't every night, but we could. I have memories of that with him. It wasn't often; it wasn't on a daily basis. It was when he was in the mood, when he was home, when he was around.

Rachel speaks of him as an absent father who was always occupied with work. In parallel with the fun moments that she occasionally shared with her father, she also spoke of him as being a *volatile tyrant* and *mafia man* [Rachel's words]. Without providing too many details, she described him as a businessman who ran multiple companies in Chicago. Rachel did not know much about what his work actually entailed, but she knew that he was in the kind of business which *tricked other people out of their money* [Rachel's words]. Rachel describes him as an unpredictable person who was unpleasant to be around because she never knew what mood he would be in or how he would end up behaving. However, Rachel points out that her father's changeable moods were not directed towards her personally. Everyone felt the brunt of his erratic behaviour. Rachel highlights that this understanding made it easier for her to accept her father's behaviour. She also views this as the primary reason why she did not miss something from that relationship. In contrast, Rachel viewed her relationship with her mother as far more complicated in nature.

Rachel perceives her mother to have been emotionally abusive throughout her whole life, and she says that this abuse was directed specifically towards her. Rachel does not recall ever feeling accepted by her mother. Although she thought that something had to be innately wrong with her mother for behaving the way she did, she never fully understood why she behaved that way. Rachel remembers that, as a child, she seldom fully understood her mother's insults. Growing up, Rachel did not perceive her mother's behaviour as mean or hurtful. If Rachel's mother called her ugly during childhood, Rachel would not see it as a bad thing at the time. Instead, Rachel would reason that being ugly is not a problem and there are other more pressing things to be concerned with. Rachel described her mother as someone who thought the image a person presented to the outside world was of great importance, with particular regards to what it meant to be a woman.

Rachel: [As a woman] You could never be too rich or too thin. This is something I've heard [from her mother]. Imagine that there are hundreds of cameras on you, all around you, every angle, and that they can see everything, so make sure everything is perfect. Literally, this is what she'd told me: *Imagine there are cameras everywhere* [imitating her mother]. I wonder why I have panic anxiety [laughter], why am I a control monster, why can't I pack light, because they're [the cameras] everywhere, and people think that what you can't see is exactly what they do see, and you only have one chance to make a first impression. *Don't laugh so loud, ladies don't, that's not very lady-like* [imitating her mother]. Women are supposed to be well-dressed, smell well, smell nicely, and look a certain way. And they are not supposed to be too smart. So, if you're smart, you're supposed to hide it. They are supposed to have a boyfriend. You're worthless if you don't have a boyfriend, you're nothing if you don't. And I never wanted a boyfriend. I liked doing my own thing. I never wanted to be tied down, which irritated her: *You're never going to find a boyfriend if you're going to act like that!* [Imitating her mother]. Divorced women were trash, nobody wants them. This is something I heard growing up before I was divorced. Divorcee — that's only for nouveau riche and actresses!

According to Rachel, these views were constantly projected onto her, and consequently she never felt accepted by her mother. Rachel perceived that, in the eyes of her mother, she was, simply put, not good enough, and she could not meet her mother's expectations. Looking back, Rachel does not consider herself to have ever fitted in or to have truly been part of her family. She recalls that she was allowed to be present with her family, but she was not allowed to be one of them. Instead, she felt like she was continuously cast aside in some way. Rachel describes how her father had always wished for a son and how her

mother was emotionally detached from her, expressing more fondness for her brothers than for her own daughter.

Rachel: Well, it was strange. She [Rachel's mother] didn't like me at all. Or I don't know how she felt. I can't say how she felt, but she acted as if she didn't like me. I was never good enough. She would always say how ugly I was. She would always prioritise her brothers [Rachel's uncles]. One was 8 years older than me and the other was 5 years older than me, so they were closer to my age than hers, and she actually preferred her brothers, which growing up like that you don't realise that it's wrong. That's just the way it is. I never felt jealous towards that. It was just the way things were, that her brothers were more important to her. She was closer to them. I mean, she had deprioritised me already then. I remember a comment once, that I hear in my head like every now and then, when I had asked her something about coming over for Christmas to see my family, and she said: *What do you mean your family?* And I would say: *Well, you know my uncles etc.* And she would say: *That's not your family, that's my family.* So, I was sort of marginalised. I was allowed to be with the family, but I wasn't embraced by the family. You know what I mean. I had the password to get in, but I wasn't allowed to be with them.

In a household where Rachel can be seen as the uninvited guest in the eyes of her family [mother, father, and uncles], one may interpret her upbringing as a lonely one. However, Rachel did not feel lonely at the time. Rachel points out that she liked spending time by herself and found it easy to withdraw from the group of family members. Although she felt as if she did not belong in the family, it did not bother her so much, at first. Indeed, this type of family dynamic was all that she knew and all that she was used to. In response to

that, she recalls having developed her own ways of navigating her family household and adapting to the behaviours of her family members.

When Normal Stopped Being Normal

As a child, Rachel tells me that she was not aware that her life and upbringing were any different from anybody else's. However, as she grew a bit older and became a teenager, a new reality began to dawn on her. Rachel recalls that when she had started boarding school at the age of 14, she began to understand that the way she was being treated by her family, particularly her mother, was not normal.

During the weekends off from boarding school, Rachel would go home to her friends' houses and see how their families functioned. When Rachel witnessed how her friends' parents were being kind and loving, and giving their children hugs and compliments, she was shocked.

Rachel: Samantha [Rachel's friend from boarding school] lived in an apartment. Her mother was out and about a lot. She sort of left the kids to take care of themselves. Samantha would ask her mum: *Mum can I borrow that skirt tonight?* [Mum replies] *Of course you can honey. Oh, you look better in it than I do actually! Why don't you just keep it?* Things like that. And wow, I mean, woooooow [laughter]. Yeah, I mean, things like that. There would be different things. These are just things that stick out in my head. There were different things like every time you went to someone's house, and it was maybe over a period of 2-3 months, maybe it was just that fall term.

Eleonora: When you had just started boarding school?

Rachel: Yeah, and you put it all together and suddenly you start thinking. You start putting together one thing to another, and you go home over Christmas break,

and you start thinking about Nilla and what's really going on here. And you're comparing her [Rachel's mother] to my friends' mothers, and then all of a sudden by spring, or the spring show, because I remember we were doing a show, and that is when I tried the attempted suicide thing, it was in the spring term. I think, by then you really had just questioned everything, and you had realised that what was real was horrible, what was nice was fake, and it really was mind-blowing.

Eleonora: You said what was nice was fake. What was that?

Rachel: Nilla. I know now that it wasn't true [that Nilla was fake], but at that time, at that moment, the nice thing was Nilla and she was fake.

Eleonora: Because it was her job and she was getting paid to be nice?

Rachel: Yeah. My father was nice, but he was also a psycho. I mean, he was a tyrant. He was only nice on certain points.

Eleonora: It was not unconditional?

Rachel: No, it was not unconditional and that's part of the reason too that when I left there was this huge fight between us because he wanted me to take over the family business and I was not interested. And that was a horrible ordeal because I think it hurt him very badly, but he was unwilling to understand it from my point of view. And I mean, we're not talking about a family business about property or a shoe store, we're talking [silent pause], we're talking things that I just don't want to do. We're talking [silent pause], I can't do those kinds of deals, I can't threaten people, I can't cheat people, I can't. I don't have that capacity. I'm not that kind of a person. I couldn't live with myself. And it wasn't because [it was] the building branch, it wasn't because [it was] the garbage branch. I don't care what branch it was in. I just can't do business like that. It was not legit and just. I don't want to do things that aren't legit. So no, I don't want to go and do deals with people and do threats.

It was a very weird situation to realise that what you have and what you've always had is just not what other people have. And it was not because what they had was better, it was just because mine was so weird that I had put up with it. I mean, it must be like children who find out that being sexually abused is not something everyone has to do, or like you know, growing up locked in a closet. When you find out that that's not normal then I think it's much worse than the actual experience itself. Why did I have to have this when everyone else doesn't have to live in a closet?

Seeing the relationships that her friends had with their parents was shocking to Rachel. She says that it made her question everything about her own family life and the relationships that she had with her parents and with Vanilla. The realisation led her to attempt suicide at the age of 15, as a way of trying to put an end to what she describes as *the pain, the weird life, the weird situation, the weird family* [Rachel's words].

Rachel: I tried to commit suicide by taking a bottle of pills with a bottle of rum, so I was incredibly hungover [laughter], and my stomach was hurting because I'd been throwing up for probably 16 hours straight, so I was in physical pain. They brought me home from boarding school, and I woke up there with no memory of how I got there, and she [Rachel's mother] said: *Well, you're going back to school today.* And I thought, please kill me instead. The hangover was probably the worst I've ever had. She said something like, I don't remember the exact words, but: *After doing something so stupid you're going back to school, and you have no right to be here. Your punishment is that you're going to have to go on and face everybody after what you've done.* And I didn't really understand because I didn't really feel embarrassed. I

didn't understand why facing people would be so bad. But I didn't understand why being ugly would be so bad either.

I don't think we [Rachel and her mother] had the same priorities. I also don't think we saw what I had done [the suicide attempt] from the same viewpoint. So, when I got to school, the principal asked me in and talked to me for a while and then realised what the problem was, and she took measures to make my life a little more pleasant. I got to take extra classes, I got to stay in school on the weekends instead of having to go home to them, so she kind of protected me from them. She was a nun [laughing]. They understand stuff [tearful].

During Rachel's teenage years and young adulthood, she began spending less time at home. Rachel did not feel the need to be with her family. She did not miss being home, and she felt happy keeping her distance. During college, whenever Rachel had a school break, she would rent a holiday house abroad, finding solace in being alone. The older Rachel got, the more she distanced herself from her family. She recalls that this brought her a sense of freedom and relief, and what seemed to be a calm confidence and contentment about going her own way.

Severing the Ties with the Family

In 1985, through an apprenticeship programme, Rachel had the opportunity to go to England for a year. Once there, she decided to marry a man, whom she refers to as *Dress Rehearsal* [Rachel's words]. Rachel's marriage with Dress Rehearsal became her chance to get a visa to stay in England permanently. After a few years of marriage, they divorced in 1988. When this happened, Rachel describes how her mother disowned her and cut her out of the family funds.

Rachel: When I got divorced, my mother totally freaked out and screamed: *What am I gonna tell my friends?* Well, I didn't understand what the problem was, but for her this was the worst thing a woman could do. At the time I thought it was social, which it probably was, but now I can think it was probably fear of herself not being able to survive without a man and projecting that fear onto me. But what she did was she hopped on the first best plane, got over to London, told Dress Rehearsal to take everything because she [mother] had paid for it anyway. *If she wants a divorce then you take everything because we've paid for it anyway, so I've decided that you should have it and not her* [imitating her mother]. And I thought: *Yeah whatever, it's just stuff, everybody just go away.*

She took Dress Rehearsal's side and then she took me to lunch, and she asked me for my credit cards because I had credit cards where the bills would go home to my parents, regular credit cards, and gas cards for the car. And she asked the waiter for a pair of scissors and she cut them all in front of my face, and it was, at risk of sounding funny, it was as though she had cut my hands off. I had never really, I mean, I had always wanted to be independent and always worked, but I could never live off of what I'd made. I mean, I was tapping into the family funds, and the first few months after that were horrible because I really had no idea what money was worth. It was a real situation of saying: *How can I be overdrawn? I still have cheques left.* So, I had to relearn how to economise and make the wages last for rent and food. It was a rude awakening for me. I was in my late twenties and it was a shock, a real shock.

I didn't regret it once. I didn't even think about: *Oh, I should've done this instead.* It was a freedom. Everything has its price, and this was the price I had to pay for freedom, and I was willing to pay this price for freedom. It was shocking. I've always had an incredible sense of humour about it. I could always see how funny it

was that a woman with my education and my background really had no understanding that I was overdrawn, although I had cheques left. But it was a freedom, and freedom is expensive, and that was a very expensive lesson to learn, but I'm glad I did it.

This meeting in the restaurant was one of the last personal encounters Rachel would ever have with her mother. Rachel remained in England where she created a life for herself. Whatever communication she had with her mother would now continue through occasional phone calls, letters, and emails. The separation from her family led Rachel to experience relief as she did not have to be part of, or have to interact with, her family as often. As time went by and Rachel grew older, she felt that she had succeeded in creating a life independent from them. She recalls gaining the strength and confidence to not tolerate her mother's abuse to the same degree as she had done while she was a child and teenager. Yet, despite this, her mother continued with her abusive behaviour, albeit from a distance, and this continued to hurt Rachel.

The Final Meeting

Following her relocation to England, Rachel returned to the United States on three occasions, in 1991, 2002 and 2012. When Rachel's maternal grandmother died in 2012, she went back to go to the funeral. This was the last time Rachel spent time with her mother in person.

Rachel: I saw her [Rachel's mother] at my grandmother's funeral the year before she died. My grandmother was over 90, and I went to Chicago to the funeral, and my mother was also there and she was very ill. She was in a wheelchair. She had rented an ambulance airplane to fly her to my grandmother's funeral, and my mother was

very vain. She was also very beautiful, even when she was ill. She had the funeral parlour painted in a very special shade of lilac purple. It sounds ugly but it wasn't, and she had a really lovely outfit made in navy blue with a scarf in the same colour as the walls, and she did it so people wouldn't see how ill she was. She was very ill, she was very thin, and she was cancer ravished, and they drove her up to the door in the wheelchair, and she got out by the door and walked to the front of the funeral parlour where the sofa was for the closest family. And it was quite the sight with her and this scarf that was the exact same colour as the wall. And she had a flare for making entrances, there was no doubt. She had incredible taste, she really did, and she looked good, and she had this outfit made to hide the fact that she was very thin because of the cancer, thinner than perhaps she ever wanted to really be, and it was quite the [interrupts herself], and we sat at the funeral and we weren't very close, and she basically said nasty things about my father and my father tried to be civil, and I was persona non grata. My uncles refused to enter the funeral parlour as long as I was there, so I said to her: *Well I think I'll go. I think everyone will be more comfortable.* And she said: *Okay, I think you're imagining things but Okay,* and I left. And I heard that as soon as I'd left all three of my uncles went into the funeral parlour, so I wasn't wrong.

The next day I phoned her from my hotel and asked her if she wanted to do something before I left because I was flying out that evening. *We could go out to a museum, and I'll push you around in the wheelchair.* But she refused to be seen in the wheelchair. She didn't say that, but I think that's what it was, and she said: *No, I don't really have time.* It was New Year's Eve the night before, after the funeral, and she didn't invite me to see her and spend the evening with her, and the next day, on New

Year's Day, I asked her if she wanted to go to the museum or something before I left that evening, and she didn't want to, so I never saw her again.

When Rachel's mother died in November 2014, Rachel decided not to go to the memorial service. Rachel did not want to face her father or uncles, and she saw little point in going to the service now that her mother was dead. Rachel did not feel a need to gain a sense of closure. Rather, this process was something that she felt she could better go through on her own. Rachel said that many people may view her decision as controversial. Yet, she did not care about the social expectations of others in this case. Instead, she thought it was important to be open and honest about the fact that one does not have to grieve someone just because they were your parent.

Breaking Social Expectations

Rachel describes the social expectations surrounding grieving as laughable. She thinks that when someone dies, people tend to idealise the dead person and forget all the bad things they did. Rachel's experience is that whenever she has spoken openly in social circles about her mother, there is an underlying expectation that people are not supposed to dislike their mothers. She seems to draw pleasure from challenging this expectation by presenting the opposite view. She is honest about the dislike she feels towards her mother, which she expresses in a comical way. Rachel feels comfortable joking about her mother's death, yet she points out that sometimes it seems to make other people uncomfortable. This does not stop Rachel from wanting to challenge existing social norms, as she says that someone needs to break the taboo of talking about death, the loss of one's mother, and the dislike one may have felt towards her.

Rachel: It seems like you're not allowed to find it funny, you're not allowed to dislike your mother, and if you do then you're supposed to keep it quiet. You can't say: *The ol' hag went up and died on me before we even had a relationship!* And they just don't [interrupts herself followed by a brief pause], I want to force them to see how that could be funny, and I want to force them to admit that perhaps they can feel a little bit like that too. Maybe not about their mother, but maybe about a sibling and a co-worker or a friend. Because I know that I'm not the only one, I know that. And I refuse to play the game and pretend that she was a saint and that I miss her because I don't. Life is supposed to be like a Pampers [a brand of baby diapers] commercial. Everyone's happy and thin, and all the babies are clean, and all are using Pampers, and that is not what it is like. Life is messy and disappointing and it's ugly and it's [interrupts herself], just deal with it!

I don't understand how you can't grieve someone who's gone even if you didn't like them. They were still shit, they were still stingy, or still nasty, but now they are gone, and that is too bad because even though they were this negative person in your life, they were still there. It was part of your life. I don't understand why we're expected to turn the deceased into a saint. Why can't we grieve somebody that we didn't like? Why can't we grieve people we know and don't like, and still not like them?

Pre-Loss Grieving Followed by Post-Loss Relief

As Rachel grew older, she became increasingly aware of her relationship with her mother and what she considers to be her mother's relentless abuse. In the process, she started to realise what she had missed out on as a child. This led Rachel to experience overwhelming feelings of loss that set in motion a grieving process, which she says continued until her

mother's death. During the time that her mother was still alive, Rachel recalls grieving the notion that she had never had a loving and accepting relationship with her mother during her childhood, as well as her inability to improve their relationship during adulthood. It was a time of pain and sorrow where she still remained hopeful that perhaps their relationship could evolve for the better somehow. This hope diminished when her mother died, and it left Rachel feeling angry and let down post-loss.

At the time of our interviews, Rachel perceived her grieving process pre-loss to have been a combination of pain, disappointment, and sadness. Alongside her grieving co-existed the hope that perhaps one day she and her mother could develop a normal and healthy relationship. Unfortunately, their relationship continued to be difficult, even towards the end of her mother's life. Rachel recalls how she was trying to engage in some form of communication with her dying mother but that her mother persisted with the patterns of abuse. Apart from some sporadic communication, her mother showed little interest in interacting with Rachel, even towards the end of her life.

Throughout her adulthood, Rachel perceived that her mother continued to discredit her life choices. Any communication that Rachel had with her mother was relentlessly abusive and caused her great sadness. Rachel describes this as living with a sense of quiet unease, in the knowledge that her mother was still around, and that Rachel could be contacted by her at any time. Knowing that her mother could suddenly appear in some way added a level of apprehensive anticipation to Rachel's life. This explains Rachel's relief when she found out that her mother had died, as it meant that she no longer had to foresee, experience, or deal with her mother's abuse. Rachel perceived that her grieving could be resolved when her mother died, and the loss helped to heal the pain that Rachel had lived with for a large part of her life.

Rachel recalls that her initial reaction to her mother's death was instant relief. Rachel perceived herself to now be free from the tension and burden that her mother had brought to her life. She recognises that she did feel initial guilt for feeling such relief since *that's not what you're supposed to feel when your mother is dying* [Rachel's words]. Yet, she seemed to quickly dismiss her guilt and instead chose to acknowledge her true feelings while ignoring the social expectations which she perceived to surround the death of a mother.

Regarding post-loss grief, Rachel only considers herself to have grieved her mother's death during the 2 days after finding out about the loss, and she insisted that this sadness was not caused by the loss of her mother. Rather, she grieved having lost the chance to have a proper relationship with her mother. She explains that after 2 days of grieving, her sadness turned into anger, while pointing out that the real grieving took place over many years during the time her mother was alive.

Rachel: The grieving I felt was throughout our relationship. It was like a scab. I was never able to fill that deep dark grey chilly anxiety-filled chasm that she had dug out in my chest with any love because she kept picking at the scab with her behaviour and the hate that she projected and the disappointment in me. So, Mum, when she died, the relief I felt was like an E.T. finger, just wiping over that hole [moves her finger across her chest] and healing it, like nobody will ever pick at it again, and that's how I feel. It sounds so horrible, but I think if it were a friend or a co-worker it would be accepted, but when it is a family member, especially your mother, people don't expect it. But I find the more people I speak to, the more feel maybe less perfect about their mothers. I don't feel we're allowed to say it, but I'm saying it because I can't face reality by lying about it.

We had quite the horrible relationship, and I just felt relief that there would be nobody there to tell me how ugly I was anymore, or how incompetent or worthless I was, and it was just like a load off my back, and I felt how everything fell off, and I felt relief, and it took not many seconds when I became really sad, and it wasn't because she was gone: it was because her death meant that we would never ever have a chance to have a normal relationship. And since I was a child, I wished that somehow, we could have a real relationship.

I think it was more a question of not being so aware of the relationship that I had with my mum as a child, but as a child I just wanted to be good enough. I wanted her to think I was good enough just because I was me. She would always point at other girls and say: *Oh look at her, she's so pretty. Her mother must be proud, unlike me. I'm not proud of you.* And I think I just wanted her to be proud of me, just because I was me.

I grieved the mother I always wanted, and when I say that [silent pause], I didn't want to go shopping with her, I didn't want to go cooking with her. I wanted her just to think I was great, not because of what I did but because I was me. Do you understand? [tearful]. Just being short and ugly and mediocre, that that would be enough for her because that was me. I didn't want to constantly have to produce something, I didn't constantly want to be over the top, I didn't want to be special, and I didn't want to work so hard. I just wanted to be me and have that be good enough.

As I got older, I realised what I had missed, and I think that's when I realised I wanted a real relationship with my mother. Being taken seriously, being accepted for the person I was, even if I wasn't the person that she had wanted as a child. I looked wrong. I mean, everything I did was wrong. So, after the initial few moments of relief

that the wicked witch was dead, I was so sad and felt so disappointed that I had lost the chance to have a real relationship with her. She took it with her.

I think I grieved for about 2 days before I got angry. I was angry with her for dying. I thought that was a really cheap and trashy thing to do, that she went up and died on me when she could have had a relationship with me! She had died without ever trying to have a real relationship. She left me knowing I would never have the chance to have one with her. And it took me about a year after she died, for me to realise that she was more helpful as my antagonist than she would have been as a loving mother. I feel grateful. I know what I don't want to be. I don't want to be like her, so I'm much more thankful for what she accomplished with me. Whether it was intentional or not I don't know. Did she do it on purpose to give me some kind of strength, or was she really just an evil person who just wanted to be mean to me because I don't know why? The why is not important.

Eleonora: What were those 2 days of grieving like for you?

Rachel: It was a lot of weeping [laughing]. I wept a lot, it sort of [interrupts herself], and I thought it was weird because I thought I was over her, so I was almost, almost embarrassed that I was so sad that she was gone. And I could, you know, walk around the house or leave the house to do something and I would just start to cry because I'd remember her, and, you know, I thought it was so weird, like why am I reacting this way? Because I thought this was over a long time ago, but after 2 days I just became angry.

Those 2 days were sad, like I didn't regret it, I didn't miss her, I didn't see her, I didn't feel like going to the States, I didn't, I wasn't longing to go back. I wasn't: *Oh, I wish she would just be alive. Oh, I wish I had made it there in time.* Nothing like that. Just like, this is over, this is sad. Somebody's gone that will never be there again.

There will never be another mail in my mailbox from her, love her or leave her, it doesn't matter. It's permanent, it's a permanent change. It's not like they're on vacation and will be home in 2 weeks, and I think that permanence is scary somehow. It wasn't love. I didn't say: *Oh, I'm so sorry*. It wasn't like that at all. It was just a very emotional 2 days of like getting used to the fact that from now on things will be different. For better or for worse, I mean, even if a person isn't very nice, it is still sad when that person is totally gone.

The Antagonistic Mother

As time passed, Rachel began to view her mother from a broader perspective. Rather than just seeing her mother as the “wicked witch”, she focused on the strength and resilience she had developed because of their relationship. This perspective grew with time, and about a year after her mother's death, Rachel was able to draw some benefit from their relationship and develop a sense of gratitude that she had not felt before.

Eleonora: Today, what does your mother's death mean to you?

