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***You Only Live Twice: A constructivist grounded
theory study of
the creation and inheritance of digital afterlives***

by

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A thesis submitted in partial fulfilment of the
requirements for the degree of Doctor of Philosophy in
Sociology

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Declaration

The work presented in this thesis is entirely my own work and has not been submitted, in full, or in part, for the award of a higher degree at any other educational institution. Selections of this thesis have been published in peer reviewed journals, presented at conferences or disseminated via media outlets. All of these materials arose from working on this thesis during my period of study and are detailed in appendix 4.

Abstract

We live in a digital era, where ubiquitous social media is a part of the everyday lives of many. Social media platforms were designed for the living; however, they are being used to nurture ongoing relationships with the dead, and are increasingly being used to discuss death, dying and grieving. In this digitized world, technology exists that enables us to create avatars that will allow us to “live forever” and advise future generations. This convergence of death related issues and technology has become a growing and important area of research across many disciplines. Using qualitative methods, this thesis advances existing research by focusing on the creation and inheritance of digital messages, social network profiles, thanablogs, posthumous chatbots, posthumous messages, and posthumous avatars. I interviewed 48 participants in-depth, utilising a qualitative approach based on constructivist grounded theory to explore the data. In this thesis, using the voices of the participants, I will demonstrate how digital afterlives, enabled by thanatechnology, are far more than data as they are experienced by the bereaved as possessing the essence of the dead. Moreover, ubiquitous smart technology ensures the dead permeate into the everyday lives of the living, which this study will show, challenges existing models of bereavement.

The original contribution to knowledge presented in this thesis and generated from the research data is my substantive grounded theory of The Fear of Second Loss. This emergent theory describes the fear of losing precious data which contains the essence of the dead; the Fear of Second Loss is a nascent phenomenon rising from the inheritance of digital afterlives. Digital afterlives are not permanent: obsolete technology and platform failure can lead to digital erasure, and in our digital society it may be worth remembering – you only live twice.

Abbreviations

AI	Artificial intelligence
DAI	Digital afterlife industry
DC	Digital creators
DDNR	Digital do not reanimate
DI	Digital inheritors
DMAM	Digital memories and messages
DNR	Do not resuscitate
HCI	Human computer interaction
QDA	Qualitative data analysis
SNS	Social network site
SP	Service providers
STS	Science, technology and society
TSD	Thanatosensitive design
UK	United Kingdom
USA	United States of America

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1 Chapter One: Introduction

“Did you know that a man is not dead while his name is still spoken?”

Going Postal – Terry Pratchett

1.1 Background

Nine years ago, my friend’s daughter, Annie, died suddenly aged 18. At the time of her death she had an active Facebook page, and, on this page, Annie still appears socially “alive”, as her page is updated and photographs occasionally changed and added. I became interested in why my friend – and many others – still spoke to Annie as though she was still alive on her Facebook page. At this time Facebook allowed pages to be memorialised after the death of a user, however, some users choose not to do this as this results in some of the content being archived and therefore not accessible by the bereaved. Not informing Facebook of her death, and not deleting the account, enables Annie, and many others, to appear socially active in a digital afterlife. Some companies go further in their ability to create digital afterlives, using artificial intelligent algorithms to create digital doppelgängers, which they claim could interact with the world after your biological death. This technology is providing a new medium for people to communicate with, and to foster ongoing relationships with the dead. Considering grief and technology, I began to wonder how this type of posthumous digital endurance was being experienced by the bereaved. Moreover, I wanted to understand the platforms being used by those creating and inheriting digital afterlives: my research had begun.

1.2 Taxonomy

In a 2015 paper, I called for further discussions around the terminology being used by thanatologists who explore posthumous digital endurance (Bassett 2015). Since this area of research is relatively new, I found no suitable framework existed to categorise what I identified as three distinct areas: the types of digital participants that exist; the types of messages and memories being created; and, the types of websites being provided and utilised to create digital afterlives. Therefore, in order to fully explore how the creators and inheritors of digital afterlives are experiencing

digital artefacts, I devised a framework which has been adopted throughout the thesis. This short section is meant to introduce these terms and be used as a reference page when reading this thesis.

First, I became aware that the term digital legacy was being used interchangeably to describe very different aspects of online, posthumous digital artefacts. In my 2015 paper, I suggested using two different terms in an effort to clarify the data being described: “digital legacy” should be used for passwords, account information and digital assets, while “digital selves” should be adopted to describe personal videos, messages, photographs and blogs. This suggested terminology is discussed further in Chapter two.

Second, in an effort to achieve my research aims I began to recruit participants. From the start of this recruitment process I realised that to treat the participants as a single group was unhelpful, as their experiences and motivations were linked to their roles in the creation and inheritance of digital afterlives. I needed to distinguish between the various people who were involved as they had different – but sometimes overlapping – characteristics. Table 1 below shows the categorisation of those involved in the creation of digital afterlives: however, it should be noted that these participant categories are not mutually exclusive, as will be discussed in Chapter three. A total of 48 in-depth interviews were conducted with participants across three categories (SPs, DCs and DIs).

Category	Abbreviation	Description
Digital Creator	DC	The creators of posthumously persistent digital memories and messages
Digital Inheritor	DI	Those who inherit the digital memories and messages enabled by thanatechnology
Service Provider	SP	Company whose websites, SNSs and Apps enable the creation of enduring digital artefacts

Table 1.1 Categorisation of participants involved in the creation of digital afterlives

During an initial review of the existing literature in the field of thanatechnology, I realised that all types of posthumous digital artefacts were being discussed as if they were one category. I identified a need to distinguish between messages and

memories *intentionally* created to be left after the death of the creator, and those that *accidentally* become posthumous digital artefacts. Table 2 shows this distinction – described further in Chapter four.

Category	Description
Intentional digital message or memory	Messages intentionally created to be inherited by DIs OR DIs messaging the dead as though still alive
Accidental digital message or memory	Not intentionally created to be delivered posthumously

Table 1.2 Categorisation of the intentionality of the DCs

With the above taxonomy in place for my participants, I noted in the literature that digital afterlife platforms were also being discussed as one homogenous group. Once again using “intentionality” as a basis, I categorised the two different types of platforms involved in the creation and storage of posthumous digital artefacts memories and messages. Table 3 shows this distinction, which is explored further in Chapter four.

Category	Purpose	Example
Accidental posthumous site	Designed for the living	Facebook, Twitter
Intentional posthumous site	Designed for the dead	LifeNaut, Eternime

Table 1.3 Categorisation of the intentionality of the SPs

In my 2015 paper, I also introduced the term “digital zombies” to describe a posthumous, digital representation of the deceased: whereby the deceased are resurrected and reanimated and do things in death they did not do when alive. For example, avatars and thanabots. The term “digital zombies” is useful when discussing SPs, as it distinguishes between the creation of posthumous digital memories and messages, and the reanimation of the dead. Moreover, the term makes visible any differences in the impact of these two types of posthumous creations.

1.3 Thesis topic

The ubiquitous nature of hardware technology, such as smartphones and wearable technologies, ensure social networking sites have become part of the everyday “norms” and routines of many people. The proliferation of social media platforms and the omnipresent nature of smart technologies have resulted in social media becoming a fundamental part of people’s lives in the early 21st century. Since its advent in 1982, the Internet has fundamentally changed our cultural understanding of social interactions and personal relationships by mediating our daily lives. However, whilst some use these sites to report important – and not so important – life events, others are using these sites to discuss the serious, complex and emotive issues of death, dying and grieving. It is hardly surprising that we have appropriated this technology to communicate with and remember the dead: loss is experienced personally, but it also takes place within a socio-cultural and framework and human-computer interaction (HCI) is creating a new space for death and mourning (Brubaker 2013). This new space is expanding: it is estimated by 2100 around 1.4 billion Facebook users will have died. This estimate assumes Facebook still exists in 2100 but attracts no new users (Öhman & Watson 2019). Therefore, the emerging field of scholarship concerned with the data of the dead will become evermore important if we are to understand the impact of enduring digital afterlives.

Before this digital era, how we remembered the dead was a matter of individual and collective memory through the stories and biographies we painted of our loved ones; sometimes in abstract, sometimes in fine detail. However, these precious memories and messages are now mediated through apps, bots, small enterprises and global companies. This thesis is an invitation to consider how our social media presence – including digital messages, social network profiles, thanablogs, posthumous chatbots, posthumous messages, and posthumous avatars – are engendering digital afterlives, and how these digital afterlives are being experienced by their creators and their inheritors.

The impact of thanatechnology is a growing area of research across many different disciplines including sociology; HCI; Science, Technology and Society (STS); cyberpsychology; death studies; and psychology. My study aims to contribute and

expand on the growing number of studies by adopting qualitative methods and a constructivist grounded theory methodology, so as to holistically explore the nature and impact of digital afterlives enabled by thanatechnology. This study is underpinned by constructivist grounded theory within a symbolic interactionist theoretical perspective. Throughout this thesis, I will present screenshots of memos created within NVivo which documents the coding and conceptual decisions made during this research. Moreover, in order to be transparent, I will acknowledge how my experience, decisions and interpretations as a researcher (Charmaz 2014) have affected the research process.

The way we remember, celebrate and communicate with the dead is changing in our digital society, and the Internet, social media and smartphone technology are changing the vernacular around death dying and grieving. However, the presence of the dead within culture and society is nothing new. The Victorians took photographs of the dead as a way of sharing the death of a loved one with relatives or friends unable to attend the deathbed or funeral: funeral selfies and live streaming of funerals can be seen as a technologically mediated continuation of this cultural practice. However, in our networked society the dead are with us as we go about our everyday lives – within our mobile devices and in the palm of our hands. Accordingly, this study looks at the impact this co-presence of the dead is having on the “norms” and cultural practices of grief and bereavement.

As this thesis will show, digital afterlives may be altering how we view the dichotomous states of being alive or being dead. In cyberspace these states are becoming blurred. Crucially, as I will demonstrate in this thesis, the presence of digital afterlives is not a denial of death on the part of the bereaved – they know the dead are dead – however, it appears that for many, the dead are still part of their everyday lives. Following the collection and analysis of the data, I will describe how posthumous digital artefacts are deemed to embody the essence of the dead, before asking the question: where do the dead reside? In an attempt to provoke further philosophical discussions, I put forward the notion that the dead exist in a digital *dasein*. Thanatechnology enables the dead to exist “somewhere” and my suggestion of a digital *dasein* describes this posthumous essentialism, and, as my research will show, the idea that the dead continue to be “somewhere” can bring comfort to the

bereaved. This concept of digital *dasein* is useful as it highlights the problematic tension between the bounded nature of *dasein* and reflects on whose digital *dasein* we are talking about: the DC's or the DI's. I will unpick these issues in the following chapters.

The original contribution to knowledge developed from the data and presented within this thesis is the theory of The Fear of Second Loss. This emergent theory describes the fear of losing precious data which contains the essence of the dead. The Fear of Second Loss is a nascent phenomenon rising from the inheritance of digital afterlives. In this thesis I will demonstrate how digital afterlives are not permanent because obsolete technology and platform failure can lead to compatibility issues and digital erasure. This theory of The Fear of Second Loss needs describing, as it is a new phenomenon which is implicitly and explicitly expressed in the interviews conducted with the DI participants of this research. Moreover, its existence could have profound implications for bereavement in our digital society.

1.4 Research aim and objectives

This thesis aims to take a holistic approach to explore how the nascent phenomena of digital afterlives enabled by thanatechnology are being created and inherited in our digital society. This approach will enable the following objectives to be met: (1) To develop an in-depth understanding of the motivations of the people who created digital afterlife service platforms (SPs); (2) To develop an in-depth understanding of why people are creating digital memories and messages to be left posthumously or memorialise the dead (DCs); and (3) To develop an in-depth understanding of how people experience the inheritance of posthumous digital memories and messages enabled by the Internet (DIs).

1.5 Research questions

This study is concerned with the nascent phenomena of posthumous digital memories and messages enabled by thanatechnology, and whether these digital artefacts will affect existing grieving practices and protocols. The overarching question in this research is: "How are digital afterlives experienced by their creators and inheritors?". To explore this area of research, I will focus on the following five

research questions:

RQ1: What are the motives behind those providing intentional digital afterlife services?

RQ2: Why do some people create intentional digital memories and messages to leave posthumously?

RQ3: How do the bereaved experience the inheritance of digital memories and messages?

RQ4: Is thanatechnology creating a disruption to the existing models of bereavement?

RQ5: Are digital memories and messages experienced differently to other posthumous possessions?

A focus on these questions will ensure that the thesis topic will be explored, interrogated and produce defensible and credible findings. Moreover, this thesis will provide a substantive understanding in relation to posthumous digital remains, whether accidentally or intentionally created and left on the Internet, affect the way people grieve in our digital society.

1.6 Thesis structure

In order to answer the research questions, this thesis is structured around eight chapters. This chapter introduces the research topic, aims and questions. It also presents useful taxonomy developed during the early stages of this study and used throughout the thesis.

Chapter two is an interdisciplinary literature review which covers a wide body of scholarship. The aim of this preliminary literature review is to provide context to the study, and to explain the existing theories of bereavement which will feature in the discussion chapters of this thesis. The literature also addresses how the world wide web is changing the “norms” and the protocols of bereavement, before moving on to look at how philosophy is approaching the phenomena of digital afterlives. From philosophy, the chapter then progresses to the literature concerned with the sociology of death and dying. Throughout Chapter two I identify gaps in the current literature which this thesis addresses.

Chapter three focuses on the methodological considerations involved in choosing constructivist grounded theory as a suitable approach to my research, along with the theoretical perspective of symbolic interactionism. It also provides a step-by-step guide to the recruitment of my 48 participants and the collection and analysis of their data. Importantly, this chapter considers and addresses the ethical challenges encountered within this research, which involves the sensitive issues of death, dying and bereavement.

Chapters four, five and six are organised by employing the three groups of participants identified in this research: SPs, DCs, and DIs. The findings from the SPs are presented in Chapter four, which starts by advocating for a distinction between accidental digital afterlife providers and intentional afterlife providers. With this distinction in place, the chapter gives an overview of the Digital Afterlife Industry (DAI) before presenting the findings from these SP participants, which are organised around three themes: (1) It's personal, (2) The mortality of the immortality platforms, and, (3) Timed posthumous messages: the unintended consequences.

Chapter five focuses on the findings from the DC participants. These participants are further categorised by the types of digital memories and messages that they have created: thanabloggers; creators of posthumous messages; grieving digital creators; and, early adopters. The findings are then organised around five themes: (1) Benevolence (2) Therapy (3) Continuing bonds (4) Technophilia, and, (5) The quest for digital immortality.

In Chapter six, I present the findings from the DI participants. This chapter draws attention to how digital artefacts are experienced by the bereaved as containing the essence of the dead. This chapter is organised around the five themes developed through data collection and analysis: (1) The voices of the dead, (2) Timings, frequency and triggers, (3) The digital versus the physical, (4) The comfort, disruption and confusion of digital afterlives, and, (5) The comfort of knowing others care. This chapter then considers how thanatechnology has resulted in changes to a theory mentioned in Chapter two, Mori's uncanny valley.

Chapter seven focuses on drawing together the findings of the three data chapters above, and synthesising them into the existing literature. This penultimate chapter draws together discussions about the suitability of existing models of bereavement to accommodate digital afterlives, along with philosophical questions about where the dead reside. In this chapter, I present a new substantive theory of The Fear of Second Loss before calling for a new voluntary framework for the DAI.

In the final chapter, I present an overview of this study by discussing the strengths and limitation of this work before a final reflexive comment. I also highlight how the research aim was achieved through an outline of the key findings and contributions presented in this thesis, and, importantly, I consider the broader implications of this study for practice and future research.

2 Chapter Two: Literature Review

A guided tour through the literature – The entangled approaches to the land of thanatology.

2.1 Introduction

Death is an undisputed reality of the human condition, and this emotionally laden topic has been researched and written about across many different disciplines. So, it is inevitable that there is huge amount of literature dealing with such a complex and diverse area of scholarship. Therefore, this thesis needs to explore various bodies of work and take a few detours in order to provide an interdisciplinary overview of the various academic perspectives of thanatology – the study of death and dying – before arriving at its final destination. Our first stop will be within the classic theoretical literature, taking a look at death and dying from the psychological and sociological perspectives. We will then progress to the relevant literature on human-computer interaction (HCI), and Science and Technology Studies (STS). Beyond these bodies of literature we will move on to digital anthropology, social anthropology and new media theory. Next we explore the modern landscape of the Internet and thanatechnology before looping back to the theories. Finally we end our journey in the heart of the sociological literature on death, dying and bereavement.

Time is limited, and we cannot visit every destination on this literature review: this thesis, and therefore this literature review, focuses on a Judeo-Christian perspective of death and dying. This focus results in a culturally narrow understanding of the phenomena of digital afterlives: specifically, it views the literature through the lens of Western culture. In addition this literature review is limited to texts written in the English language – or those that have been translated into English.

Bon voyage.

2.2 First stop – the theories

“Grief doesn’t have a plot. It isn’t smooth. There is no beginning and middle and end” – Ann Hood

2.2.1 Stage theory

The quest to understand how humans experience grief has been a topic of academic endeavour for many years. The theory of “grief work” was introduced by Sigmund Freud in 1919, this psychological perspective views grief as something the bereaved have to work through in order to eventually detach from the deceased (Kastenbaum 2016). Both Bowlby’s 1969 work on attachment theory and Kubler-Ross’ stage theory in 1996 supported this theory of “letting go and moving on” (Bowlby 1980; Kubler-Ross 2009). Elisabeth Kubler-Ross (2009) interviewed dying patients to develop her stage theory of dying and grieving. She described five states that people experience (1) denial, (2) anger, (3) bargaining (4) depression, and finally, (5) acceptance. Clinicians and professionals quickly adopted this model as a simple and organised way to conceptualise grief, and although it was not Kubler-Ross’s intention that this should be a linear process, it nevertheless has a start and an end point.

2.2.2 The Dual Process Model

Few would deny that stage theory made a huge contribution to understandings of dying and grief, nevertheless, this overarching theory assumes that grief is pathological: that an end conclusion can be reached by working through the stages described above. However, this theory fails in its understanding of the deeply complex and personal way in which people deal with grief; it assumes a “process” which is predominantly linear in nature, and assumes a desire to “let go and move on” (Kubler-Ross 2009).

In an effort to address the issue that the bereaved want or need to “let go” of the deceased and, as a response to some of the limitations and shortcomings of traditional grief work, in 1999 Margaret Shroebe and Henk Schut proposed a Dual Process Model of Grief (DPM). The DPM suggests that healthy grieving involves an

oscillation between “loss-oriented grief” and “restoration-oriented grief” – a movement between confronting and avoiding grief. Stroebe and Schut suggest that loss orientation focuses on the experience of loss itself; confronting the loss, attempts to accept the loss, and other forms of classic theories of “grief work” (Bowlby 1980)

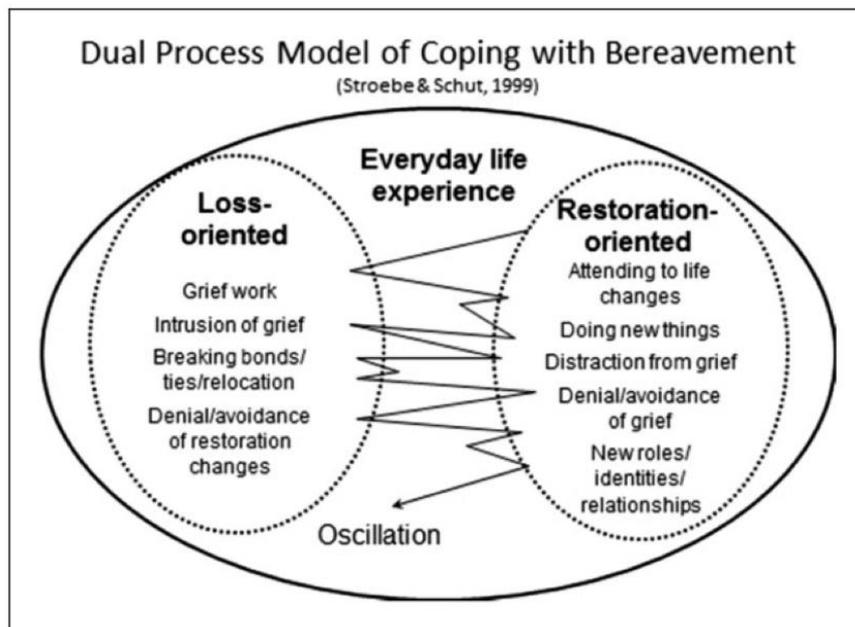


Figure 1 The Dual Process Model of Coping with Bereavement (Stroebe & Schut 1999)

While restoration-orientated stressors do not come directly from the loss, the figure above shows that they are important secondary stressors. They deal with changes to the daily lives of the bereaved following their loss, such as childcare in the case of the death of a partner, financial problems following the death of the household’s breadwinner. Thus, a period follows which requires a readjustment to the way the world has changed because of the death of a loved one. It is the oscillation between the two stressors that is conceptualised by the DPM, the idea that the bereaved can adjust to the changed world can be achieved by moving back and forth between the loss-oriented and restoration-oriented stressors: This psychoanalytical/attachment model of grief focuses on how people take respite from grieving by balancing what might be considered as, their “dosage” of grieving (Schut & Stroebe 1999).

In a paper written 10 years after the proposal of their model, the authors call for further empirical research into the usefulness of the DPM, however, their call for the

identification of a “specific cognitive process” of the DPM is unhelpful as this still assumes grief to be a purely psychological process rather than a psychosocial process (Stroebe & Schut 2010).