Rachel: Relief. Relief [pause]. Because [laughing], no matter how ugly I am or not, it doesn't matter. Why make a big deal out of it? It's a relief that I can be who I want to be without having to hear that I'm not good enough because I don't fit into her idea. Just relief, relief in 10 different ways. Just relief. The world feels bigger and easier and brighter and I feel just so much more competent. Also, a relief at being able to say thank you for being such a horrible woman because I learned who I don't want to be. If she hadn't been so horrible then maybe I wouldn't have developed other skills that I can use now when any beauty I may have had would've been gone anyway due to age, so, thank you. I mean, the relief of actually being able to say thank you for her achieving this is something that I feel is very positive.

Rachel points out that her mother was more useful to her as an antagonist, rather than as a loving mother. Rachel considers her mother's behaviour to have made her stronger, proving to Rachel that she can deal with any hardship. According to Rachel, her mother's bullying has led her to develop different properties and skills on which she now builds her character. This view seems to have supported Rachel in healing the wounds from her past and moving on with her life. Rachel seems to have accepted the situation for what it was, is grateful for the life lessons learned, and is now moving forward, freer, and more at peace with life in the absence of her mother.

Rachel: I realise that it doesn't matter if I'm ugly — her telling me how ugly I am my entire life made me have to develop different properties. I had to study at school. I'm lucky because I'm smart, so studying was easy. I had to learn to be funny, how to entertain people, to be less sensitive about certain things. So all of her reactions to me had given me all these gifts that I probably wouldn't have had if I did have a loving mother. I wouldn't have had to develop these survival techniques, these alternative gifts or skills that pretty girls maybe don't need. And now at my age, well I've turned 29 quite a few times, I realise that even ugly girls have the beauty of youth, whereas I'm old and ugly, and I'm happy that I've developed these skills. Because even if I had been beautiful, my beauty would have been gone now, but that doesn't matter because I still make people laugh. I can still not care about things that other people get hung up about, weighed down about, what people think of what I wear, how I look or how I act — I feel happier with people around me because I don't have the weight of these surface façade materialistic things, and I have her to thank for that — oddly enough.

At the time of the interviews, Rachel had not bothered much to find out why her mother had acted the way she had. Neither did Rachel think that any explanation would justify her mother's behaviour towards her.

Rachel: I think it was just the way she is, I mean, some people are just evil. I mean, Hitler was evil. My mother wasn't Hitler, but just as an example that some people just are that way. I've always felt that there was something wrong with her. She was just a mean person. She never laughed with people. She would only laugh at them, and somehow you feel that there is something wrong here. You can't put your finger on it, but you know that friends at school laugh with each other, whereas I have never laughed with my mother. Somehow you can't put your finger on it. You just feel like there is something wrong with her. Maybe that's why it was so easy for me to ignore what she had said.

Although Rachel never felt the need to ask why her mother behaved the way she did, she still experienced the need to come to terms with her mother, a need which grew stronger after her mother's death. Rachel wanted to connect with her family history to gain a better understanding of who her mother was as a person and what had shaped her character. According to Rachel, pursuing this exploration further helped her to understand her own legacy and life purpose in the world moving forward post-loss.

Connecting with Her Family History

The death of Rachel's mother partly contributed towards Rachel reflecting on her own mortality and purpose in life. Her mother's death reminded Rachel that we are all going to die and that none of us are *getting out of this alive* [Rachel's words]. Rachel felt that her own

death was now moving closer. However, she did not attribute this feeling solely to her mother's death. It was also down to her own age. Her mother's death strengthened Rachel's desire to find out why she was here on earth and what she had to do with her life. This was further driven by Rachel's family history on her mother's side and how her maternal grandparents and mother had survived the camps during the Second World War.

Rachel felt that she was here for a specific reason. Her family had survived the Holocaust, and now she had to do something with this fact. She refers to this as a form of *survivor's guilt* [Rachel's words] that came with a sense of burden. She felt indebted to her family and to finding a way to give back to the world in exchange for them having survived the war. This contributed towards her decision to visit the concentration camp Bergen-Belsen to see what her grandparents had survived and where her mother had been born. Rachel did not go to Bergen-Belsen for her mother alone. Rather, it was also to understand her grandparents' history and to gain some answers about her own life and future path.

Rachel: What I thought at the time, a thought that reoccurred to me often was, I really wanted to see the sky from where my grandparents stood when they were there. I mean, we know what happened there, we know what that time was like, but I wanted to see what they saw. I wanted to see the sky from where they stood. I wanted to see [crying], if I could find an answer: *Why am I here? Why did they survive?* I thought that if I went there, I would find out. It was a question I have always asked since I saw the first documentary films on television when I was a kid about the camps and my grandmother telling me about them, and I always wondered why our family survived and why I am here. I always felt there was a reason that I had some sort of a [silent pause], I had to pay back, I owed something. That sounds like I think I'm special. I

don't, I just [silent pause], I don't think you have a family who survives that and that you don't think that you owe back. You owe.

Like, my family didn't survive just for no reason at all. I mean, I'm here, so I have to do something. I have a quest, I have something I need to do. And as I got older, I started to panic because I didn't know what it is. There is a term for it, it is called survivor's guilt. And it is a burden, but I think some people find it sort of, *Who do you think you are? You're not special*, but you feel that way. And I wanted to go. I wanted to see if I could find the answer. Because as I got older, I was starting to panic knowing, I say knowing even though it was a feeling that was knowing, I had a job to do to pay back. And not knowing what it is, I was thinking this is really bad because I don't know what it is, and finally the desperation of basically screaming out into the night, *I'll do anything you want! Just tell me what it is and I'll do it because I don't know what it is*. So, I thought maybe going to Bergen-Belsen, standing where my grandparents stood and looking at the sky from that particular place on earth [interrupts herself]. I don't know why that was so important to me, but I just felt there was some kind of an answer there. I think it was more a question to find the answer to what my job is, what am I supposed to do to say: *Thank you*.

Eleonora: And you said you found the answer?

Rachel: Yeah, I did.

Eleonora: Are you open to sharing it?

Rachel: Of course, I am. Why not. There was an exhibition there at the time, and this is a really weird thing because I'm the kind of person who, I mean, I'm my mother's daughter, and I'm also a control monster in the sense that when I go somewhere I do all the research I can, I find out what exhibitions are there, what restaurants, so I really plan my time so every minute is full, and I know what

restaurant is close to the museum after I see that exhibition, and then I go to the next, and I really sort of, put it all in there. I probably get more out of 3 days somewhere than most people do out of 2 weeks.

When I went to Bergen-Belsen, I spent a lot of time researching how to get there from Hamburg. I didn't want to stay in Hannover. I wanted to stay in Hamburg where I felt more at home. A lot of time went into researching bus schedules, train schedules and getting there, weather, and to be honest, I had not thought of finding out if there were any exhibitions at the camp or what they were. And this for me is very odd because like I said, I can't walk out the door without knowing what exhibition and restaurants and everything is nearby, and here all I did was get train schedules and download apps to buy tickets. And it was really weird because I got there and there was an exhibition about children that grew up in the camp, and it just blows my mind because I had been to Auschwitz in '94, '93 or '94, I don't remember, and it just took such a toll on me, and it took all these years to go back until 2018, and what are the chances that when you finally get there, there is an exhibition¹² about children who grew up in this camp, and that's what my mother did. It just blew my mind, and it turns out that they have exhibitions all the time, and it was just this particular one when I was there. I could've gone a year earlier, and I would've missed it. I could've gone 3 months later, and I would've missed it [crying while speaking]. It was interesting because they had all these stations that you could go where they talked about food, and they looked up all these survivors, all over the world, these children that were taken to the camp — or like my mother — born at the camp, and they found them all over the world and they interviewed them on different subjects like food.

¹² The travelling exhibition is called 'Children in the Bergen-Belsen Concentration Camp' (Bergen-Belsen Stiftung, 2020).

What was the food like and how did you get food, and they told about the hunger and toys, what were the toys like? *Ah we didn't have toys, we took mud*, all these different aspects and every single aspect they always came back to the same thing: helping each other. The food part, they said: *We didn't have a lot of food, but my mother would save the bread rations which were very small, and, She would break up half and she would save half in a piece of paper, and those halves were hard and they were mouldy, but she would save it as somebody else might need it more.* And they said that some women gave birth in the camps, and those small hard mouldy pieces of bread were probably the difference between them surviving and not [crying]. I realised that my grandmother was one of those who had perhaps been given one of these hard-mouldy rations, and it just hit me that this is my job.

I've always helped people, no matter how. I mean, I've always been there for people. I've always tried to help. I've always felt like I should do more. I mean, I can't help everybody, but I wish I could — I should do more, and I was out there hearing this, and I realised that I've been doing all along what I'm supposed to be doing. I'm helping people. It's just that I don't need to worry about helping everybody, and I don't need to worry about doing a lot [crying]. It's just that little piece that can make all the difference. So, to understand, it was so much easier to go there [Bergen-Belsen] because there was the relief that: *Oh my God, not only am I doing the right thing but I don't have to worry about not doing enough. It's just that little piece of bread that can be the difference.* So, the smallest thing you can do for somebody, just give them a smile and you might change their day. Give them a smile and they might not try to commit suicide when they're 15. It's just that little gesture, that little thing, that can be a lot. So, it took me that long to figure that one out [laugh]. I had to go to Bergen-Belsen. But now we know [smiling].

Rachel's trip to Bergen-Belsen can be seen to highlight the part that Rachel now plays in her family legacy. Her mother was the child that was born in the camp, and Rachel now perceives herself to be the one whose role it is to carry on doing something to pay back for her mother and maternal grandparents' survival. Recognising that legacy was a way for Rachel to find her role in a family that had never given her a place to exist within the family structure.

Rachel: She gave me life and I have to continue doing what I do. So yes, it was part of closure, maybe not so much only with my mother but also my entire family. I mean, with a family like that [laughter], maybe you put things more into perspective when you visit a part of their beginning, or a step of their beginning.

Rania's Life History

Rania Jayasinghe is of Sri Lankan origin and was born in London, the United Kingdom, in 1981. Her mother and father were first generation immigrants to the United Kingdom who arrived in England through Germany. Rania was raised in London by both parents and remained connected to her Sri Lankan heritage and its cultural customs while also identifying herself as a Londoner. In early 2016, Rania's father was diagnosed with dementia, which had a life-changing impact on the whole family. Rania, her mother, and sister took it upon themselves to care for him. Almost 3 years after falling ill, on November 8, 2018, he died from a stroke. Rania was 37 years old at the time.

Rania's life history gives insight into the lived experience of caregiving for a family member with dementia and demonstrates some of the challenges that can come with this responsibility. Her life history aims to capture and represent some of her experience of caring for her father until his death, and the unconditional love that seemed to carry her, her mother and sister, through the difficult years of caretaking. It further offers insights into Rania's grieving process both pre- and post-loss, as well as her adaptation to life without her father, which followed in the first year after his death.

Brief Childhood and Family Background

Rania's father, Wilfried, was a first-generation immigrant who migrated from Sri Lanka to Germany and later from Germany to London. Rania describes how her father came from a poor working-class family and that he travelled alone to Europe in search of job opportunities and a better life. She speaks of him with much awe as she narrates his achievement of moving from Sri Lanka and arriving in Germany with only 20 cents in his pocket, and later running his own business while co-raising two daughters with his wife in London, the United Kingdom.

Growing up, Rania had a close relationship with her family and her father in particular. She perceives herself as a *Daddy's girl* [Rania's words] and recalls the deep affection that they both shared for each other. As Rania grew into adulthood, she remained close to her father, and despite the ups and downs that the family experienced over time, they always looked out for each other, persistently stayed together, and did what they could to help each other. According to Rania, putting the family first had always been a non-negotiable priority for all immediate family members.

A Sudden Unexpected Change

Rania describes herself as a woman who loves to travel and explore different countries and their cultures. From 2014 to 2016, she used her life savings to go travelling around the world, a trip that involved inviting her father to meet her in India at the end of March 2016. Together they were going to embark on what she calls a *sacred pilgrimage* [Rania's words]. However, their plan took an unexpected turn.

Rania: In 2014 I decided to go travelling, so I took all my savings and went on this trip around the world. And about a year and a half later, I invited my father to join me in India. And while I was in India on the very first day that he landed, on the very first night, someone came to me in the middle of the night, woke me up and said: *Your father is walking outside without his shirt, and he looks very confused.* And I was like: *What?* And we were in a Buddhist monastery in Northern India, doing a sacred pilgrimage — we are Buddhists — and I came out and he was just standing there without his shirt, in his pyjamas, barefoot, walking around, and I just sort of went: *What is going on?* And he just went: *Where are we? Where are we?* I think I'll never forget that moment in my life because I've never physically experienced anything like

that. I had this cold shiver run down my back of acute fear because I realised immediately that he'd lost his mind, you know, and I immediately knew: *We have a huge problem here.*

It was very, very stressful, and I was absolutely baffled because he went from normal dad to [silent pause], he just wasn't there anymore. His personality changed, he wouldn't talk, he was constantly irritated, and I had no idea what was going on. While we were together, he had lots of incontinence issues. In the middle of the night, he would try and make it to the bathroom and not make it. He slipped on his urine, he hit his head, I was in the ambulance with him. Like all this was happening the first 3 weeks of, like this experience of [silent pause], you know, we came back to the UK and it took 6 months for us to get a specialist diagnosis that he had dementia. They couldn't give us a full diagnosis because he had like a haemorrhage in his brain, so the brain scans wouldn't show us what he had.

Rania went from having what she perceived to be a healthy father, whom she had expected to be travelling around India with, to now being faced with a very different situation. She decided to immediately cancel their travel plans and brought her father back home to London to ensure that he would receive the necessary medical care. In a short space of time, Rania's world, as she knew it, was about to change.

Wilfried's sudden illness brought major changes to the family, which came with a new set of responsibilities for Rania, her mother and sister. As they adapted to care for his health, increasing pressures were experienced in the family's daily life. The shared workload between Rania's mother, sister and herself required both time and physical effort. Rania describes this as an intense period for everybody involved that put significant strain on her relationship with her sister and mother. They all lived together in the same house, and at

times Rania would experience the home environment as abusive and toxic, which seemed to inflame an already stressful and difficult situation. She describes some of her own experiences and the tasks involved when caring for her father:

Rania: So, he went from a guy who was disoriented, didn't know where he was, with sporadic incontinence issues, to very quickly lots of incontinence issues. Then suddenly, first urine, he couldn't even, you know, go to the bathroom to do a poo. You know we would be somewhere, and he would be standing in the living room like, shitting on the floor. Excuse my language, but you're kind of going: *What is happening here?* Then he lost all his social ability. The visible things were that he couldn't remember how to dress himself, like he'd come downstairs wearing his undershirt over his shirt, you know. He suddenly couldn't remember how to put on his socks. You know, we'd be in the car and I would be like: *Where are your socks?* He'd walk out the door without his shoes, and he just [silent pause], slowly, slowly began just fading away. I remembered he grabbed my hand when we were going to cross the street one day, and it really threw me, because I used to grab his hand for safety, but he grabbed my hand for safety. He was afraid to cross the road himself, and that for me, that was like the first moment, everything changed, like, I'm in charge of my father now.

For us, the most traumatic thing was knowing there was absolutely nothing we could do for him. All we could do was to keep him clean, keep him safe. Keeping him safe became the most stressful aspect of the entire caregiving journey because people with dementia, they just like, want to break out of the house, they switch on stoves, they spill milk and then slip on it and hit their head, they're constantly falling down the stairs. I was in an ambulance, on average, twice a month. We were always in

ambulances, we were always calling the emergency numbers. They were all on our redial button, you know. And I'll never forget, about a few months in, in the emergency room, the consultants and the doctors and even the paramedics would be like: *Oh are you a doctor?* Because of the way I was able to relay all the necessary information. Like I'd be like: *Oh I've re-checked his blood pressure and blahblahblah and this,* and I would like rattle down this list of data that they needed for their assessments, and we became these highly vigilant self-medically trained people looking after a 70-kilogram man who would break out of the house, and the neighbours would find him on the street. One time he completely disappeared, and we had to call the police. It was just very, very, very, very stressful. And it was my mum, my sister and me, three of us, so let's split that up into 8 hours each, 8 hours a day, you're in charge of someone. That's a lot.

In the end we were feeding him. He couldn't remember how to pick up a spoon anymore, you know, we had, buying a wheelchair became [silent pause], I was like completely overwhelmed by this. I never had to buy a wheelchair in my life, and I suddenly needed it very urgently, and I just didn't know how to do this, you know, and you kind of start googling it, and you end up ordering this wheelchair off Amazon, and you don't really know if it's the right thing but you're like: *This just needs to work now. I just need to get him from A to B, and I can't carry him.* The physicality of the caregiving was exhausting. I mean, I had back problems because I constantly kept pulling my back because I was lifting my father and trying to, you know, it's very physical, he's constantly falling on the floor, you're lifting him from the bed to the chair.

Navigating Social Relationships and Cultural Differences

Rania would at times experience stark cultural differences within her social environment in London. Rania is of Sri Lankan origin, and, although she identifies herself as a Londoner, having been born and raised in London, her family, in particular her parents, very much relate to and live by Sri Lankan culture. Rania describes her Sri Lankan family background as the core of her values and motivation to take care of her parents. She also views this as one of the key reasons that she, her sister, and her mother, together chose not to send Wilfried to a care home, since they wanted to care for him themselves. These choices were something they, as a family, agreed upon and stood by firmly.

However, Rania described how many people seemed unable to relate to this type of family arrangement. Additionally, Rania pointed out that none of her friends and colleagues had experience in caring for a parent with dementia, which added to the lack of understanding she felt, nor did Rania feel that she received the support that she needed. Caring for her father had a significant impact on Rania's social relationships outside her family. She recalls having to constantly cancel meetups with friends, and her professional work was compromised due to her not being able to perform to the best of her ability. She recalls that there were only five friends whom she received support from. Although this deepened her relationship with these five, it also put a big strain on her other relationships, with some people not appearing by her side at all.

Rania further described the social aspect as a double-edged sword, with some people offering moral support but at the same time not knowing how to be practically supportive. There were also people who seemed to question the family's choices and to tell them that they were doing the wrong thing by not having a professional caregiver. Rania perceived that these comments came from a place of ignorance, from people who had no experience in the matter. Such comments added to the feelings of not being understood or supported

constructively. Yet Rania, her sister and mother, remained persistent in being the main caretakers for Wilfried, despite the challenges that came with it.

Rania: My entire life fell apart. I actually got a job quite quickly after I came back [from travelling in India], a very high-powered job in the investment industry, very stressful, and I ended up getting fired over performance issues. They were like: *You're not doing your job well.* So, the strain of all this impacted everything. I mean, the worst thing for me was financially, I'd gone on a sabbatical with a view of returning and having a little bit of money, you know looking for a job, but I kind of had a little safety budget, but because I had lost my job, I ended up financially running out of money, you know, and I mean, it was sort of like, things just couldn't get any worse. I had to then borrow money off people who knew me well, who knew that I was very educated and highly skilled and very capable of paying them back, which I did in a matter of 2 months, but the thing is the social [interrupts herself], the shame of all this, there was a lot of, sort of, it was very difficult to articulate to people what was happening because there was the emotional strain of it, being psychologically overwhelmed by it. But you know [silent pause], I kind of managed to get out of bed, put on my make-up and to go out on the street and look like a normal, professional, middle-class, educated person, so I think people just couldn't understand that we were imploding in the family.

I mean, everything was a negotiation, like if I wanted to go and see a friend for dinner, I would need to talk to two people, you know. I needed to check in with my sister and I needed to check with my mother and like: *Who is feeding Dad for dinner?* Because I would like to go to Camden and hang out with my friends. So, I would go and make those plans, and then I would be ready to walk out the door, and then

suddenly something would happen. You know, my father would fall, or my sister would be stuck in traffic, or something could happen. I mean, if he fell and hit his head, I would then have to call the ambulance, you know. I had people who just disappeared because they just couldn't understand why I was just cancelling them at the last minute. They couldn't understand just [interrupts herself], I mean, it's like being a young mother with a child except that people don't kind of understand. They see more of the young mother, they see them pushing them outside in the pram. You don't actually see a lot of adults pushing their parents in wheelchairs. I realise that the elderlies are hidden away, they are hidden away in these care homes, and I think, we in our family, we just refuse to participate in that kind of lifestyle for our father.

I think, for me the biggest shock was that I knew no one in my peer group who had experienced the same, and it was the most socially isolating experience of my life. I think that the lack of social awareness around that is, it's an incredible thing [silent pause], I mean, I lost a lot of my friendships over this. There was a lot of onus on me to explain to them what was happening, and it was like I had to tell people how to support me, like I had to put in all the work. People just had zero experience and awareness. I mean, I'm 38 years old now; I was 36 when it started. Most people still have their parents at that time. The other problem was that people would say: *Oh I really understand, my grandmother has dementia*. And I would be like: *Actually, you actually don't understand. You have zero, like, responsibility to look after your grandparents; your parents are doing that for you*. And as Londoners, most people's families are not here. Most people's families are in like Russia, Italy or Spain, and they are far away. It's like you're here running your life, and someone at home is doing the caregiving and the strain and the responsibility, and that's fine but I'm just saying: *You don't understand what we're going through*, you know [laughter].

I think besides from the fact of what was happening to my father, I was horrified that other people, even older people, like you know, my boss, had no experience of this because they didn't have that relationship to their parents. Even in the last few years I realise I don't really meet a lot of people who are that close to their parents. They think of caregiving as something that you outsource and that you get professionals to do, whereas for us it was emotionally and spiritually absolutely non-negotiable. I'm ethnically Sri Lankan and our culture is to care for our parents, and neither employers nor my friends understood what I was trying to do, which was basically to journey with him. It was non-negotiable. We were going to all his appointments. I was in the middle of work meetings, and I would get a phone call from like some consultant neurosurgeon, right, and I would, just like, run out of the meeting to take the call because of course, you know, I have to go along with the NHS schedule, right? And it was, I mean, it was just absolutely horrific.

We only got professional carers for him in the last 4 months of his life. We spent 2 years and 6 months every single day dealing with the diapers, showering him, shaving him, brushing his teeth, putting on his socks, making sure he was warm enough, you know, changing the diaper again. Eventually we got some carers to help us with the hygiene. So, they would come in the mornings, help clean him up and so on, and that went on for 4 months until one night, in his sleep, I was actually away when it happened, and that was actually a blessing and I have no regrets about that at all, but one night he just died in his sleep. He closed his eyes, and he had a stroke and he died. He was found in the morning, not by my mother luckily. The carer came in, and it was the carer who touched his leg and realised he got cold. And he, you know, we're very grateful that there wasn't like a hospice, we're really grateful that his disease didn't drag on for 20 years, which can also happen, but he, he recognised us

until the end, even if he didn't know our names, even if he couldn't speak anymore and, yeah, he had a very peaceful death.

Post-Loss Challenges and Obligations

Rania finds it difficult to remember much from the first 2 months following her father's death. She recalls the exhaustion and distress wrought by her father's death and considers it to be a significant part of her grieving. She was sleeping 16 to 18 hours a day and describes herself as being *paralysed with grief* [Rania's words]. She experienced a pain in her heart and chest, and she could hardly find the energy to participate in any activities. It was a time of emotional and physical struggle with strong grief responses, which simultaneously led to further self-discovery and healing. Gradually she got her energy back and she returned to work, practised yoga, and began to participate in social activities, albeit to a minimum. However, in March and April 2019, Rania began to experience anxiety, heart palpitations, and difficulties breathing. She would wake up in the morning covered in sweat and her heart was pounding intensely. Her performance at work also began to get compromised because of her declining mental and physical health. After experiencing what she called an emotional meltdown, she realised that she needed to seek professional help. Thanks to her private medical insurance, she was able to receive expert medical care from the Priory Hospital in London. She was diagnosed with Complex Grief and Post-traumatic stress disorder and took part in a series of treatments including EMDR (Eye Movement Desensitization and Reprocessing) and bio-acoustic therapy, which quickly had a positive impact on her physical and psychological well-being.

Rania perceives her father's deterioration and death as a traumatic experience that got locked in her body. As she began what she referred to as her *healing process* [Rania's words], she was adamant that she would do the best she could to take care of herself. She explored

various healing modalities such as yoga and meditation, massage therapy, and psychiatric interventions. She also sought out support from bereavement groups, which she found helpful, as it provided a space where she could speak with and relate to other bereaved people. It enabled her to navigate her own feelings in relation to other grievors and to see that she was not alone in her struggle. Rania's perception is that going through death and grief can be a lonely experience, as it is something that is not talked about socially. However, she felt that bereavement groups and death cafés¹³ can help to normalise the process of speaking about death and can offer support to people in need.

In July of the same year, Rania's physical and mental health gained in strength. At the time of our interviews, she acknowledged that she was still in a process of adapting to this new period in her life. She was still grieving, although she said it expressed itself differently from before. For Rania, it was a matter of constantly navigating her grieving process and its continuous developments. Although the acute distress that she was experiencing shortly after her father's death had subsided, there were times where she was triggered by a memory or a piece of music that she associated with him, and then suddenly burst into tears.

In addition to their grieving, there existed practical obligations and a lot of decision-making that the family had to address. Rania describes this as frustrating and difficult to cope with; yet, it had to be done. For example, it took the family 6 weeks before they could have the funeral. This was a lengthy process because they had difficulty with getting the paperwork sorted. More so, as Wilfried had died at home, additional procedures needed to be carried out to rule out any suspicious circumstances. Rania describes it as a stressful period and one that required the family to learn as they went along, since none of them had experienced a death and burial in London before. There were multiple bureaucratic and

¹³ Death Cafés are held on a non-profit basis. They exist all around the United Kingdom, serving as places that offer no-agenda group discussions around death. The concept was created by Jon Underwood in 2010 and has spread widely around Europe, North America and Australasia (Death Café, n.d.).

logistic hoops to get through that they had not expected, nor had they ever encountered before.

Rania: I completely fell apart, unable to deal with anything. My sister had to have some very strange conversations where the coroner called her and was almost questioning her: *Do you suspect any suspicious circumstances?* And my sister was like: *No, no. My mother didn't kill him, I didn't kill him. Like, you just need to sign this piece of paper so we can do the funeral.* So, she just had to have those conversations and then we had a funeral date booked, then this was cancelled by the coroner who decided my father's body needed a post-mortem, and then I had that additional layer of thinking about my father's body being cut into. You just kind of go, oh my God you know, this is not what I want, but you don't have a choice in this.

Eleonora: And also, that you feel as if you're being questioned, it's almost as if someone is [searching for words]

Rania: Accusing you.

Eleonora: Yeah, accusing you of something.

Rania: Yeah, and we had just been through two and a half years of caregiving and loving and you know, spiritual service [laughter], and then you're at this point now.

Eleonora: How did that make you feel?

Rania: Well, you're just [silent pause], it feels like [silent pause] some kind of an existential injustice. You kind of go, life just isn't fair. Life isn't fair at times. You're suddenly talking to strangers who you've never met before who are in the death profession, and you're just another family that they have to deal with, and no they are not empathetic, because you're like the tenth conversation they've had that

day about another dead body. You're in the middle of the worst experience of your life and they are just doing their job, and you just kind of have to sit there and contextualise the whole thing.

From a cultural perspective, organising a funeral in London, the United Kingdom, was perceived as an unfamiliar and conflicting experience for Rania and her family. As Sri Lankan Buddhists, they were used to the Buddhist rituals of death and funerals in Sri Lanka. However, there was little chance that they could arrange a Sri Lankan funeral in London, since the cultural differences in funeral practices were too far apart from what the circumstances could allow. Rania describes the process of organising the funeral in London as being far more formal, bureaucratic, and emotionally detached than what she was used to from the Buddhist funeral rituals in Sri Lanka. These rituals, which extend over a number of days, normally involve cremating the body, chanting verses about impermanence, and offering a white cloth that is stitched into monastic robes during the funeral ceremony. A week after the ceremony, monks come to the house to offer a sermon, while 3 months after, an alms-giving ceremony takes place. This was a stark contrast to the circumstances in London whereby the family had to adapt to a culture and to values that were different from their own in the context of funeral rituals. One situation that describes this quite well is when Rania speaks about the food for the funeral.

Rania: There was a lot of I guess, westerners running funeral type businesses telling us how things are done, and because we're in the UK and we're like: *Well I don't know how this is done, and no, this is not what we want.* And then you're looking at menus of sandwiches and my mother goes: *We don't eat sandwiches. We eat Sri Lankan food.*

For Rania and her family, the funeral became a negotiation between incorporating the Buddhist funeral traditions of Sri Lanka, with which they had an ethnic, cultural and emotional bond, while overlapping these with practices that reflected their role as citizens of the United Kingdom and residents of London. The funeral was able to affirm their cultural history to a certain degree while interweaving it with the westernised approach that was dominant in London, the United Kingdom. Although this was at times frustrating for the family, they seemed able to find a middle ground that worked for them.

According to Rania, the social obligations and financial demands of the funeral and wake were also a source of stress. Rania experienced conflicting emotions, in the sense that while finding meaning in the ceremonial honouring of her father's life, she also had to face the obligations that came with that, such as playing the role of the host and making sure that, together with her sister and mother, the event ran smoothly.

Rania: My father's funeral was a source of great cultural confusion and stress and pressure and financial burden. I mean, the ritual of it, yeah, very, very important, but in terms of saying goodbye, because my father had been ill for so many years. I'd been doing that for almost 3 years, of saying goodbye to him, so to me the actual day of the funeral was kind of like: *Okay this is a social obligation. There is a body here that we need to cremate, and it needs to be done in a certain way.* What was really hard for me was that, as an ethnic Sri Lankan in London, we had no guidance on how to do this. Like, how do you have a Sri Lankan funeral in the middle of London? And any funeral traditions I knew of were funerals that I had attended in Sri Lanka.

I mean, in Sri Lankan culture, the tradition is that when someone dies, first of all the body is embalmed and then returns to the home, and then the home is opened up. And then there is an announcement. Like it's very, very public. People basically

print posters of the dead person, and they just hang these posters all across town, so that absolutely freakin' everyone knows that this person has died. Then the culture is that the community has a duty to show up, to show their face to the families, and the family are expected to shake hands with literally 400 people walking through the door. They hand out white flags, they decorate the house in this huge display, so even if you didn't see the poster, you would go past and know someone has just died there, you know. And because it's so public, going to a funeral is like a weekly thing. People kind of do it, just all the time. And it kind of softens the whole thing and the invisibility and tragedy is like totally diffused, and caterers show up, they cook food in the back of the house of the dead body, so the dead body is in the living room, but you're not allowed to cook in the house. They set up marquees, and then there's like people cooking food and serving food, and folding chairs are laid out and it's almost like a wedding, and this goes on for 3 days and all these people show up, and it's like a big social event. And then you kind of chitchat and gossip, and it's not like people sit there quietly. There're kids running around and it's just like: *Okay another one has gone*. And I think, for me, because that was my only experience of family funerals, having to do this on my own here [in London] without all of that, was very difficult. Because I, I guess, I didn't, I don't generally identify myself with Sri Lankan culture, but I guess I didn't have any other funeral teaching, or learning, other than my grandmother's funeral, my uncle's funeral, my aunt's funeral, my cousin's funeral. I didn't really know how to go to, you know, Morley Crematorium in West London. I just didn't know any of this; I just didn't have any training or exposure.

The whole Sri Lankan community experience, you know, you're never left on your own. It's actually forbidden to leave the body on its own and the bereaved on their own. So, the body is there for 3 days, and then it's taken and cremated. The body

is carried by family members through the town, to the cremation site, and a member of the family lights the fire, you know, but then for actually 7 days since the person died, all the windows and the doors of the house are kept open, and people are there to guard the house, so friends would just volunteer to hang out in the living room with all the doors and windows open, and this is a tropical country, so it's warm and wouldn't be feasible in the west, but this is the tradition. So, for 24 hours, for 7 days, the lights are on, and people just kind of congregate in the living room, they hang out, they just talk and yeah, that's what you do.

Now this is not what happened, you know. It's like my father died in the living room, and like the ambulance is called, the police show up, the coroner shows up. I mean, I wasn't there for all of this, my sister dealt with all this, and then my father's body was just taken away, and we were not even given access. You're not even allowed to go and see the body when you want to. You have to wait for paperwork to take place, and this is, you know, that was really hard to suddenly have someone tell you that the body belongs to the government of the UK, you know. It's like: *What do you mean? That's not your dad, that's my dad*, you know.

It was all just sort of a big, big blur that happened very quickly, and then before you knew it, it's time to [interrupts herself], the coffin is then, it's almost like shoved through this little window and then everyone moves away, and then we have to go to the back of the chapel, and then there is this big freakin' oven, and I mean, that is just [silent pause], I still have that image very strongly in my mind, like of these people shoving a coffin with my father's body into this burning machine. And there were issues with the temperature. They couldn't get the oven hot enough, and there was a delay, and we were all standing there like: *Oh my God*. Like this is so dumb. Now we have to sit around here waiting and then boom, they just shoved this

thing on and I can't even [interrupts herself], to this day I keep thinking, from the way they shoved the coffin, my father's body, like his head must've hit the top of the coffin, you know. I don't know how the bodies are. I don't really remember the inside of the coffin, if it's like secured in or, and you just think: *Okay wow, this is so weird*, in comparison to a Sri Lankan funeral where the body lays and then there is a funeral fire, and you circle it. It's far more gentle in a way, you circle it with the family, and then a member of the family lights the fire, and you sit there and watch it happen. You really have to sit there and watch it happen, and actually the tradition is that you must return and go look at the ashes, and there will be pieces of bone in there and stuff, and you're supposed to go and do that, and really confront the fact that this is over. That this body has been let go, it's been burned, that this is what is left, and you sit there, and you really healthily really sit there and process this. Here it's kind of like: *Oh ok*, all of this is so [silent pause], it felt really formal and detached and the relationship to the body was very detached. I mean, again, in our culture, you go there and like, the same night you see the ashes, and you can do what you want with them: you can bury them, you can leave them there, or whatever. Here it's like: *Oh no you have to book an appointment and then you go and collect them*, and that itself became a very weird thing. There was like this other layer of like this whole process that we have to wait around for, you know.

Developing Continuing Bonds

Rania: Something I learned, I really liked this definition of grief, it said: *Grief is love with nowhere to go*, and I think this is very accurate, you know. That is really the problem that you just love something or someone, and you have a relationship with it, but you don't really know where to go with it anymore because it no longer exists. I

have to accept that that will go nowhere, it will never go anywhere. This one relationship, you know, is irreplaceable, so [silent pause], yeah.

Despite this sense of having nowhere to send her love and that her relationship with her father, as she knew it, no longer exists, Rania still talks about how her father remains present in her life, albeit in a different way. At the time of our interviews, she describes how she still talks to him and perceives him as being with her during parts of her day. She further sees similarities between what she does and what her father used to do while he was alive, thus forming a certain symbolic connection.

Rania: I remember my sister, 3 or 4 months ago, she happened to be here in the house, and I remember the way she looked at me because I switched off the lights and I said, *Okay goodnight Dad*, and I went upstairs, and she just looked at me like [silent pause], *You're saying goodnight to Dad?*, and I said, *Oh yeah, I'm sorry I do that every night* [laughter]. You know, I'm sorry it's just what I do. I say goodnight today. I kind of still acknowledge that he was still part of my day. I mean, I was thinking of him and yeah, I mean, he's not alive anymore, but this is what I do. I switch this button here and I turn off the lights and I say goodnight to him.

I made a beautiful lunch for my mother, and I just kind of like laughed and went: *Everything in this dish, is my father!* Like all his skills that he taught me, just by cooking for me. I mean, he didn't sit there and say: *Here's how you cut the carrots in this beautiful way*. I just learned it because that's how he fed me, you know. And I kind of went: *I wonder if she can see that, I wonder if she sees that, I wonder if she can taste my father in this dish*, you know. So, it's just little things like this.

Rania's grieving process also included reflecting upon her previous and current life expectations, and whether those had now changed, or were in a process of changing, post-loss. She assessed previous expectations, assumptions and dreams that involved her father and re-organised these in a world where he was no longer present in the same way as before. Rania gives an example of this, where she includes her father as part of her future life plans, albeit in a different way.

Rania: I always thought my father would walk me down the aisle when I get married, you know, and we're talking about decades and decades of like social programming and conditioning and seeing films and bridal magazines, and that's just what you do. That's what your dad does, but then, okay, I'm 38, I didn't get married. I hope I do still, but my dad is not going to be there, and then I have to just sit there with that and kind of, mourn the loss of that, and then I actually just want to talk to someone about it, and I said to my sister: *You know, I was thinking like when I get married one day, I would just have a picture of Dad, and I'd like to carry a picture of Dad when I walk down the aisle.* And she said: *What? This is such a weird thing to think about!* And I said: *Well, no, I lost something. I lost the fact of that ever happening, and I kind of want to have a plan, you know.* And as soon as I know that this is what I'm going to do, I don't want to sit there going: *Oh this is missing, this is missing,* like, no, no, no. I'll get a nice picture of him, and then I'll have my beautiful white dress, and I'll just walk down the aisle with my dad's picture because I want him to be a part of it in a way.

Grieving During the Pre-Loss Period

Rania describes her grieving as an excruciatingly painful experience that she experiences individually, and at times it is also shared with her sister and mother. She perceives grieving to be about radical acceptance and a practice of detachment from ideas about the future; a source of liberation that put other aspects of her life into perspective. Furthermore, the grieving process for Rania was not something that solely occurred after her father's death. Rania says it began from the day that he got ill, and she witnessed his health deteriorate over the course of two and a half years.

Rania: I began grieving from the point of that night [in India]. I immediately realised something irreversible was happening. I knew, I knew straight away that this is something I can't fix, and then, you spend two and a half years of your life in pre-bereavement. So, your father is gone but he's still alive, you know. I mean, it [the pre-bereavement grieving period] was almost worse. I mean, now I can just wake up and grieve. Before, I would wake up and [would be] sobbing and changing his diapers and brushing his teeth.

Rania distinguishes between the grieving process from pre- to post-loss. She points out that since the external circumstances were different during each of these periods, they affected her grieving in variable ways. Rania points out that the grieving that took place pre-loss, when she was seeing her father deteriorate, was tougher at times than when her father was no longer alive, in the sense that the external circumstances and responsibilities made it a burden that was extra heavy to carry. Her pre-loss grieving encompassed grieving the deterioration of her father, losing the father she knew, and the life she knew and was used to.

Simultaneously, Rania further recalls having to juggle the responsibility of caring for her father, along with her own emotional distress and exhaustion while he was alive.

Although the caregiving came with great challenges, it remained a significant and valuable period for Rania. Rania perceived her caregiving responsibilities as a form of spiritual service, whereby she could journey with her father through his illness and show him love, care, and appreciation in the midst of her own grief. Rania also used this time to honour who her father had once been, what his past interests were, and the activities that they used to do together, by integrating these aspects into her care for him. She describes this as a way of replicating his life, which did not always come without its challenges. Nevertheless, it was something the family was adamant about.

Rania: We very adamantly replicated his entire life, and I mean, there is a tremendous poetry to that because you know, he couldn't remember what he wanted to eat, he couldn't remember what beer he wanted to drink or what he would be wearing to a certain event, but we did, you know. And we'd keep dressing him, and we'd take him to the pub until the last month of his life, and he couldn't have alcohol but I'd get him a non-alcoholic beer, and I knew it made him happy. It was socially very awkward, because you're pushing a wheelchair into a pub. Some pubs don't even have the ramp to get up the stairs. I had to leave my father outside in a wheelchair on the street, run inside and say: *You need to put a ramp outside right now because I need to put this wheelchair in.* And then there's a lot of commotion. It draws a lot of attention, but, I was committed to saying: *No Dad, it's Saturday night and we're gonna have a beer because that's who you are.* And so, there's like a lot of this where we in the family were, I feel, really breaking social boundaries. You know, we took him to restaurants. My sister once was asked to leave with him because he

was incontinent and I don't know what happened with the diaper but he, you know, he peed on the floor of the restaurant and they asked him to leave, you know, and it's like, it's all this kind of stuff.

The time pre-loss was also an opportunity for Rania to seek closure and to say goodbye to her father.

Rania: I think my process has actually been quite healthy and balanced because, you know, I spent months, if not every night, before my father went to sleep, like holding him and you know, especially when he could no longer speak, I would just curl up in bed and rock him to sleep, and I would just be crying into his shoulder, and I would just say goodbye, you know, quietly, and I had a very, very long time of doing this, and I kind of physically decided to hold him, you know, and cradle him and thank him, and I guess, mark his departure because I knew it was inevitable. The fact that I wasn't there the moment he died, there is no problem for me with that, because I said my goodbyes, and even when he was still able to comprehend words at the very beginning of his disease, I sat with him and I thanked him for his life's work. So for me the period of pre-bereavement, as undignifying as it was, I mean, I was wiping my dad's bum and dealing with his dirty diapers, and I had like shit in my hands, in my hair, you know. I mean, this is, this is, I mean, all these boundaries are completely breached. You see your father naked, you see his genitals, you see all this stuff that you don't think you need to ever face right, and even though all of that was happening, I do know that I am very, very fortunate that I have had the time to live a pre-bereavement.

Although Rania experienced many losses of her father during the pre-loss period, she did not feel as if she had completely lost him to dementia, as the love they shared for each other was still there.

Rania: The love, you know, stayed all the way to the end. I mean, I'm absolutely convinced that even to the last day, he probably didn't know I was his daughter anymore, but he knew I was someone he loved.

The grieving that Rania experienced before and directly following her father's death, with the demands that each of these periods entailed, began to change once all the urgent practical matters had been somewhat resolved and a bit of time had passed since his death. Rania speaks of a sense of heaviness that weighed her down during the pre-loss period and in the weeks following her father's death but highlights that this gradually started to lift, making her feel lighter again. During our interviews, 10 months after her father has died, she recognises that she feels much better, yet she does not know what the future is going to be like and how her grieving will evolve. She is not expecting it to stop hurting, yet she believes that the hurt is part of life and that everything moves in cycles.

Sophie's Life History

Between the years 2017 and 2019, Sophie lost both of her parents. Her mother died of cancer on February 1, 2017, and her father died of a sudden heart attack on March 25, 2019. At the time of our interviews, Sophie speaks of her loss as an ongoing and life-changing experience. She describes these losses as being present in her life on a daily basis, and they continue to impact her in both emotional and practical ways.

Sophie describes her response to the loss of each of her parents as very distinct, differing in terms of how each of her parents died and how Sophie experienced and grieved each respective loss. Sophie attributes her distinctive grieving processes to how different her relationship was with each parent and relates this to her parents' own upbringing and historical past. She also relates this to the different personalities and roles that her parents had in the family, including the roles they each had in her life.

What follows is a representation of a part of Sophie's life story about having lost both her parents during adulthood and the impact this has had, and continues to have, on her life. Sophie shares some of her family history, the relationship she had with her parents, and her perception of how different yet connected each loss experience has been for her.

Brief Childhood and Family Background

Sophie was born in London in 1961, into a family of Jewish origin. She grew up with her mother, father, and two younger sisters. Sophie's maternal grandmother was Jewish and born in East London, as was Sophie's mother. Her maternal grandfather was a Russian Jew who left Russia in 1917 or 1918 (the exact year is unclear for Sophie). He came to England and settled in East London, which was known for its strongly developed Jewish community at the time.

As Sophie continued to share more about her family history during our interviews, the focus moved primarily towards her father. Sophie's father, who was 3 years old at the time, arrived as a Jewish refugee with his mother, from Berlin, Germany to London, the United Kingdom in September 1939, at the beginning of the Second World War. Sophie's paternal grandfather was taken and held at the concentration camp, Sachsenhausen, north of Berlin. Through the help of his wife, Sophie's paternal grandfather was able to eventually get out of Sachsenhausen. He joined his family in England where they were taken to the Isle of Man and, like many Jewish refugees fleeing Nazi Germany, were kept imprisoned as enemy aliens for most of the war in internment camps under the supervision of both military and civilian personnel.

Sophie: My [paternal] grandmother managed to get him out and to England, which was some feat at that time. How? Because you had to have not only an exit visa from Germany. You had to have an invitation to work in order to be allowed out. And for whatever reason they managed to get an invite from somewhere in England. You had to be able to speak English. My [paternal] grandfather spoke English, so that is how he managed to get out.

Now I obviously, you know, didn't quite realise how close the war was still to my [paternal] grandmother. I mean, she lost her sister at Auschwitz, and she never ever got over it. I still get upset [crying], because all she did was cry to me. So, you know, growing up, my father was obsessed basically. I've still got boxes, I've got one box left of his Holocaust books, and yeah, the war, you know, people survive, physically, but somehow don't survive mentally, even if they survive, you know. I mean, relatively, they had quite an easy time because they were in England, you know, '39-45, they were aliens. They were called enemy aliens, so they were put on

the Isle of Man. Germans were taken from England and put on the Isle of Man, so they spent most of the war on the Isle of Man, '39-45.

I mean, he [Sophie's father] was three and a half, but I just often think, he spent the first 3 years of his life in Nazi Germany. By then, the National Socialists were quite prevalent. There were banners everywhere, they couldn't go to school, they couldn't have radios, they couldn't have pets, they weren't allowed to sit in a park on a park bench, they had to wear a badge. He's got *Jew* stamped on his passport, and they had to change their names.

Eleonora: What was it like for you to grow up with your parents coming from that history?

Sophie: It was quite difficult in terms of, my mum was quite [silent pause], I wouldn't say she was materialistic, but she definitely enjoyed, you know, she always called it window shopping. Someone would say it was a bit more than that [laughing]. She definitely enjoyed it, whereas my father was very scared of spending money his whole life. Money got them out of Germany. Not only did you have to have all the papers, but you had to bribe everyone to let you through. So, it was luck, papers, tenacity, and money. So, you know, he definitely had that chutzpah about life; you didn't listen to rules. If somebody told you to go left, you go right, and don't listen to anyone! So that kind of came through to all of us. To a lesser or greater extent.

We were always told, and that was quite hard as a child, how lucky we were. That was the expression all the time: *We're so lucky. You don't know how lucky you are!* And of course, compared to him and his circumstances, you know, when they came to England, they'd come from Germany. My [paternal] grandmother being this successful musician, she'd lived with her brother and her sister in this lovely block of flats in Berlin and come to London and got nothing, and you can't speak the language.

She [paternal grandmother] didn't want to be here, she didn't want to go back to Germany, she never went to Israel. She wanted to be back in the Germany that she knew, but it wasn't there anymore, so it was very hard for people to adapt.

The Father-Daughter Relationship

When remembering her father, Sophie describes him as a tormented soul who was larger than life. She points out that his family history had had a strong impact on him and shaped him to be the person she knew him to be. She describes him as a hyperactive, social and adventurous man who, in the opinion of Sophie, should not have got married or have had children. However, Sophie recognises that it was the status quo at the time and therefore the natural thing to do at a young age. According to Sophie, being married with children tied him down, which in turn seemed to cause him a lot of frustration. He wanted his freedom and having a family negated that possibility. Although Sophie remembers her father as a loyal family man, he did not seem happy in his role. His anger was frequently taken out on the family, especially on Sophie. She describes her relationship with him as complicated and very argumentative. It carried with it, and still does, many unresolved issues from the past.

Sophie: He was always like: *If it weren't for you, I would be driving around in a Volkswagen.* He had this mad thing. I don't know why it had to be a Beetle van.

Maybe those were the things you aspired to then, going in a Volkswagen van driving around Europe. You know: *If it weren't for you!* He was always tied, and that was it.