Limitations of this model have been acknowledged by Stroebe and Schut: in a 2016 paper they suggest that there may be a “missing link” in their model through a failure to identify bereavement “overload” where individuals experience multiple losses in close succession (Kastenbaum 1969).



Figure 2 Grief Complications & The Missing Link in the DPM: Additional Effects of Overload (Stroebe & Schut 2016)

The useful notion of “confronting” or “avoiding” grief will be discussed at length in the data chapters of this dissertation. However, the language of “moving on” from grief is still evident in the DPM and – as will be discussed – this is not a theme found in my research. Whilst moving on and letting go may be useful concepts when coping with relationship breakdowns, many thanatologists acknowledge they are not helpful when faced with the complexities of grieving, as they do not allow for the need to continue a relationship with the deceased (Loftland 1985; Klass et al.1996; Small 2001; Lloyd 2017).

Although a well cited and useful model, there are limitations to the DPM: this psychoanalytic approach suggests that there is agency in how people grieve, yet it

does not account for the “wave” of grief that can take people by surprise when it is unexpectedly brought to the forefront of their minds. In a 2010 paper Stroebe and Schut asked researchers to put the DPM to “stringent empirical test” (Stroebe & Schut 2010).

In Chapter seven of this thesis, I will discuss how digital memories and messages enabled by thanatechnology could be causing an interruption the necessary oscillation which forms a crucial part of the DPM of bereavement. I will then suggest how this psychological model could be expanded, to incorporate a sociological and element which may be of more use in our digital society.

2.2.3 Continuing bonds theory

In 1996, Klass Silverman and Nickman introduced the theory of “continuing bonds”. This concept – in contrast to stage theory – suggests that rather than moving on and letting go when someone dies, people create an inner representation of the deceased: the relationship is renegotiated, dynamic and on-going (Klass et al. 2014). In 2006, Klass drew attention to a limitation in relation to how continuing bonds were being discussed in the literature. Continuing bonds were considered as a personal or inner-process which was being experienced by the bereaved; in contrast, Klass called for those using the theory to expand its usefulness by acknowledging the social aspect of grief and bereavement along with what he called the “social and communal nature of continuing bonds” (Klass 2006). Since then, other researchers have highlighted how SNSs are being used by the bereaved to facilitate continuing bonds (Getty et al. 2011; Degroot 2012; Kasket 2012a; Walter et al. 2012; Pennington 2013; Bouc et al. 2016).

Although this paradigm shift towards continuing bonds is evident in much of the academic death studies literature, stage theory is still part of popular discourse for many people; those who have not suffered the loss of a significant other often feel that the bereaved should move on with their lives. However, many practitioners who work with the bereaved find that continuing bonds is a more useful model rather than suggestions that closure can be achieved (Kasket 2012a). As Klass points out in an additional paper written in 2006, these bonds although “inner representations” also

have a “social and communal component” which he suggests are crucial. Through conversations with the living, continuing bonds can be renegotiated with the dead with the suggestion that these bonds may assist the bereaved in their adjustment to the physical absence of their loved one (Klass 2006). Walter’s 1996 work on “meaning reconstruction” is useful here to explain how relationships with the dead are dynamic rather than lifeless, and how the bereaved can still be connected to the dead whilst moving forward and restructuring their lives (Neimeyer 2001). People attempt to make sense of what they are experiencing by finding meaning in their loss. This point seems to echo Walter’s suggestion of the construction of a “durable biography” which is achieved by the active process of conversing with others about the deceased. Such activities often take place through obituaries and funerals (Walter 1996). This literature review will return to the important work of Neimeyer and Walter during the next section, where continuing bonds in the age of the Internet will be discussed.

2.2.4 Off the beaten track – Growing around grief

There is a theory of grief that is absent from most of the academic death studies literature: “growing around grief”. In a workshop run by grief counsellor and writer Lois Tonkin, a woman described a model which seemed to encapsulate how she experienced grief after the loss of a child (Tonkin, Lois TTC 1996). The woman drew a circle and shaded it in to represent how grief completely consumed her, she then explained that rather than grief shrinking over time her life grew around the grief (sometimes described as the fried egg model). In practice this growing around grief model seems to resonate with others who feel as though grief is not something you can work through until you reach a resolution: rather, the grief becomes part of you and you move on *with* grief not *from* grief. Tonkin goes on to explain that for some it “explains the dark days” (1996, p.10) – what I described earlier in the chapter as the unexpected “wave” of grief. This model of grief illustrates how grief and attachment to the deceased remain, but the world around bereaved grows over time (Lloyd 2018).



Figure 3 Growing Around Grief (Tonkin 2018)

Adopting an inductive approach, this thesis will focus on the usefulness of the existing frameworks of continuing bonds, the DPM and growing around grief, whilst remaining open to the potential that the nascent phenomena created by the proliferation of digital data (by and about the dead) may result in a new model being developed, or whether the existing models could be expanded to incorporate how enduring digital memories and messages enabled by thanatechnology could be affecting the bereaved.

2.3 A tour around the World Wide Web

2.3.1 The Internet as a site of memorialisation

The academic literature discussed so far in this thesis has concentrated on “traditional” death systems (Kastenbaum 2016). However, there is evidence to suggest the Internet is changing the way some people grieve (Sofka et al. 2012; Walter et al. 2012; Brubaker et al. 2013). In his book “The Revival of Death” Tony Walter suggests dying, funeral practices, mourning and beliefs about the afterlife are continually evolving (Walter 1994). Building on the work of Walter, I suggest that technology is accelerating this evolution exponentially, and that, as a result of this accelerated evolution, researchers are struggling to keep pace with the way people are using the Internet to grieve.

In 2006, Facebook was launched to anyone with an email account as a social networking website where people could create an online profile and connect to others. However, in 2007, Facebook dealt with the death of some of its users following the Virginia Tech shootings. At that time relatives requested the pages of those killed, mainly young students, to be left active. Facebook decided to memorialise the accounts, rather than switch them off, enabling friends and relatives to write messages of support in their time of grief. The immediacy of Facebook, along with online obituary pages and memorial websites such as Legacy.com, enable people to use social media for public grieving. Social Networking Sites (SNSs) are described by Ellison as “web based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with who they share a connection, and, (3) view and traverse their list of connections and those made by others within the system” (Ellison 2007). They provide a mediated environment for communication in a networked age, and quickly became a new site for grieving (Brubaker et al. 2013). In their 2013 paper “Beyond the Grave: Facebook as a Site for the Expansion of Death and Mourning” Brubaker et al. consider how SNSs are producing new arenas for grieving and they explain how: “Facebook is associated with an expansion of death-related experiences – temporally, spatially, and socially”

They argue that these arenas create a socially situated space where the bereaved can engage. Significantly, these new spaces are situated in people's daily lives, thus ensuring death becomes part of the everyday. However, Walter argues that rather than just making grief public, SNSs are enabling grief to "become more communal, that is, shared within the deceased's social networks" (Walter 2015a).

The Internet and the proliferation of smart technologies are changing the landscape of grief from the physical to the virtual (this distinction is discussed later in this chapter). In her seminal paper Sofka (1997) coined the term "thanatechnology" to describe the convergence of death and technology. It is the impact of thanatechnology, in all its guises, that forms the basis of this thesis.

In their 2012 book, editors Sofka, Cupit and Gilbert provide a detailed overview of how dynamic and fast-moving social media platforms, such as Twitter, Facebook, Skype and YouTube, provide both challenges and opportunities for diverse groups such as counsellors, researchers and death educators. The authors argue that these platforms allow for the datafication of end of life communications and the creation of "new sites" of grieving (Walter et al. 2012; Brubaker et al. 2013). Although digital immortality is very briefly mentioned in the book, it is discussed in the future tense, rather than exploring how technology and platforms readily available today are being used in the quest for immortality. As will be discussed later in the data chapters of this thesis, WhatsApp and LinkedIn – which are absent from the list of platforms listed by Sofka et al. – are mentioned by the bereaved as favoured platforms for the creation, storage and retrieval of digital memories.

The implications of thanatechnology and the phenomena it produces, has resulted in a growing body of research and literature. Much of the research has been focused on how the bereaved are using SNSs specifically to discuss their grief. In 2013 Brubaker et al. conducted inductive analysis of interview to examine how online identities persist after a user's death, and how friends and family use these sites as a space to grieve. It concludes that rather than causing a disruption to the traditional practices and rituals of grieving and memorialisation, SNSs are providing a "socially situated" space to grieve which is a part of the daily lives of the bereaved (Brubaker

et al. 2013). The work completed by Brubaker et al. focuses specifically on Facebook, however, this thesis builds on the work of Brubaker et al. to examine whether this is the case for other SNSs.

Other researchers are exploring these new sites for grieving: Carroll and Landry's research suggests that those who are marginalised by traditional forms of grief are using SNSs to stay connected to the dead. These sites enable and empower groups of disenfranchised grievers to feel like part of a grieving community (Carroll & Landry 2010). Doka defined disenfranchised grief as "grief experienced by people that is not or cannot be openly acknowledged, publicly mourned or socially supported" (Doka 1999). SNSs enable the creation of support groups and memorial sites for those who are bereaved following Aids related death, suicide loss, pet bereavement or perinatal loss (Sofka 1997; Walter et al. 2012; Borgstrom 2017). Carroll and Landry's suggestion that friends are often disenfranchised grievers, will be discussed in Chapter six of this thesis, as the findings of my research question that this is still the case.

Research is finding that the public nature of grieving on the Internet has both positive and negative consequences: Marwick and Ellison's paper discusses how they can be problematic for those engaged in impression management of the dead and how context collapse – when diverse social categories collapse into a "flat" category of "friends" – can compromise this action when "grief tourists" and Internet trolls get involved in communications of the dead on SNSs (Marwick & Ellison 2012). Other researchers have examined the complexities of online trolls and grief tourists who target Facebook memorial pages and the impact that these RIP trolls have on the bereaved (Phillips 2011; Riechers 2012; Seigfried-Spellar & Chowdhury 2017).

In a 2012 paper "Does the Internet Change How We Die and Mourn? An Overview" Walter et al. were the first to summarise the possible implications this fast and dynamic phenomena were having on thanatology. They proposed that there are three types of death: traditional, modern and postmodern (Walter et al. 2012). Traditional death took place in the community, which shared a common theology, and thus produced a bereaved community. Modern death happens at home or in a hospital

where death becomes private, hidden away, medicalised and sequestered (Giddens 1991): thus ensuring that death does not disrupt the everyday routines of the living (Mellor & Shilling 1993). According to Mellor, death disturbs Giddens' notion of "ontological security" (Mellor 1992). However, Walter et al. suggests that, in postmodern death, the public and the private are combined: SNS communications produce private feelings expressed in public spaces (Kasket 2012a; Marwick & Ellison 2012; Brubaker et al. 2013; Pennington 2013). Walter et al. argue this then creates a community of "diverse mourners" which supports the notion that the Internet is indeed changing how people deal with death, dying and grieving.

Those who research online memorials (Valentine 2008; Getty et al. 2011; Kasket 2012a; Marwick & Ellison 2012; Pennington 2013; Harju et al. 2014; Bouc et al. 2016) have found that continuing bonds theory is a useful framework to describe how technology is enabling the bereaved to continue a relationship with the deceased. In a 2013 paper Pennington found that Facebook users "Don't De-Friend the Dead" (Pennington 2013). Instead, she suggests the living "renegotiate" their relationship the dead: this active process and restructuring of the relationship echoes Walter's "durable biography" (Walter 1996) and Neimeyer's "meaning making" (Neimeyer 2001), but in the virtual world rather than in the physical world – later in this chapter I will discuss why the term "real" world is intentionally not used here. In her 2013 research, Pennington examined Facebook profiles of college students to analyse grief communications; she found the majority of participants – the "silent majority" – did not actively engage with the site of a deceased friend, although most found support by "lurking" on these sites. The "vocal minority" – those who did post messages – addressed their posts directly to the dead, supporting the theory that some believe that online "the dead are listening" (Kasket 2012a). Pennington also notes how some students hide the posts written by dead friends from their timeline because they find them distressing (Pennington 2013). Brubaker et al. also note that caution is needed, as for some, public expressions of grief are distressing (Brubaker et al. 2013). Social media may provide a space for a renegotiated relationship with the dead but it should be acknowledged that not everyone grieves in the same way.

2.3.2 A quick loop back to the theories

Many researchers who explore online grieving find support for the framework of continuing bonds (Ellis Hoven et al. 2008; Odom et al. 2010; Degroot 2012; Kasket 2012a; Massimi 2012; Walter et al. 2012; Gray & Coulton 2013; Pennington 2013; Walter 2015; Bouc et al. 2016;). This perspective argues that, rather than working towards closure following the death of a significant other – as suggested by stage theory - many bereaved seek to continue their bonds with the dead (Klass et al. 1996). Researchers are also finding the Dual Process Model (DPM) useful: Brubaker et al. suggest the DPM is a more “clearly defined and operationalizable” theory when researching online memorials. In addition, in their 2015 paper “Death ends a life *not* a relationship: Timework and ritualization at Mindet.dk”, Christensen and Sandvik provide an example of this “oscillation” being played out in the digital environment of the Internet (although they do not mention the DPM by name). They suggest that Mindet.dk, a Danish website used by the parents of children who die very young or who are stillborn, creates a community of mourners. This space, they suggest, ritualises grief work through performances such as lighting a candle and writing messages to the child they have lost. This “parallel existence” enables the parent to move on with their lives whilst maintaining a relationship with their dead child by “continuously keeping hold” (Walter in Refslund Christensen & Sandvik 2015). Although the DPM of grief is evident, the continuity of the relationship still echoes the theory of continuing bonds, showing the individual complexity of grief and bereavement.

2.3.3 Digital immortality and the fourth path

The notion of digital immortality can be seen as a relatively new variation of what Robert Jay Litton describes as symbolic immortality: the need to pass on memories and attempts to influence future generations (Litton 1979). This quest for immortality is certainly not new: in his 2007 text, Robert Kastenbaum illustrates how the promise of an afterlife is woven throughout the world’s main religions, and how through history, people have attempted to continue relationships with the dead. From stone monuments and time capsules to cloning and reproducing, people have always pursued immortality in an attempt to escape death or avoid nonexistence; and since the invention of technology which enables voice recordings, technology has

mediated this “assisted immortality” – or assisted survival (Kastenbaum 2016). According to Bauman, posterity is the site where the hope “if not certainty” of the ego’s immortality can be invested (Bauman 1992), and technologies available in the digital age give us perhaps the greatest opportunity to explore the possibilities of assisted immortality.

Writing in 2017 Tony Walter suggests the ways in which the dead survive is achieved by (1) becoming ancestors, (2) becoming immortal, or, (3) surviving in the memories of the living (Walter 2017). Philosopher Stephen Cave suggests there are four narratives which dominate the path to immortality: (1) Stay alive – the cheating of death with an elixir of life, (2) Resurrection – physically rising from the dead in the body we inhabited in life, (3) Soul – spiritual survival where the body is not needed, (4) Legacy – with everlasting fame (Cave 2012). Chapter five of this thesis will examine the motivations and hopes of those seeking Cave’s fourth path “Legacy” and how this legacy may affect the bereaved.

Each time we interact online, we generate digital crumbs, creating what is described by Paul-Choudhury as “digital souls” (Paul-Choudhury 2011). These “narrative bits” of information are what Mitra calls “narbs” (Mitra 2010), and the more we interact with technology the more our digital selves evolve into a realistic representation of our “real” selves. Thanatechnology enables the proliferation of these “posthumously persistent” (Kasket 2012a) narbs, and offers the promise of immortality by way of a digital afterlife. Mitra explains:

“The identity of an individual is eventually constructed by the combination of narbs that are available on a social networking site where different kinds of narbs work together to produce the composite narrative of a person at any moment in time” (Mitra 2010, p12).

The more we interact with technology, SNSs and virtual worlds, the more our digital selves evolve into realistic representations of ourselves. Writing about virtual worlds in 2011 Braman, Dudley and Vincenti suggest that the more we inhabit virtual worlds what we leave behind posthumously becomes important, for some, to

consider and protect (Braman et al. 2011).

During the literature review for this thesis I became aware that the terminology being used by various disciplines was confusing: the terms digital legacy, digital assets and digital footprints were being used interchangeably. In my 2015 paper I suggested that this issue should be addressed, and that there should be clarity and agreement in the terminology being used to discuss two very distinct categories “digital legacy” and “digital selves”. Similarly, in their book chapter Pitsillides, Waller and Fairfax attempt to address the issue of terminology by including a key terms and definition section. They used the term “digital heritage” to describe “The accumulation and curation of digital data online, which could form the basis of an inexhaustible resource containing the exact documentation of our digital past”, and the term “digital historical artefacts” to describe “digital objects, which contain information for the building up of archives or *Digital Heritage*, for example Social Networks” (Pitsillides et al. 2013). In my paper, I advance this discussion by suggesting “digital legacy” should be used to discuss digital data, passwords, account information, digital assets and digital property: in essence, things that belong in a digital safe or vault that are static once the user has died. However, the term “digital selves” should be used for memories, messages and data that represent our digital selves: personal videos, messages, photographs and blogs, which belong in an imagined digital memory box rather than an imagined digital vault. The term “durable biography” is useful here since these biographies belong in a digital memory box of sorts, as they require storytelling, on-going narratives, memorization and “renegotiated” relationships with the dead in existing in a digital afterlife (Walter 1996). The categories of digital legacy and digital memories are often discussed alongside one another – or in some cases blended together. See digitallegacyassociation.com and my 2015 paper, which call for thanatologists and professionals to adopt a common terminology that makes clear what is being discussed.

2.3.4 Studying the “real” world: space, place and heaven

Dichotomous terms such as online/offline and real/virtual are not useful in research based on society’s use of the Internet. As Boellstorff points out, to talk about offline as the “real” world insinuates that online is somehow “unreal” and therefore

delegitimises it as a field of study (Boellstorff 2014). Boellstorff does not agree with the notion that the virtual and the actual are fusing into one single domain, he suggests that they are still separate entities. However, his digital anthropological research focuses on on-line gaming in virtual worlds such as “Second Life” and therefore the context of online and offline can be seen as different to that when discussing “intimate computing” (Bell 2004) available on devices that are incorporated into the everyday lives of many. In her 2015 book “Digital Sociology”, Deborah Lupton also discusses the terminology around the issue of online/offline and virtual/real. She suggests the term virtual reality is “nonsensical” in our digital society; as almost all “reality” is now virtual, enabled by the ubiquitous and mobile nature of the Internet which ensures our everyday lives are extended, or rather augmented, by the mobile nature of the technical devices we use on a daily basis. Moreover, we are not separate from our online selves, our digital selves are now part the self (Jurgenson in Lupton 2015).

It is hardly surprising therefore, that this blurring of “real” and “digital” lives – what Floridi (2015) describes as “onlife” – is becoming evermore evident in discussions around death and dying. The ability to see people as having lived, and to give a narrative to the deceased, was once the job of clergy, obituary writers and eulogy writers. Respect for the dead requires remembering them (Kasket 2012a). The need to be remembered and the ability to pass on memories is an ancient need: from the first cave drawings and the magnificent mausoleums of the Egyptians, we can see the symbols of their quest for immortality (Sofka 1997).

The bringing together of the virtual and the physical is clearly demonstrated in Wallace et al.’s research, which looks at how the design of digital lockets (lockets with digital screens), inspired by Victorian mourning jewellery, could help people to remember or forget the dead. These lockets can also be used to illustrate the effects of the experiences of people with dementia (Wallace et al. 2018). There are four lockets in total: remember; forget; Daguerre and Orpheus. The “remember” locket they suggest, could hold multiple images, but display only one which changes on the opening of the locket. The wearer of the locket controls when to open and close the locket and they Wallace et al. suggest the randomness of the image shown could be valuable. The “forget” locket can hold multiple images but can only display one per

day. Once the image is displayed is degrades until it is finally deleted. For Wallace et al. this demonstrates forgetfulness and the memory loss of people with dementia. Importantly, there would be other copies of the image, however, this does demonstrate the possibility of digital loss. This potential loss of precious digital memories and messages and the effect this has on the bereaved, will form a major part of this thesis. The third locket, Daguerre contains a small camera which can hold one image at a time. Once an image is taken with the tiny camera it then appears in the locket and any previous image is then deleted. Finally, the fourth locket, Orpheus named after the Greek mythological hero, who searches for his dead wife Eurydice on the condition that if found he must not look at her. However, Orpheus cannot resist one more look at his wife and consequently she fades away. Reflecting this myth images held within the Daguerre locket can only be viewed twice: once when the image is taken and one more when it is displayed briefly for a few seconds at which time it fades until it is completely deleted. In the discussion chapter of this thesis I will discuss the complex issue of remembering and forgetting the dead, and how Wallace et al.'s theory of ongoingness is a useful addition to the theory of continuing bonds in our digital society which enables techno-spiritual relationships with the dead.

In his 2015 paper, Walter posits that the “presence” of the dead is partly dependent on the communication technologies available in a given society (Walter 2015a). Undoubtedly, these communication technologies affect how we communicate with the living, and Walter considers how they affect the way we communicate with the dead. Furthermore, he argues that these technologies ensure that the dead are more “socially present” and chronicles the use of communication media from stone and sculptures, which need mediating, to writing, music and printing:

“The presence of the dead within a society depends in part on available communication technologies, specifically speech, stone, sculpture, writing, printing photography and phonography” (Walter 2015a, p215).

Walter noted that QR codes on gravestones and memorials are just one example of this. When scanned the quick response (QR) code takes you to a website containing the “story” of the deceased. However, as Briggs and Thomas (2014) found in their qualitative study, older users found QR codes on gravestones in “bad taste” and were

concerned about technological exclusion, business practice and digital vandalism, which surround this type of technology: One can imagine the distress caused to the bereaved if the website was hacked and insensitive or false information was included.

Since the Copernicus revolution, science and religion have been seen by some as dichotomous and competing in the debate about the existence of an afterlife: however, it could be argued that thanatechnology encourages the notion of a “digital heaven” where digital angels exist, thereby fusing science and religion together. As Walter et al. (2012, p.16) point out: “The digital revolution enables a plausible geography of the dead residing in cyberspace”. It has been suggested that users of thanatechnology often adopt the Christian notions of heaven and angels in their communications with the dead (Brubaker & Vertesi 2010; Gustavsson 2011; Walter et al. 2012; Brubaker et al. 2013; Refslund Christensen & Sandvik 2015; Walter 2015b). Furthermore, following qualitative research Kasket suggests that some of her participants believed the dead were logging on from cybercafés in heaven (Kasket 2012a), although as Marwick and Ellison 2012 comment “There isn’t Wi-Fi in heaven”.

Whether the dead are experienced by the bereaved as living in a cyber-heaven, the “real” world or a “virtual” world, – therefore where they think the digital dead reside – is an important issue for digital thanatologists and will therefore form an important and ongoing thread throughout this thesis.

2.3.5 The resurrection of the dead – socially active digital zombies

In her 2014 book, Candi Cann suggests that through the use of technology which provides links to videos, conversations, memories and pictures, the dead remain alive. But how do the bereaved experience the technologically mediated dead? Brubaker et al. emphasise how the bereaved can find “unexpected encounters” with the dead distressing (Brubaker et al. 2013). Anyone who has made the difficult decision to delete a dead person’s telephone number off a device only to have the number re-appear from a storage cloud may relate to the distress “Internet ghosts” (Cann 2014) can cause. Other researchers agree that allowing mourning to “leak into

everyday life” causes a mixing together of life and death which could be problematic (Walter et al. 2012). The data chapters of this thesis will examine whether this is still the case, and whether people’s actual experiences with the dead popping up differs between the different types of platforms.

Although the Internet ghosts discussed above may come back to haunt the bereaved, importantly they remain dead. However, what about those who rise from the dead and become socially active? Sherlock (2013) discusses how these “posthumous representations” add to an advanced type of symbolic immortality. Bollmer suggests that it is not just the “presence” of the dead that causes anxiety, it is the “near full representations of the authentic identity of the human being” which communication technology enables, to the point that networks cannot distinguish between the living and the dead (Bollmer 2013). In a 2015 paper I introduce the term digital zombies to describe the online dead who are resurrected, reanimated and socially active. These digital zombies are at the same time dead and alive; moreover, they do things in death they did not do when they were alive (Bassett 2015). According to Nansen et al. the “restless dead” are “exhumed within a network of social and technical connections previously delimited by cemetery geography and physical inscription in stone” (Nansen et al. 2014). Nansen et al.’s distinction between animation and repose when describing the dead is crucial here as it draws attention to the difference between Cann’s Internet ghosts which are in repose – and therefore not restless – and my digital zombies which are resurrected, reanimated and socially active.

An example of socially active digital zombies is the use of dead celebrities in advertisements. Four years after he died, Bob Monkhouse appeared in an advertisement to raise awareness for prostate cancer. In the video he appears at his own graveside, discussing his own death. The video, which used film recorded whilst he was alive, was edited with new footage, featuring a body-double and a voiceover by an impressionist, to create the final advertisement. Using this “modern necromancy” (Sherlock 2013) he was digitally resurrected from the grave, thus making him an “accidental” digital zombie – this important distinction between accidental/intentional will be discussed in the next section of this literature review. Other accidental digital zombies included Tupac Shakur and Michael Jackson, both digitally resurrected and recreated to perform “live” on stage years after their deaths. Sherlock suggests that dead celebrities being used in this way adds to what she

describes as an advanced type of symbolic immortality (Sherlock 2013). The ubiquitous nature of digital technology, and the exponential development of thanatechnology, not only enables celebrities to become socially active digital zombies, but crucially offers anyone living in our digital society the opportunity to be reanimated and resurrected following their biological death. Platforms that enable the creation of posthumous avatars are discussed in next section of this chapter, then in Chapter five I will present the findings from people who are creating these avatars, before moving on to discuss whether the bereaved actually want to encounter these socially active digital zombies in Chapter six.

2.3.6 Accidental and intentional digital afterlife platforms

In the introduction chapter of this thesis I introduced the terms accidental and intentional and their usefulness in differentiating the intentionality of digital memories and messages enabled by thanatechnology. As previously mentioned, they are also useful when discussing the platforms which enable digital afterlives. Platforms such as Facebook, Twitter and WhatsApp were created for the living as a place to socialise with the living; they were not created as a place for the dead reside. This makes them accidental digital memory platforms. However, some platforms exist that are what I term “intentional” digital afterlife providers for the dead. These intentional digital afterlife companies form a major part of this thesis, and in Chapter four I present findings from these SP participants. However, this literature review will use the two terms to give context to the emerging literature about posthumous avatars.

Eternime and LifeNaut (both based in the USA) have launched platforms that enable people to control how they are remembered after they die. Eternime will take your digital footprint, tweets, online messages, vlogs and photographs to create an avatar of you. They use artificial intelligence algorithms to create what they claim will be a virtual interactive “you”. Your avatar will become more like the “real” you by learning from you each time you interact with it. They claim is that your relatives will be able to visit you online for support and advice after you have died. Furthermore, they state they are trying to solve an “incredibly challenging problem of humanity” (Eternime 2018). Bell and Gray of Microsoft Research seem to agree

that it may be possible that a “cyberized” version of you will be able to learn and evolve, and eventually “take on a life of their own”. This idea of avatars being able to evolve will be expanded on in Chapter eight of this thesis. These companies offer to store your personalities and these types of technologies may seem to be the stuff of science fiction, however, according to Rothblatt the exponential growth of the emerging technologies needed to deliver and support the cyberconsciousness, mindclones, mindware and mindfiles do not seem far away (Rothblatt 2014).

The people behind some of these digital afterlife companies – both accidental and intentional – are participants in this research and the motivations and hopes for their platforms will be presented in Chapter four.

2.3.7 Not only the dead – the dying

Available technologies together with platforms, such as Twitter, Facebook and YouTube allow people to create their own digital narratives by writing, filming and publishing details of their lives. These blogs, tweets and videos then form a collection of enduring digital memories – digital footprints or digital fingerprints which are created and stored on various SNSs and platforms on the Internet. In their 2014 paper entitled “Palliative Social Media” Taubert, Watts, Boland and Radbruch explore how thanatechnologies and social media platforms offer challenges and opportunities to both the terminally ill and professionals involved in end of life care. Taubert et al. discuss how microblogs can provide professionals with an alternative space to openly discuss health scares and controversial end of life issues, such as the Liverpool Care Pathway. Technology also enables live feeds of conferences focused on palliative care allowing people to remotely attend such conferences. However, as the authors point out, the UK’s General Medical Council and the British Medical Association have urged caution about social media being used for open debates around death and dying pointing out there are potential pitfalls for those healthcare professionals who choose to do so, such as disclosing their full names online (Taubert et al. 2014).

Nascent smart technology is enabling “ordinary” people to create and curate their own narratives, ensuring that they leave behind digital memories for others to inherit

following their death. The term “thanablogs” was coined by Sofka to describe how the terminally ill are using the Internet to enable them to take control of their finite time by blogging about their experiences of end of life care and creating enduring digital memories in the process (Sofka, Cupit & Gilbert 2012). Terminally ill Dr Kate Granger who died in 2016 used the Internet to blog, tweet and make videos during her illness to share her experience of cancer and in the hope of destigmatising discussions around death and dying. She used the Twitter handle #deathbedlive throughout her terminal illness and right up to hours before her death in July 2016. At the time of her death Kate Granger had over 48,400 Twitter followers and had Tweeted over 12,500 times. Interestingly over three years after her death, Kate still has 43,600 Twitter followers, supporting the findings of research by Natalie Pennington (mentioned earlier in this chapter) people “don’t defriend the dead” (Pennington 2013).

In an effort to shed light how these thanablogs are being experienced by both the dying and the bereaved, in Chapters five and six of this thesis I will present findings from two groups of participants 1) those creating thanablogs, and 2) those who inherit the blogs following the death of the author. Next in this chapter, I move on to discuss how social media are changing the social norms and societal attitudes around death and dying.

2.3.8 Discussing death: from taboo to the dinner table

Mourning is described as the act of making visible responses to grief through the creation and curation of materials (Small 2001). Mourning practices change, as social and cultural rituals change. During the Victorian era, which is described as the “high” period of mourning, the dead were very much part of life with the use of death masks and corpse photography (Walter 1999; Gray & Coulton 2013; Stokes 2015).

Gorer (1965) suggested that secularisation in many Western societies had begun to affect the grieving practices of many, as the religious rituals once used to guide people through grief and mourning, were beginning to lose their significance. This post-war influence and the mass mourning it led to, resulted, he suggested, in a

rejection of death and its practices. In his earlier work Gorer suggested that sex and death had switched positions, and death had become the more taboo subject (Gorer 1955; Aries 1981). A 2008 paper by Jacque Lynn Foltyn updates and extends Gorer's 1955 essay with discussions around what she calls "corpse porn" (Foltyn 2017). The notion that discussions of death and dying are taboo may be changing, but as Walter points out, this may be dependent on the spatial and temporal nature of the discussions taking place (Walter 2014).

Walter suggested that in the 1960's people were able to express themselves in a more open manner. Following two world wars, Britain was experiencing a time of peace and the notion that it was good to talk about emotions began to gain momentum. According to Walter (2009), this momentum was fuelled in part by the very public death of English reality-television personality, Jade Goody, which dominated much of the British media during her illness and following her death in 2009. The public nature of her death was unprecedented, as Walter points out for ordinary people the rituals and practicalities of dying remain private. But what about those who become famous *because* they are dying? The Internet is challenging the idea that non-celebrities die privately: as discussed earlier in this chapter thanabloggers bring dying into the public sphere, and these bloggers form an important part of the data chapters of this thesis. They blog, tweet and create YouTube videos about their own impending death, thereby experiencing what I term a status of "thanacelebrity" from their digital deathbeds.

The recent emergence of death cafes also signals a move that more open debates about death and dying are taking place in a public sphere. These death cafés are not altogether new: their roots lie in salons and coffee shops of the 17th century (Brennan 2015). Death cafes take place in over 51 countries worldwide, in Britain the first death café was held in London in 2011 by John Underwood. Their mission was to "increase awareness of death with a view to helping people make the most of their (finite) lives" (Death Cafe 2016).

Discussions about death in the public sphere seem to be growing: Death Over Dinner, is an organisation which encourages conversations about what people would like to happen when they die – and importantly while they are dying (Death over

Dinner 2017). It hopes to get people discussing important issues about death and dying over the dinner tables of the world. What people want in terms of end of life care; whether they want to die at home or in an institutional setting; what type of funeral they want and how they want their body to be disposed of are all issues which the organisation suggests should be openly discussed over the dinner table. Since its launch in 2013 it estimates there have been over 100,000 “death over dinner” parties held in over 30 countries (Thrive Global 2017).

2.3.9 Designing for mourning in a digital society

The literature addressing distress at online expressions of grief is relatively new, however, there is evidence that in a short amount of time these attitudes are changing, moreover, with the rapid growth of the Internet and the ubiquitous online nature of socio-technology we have seen a normalising of grief on the Internet (Walter et al. 2012; Pitsillides, et al. 2013; Brubaker et al. 2014; Christensen & Sandvik 2015; Paulus & Varga 2015; Wagner 2018). But the normalising of grief may also have something to do with the growing amount of research into thanatosensitive design (TSD) (Massimi 2012). When I started writing this thesis many of the accidental digital memory platforms seemed to be playing catch-up with the fact that their users were using their platforms to discuss death, dying and bereavement, and also to store digital memories of dead users. However, researchers and practitioners were beginning to discuss how platforms could be designed to be more sensitive to the bereaved (Massimi & Charise 2009; Massimi 2010; Brubaker et al. 2013; Ellis Gray 2015; Brubaker et al. 2016)

The idea of designing for bereavement was being discussed before the ubiquitous use of SNSs: in his 1995 paper Edwin Bos predicted the emergence of platforms such as Eternime by discussing the possibility of an “extension” of life by the design of interactive talking photographs. He suggested that designing such technology needs to consider the bereaved, who he suggests could be supported by such technology. This notion of designing for death was also discussed in a 1997 book by transhumanist Timothy Leary (see Ellis Gray 2015). Leary was terminally ill when he wrote his book, which suggested that systems could be designed to upload and record events during your life, which could be used to immortalise your

consciousness after death. The idea that material remains can play an important part in the process of grieving, and how technology can be designed to assist with this in a positive way, was taken up again at the SIMtech event at Microsoft Cambridge in 2008 (Foong & Kera 2008; Hoven et al. 2008; Kirk & Banks 2008).

In 2009, Michael Massimi along with fellow PhD student Andrea Charise argued for the use of death sensitivity – what they termed “thanatosensitivity” when designing systems. It was suggested that systems needed to be designed respectfully and compassionately, as they were being used by people who were facing the end of their own life and also those who were coping with the loss of a loved one. During his PhD Massimi designed a new home technology called MyShrine to create an ongoing long-term support network for the bereaved by connecting bereaved individuals together. Massimi and Baeker suggest digital objects or technological artefacts from our lives can help people overcome loss (Baeker & Massimi 2010). However, throughout this thesis I will challenge terms such as “overcoming” as it echoes the ideas of stage theory; the notion that people can work through grief and reach an end resolution.

Massimi’s work is important to this thesis as it is underpinned by the need to design systems with the bereaved in mind. Other researchers have been looking at designing technology in an effort to help the bereaved remember the dead (Odom et al. 2010; Getty et al. 2011; Mori et al. 2012; van den Hoven et al. 2012; Brubaker et al. 2013; Maciel & Pereira 2013; Ellis Gray 2015). Research into the design of a tangible digital memorial by Moncur and Julius resulted in a “story shell” which could “capture and replay” the stories of the dead which were posthumously created by the bereaved (Moncur & Julius 2014). Their research showed how the creation of the story shell helped the bereaved to sustain continuing bonds with the deceased. This co-creation and curation of digital memories can be seen in other works such as Memory Artist Nancy Gershman’s work with end of life clients in order to collect stories, photographs and mementoes to co-create a tangible book and digital file to be inherited by their loved ones after death (Gershman 2015). How much emphasis the service providers of intentional digital memory platforms put into TSD will be discussed in depth later in this thesis.

By 2012, research about the importance of appropriate TSD began to gain momentum, as stories began to emerge regarding the impact on the bereaved of designing *without* TSD. A 2012 paper by Mori et al. contributed to this discussion by comparing comments on three online platforms following the murder of Anna Svidersky. Nine design considerations were suggested by the authors, although it was acknowledged that Facebook (not one of the three platforms examined) may have been a more suitable platform to include because of the changes to how users can memorialise profiles.

2.3.10 Designing *without* thanatosensitive consideration

Facebook have been criticised for a lack of compassion when dealing with the families of the bereaved. In 2014, 20 year-old Hollie Gazzard was murdered by her ex-boyfriend and at the time of her death there were several photographs on Hollie's Facebook page of her with posing with her murderer. Following her death, her family asked for the photographs to be removed. Facebook refused to take down the photographs, stating it was against their policy to delete photographs from memorialised profiles. A year later Facebook removed the photographs commenting that they were removed because of a copyright claim.

During this PhD research Facebook have made several changes to the way they deal with memorialised profiles. The ability to memorialise a Facebook account has been possible since 2007; however, in 2015 Facebook introduced its Legacy Contact feature, which allows users to nominate a friend or family member to take "stewardship" of their Facebook profiles after they die. In a 2016 paper Brubaker and Callison-Burch set out the design choices that led to the development of the Legacy Contact feature.

"Adopting stewardship as a framework enabled us to strike a balance between the needs of the account holder and the bereaved community"
(Brubaker & Callison-Burch 2016, p2)

Importantly, the authors point out that "design research" played a part in this new feature, demonstrating that platforms such as Facebook are using academic research

from the various disciplines to inform how digital platforms can be designed with compassion and thanatosensitivity in mind, in an effort to better support the bereaved in a socio-technical society. Further discussions around changes made to posthumous Facebook pages which have occurred during the writing of this thesis will be discussed in Chapter six.

2.4 From design to *dasein* – a short philosophical detour

Spending time with the data of the dead is not specific to the digital age. Many academics spend time with the unpublished writings of dead academics. These unpublished works, which can include manuscripts, correspondence and notes are known as *nachlass* (from the German word *nachlassen*: to leave behind). Multiple works based on the *nachlass* of the influential philosopher Nietzsche were published after his death, moreover the philosopher Wittgenstein only published one book during his lifetime, all other works were compiled by other academics from his *nachlass*. However, many of the people spending time working on the *nachlass* of these dead academics can be emotionally invested in the data, with feelings of responsibility for continuing the work of the dead scholar. While some academics are actively involved in the creation and preservation of their *nachlass* other scholars such as Alfred Whitehead wanted all unfinished and unpublished work destroyed after his death because he preferred to allow young academics to develop their own ideas (Lowe 1982). In our digital society posthumous digital remains left on the Internet could be viewed as unfinished work left for others to interpret and finish or a “digital *nachlass*”.

Technology that has changed how we spend time and communicate with others, and the space we inhabit when we use the Internet has also changed. It was only in 2013 that in the UK, British Telecom turned off its dial-up service, which required computer hardware to be hard wired for Internet connection. But in a relatively short space of time we can now connect to the Internet via Wi-Fi, Bluetooth and 4G, which allows us to use the Internet on the move, at any time, in any place (providing the infrastructure is available). Now, we can WhatsApp and FaceTime with people on aeroplanes, trains and cars. The Internet is not only providing new spaces for people to communicate, it is a new space in itself (Brubaker et al., 2013).

Technology and the Internet are blurring spatial boundaries by enabling people to be co-present: that is physically present and virtually present at the same time in different spaces. But can the virtually dead on the Internet ever be considered as “persons”?

Meese et al. suggest that a person’s personhood can be extended after death by digital media (Meese et al. 2015). Stokes seems to agree as he discusses the distinction between “persons” and “selves” to argue that SNSs “offer a particularly significant material instantiation of persons” (2015). It is these persons who Stokes reasons persist as ethical patients after death. Meese et al. note that they, along with other researchers, have found social media platforms to be “implicated in the continuing social presence and agency of the dead” (2015). Extending existing notions of de-centred personhood (see Hallam et al. 1999; Hallam & Hockey 2001; Hockey et al. 2010). Meese et al. go on to suggest that online platforms make the difference between the living and the dead increasingly indistinguishable in a techno-social context; moreover, the difference can be inconsequential at particular points. The key idea is, that if the persona of the dead use the same social media platforms as those of the living, then they may be considered as a kind of “person”.

The terms absent and present describe states of “being” and are associated with the works of the German philosopher Martin Heidegger. In his 1927 work “Being and Time”, he analysed the concepts of “being” and introduced the notion of “*dasein*” a German word for which the literal translation is “being there” (Heidegger 1962).

In a 2011 presentation Elaine Kasket discussed Heidegger’s existential concepts of Being-in-the body, Being-with-others-in-the-world and Being-towards-death. In this presentation Kasket asked four questions: 1) What is the nature of the digital being of a Facebook profile? 2) What about when someone dies? What is the nature of their Facebook profile then? 3) Is building a durable biography in life a denial of Being-towards-death? 4) Does interacting with deceased others make us more aware of our own Being-towards-death? (See Kasket 2012b). But Kasket’s presentation does not ask questions about the digital memories created in life that becomes part of a digital afterlife following death. In another 2011 paper, Joohan Kim suggests that in addition to Heidegger’s *res extensa* (being of nature) and *res cogitans* (being of

mind) there is now a third entity which he calls “*res digitalis*”, which he suggests sits between the two. Digital-beings he suggests forces us to reread Heidegger’s concept of “*Dasein* as being-in-the-world” since he suggests *dasein* becomes digi-sein: “being-in-the-world-wide-web” (Kim 2017). Heidegger, Kasket and Kim’s notions of *dasein* will be discussed further in Chapter six of this thesis, where I will present my concept of a digital *Dasein*

2.5 The final stop over – sociology and death

During the process of this thesis I was asked to justify the sociological interest within my research. Based in the Department of Sociology I found this to be a rather odd enquiry: of course it is sociologically based, death affects society just as society affects death was my reasoning. How a contemporary Western society deals with death, dying and bereavement is fundamentally social. The death of someone is a life-changing event and is experienced by individuals and society. Bereavement triggers social processes, and how individuals deal with death dying and bereavement is complex, as death and society are entwined. For sociologists, death is a social fact not just a biological fact, and importantly, grief does not only affect individuals, it affects wider groups. During the writing of this thesis there have been terror attacks and mass shootings in Paris, Orlando, Manchester, London, Las Vegas, New Zealand and Sri Lanka. During the various iterations of writing of this thesis I have revisited this section several times to update this list, and the effect that this has had, on me as a researcher, is something I discuss in the next chapter. These attacks highlight the social context of death and grief, and how public displays of grief are changing in the 21st century (Walter 2008). Social media have played an important part in these social demonstrations of mourning and solidarity: the hashtag #JeSuisCharlie was used over 6,500 times per minutes following the deadly attack on the offices of Charlie Hebdo in 2015 (Whitehead 2015). Facebook quickly introduced a French flag meme for their users to incorporate on their profile page following the Paris attack, so their users could show solidarity with the country that had been affected.

How people deal with grief is complex, it is entwined and embedded within issues of

gender, race, class and culture: within a social context. It is not just social grief that is context specific, individual or private grief also happens within a social context that is amplified and made increasingly visible by social media.