He was very loyal, always, always, very loyal, but he was a tormented soul. What can I say, he was a tormented soul.

Eleonora: What was it like for you to hear those things?

Sophie: I didn't feel lucky, and he was very physically violent with me. Very physically violent. So, I didn't feel lucky at all. And I'd spend as much as I could at a friend's house, but I was very protective of my mum. Very close, very protective.

Eleonora: Was he physically violent with your mum as well?

Sophie: No, but I think, because I stood up to him a lot, I think that came [silent], who knows. As far as I know, he wasn't. But his worldview, which he kept to the day he died was: *The world is wrong. I am right.* So, you can't move with that because there is nothing wrong for him to move with. It's everyone else that needs to change.

It was very difficult. So, Francis [Sophie's older sister] left, and Edith, my youngest sister, fought back. I never fought back, and she [Edith] always said afterwards: *Why didn't you fight him?* So she fought back, and that stopped him in his tracks, somehow. Maybe he realised that you shouldn't be hitting a kid this way. Anyway, so that was, you know, growing up felt very hard. When my father was home it was argumentative, that was the thing. The abuse took place in my bedroom. I'd leave the kitchen. There had been some crazy arguments, and I'd leave the kitchen and go to the bedroom. My mum never crossed the kitchen threshold, okay, and there really was this kitchen threshold. She never crossed the kitchen threshold. And in therapy I got very upset about why didn't she save me?

Eleonora: When you crossed the threshold and went into your room, what happened?

Sophie: I just got hit, a lot. But I, you know that thing that's come up now: fight, flight and freeze. I'm a freeze. I freeze. I did speak to him. I did try to speak to him about it, but the thing is, as I said, I kept a lot of anger with him. I think I was very hard on him my whole life. I didn't let him get away with anything.

The Pain of Not Being Able to Set Things Right

At the time of the interview, Sophie described feeling hurt about the relationship that she had had with her father. It seemed that her father's death was the loss of an opportunity to resolve past issues and to make amends with him. Her grieving seemed to include the pain of their complicated relationship, the unanswered questions she wanted to have asked him while he was alive, and the inability to set things right before his death.

Sophie: I'm left with all the could've, would've, should've with him. The questions I didn't ask [crying], the conversations I couldn't have, and that is harder in a way than with my mum. I miss him less because we had such a difficult relationship but the fact that I never got through to him. You know, my other sister, she was his buddy. They were friends and they went out and did what friends do. But I never had that with him. It was just a completely different relationship and very argumentative. Both of us jumped when the other one spoke. We just kind of misunderstood each other all the time. I was always on his case. I didn't let him get away with a thing. Well, I did, that's kind of why I [silent pause]. It's so connected with my childhood relationship, which was terrible. So, as an adult, when you have that, it continues because it never got sorted. It never got addressed because I didn't speak to him for 2 years in my early thirties, and after that we spoke once and had a really honest conversation. But after that it was kind of like: *Oh well, we've had that, we've moved on, it's all fine.* You know, some things just don't go away. Also, we didn't see him [just before and after his death]. I didn't get to say goodbye.

The Avoidance and Unexpected Nature of Death

Sophie experienced her father's death as unexpected. Rationally, Sophie could understand why he died when he did due to his old age and poor health. Yet, his death still took the family by surprise for several reasons. After Sophie's mother had died in 2017, Sophie's father had moved into a home for older adults, where he was rebuilding his life anew. He was discovering new friendships and hobbies and participating in various activities that he had not shown much interest in before. He was also in the initial stages of planning for his second Bar Mitzvah, a Jewish ritual that is carried out again in later age if a man, who had a Bar Mitzvah when he was 13, reaches 83 years old. His focus was on celebrating life and planning a big party for his upcoming birthday.

Sophie recalls that he never wanted to speak to anyone in the family about death, as he was fearful of dying. More so, his unwillingness to speak about dying meant that the family avoided the topic altogether. Death was not something to consider at the time, and this is one of the reasons why his passing took Sophie and the rest of the family by surprise.

Sophie: His very sudden death took me unexpectedly, even though he was in a wheelchair full-time, he had diabetes, and had been injecting himself for 20 years but took absolutely no notice of, you know [silent pause]. He kind of adjusted his medication according to what he wanted to eat. It's a ridiculous approach, but he lived with it for a long time. He wasn't able to breathe without oxygen, so he was incredibly sick. But when you spoke to him, you didn't think he was a sick person. He was a larger-than-life character, and he kind of defied the fact that he was going to die.

So, he'd gotten to this ridiculous flying club with his carer to go up a glider, because my dad loved gliding and none of us would do it; none of us are thrill junkies.

But he kept saying: *It's not a thrill*. He said: *It's not*. He said: *It's peaceful*. He said, *It's like scuba diving*. But [silent pause], he took his carer for his carer's birthday. His carer couldn't say no [laughter]. He [her father] went out on a high. You know, this is a man who loved natural highs.

Sophie's father had a heart attack at the gliding club during his excursion, and he died immediately. Sophie received the news through a phone call coming through from her father's phone. When she picked up the phone, expecting her father to be on the other end of the line, it was the police informing her that her father was dead.

A Grieving Experience with Several Dimensions

Sophie's grieving experience after losing her father had several dimensions. One dimension was experiencing the loss of a person whom she loved. Although they did not have a close loving father-daughter relationship, Sophie still loved and cared for her father. Sophie spoke of how strange it felt to her when one day her father was there and the next day he was not. Another dimension of her grief seemed to be the regret she felt for how their relationship was and for what could have been different. Sophie perceived there to be a lack of closure with her father, in that she never got to say goodbye to him. She also realised that the problems in their relationship were left unresolved. This lack of closure came with a sense of regret and aggravated the sorrow that Sophie felt after her father's loss.

Sophie: I think on that level it's that thing of, yeah, I've got no regrets with regards to my mum. I've got one but not many, but with my dad I've just got loads. I've been in therapy for years, off and on, and I still haven't managed to change that relationship

with my dad too much. So, it goes, it's the way sometimes. You can want things, but you just can't quite direct it.

Sophie did not get to see her father before his death, and the feeling of not having said a proper goodbye seemed to have left Sophie feeling that an opportunity had been lost and that she hadn't done enough.

Sophie: I'd come back [from Greece] on the Saturday. So, I spoke to him on the Saturday. It was somebody's birthday on Sunday. I was going to see him on the Monday, but I was given some stupid government meeting, so I didn't see him on the Monday. I was going to see him on the Tuesday. So, I did something else on the Monday, and he died on the Monday. So, I've got this terrible kind of sequence of events of going back: *Could've seen him, but went to somebody's friend's stepmum's birthday. Didn't see him on the Monday because [of] this government meeting that I was supposed to have, and then Tuesday he had gone.* I keep replaying what I didn't do. That's what I'm left with.

The Mechanical Aspects of Loss

After the death of Sophie's father, there were practicalities that needed to be dealt with and decisions that needed to be made within the family. For example, the father's funeral required quite a lot of organisation. Sophie and her sisters were required to juggle bureaucratic paperwork, communications with the coroner, and organising the Jewish rituals for the funeral. At the same time, Sophie describes how her grieving, along with the added pressure and stress of these practical matters, made this an increasingly difficult time. Sophie points out that she and her sisters were ill-prepared for dealing with the experience. They did

not know what to expect, nor were they aware of what it entailed until they were in the middle of having to deal with it all.

Sophie: It was one of those you had to get y before x, but we only had it the other way around, and it was quite difficult because obviously everyone's in a bit of shock and a bit of mourning, and it felt harder. All the hoops and especially the thing about the burial and timing and also because the coroner won't give you the timing. You are allowed to say for religious purposes what you need, but they don't have to do it. And that was quite stressful because we wanted to book, and you can't book until you've got the coroner's report. So, for me, because I do like to know a few things, it was like, you know, it was completely unknown, and then suddenly you get the coroner's report, and it says, the burial ground just allots you a time: *Oh, it's 11:30 a.m. tomorrow*. And suddenly you have to tell everyone who you think want to come that it's going to be 11 o'clock, so you've got to be quick.

And then there is the organisation of the funeral, the prayers, who is going to do the prayers. You know, it was like, there were lots of decisions to be made, how many nights are we going to say prayers for. It's supposed to be 7. Some people do a day. We went to 3. I wasn't able to think and yet we had to make some decisions, you know like the first night of prayers, like that was really weird because you know the synagogue which he belonged to, they just decide people to, if you can't get a rabbi because if the rabbi is out doing a wedding, then somebody will volunteer. But the person who volunteered [laughing], he was reading as if he was racing news, and when he left, we kind of, me and both of my sisters, kind of looked at each other and said: *Uh no, we can't do that again. We've got to find somebody better*. So, we were scrambling for a rabbi whom one of us had met before.

After the funeral had been completed, Sophie and her sisters had to address another task. Their father owned a lot of assets, which they had to decide how to manage. Sophie referred to this as the *mechanical aspect* [Sophie's words] of death, which concerned solving practical issues such as their father's probate, belongings, and the will. These tasks seemed to become a heavy load of practical responsibilities that the daughters had to carry, in addition to their emotional distress. This was no easy task. Sophie and her sisters were responsible for their father's probate, assets, and business, and they needed to resolve these matters quite urgently. At the same time, they had to manage their emotional distress and other responsibilities and obligations in their personal lives.

The Connectedness of Her Parents' Lives and Deaths

Sophie's narrative of the death of her father was often interwoven with the loss of her mother. She would sometimes compare their different death experiences and the relationships she had with each parent. Sophie spoke of them as separate individuals, yet her narratives would often include her parents in relation to each other or in relation to herself. As we began our interviews, I asked Sophie which parent she would like to talk about first. She responded:

Sophie: I think once I talk about one, it will connect to the other because they were married for 58 years. So, my whole experience of being was with them when they were together. So, it kind of connects because they have connected in life and they have connected in death.

What becomes evident in Sophie's life story is that her experience of losing her mother was significantly distinct from the loss of her father. She speaks of the circumstantial and relational differences that seemed to have had a major influence on how she experienced

their deaths. In contrast to her relationship with her father, Sophie shared a strong emotional bond with her mother, whom she considered to be her primary attachment figure. They shared a loving and supportive mother-daughter relationship, and they felt a closeness with each other that Sophie did not perceive to have had with her father.

Sophie: I was very close to my mum. Especially I suppose the last 20 years, I felt very close to her. I mean, we talked. I didn't go around. I saw them once a week, if not twice. It was hard when I was working full-time and I was travelling so much. It was quite hard. But I would always when I was in London, once a week, sometimes twice, but I'd spoke to my mum a lot. She gave such good advice; she was very measured, and she could see other people's point of view very easily.

She [her mother] was so sweet. She was so sweet [starts crying]. A really nice lady. I don't know, I think, you know, I spoke to her a bit about why she stayed with him. We didn't really talk about stuff [silent pause]. She said he was exciting. He wasn't the run-of-the-mill man that she got to meet. He had a lot of, as they say, *vavavoom*. He had a great sense of humour, and he didn't see the world as we were brought up to see it, from his own experiences, but resulting in, as I said, his lack of respect for authorities was, it was a good lesson really, it was a good lesson.

The fact that he was very loyal every time she got ill, and she got ill every 10 years, and that's hard, and I think economically she felt very dependent on him. He was very, I think he reduced what she contributed to the household in terms of love, and also she was a great cook and a great entertainer, you know. The dinner parties that they had, it was all the time, all the time. She was the carer. And I think she tried desperately to care for him in his crazy [ways], with his demons, because they [the

demons] were huge and overwhelming. And that's the thing, he was so troubled. It's such a shame. He never managed to reflect on them [the demons].

Sophie's mother had lived through cancer several times during her lifetime. When speaking of her mother, Sophie gives the impression that she is in great awe of her mother's strength, quiet determination, and humility, in getting through these life challenges.

Sophie: So, she had breast cancer three times. My mum had breast cancer at 33, and so they just removed her breast. They didn't do reconstruction, nothing. It was severe. It was a really severe operation.

The second time she got breast cancer, they just had the lump removed. It was so stupid. They just take the lump out literally and give you chemo. Then she got breast cancer again, so they took the whole thing, and by then she was 60, so she said: *I'm not going to get them done.* And then she had ovarian cancer, and let me tell you, she was unbelievable.

Francis [Sophie's sister] is friends with a woman who was a nurse on the ward that my mum was in, and she said that everyone wanted to be her nurse [crying]. She [mother] really was a really nice person, the only thing she did do. She was lovely to everyone's face and that was the thing, as well. She was lovely to everyone's face and she was very, she always used to, you know, my mum was conservative, and she did like tablecloth and napkins and you know, everything. My grandma used to say there is a right way and a wrong way, and she did it the right way. English 1950s, think the housewife, perfection. We always used to call my mum Jane Austen. She was always on the phone, I mean, literally, always on the phone to people, making arrangements, like. I mean, her diary, it really was a dance card, you know: *My dance card is full!*

[laughter]. She really was, and she kept it up. She kept up all the social things, which I think at times were quite hard for her.

I think she, you know, I know now unfortunately lots of people who've had cancer diagnoses and the way, it's so interesting the way different people take them and deal with it or not, or how it changes your life. I think for my mum, it made her want to live fuller, more, yeah; she didn't dwell. She didn't say: *Why me?* She said, *Why not me?* Which is a very different approach. So, then she got ovarian cancer, and again managed to survive very well after it. By then they diagnosed her with this BRCA 1 gene, which I got tested for and Francis got tested for, and we didn't have it thankfully. Edith, my other sister has it.

At 80, she got diagnosed with pancreatic cancer, which is a real hard one to get over. They did offer her this operation, called the Whipple operation, which is an 8-hour operation, and we had a huge family powwow about: *Is she gonna have it? Is she not gonna have it?* I've never thought she'd want it at 80. I just didn't, because the chances of you actually going through the operation aren't great. She said she wanted it, and that was it.

Sophie's mother had a successful operation and was able to continue with her everyday life. She returned home from the hospital and lived with her husband for another 15 months before her health began deteriorating once again. Around the same time, the health of Sophie's father was subsiding. Two of the three sisters, Sophie and Francis, came together to help care for their parents, a stressful time that involved much back and forth between hospital visits. The third sister, Edith, was in the United States, where she is a resident.

Sophie: Come January [2017], it must've been around January the 3rd, she [her mother] was booked to have tests in a private hospital because the National Health was just not coming through, but she wasn't due to go in for a week. But I went around to see them, my parents, and I called up Francis [sister], and I said you've got to come now. You've got to get in a car and take her to the hospital. Doesn't matter if she's booked in or not. She's not well. So, we went to that hospital and then an oncologist came and said: *Look, I haven't done tests, but I think it could be [silent]. Do you want to go?* [silent]. And it's you know, you're told like, she was with my sister, and she was told at 10 o'clock at night: *There is no point in you staying in this hospital. We can't treat you if you've got cancer here. Do you want to go to this other private hospital, or do you want to go to Edgware hospital?* Which was Barnet, miles away. And they made the decision to go to Barnet for whatever reason. I don't think any outcome would've been different. So, she went to Barnet. Meanwhile, my dad got ill again and was in the Royal Free [hospital]. So, we were working out which hospital to go to when. It was horrible and for them [their mother and father] to be that far away from each other, and my dad couldn't see her. So, it was absolutely terrible, absolutely terrible.

That went on for a few weeks [silent pause], and the day, one of the days when she was in the private hospital, that was the day, because Edith [sister in the United States] had said, you know: *If you ever need to call me to come over, you just call.* And I phoned up, and I said: *I think I'm saying it.* It was horrible making that call [crying]: *I think I'm saying you've gotta come over.* She [her mother] hadn't been diagnosed yet, and Edith, she said in fact, that day my father and Francis had called her to say to her to come over, so I wasn't the only one.

She [her mother] was completely lucid then. She was completely okay. But she was just very fragile and very frail. And in Barnet hospital, I mean, for no fault of their own, it took them 3 days to admit her. So, for 3 days she was on A&E on some side [silent pause], you know. It was just horrible. And then when she was in the hospital itself, it was much better than the Royal Free. It was cleaner but still lack of staff, so real basic needs, which for my mum was so humiliating, you know. They didn't change [silent pause], those basic things, and left her for hours when she needed to be changed for her hygiene. When she had needed to go to the toilet, she couldn't go to the toilet of course so they had her in nappies, whatever they call them for old people. And for my mum, when you know, the dignity is gone, that's the problem. And there, that's when they gave the diagnosis in that hospital. Pancreatic cancer, it was back.

So, she wanted to go to a hospice. Yeah, and if we'd have known it, because there were 3 weeks between her going to this private hospital and then finding out [that the pancreatic cancer had returned] in Barnet and if we had known earlier, we would have just gone to the hospice. It would've been so much better. Because they schlepped her on trollies with this test and the other test, and it was just exhausting. Some of it was humiliating; it was just horrible. All that stuff with the body and what they are testing and ramming up inside you, and you know, it's not pleasant but we didn't know.

So as soon as she knew [that the pancreatic cancer had returned], and she asked for it [to be brought to a hospice], there were another 3 weeks in the hospice, which were very, very tough. But they admitted my father there as well, so he was in the hospice with her. Oh God, and they had them on a ward together at that time, because they didn't have other people coming in, so they had the two of them in this

ward for six, and that was incredible, that really was incredible. The hospice was unbelievably fantastic, fantastic. They had pets coming around – dog therapy, they had a drinks cabinet, the woman next door was taking cannabis. They didn't care, they didn't care. They said if it soothes you, if it's good for you, then have it. What's the difference? You're gonna die. What are they gonna do? You know. They did everything they could to accommodate you in that time, which was really nice, and the fact that they brought my dad in, he was there, and then he stayed for a couple of days after she died as well.

He [her father] didn't go in the last few days, he didn't go in, he couldn't. She hadn't eaten for 2 weeks, and she was just breathing, she was just there breathing. It was her, it was still her. No, he couldn't face it. He went in, when she died, he came in. We all read the prayer for the dead that you read, and then he left. That was enough for him. Which was, that was fair, it was his wife for 58 years, you know, through good and bad. I think there was a lot of love there. I don't think they got on. I think things could've been [silent pause], you always think could've, would've, should've. Yeah, they didn't get on very well, but there was a lot of love, and he was very loyal. So, my mum's death was completely different to my father's, as different as they were. Actually, as different as the two of them were as people, and that was quite interesting.

The Different Responses to Her Parents' Deaths

Eleonora: If I've understood it right, it was a difference in how you responded to each of their deaths?

Sophie: Yes, I mean, my mum I just, well, yeah I mean, it was different because I just loved my mum unconditionally, whereas I loved my dad with huge

conditions, and [it was] a very troubled relationship. I mean, I was very lucky that my last conversation with him was good because one out of three definitely wasn't. I miss my dad as well, because you know, in Jewish family you have so much contact, so it's very hard not just to pick up the phone. I don't miss a lot of the ways he was with me. I miss him but not a lot of how difficult it was, whereas with my mum I just miss talking to her, and being with her, and having her advice on things. I still went to her for advice. I miss her advice. I miss her company. I miss her. But it's the nature of the beast, isn't it? Death. It really is.

Sophie's mother died of cancer on February 1, 2017. She had been diagnosed with different kinds of cancer approximately every 10 years from the age of 33. Sophie describes this as having brought the feeling of being on *borrowed time* [Sophie's words] with her mother. Despite this, Sophie had thought that her mother was going to outlive her father, and so when her mother died first, she recalls having initially experienced a lot of resentment towards her father for still being alive. This resentment seemed to be a part of her grieving experience for the first year after her mother's death. As Sophie's mother had died, her father was now reinventing his life and starting over again. Sophie perceives this as being a difficult contrast to come to terms with. Yet, in hindsight, she now thinks that it was perhaps for the best that things turned out the way they did. The gap between her mother's and father's deaths provided Sophie with the space and time to grieve her mother in a way that she does not think she would have been able to, if her father had died first. Sophie pointed out that there were not as many practical responsibilities following her mother's death, apart from having to manage her mother's material possessions. In that sense, sorting out practical matters was quite a straightforward process, which allowed Sophie the time to grieve her mother's loss. In contrast, the aftermath of her father's death turned out to be far more

complicated and time-consuming, and so Sophie feels relieved that she did not have to live through that while her mother was still alive.

The Tectonic Plates Have Shifted

Sophie described that in the Jewish religion, as the chief mourner, you are not supposed to have any celebration for a whole year after the person's death. Additionally, at the end of that year, the headstone of the person who has died is supposed to be erected. During the time of our interviews, Sophie and her sisters were in the process of writing up the inscription for their father's headstone, and seeing as their parents are now buried together, they will arrange one big headstone for both of them. Sophie describes this as a strange realisation whereby it is not just one or the other, but it is both of her parents who are dead. When I asked Sophie what it is like to not have her parents around in person anymore, she described it in the following way:

Sophie: Before this conversation, I was thinking, how do I describe the change, and a friend of mine, her father passed, and she said for her it was like the planets had realigned. But for me, oh God I don't know if I'm going to be able to do this [crying]. It's like the tectonic plates have shifted, so everything that I thought I knew is not so. I'm not down the rabbit hole. I was for a while. I felt I really was down the rabbit hole. I'm not down the rabbit hole, but the world, well of course it's a different world.

The changes that Sophie experienced in relation to her parents' deaths can be perceived as both external and internal. At the time of our interviews, Sophie still seemed to be navigating through and adapting to the changes that resulted from losing her parents. The external changes can be perceived as circumstantial and relational. An example of a

circumstantial change is that Sophie is not able to contact, call or visit her parents when she feels like it. She seems to have adapted to this by finding other ways of connecting with them, i.e. through visiting physical locations that she associates with them, such as joining a synagogue, visiting their graves, or going to places where they have shared memories together as a family. These actions can be perceived as a way of maintaining a comforting connection with her deceased parents.

Sophie: I think going to the places that they used to go to. If I go to Regent's Park, you know, go through the rose bushes, the rose garden, you know certain things like that. If I do things that I would've spoken to them about, like my dad collected art and my mum studied it and liked it on a more kind of thinking level rather than emotional. But I went to this exhibition on Leonardo da Vinci's drawings, they were amazing, 200 drawings, and then afterwards it was like, you know those connections: *they would've liked*, you know. I would've gotten the kettle on for them, all of those kinds of ongoing scenarios that aren't there.

After the loss of her father, adapting to the circumstantial changes wrought by loss involved a new set of responsibilities that required having to deal with her father's probate, selling real estate, and organising assets. As described earlier, Sophie referred to these activities as the *mechanical aspects* of death. These practical tasks and responsibilities continued to be present even up to almost a year after his death, which made it seem for Sophie that her father was still around. Dealing with the father's probate was described as a testing time for Sophie, in terms of her relationship with her sisters, in particular her youngest sister. Sophie perceives that all three of them are processing the situation differently, and they have been required to compromise to reach mutual decisions about how to resolve particular

situations. According to Sophie, this has not been a smooth process, and at the time of our interviews she tells of how the relationship with her youngest sister has faltered. Thus, the changes that have resulted from the loss seem to have also been relational.

In terms of the internal changes, the death of Sophie's parents seems to have resulted in quite fundamental shifts in her perspective on life. Sophie is not as fearful of death as she used to be, while simultaneously recognising that she is now next in line, i.e., there is no-one standing between her and death anymore. This has brought Sophie to reflect on the fact that neither she nor her sisters have any children, so once they die there will be nobody to carry on their genetic legacy. During our interviews, Sophie describes feeling a stronger sense of responsibility post-loss. Nobody else is going to prepare the holiday dinners or organise what was usually organised by her parents. Rather, it is now up to her to undertake some of these initiatives. Sophie also notices a change in her behaviour, as she is learning to channel her mother's peacekeeping behaviour during situations that could easily lead to conflict.

Sophie: I used to be terrified of dying, but then I'm not anymore. And that's a complete change. I mean, I was really scared of it. I was really scared, and it changed when my mum died, and I think actually, some of my fears, I think that changed, you know. I'm not that scared of things now.

Eleonora: So, it's a feeling of you're not scared of death, you're not scared of...?

Sophie: Returning to my past.

Eleonora: Are there any other changes that you've noticed in yourself as a result of the death of your parents?

Sophie: Sometimes, especially, since I'm becoming estranged from one of my sisters, that I am trying to channel my mum, because my response is often more like

my dad, which is often going to anger. I just go to anger; that's the quickest thing. If someone picks up a brick, you pick up a bigger brick, yeah, that's my dad. Whereas my mum is kind, and calm and considered, and that is a much nicer way to be if possible. So, in certain situations, though my immediate response wants to be towards my dad, I try to channel my mum. What would my mum do in this situation? How would she have been? How would she have behaved? And that's not a bad thing because she behaved well, and she behaved nicely. So, they're all good things, so I feel a bit, I wish I'd learnt it early, that's all. It came late. Just came quite late, but it's okay.

Eleonora: Because it came.

Sophie: Because it came, yeah. But the fear of death, was, is, has taken me by surprise that it changed so much. I suppose, what has been quite difficult in the sense that neither me nor my two sisters have got children. We're all childless and that was always odd. Their deaths [the parents] have brought up the fact that none of us got any kids. I thought Francis and Edith would, you know. I just thought they would. And they wanted to but things didn't happen. You know, for whatever reasons it didn't happen, and that felt very odd at both their deaths, and also when they were alive towards the end, it was that lack of grandchildren. It was very apparent. It was the elephant in the room then, so [silent pause], that's changed. But I think it's also, I don't know how it changes you, but it's that thing of: *Finally I've got to be an adult!* Nothing I've ever wanted to be. Gotta be it! You know, because they are not there, so who is? Is this thing of there's nothing above, as they say. We're at the top of the tree now, but with us there's no-one beneath us.

Chapter 5: Discussion and Conclusions

Research Overview

The lack of recognition of and investigation into adult children's experiences of parental death is problematic as it risks disenfranchising their experience and limiting the potential to offer more understanding and compassionate support. This study was motivated by the paucity of research on the experience of losing a parent in adulthood. Specifically, it addressed the need for qualitative research that provides rich descriptions, captures the time pre- and post-loss, and locates these experiences within the context of family history. Thus, this thesis sought to pursue two connected inquiries: the influence of the women's life history experiences, particularly the history of the parent-child relationship, on their experiences of parental death in adulthood; and how the meanings included in their narratives, as related to loss and grieving, yield insight into these experiences.

The thesis was explored through the following research questions: (i) How are loss and grieving experienced across time by five women in relation to parental death in adulthood?, (ii) What is the significance of the parent-child relationship across time for the women's loss and grieving?, (iii) What meanings can be identified from their loss and grieving experiences?, and (iv) What insights do these meanings bring to our understandings of loss and grieving?

I will discuss my findings with regard to these questions within what I refer to as a meaning-centred framework,¹⁴ to identify the meanings within the life stories of each woman and to explore what insight these meanings bring to parental death in adulthood. The meanings will be identified and organised according to four meaning activities. The first three meaning activities, as seen in Neimeyer and colleagues' meaning reconstruction model, are:

¹⁴ Neimeyer and colleagues' meaning reconstruction model is described in detail in the literature review (see pp. 46-67). My choice of changing the name from a meaning reconstruction model to a meaning-centred model is explained on pp. 62-66.

sense making, benefit finding, and identity change.¹⁵ The fourth meaning activity, *assigning importance*,¹⁶ is my own addition to the model based on my observations and engagement with the data. The added category captures additional meanings identified in the women's narratives, which fall outside the scope of the initial three meaning activities. This discussion is followed by my reflection concerning the study's limitations and future research recommendations, including my conclusions about the study's original contribution to knowledge.

Sense Making

Sense making relates to meaning in that for someone to be able to understand something, it must have a clear meaning. Therefore, meaning in this context refers to seeking to understand an experience, i.e. if it makes sense, one can understand it and vice versa. When speaking of their parent's death, each of the women made sense of the loss by explaining why and how it happened. They also described what the loss meant to them and to their lives. In other words, sense making was a way for the women to try and understand their overall loss and grieving experience, what it meant, and the role this had in their lives. In light of this, the following sense-making themes were identified from the data: i) explaining how their parent died, ii) describing the meaning of loss through metaphor, and iii) narrative creation: stories that bring context. These themes encompass aspects of sense making as a meaning activity and will be explored further in this discussion.

¹⁵ For a definition of sense making, benefit finding and identity change, see pp. 49-51, pp. 51-52, and pp. 52-58.

¹⁶ For a definition of assigning importance, see pp. 112-113.

Explaining How Their Parent Died

Most of the women seemed able to explain the reasons for their parent's death and therefore make sense of it. Rachel spoke of how her mother had lived with cancer for several years and that she was aware of her mother's health deteriorating as she got older. Thus, it seemed like a straightforward process for Rachel to make sense of what had caused her mother's death, and she showed little interest in reflecting on the cause of death any further. As for Kim, she knew that cancer was the cause of her parents' deaths and did not see the point in asking why her parents had died the way they did, or why this had happened to her. The sense she made of it was that everybody is going to die, and it can happen to anyone at any time. Rania and Sophie had witnessed the illness of their parents and seen their health deteriorate as they got older. They had cared for their parents during their illness, so they were aware of the seriousness of the health conditions that eventually led to their death. Due to this knowledge and understanding, they could easily make sense of why it had happened.

The four women's accounts reflect a degree of anticipation of their parent's death, which has been observed in previous studies. Such anticipation amongst adult children has been associated with a lesser grief response, as the death is seen as a normative experience which happens "on time" (Hayslip et al., 2015; Leopold & Lechner, 2015; Rostila & Saarela, 2011). However, the women's accounts suggest otherwise, as they still reacted strongly to their losses in ways that had a significant impact on their life. Although one cannot know how the women would have reacted if their losses had not been anticipated, these findings nevertheless suggest that the anticipated deaths, which the griever had also been able to make sense of, can cause strong grief reactions and should therefore not be underestimated.

In contrast to the other women, Amara struggled at first to make sense of her mother's death. This lends support to earlier findings, which suggest that sense making is more difficult for people who have lost someone to a fatal accident (Currier et al., 2006;

Lichtenthal et al., 2013). Amara was unclear as to whether it was an accidental fall that had led to her mother's head injury, or vice versa. This lack of clarity continued to upset Amara because she thought that if it had been an accident, she could have been there to prevent it. However, if it had been a stroke which had led to her mother's fall, then Amara knew that there was little she could have done in that moment. Thus, Amara was missing a piece of information, leaving a hole in her narrative, which made it difficult to know what had happened to her mother. The inability to make sense of her mother's accident caused Amara a lot of frustration and sadness. This resonates with Davis et al's (2000) findings, which suggest that people who have failed to make sense of a loss report higher levels of distress compared to those who have made sense of the loss. However, with time and further reflection Amara became able to offer a more symbolic explanation of her mother's death by concluding that it was her mother's time to go. Thus, she eventually made some sense of her mother's death, although it is unclear how much this helped her come to terms with her loss, as she was still experiencing deep sadness at the time. This can imply that sense making, in that one can explain why someone died, may not always help the bereaved person feel better. In other words, one may understand and explain the loss of a loved one, but this type of sense making does not necessarily alleviate and/or make a difference to their grieving (as can also be seen in the narratives of the other four women). This contradicts earlier findings that demonstrate the usefulness of sense making for loss adaptation (Coleman & Neimeyer, 2010; Currier et al., 2006), thus making it a worthy subject for further research.

Describing the Meaning of Loss Through Metaphor

The women's life stories included metaphors¹⁷ that described their bereavement experience and what it meant to their lives. The metaphors offered the women a particularly

¹⁷ See pp. 50-51 for a description of metaphors and how they relate to sense making.

vivid and accessible way to illustrate how they understood their loss and grieving and seemed to aid them in making sense of, and giving voice to, what they were feeling in a symbolic manner.

Amara's Kilimanjaro climb held a certain symbolism, which could be seen as a metaphor. She spoke of how she needed a physical challenge to purge the intense grief that she felt after her mother's death. For Amara, the climb was meant to be a "cleansing" (see p. 147) trip where she could clean away her grief and free herself from the pain and guilt of her loss. Related to this, Amara also described the climb as "cathartic" (see p. 147), a term used by Freud (1917) in cases when the griever would confront and purge their grief through what he referred to as a process of catharsis (see literature review, pp. 31-32). The notion of catharsis is perhaps relevant and helpful to Amara, and to other grieverers as well.

The feeling of not having been there enough for her mum while she was alive also continued to trouble Amara. Knowing how much her mother had sacrificed for the family enhanced the feeling of not having given back enough to her mother while she had been alive. Thus, the Kilimanjaro climb was a way for Amara to symbolically give something back to her mother, as reflected in Amara's own words:

That climb was also about: *You know what? You could do this, Mum. You just didn't have the opportunity, but I'm doing it, and it's for you.* So that climb, it was definitely about me, but it was also about her. (see p. 147)

For Kim, losing her parents meant that "Your whole landscape changes" (see p. 168). This could be interpreted in a literal and a figurative way. For example, after her father's death, Kim and her mother rearranged their family house, disposed of her father's bed, and refurbished the living room to reclaim the space as theirs. After her mother's passing away,

Kim sold the family house, moved to a different town, and created a new home for herself. This was new territory for Kim, whereby she was constructing a new life while she was simultaneously dealing with her losses. Her parents' death also meant that she had to adapt to and navigate a landscape where her parents were physically absent. Yet, she still made sure to remain connected with her parents in meaningful ways, for example, by planning to plant some of her parents' ashes in her new garden, as this meant having them close by. The establishment of such a metaphorical "continuing bond" (Klass et al., 1996) seemed to offer Kim a sense of comfort and safety in the absence of her parents

Rachel pictured her grief as a "deep dark grey chilly anxiety-filled chasm" (see p. 199), which had been dug out in her chest by her mother. This suggests her grief was connected to a physical location and sensation; there was a deep wound in her chest that had been caused by her mother's abuse. These metaphors depict the abusive relationship that Rachel had with her mother and the hurt and anxiety that she had to endure because of it. Rachel further used a metaphor to describe the grieving she had felt during the time her mother was alive. She spoke of it as a "scab" (see p. 199), which represented a wound that failed to heal because her mother kept picking at it. Rachel perceived that her mother's presence prevented the wound from healing. Instead, it continuously ruptured the scab, causing more pain. It was not until her mother's death that Rachel felt her wound heal. Rachel's metaphor depicts the embodiment of grief first mentioned by Lindemann (1944) and how a physical sensation of grief can be verbally expressed through metaphor to explain, and make sense of, an internal felt experience.

Rania, who had a very loving relationship with her father, described her grieving as "love with nowhere to go" (see p. 226). This can be seen to reflect the relationship she had with her father and the love that she felt towards him. To find a place for her love, it seems that Rania developed her own continuing bonds (Klass et al., 1996) by expressing love for

her father in new ways. For example, by speaking to him after his death and acknowledging the parts of him that continued to live through her. Similar to Kim, the development of continuing bonds seemed to offer Rania support in her grief.

Sophie described her loss as: “It’s like the tectonic plates have shifted” (see p. 251). The tectonic plates can be seen to represent a description of what made up the ground of Sophie’s world. The solid foundation she once had relied upon had now shifted, and she was faced with a new world where what she thought she knew had changed in meaning, i.e. “everything that I thought I knew is not so” (see p. 251). Sophie’s metaphor resonates with Janoff-Bulman’s (1992) idea of the loss of assumptive worlds, where the world as she knew it had been lost, and she is now faced with a very different reality. It further illustrates how much she relied on the support of her parents, who served as a source of stability in her life, and now that they were gone, that stability was disturbed and shifted into something more unfamiliar. Sophie described her grieving by drawing on a metaphor once again: “I’m not down the rabbit hole. I was for a while. I felt I really was down the rabbit hole. I’m not down the rabbit hole, but the world, well of course it’s a different world” (see p. 251). This rabbit hole can be interpreted as a metaphor for being transported into a dark and troubling place where Sophie was constrained and could not escape. The notion that she is not down the hole anymore suggests that she is not experiencing the same darkness and despair she did at a different point in time and that her grieving had subsided in intensity.

These examples add to existing findings, which suggest that metaphors are useful when communicating about loss and grieving, especially when literal descriptions do not suffice (Nadeau, 2006). Furthermore, metaphors can be particularly useful in grief therapy, as “they provide signals from the interior lives of our clients” (Nadeau, 2006, p. 220) and can therefore cultivate awareness of internal experiences that one might be unable to reach, or would otherwise overlook (Neimeyer, 2000). Thus, metaphors can provide further insight

into how the women perceive their loss and grieving and what they find helpful amidst their struggles. These insights can help grief therapists and other counselling professionals to develop appropriate interventions that facilitate grieving (Neimeyer et al., 2010). In light of this, it is imperative that metaphors are explored further in narratives of the bereaved, and additional inquiry into this matter is suggested.

Narrative Creations: Stories That Bring Context

Neimeyer (2006) addresses people's need to make sense of knowledge and experience by organising it in storied form, and he considers this to be a pervasive aspect of being human. This process can be referred to as narrative meaning making or narrative creation/storytelling (Hartog et al., 2020; Rolbiecki, Washington, Bitsicas, Teti et al., 2021). It includes arranging and connecting separate experiences and/or events into a story that brings meaningful congruity and context to what is being told. This is also a key trait of life history research, as it focuses on the chronological sequencing and contextualisation of events to get to the heart of human experience (Goodson & Sikes, 2001). As Clandinin and Connelly (1994, as cited in Goodson & Sikes, 2001) assert:

Stories are the closest we can come to experience as we and others tell of our experience. A story has a sense of being full, a sense of coming out of a personal and social history... Experience ... is the stories people live. People live stories, and in the telling of them reaffirm them, modify them, and create new ones. (p. 44)

Indeed, without the story, one could not make sense of an experience in such an in-depth manner. The women's stories have therefore been essential to learn more about and

make sense of their experiences of loss and grieving, as well as the process behind these experiences.

The women organised a narrative in a meaningful way to make sense of an experience when constructing their life stories and telling them to me. They chose to speak about certain events and experiences relevant to their loss and grieving, and they did this in a sequential order that oriented their narratives and experiences in a specific time and place. When telling their life stories, they were as Neimeyer (2006) suggested, organising their experience in a storied form, to make sense of their relationship to their parent/s, their family history, their loss and grieving, and the present moment that they were now in. Subsequently, it was my responsibility as a researcher to reconstruct this data through life history analysis. When doing this, my own sense making was taking place. I decided what key parts of the data to keep and how to link these parts in a chronological order, in a way that made sense, was relevant to my research inquiry, and that could represent the women's life stories as a "meaningful whole" (Hartog et al., 2020, p. 740). I was also careful about the parts I chose to leave out to ensure that their absence would not misconstrue the women's life histories. Thus, each woman's life history was a co-construct and a reconstruction made up by both the life storyteller and the life history researcher.

When sharing their history of loss and grieving, each woman spoke about the time before the death and their relationship with the parent in question. What stood out significantly was that the parent-child relationship was central to their storytelling. When describing this relationship, they considered their parent's life history, as there was a need to understand it in context, to further understand who their parent was and how their parent related to others, themselves included. The women's life stories were closely connected to their parents' past, who their parents had been, and how that had affected their parent-child relationship. The women also considered their own role and history in relation to their

parent's life. This seemed to be a way for each woman to position herself in relation to her parent and to make sense of her loss and grieving within a larger context. For example, through life history interviews, Amara's narrative was connected to her mother's past and the sacrifices her mother had made as a woman, wife, and a mother of three children. This brought Amara to reflect upon her own role within her family and how her family history had shaped her, including how she wants to continue to shape her history after her mother's death. Kim described each parent's illness and what was happening during the time leading up to their death, as well as the role she played in supporting her parents throughout their illnesses. This sequential account helped to explain some of the difficult changes she faced both pre- and post-loss and how these related to her relationship with her parents. Rachel arranged events from her family history, from her grandparents' life to where Rachel was today. This included exploring her mother and her maternal grandparents' history of surviving the Holocaust to better understand where part of her family originated from, how she came to be who she was during her life, and to find out her life purpose after her mother's death. For Rania, talking about her father's journey through dementia seemed of central importance when making sense of her grieving experience. She narrated and sequenced her grieving into pre- and post-bereavement to highlight the differences in her experience of each period. Sophie's story showed how interlinked the life narratives of both parents were while explaining how different her grieving was for each parent and why that was the case.

These findings resonate with Umberson's (2003) work, which proposed that the most important thing to do when researching the experience of parental death in adulthood is to look at the adult child's unique life history, which often reflects a lifetime of interactions with the parent. In her study, Umberson (2003) noted that when adult children spoke of their bereavement experience, their personal and family history unfolded in front of her. This was also the case in my study, which confirms to the reader that: "Grief and loss are much more

than a list of symptoms. Each loss is a profound story for the bereaved person” (Umberson, 2003, p. 201). This suggests that making sense of loss and grieving through storytelling can be a powerful way to gain insight into aspects which would otherwise risk going unnoticed if one were to only focus on symptoms. Certainly, as I constructed the life histories, the particular theme of intergenerational trauma ran across three women’s stories. This theme added significant context and thickness to what was being told, as it illustrated how much the experience of bereavement is shaped by past events quite separate from the bereavement itself. I will turn to this next, as it is a valuable example, unique to bereavement research, which shows the power of sense making through stories.

Intergenerational Trauma and Its Impact on Bereavement

Three of the life histories presented the theme of traumatic experiences that were passed between generations, also referred to as “intergenerational trauma” (Sangalang & Vang, 2017, p. 2).

In Amara’s life history, the intergenerational trauma was linked to both her son and her mother, as seen in her description of the 4 months spent taking care of her mother at the hospital. Amara described this time as a trauma upon trauma because while in the ICU caring for her mother, she was simultaneously remembering and reliving part of an earlier trauma that she had experienced with her premature baby years before. The current situation evoked painful memories, which opened old wounds from the past and led Amara to experience additional distress. More so, she felt that her immediate family were unable to relate to this struggle as they had not lived through it themselves, which seemed to further isolate Amara in her pain.

When analysing Rachel’s story, I decided to look deeper into the history of her family, in the search for an explanation as to why her mother might have been so abusive

towards her. I believe this could help to make better sense of Rachel's relationship with her mother and how it influenced her experience of loss and grieving. Unlike myself, Rachel did not think it was important to find out why her mother behaved the way she did. She did not look for an explanation of her mother's behaviour, nor did she think that her mother being born in Bergen-Belsen concentration camp had anything to do with it, as she believed that people choose who they want to be. Instead, Rachel thought she could only be responsible for how she responded to her mother's abuse, which is what she seemed to focus on. I wonder if this view may have helped Rachel to move forward with her life and to avoid ruminating on the past in the search for answers that could explain their painful relationship. That said, I did not want to overlook the significant fact that Rachel's mother had spent the first (circa) 3 years of her life in a concentration camp. Thus, I decided to explore it further by searching for links between the mother's past and her behaviour towards Rachel, and by exploring whether this was a manifestation of intergenerational trauma passed down from mother to daughter. However, I did not take this decision lightly as I was (and still am) aware that I may be wrong in how I perceived the connection between Rachel's mother's behaviour and her past. My interpretation of my observations are mine alone, and I hope that by treading carefully these amount to more than mere speculation.

Rachel's account resonated with Dashorst et al's (2019) study, which shows how Holocaust survivors' experience of trauma can have an influence on parenting style. This can present itself through an inability to provide physical and emotional care, and the use of coercion, as exemplified by pushing the child to support their needs and to achieve their unfulfilled ambitions. I observed this parenting style in Rachel's story, which revealed her mother's lack of affection and care towards her daughter. According to Rachel, she was never good enough for her mother, nor could she ever become the person that her mother wanted her to be. Not only did this have an impact on their relationship, but it also seemed to

have a significant influence in shaping Rachel's response to her mother's death and how she verbalised it, as mirrored in this statement:

I just felt relief that there would be nobody there to tell me how ugly I was anymore, or how incompetent or worthless I was, and it was just like a load off my back, and I felt how everything fell off, and I felt relief. (see p. 200)

My attention was also drawn towards the traces of intergenerational trauma in Sophie's story, as she too was the daughter of a Holocaust survivor. Sophie described her father as a tormented soul. She considered their relationship to be complicated and argumentative due to her father's sometimes volatile behaviour towards her and their recurring inability to communicate constructively with each other. Unlike Rachel, Sophie made causal connections between her father's behaviour and his past. She attributed some of his behaviour to his family history and the trauma of having lived in Nazi Germany during the first years of his life. The repercussions of this on Sophie's grieving process after losing her father were significant. Due to their complicated relationship, Sophie felt unable to resolve many of the conflicts she had had with her father. At the time of our interviews, she felt that there were many things that had been left unsaid between them, which caused her much sadness in the aftermath of his loss.

The experiences of Amara, Rachel, and Sophie demonstrate how stories in context are significant in making sense of and gaining insight into a life experience. Indeed, such an event is held together by the thread of storytelling. If significant life events are kept separate and seen in isolation, and/or taken out of context or out of sequence, then they might not carry much weight, or might not make sense. It would be like only seeing one small piece of an entire puzzle (which yet is a puzzle that is always in the making!).

Instead, these rich life histories made it possible to see the bigger picture. Indeed, seeing the women's life in the context of their family history helped to illustrate how and why intergenerational trauma can impact how parents sometimes relate to their children, how children sometimes relate to their parents, how grief and grieving is experienced, and how the bereaved person makes sense of their experience. Their stories also demonstrate how intergenerational trauma can be experienced and passed on in different ways, i.e. Amara's re-experiencing of previous trauma through almost losing her son due to a premature birth and then the gruesome accident and unfortunate loss of her mother years later, the bodily trauma of internalised misogyny related to Rachel's mother's obsession with image, and the trauma of physical violence and argumentative relationship that Sophie experienced at the hands of her father. Exploring family history in relation to bereavement could therefore aid a better understanding of the grieving process of a group of people with particular and sensitive life histories. To my knowledge, no empirical research has been conducted on sense making and the impact of intergenerational trauma in relation to bereavement and grieving. These findings thus point towards a topic worthy of future research. They also have implications for life history research in that some of the women's life histories precede or succeed the birth of the participant, which is an innovative approach to the methodology when applied to bereavement research. To better understand the implications of these results, future studies could address cross-generational history, particularly concerning intergenerational trauma, as this is an understudied area of bereavement research, which could be explored in depth using life history methodology.

Benefit Finding

The meaning activity *benefit finding* relates to the pursuit of a silver lining, whereby one experiences unsought benefit from a negative experience (Davis et al., 1998). It may seem

paradoxical that one can find elements of benefit in the loss of a loved one, and this idea is also not always welcomed by the griever (Lichtenthal et al., 2010). Yet, as it turns out, the ability to do so in the long term can facilitate a person's loss adaptation. All five women could derive some personal benefit out of certain aspects of their loss experience, and this did indeed seem to offer them some support in their grieving, which is consistent with prior findings (Frantz et al., 2001; Neimeyer et al., 2006).

Amara's felt lack of closure with her mother was highly unfortunate, yet what succeeded were some valuable initiatives that preserved and strengthened her existing family bonds. Amara became motivated to learn more about her mother's history and their family's history overall. She shared this history with her sons to keep their family legacy alive and to ensure that they would not be left with unanswered questions about their past. She also wanted to capture her father and some of his history on video camera, resulting in a recording of him sharing his life story, which Amara knew she could return to after his death. With an increased sensitivity to her father's mortality, Amara sought closure with him while he was still alive by saying what she needed to say and leaving old quarrels behind, before it was too late. These actions seemed to strengthen her existing relationship with her father, a benefit that can be seen amongst surviving family members in the aftermath of loss (Gillies & Neimeyer, 2006; Rolbiecki, Washington & Bitsicas, 2021).