The links between sociology and death started with Durkheim and his discussions about funeral rites and suicide (Durkheim 2001). However, in 1958 Faunce and Fulton found it necessary to write a paper entitled “The Sociology of Death: A Neglected Area of Research” in an effort to redress what they saw as a lack of academic research into death and dying from a sociological perspective. Their claim was that this lack of research was probably connected to society’s reluctance to contemplate death and dying (Exley 2004).

This hiding away and sequestration of death is intended to ensure it does not interfere with everyday life (Walter et al. 2012). However, there are signs that social media provide platforms where people are openly discussing the issues surrounding death and dying (Taubert et al. 2014). Moreover, as a result of the hospice movement many dying people in the UK have access to assistance that allows them to die in their own home which results in them remain in their community rather than being removed from the everyday lives of friends and family (Nahh.org.uk 2015).

This desequestration of death could also be linked to 24-hour rolling news channels which are available to many in the Westerners world. This ensures that the inevitability of death is brought into our homes and onto our screens with ever-growing ease. The mass media have always reported on the dramatic and spectacular dead; however, the ubiquitous and mobile nature of social media engenders the availability of information about the non-spectacular dead. In October 2014, terminally ill Brittany Maynard, in conjunction with the organisation Compassion and Choices uploaded a YouTube video advocating assisted dying (CompassionChoices 2014). This video has received over 11 million views and has succeeded in galvanising debates and discussions about changes to the law on assisted dying and the right to die. The use of social media as an advocacy tool for the dying is evident in many of the thanablogs discussed in Chapter six of this thesis where I look at the motivations for using these tools.

In his classic ethnographic study, Sudnow emphasised the culturally and institutionally acceptable way in which people could “pass on” (Sudnow 1967). His study, carried out in hospitals, looked at how death and dying had become socially institutionalised and how the status of both the dying person and the bereaved plays a significant role in the societal practices involved in bereavement. He noted that even in hospitals, other patients still needed to be distracted from death and the dead body. Death was hidden away: hospital staff would attempt to move dead bodies from hospital wards without the knowledge of other patients (Becker 2014). Also writing in the 1960’s, Glaser and Strauss suggested that knowledge of impending death should not be hidden from the dying patient (Glaser & Strauss 1966). The sequestration of the dead during this time resulted in a culture where death-denying prevailed, and death and dying became a taboo subject in many Western countries. Sudnow’s work highlights how news spreads through communities following the death of one of its members. He describes this communication as a series of concentric circles with the immediate family at the centre point, suggesting that the further away people are from the bereaved would be illustrated by expanding the outer circles (Sudnow 1967). Though social relationships and especially family structures have changed since Sudnow’s study, I would suggest that they have never been this symmetrical and Sudnow’s use of concentric circles fails to acknowledge the complexities within personal relationships and social structures. Here, it is important to acknowledge that the Internet also challenges this paradigm by completely disrupting the hierarchy of the bereaved and changing who is now considered to be the disenfranchised grievers. The Internet is making mourning practices more visible in our digital societies, and research which is embedded within a sociological perspective will be essential in order to shine a light on how desequestration, and public mourning, will affect societal attitudes, and the culturally shared narratives around death dying and grieving.

2.6 Conclusion

In this chapter I have looked at how the topics of death, dying and grieving have been discussed across many different disciplines, and how thanatechnology and its effects on the bereaved is now emerging as an interesting and important focus of

research for thanatologists. This literature review has opened up a space for the exploration of the research questions for this thesis.

In order to begin to explore this complex and diverse area, in the next chapter I will explain the research methodology which guided this research, along with the research questions and the research aims. The literature dealing with the ethical concerns that arise when conducting bereavement research and Internet research more generally, has been absent from this literature review, and this will also be dealt with in the next chapter.

In chapters four, five and six of this thesis, I will introduce you to the bereaved, the dying, and the people behind the companies who make digital afterlives possible – my participants.

3 Chapter Three: Methodology and Methods

3.1 Introduction

The training and personal values of the researcher cannot be ignored. They form a component of the context of social research methods in that they may influence the research areas, the research questions and the methods employed to investigate these (Bryman 2012, p7).

Research projects are deeply embedded within the epistemological and ontological assumptions of the researcher. This thesis explores how digital memories afforded by the Internet affect how people grieve, and seeks to understand the way people make meaning of death, dying and grieving in our digital society. In order to explore these issues, careful consideration needs to be given to both methodology and methods. The focus of the methodology chapter is to outline and justify the decisions made and the rationale behind the qualitative methodology and methods used to guide this thesis.

The chapter starts by outlining the epistemological and ontological assumptions which underpin the thesis and assist me to explore the research questions and research aims discussed in the introduction of this thesis. Moving on, I provide a pragmatic account of the qualitative methods used in this study: including how I recruited my participants, how I collected the data and how the data was analysed.

According to Johnson and Clarke (2003) socially sensitive topics evoke emotional responses in both the participants and the researcher; thus, as this research deals with the sensitive and emotionally laden subject of death, dying and grieving, it has demanded the highest standards of ethical consideration. Whilst I acknowledge that all research demands high ethical standards, there are strong and robust guidelines to follow for the majority of projects. However, the ethical guidelines for Internet research and specifically thanatological Internet research are still in their infancy. As a consequence, my research highlights some of the complexities of the ethical dilemmas facing thanatological Internet researchers, and these issues are discussed throughout this chapter. Next I move on to discuss the limitations of the

methodology and methods used within this study, before finally – through the process of reflexivity – the chapter ends with an insight into the motivations behind my research, and how this research has been affected, and in turn, has affected me as the researcher.

3.2 The philosophical framework – epistemology and ontology

Any attempt to understand social research without a clear understanding of the epistemological and ontological assumptions of the researcher, is naive. These assumptions influence the design and therefore the findings of any research study. Consequently, this chapter will explain the positions taken throughout this research to allow the reader to fully understand the frameworks which have guided the research design.

As a sociologist I believe attempting to understand how people make meaning of the world around them is the cornerstone of sociological research. With this in mind, my research adopts a qualitative methodology which allows for the collection of rich data in order to gain a contextual understanding of how people experience grief in a digital society. As a researcher, I am interested in experience rather than causal relationships, and I believe this cannot be achieved by quantitative methodologies as they fail to highlight the richness and depth of how people experience any given phenomena. Qualitative methods are best suited to illuminate how grief is experienced; yet my research is not trying to explain grief, it is trying to understand how people experience grief in our digital society. Qualitative research can also reveal how the practices, protocols and social norms of grief and bereavement may be changing in the emergent spaces created by the Internet. This research is underpinned by a social constructivist perspective, which is characterised by the assumption that reality is subjective and that phenomena and their meanings are continually being accomplished and revised by social actors (Bryman 2012, p33). Furthermore, my ontological position assumes that through interaction, reality is socially and culturally constructed (Charmaz 1980; Denzin & Lincoln 2011).

3.2.1 Grounded Theory

Because this study focuses on the nascent phenomena of digital memories and messages created and consumed on the Internet, I wanted to ensure I would be open to the possibility of developing new theories around death, dying and bereavement, rather than testing existing theories which were developed before the existence of social networking platforms. Grounded theory, the iterative approach to the analysis of qualitative data, has become one of the most widely used frameworks in qualitative data analysis (Bryman 2012). Moreover, grounded theory has historical links with thanatology. Its developers Glaser and Strauss's studied the awareness of dying and, importantly, theirs was one of the first major studies to use grounded theory as a research process (Glaser & Strauss 1967). This method seemed an obvious start point when seeking a methodological framework for my thanatological study, as Glaser and Strauss's 1965 book, "Awareness of Dying", put the experience of death and dying onto the agendas of grounded theorists. This classic study did not have theory as its starting point; rather it developed theory from carrying out and comparing case studies (Glaser & Strauss 1965). Their concern was that with other methods of qualitative data analysis researchers could manipulate facts to "fit" theory (Glaser & Strauss 1967, p29). This systematic inductive method assumes that theory is "grounded" in the data, rather than empirically testing existing theories (Flick 2018). This grounded approach uses the data to construct middle-range theories (Belgrave & Charmaz 2014) rigorous scrutiny, simultaneous data collection and the development of the researcher's emergent theoretical categories.

Initially, I was drawn to the open-minded approach to data that grounded theory offered, and I considered grounded theory as a potential suitable method for my thanatological study. Although I thought it could possibly help me to achieve my research aims, it felt somewhat inflexible in its approach (or lack of approach) to reflexivity. Moreover, its assumption that data and relevant facts are "there" to be collected – what Kelle called "naive empiricism" (cited in Charmaz 2015) did not take into account my epistemological position, that meaningful qualitative research should acknowledge the role and biography of the researcher, along with the agency of the participant in the co-production of knowledge. I therefore sought a methodological framework which would overcome some of the "epistemological

shortcomings” that I found in grounded theory (Flick 2018).

3.2.2 Constructivist Grounded Theory

Building on the works of Glaser and Strauss and Strauss and Corbin (1967, 1990), in 2000 Kathy Charmaz developed constructivist grounded theory: this method attempted to address what she saw as the “objectivist” nature of traditional grounded theory which she suggested aimed to uncover a reality external to social actors (Charmaz 2000). This new version of grounded theory preserved the useful strategies developed by Glaser and Strauss and Strauss and Corbin, but importantly integrated more recent developments in qualitative research such as reflexivity and the co-construction of data (Charmaz 2014). Constructivist grounded theory still shares some of the central assumptions of traditional grounded theory such as (1) theory can be generated by systematic, comparative, inductive qualitative research; (2) qualitative research must be judged on its own canons; (3) theory construction is the purpose of grounded theory; and, (4) you can raise the theoretical level of the emerging analysis by using the strategies of grounded theory (Belgrave & Charmaz 2014). Charmaz’s constructionist version of grounded theory also assumes that “social reality does not exist independent of any human action” (2000, p521). To be more precise, she recognises that categories, concepts, and theoretical levels of an analysis emerge from the researcher’s interaction within the field and questions about the data (Charmaz 2014).

“Constructivists view theory as constructed rather than discovered, data as defined rather than self-evident, the meanings of data as multiple rather than singular, and analyses as located in time, space, situation and the research process” (Belgrave & Charmaz 2018, p36)

Constructivist grounded theory draws on the ontological perspective of constructivism, which views and assumes that people, including researchers construct the realities in which they participate, moreover, it acknowledges that a researcher’s interpretation of a phenomenon is itself a construction (Charmaz 2014). Crucially Belgrave and Charmaz (2014) suggests that constructivist grounded theory can play a significant role in the field of thanatology, as it goes deeper into participants’ meanings of illness, dying and death. After further consideration I decided this framework was suited to my study as it reflected my constructivist

ontological position whilst also enabling me to achieve my research aims.

3.2.3 Symbolic Interactionism

Symbolic interactionism is a theoretical perspective based on pragmatism, which is tightly linked to both constructivist grounded theory and thanatology (Belgrave & Charmaz 2018). It assumes individuals are active, creative and reflective (Charmaz 2014, p345) and that in and through human interaction meaning is constructed and takes place in a social world (Belgrave & Charmaz 2018). Building on the work of George Herbert Mead, Blumer coined the term symbolic interactionism to argue that individuals continually interpret the symbolic meaning of his or her environments (including the actions of others) and acts on the basis of this imputed meaning (Bryman 2012). In other words, it examines human behaviour and the meanings people attach to elements of their lives. Goffman (1959) claimed that people act and react along similar means and constraints universally, and a unified image of reality is achieved by collective understanding. This is crucial to my research as no knowledge about grief is culture free, rather grief is shaped by sociocultural processes which in turn help to establish the meaning of a loss (Neimeyer 2001; Rosenblatt 2008). Therefore, a symbolic interactionist approach to this research is suitable as it highlights how the individual is influenced by, and in turn influences, social norms surrounding loss and grief. Using this theory as a framework also ensures the study is focused on my research questions, which ultimately seek to explore the “social” in social media to understand how posthumous digital remains, accidentally or intentionally left on the Internet, affect the way people grieve in our digital society.

This study draws on symbolic interactionism to provide the foundation for this study; it allows an exploration into how posthumous digital memories and messages are perceived and interpreted by both digital creators and digital inheritors; but importantly helps me to understand how meaning is jointly created and how this is shaped by the wider societies we inhabit. Although my research explores the lived-experiences of individuals, loss takes place within a cultural context (in the case of this thesis within the cultural norms and rituals of a Western society) and using symbolic interactionism as a theoretical perspective allows this to be taken into

account. Therefore, this theory-methods package of symbolic interactionism and constructivist grounded theory (Charmaz 2014), directly aligned with this sociological thanatological study.

With my interpretivist epistemological position and my constructivist ontological framework in place, the next part of this chapter moves on to discuss the important issue of ethics, and the ethical challenges and opportunities faced throughout this doctoral study, which deals with the existential issues of death and dying.

3.3 Data collection

3.3.1 Digital Scholarship and Digital Sociology

With the ethical framework of this study at the forefront of my mind, I moved on to the data collection stage. In this next section I will discuss the how data was collected. However, it should be noted that rather than following a linear process, in grounded theory research, reviewing the existing literature, collecting data, coding and sorting the finding, identifying themes, identifying relationships and drawing conclusions to produce conceptual theories, all happen simultaneously in this iterative methodology.

Throughout this thesis I have engaged in what Weller describes as “digital scholarship” (2011). As this thesis explored how others experience certain phenomena within the digital realm, digital scholarship seemed apt. In the early inception of this thesis I realised that in any attempt to understand and explore our digital society required me to fully immerse myself within that digital society. Digital sociology focuses on how people use digital technology and also on the digital data they produce (Lupton 2015). During this research I have adopted what Lupton describes as a “professional digital practice”, that is, I have used digital tools as part of my sociological practice. Previously, as will be discussed in the reflexivity section of this chapter, I did not have an online presence.

Social media differ from other media as they have specific characteristics; persistence, visibility, spreadability and searchability (Boyd 2014). These

characteristics offer researchers opportunities, not least due to the lack of established gatekeepers forming a barrier to ethnographic research (Carrigan 2016). In addition to other positive reasons for using social media, using them to communicate with other academics via Twitter and blogs proved invaluable during this research. It supplemented the face-to-face discussions at conferences and networking events with other thanatologists and those working on similar topics, by offering further opportunities for fruitful collaboration and clarifications long after leaving conferences and events (Carrigan 2016).

In order to elicit rich, detailed and first person accounts, and gain a unique perspective into how people experience the creation and inheritance of digital memories and messages, a qualitative study using a mixture of in-depth interviews and virtual ethnographic methods was deemed suitable. Ethnographic immersion into social media sites and platforms was identified as being able to provide suitable online data from thanablogs and tweets. Unobtrusive methods were considered for this research, such as examining tweets without seeking approval from the authors as they were in the public domain; however, “lurking” is considered a covert research method (Hine 2003) and something I wanted to avoid. There are on-going debates around the public/private nature of Internet research (Markham & Buchanan 2012) and special consideration needed to be given to Culpit’s warning of being perceived as an “ambulance chaser” (2012). Following careful consideration of these debates I chose an overt role as a researcher whereby I disclosed my research topic and university affiliations to all potential interview participants and authors of specific tweets I wanted to use as digital data. I also used overt methods by gaining permission as a researcher to gather data from a number of replies and comments to thanablogs and YouTube videos that were useful to my research, and were coded in the same way as other online narratives (this is discussed later in this chapter).

Because of the sensitive nature of this study, and because I required methods which would allow me to explore digital memories and messages in a much deeper way, I concluded that a non-participant observation method would not be suitable, therefore consistent with an constructivist grounded theory approach I adopted a qualitative method of data collection using in-depth interviews for all three groups: Service Providers (SP) Digital Creators (DC) and Digital Inheritors (DI). Constructivist

grounded theory allows context to play a role; according to Johnson and Onwuegbuzie (2004) data emerges within a context and should be viewed within that context. This idea is compelling when looking at how the Internet, social media sites and artificial intelligence algorithms are being used to create a new space – a new context – for death, dying and grief.

Following the constructivist grounded theory approach to data collection, this study followed a theoretical sampling approach, which involved concurrent data collection, data analysis and coding. Rather than being a linear process this study involved an iterative approach. Following an initial round of data collection and analysis, I sought out participants whose experiences were relevant to, as well as meaningful regarding the ideas and concepts developing from, and linking back to, the previously collected and coded data. Doing so enabled me to elaborate and consolidate my developing theory (Flick 2018).

Across the 3 groups a total of 48 participants took part in this study. It is suggested that studies using grounded theory recruit between 10 and 100 participants dependent on when saturation is reached (Starks & Trinidad 2007): theoretical saturation is the idea that sampling theoretically continues until a category has been saturated with data (Bryman 2012). According to Strauss and Corbin (1998, p212) theoretical saturation occurs when (a) no new or relevant data seem to be emerging regarding a category (b) the category is well-developed in terms of its properties and dimensions demonstration variation, and (c) the relationships among categories are well-established and validated. As noted by Flick (2018), this does not mean there is no more data to collect or more cases to include, it only means that data collection is no longer necessary for developing an emergent theory or no longer suggests new dimensions within an existing category.

3.3.2 Twitter as a recruitment tool

Following the extensive literature review for this doctoral study I wanted to start with research into thanablogs. I discovered that many thanabloggers were using Twitter, the social media platform, to discuss their diagnosis, treatment, and their views and wishes about death and dying. In an attempt to recruit participants to take

part in in-depth interviews, I created a research Twitter account @ [REDACTED] and wrote a brief description of my research and affiliations in the profile section. To recruit my digital creators, rather than tweeting to a random population of Twitter users, I decided to introduce my research to targeted groups which were already discussing death and dying on blogs or on Twitter, for example @abcdiagnosis (After Breast Cancer Diagnosis). I then compiled a list of groups and individuals who may be interested in my research and I tweeted the recruitment tweet with the @ symbol to the list with the hope they would follow me and retweet the tweet to their followers.

I started recruitment in June 2016 and in the first wave I directed the recruitment tweet using the @symbol to the list of groups and individuals I had created. I used Twitter analytics to track the effectiveness of the tweets: the original recruitment tweet resulted in 5930 impressions on Twitter (impressions mean that a tweet has been delivered to a Twitter account's timeline but not necessarily that the tweet has been read). I then tweeted four more recruitment tweets during the next 3 months resulting in a total of 12,983 impressions, resulting in 8 likes and 5 replies. I amended the recruitment tweet that asked about deleting social media pages of deceased loved ones which I then sent to the original list.



Figure 4 Screenshot of a DI recruitment tweet

This stage resulted in an impression rate of 3132. In the planning stages of this research I thought digital inheritors would be the hardest participants to recruit, however, this was not the case: following extensive research on social media platforms I found that Twitter was being used by many support groups and charities to discuss grief and bereavement. Following recruitment tweets directed at this group I found people were self-selecting in response to the tweets. Later in the section I discuss using Twitter as a data collection tool.

During the fourth year of this research I wrote short article for the online news website The Conversation (2019). As a result of this article I was invited to do two media interviews: one with an American radio station and one with a Canadian radio station. Following these media interviews I was contacted by three people who wanted to tell me about their experiences of inheriting posthumous digital memories, and requesting further details about my research. All three asked if they could take part in the study and became participants in the DI group.

For the service provider group emails proved to be a more successful tool recruitment tool. However, using email for potential participants of the digital inheritor category was not without its problems: during the early stages of recruitment I approached a potential digital inheritor via email. I received a reply almost immediately complaining that I had used the phrase “digital immortality” within the email when describing my research, which they found offensive as it insinuated that their loved one had not really died (they later agreed to take part in the research). This resulted in some reflection, after which I amended recruitment emails and tweets to ensure the term digital immortality was removed. The term was also changed part way through the thesis as a result of data collection and emergent themes. This decision will be discussed further in Chapter seven of this thesis.

Type of recruitment	Total
Responded to recruitment tweet	14
Responded to recruitment email	19
Heard about my research and contacted me	7
I approached following a related tweet	5
Snowballing	3
TOTAL	48

Table 3.1 Participant recruitment

Here, it is important to clarify that these groups of participants (DIs, DCs and SPs) are not mutually exclusive: participants can appear in more than one group. For instance, a DC who has created digital memories or messages to memorialise their deceased loved one – or in an effort to continue their relationship with the dead – will then inherit that digital creation and therefore also possesses the characteristics of, and therefore become, a DI. In addition, a SP participant may also create memories and messages on their own sites, to be left posthumously, therefore also becoming a DC. The diagram below illustrated this overlap of participants.