Kim had spent several years caring first for her father, and later for her mother, who had both been diagnosed with cancer. She devoted her life to caring for her parents during the period of their illness and, consequently, she spoke of experiencing high levels of workload, stress, and exhaustion. Kim's caretaking responsibilities took a strong toll on her overall health, and she further expressed concern about her parents' suffering. By the time of each of her parents' deaths, she could not help but feel a strong sense of relief both for herself and for her parents. Kim was relieved that their suffering had ceased, that she was freed from her

caretaking responsibilities, and that she could resume her life on her own terms. Although these benefits were much needed for Kim, they did not come without guilt. This resonates with previous accounts, whereby the adult child experiences relief when being freed from burdensome caregiving responsibilities, yet at the same time feels guilty for not having done enough (Umberson, 2003).

Rachel perceived several benefits of her mother's death, which reflected their destructive relationship. While her mother was alive, Rachel felt apprehensive about the risk of being contacted by her, as this would entail being on the receiving end of abusive and hurtful behaviour. When her mother died, Rachel knew that she no longer had to endure this abuse, and this was a great relief for her. She could finally close that chapter and put an end to a relationship which had caused her severe pain throughout her life. This relief speaks to earlier findings, which highlighted that adult children who have had conflicted relationships with their parents feel a sense of relief and freedom upon their parents' death (Umberson, 2003; Umberson & Chen, 1994). Furthermore, the loss was beneficial for Rachel, as it made it possible for her to distance herself from her mother and to gain a broader perspective on her mother's behaviour and their relationship. Over time, Rachel's perception of her mother changed from only seeing her as a source of pain, to now serving the purpose of an antagonist towards positive growth. Rachel was convinced that her mother's abuse helped make her a stronger person, as it had required her to develop an intrinsic self-worth and confidence, which has helped her throughout her life. From this perspective, Rachel felt that she was able to make peace with her mother's behaviour and some of her past. Her enhanced perspective led Rachel to express gratitude towards her mother, which is different from the anger she initially felt. The benefit of enhanced perspectives in the aftermath of loss is in line with earlier findings, which highlighted that the bereaved facilitate their grieving over time by gaining additional perspectives on their loss (Davis et al., 1998).

Rania viewed her caretaking responsibilities as something positive, even though it was exhausting and difficult for her and her family. She viewed it as a spiritual service, whereby she selflessly devoted herself to caring for her father, and she believed that her purpose was to journey with him through his illness. She viewed this journey as a preparation for her father's death, and when he died, she said she felt no regrets. In addition, she was grateful that her father did not suffer for too long, but that he instead died peacefully in his sleep. The seizing of a loved one's suffering is thus another benefit that can be found in the midst of loss, as seen in previous studies (Davis et al., 1998; Rolbiecki, Washington & Bitsicas, 2021).

Sophie had a strong and close relationship with her mother, whom she loved and cared for very much, and although she loved her father, she had a very troubled relationship with him. That is why she initially resented the fact that he outlived her mother. However, as she reflected on their deaths in hindsight, she saw the positive aspect of losing her mother first, as her death involved fewer practical arrangements like dealing with bureaucracy and the estate. Sophie referred to these aspects as the "mechanical aspect" (see p. 243) of death, which can be likened to Stroebe and Schut's (1999) restoration-oriented stressors. Thus, the timely order of her parents' deaths gave Sophie the chance to grieve her mother in peace, without having to worry about the stressful practicalities that she was now forced to deal with after her father's death.

The women demonstrated a diverse range of constructed benefits in relation to their loss, which seemed useful in helping them cope with their grieving. These so-called silver linings included strengthened family ties and further knowledge about family history, relief from caregiving burdens, ending conflicted relationships, enhanced perspectives, a seizing of suffering in the deceased, and the timely order of parental death. This suggests that benefit finding as a meaning activity can take many forms, including some which may be more

common to the adult child and can indeed serve as a comforting support in a time of grieving. Findings also show that benefits can be constructed alongside a person's grieving without relinquishing or invalidating the pain a person is feeling. Thus, there seems to be an important balance to strike between allowing grief to take place while also giving room for any positive aspects that arise from the loss to comfort the griever.

Identity Change

Identity change, when favourable, can express itself as a form of post-traumatic growth (Neimeyer & Anderson, 2002). It involves the ability to transform hardship into meaningful personal growth in ways that benefit the bereaved (Lichtenthal et al., 2010). This meaning activity was seen in all five women, although it manifested itself differently in each person. This suggests that the impact of loss on post-traumatic growth can be highly individual, depending on a person's life history.

Amara felt she did not receive enough support and empathy from her husband and one of her sons while caring for her mother at the hospital and after her mother's death. In response, Amara decided to start putting herself first and to stop sacrificing her needs and wants for the family. Her change in priorities led Amara to do more things for herself, and as a result, she became more independent and seemed to reclaim some of her strength.

The loss of her parents taught Kim that life was too precious and too short to be spent arguing with people. This was a valuable lesson, as she perceived her family life to have been very argumentative, and she did not want to spend time fighting anymore. As a result, Kim made it her priority to act with more kindness and compassion towards herself and other people, more than she perceives herself to have done before.

Rachel's loss, combined with her felt sense of "survivor's guilt" (see pp. 205-206), motivated her to search for her life purpose. Rachel's survivor's guilt seemed to stem from

the feeling of having to make up for the fact that her family had survived World War II, while so many other Jewish people perished. In addition to Rachel's guilt, her feelings can also be perceived to have reflected "existential feelings of unworthiness" (Juni, 2016, p. 324). For Rachel to feel worthy of being alive, she had to find a reason for why she was alive and what her purpose on earth was. Finding her purpose would be her way to pay back to her maternal family what she felt she "owe(d)" (see p. 205). In search of her life purpose, Rachel reflected on her family history leading up to where she was today. She decided to return to her roots in Bergen-Belsen where her mother was born, and during her visit she discovered that the meaning of her life was to help other people. Rachel's discovery seemed to reassure her of how to move forward with her life while coming to terms with her family's past, including the death of her mother.

Rania experienced multiple changes in her social roles and life responsibilities after her father fell ill with dementia. Within a brief timeframe, Rania was required to take on new caregiving responsibilities, which resulted in a perceived change of roles within the family. Rania could no longer rely on her father's presence to support her in the same way it had done before, and she went from seeing herself as a Daddy's girl that was being cared for, to the daughter now taking care of her father. These changes took a strong toll on her general well-being, as well as her job performance, which resulted in losing her job and suffering financial difficulties. Her social life was impacted negatively, and she lost many friends. Furthermore, the strain on her family led to a stressful home environment, which did not help to ease the burden. However, Rania believes that these difficulties transformed her into a fully grown woman who had become stronger and more resilient because of the increased responsibility that came with taking care of her father, hence reflecting a sense of post-traumatic growth (Tedeshi & Calhoun, 1995).

For Sophie, losing her parents meant that she saw herself as being closer to death. This view resonates with Anderson's (1980) assertion that losing a parent in adulthood can intensify one's sense of mortality. Her parents' deaths also made her reflect on the fact that none of the sisters in the family had children and that there was no one to continue the family line, i.e. "We're at the top of the tree now" (see p. 254).

Accordingly, she describes herself as being less fearful than she was before. For example, she felt that her fear of death had completely vanished, and instead it was time to become an adult. Being the adult meant taking on more responsibility and taking initiative in ways her parents had done. In doing so, she speaks of how she also tried to channel some of her mother's behaviour, by being kinder and more considerate, particularly toward her sisters.

The deaths of their parents reflect a turning point in the women's lives, signifying what Umberson (2003) describes as: "a period of substantial change and redirection in the way we view ourselves, our relationships to others, and our place in the world" (p. 85). This turning point also resonates with the meaning activity that Neimeyer and colleagues often refer to as identity change (Neimeyer & Anderson, 2002). The identity changes observed to various degrees across the five women in this study seemed to help them to cope with their loss by providing them with a sense of meaning and direction. In other words, it gave them the strength and purpose to carry on with their lives, thus demonstrating the value of their perceived identity change. However, after analysing my data, I consider it questionable whether such an identity change is a meaning-finding or meaning-making activity, or, rather, an extended outcome that emerges during or following that activity. In other words, identity change may not itself constitute a form of meaning making/finding but is, instead, a product of these activities. In essence, by the time we undergo a change in our identity, we have *already* engaged in meaning-related activities. I conclude that a view of identity change as a

meaning-making/-finding activity is not altogether clear, and further analysis is required to clarify its place within a meaning-centred model.

Assigning Importance

My findings illustrate the different emphases the women had and what was important to each individually. In relation to this, I identified three strong themes relating to *assigning importance* from the data: i) the importance of closure, ii) the importance of honouring the deceased and continuing bonds, and iii) the importance of empathy and support. Some, or all, of these themes could be seen across the women's life stories.

The importance of Closure

Four women seemed to give strong importance to the need for closure. They described closure as the feeling that certain conflicts or questions had been resolved within themselves, or with the deceased parent, and/or the events surrounding their death. Closure was not, however, about relinquishing any bonds with the deceased, thus distinguishing it from the detachment suggested by Freud (1917) and Lindemann (1944). Some women spoke of having sought and found closure, whereas others had not or were still in the process of doing this.

Amara described how she had not gained complete closure with her mother, as she felt that there were things left unsaid and questions that still needed answering. Due to her mother's accident and hospitalisation, Amara was unable to communicate with her mother in the same way as before. Furthermore, Amara recalls that the sheer exhaustion and panic of keeping her mother alive made it difficult for her to focus on anything else. Thinking back on this period, Amara recalls that she was not in a clear state of mind to ask the questions she wanted to ask and to say the things that she wanted to say to her mum at that time. Amara

also questioned whether she had expressed her gratitude enough, and she voiced regret that she had not been sufficiently explicit about the love she felt for her mother throughout their relationship. Amara experienced regret and guilt for what had not been said or done and the things that she thinks she could have done better.

After her mother's death, Rachel seemed able to find closure in some matters while there were other aspects that were left unfinished. As told by Rachel, her mother's death allowed her to stop grieving the mother she had wished for but never had had, and she could now free herself from the hope that their relationship might one day improve. However, alongside this, Rachel also described her mother's death as losing the chance to ever have a normal, healthy mother-daughter relationship. Rachel felt that the chance of setting things right was lost upon her mother's death, thus leaving some of their problems unresolved. However, over time, Rachel took it upon herself to find closure with her painful family history and the relationship with her mother. For example, Rachel's trip to Bergen-Belsen helped her to come to terms with her family history and to discover her life purpose. This was important to Rachel, as it helped her put the painful past behind her and move forward with her life.

The closure sought by Rania occurred alongside the worsening of her father's dementia, whereby she witnessed him change from the father she knew to a father who was now entirely different. This gradual transformation led Rania to experience multiple losses over time while her father was still alive. During this time, Rania sought a form of ongoing closure, which involved telling her father how much she loved him and saying her goodbyes to him continuously over time while caring for him up until his death. Upon his death, Rania had already gained her closure in the sense that all had been said and done, and alongside this, she continued to grieve her father.

Her father's sudden death had left Sophie with a lot of unresolved pain and regret. She regretted her inability to solve the problems she had had with her father while he was alive, as reflected in Sophie's words: "I'm left with all the could've, would've, should've with him. The questions I didn't ask [crying], the conversations I couldn't have" (see p. 238). Sophie's perception of being unable to resolve the past and find answers to her questions appeared to cause her a great deal of sadness. This was exacerbated by having to solve her father's real estate issues, probate, and other unfinished business that he had left behind. Sophie's story suggests that when closure is difficult to achieve, for both emotional and practical reasons, it may intensify the grieving experience during a particular period. However, time and circumstance certainly play a role in this. The period during which the interviews took place was highly taxing, as Sophie was in the middle of solving her father's probate. If I were to speak to her at a later period when such practical matters had been resolved, then the situation and her sense of closure might have been perceived very differently.

The women describe diverse routes toward closure that can emerge in relation to bereavement (both pre- or post-loss), and these closures (or lack of) seem closely related to family history and the parent-child relationship. Furthermore, the women's accounts illustrate that losing a parent during adulthood can sensitise one to unfinished business within the family (Hayslip et al., 2015). Such unfinished business can be a painful and stressful experience that aggravates grieving, which is why finding closure in such matters can be helpful to the bereaved adult child.

Additionally, these findings show that closure is part of the grieving process rather than a point which marks the end of grieving. Indeed, a person can find closure but still experience sadness and longing for the person that has died, as seen in Rania's case. This suggests that one can need closure and/or have sought closure and found it, without having to detach from the deceased, as suggested by earlier traditional grief theories (Freud, 1917;

Lindemann, 1944). In other words, the processes of finding closure and developing continuing bonds can go together. This is an important finding that could be useful in complementing future literature on the concept of continuing bonds in bereavement studies. Lastly, the time of the interviews is an important factor to consider, as for some women, closure might be found later in their process, depending on their circumstances. And for some, it may not be found at all. At times, closure can even come undone if memories or events from the past are rekindled and seen in a different light. Future research is recommended on the role of closure in bereavement, the aspects one seeks closure for, how closure can coincide with continuing bonds, and whether closure changes over time.

The Importance of Honouring the Deceased and Continuing Bonds

It was important for most of the women, except for Rachel, to pay tribute to their deceased parents by honouring them in some way. The purpose of such honouring was to show appreciation for the value that their parent had in their lives. They did this through meaningful actions that demonstrated love towards the deceased parent. Different women expressed their love in different ways, each of which was important for that woman because of her life history. These expressions further helped each woman to remain connected with her deceased parent, which seemed to comfort them in their grieving.

For Amara and her family, it was important to honour Indira's wishes and religious beliefs when it came to organising and conducting her funeral. They conducted the funeral in London where they integrated elements of Hindu rituals and prayers. This was followed by taking her mother's ashes to India and scattering them into the river Ganges. After some time, the family arranged a 1-year anniversary where the closest family members got together in the house of the parents and recited prayers in honour of Indira. The purpose of this activity was to remember and pay tribute to her life, a symbolic act which seemed to facilitate the

family members' connection to Indira, despite her physical absence. Hooghe and Neimeyer (2013) refer to such rituals as a form of *collective meaning making*, which assign meanings to the death so as to make sense of it and to cultivate a connection between family members and communities, thereby supporting them in their grieving (Hooghe & Neimeyer, 2013). These rituals can provide symbolic and communal validation for the loss and the changed reality of the bereaved. Furthermore, rituals can be a way of maintaining continuing bonds with the deceased by recognising the place that they had, and still have, in the lives of the bereaved.

Kim and her parents were not religiously or spiritually inclined, so she gave little importance to honouring them through their funerals or spiritual rituals. Instead, Kim can be seen to have engaged in a form of digital storytelling online (see Rolbiecki, Washington & Bitsicas, 2021), whereby she would demonstrate how much her father meant to her. She did this by sharing YouTube videos of his acting career on her Facebook page to express pride over his achievements and to stay connected with her father.

Through her caretaking, Rania wanted to honour the person her father had once been, the relationship they had once shared, and the relationship they were having in the moment. With the intent to honour her father, it was important for Rania to preserve her father's interests and activities from his pre-dementia life, and to continue with these, albeit in a modified form, by adapting their old world into a new world to deal with the life change. In other words, because of wanting to honour her father, Rania was bridging "what once was and what now is" (Neimeyer, Botella, Herrero et al., 2002, p. 34).

Sophie would honour her mother's memory by returning to locations where she used to go. She would visit the rose garden, a place that was meaningful to her mother, because it offered a sense of comfort and a way to reconnect with her mother. Since the rose garden had been meaningful to her mother, it was now meaningful to Sophie, and it served as a valuable way to both honour and maintain a bond with her mother.

The honouring of the deceased parent through the conduct of rituals, digital storytelling, purposeful caretaking, and visiting meaningful locations, helped the adult children maintain a connection to their (alive or) deceased parents, which brought them a sense of comfort. These findings are in keeping with previous literature, which suggests that continuing bonds can provide a meaningful connection to the deceased person, by supporting the bereaved in their grieving (Bonanno & Kaltman, 1999; Klass et al., 1996; Neimeyer, 2014). Thus, practices of honouring the dead and the establishment of continuing bonds ought to be supported and encouraged when deemed suitable, to help the bereaved adult child throughout their grieving process. It is also a powerful way of raising awareness of death and grieving within one's family and within one's communities, as it makes visible the fact that the dead are still remembered while also sensitising people to their own mortality. This can help foster an attitude towards death and grieving that is more inclusive and integrated as part of our daily lives, rather than keeping the subject invisible and silent within societies. Such recognition is therefore important, as it could also help to reduce any existing disenfranchisement in loss and grieving, while reminding us of the preciousness of being human, and that nobody escapes death.

The Importance of Empathy and Support

Amara and Rania gave importance to receiving empathy and support in bereavement. This seemed to be particularly significant to them as they felt that they had not received enough of it themselves. The perceived lack of such support often resulted in a sense of isolation and frustration, whereby they did not feel validated in their experience, thus reflecting a level of disenfranchisement (Thompson & Doka, 2017). Such disenfranchisement can have psychological implications for the griever, making their grieving a "great deal

harder” (Thompson & Doka, 2017, p. 182) to bear, and this did certainly seem to be the case for Amara and Rania.

Amara expressed disappointment and anger in how her husband and youngest son had approached her loss and grieving. She perceived that none of them had demonstrated sufficient understanding and support, as seen in their physical and emotional absence. She was particularly saddened that her husband, the person she thought she could rely on, was not there when she needed him the most. The husband and son’s lack of relatedness can be viewed as a type of empathic failure (Thompson & Doka, 2017), whereby they seemingly failed to understand the meaning of Amara’s experience. This echoes the accounts from Umberson’s (2003) study where women also expressed a felt lack of empathy and support from their spouses. Umberson (2003) attributed this to the social conditioning of gender roles, whereby men and women are encouraged and taught to respond to emotions according to their gender stereotypes. Amara pointed this out herself as she wondered whether her son and husband’s inability to show empathy was influenced by their male gender roles. Regardless of what the cause might have been, it was clear that the felt lack of support had a negative impact on Amara’s relationship with her husband and youngest son, adding to the notion that parental death can bring relational challenges with immediate family members when such support is not present (Umberson, 2003). Amara also highlighted how adults may be expected to be less vulnerable than children and better able to cope with their parents’ death, as it is an anticipated event. These expectations are in line with findings showing that adult children demonstrate lower levels of distress compared to younger children when faced with parental death and that this may be due to the event being anticipated (Hayslip et al., 2015; Leopold & Lechner, 2015; Rostila & Saarela, 2011). However, Amara’s experience does not align with this view, as her mother’s death left her in a highly vulnerable state where she experienced intense levels of grieving. More so, she pointed out that although she knew

that her parents would die one day, it was still an event that was difficult to prepare for, nor did she know what to expect from it. Considering this, such societal expectations may be harmful as they risk leaving the grieving adult child to fend for themselves without adequate support, as seen in the case of Amara.

Rania described her experience of caretaking, loss, and grieving as the most “socially isolating experience” (see p. 217) in her life. She felt that nobody in her social circles understood what she was going through as none of them had ever cared for a parent with dementia. Studies suggest this to be a common experience amongst dementia caregivers, who report an increase in social isolation due to a lack of understanding from others and a deterioration in social relationships due to the emotional burden of their caregiving duties (Cheung et al., 2018; Large & Slinger, 2015). This was also the case for Rania, who ended up experiencing problems at work and amongst friends due to her caregiving burdens. Rania got fired from her job because she was not performing as well as she normally would, and she also lost many friends during this period. Thus, the lack of understanding and support from other people, as Rania perceived it, had emotional and practical implications for her life, which added to her levels of distress and seemed to exacerbate her grief.

Rania also felt a lack of support and understanding in the planning of her father’s funeral, which she described as a “source of great cultural confusion” (see p. 223). Indeed, the attempt to arrange a Sri Lankan funeral in London meant that her family had to make several compromises, which Rania described as a highly stressful experience. Unlike their experience of death and funeral ceremonies in Sri Lanka, the removal of her father’s body from their family home was done rapidly, and the family were not permitted to visit the father’s body whenever they wanted to. The body was stored alone in a dark room at a mortuary, which is a far cry from being surrounded by friends and family in the home of the deceased, as would have occurred in Sri Lanka. Furthermore, Rania perceived the

communication with the coroner to be impersonal and lacking in empathy. Upon the cremation of her father's body, the atmosphere of the location and the way it was done felt clinical and impersonal to Rania. Rania's beliefs and values about what a funeral should be about, based on her previous experiences from Sri Lankan funeral customs and her Buddhist beliefs, was confronted by the practical realities of what it meant to organise her father's funeral in London. This may explain the cultural confusion that she experienced and the conflict of not being able to organise things according to the family's wishes. Indeed, Rania's narrative reflects the difficulty highlighted by Shapiro (1996), who speaks of the cultural clashes that can arise between culturally prescribed rituals and the culture of a particular family within a society. The cultural diversity of practices that accompany loss and grieving can become a problem when culturally prescribed rituals that are designed for the wider community end up clashing with the needs of a particular family (Shapiro, 1996). Different cultures approach death and grieving with different assumptions, and families within any one sociocultural structure "draw on many sources in both culture of origin and current culture for family organization as well as for guidelines in family bereavement" (Shapiro, 1996, p. 2). For Rania and her family, arrangements for the funeral required a process of negotiation, so as to incorporate both the Buddhist funeral traditions of Sri Lanka, with which they had an ethnic, cultural, and emotional bond, and the socio-cultural practices associated with their role as citizens of the United Kingdom and residents of London. The funeral affirmed their cultural history and values to a certain degree while simultaneously including adaptations that reflected elements of a westernised approach commonly practised in London. However, the funeral planning was a stressful, confusing, and frustrating experience. This suggests a need for mortuaries and other funeral services to take cultural differences into account and to become more adept in providing inclusive services which are understanding and supportive of the diverse needs of families from different cultures.

These findings demonstrate that Amara and Rania experienced a degree of disenfranchisement in their grieving, as exemplified in their perception of not having received sufficient understanding and empathic support. This played out in various contexts: within the workplace, the funeral service, a social network of friends, or amongst immediate family members. In response, the women seemed to be left to deal with much of their struggles alone, causing them further distress. This suggests the importance of an empathic and supportive social network that can help facilitate the grieving process of the bereaved, one that ought to pay attention to grievers' needs, which may vary according to context.

The meaning activity of *assigning importance* stretched across multiple experiences and events that were highly personal and seemed integral to how the women responded to their loss. It shone a light on the specific needs of the griever, and these needs often differed from woman to woman due to their personal and family history. The insights gained through this meaning activity in relation to the importance of closure, honouring the deceased, continuing bonds, and empathy and support, can thus sensitise people to the different priorities and needs seen among bereaved individuals. This is important, as it can help diversify the support offered in social circles and workplaces, as well as by funeral services and bereavement professionals.

Limitations and Future Research Recommendations

The limitations of this study concern participant selection and representation, the lack of a longitudinal perspective, challenges with the theoretical framework, and methodological challenges. I will discuss these limitations and how I overcame them, including recommendations for future research.

Number of Participants and Their Representation

Five women partook in this study, and each told a certain story which portrayed a small-scale range of experiences related to loss and grieving. Because of this, I could not aim to provide representative cases, and this is often considered a typical limitation and criticism of life history research (Goodson & Sikes, 2001; Plummer, 2001). However, such criticism does not stand if one considers the purpose of life history research, which is to gain “insights, understandings, appreciation, [and] intimate familiarity” (Plummer, 2001, p. 153) into a particular human experience. Life historians value the subjective experience by examining “how individuals talk about and story their experiences and perceptions of the social contexts they inhabit” (Goodson & Sikes, 2001, p. 1). Thus, life history research usually consists of smaller groups, ranging from 1 to 25 people, and draws on long in-depth interviews that amount in large quantities of rich data.