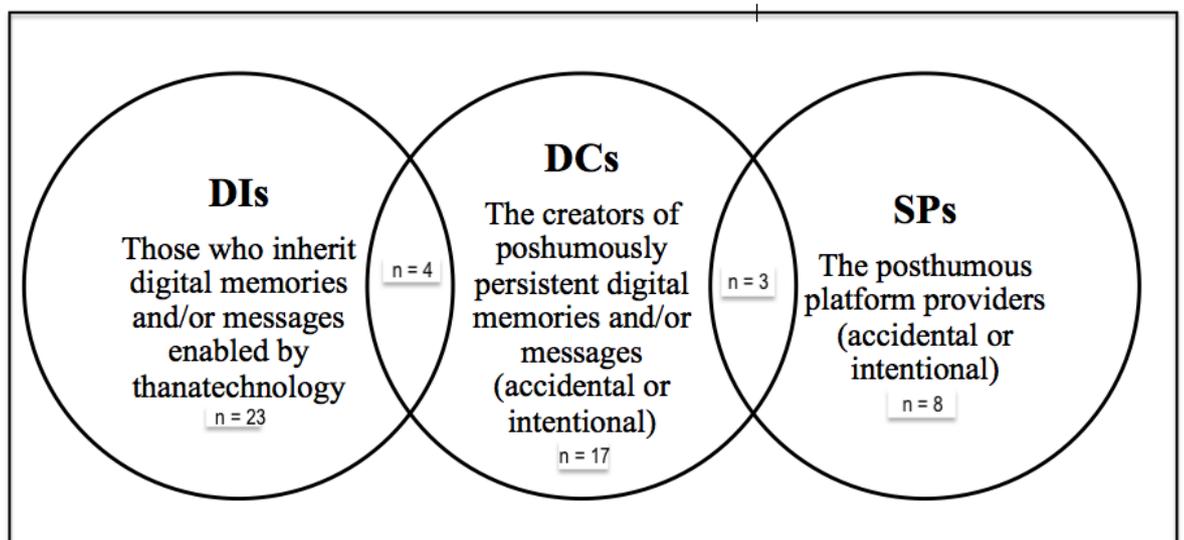


Figure 5 Venn diagram showing overlapping participant groups

In Chapter six of this thesis I present findings from my DI participant which includes tweeted comments about posthumous digital memories and messages following a tweet from James O’Brien the Radio LBC disc jockey. Although I have permission to use the tweets included in this thesis, I have not added these DCs into the total number of DCs, as I did not carry out in-depth interviews with any of these DCs.

To ensure the well-being of my DI participants I created a criteria list which I followed during the recruitment process:

- DI Participants should be recruited via Twitter or email, no follow-up email is to be sent if no reply is received.
- DI Participants must be bereaved for 6 months prior to participating in the research – in an attempt not to cause further anxiety in the early months

following their loss

- The deceased did not die by taking their own life – to protect me as the researcher – see reflexivity section of this chapter for further explanation.

Information from outside agencies was made available if requested. I explained that the interviews were for research purposes only, and not intended to be a form of therapy, although Dickson-Swift et al. (2006) suggest that by telling their story interview participation can feel therapeutic to some participants. A follow-up email from one of my participants illustrates this:

“As much as I do not shy away from talking about the loss of my brother, I find, that when the conversation is led by someone else it is a cathartic release. I came off the phone once again, slightly more connected with my grief. It's never a negative or bad thing to talk about my brother Josh, no matter how painful or sad”

In this quotation above, I have not changed Josh's name, as my participant specifically requested that I not do so. The issue of ethics is complex, especially when researching the emotionally laden topics of death and walking this ethical tightrope between guidelines and loyalty to participants has not been easy. These issues of research as therapy, and not changing the names of the dead are discussed further in the ethics section of this chapter.

3.3.3 Collecting data – using Skype the why and the how

Qualitative research interviews are probably the most common method of data collection in sociological research (Bryman 2012). Using a semi-structured framework allowed the flexibility to ask open questions, which I hoped would elicit the rich description needed for this study. I created an interview guide, ensuring the questions were consistent with the research questions, as a memory prompt for each of the 3 sectors from which I was collecting data (Bryman 2012, p471). This ensured I addressed the issues I was attempting to understand, whilst giving me the flexibility to facilitate all my participants at the time and within the environment of their choosing, to encourage them to give rich descriptions of the phenomena I was exploring. Crucially using these tools also allowed me interview participants who

had “time and place limitations” (Janghorban et al. 2014).

Although qualitative research has traditionally taken place in face-to-face settings, I wanted to use current technology which offer researchers more research tools, and using Skype, the telecommunication software product, became an early research decision. The use of VoIP (Voice over Internet Protocol) technologies such as Skype as a data collection tool is becoming popular with some qualitative researchers (see Cater 2014; Janghorban et al. 2014; Lacono et al. 2016; Weller 2017). Moreover, because my research focuses on the use of the Internet and thanatechnology, it felt appropriate to be part of what Deakin and Wakefield describe as the new “methodological frontier” (2014) and attempt to use technological methods to collect the data rather than more conventional methods.

The issue of “being and feeling present” and the effect this has on the rapport between interviewer and participant when using Skype is an important issue (Weller 2017). Although, having completed the interviews for this research, I would argue that rapport is easily achieved in Skype interviews as all the participants seemed very relaxed during the interviews even with the sensitive nature of the research. Moreover, I would suggest limiting the term “face-to-face” to traditional interviews does not allow for feeling of co-presence participants get from interviews conducted via Skype (see Weller 2017). A Skype interview does enable face-to-face communication albeit mediated by the Internet.

The ability to record Skype interviews means that body language, facial expressions and gestures, which could be easily missed via traditional interviews, can be re-examined on replay. While body language did not form part of my analysis it enabled me to feel “back in the room” when transcribing and therefore closer to the data. In a 2014 paper, Cater noted that using Skype can negatively affect the rapport between the researcher and participant. I would argue that this was not the case in the interviews I conducted for this study: maybe because although the subject matter was emotive, participants have none of the disadvantages of traditional interviews (where they are physically present) such as inducing anxiety or being intrusive (Weller 2017). Moreover, I found that many of my participants were relaxed and responded with in-depth answers to sensitive questions. The ability to create a

feeling of co-presence without problems of anxiety and being intrusive was imperative to this study and using technology proved to be successful in achieving these goals. Being able to monitor how the interview may be affecting the participant is important in qualitative interviews, especially when the study involves existential issues (Pietkiewicz & Smith 2014). Prior research suggests that a limitation of using Skype for semi-structured interviews is the loss of social contact (Lacono et al. 2016). For me, this was outweighed by the advantage of being able to conduct the interviews in participants' own homes, giving the power to the participants if they wished to end the interview. None of my participants ended the interview early, moreover, several participants extended their interviews by asking for further details about the research once the original set time had elapsed, and some discussed their enjoyment in taking part in the research. But, they did have the ability to stop the interview early if they were feeling uncomfortable, without the anxiety or embarrassment of having to ask me to leave. In addition, risks to my personal safety were also eliminated by using Skype as a data collection tool, as I, along with the participant had the ability to stop the interview at any time.

In her 2016 work Seitz makes an important point about potential technological problems, which can result in the lack of rich non-verbal cues, however, I did not have technical issues with sound or audio during any of my interviews. I do, however, acknowledge this is a limitation of this method of data collection in some areas where VoIP service is limited or intermittent.

Many of today's computers have video cameras built in, which makes it easy to use a video communication platform such as Skype for qualitative research (Cater 2014). The software is easy to download and simple to use, moreover, in all cases, my participants were familiar with its use; this is probably because my participants for all three sectors can be described as digital natives (see recruitment). The nature of the research into digital afterlives enabled by the Internet pre-assumes a certain level of computer literacy by the people who self-selected via my Twitter recruitment campaign.

I downloaded and used Call Recorder software onto my MacBook, which recorded both audio and video during each Skype interview, thereby ensuring every aspect of

the interview was being captured. Once downloaded and installed the Call Recorder opened automatically when I started Skype and during the data gathering for this study I found the software to be extremely reliable. Using Skype allowed me to recruit participants globally without any geographical, time, or financial constraints (Janghorban et al. 2014) and furthermore, participants' feedback showed they were comfortable using the technology. In addition, because there were no geographical limitations as to who could take part in the research this resulted in ensuring variety in the sample (Lacono et al. 2016). I have two screens on my work desk, where I sat for the interviews, thus enabling me to discreetly have files, photographs and notes clearly visible on one screen during the interview whilst running the Skype interview on the other. This assisted me to keep the interview focused on answering my research questions.

For the semi-structured interviews I created a list of questions and prompts (shown below) but I found I rarely needed to use it. I wanted the interviews to have a natural flow, which they did, however, knowing the prompt were available during the interviews, provided confidence in the knowledge that I could refer to them if needed to.

Digital Inheritors

Can you tell me about the digital memories/messages you have inherited?

Can you me what these digital memories/messages mean for you?

Can you tell me how you store these memories/messages?

Is there anything else you would like to add that we have not included?

Digital Creators

Can you tell me about the digital memories/messages you have created?

Can you tell me what you hope to achieve with these creations and how you felt when you created them?

Is there anything else you would like to add that we have not included?

Service Providers

Can you tell me about your motivations for starting your digital afterlife platform?

Can you tell me your future hopes for your platform?

Is there anything else you would like to add that we have not included?

Confidentiality and storage are fundamental aspects of academic research and for this study interview data was transcribed verbatim, anonymised and stored using the University of Warwick's Dropbox facility. All storage devices were password protected and all data files and paper files will be deleted on completion of the PhD in accordance with the Data Protection Act 1998. Skype encrypts messages although as Gough points out (2007), there are some countries where law enforcement can tap into Skype communications (2007). Each interview was started with an explanation of the anonymisation of participants names within the thesis (an area which will be discussed further in the ethics section of this chapter).

3.3.4 The interviews

In order to check that the technology and software worked in the way I expected, it was important to test my methods by conducting pilot interviews (Bryman 2012). Moreover, I needed to ensure this method of data collection was suitable for the challenging nature of my research topic. These pilot interviews also enabled me to assess how long each interview should ideally be, by making sure they were long enough to elicit the rich data I required, but because of the anticipated emotional nature of the interviews I wanted to ensure my participants did not get emotionally tired during the interviews.

Using the replay function on the Call Recorder software allowed me to see and hear both myself and my participant, which I found invaluable as it allowed me to assess my body language and interviewing skills during these pilot interviews. This resulted in me changing some of my interviewing techniques, such as making sure I did not talk too much and to avoid asking leading questions. Watching the playback I noticed that I looked a little too relaxed, which resulted in me thinking more about my body language and changing my chair during interviews to ensure I sat more upright for Stage 2 of my data collection. Following the pilot interviews I concluded that using Skype and the Call Recorder software had proved successful and were suitable methods for collecting data for this study.

Before the interviews I used email to confirm interview dates and times, and attached an information sheet (see appendix one) and a consent form (see appendix two) for each participant. At the beginning of each interview I reminded the participants that they were being recorded and that the interview would be transcribed, then, and also at the end of the interviews, I reminded participants they had the right to withdraw consent up to the submission of the thesis.

In order to address my research questions I needed to ensure data collected via the in-depth interviews would be rich in detail. One of my initial concerns with using Skype as a data gathering method was that I wanted to ensure that my participants would not feel disconnected or not emotionally involved during the interviews, and moreover I wanted to gain my participants' trust during the interviews. In reality using Skype provided more than I expected: each interview lasted far longer than I had anticipated as participants seemed relaxed during the interviews and were generous with their time. Each participant agreed to an interview of 20 minutes yet the average length of the interviews was 70 minutes. I always acknowledged we had taken more time than they had agreed to, in spite of that all participants wanted to continue the conversation. All of the interviewees offered to participate in further interviews without being asked, indicating their acceptance of the method being used. Skype also ensured that I was looking after my own well-being and security by not interviewing people in their homes, which afforded me with a period of reflexivity and reflection immediately following each interview. Note taking during interview was kept to a minimum, as I knew I had both audio and video recordings to assist me during transcription and coding. Any notes that were taken, were done so in a more discrete way than during a traditional interview. Note taking during a traditional interview can be obtrusive and distracting to participants (Knox & Burkard 2009). The flexibility of using Skype to collect data worked for me as a researcher as there was no travel time to consider and I managed to interview participants from the UK and the USA in the same day on 3 separate occasions.

At the end of each interview I imported the video file into ExpressScribe transcription software. ExpressScribe allowed me to see the video along with the audio while transcribing which once again ensured I remained deeply engaged with the data. Being able to see the words being spoken helped with parts of the audio

words were inaudible. A further advantage of using Skype for interviews was that on three occasions participants had to rearrange interviews; however, this was not inconvenient as the interviews required no travelling on my part, and I could therefore rearrange dates and times convenient to the participants. When transcribing interviews, ExpressScribe has the advantage of allowing you to slow down the playback, which is useful, when the audio may be unclear. Having the ability to watch and listen to all the interviews at various stages of coding and writing data chapters has been an extremely useful tool for this research, and having the ability to “relive” the interaction (Lacono et al. 2016) between me and my interviewees has been invaluable in allowing me to watch and hear the interviews long after they ended.

A total of 46 in-depth interviews were carried out via Skype: consisting of SPs (n=6), DCs (n=17) and DIs (n=23) – some of which appeared in two groups – with participants from the UK, Canada, Germany and the USA. In an attempt to provide a broad and rich background to this study, when recruiting service providers, I wanted to ensure that the service providers were from at least two different countries, and that company sizes varied. Recruitment emails were sent out to some of the service providers alongside tweets to other organisations. The recruitment of service providers took longer than the other categories: I wanted to interview the person who had started the company, typically the CEO and therefore finding time when they could be interviewed proved difficult. I achieved interviews with six of the companies, but arranging a final interview was problematic for two companies, therefore I suggested I could email the questions to them rather than arranging an interview, which resulted in their agreeing to participate. Data collected from these emails was coded in NVivo (see the data analysis section of this chapter) using the same coding method used for the interview transcripts. I would have preferred interviews rather than emails, however, the data collected from these online communications has provided important data, which has made a valuable contribution to the findings presented in this thesis. I also used follow-up emails to other participants to further clarify my thinking during data analysis.

3.3.5 Twitter as a data collection tool

In addition to using Twitter as a recruitment tool I also used it to collect data, although it should be acknowledged that Twitter was used to supplement the data collected via semi-structured interviews, and was not as the primary field of study. At the beginning of this research I did not intend to use Twitter comments as data, as I used them primarily to recruit potential participants, which I did successfully throughout the study. However, I found that people were replying to other people's tweets with comments that did not need any further exploration but were nevertheless extremely useful to my research. Here I acknowledge that I did not use Twitter as a field of study whereby I immersed myself in a longitudinal research on the social media site, however as Hine (2004) notes, intermittent engagement rather than long-term immersion can be seen as virtual ethnography. Having asked authors for permission to use the tweets for my research, these tweets were used to supplement data collected from the in-depth interviews, which allowed me to capture appropriate data to fully explore my research questions. It should be noted that during my study the world limit on Twitter changed from 140 characters to 280 characters enabling people to write longer tweets.

I also created a list of Hashtags to follow:

#digitalimmortality

#digitalafterlife

#digitalmemories

#digitalmessages

#posthumousmessages

These hashtags enabled me to see Twitter discussions on issues relating to my study, and also to identify stories from media outlets about digital memory platforms, griefbots, and avatar creation companies that were being formed as I conducted the present research.

3.3.6 Using social media platforms

As Hine (2004) points out, having a website to support research and create an "appropriate researcher presence" is important. In order to encourage and allow

potential participants to find out information about my research I purchased the domain name debrabassett.co.uk. Using Squarespace, a website builder and hosting platform, I designed a website with details of my research, information about me as the researcher, and a blog page. The blog page enabled me to add thoughts and findings during the process, which I discuss in the reflexivity section of this chapter. I included my website address on each of the recruitment tweets and the analytics section of the website enabled me to see if the recruitment tweets I used resulted in driving traffic to the site following each wave of recruitment. Checking these analytics resulted in me tailoring my tweets until I could see the tweet had successfully directed traffic to the website which indicated interest in my research. In addition, in an attempt to ensure potential participants could read about my research on SNSs I created a Facebook page explaining my research and signposting visitors to my Twitter account and website.

3.3.7 Thanablogs, YouTube and virtual worlds

The Internet has seen an emergence of thanabloggers: people who use the Internet to create their own digital narratives about their end of life experiences. In an attempt to understand the motivations of the terminally ill to communicate using thanablogs and to explore how they hoped these digital memories would be used after they had died I targeted recruitment tweets to five thanablogger's Twitter accounts asking them if they would like to participate in my research. In total three of the five participated in the interviews. I also carried out textual analysis of two further blogs, and although these blogs are in the public domain I asked permission to use the content from the authors. All those contacted gave their permission for their blogs to be used in my research. As noted earlier in this chapter I also asked permission from authors to collect data from comments left on thanablogs and YouTube videos (see YouTube video discussions below). The blogs and comments were coded using NVivo.

During the research I found a number of YouTube videos created as goodbye messages from people who knew they were going to die. These were useful to my research and provided data for me to explore the motives of DCs and the comments

underneath the videos allowed me to see how people were reacting to these posthumous messages. I transcribed and coded relevant comments that appeared below the videos. From the comments it was possible to identify that many of the respondents to these videos were tertiary mourners, that is they did not know the deceased (Walter 2015), – also described as “emotional rubberneckerers” (DeGroot 2014). However, for my research I only captured and coded comments where it was obvious that the person leaving the comments knew the deceased. These transcripts provided vital data from a “missing” group of digital inheritors: those who may have been reluctant to take part in in-depth interviews.

Following extensive research, I found people who had created avatars of their deceased loved ones and placed them into virtual worlds. In addition, I found a game design company who had created an avatar of a superfan of their game and placed them into the game. I contacted each of the digital inheritors (some were also the digital creators) via email. These participants only agreed to email correspondence; therefore these emails were coded for the research.

3.3.8 Follow up questionnaires and posters

12 months after the initial wave of interviews I produced a qualitative questionnaire using Google Forms. This online survey allowed me to see if my participants had changed their habits of how and when they used the digital memories of their deceased loved ones. Surprisingly there was a 100% response rate to these follow-up questions.

During the research I produced two recruitment posters for two sites (University of Warwick campus and Coventry University campus). Neither site resulted in any new participants. This could suggest that in order to recruit people to discuss a topic regarding Internet use you need to use the Internet. The limitations of only using digital natives are discussed later in this chapter.

3.3.9 Administration tools

For referencing I used Mendeley (referencing management software). I found it simple to learn and easy to use. It also stores all relevant literature in a library which

enabled me to quickly and efficiently search various keywords across hundreds of academic journal articles in seconds. Books were catalogued in the software using keywords to ensure they were included in any relevant searches. The word processing package Scrivener had probably the most positive affect on the writing-up part of this thesis. The package is far more flexible than Microsoft Word for working on large documents, and the corkboard facility allows for easy writing and retrieval of notes whilst working. The ability to see the thesis as a whole document whilst still being able to sort, organise and change chapter sections proved invaluable in the writing process.

3.4 Data analysis

Qualitative research produces qualitative data; in my research this consists of a large amount of textual material from interview transcriptions, tweets, thanablogs, YouTube comments and emails. As pointed out in the data collection section of this chapter, data analysis in grounded theory is inductive and occurs simultaneously with data collection, theoretical sampling, and constant comparison (Charmaz 2014). Following a constructivist grounded theory methodology to analyse the data (Charmaz 2018), in an effort to be reflexive I gathered and made detailed notes from the interview transcripts, Twitter comments, Skype comments, and emails, with my initial thoughts and comments. The interviews were transcribed verbatim using the playback facility of the Call Recorder software, Express Scribe software and a foot pedal, which enabled me to stop, pause, rewind and slow down the playback. Here it is important to acknowledge transcribing is not just a technical task (Bailey 2008); as transcripts are not neutral records of events, but reflect researchers' interpretations of data. As discussed in the data collection section of this chapter, I felt that the ability to recorded audio and video of each interview via the Call Recorder software enabled me to immerse myself back in the data by closing any time gaps between the interviews, transcription and coding. Any further notes or comments were added to my field notes at this point and consistent with constructivist grounded theory methods, data collection continued during data analysis.

The intention of grounded theory is to construct substantive theories that explain a

phenomenon or an experience (Charmaz 2014). Via an analytical interpretation of the data grounded theories depict relationships between concepts by comparison. To assist with the organisation of the data and the analysis I used NVivo, a computer-assisted qualitative data analysis (QDA) computer software package that I had installed onto my laptop. NVivo enables the researcher to “code-and-retrieve data” (Lee & Fielding 1991) that is, it allows the data to be coded and then retrieved, showing all texts coded in a particular way. I attended workshops on using NVivo run by the University of Warwick and also referred to Bryman’s social research methods book (2012). The significant amount of time and effort taken to learn this new software package proved to be invaluable, as NVivo allowed me to be innovative and creative in how I have presented my data. I think and learn “visually”, and the ability to produce word clouds and mind maps within NVivo brought my data alive in a way that traditional data analysis tools could not do: in addition NVivo has the ability to easily compare and contrast themes which is a useful iterative tool and essential in constructivist grounded theory methods.

Each interview transcript, email correspondence, Twitter post and Skype comments were copied into NVivo. Consistent with a grounded theory approach I followed the two-step guide to coding: initial line-by-line coding: the study of fragments of data, words, lines, segments and incidents. Followed by focused coding: studying, comparing and synthesising codes that resonated with multiple experiences (Charmaz 2014). The iterative nature of these steps were made easier by NVivo, as nodes and document attributes allowed the creation of sets, and filtered out certain participants or themes on the basis of known characteristics (Johnston 2004) this in turn helped to develop the final thematic categories.

The role of memo writing is another important and significant step in grounded theory methods, as these form informal analytic notes as well as chart, record and detail the analytic phases of the research. Although Charmaz suggests that the construction of theoretical categories is their central role, memos are important as they are useful to explain the decision-making process throughout the research which gives increased transparency to any findings and theoretical developments.

Using NVivo enabled me to look at various perspectives of the data quickly and

easily and assisted with my familiarisation of the data in early stages, and my deep immersion in the data in later stages. As Charmaz points out, grounded theory coding requires the researcher to stop and ask analytic questions of the data (2014). NVivo has been a powerful and functional tool, however, it is important to stress that NVivo *assisted* with the data analysis for this study – it did not *produce* it.

Throughout this thesis I have tried to embrace the “methods revolution” (Richards 2005) and whilst I acknowledge that in certain circumstances NVivo and other QDA software programs could result in the researcher feeling somehow disconnected from their data – especially if others are involved in transcribing and coding the data – in my research I did all of the transcribing and coding myself and, moreover, because all the interviews were audio and video recorded I felt completely connected and immersed in my data throughout the study, frequently revisiting the recordings of the interviews to clarify my thoughts about coding and themes.

3.4.1 Coding

All interview transcriptions, relevant tweets, YouTube comments, questionnaire comments, emails and field notes were imported into the NVivo program. Within NVivo, cases were created for each participant, and the relevant texts were imported into each case enabling me to view each case separately. I read through the transcripts and began line-by-line coding (Charmaz 2014) in order to elicit participants’ meanings and look for emergent themes. Although grounded theory methods encourage the researcher to produce conceptual theories with an open mind, Glaser and Strauss did acknowledge the researcher “does not approach reality as a tabula rasa. He must have a perspective that will help him see relevant data and abstract significant categories from his scrutiny of the data” (Glaser & Strauss 1967). This idea of “seeing” the relevant data and the concept of “emergence” in classic grounded theory is difficult in practice (Charmaz, 2014, p196), however, in a 2004 paper Barney Glaser explains the idea of what he terms theoretical sensitivity:

“The ability to generate concepts from data and to relate them according to normal models of theory in general, and theory development in sociology in particular, is the essence of theoretical sensitivity. Generating a theory from

data means that most hypothesis and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research” (Glaser & Holton 2004, p43).

With Glaser’s theoretical sensitivity in mind, and with an open mind of my own, I began the process of coding the data. In grounded theory conceptual coding is the essential relationship between data and theory (Holton cited in Bryant & Charmaz 2007). Using Charmaz’s constructivist grounded theory methods I began the process of “initial” coding. This process requires the study of fragments of data: words, lines, segments and incidents and requires the researcher to label segments of data under emerging themes (Charmaz 2014, p110). Figure 6 below shows a transcript excerpt from one of my interviews along with the coding stripes produced within NVivo.

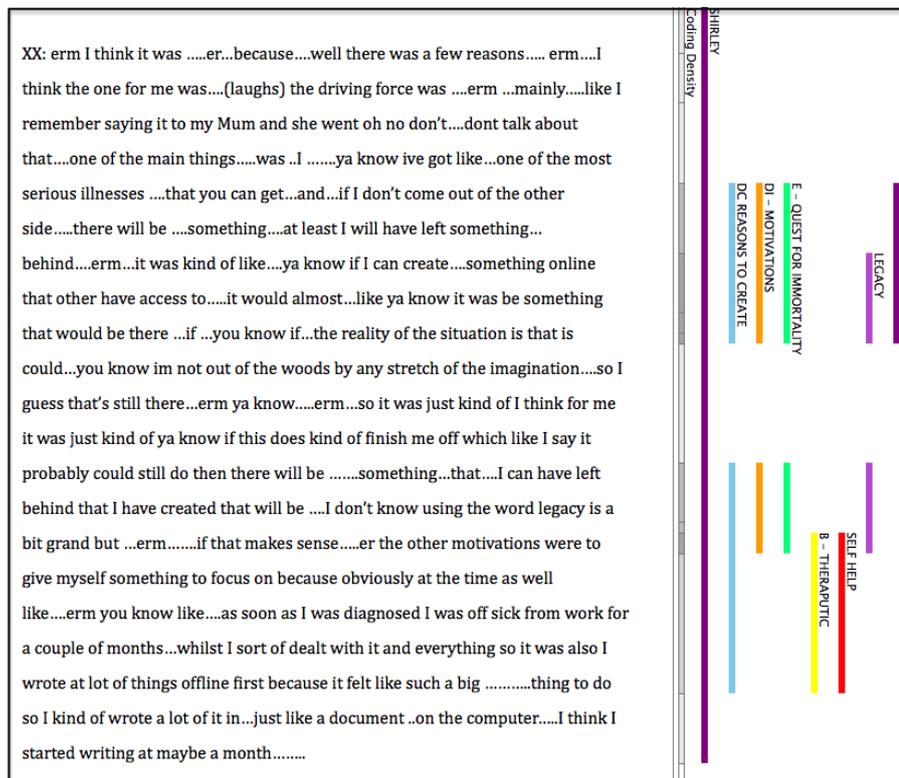


Figure 6 Image showing coding stripes created within NVivo

Because I conducted most of the interviews for my research using Skype, I also gained useful insights into non-verbal behaviour, which I made notes of in the form of memo writing. Memos or “informal analytic notes” (Charmaz 2014, p.62) form a core stage in the process of grounded theory methods. Memos are used to construct theoretical categories, but also had a wider role to play in my research in that they

helped me actively engage with my data. The ability to document thoughts and ideas during transcription – whilst listening and watching the recorded Skype interviews – enabled me to track my decisions from the beginning of the analytic process and proved extremely useful in the iterative nature of conducting this grounded theory study. Using NVivo enabled me to move easily between the interview transcripts and memo writing without disrupting my focus, which ensured the memos containing my interpretative notes were spontaneous and not mechanical (Charmaz 2014, p164). Glaser (2007) notes that writing memos slows down the researcher’s pace and allows for constant comparison within the data, and helps point out gaps in existing analysis. Moreover, in my research, memo writing created an audit trail: a written account of my ongoing thoughts and analytical decisions which adds transparency and therefore validity to my findings.

Following Charmaz my research used codes to “preserve participants meaning of their views and actions” (2014, p134). During the initial coding stage I read through the transcripts line-by-line and using NVivo I opened “nodes” for each code as it emerged from my interpretation of the data; for example, I created a node to code for “comfort” and wrote a descriptive label for each new code as it was created. Simultaneously I made a note of further thoughts and ideas by writing them in correspondingly labelled memo files. Using NVivo to assist with coding, I further broke down the codes by creating “child” nodes: For example, my “comfort” node was further broke down into “comfort – when having a good day” or “comfort – when having a bad day”. Each transcript was coded following this procedure, and a descriptive label was given to each theme (Pietkiewicz & Smith 2014).

As Charmaz noted (2014, p138) initial coding gives a number of possible paths; focused data coding allowed me to identify meaningful, significant or frequently used initial codes. I then looked for connections between the emerging concepts and grouped them together according to relationships and conceptual similarities. Theoretical sensitivity and coding influence each other (Charmaz 2014, p161) and the iterative processes of constructivist grounded theory were useful to help me clarify my research aims and questions simultaneously while coding the data.

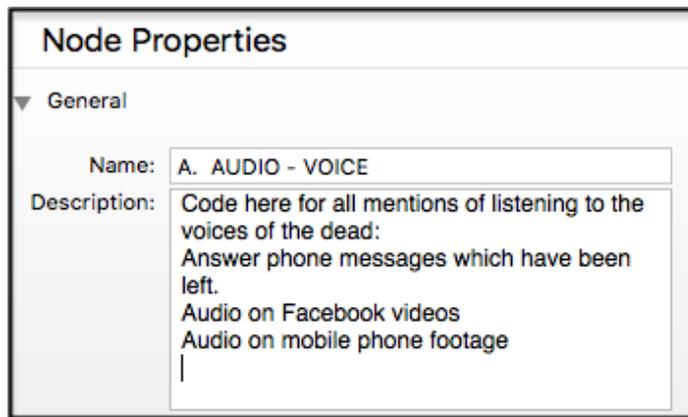


Figure 7 Image of coding note created within NVivo

The research steps described above are an extremely brief overview of the analysis of the data, because the iterative process of using NVivo to do grounded theory makes it difficult to describe the process in a linear way (Bringer et al. 2004). Moreover, describing the process of coding and analysis without revealing the research findings is challenging; therefore I will discuss NVivo and grounded theory in more detail within the data chapters, and will use the tools within NVivo to illustrate my research and my findings in an effort to maximise the transparency of this thesis (Bringer et al. 2004).

3.5 Ethics

3.5.1 Conducting qualitative research with the bereaved

Ethical rules and procedures are an important part of all research projects, but when the research focuses on death, dying and bereavement then ethical guidelines must become a major part of the research and must be embedded within the whole research design. This is further complicated by the fact that Internet research is a relatively nascent research area and the guidelines are dynamic and still evolving in this field, therefore a study such as this faces a set of unique ethical challenges, which will be addressed in this section.

This research followed the British Sociological Association's ethical guidelines and the policies and procedures of the University of Warwick's Humanities and Social Sciences Research Ethics Committee (HSSREC). I also followed the

recommendations set out in the Association of Internet Researchers (AoIR) “Ethical Decision-Making and Internet Research” guidelines (2002) and the 1964 Helsinki declaration and its later amendments. These guidelines enabled me to acknowledge and consider the context-specific ethical problems created by Internet research. In addition, Hine notes that virtual ethnography is adaptive to the conditions it finds itself in (2004). For my study I knew ethics would form an integral part of the research, and as Markham and Buchanan point out: the greater the vulnerability of the participant the greater the obligation is on the researcher (2012).

Taking these obligations on board I gave special attention to what Vivat calls “situated ethics” which advocates that ethics are not context free (2002). Whilst not aimed at Internet research I have found Stroebe and Schut’s suggestion of “methodological sophistication” important to ensure the choices made for the recruitment and data collection tools were suited to this emotive and sensitive topic (2013).

It is important to acknowledge that ethical guidelines are part of the iterative process of any research but this is further complicated as dynamic guidelines for Internet research are still in their infancy and therefore there is a strong reliance on the researcher to ensure that when we swim in the “murky ethical waters” (Carmack & Degroot 2014) of death and grief on the Internet, we not only follow the ethical guidelines that exist, but we take time to feedback and contribute to the debate about the ethical implications of our research. Because of the dynamic nature of research into death and bereavement on the Internet, Carmack and Degroot suggest dialogue should be ongoing. In an effort to continue to question the ethical regulations of researchers I suggest going further by ensuring ethics form part of future conferences pertaining to thanatechnology and its related fields.

The need for ethical guidelines is obvious and important – especially with the challenging nature of topics like death, dying and grieving on the Internet. However, in addition, the responsibility to act in a moral and ethical manner must lie with the researcher. Simply following ethical guidelines will never be enough to ensure potential participants are not offended or harmed, thus integrity and common sense must be relied on. Ultimately responsibility must lie with the researcher in this

nascent field of study to ensure not only the guidelines are followed but also the “spirit” of the guidelines.

Because I intended to interview participants who are terminally ill, or those who are grieving, I felt it prudent to ensure I had the support of outside agencies that specialise in end of life or bereavement support. I wanted to ensure that, following the interviews I could signpost such agencies that would be able to support my participants if they indicated they needed it. I made contact with relevant outside agencies that confirmed they were happy for me to forward the details of their websites and telephone support helplines to any participants who requested support (see appendix 5). No two participants are the same and therefore I found Markham and Buchanan’s suggestion of attending to the specific ethical needs on a case-by-case basis useful (2012).

3.5.2 Lurking and the public/private dichotomy of social media platforms

Virtual ethnography is the practice of observing and/or participating in an online group or online community over a period of time (Hine 2000; Miller & Slater 2001), and although Twitter challenges the traditional notion of a “bounded” field site (Marwick 2014) I felt Twitter was an appropriate recruitment tool and a site for data collection because it fitted within my philosophical frameworks to be open throughout the research process, and enabled me to explore my research question and achieve my research aims. However, using Twitter, thanablogs and YouTube comments raised ethical concerns, not only at the start but also throughout the study. Firstly, I needed to consider the public/private nature of tweets, thanablogs and YouTube comments in an effort to decide whether I needed, or wanted to, obtain consent for any tweets or comments I wanted to use. The public nature of online blogs, YouTube videos and comments has been discussed by many (see Lange 2007; Qian & Scott 2007; Viegas 2005). However, using people’s tweets about dying and bereavement needed even further considerations because of the emotional content of the data being created and used.

In their 2014 paper Carmack and Degroot discuss the case of bloggers who become public figures and how this complicates the public/private debate. I also wanted to

use posts and tweets from a “celebrity thanablogger” who blogged throughout her illness. At the time of her death in 2016 she had over 47,000 Twitter followers and had appeared on multiple media outlets where she had discussed her decision to tweet about her illness. However, when I started to read her tweets and blogs as a thanatologist – rather than just a fellow Twitter user – I asked her permission to use her public posts in my research. She gave permission for me to use anything that was in the public domain and I have subsequently asked the permission of other thanabloggers to use their posts and tweets. All participants are unique, and it should be noted that the expectations of what is public and what is private may vary between people. When communicating on social networking sites authors may not be aware that researchers are part of the audience (Moreno et al. 2008).

Following a review of the literature I made the decision that, because my research focused on the terminally ill and the bereaved, no form of ethical “lurking” would be appropriate; therefore I would seek consent to use *any* data in whatever form it took. I did not see this as a problem for my research as seeking consent should not just be seen as an ethical duty; seeking permission can actually enhance the researcher experience (Hine 2004). In my study, contacting people to ask permission to quote people’s tweets and comments resulted in the recruitment of three of my digital inheritor participants. I found that people were interested in learning more about my research and all those I contacted gave their permission to use their tweets, I did however anonymise the data, which is discussed in the next section.

3.5.3 #saytheirname

The hashtag “saytheirname” is used on Twitter and advocates for people to use the names of their deceased loved ones as hearing their name brings comfort to the bereaved by helping them to maintain continuing bonds (the theory of continuing bonds is woven through the data chapters of this thesis).

The assurance of participants’ anonymity is a cornerstone in social research and forms a major part of the general maxim of do no harm. When conducting research which confronts sensitive issues special consideration needs to be given to anonymity. In this thesis the names of all participants are changed along with other identifiable

features, and all texts collected for analysis from Twitter, thanablogs and Skype comments have been redacted in an effort to reduce the identifiability of the author. However, the Internet is an archived and searchable network, and there is evidence that even when data are anonymised an individual may still be identified (Zimmer 2010; Markham & Buchanan 2012; Shklovski & Vertesi 2013; Fossheim et al. 2017).

One major cause for ethical reflection became apparent during the research when three of my participants asked me not to change the names of their deceased loved ones. In all three cases they said it was important that their loved ones were named, and in one instance made it a condition of their participation (their reasons are detailed in Chapter six of this thesis). It is important to acknowledge that the deceased were not my participants, and importantly post-mortem privacy is an issue debated by many (Smolensky 2008; Edwards & Harbinja 2013; Prates et al. 2015). However, as I wanted to stay within the “spirit” of the ethical guidelines, I needed to consider the ramifications of not changing the names of the deceased and the impact on the anonymity of my participants. The names of the dead were only being changed in order that my participants should not be identified, however, not naming their deceased loved ones seemed disrespectful and dishonourable to my participants and moreover I felt it was an abuse of power as the researcher in this qualitative study. I discussed this with other Internet researchers at conferences and also with my supervisors before I made my decision. I decided *not* to change the names of the deceased for three cases where my participants had made the request. However, I did use pseudonyms for all others.

My research is not unique here: other researchers have faced similar ethical dilemmas (see Pitsillides 2017). In 2015, Walter discussed the problem of changing the names of the deceased where the deceased had been memorialised on the Internet. He suggests that when the bereaved have taken steps to memorialise the names of their loved ones online, then it seems unethical to remove the names for research purposes (Walter 2015). In addition, in a 2015 study into designing a digital memorial Moncur and Julius gave their participants the choice whether to have their name or those of their deceased loved ones changed.

“You are now capturing and creating knowledge out of that and that makes me feel very ... I wont start crying but ... that makes me ... Gloria will be in your papers ... Gloria will be in your data”

In her 2017 thesis, Stacey Pitsillides addresses the preconception of seeing bereavement as a vulnerable condition; this clinical view of bereavement she suggests, can create an imbalance of power between participants and researchers. Rather than seeing the anonymity issue as a problem or limitation of my study, here I challenge the traditional notion that a one-size-fits all approach works in regard to anonymity, by arguing my participants are not passive social actors in my research, rather, I argue they are co-producers of knowledge (Phillips et al. 2013). As noted by Carmack and DeGroot (2014) an important issue is whether the benefits outweigh the costs – here I am talking about the benefits and costs to my participants – and how important the area of thanatechnology is to the wider field of death and bereavement. Whilst never ignoring my responsibility to do no harm, I argue the Internet creates a blurring of the traditional dichotomous researcher-researched relationship because of what Marwick and Boyd describe as context collapse (2011). They use the term to describe how SNSs “flatten out” traditional notions of hierarchy for the bereaved; however, I think the term is useful to describe how the SNSs and especially Twitter blur and flatten the traditional imbalance of power between the researcher and participants. One consequence of this context collapse during this research is discussed in the following section.

3.5.4 When participants “out” themselves

Following the publication of one of my articles in Discover Society, during early 2017, I received feedback from several participants via Twitter about the last paragraph of the article in which I wrote:

“When those involved in my research give their time and emotional energy to discuss their darkest moments and deepest grief, the use of terms such as “participants” and “preliminary findings” seems disrespectful. In this article I use the terms with sincere respect and thanks to all those who have given time for this study”

I tweeted the paragraph describing it as the most important part of the paper, and one

of my participants replied to the tweet:

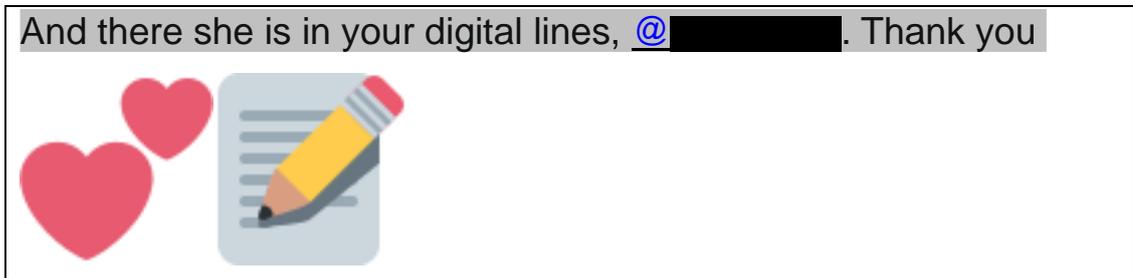


Figure 8 Screenshot of the reply to my tweet

I have redacted the details of the author of this tweet however it illustrates how participants see their loved ones in researcher's writing whether they are named or not, there were many such instances where my participants "outed" themselves by commenting on my Twitter feed, retweeting and liking my tweets.

As discussed in earlier in this chapter some of my participants expressed how they enjoyed being part of this research as it gave them a chance to talk about their grief:

"I got so excited after we connected on Twitter and agreed the interview. It will always stay as a deeply personal, meaningful and memorable experience with me" (follow-up mail correspondence with Amy)

"I hope this is of some use to you, it was an unexpected opportunity for me to write (for the first time) how I felt about this picture and my relationship with it. Thank You for giving me that opportunity" (follow-up email correspondence with Jeremy)

These quotations support the suggestion by Dickson-Swift et al. (2006) that some participants find it therapeutic to participate in research, as it gives them the chance to talk about their deceased loved ones. To treat my participants as passive agents in my research is to treat them as "vulnerable" people who need protecting from their own decisions. We meet and engage with the bereaved as we go about our daily lives (Pitsillides, 2017) and here I suggest a new contemporary approach, which allows for a more equal collaboration between researcher and participant. This, I argue,

could redress the power imbalance (Pitsillides 2017) and may lead to a deeper understanding of death dying and bereavement in the emergent spaces enabled by the Internet. Moreover, I argue giving the participant the choice in the anonymisation of their deceased loved ones may be nearer to the central tenant of sociological research: to do no harm, as these participants expressed their negative feelings when they considered taking part in research which resulted in the names of their loved ones being change prior to publication. However, I suggest that anonymisation of names should always be included in the information sheets given to participants, the deceased's name should be anonymised unless the participant requests that the real name is used, as was the case in this research.

By the time of submission almost three years had passed since the three participants who had requested that I did not change their loved one's names were interviewed for this research. Therefore just before submission, I emailed each of the three to check if this was still the case. All three participants still felt the same way, therefore their loved one's names have not been changed in this thesis.

3.6 Research limitations

This study was subject to several important limitations. In the reflexive section of this chapter I discuss how my dad's death from suicide created a gap in this research, which could be filled by other researchers. I will address other gaps in the research here in this section.

Twitter has been my main research recruitment tool and as such most of my participants are "digital natives" (Prensky 2001): that is, they are familiar with and regular users of social media platforms which is evidenced by the fact they have Twitter profiles. This then creates a gap – a digital divide – which could be significant to the findings of this study: it is the "digital immigrants" (those who are not familiar with digital technology) who may find digital afterlives a disruption to their grieving. However, these terms "native" and "immigrant" are contested by researchers; as Sofka et al. (2012) note this issue is multi-layered rather than dichotomous. However, I have found them and Massimi's term "technologically

comfortable” (2012) useful categories when thinking about recruitment. In an attempt to fill this digital gap I created a recruitment poster (see appendix three), which I posted at the campuses of both the University of Warwick and Coventry University. Interestingly, as discussed earlier in this chapter, I did not get any participants from the poster campaign. Another more successful attempt to recruit digital immigrants was by snowballing and word of mouth, however, I recruited just one participant for the DI group using this method. A further limitation of using Twitter is that it does not represent society as a whole: Twitter creates an echo chamber which narrows the field of recruitment to those who follow you, those who you follow, or those following hashtags you use. The vast majority of my thanablogging participants from the digital creator group were women; I attempted to recruit male thanabloggers by following prostate cancer patient groups on Twitter (the same method I had used with breast cancer thanabloggers). However this did not work: I found there were fewer male thanabloggers than female, and they did not respond to my recruitment emails.

In addition, focusing on a relatively small sample size is of course a limitation, however, generalisability was not a goal of this research and focusing on “big data” also has limitations (see Crawford 2011). In my research I wanted to explore how people make meaning of digital memories and messages in our digital society, therefore a qualitative approach seemed a more suitable method in order to achieve this. The big data approach of quantitative research is not without its limitations as it can overlook the “hows” and “whys” that qualitative research seeks to understand (Boyd & Crawford 2011).