Lack of a Longitudinal Perspective

The interviews were conducted over the course of a few weeks, up to a month. The women’s stories were told at that particular time, and their feelings and views are representative of that period. If I were to interview the participants 12 months later, they would most likely feel and think differently about their loss and grieving. A longitudinal study could therefore help to offer a broader view of bereavement and how it can develop over time. However, life history can offer a different, retrospective longitudinal perspective in the sense that it presents a constructed chronological sequence of life events within a historical context that stretches across several years of a person’s life span, as was the case with the women’s life histories. More so, specific to this study was the unique contribution of a cross-generational perspective, and these implications will be better understood if future research continues to explore bereavement through life history methodology, particularly in

relation to the time pre-loss as well as longer time spans, which can identify potential intergenerational trauma relevant to loss and grieving.

One Person Shares Their Side of the Story

As the participants spoke of how they perceived their family relationships, I was aware that what was being told was their side of the story. The people that were spoken about were not there to share their perceptions with me. Indeed, this gave me a limited and one-sided set of data to work with. I was also aware that the women could misremember things, misunderstand themselves or others, exaggerate or understate an experience, or choose to withhold certain information. However, that does not by any means invalidate the women's accounts. I trusted the women to share their story (which they deemed appropriate to share) with me with the intention to tell me their honest perceptions (as they remembered them). I also trusted that they did not have the intent to paint someone as something they were not or to make false accusations or statements. Subsequently, my role as a researcher was to narrate to the reader what I had heard from my research participants and to do so in a way that was accurate and faithful to the women's accounts, but which gave it the added structure of an alternative narrator and an observable context. In light of this, I remained transparent about the notion that the stories shared by each woman arose from her perceptions and were retold by me through a life history framework. While it was not within the scope of this study, future studies could include additional family members (across generations if possible) and conduct a form of collective life history research that captures the perspective of various members within the same family across time. Certainly, these added voices would enrich the stories by adding personal perspectives and cross-generational contextual detail.

What Does Meaning Reconstruction Mean?

A previous study by Currier et al (2006) suggested that the gap between how participants understand meaning making and the operational definitions used by researchers can have implications for the outcomes of studies, since it impacts participants' responses to meaning-making questions. In their study, Currier et al (2006) asked their research participants: "How much sense would you say you have made of the loss?" (p. 412). Yet, participants interpreted this question to mean different things, and therefore their responses were not quite what the researchers expected. This was brought to light in the authors' assessment of the limitations of their study: "A further limitation obtains at the level of assessment of sense-making [...] The straightforward operational definition of this core construct limits our understanding of what is meant by sense-making when it is asserted by bereaved persons" (Currier et al., 2006, p. 423). Indeed, researchers must be sensitive to how to approach their topic of study in a manner that is accessible to their research participants, while at the same time collecting rich data from which meanings can be identified. I realised this dilemma early on and, more so, I could tell that the participants of my study were unsure of the meaning of 'meaning reconstruction', which is understandable given the complexity and abstract nature of the term's various conceptualisations. I worked around this difficulty during my interviews by asking open-ended questions to the women, which gave them the possibility to speak of their loss and grieving experience in their own way. They told their story as they wanted to, and at times I would step in and ask questions. My questions were focused on their story and did not mention meaning reconstruction itself, although they were guided by the framework of meaning reconstruction theory. I did not therefore ask my participants whether they had made sense of an experience or not, or what meanings they had found or made out of their experience. In fact, I had attempted to do this with my first research participant, during our first interview, and I quickly understood that this was simply

not going to work. They had little understanding of what I meant by those concepts (and I do not blame them).

The meaning reconstruction model as a theoretical framework is difficult to fully grasp without becoming caught up in that which is simply too abstract. Therefore, it was crucial that I tried to navigate through this fog as much as possible. I got a little closer to clarity by further refining some of the terminology and by expanding the model by adding a fourth meaning activity. Researchers ought to be more careful in how they refer to and use terms such as reconstructing, making and finding meaning, and be clear about the distinctions between terms. This will help to maintain a clearer consistency across studies and make it easier for subsequent research to relate to, and draw from, previous results and definitions.

Meaning Outcomes, not Processes

This research focused on meaning outcomes and the insights brought by them, but that leaves out a significant piece of information on how the participants arrived at such outcomes. Was it through finding or making meanings? These meaning processes, whether they occur through assimilation or accommodation, warrant further attention, as learning about these processes can help bereavement professionals and general counsellors to develop meaning-finding and -making strategies, which can be utilised by the bereaved to facilitate their loss and grieving, particularly those who are struggling to attach meaning to their loss.

Distinguishing Between Perceptions

This limitation concerns my positioning as a researcher within my research study. Once I had collected all the data and transcribed the women's narratives, I engaged with the material by rigorously dissecting it. I was therefore able to identify what I interpreted to be the meanings included within their accounts according to a modified meaning-centred model.

When doing so, I had to be careful to distinguish between the meanings as seen by the participants and how I saw them myself. When I was searching for the meaning outcomes within the participants' stories, I had to be careful not to jump to conclusions and project my own meanings onto their experience, or to confuse my meanings with theirs. When identifying and extracting examples of meaning activities and meaning outcomes from the data, I needed to carefully distinguish between what I perceived to be their intended meanings as distinct from my own. This was particularly the case when it came to the activity of sense making. There existed the sense making that was done by the participants as they constructed and joined events and experiences together to form their own narrative of how they perceived something to be. This was their story as told and put forward by them. Parallel with this there was my own sense making that took place when engaging with the data from the perspective of the researcher. During our interviews, while listening to each research participant's narrative, I would make connections between the events and experiences which she spoke about, and at times I would find patterns that emerged across several of the women's accounts. I would make my own interpretations around these connections, with regards to what was being said, which in some instances was slightly different from the participants' interpretations. More so, my interpretations evolved over time as I was listening to, transcribing, and analysing the recorded interviews. This further influenced my decisions on what data to use and which elements of their story to highlight. Thus, based on my interpretations, I then decided on how to link different parts of their story together in a way that would make sense to me as a researcher, to the reader, and to the storyteller herself. As I did this, my aim was to capture what I perceived to be the essence of our conversations as relevant to my research inquiry. Hence, my own sense making was present throughout this process, and it culminated in a standalone life history (constructed by me) for each woman that aimed to represent her life story (as told by her) in relation to her loss and grieving.

Each of the women's life histories has been put together by me, through my own interpretation and sense making, hence I (co-)constructed the life history from the data that had been collected and analysed by me. At the same time, long quotations from the women, as presented in each chapter (that were chosen by me), offered examples of the meanings embedded within their own stories. This required me to navigate the tension between my perceptions and what was told by me, and their perceptions and what was told by them, and I did my best to clarify these distinctions in explicit writing when I was presenting and discussing my findings. I also pointed out when my interpretation was not seen in the same light as the women themselves. Furthermore, I was aware that when making my own interpretations I had to be careful to not speculate or impose preconceived ideas onto the data. Instead, I allowed some room for sharing my own perspectives and observations without jumping to conclusions or assuming too much, while remaining faithful to the women's narratives and placing their voice at the centre of the life history.

Conclusions

This study explored five women's experiences of losing a parent in adulthood through life history methodology, and was located within a meaning-centred theoretical framework. The richness of the participants' narratives, and the construction and contextualisation of these into life histories, helped to offer an in-depth account of each of the five women's loss and grieving, including the meanings they had attached to their experiences. Based on these findings, my contribution to knowledge can be summarised into three main conclusions.

Firstly, the study contributes to the small but growing body of literature on adult children's experiences of parental death, adding to the discussion of an area that has mostly been overlooked in bereavement research. The research participants' narratives and their life histories confirm that the normative expectations surrounding the experience of losing a

parent in adulthood can underestimate how distressing, unexpected, and unpredictable this event can be. My findings highlight that although it is a common and often anticipated event, it nevertheless warrants more attention due to the significant impact it can have on the lives of adult children. The substantial difficulties seen in the bereaved also confirms the importance of having a supportive network of friends and family, and when necessary, support in other contexts, for example one's employment, the National Health Service, and charities like Macmillan Cancer Support and Death Cafés. More so, identifying challenges specific to the adult child can be helpful when developing strategies for (pre)bereavement support that are unique to their needs and life situations. This may be of particular importance to family members who take on the role as informal caregivers or have experienced forms of intergenerational trauma.

Secondly, the study lends support to the rapid development of postmodern bereavement studies, with a particular focus on exploring meanings embedded within narratives of loss and grieving. It demonstrates the value of the meaning-centred model (beyond regulating psychopathology) in yielding insight into narratives of loss and grieving. The meaning outcomes revealed insightful perspectives that informed the reader of how the women's grieving was experienced, including their different needs and priorities. Additionally, by critically engaging with the theoretical framework, the current study has added clarity to some of the model's terminology. This was done by proposing a name change from a *meaning reconstruction model* to a *meaning-centred model*, thus making a distinction between the title of the model and its meaning processes of finding and making meaning. This avoids potential confusion between the terms reconstruction, making, and finding meaning, as they are not synonymous and should not be applied as such (a valid critique of much previous research). I also decided to expand on the meaning-centred model's three meaning activities (sense making, benefit finding, and identity change) by including a

fourth meaning activity, which I titled: *assigning importance*. This helped me to include additional meanings identified within the narratives, which would otherwise have been overlooked. Lastly, a discussion was also raised as to whether identity change constitutes a meaning-finding/-making activity and meaning outcome, or whether it is a product of these. Indeed, this is a topic worthy of further investigation. These contributions may serve to expand on existing theories, as well as to generate new theories regarding meaning in bereavement, thus offering valuable insights for future research and practice.

Thirdly, the study lends substantial support to and extends life history methodology as a means of exploring and gaining insight into five women's experience of losing a parent in adulthood. It further demonstrates that life history methodology is a valuable method when exploring the influence of family history, specifically the parent-child relationship (including any intergenerational trauma) on loss and grieving. Through life history methodology, this study was able to honour the individuality of each woman's loss and grieving across time, while acknowledging the influence of historical, social, and some cultural factors relevant to her personal experience. More so, each life history presented a long timeline perspective, unique to its methodology, which concerned both the pre- and post-loss period. The timeline sometimes preceded the birth of the bereaved adult child by exploring the deceased parent's own history, thereby taking a cross-generational approach which, to the best of my knowledge, is innovative to life history research on bereavement. This timeline perspective revealed the impact of intergenerational trauma on grieving and emphasised that grieving not only concerns the time post-loss, but a significant part of this experience can also include the period leading up to the death. This was particularly the case for the women who had been caring for a sick parent. These are important findings which warrant further attention in research and consideration amongst bereavement professionals.

It is my hope that these insights can contribute towards an increased understanding of what it is like to lose a parent in adulthood and inform future conversations about adult children's loss and grieving amongst relevant stakeholders and the general public. More research in this area is encouraged to raise awareness of the multiple repercussions parental death can have on the bereaved adult child, giving adult children the attention they both need and deserve, and making their presence known in an academic field where they have too often been overlooked. This research can help bereavement practitioners to develop supportive practices specific to people who have lost a parent in adulthood. It can also provide a rich source of information that can educate the general public, particularly those who will lose or have lost a parent in adulthood, or those who come across a bereaved adult child within their social network. Such increased awareness can help dismantle disparities between the societal expectations of losing a parent during adulthood and how the adult child perceives the experience to be. It can further cultivate a social environment where their grieving is increasingly accepted and integrated as part of life, thereby lessening the risk of grief disfranchisement. Seen together, this can support people in becoming more adept at speaking about loss and grieving within families, social circles, and society in general, while providing bereaved adult children with necessary and well-informed support.

In addition to these conclusions, I wish to shed some light on alternative research methods to bereavement moving forward, particularly regarding arts-based research. My professional and educational background in dance and yoga is not academic in nature; thus, stepping into the academic field was daunting, and it has taken me time to find my place within it, in a way that feels comfortable and allows me to be true to who I am as a person. Although I chose to conduct a conventional PhD study and to keep a "clean" approach by solely focusing on life history research, I would love to explore more arts-based research methods in the future. This would allow me to cross methodological boundaries and combine

different methods more freely (Bagley & Cancienne, 2002). Arts-based approaches would also be particularly useful in bereavement research as more abstract forms of communication such as imagery, poetry, dance movement and so on, offer useful alternative ways to convey aspects of loss and grief that cannot be put into words (Thompson & Neimeyer, 2014). For example, as well as conducting interviews, I could also explore alternative ways of collecting data such as asking participants to draw an image of their story, or to enact their loss and grief through dance, song or poetry. In addition to (or instead of) presenting research through peer-reviewed journal articles, the data could also be presented in the form of an art exhibition, a movie, or a live performance of some kind. I believe that these approaches offer a way to work with research participants who feel more comfortable using channels that are different from traditional speech to tell their story, and a way to make research more accessible to those who are not drawn to, or indeed do not have access to, academic research literature (Leavy, 2018). Rather, arts-based methods allow people to seek something that is easier for them to relate to. I have already begun to explore such methods in two research projects that I conducted in parallel with my PhD studies, which focused on exploring how dance movement could act as a means to connect with and demonstrate the experience of loss and grief (Ramsby Herrera et al., 2018; Ramsby Herrera & Dilworth, 2019a, 2019b). These projects were presented in the form of a live dance and music performance, a short film that was screened at two arts festivals, and a published article in a peer-reviewed journal. I believe that this allowed for our research to be seen by a wider and more diverse audience than would have been possible if we had only spoken to a group of academics.

Closing Personal Reflections

It has been over 4 years since I began my doctoral studies in September 2017, and much has happened since. This journey, which has required patience, commitment and

persistence, has without a doubt had a strong impact on me. For example, on a personal level, my doctoral study brought me closer to my own experiences of loss and grief. Learning about bereavement in an academic context helped me to reflect on my father's death and to put words to internal experiences of loss and grief, which I had not been able to do before. Furthermore, by engaging closely with the women and their stories, there were aspects of their experiences that I deeply related to, which have without a doubt come to influence my views on certain matters. This particularly concerns two points, which I would like to highlight here: first, the felt expectations and "feeling rules" (Hochschild, 2012, p. 56) around loss and grief; and second, the role of the mother within the family.

I was not prepared for the personal and social expectations regarding feelings that I was faced with in the aftermath of my father's death. This lack of preparedness (can one ever be prepared?) left me in a state of confusion as to *what am I supposed to feel?* In the early days after his death, I remember being afraid of not feeling sad anymore, as if the lack of sadness would constitute me forgetting my father in some way. So, I held on to that sadness as much as I could, and sometimes I even induced it, as my tears would serve as a marker for the love I felt for Dad. I realise now that I was imposing my own "feeling rules" (Hochschild, 2012, p. 56) so as to minimise my guilt or worry about grieving in the *wrong* way. I also recall that shortly after Dad died, people expected me to travel abroad to be with my mother immediately after our loss (I lived in London, and my parents' home was in Sweden). I did not submit to these so-called "sanctions common to the social scene" (Hochschild, 2012, p. 58). In fact, the first time I saw my mum again was at my father's funeral a couple of months later. In that sense, my actions might have seemed inappropriate or strange to outsiders. Hochschild (2012) refers to this as the "inappropriate affect" (p. 59), which concerns "the absence of expected affect" (p. 59); yet, what was expected of me and what I needed in that moment were two different things. As part of my research, Hochschild's (2012) articulation

of feeling rules and emotional management helped to put words to these experiences, and her concepts also resonate with the women's accounts in this study. For example, Rachel spoke of how her feeling of relief was not something one was supposed to feel when one's mother had died. Amara questioned whether it was appropriate for her to lean on her son for support in her grief. Kim felt guilty about smoking marijuana in her room to take a break from her daily caregiving responsibilities, since she felt that she should have been spending that time with her sick parent instead. This has opened my thinking about the women's life histories, and my own, in relation to managing emotions and expectations in bereavement, and this is something that I want to explore in future research.

In three of the women's accounts, the late mother had been the silent force that held the family together, and who never complained about her responsibilities and sacrifices. Not only do I recognise this in my own mother's past and current behaviours, but I also recognise this in myself as a woman. This reflection becomes even more relevant to me now, as I am soon to become a mother myself (as I am writing this, I am 37 weeks pregnant). Indeed, it sensitises me to what kind of mother I want to be, and the relationship I wish to build with my future child as well as my husband. Like Amara, I do not want to become the self-sacrificing mother who puts others' needs first in front of her own. At the same time, I also admire these women (all research participants, and Amara's mother, Sophie's mother, Kim's mother, my own mother) for their strength, and hope that I too will have the same ability to face life's challenges with grace and grit, the way they have done.

As my research has come to an end, it feels like I have come "full circle". It was my father's death that ignited this study, and now I am standing at the very beginning of the birth of a new life – my unborn child. This makes me think of a question that many people have asked me over the course of this study: Is it not sad or difficult to research the topic of dying, death and grief? My response has not changed over the years. Although this topic does

require a significant degree of managing and handling emotions, my own and that of my research participants – what is conceptualised by Hochschild (2012) as “emotional labour” (p. 11) – I nevertheless find death to be one of the most beautiful human phenomena to explore, as it inspires us to learn about ourselves and to be fully present in our lives in the midst of uncertainty. In light of this, I wish to close my thesis with an ancient quote by the Japanese Buddhist monk Dōgen that was introduced to me by my late meditation teacher Michael Stone. A quote which serves as a useful reminder to us all:

Life and death are of supreme importance. Time swiftly passes by and opportunity is lost. Each of us should strive to awaken. Awaken! Take heed, do not squander your life.

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Appendix A

ETHICS APPLICATION FORM

Institute of Education



UCL

Doctoral Student Ethics Application Form

Anyone conducting research under the auspices of the Institute of Education (staff, students or visitors) where the research involves human participants or the use of data collected from human participants, is required to gain ethical approval before starting. This includes preliminary and pilot studies. Please answer all relevant questions in simple terms that can be understood by a lay person and note that your form may be returned if incomplete.

Registering your study with the UCL Data Protection Officer as part of the UCL Research Ethics Review Process

If you are proposing to collect personal data i.e. data from which a living individual can be identified you **must be registered with the UCL Data Protection Office before you submit your ethics application for review**. To do this, email the complete ethics form to data-protection@ucl.ac.uk. Once your registration number is received, add it to the form* and submit it to your supervisor for approval. If the Data Protection Office advises you to make changes to the way in which you propose to collect and store the data this should be reflected in your ethics application form.

Please note that the completion of the UCL GDPR online training is mandatory for all PhD students. The link is here: <https://www.ucl.ac.uk/legal-services/ucl-general-data-protection-regulation-gdpr/gdpr-online-training>

Section 1 Project details

a. .	Project title	The Lived Experience of Losing a Parent in Adulthood: Five
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		Life Histories of Adult Children.
b.	Student name and ID number (e.g. ABC12345678)	██████████ ██████████ ██████████
c.	*UCL Data Protection Registration Number	██████████ Date issued 16/07/2019
c.	Supervisor/Personal Tutor	Primary supervisor: John Vorhaus Secondary supervisor: Eleanore Hargreaves
d.	Department	Department of Education, Practice and Society
e.	Course category (Tick one)	EdD PhD <input checked="" type="checkbox"/> DEdPsy <input type="checkbox"/>
f.	If applicable, state who the funder is and if funding has been confirmed.	Not applicable. Non-funded project.
g.	Intended research start date	1 July 2019
h.	Intended research end date	1 September 2020
i.	Country fieldwork will be conducted in <i>If research to be conducted abroad please check www.fco.gov.uk and submit a completed travel risk assessment form (see guidelines). If the FCO advice is against travel this will be required before ethical approval can be granted:</i> http://ioenet.inst.ioe.ac.uk/about/profservices/international/Pages/default.aspx	United Kingdom
j.	Has this project been considered by another (external) Research Ethics Committee?	
	Yes <input type="checkbox"/>	External Committee Name:
	No <input checked="" type="checkbox"/> go to Section 2	Date of Approval:
<p>If yes:</p> <ul style="list-style-type: none"> - Submit a copy of the approval letter with this application. - Proceed to Section 10 Attachments. 		

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES) or Social Care Research Ethics Committee (SCREC). In addition, if your research is based in another institution then you may be required to apply to their research ethics committee.

Section 2 Research methods summary (tick all that apply)

- | | |
|--|---|
| <input checked="" type="checkbox"/> Interviews
<input type="checkbox"/> Focus groups
<input type="checkbox"/> Questionnaires
<input type="checkbox"/> Action research
<input type="checkbox"/> Observation
<input type="checkbox"/> Literature review | <input type="checkbox"/> Controlled trial/other intervention study
<input type="checkbox"/> Use of personal records
<input type="checkbox"/> Systematic review <input type="checkbox"/> <i>if only method used go to Section 5.</i>
<input type="checkbox"/> Secondary data analysis <input type="checkbox"/> <i>if secondary analysis used go to Section 6.</i>
<input type="checkbox"/> Advisory/consultation/collaborative groups
<input type="checkbox"/> Other, give details: |
|--|---|

Please provide an overview of the project, focusing on your methodology. This should include some or all of the following: purpose of the research, aims, main research questions, research design, participants, sampling, data collection (including justifications for methods chosen and description of topics/questions to be asked), reporting and dissemination. Please focus on your methodology; the theory, policy, or literary background of your work can be provided in an attached document (i.e. a full research proposal or case for support document). *Minimum 150 words required.*

What?

I will conduct a life history research project that aims to explore the process of grieving, in relation to meaning-making and identity formation, as experienced by five adults in the aftermath of losing a parent during adulthood. My thesis is that meaning-making and identity formation are two important aspects of grief, which are experienced in the aftermath of losing a parent as an adult child. I will explore this thesis and seek to identify to what degree it is relevant to the five adult participants in question, by investigating the following research questions: (i) How is the process of grieving experienced by five adults in the aftermath of losing a parent during adulthood?; (ii) What meaning do they make out of the experience of losing a parent?; and (iii) What is the influence of losing a parent on the identity of the adult child?

Why?

Through the focus of meaning-making and identity formation, I wish to highlight an aspect of the grieving process that has received limited attention in the field of bereavement studies, with particular regards to parental loss of adult children. This is reflected in the large number of studies that engage with childhood loss of a parent, with an absence of studies examining adult children's loss of a parent.

How?

I will conduct a qualitative methodology of life history research as this methodology seeks to explore, in great depth, a particular aspect of a human's lived experience within a larger socio-cultural context. For that reason, it is an appropriate methodology for exploring such a personal and intricate topic as grief in a contextualised manner. I will draw from three theoretical frameworks that resonate with and illuminate what I wished to explore in my research. These are Robert Neimeyer's meaning reconstruction approach (2000), Thomas Attig's (1996) theory on grief as re-learning the world, and Jack Mezirow's (2000) transformative learning theory. Neimeyer's (2000) and Attig's (1996) work is useful for challenging pathological and linear approaches to grief and for focusing on meaning-making and identity formation as part of the grieving process. Mezirow's (2000) work is useful for exploring what the person in question may have learnt from the bereavement experience, and how this may have transformed their felt sense of identity, which is partly constructed by their socio-cultural habitats, their habits of mind and frames of references.

Using opportunistic sampling through pre-existing channels, I will work with five adult research participants (25+ years) to gain enough breadth and depth of the topic in question. It is convenient for the purposes of my research, as it will allow me to invite people who have directly expressed an interest in my research, and who I have easy access to. I have chosen to collaborate with residents in the area of London since this is where my University is based and where I am part-time based. I will collect rich, detailed qualitative data, provided through extensive one to one interview conversations, linked to contextual information. Interviews will be audio-recorded and transcribed. Examples of questions asked include:

- Where did you grow up? What was your upbringing like? What part did your parents play in that?
- What was your relationship with your mother/father. What influence did it have on you as a person?
- What does this life artefact mean to you in relation to your parent?
- How did you first hear about the death? What were your first reactions?
- What does grief mean to you?
- How does the grief of having lost a parent express itself in your life?
- How do you at this day and age respond to your own loss?
- What are the external social or cultural influences on your experience of losing a parent?

For more information on the structure of interviews, see attachment appendix 4: *Interview procedure example*. Once data collection has been completed I will conduct a thematic analysis with an inductive approach, taking into account each adult's life story and contextualising it accordingly. The final thesis, once accepted, will be published and available to the public in the University repository and online. Subsequent publications may be made as well. However, the participant will have permission to withdraw from future publications if they want to.

Aims

- Develop a broader understanding of grief through a shift of focus, from viewing grief through a pathological lens, to conceptualising it as a socio-cultural process of meaning-making, identity formation, and transformational learning.

- Contribute to the literature on parental loss in adulthood as well as adding a valuable dimension to life history research methodology.
- Bringing awareness to a sensitive topic that happen to most people at some point in their life. Even though it may be considered a normal life event it doesn't make it less significant thus it also needs to receive attention and be given a voice.
- Inform how future empirical researchers design and conduct their research, which may contribute to the development of new theories and conceptions of grief which support both professionals working in the field as well as the bereaved adult child.

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Section 3 Research Participants (tick all that apply)

Tick <input type="checkbox"/> Early years/pre-school <input type="checkbox"/> Ages 5-11 <input type="checkbox"/> Ages 12-16 <input type="checkbox"/> Young people aged 17-18	<input checked="" type="checkbox"/> Adults <i>please specify below</i> <input type="checkbox"/> Unknown – specify below <input type="checkbox"/> No participants See attachment "Ethical issues and risk assessment" for choice of sampling
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NB: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES) or Social Care Research Ethics Committee (SCREC).

Section 4 Security-sensitive material (only complete if applicable)

Security sensitive research includes: commissioned by the military; commissioned under an EU security call; involves the acquisition of security clearances; concerns terrorist or extreme groups.

Will your project consider or encounter security-sensitive material?	Yes <input type="checkbox"/> *	No <input checked="" type="checkbox"/>
Will you be visiting websites associated with extreme or terrorist organisations?	Yes <input type="checkbox"/> *	No <input checked="" type="checkbox"/>
Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?	Yes <input type="checkbox"/> *	No <input checked="" type="checkbox"/>

* Give further details in **Section 8 Ethical Issues**

Section 5 Systematic reviews of research (only complete if applicable)

- | | | | |
|----|--|--------------------------------|-----------------------------|
| a. | Will you be collecting any new data from participants? | Yes <input type="checkbox"/> * | No <input type="checkbox"/> |
| b. | Will you be analysing any secondary data? | Yes <input type="checkbox"/> * | No <input type="checkbox"/> |

* Give further details in **Section 8 Ethical Issues**

*If your methods do not involve engagement with participants (e.g. systematic review, literature review) **and** if you have answered **No** to both questions, please go to **Section 8 Attachments**.*

Section 6 Secondary data analysis (only complete if applicable)

a.	Name of dataset/s		
b.	Owner of dataset/s	340	
c.	Are the data in the public domain?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
		<i>If no, do you have the owner's permission/license?</i> Yes <input type="checkbox"/> No* <input type="checkbox"/>	
d.	Are the data special category personal data (i.e. personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation)?	Yes* <input type="checkbox"/>	No <input type="checkbox"/>
e.	Will you be conducting analysis within the remit it was originally collected for?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>
f.	If no , was consent gained from participants for subsequent/future analysis?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>
g.	If no , was data collected prior to ethics approval process?	Yes <input type="checkbox"/>	No* <input type="checkbox"/>

* Give further details in **Section 8 Ethical Issues**

*If secondary analysis is only method used **and** no answers with asterisks are ticked, go to **Section 9 Attachments**.*

Section 7 Data Storage and Security

Please ensure that you include all hard and electronic data when completing this section.

a.	<p>Data subjects - Who will the data be collected from?</p> <p>I will be collecting all the data from 5 adult participants, of any gender, ethnicity, class or sexuality, aged 25+, and based in the UK.</p>
b.	<p>What data will be collected? Please provide details of the type of personal data to be collected</p> <p>I will conduct in-depth interviews which will be audio recorded digitally. These interviews will explore the participants' experiences of having lost their parents as adult children. The interviews will be free-flowing, but a number of questions will be used to drive the interviews. In addition, participants can engage with life history artefacts that enable them to make sense of their experiences. These audio recordings will be transcribed digitally as well by myself. All the collected data will be stored in an encrypted file on my encrypted laptop computer. I will be the only one who has direct access to these. For the type of data collected, questions asked and the procedure of interviews please refer to section 2 in this document and appendix 4: <i>Interview procedure example</i>. For storage of data and the following of GDPR regulation, please</p>

refer to appendix 1: <i>Ethical issues and risk assessment</i> and appendix 2: <i>Information sheet example</i> .	
c.	<p>Is the data anonymised? Yes <input type="checkbox"/> No* <input checked="" type="checkbox"/></p> <p>Do you plan to anonymise the data? Yes* <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p>Do you plan to use individual level data? Yes* <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p>Do you plan to pseudonymise the data? Yes* <input checked="" type="checkbox"/> No <input type="checkbox"/></p> <p><i>* Give further details in Section 8 Ethical Issues</i></p>
<p>i. Disclosure – Who will the results of your project be disclosed to?</p> <p>The raw data will only be shared with my supervisors and the research participant in question. The final representation of my findings will be publicly published as part of my doctoral thesis through my Universities repository and online library. My thesis will also be shared directly with the research participants as they will receive their own digital copy of my doctoral thesis upon completion. Subsequent publications may be done as well. The participants have the right to withdraw from subsequent publications if they want to.</p>	
<p>e. ii. Disclosure – Will personal data be disclosed as part of your project?</p> <p>The research participants will be anonymized and made non-identifiable in the published thesis by changing names, locations and if necessary also modifying life events to the degree where they are not exposed in a way that may risk compromising their anonymity. In my written and published thesis I will present personal data about myself in relation to my personal life history in relation to the research topic with the purpose of being transparent with regards to my background and the influence this has on my work as a researcher. See appendix 1: <i>Ethical issues and risk assessment</i> for more information.</p>	
<p>Data storage – Please provide details on how and where the data will be stored i.e. UCL network, encrypted USB stick**, encrypted laptop** etc.</p> <p>The data will be stored on my personal encrypted laptop in an encrypted file. My laptop is secured through a Virtual Private Network, an anti-virus software and a password protecting software. I will further have a full back-up secured on an encrypted folder through my personal encrypted Dropbox account that I have sole access to.</p> <p>** Advanced Encryption Standard 256 bit encryption which has been made a security standard within the NHS</p>	
g.	<p>Data Safe Haven (Identifiable Data Handling Solution) – Will the personal identifiable data collected and processed as part of this research be stored in the UCL Data Safe Haven (mainly used by SLMS divisions, institutes and departments)?</p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p>
h. How long will the data and records be kept for and in what format?	

<p>The data will be saved as digital documents on an encrypted file on my personal encrypted laptop. I have sole access to this. According to the UCL Code of Conduct for Research, upon the completion of my research study and the publication of the thesis, all the stored data will be kept for 10 years from the date of publication of my thesis and the “data which has been stored should be checked periodically to ensure that it remains accessible should it be necessary to consult this data” (accessed on UCL’s website, 11 Aug 2019). Once it passes the 10 year mark, I will permanently delete all the data.</p> <p>Will personal data be processed or be sent outside the European Economic Area? (If yes, please confirm that there are adequate levels of protections in compliance with GDPR and state what these arrangements are)</p> <p>No</p> <p>Will data be archived for use by other researchers? (If yes, please provide details.)</p> <p>No</p>
<p>If personal data is used as part of your project, describe what measures you have in place to ensure that the data is only used for the research purpose e.g. pseudonymisation and short retention period of data’</p> <p>None of the raw data will be disclosed to anyone but myself, the research participants and my supervisors. The completed data analysis and representation will be presented as part of my thesis and made public upon approval from the research participants in question and my supervisors. All the research participants will be kept anonymous and I will replace their names with pseudonyms and ensure that they, and the people whom they have mentioned during interviews, are not identifiable.</p>
<p><input type="checkbox"/> * Give further details in Section 8 Ethical Issues <input type="checkbox"/></p>

Section 8 Ethical issues

Please state clearly the ethical issues which may arise in the course of this research and how will they be addressed.

All issues that may apply should be addressed. Some examples are given below, further information can be found in the guidelines. *Minimum 150 words required.*

- | | |
|---|--|
| <ul style="list-style-type: none"> - Methods - Sampling - Recruitment - Gatekeepers - Informed consent - Potentially vulnerable participants - Safeguarding/child protection - Sensitive topics | <ul style="list-style-type: none"> - International research - Risks to participants and/or researchers - Confidentiality/Anonymity - Disclosures/limits to confidentiality - Data storage and security both during and after the research (including transfer, sharing, encryption, protection) - Reporting - Dissemination and use of findings |
|---|--|

Please see attached document on “Appendix 1: Ethics issues and risk assessment”.

Please confirm that the processing of the data is not likely to cause substantial damage or distress to an individual Yes

Section 9 Attachments Please attach the following items to this form, or explain if not attached

Information sheets, consent forms and other materials to be used to inform potential participants about the research (<i>List attachments below</i>)	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
<ol style="list-style-type: none"> 1. Ethical issues and risk assessment 2. Information sheet example 3. Consent form example 4. Interview procedure example 5. Suggested Timetable 		
<i>If applicable/appropriate:</i>		
Approval letter from external Research Ethics Committee		Yes <input type="checkbox"/>
The proposal (‘case for support’) for the project		Yes <input type="checkbox"/>
Full risk assessment		Yes <input type="checkbox"/>

Section 10 Declaration

I confirm that to the best of my knowledge the information in this form is correct and that this is a full description of the ethical issues that may arise in the course of this project.

I have discussed the ethical issues relating to my research with my supervisor. YES

I have attended the appropriate ethics training provided by my course. YES

I confirm that to the best of my knowledge:

The above information is correct and that this is a full description of the ethics issues that may arise in the course of this project.

Name	Maria Eleonora Ramsby Herrera
Date	25 th of August 2019

Please submit your completed ethics forms to your supervisor for review.

Notes and references

Professional code of ethics

You should read and understand relevant ethics guidelines, for example:

British Psychological Society (2018) *Code of Ethics and Conduct*

or

British Educational Research Association (2018) *Ethical Guidelines*

or

British Sociological Association (2017) *Statement of Ethical Practice*

Please see the respective websites for these or later versions; direct links to the latest versions are available on the Institute of Education

<http://www.ucl.ac.uk/ioe/research/research-ethics>

Disclosure and Barring Service checks

If you are planning to carry out research in regulated Education environments such as Schools, or if your research will bring you into contact with children and young people (under the age of 18), you will need to have a Disclosure and Barring Service (DBS) CHECK, before you start. The DBS was previously known as the Criminal Records Bureau (CRB) . If you do not already hold a current DBS check, and have not registered with the DBS update service, you will need to obtain one through at IOE.

Ensure that you apply for the DBS check in plenty of time as will take around 4 weeks, though can take longer depending on the circumstances.

Further references

The www.ethicsguidebook.ac.uk website is very useful for assisting you to think through the ethical issues arising from your project.

Robson, Colin (2011). *Real world research: a resource for social scientists and practitioner researchers* (3rd edition). Oxford: Blackwell.

This text has a helpful section on ethical considerations.

Alderson, P. and Morrow, V. (2011) *The Ethics of Research with Children and Young People: A Practical Handbook*. London: Sage.

This text has useful suggestions if you are conducting research with children and young people.

Wiles, R. (2013) *What are Qualitative Research Ethics?* Bloomsbury.

A useful and short text covering areas including informed consent, approaches to research ethics including examples of ethical dilemmas.

Departmental use

If a project raises particularly challenging ethics issues, or a more detailed review would be appropriate, the supervisor **must** refer the application to the Research Development Administrator (via ioe.researchethics@ucl.ac.uk so that it can be submitted to the IOE Research Ethics Committee for consideration. A departmental research ethics coordinator or representative can advise you, either to support your review process, or help decide whether an application should be referred to the REC. If unsure please refer to the guidelines explaining when to refer the ethics application to the IOE Research Ethics Committee, posted on the committee's website.

Student name	
Student department	
Course	
Project title	
Reviewer 1	
Supervisor/first reviewer name	John Vorhaus
Do you foresee any ethical difficulties with this research?	No, but see TW note below
Supervisor/first reviewer signature	
Date	2.9.19
Reviewer 2	
Second reviewer name	Tom Woodin
Do you foresee any ethical difficulties with this research?	Clearly the relations with interviewees will have to be managed carefully based on an awareness of the boundaries of academic research. But the student is well-prepared and has given considerable thought to these issues.
Supervisor/second reviewer signature	
Date	2/9/19
Decision on behalf of reviews	
Decision	Approved <input type="checkbox"/>
	Approved subject to the following additional measures <input type="checkbox"/>
	Not approved for the reasons given below <input type="checkbox"/>
	Referred to REC for review <input type="checkbox"/>
Points to be noted by other reviewers and in report to REC	
Comments from reviewers for the applicant	

Once it is approved by both reviewers, students should submit their ethics application form to the Centre for Doctoral Education team: IOE.CDE@ucl.ac.uk.

Appendix B
INFORMATION SHEET

The Lived Experience of Losing a Parent in Adulthood:

Five Life Histories of Adult Children.

My name is Maria Eleonora Ramsby Herrera and I am inviting you to take part in my research project *The Lived Experience of Losing a Parent in Adulthood: Five Life Histories of Adult Children*. I am a PhD candidate in the department of Education, Society and Practice, the Institute of Education at University College London and this research project is part of my PhD studies.

I will conduct a study which aims to find out what the grieving process is like for an adult who has lost a parent to death during adulthood, how they make meaning out of losing a parent and whether or not this has influenced their identity in any way. This project has been reviewed and approved by the UCL IOE Research Ethics Committee. Further details of the project can be given in the answers to the questions on page 2-4. Please feel free to contact me if there is anything else you would like to know.

I very much hope that you would like to take part.

Thank you for your time,

Maria Eleonora Ramsby Herrera

UCL Institute of Education

The Department of Education, Society and Practice

20 Bedford Way, London WC1H 0AL

Who is carrying out the research?

I will be carrying out the research under the supervision of my primary supervisor Professor John Vorhaus and secondary supervisor Dr. Eleanore Hargreaves.

Why are we doing this research?

I hope to answer the following main research questions through my study,

1. How is the process of grieving experienced by five adults in the aftermath of losing a parent during adulthood?
2. What meaning do they make out of the experience of losing a parent?
3. What is the influence of losing a parent on the identity of the adult child?

Through the focus of meaning-making and identity formation, I wish to highlight an aspect of the grieving process that has received limited attention in the field of bereavement studies, with particular regards to parental loss of adult children.

Why am I being invited to take part?

I am looking to work individually with five adult research participants who have experienced losing a parent during adulthood. I am aware that this is a life experience that you have had and therefore I wish to invite you to take part in my study. I have reached out to you specifically because we have a pre-existing relationship or you have been connected with me through a mutual contact. By sharing your experience about losing a parent, you would contribute with valuable insight to the field of bereavement studies. This can help to support future research in the field as well as helping other people who have had a similar experience to yourself to gain further understanding about what it can be like to lose a parent in adulthood.

What will happen if I choose to take part?

We will schedule four interview conversations over the course of autumn 2019. The interviews will take place in the privacy of your own home, or another preferred location, at a time that is convenient for you. Interview conversations are audio recorded to ensure that what you share is captured accurately. Interviews may vary in time range between 1-2 hours. We

will mutually decide how much time is spent on each occasion. Example of interview questions are:

- Where did you grow up? What was your upbringing like? What part did your parents play in that?
- What was your relationship with your mother/father? What influence did it have on you as a person?
- How did you first hear about the death?
- What were your first reactions?
- What does grief mean to you?
- How does the grief of having lost a parent express itself in your life?
- How do you respond to your own loss?
- What are the external social or cultural influences on your experience of losing a parent?

After each interview, I will offer to do a brief check-in with you a couple of days later over phone or e-mail to see how you are and whether or not you wish to share any further reflections with me. The audio recordings from the interviews will be transcribed into written transcripts. I will select relevant sections for the research study. You will be invited to read through the transcripts and comment on them, make alterations and/or ask me to delete any information you wish not to share. It is up to you whether or not you wish to do so, and how little or how much you wish to participate in this process.

Once the interviews are completed and have been transcribed, I will analyse the findings and include it in my PhD thesis. I will present longer quotes of what has been said by you along with my own interpretation and discussion around the topic. To safeguard your privacy and ensure anonymity, all the names will be changed, and locations and some life events might be changed, to ensure your anonymity and the anonymity of other people that

may have been mentioned. The research process and the raw data remains confidential and is only shared and discussed between yourself, me and my two supervisors. Once the thesis is completed, it will be published and available for the public through my PhD thesis. You will receive your own digital copy of the thesis as a token of appreciation for your time and participation. Subsequent publications in other journals, books etc. may be done as well. You reserve the right to withdraw from any future publications subsequent to the PhD thesis should you wish to do so.

Do I get paid to participate?

This research study asks for your voluntary participation. Thus, there are no funds to compensate you for your participation.

Is this therapy?

No. I am not a qualified therapist nor is it my intention to offer a therapeutic intervention. The study is for research purposes only i.e. to understand more about the topic in question through your shared insights. I, as a researcher, cannot take on the responsibility and the role of a therapist, however I am happy to offer you referrals if you feel the need to see a therapist as a result of this participation. I hope that you will still find value and enjoyment in sharing to talk about your parent despite the fact that I am not a professional therapist.

Will anyone know I have been involved in this research?

Only my supervisors and myself will know that you have been involved. I will not share the information with anybody else nor will I involve other members of your family. However, if I experience concerns about your welfare then it is my obligation to ensure that your safety and welfare comes first and if this means that I need to disclose information to a third party then I will need to do so. It is completely up to you if you wish to discuss your participation in this research study with your own circle of friends and family.

Could there be problems for me if I take part?

We will be speaking about a sensitive topic that is deeply personal to you and you might experience distress due to this. I will pay great attention to ensure that your participation in this research project does not compromise your well-being and I will do my best to handle our research collaboration with great care, respect and sensitivity. For example, if I feel that we need to take a break during an interview conversation or change the topic slightly, then I will take those initiatives with the intent to ameliorate any stress that may have been caused to you. You are free to take a break at any time, you are free to stop the interview at any time, and if you feel that you have over-disclosed anything then you are free to ask me to change or delete anything which you do not want to be shared. If you wish to withdraw from the research then you are free to do so at any time up until the publication of the PhD thesis without any negative repercussions.

Depending on whether or not you choose to notify your family about your research participation, you might experience questions or opinions from their part that could cause you distress. It is up to you whether or not you choose to disclose any information to your friends and relatives about your participation. If you feel that you wish to speak to someone about the process, but don't know who to reach out to, then I am happy to offer you some referrals to local bereavement support groups and counselling services, which you can access if you feel the need.

What will happen to the results of the research?

The results of the research will be published in my PhD thesis and available to the public. Subsequent publications in other journals, books etc. may be done as well.

How will my data be stored?

According to the UCL Code of Conduct for Research, upon the completion of this research study and the publication of the PhD thesis, all the stored data will be kept for 10 years from the date of publication of this thesis. The data will be stored in encrypted folders on my

encrypted computer, with me being the only person with sole access to it. After this 10 year mark all your stored data will be permanently deleted.

Do I have to take part?

You have complete freedom to decide whether or not you want to participate in this research project. I hope that if you do choose to be involved then you will find it a valuable experience. If you choose to participate but at a later stage wish to withdraw, then you are free to do so at any point in time without any negative repercussions. Upon withdrawal, all stored data related to you will be deleted.

Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk. Further information on how UCL uses participant information can be found here: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice> The legal basis that would be used to process your *personal data* will be performance of a task in the public interest. The legal basis used to process *special category personal data* will be for scientific and historical research or statistical purposes/explicit consent. *Your personal data will be processed so long as it is required for the research project.* If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Consent form and information sheet

If you wish to decide to participate in this research study then you will be required to fill out a consent form. If we together wish to amend the consent form the information sheet to better suit your needs then we will mutually agree on the terms of the information sheet and the consent form before signing. The signed consent form will be signed as a paper copy and digitally scanned for archive purposes. The digital copy of the consent form will be saved as an encrypted file on my encrypted laptop. Additionally, one signed paper copy of the consent form will be given to yourself and one for me. I will keep it safely archived in a place where only I have access to it.

Further questions?

If you have any further questions before you decide whether to take part, you can reach me at:

Thank you very much for taking the time to read this information sheet.

Maria Eleonora Ramsby Herrera.

Appendix C
CONSENT FORM

The Lived Experience of Losing a Parent in Adulthood:

Five Life Histories of Adult Children.

If you are happy to participate in this study, please complete this consent form by signing it and returning it to Maria Eleonora Ramsby Herrera in person.

- I have read and understood the information sheet provided together with this consent form. **Yes / No**
- I have been given the opportunity to ask questions about my participation. **Yes / No**
- I understand that taking part in the research will involve being interviewed and audio recorded. **Yes / No**
- I understand that the intention for this research study is for research purposes only and it is not considered to be therapy or a therapeutic intervention. **Yes / No**
- I understand that my data will be anonymised and given a pseudonym. **Yes / No**
- I understand that I can withdraw from this research at any time up until the publication of the PhD thesis, and that if I choose to do this, any data I have contributed will not be used and it will be deleted. **Yes / No**
- I understand that I can contact Maria Eleonora Ramsby Herrera at any time and request for my data to be removed from her database. **Yes / No**

- I understand that the results will be published in the PhD thesis of Maria Eleonora Ramsby Herrera and made available for the public. Subsequent publications may be made as well. I am informed that I am free to withdraw permission from any future publication subsequent to the PhD thesis should I wish to do so.

Yes / No

- I understand that once the research project has been completed and the PhD thesis has been published, the stored data will be kept by Maria Elenora Ramsby Herrera for 10 years from the date of publication of her PhD thesis. This is done according to the requirements of the UCL Code of Conduct for Research. The stored data will be kept in an encrypted folder in an encrypted computer. Only Maria Eleonora Ramsby Herrera has access to it. I am informed that my data will be permanently deleted after the 10-year mark.

Yes / No

Full name of research participant, date and location

Full name of researcher, date and location

Contact details

Researcher's name:

Maria Eleonora Ramsby Herrera

E-mail:

Phone number:

UCL Institute of Education
The Department of Education, Society and Practice
20 Bedford Way, London WC1H 0AL

Appendix D**TRANSCRIPT EXAMPLE**

Eleonora: Was this in those next three months of waiting for the next appointment?

Kim: Yes. Yeah, so we had another one in January [2018] and that's when they confirmed that yeah it was back, and there wasn't going to be anymore chemo at this point because it was just going to be too detrimental and from that point then, you are, well you're waiting for the end. You're sort of, we didn't have the mindset of "Okay! We're going to go and do everything and brace life and live it to the fullest!!!!" [said in an optimistic and determined way] You know however long she's got.. she just carried on with her normal routine and being the solid mum in the house. And I can't even remember, yeah there were no more hospital after that so from January until May it was just her getting weaker, I would you know... towards the end she got up for the toilet in the middle of the night to just hold her while she was on the loo. And I tried to be there as much as I could in terms of [stopping herself], in terms of [stopping herself] I'm going to have to stop a minute....

[a few minutes pause]

Eleonora: Why do you think it's patchier, the memories?

Kim: I think she suffered more than daddy, and I've, and I've pushed that suffering away. I think she... [crying] She suffered much more [silent pause]. Physically...,

Eleonora: Was it longer?

Kim: It was about the same length of time actually, it was about a two year illness.

Eleonora: Was there anything particular that made this worse for her?

Kim: She had the operation, he didn't have any of that. He did have chemo but you know, they mutilated her really. That's what I think about now. Pointlessly. And stupid

doctors like I said, the follow up after the operation the doctor said “Oh it was bigger than we thought when we pulled it out we nearly pulled you off the operating table!”

Eleonora: How did you respond to that?

Kim: You just can't respond, I mean... shocking. Shocking, disrespectful.