The deliberate and purposive sampling method used for constructivist grounded theory relies on the identification of participants who are likely to contribute relevant and meaningful data that answers the research questions (Charmaz 2012). This presents a limitation in this study, as the findings may not be representative of the general population. Although this study does not seek generalisability the findings may be useful to other individuals with shared experiences of death, dying and bereavement (Denzin & Lincoln 2011). A further major limitation of this doctoral study is that it only focuses on Western societies. Whether digital memories and messages enabled by the Internet are affecting how other cultures and societies

grieve and mourn is a huge and interesting area for further research.

The data collection for this study ran from October 2015 to October 2018, and due to the dynamic nature of technology at times I struggled to keep up with the changing nature of digital platforms. Moreover, participants interviewed at the beginning of the study may have different thoughts and meanings about their posthumous digital memories and messages if they were interviewed later in the data collection schedule. However, as Giddens and Sutton (2017) point out all research is nothing more than a snapshot of a moment. Technology changes fast, as do the acceptance of these changes by participants, this limitation is acknowledged here.

3.7 Reflexivity and motivations

“As I hope becomes clear elsewhere Dad, I love you very much” – Nancy Sinatra

Qualitative research is an interactive process, which involves the researcher trying to explore the experiences and imaginings of the research participants to understand the significance and meaning of how people experience a specific dimension of the social world (Mason 2012). Personal biographies can play an important part in the research project we choose (Lofland & Lofland 1995) and this thesis is an exemplar of this theory as my personal biography has influenced almost every part of this research.

There is no doubt that my own experiences of bereavement and grief have played an significant role in the choice and specific aims of this thesis. Research is never neutral and rarely comes out of nowhere; rather, it comes from within the researcher. Here I should give some context to this thesis and acknowledge that my project is heavily influenced and embedded in my own life experiences. When I was 23 my wonderful dad took his own life. A life event I knew I would never recover from, never “move on” from, and importantly a man I would I never “let go” of. Long before I began this study, I began to question all common held theories of grief that talked about stages of grieving. I felt that the notion of grief consisting of stages which could be moved through did not resonate with me (see Kubler-Ross 2009).

Following my dad's death my mother destroyed many of the photographs, letters and diaries containing any "essence" of him, which has left a painful hole in my ability to recall his face. When I became aware of technology which allowed for the reanimation of a dead loved one, and the delivery of timed posthumous messages, I began to wonder how timed messages on important days such as my wedding day or the birth of my children may have affected my ability to grieve for my dad.

I acknowledge that my dad's suicide has created a gap in this research, as I made a conscious decision in the early stages of my research not to recruit participants who were bereaved following the suicide of their loved ones, or to research online suicide support groups. I had a duty to potential participants and also to ensure my research did not adversely affect my own mental wellbeing. PhD research is a long process and the emotional labour invested by a researcher involved in researching emotionally laden topics such as death, dying and bereavement must be acknowledged (Hochschild 2012). There are many thanatologists who focus on bereavement following suicide and I would urge them to fill the important gap left in this thesis.

During my research I was asked to take part in a podcast for "Death Goes Digital". As an "ice breaker" for the interview the editor asked for my favourite film, my favourite book, and a song I would like to be played at my funeral. Without much thought I picked "UP" – the Disney Pixar film; the book "Tuesday's with Morrie" by Mitch Albom; and the song "What a Wonderful World" by Louis Armstrong. I then realised that both the film and the book focused on death, and how important the dead are to the living in shaping and adding to their lives – I had never been aware of this connection before – they were just my favourite book and film. But reflecting on my decision, I see how the experience of losing my dad is intricately interwoven in things that seem unconnected with his death, and how these things, and this thesis are results of my own life experiences.

I should also acknowledge that I have lost others I have loved; my brother Russell, died five years ago aged 46 so grief and bereavement for me, as for many others, is a life event which influences who we become and how we live our lives. Yet it is still the death of my dad over 30 years ago which effects me the most. Grief is not only

different dependent on who the bereaved is, it is different depending on the relationship with those we lose and how we lose them.

Not long after I started researching thanatechnology, I attended a funeral where the deceased had written her own eulogy – a carefully airbrushed version of her life. It could be said this is what happens at most funerals, however, to write your own eulogy insinuates that you (a) do not trust anyone else to write a complementary eulogy, and, (b) you want to control how you are remembered. This then piqued my interest in thinking of how digital posthumous messages could be seen as a form of posthumous identity management.

I would be wrong to say I had no preconceived ideas of what I would find in my research: I had presumed that I would discover that people found digital memories on the Internet a disruption to the way they grieve. This assumption quickly changed in my research, and my findings continued to surprise me throughout the process of data gathering, transcribing and coding. Acknowledging my incorrect assumption early in this research was important to the way the research questions developed as in the beginning I was aware of my own preconceived ideas and how I could ensure that they did not influence the interview questions and subsequent coding of the transcriptions. For instance, the interview questions were developed in an open way; I did not use the terms “comfort” or “disruption” in the research questions in an attempt to avoid eliciting binary comments.

Another early realisation was that, before I started my research, I had no online presence. In fact I would ask friends to remove photographs of me from their Facebook pages. I valued my privacy, and it was therefore difficult for me to realise that in order for me to research social networking sites I needed to open profiles with Facebook, Twitter and LinkedIn. As a researcher I have adopted what Lupton (2015) describes as a *professional digital practice* in order to build networks and create online profiles in order to recruit participants, publicise my research and think reflexively about my research. However, the realisation of going from no social online presence to having these profiles and a website was something I had to get used to; it became clear that my research with the blog on my website, Twitter activity, publications, interviews and press mentions was resulting in me creating my

own digital memories which I am aware will become digitally persistent, making me a digital creator, something I had not intended to become.

Whilst I acknowledge that most theses could be described as “labours of love”, it is important to acknowledge the specific needs of researchers who are exploring the sensitive and potentially difficult subject of death, dying and bereavement. In the literature review of this thesis I list the terror attacks that have occurred during the writing up process, and having to update this list throughout the numerous iterations of this thesis is an emotional task which I have found difficult. The emotional labour (Hochschild 2012) invested in research like mine is recognised by other “sensitive topic” researchers (Lee 1993; Massimi 2012; Moncur 2013; Ellis Gray 2015). I recognised that being reflexive throughout my research and not feeling isolated during the process was necessary for my own well-being. To enable the recruitment of participants for this study I opened a Twitter account at the onset of my research. I expected that I would use Twitter specifically as a recruitment tool, however, I soon found that it was being used by many other PhD students and academics as a space to discuss research problems and offer advice and support. Being part of an online PhD researcher community on Twitter has been a positive aspect of this research; sometimes research can produce a feeling of isolation but the network of fellow scholars brought together via Twitter and specifically fellow thanatologists has certainly helped with this feeling of isolation.

During this study I kept a research diary using Microsoft OneNote, which I found extremely cathartic, particularly following interviews with my participants, which could be emotionally draining. I also used my blog on my website as a form of self-reflection. I am affected by each and every interview with those who have been bereaved as I have empathy with my participants. However, it is important to acknowledge that I have also laughed with my participants, and learnt something about grieving from each and every one of them. As a consequence of the nature of the study I have undertaken, I have also had to deal with the death of a participant following data collection and during the process of writing up. I have found the “ongoing implications” of sensitive research can be both positive and negative; keeping a research diary has certainly provided a creative outlet for my emotional

responses to the death of one participant (Burles 2017). Burles (2017) also notes that this reflective journaling can, in return, produce improved understanding and assist with finding meaning in negative outcomes: I have certainly found this to be true in my research.

Although this chapter focuses on reflexivity, it is important to acknowledge that the emotionally laden subject matter of this thesis results in reflexivity weaving throughout the whole thesis. It would be impossible to embed myself in this research without becoming emotional about the people I am researching, and it would be unprofessional and unethical not to reflect on my own emotional well-being during the process. During this research, I have often been asked why I would want to study death, I reply by pointing out:

“I do not study death – I study people. My research makes me think about life so very differently, life is short, life is precious, and life is wonderful”

3.8 Conclusion

This thesis contributes to the knowledge within thanatology by using a number of important methodological tools. The use of digital technology to recruit and interview participants for this research extends previous grounded theory studies by describing the benefits to the participants as co-creators of knowledge alongside mine as the researcher. Moreover, follow-up emails demonstrated that the participants found this method preferable to “traditional” interviews.

This thesis will show how these digital research techniques are successful in making visible how participants feel as co-constructors of knowledge: the use of Twitter by participants following their interviews, adds to the ongoing research and is an example of this. This study will also demonstrate how the epistemological framework of interpretivism acknowledges the idiosyncratic nature of how people experience and make meanings of grief; while the use of constructivist grounded theory acknowledges the constructed nature of the categories developed from the data. This thesis can be seen as advocating for the suitability of constructivist grounded theory and its usefulness to thanatological studies.

This chapter began by outlining the philosophical frameworks which underpin this

study. The chapter then described the process and decisions around data collection and data analysis before discussing the limitations of the methods and methodology. Finally, the chapter used a reflexive lens to highlight how this research is influenced by my experiences of bereavement and how the research has influenced me in turn.

In the following three chapters of this thesis I introduce you to some of the people behind the companies that enable digital afterlives (SPs), those who are creating digital afterlives (DCs), and the bereaved who inherit these enduring digital memories and messages (DIs) – my participants.

4 Chapter Four: Experiences and Motivations of the Service Providers

4.1 Introduction

“The soul of man is immortal and imperishable” – Plato

In the next three chapters, I will present my findings from the semi-structured interviews conducted with three groups of participants: SPs, DCs, and DIs. These three chapters are organised around these groups to provide a holistic understanding of the various groups involved in the enabling, creating, and inheritance of posthumous digital memories and messages. To provide a firm foundation to the study, Chapter four focuses on the SPs who provide the platforms and the thanatechnology.

At the inception of this research, I attempted to explore how digital memories and messages enabled by the Internet were being created. However, it became obvious that in order to fully understand this phenomenon I needed to start with the growing number of companies who were offering digital afterlives. In this chapter, I provide an overview of platforms that are offering a place for the creation of posthumous digital memories and messages.

The Digital Afterlife Industry (DAI) is dynamic by its very nature: the ubiquitous nature of smart technologies, the affect they have on interpersonal communication, and the growing number of users, ensures this industry will continue to grow at an ever-increasing rate. Research by Öhman and Watson (2019) suggests that by 2100 there will be 1.9bn deceased profiles on Facebook. With this in mind it is unsurprising that the DAI is a fast-growing area of commerce. It was estimated that in 2018 the DAI in the United States was worth approximately US\$16–20bn per annum, and an estimated £2bn per annum in the United Kingdom (Arnold et al. 2018). But what type of companies are considered to be part of the DAI?

In the early stages of this research, whilst familiarising myself with the existing

literature in the field of thanatechnology, I realised that all Internet and App based platforms which provided a digital afterlife were being treated as a single group of providers. However, I identified a need to distinguish between platforms that were created *intentionally* to provide digital afterlives, and those that had become *accidental* providers of digital afterlives. Even though both types of service provider should still be referred to as part of the DAI, any effort to understand how these platforms deal with the data of the dead and, importantly, how they understand their role in the digital afterlife industry requires this distinction.

Following the presentation of these two types of SPs in Section 4.2, I discuss intentional digital afterlife platforms in Sections 4.3 and 4.4. Bell and Gray's conceptualisation of platforms are divided into two categories: "one-way immortality", where the dead are passive (they remain dead) but still preserve and transmit their ideas (Bell & Grey 2000); in contrast with platforms providing "two way immortality" where the dead are active and become reanimated "digital zombies" (Bassett 2015). I then present my findings regarding these accidental digital afterlife platforms by discussing how they have been appropriated to deliver messages from what Hjorth and Moon describes as the "soon to be dead" (2017), and how these platforms are used to memorialise and continue our relationships with the dead.

In order to gain an in-depth understanding of the people who create the digital afterlife platforms and thanatechnologies, I discuss the findings of in-depth interviews and email exchanges I conducted with some of the creators of these platforms, and with those who work for the platform providers in the death-tech industry. In this chapter to structure my findings, I also present three themes which arise from the data: (1) It's personal, (2) The mortality of immortality platforms, and, (3) Timed posthumous messages and the unintended consequences.

4.2 It's personal

Following a constructivist grounded theory approach – to recruitment, data collection and data analysis (Charmaz 2014) – here I explore the prevalent theme of personal motivation that emerged from the data.

All eight SP participants talked about their motivations behind creating or working for the digital afterlife platforms, and all but one said their main motivation was because they had personal experience of bereavement. Colin is the CEO of an intentional SP, and he told me that starting the company was important to him due to,

“being affected by my grandmother’s fight with Alzheimer’s and losing all her memories long before she passed away” (Colin)

Ron created, and now manages and owns, an intentional digital afterlife platform, which offers the posthumous delivery of digital messages. During our interview Ron explained how he was motivated to start his company following the death of his father:

“there was half a second of my father speaking and that is the only recording I have anywhere of his voice. So that started the idea that, what if you could have a platform where you could capture people’s voices and send them on in the future” (Ron)

This theme of personal motivation was evident in my interview with Graham, who owns a one-way digital afterlife company:

“I guess I had the idea for 10 years, message from heaven since I lost my father to cancer 14 years ago” (Graham)

Martyn runs a website which offers support, advice and the delivery of posthumous messages. His interview also echoed this theme of the deeply personal motivations of the SP participants:

“I lost my mother to cancer which is why I started the website” (Martyn)

All the interview extracts above are from owners or creators of intentional digital afterlife providers. However, I also found that personal experience can also be a motivation for some who work for accidental afterlife providers. I interviewed a participant who worked in the Compassion Department at Facebook (an accidental digital afterlife platform). He told me that each request to memorialise a Facebook profile got a “human response”, and that they were handled by a team within Facebook. This group was originally created by a man whose mother had died from breast cancer.

The stories I was hearing about personal motivation took me by surprise; I had wrongly hypothesised that the motivations of the SPs would be more grounded in the desire to create and use new technology, or for purely commercial reasons. Although many of the interview extracts from this group of participants were also coded under technophilia, the theme of personal motivation was coded most often in the transcripts. Their personal stories were in line with my findings from the DI and the DC participant groups – presented in Chapters five and six – in that, these SP participants had suffered an emotional bereavement which had affected them. This in turn had motivated them to create their platforms as it was important to them that others would have a platform which could be used to create memories and messages that could be stored, retrieved and used to continue relationships with the dead.

4.3 Intentional digital afterlife platforms

4.3.1 The mortality of immortality platforms

Earlier, in Chapter three, I discussed how the term “immortality” was unsuitable when discussing digital afterlives. However, in this section I will adopt the term once again, as it is used by many platforms offering digital afterlives, and the term helps to highlight the precarious nature of these platforms.

Founded in 2006, The Forever Social based in Sweden offers digital immortality to its users. With the promise that “you” will be able to respond to world events and other people’s posts after you die. By 14th October 2018 The Forever Social had just 27 Twitter followers (dropping to 10 by June 2019), with its last Twitter post in April 2018 and last Facebook post in May 2018. Its website is still live, and there is a possibility that its official launch has been delayed rather than abandoned. An interesting aspect of this platform was its clear rejection of religious belief in its version of a digital afterlife as seen in two of its tweets:



Figure 9 Screenshot of The Forever Social website



Figure 10 Screenshot of The Forever Social website

The Forever Social uses a “Forever Engine” which it claims, “uses algorithms and artificial intelligence to learn how you would respond to everything in the future”. This suggests that this digital zombie (Bassett 2015) would continue to evolve after the death of the creator. This platform also states:

“only you can control the legacy you - today and when you’re gone. This includes setting the date or trigger for your digital burial, blocking people whose lives you want to exit forever, and limiting who can see your digital testament” (theforeversocial 2018)

The impact of enabling a DC to have complete control over their digital afterlife once they have died is a crucial part of this research, and will be discussed in Chapters six and seven.

In 2010, Don Davidson started Intellitar, a digital immortality platform based in Alabama. By 2015, it had ceased trading. It was charging \$25 a month to users who

wanted to create their digital doubles or “intelligent avatar” who the site claimed could live on after your death. Once again the technology company created media interest, but failed to achieve the require amount of users to ensure its success. It was a similar story for others; Loggacy, a platform created in 2013, offered users the ability to store their “most precious memories” and “connect with family and friends so that you are never forgotten”. On 26th July 2017, Loggacy announced that they were closing the platform and encouraging its users to notify them within 30 days if they would like to retain any uploaded data held on their database. Its website is no longer available online.

I started recruiting participants for the intentional SP group in November 2015, and, as discussed in the introduction to this chapter, further categorised these companies using Bell and Gray’s (2000) distinction between “one-way immortality” and “two-way immortality”. I produced a list of one-way digital immortality platforms that offer users the ability to create digital messages and memories to be delivered posthumously, along with platforms offering two-way immortality where the dead can remain socially active. In 2018, Ulguim published a list of digital afterlife providers that I then amalgamated into my list.

Name	Country	Type	Start	Gender	Terms	Service
Deathswitch	USA	One-way	2009	M	Pay	Posthumous message creation
EmailFrom Death	Unknown	One-way	Unknown	Unknown	Unknown	Posthumous message creation
Futurist	Unknown	One-way	Unknown	Unknown	Unknown	Posthumous message creation
Great Goodbye	Unknown	One-way	Unknown	Unknown	Unknown	Posthumous message creation
Heavenote	USA	One-way	2013	Unknown	Free	Posthumous message creation
Intellitar	USA	One-way	2007	Unknown	Free	Avatar creation
Last Words 2 Love	Unknown	One-way	Unknown	Unknown	Unknown	Posthumous message creation
Lives On	UK	One-way	2013	Unknown	Free	Posthumous Twitter messages

Loggacy	UK	One-way	2013	M	Free	Digital memory creation
Milestoned	USA	One-way	2015	M	Free	Digital memory creation
NowSayIt	Canada	One-way	2012	M	Pay	Posthumous message creation
ThoseiLove	Canada	One-way	2013	M	Pay	Posthumous message creation
Truly Life App	USA	One-way	2015	Unknown	Free	Digital memory creation

Table 4.1 Platforms no longer operating at 28th October 2018

Name	Country	Type	Start	Gender	Terms	Service
If I Die	USA	One-way	2011	M	Free	Posthumous message creation
AfterLyfeMe	USA	One-way	2011	M	Pay	Posthumous twitter account
Afternote	Unknown	One-way	2012	Unknown	Unknown	Posthumous message creation
Bcelebrate	USA	One-way	2009	F	Pay	Posthumous message creation
Boxego	UK	One-way	2012	M	Free	Digital memory creation and storage
Forever Message	UK	One-way	2016	M	Pay	Posthumous message creation
Mygoodbye Message	USA	One-way	2013	Unknown	Pay	Posthumous message creation
Xarona	Belgium	One-way	Unknown	Unknown	Pay	Posthumous message creation

Table 4.2 Dormant platforms with no activity for 12 months at 28th October 2018

Name	Country	Type	Start	Gender	Terms	Service
GoneNotGone	USA	One-way	2016	M	Pay	Posthumous message creation
Cord.amily	USA	One-way	2017	Unknown	Unknown	Digital memory creation and storage
Dead Social	UK	One-way	2009	M	Free	Posthumous message creation, legacy advice
ETER9	Portugal	Two-way	2011	M	Free	Avatar creation
Eternime	USA	Two-way	2014	M	Free	Avatar creation
Ghostapp	UK	One-way	2018	F	Unknown	Posthumous message creation
Ghostmemo	USA	One-way	2012	Unknown	Pay	Posthumous message creation
Hospice Biographers	UK	One-way	2016	F	Free	Digital memory creation and storage
Leg8cy	Unknown	One-way	2016	M	Free	Posthumous message creation
LifeBio	USA	One-way	2009	Unknown	Pay	Digital memory creation and storage
LifeNaut	USA	Two-way	2010	M	Free	Avatar creation
Lifepost	USA	One-way	2014	M	Free	Digital memory creation and storage
My Own Eulogy	USA	One-way	2011	Unknown	Free	Posthumous message creation
Mywonderfullife	USA	One-way	2009	F	Free	Posthumous message creation, legacy advice
Once I've Gone	UK	One-way	2009	M	Free	Posthumous message creation, legacy advice
Posthumo	Italy	One-way	Unknown	M	Free	Posthumous message creation
SafeBeyond	Israel	One-way	2015	M	Pay	Posthumous message creation

SayGoodbye online	Unknown	One-way	Unknown	Unknown	Pay	Posthumous message creation
The Forever Social	Sweden	One-way	2008	M	Free	Posthumous message creation - AI tech
The legacy recorder	USA	One-way	2016	F	Pay	Digital memory creation and storage
Wishes Keeper	Unknown	One-way	Unknown	Unknown	Pay	Posthumous message creation

Table 4.3 Active SPs at 28th October 2018

Since October 2018, when I first produced these lists, I have periodically monitored the status of the platforms up to June 2019. In an effort to show the speed of the demise of these digital afterlife platforms, rather than update my tables in June 2019, I decided to highlight in red the platforms with no online activity for 12 months, or sporadic online presence which hints at the unstable background of the industry.

LivesOn was a web-based application that claimed to be able to continue tweeting for you when you die. Its slogan “When your heart stops beating you’ll keep tweeting” caused media interest during its inception in 2013. However, continuous monitoring of its Twitter account and website during this research failed to discover any further development in the platform. It has not published any tweets since 5th October 2013 and its website is no longer available.

When platforms offering digital immortality or digital afterlives cease to exist, it is important to explore what happens to the data they hold. Many of these digital afterlife companies encourage their users to upload precious files with promises of eternal storage and retrieval. However, other digital afterlife platforms are unclear about their storage and retrieval policies. During an interview with an intentional SP Ron, explained what his platform provides in terms of longevity of storage, suggesting that “forever” may only last for 20 years:

“As we get funds in we’re setting them aside so we have funds to pay it ahead if we ever need to. I don’t see any reason at the moment why we should do that ... but we may at some point see that we can pay ahead for 20 years”
(Ron)

The iterative nature of constructivist grounded theory methods and the way the interview schedule was organised, resulted in simultaneous interviewing and coding the transcripts from all three participant groups. During many of the SP interviews I was already aware of how posthumous digital memories and messages were being experienced by the bereaved (discussed in Chapter six), and therefore beginning to contemplate the profound implications of the potential loss this data of the dead for the bereaved due to company failure – and therefore storage and retrieval failure.

The demise of so many platforms offering the storage and the retrieval of posthumous digital memories and messages during the relatively short duration of this research, demonstrates the precarious nature of the DAI and its inability to offer any guarantee that the messages and memories stored on the platform will endure. However, as some digital afterlife platforms die new ones are being created. I suggest there will be exponential growth within the death-tech industry due to technological advances, and as users become more accustomed to finding the dead online (Bassett 2018).

In the next section of this chapter I look at platforms offering one-way “immortality” services that enable recording messages to be delivered following the death of their DC.

4.3.2 Messages from the dead – one-way digital afterlife platforms

“May you live to be 100 and may the last voice you hear be mine” – Frank Sinatra

This section examines the platforms that were purposefully created to enable users to write and record memories and messages to be inherited by others after the death of their creator. The impact of such timed messages – or messages where a DI is not in control of the delivery of such messages – form an ongoing thread throughout this thesis; the findings presented in Chapter six, from the perspective of the DI participants, and the discussion presented in Chapter seven lay out the problems and also suggest a potential solution to issue around this type of digital inheritance.

Digital afterlife platforms that work in a one-way direction provide a service whereby the dead remain truly dead because they are not reanimated, socially active, digital zombies (Bassett 2015), or what Nansen et al. describe as the “restless dead” (2015). In these one-way provider networks, the dead are in a static realm. Below I look at some of these platforms – those operating during the writing of this thesis – which offer services to DCs by enabling the creation of digital messages to be delivered posthumously, by notifying people that they have a message waiting for them following the death of the creator.

Started by James Norris in 2012, the UK-based organisation DeadSocial offers an “end user” planning tool and service for the creation of a “digital legacy”. Working with hospices, charities and healthcare workers, DeadSocial’s user-friendly website aims to empower those facing end of life decisions by enabling the creation and future delivery of messages – including digital memories – to those left behind, as well as practical advice regarding digital legacy issues, such as how to download social media content when someone has died. At the time this thesis was published in 2019, DeadSocial has remained active, although the website has been under reconstruction for the past 12 months. Analysing the website in 2016, I noticed the prevalent use of religious and spiritual imagery on the site: its logo includes an angel with wings, the title page includes a long winding road which ascends to the sky (see Figure 11). In its original version DeadSocial offered a “goodbye tool” where registered users can “build a legacy” to be delivered to named inheritors following their deaths. The website contained a link to a tutorial video hosted by YouTube which informed users that: “Your first messages is arguably the most important message you will ever leave”. It continued, “In this message we recommend that you tell your friends and family that you have died”. DeadSocial requires you to assign at least one digital executor to control the activation of messages following the death of the DC. The platform enabled the DC to schedule messages to be delivered to others on specific future dates. The ability to nominate a digital executor goes some way to protect the bereaved, however, it falls short of the control settings suggested in Chapter seven of this thesis.

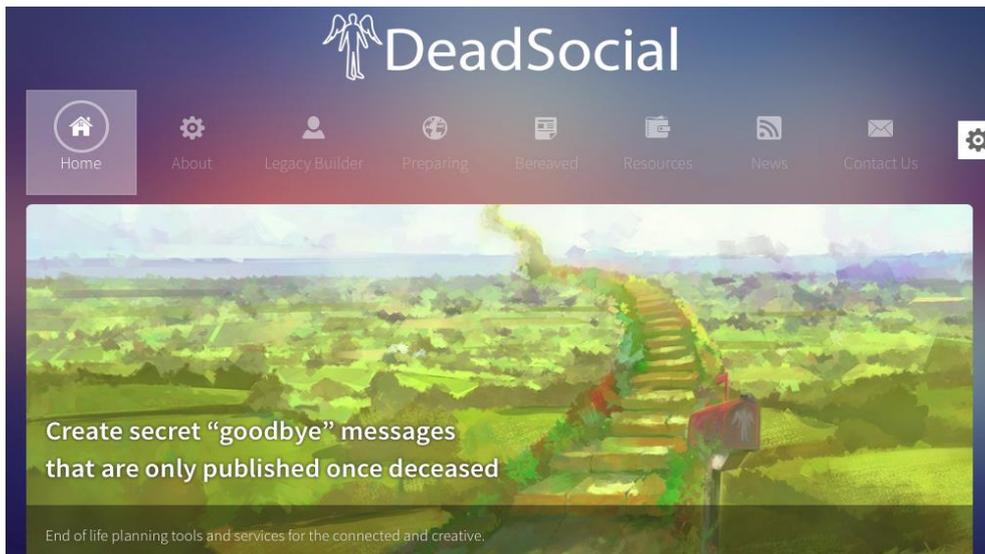


Figure 11 Screenshot of Dead Social’s website 2016

In 2019, DeadSocial was rebranded as MyWishes with a new website, its landing page no longer contains religious imagery and the website has a more informational and professional theme, as shown in the image below:

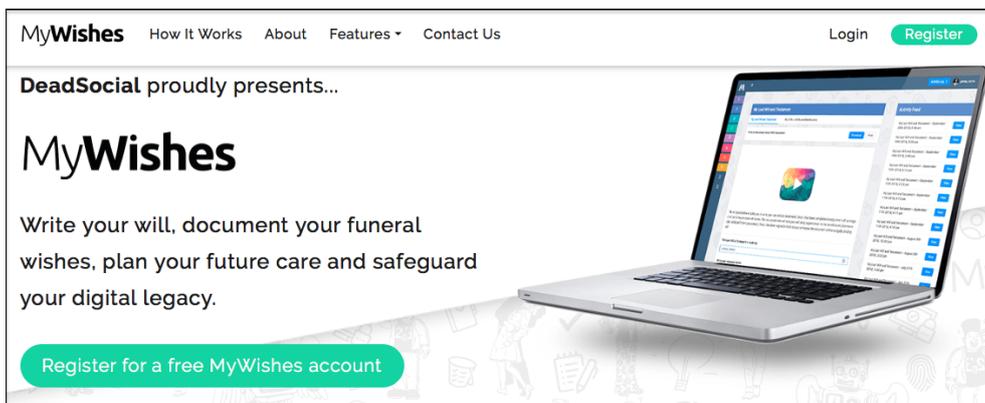


Figure 12 Screenshot of Dead Social's website August 2019

Another company that offers the delivery of posthumous digital messages is Safe Beyond. This paid for posthumous message creation site proposes 3 types of service (1) dated messages to be released on specific dates; (2) location messages to be released when the DI reached a specific geographic location; and, (3) event messages to be delivered on the occurrence of a predefined event. The site’s emotional promotional video is a professionally produced video showing a bride receiving such a message on her wedding day.

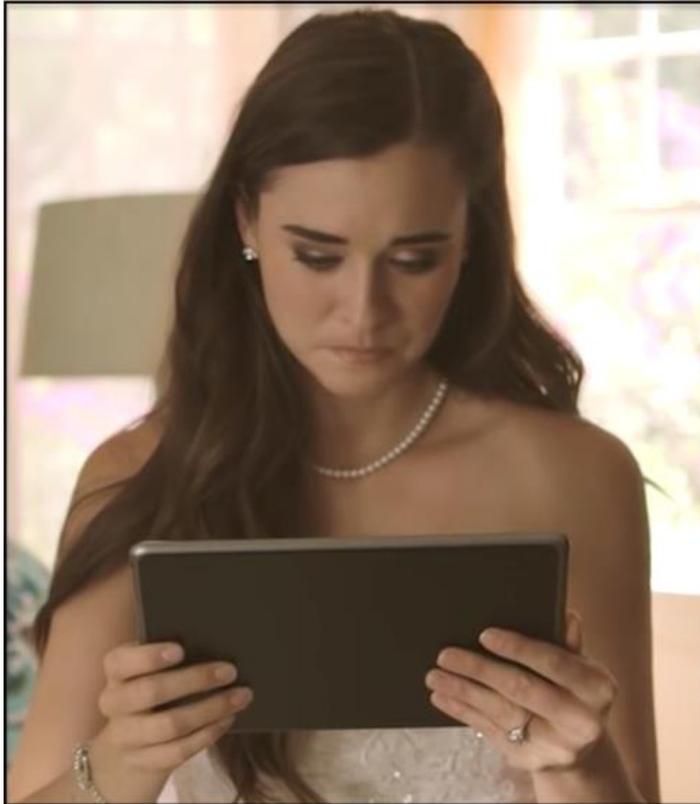


Figure 13 Screenshot from SafeBeyond website 2018

I have used this video at three academic conferences to illustrate my research, and each time it results in gasps from the audience. Wedding rituals change over time, importantly what constitutes a family changes; yet there are many assumptions within this video of a father's posthumous message to his daughter, including the assumption that his daughter would like a message from her dead father on her wedding day, that his daughter would marry the "man" of her dreams, and that his wife would not have remarried. It also assumes a patriarchal perspective that sees his son become the head of the family following his death. This video is useful, as it highlights the cultural complexities involved in the creation, and, importantly, the inheritance of posthumous digital messages.

The protection of messages offered by SafeBeyond does allow for a trustee to be nominated who would be able to control message delivery, and a tick box provides DCs with the option to reveal or prevent DIs from knowing about the existence of each message (Tick box wording: "Keep message existence revealed to heir"). Significantly, however, as with the service offered by DeadSocial, this still does not give complete control to the recipient. For example, in their Terms of Service

SafeBeyond explain what happens if their fees are not paid: “If charges are not paid such account may be cancelled and all Digital Assets may be deleted”. The terms and conditions go further: “You agree that any information you provide to the Site and/or Application may be lost or destroyed, and that SafeBeyond is not responsible for the loss of such information”.

Once again it seems that digital afterlives are only available as long as the payment arrives or the platform does not lose the data. In addition, as will be discussed in Chapter six of this thesis, the use of the term “digital assets” here does not encapsulate how the bereaved experience the existence of this precious data of the dead, and therefore I suggest the DAI adopt the taxonomy I suggested in Chapter one of this thesis; in that, the term “digital memories and messages” is more suitable to describe the precious data of the dead. However, other researchers question the usefulness of these precious posthumous digital memories and messages by claiming they may be “Unable to support the deeply contextual and ongoing practices of intimacy and reciprocity that define a contemporary family or friendship (Meese et al. 2015 in Arnold et al. 2018).

Started in the USA in 2016, another intentional afterlife platform offers its users a place where they can “Live on Digitally” by creating messages to be left for loved ones after they die. It is a paid-for service which offers timed messages to be delivered on specific life event dates (e.g. 21st birthday messages). Once activated the company will email you monthly with a link to “confirm you are alive”.

Pricing (Prepare messages with photo, audio and/or video to be delivered on anniversaries after you pass.)

Bronze Package	Silver Package	Gold Package	Platinum Package
 \$20	 \$40	 \$60	 \$100
Emails	Emails	Emails	Emails
-	Pictures	Pictures	Pictures
-	-	Audio Messages	Audio Messages
-	-	-	Video Messages
Buy Now!	Buy Now!	Buy Now!	Buy Now!

Figure 14 Screenshot from SP website

The claim on the website that the cost covers messages for “the life of the recipient” piqued my interest, as my research has shown that the digital afterlife platforms are not likely to outlive the message recipients (see Table 4.3). An important point to note is that the company do not have terms and conditions on their website, and therefore do not publish what happens to the data if the platform ceases to exist.

On their Frequently Asked Questions page they published the following about how much control the recipient – the DIs – can expect:

Q. “If I start to receive messages and I do not want them, can they be turned off?”

A. “Yes, they can be turned off and turned on again when you are comfortable for that to happen. At the point of turning back on you can access all messages due to be sent up to the current date – it is never possible to access messages to be sent in the future”

Findings from the DI participants – presented in Chapter six – suggest this lack of control could be problematic for DIs. Further arguments around the issue of control will be discussed in Chapter seven.



Figure 15 Screenshot from SP website 2018

Figure 15 above demonstrates how this platform emphasises the ability for its users to leave audio messages. How audio messages are experienced by the bereaved is discussed in Chapter six; however, here I want to demonstrate how hearing the voice of the deceased appears to be problematic for some DIs, whilst for others like Maggie it is their most treasured digital memory:

“It’s been five and a half years since my Ma passed. I have her voice mail recording, on tough days I’ll listen to it. Still comforts me to just hear her voice (Maggie).

However, Riann told me how she found the audio of her deceased brother to be disruptive, even though she found other types digital memories and messages comforting:

“There’s lots of videos on Facebook ... which I don’t want to watch cause I don’t want to hear his voice” (Riann)

Here, we are beginning to understand the complex issues around the inheritance of audio digital messages, and we will return to this issue in Chapter six.

4.3.3 Timed posthumous messages – the unintended consequences

In an effort to explore potential problems with platforms offering the posthumous delivery of timed digital messages, I ran a 24 hour Twitter poll in October 2018 which asked my followers (N=844) if they would like to receive a posthumous, timed, and digital message from a deceased loved one on a significant occasion in their lives? (Such as a birthday or a wedding). The poll received 1,755 impressions, 95 votes and 4 replies (Figure 16).

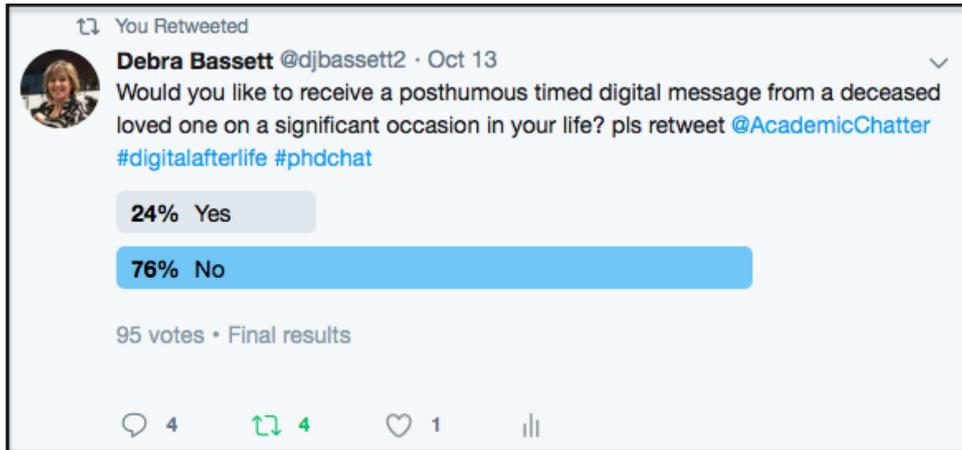


Figure 16 Twitter poll results 13th October 2018

It is important to note that the people who took part in this poll are “technologically comfortable” (Massimi 2012) users of social media networks, this may be obvious as the poll was conducted on one; however, taking their use of social media into account the number of “no” votes compared to “yes” votes were still substantial. If the majority of social media users might not want the service, it begs the question: why are one-way SPs (at least those who have formed part of this research), actively creating sites which aim to deliver these largely “unwanted” posthumous messages? Rereading through the SP interviews once again, I began to see a pattern in their transcripts which I labelled “the unintended consequences”.

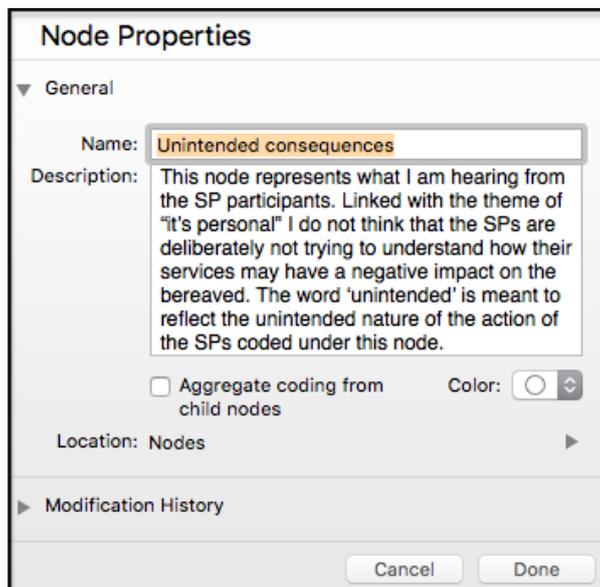


Figure 17 Screenshot of coding notes created within NVivo

Figure 17 above shows how I defined this code within NVivo. I use the phrase “unintended consequences” in a particular sense, I did not interpret any of the

interviews from the SP participants as selfish, uncaring or indicating malicious intent regarding what they were trying to offer of these platform creators – after all this research has demonstrated the personal motivations of the platform creators. Instead, the phrase represents what I interpreted as “unintended consequences” on the part of the SP participants concerning their unawareness of the complexities of the inheritance of digital messages. The complexities involved are demonstrated in Figure 18 which shows two replies to my original Twitter poll asking whether people would like to receive a digital message from a deceased loved one on a significant date:



Figure 18 Screenshot of Twitter replies 13th October 2018

This theme of unintended consequences is best demonstrated by the following quotation from an owner of one of the platforms. He explained that because the messages are not push messages (notifications which pop up on a device without permission from the receiver) he believes the control lies with the DI:

“So, if you know that this person that has left you the message, was maybe someone that wanted to harm you, you know maybe you don’t wanna hear what the ... so at the end of the day it’s the receiver sole decision whether he is interested to watch it or not” (Graham)

Another platform owner, Ron, told me how his platform does not allow the DIs to see messages which are scheduled for future delivery:

“You can just never see the stuff that’s there to be delivered in the future... you can log in anytime and then review stuff that’s been sent previously” (Ron)

In Chapter seven I address this issue of control, and suggest ways that platforms could use TSD (Massimi 2012) in an effort to mitigate potential problems for the recipients of such timed messages. Following my initial Twitter poll, I began to hypothesise whether DIs would be compelled to open timed message once they know of their existence, my initial thoughts on this hypothesis are described in the NVivo memo below:

NVIVO MEMO

Delving into this data further I am beginning to formulate a theory about the compulsion the bereaved would feel to open timed posthumous messages if they knew of their existence. Exploring this may be problematic as it is a hypothetical situation. Nevertheless, I want to get a sense of people's feelings about these digital messages.

As discussed earlier, the results of a Twitter poll asking how many people would like to receive a timed posthumous message resulted in 76% of respondents stating that they did not want to receive such a message. Almost a month later I ran a second Twitter poll in an attempt to test my hypothesis of DIs not wanting to receive these messages. This poll received 32 votes which showed 75% of respondents (n = 32) would be compelled to open posthumous digital messages (Figure 19).

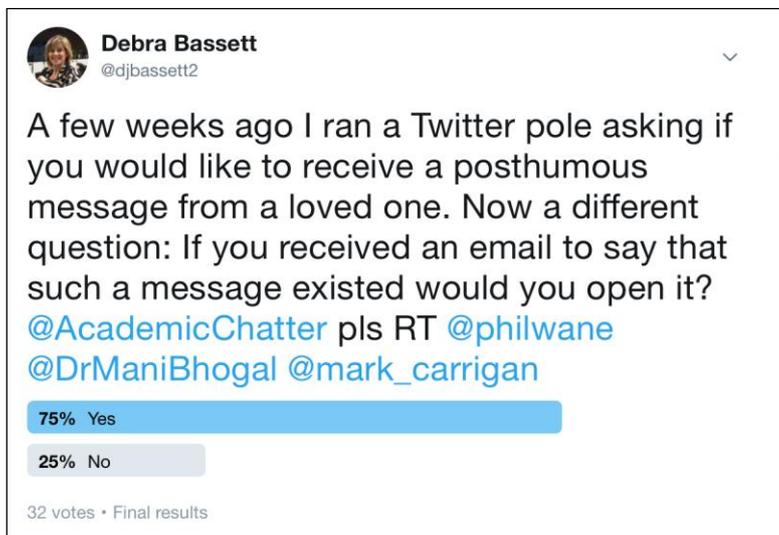
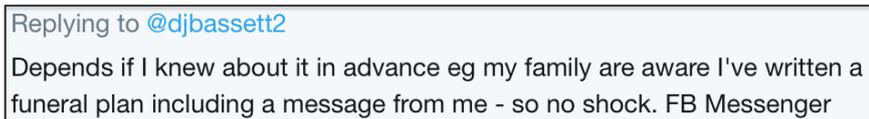


Figure 19 Screenshot of Twitter poll results 11th November 2018

Once again with a Twitter poll, it is important to acknowledge that the poll was

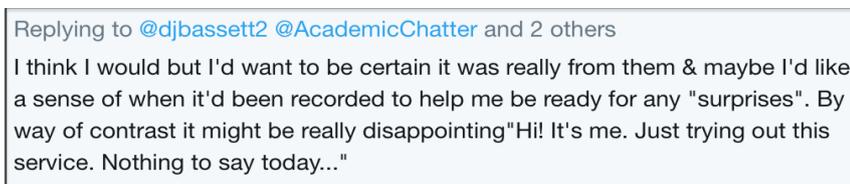
conducted on a social networking platform and therefore the respondents were more likely to be technologically comfortable (Massimi 2012) with digital messages, in addition, it is essential to note that these polls are quantitative “snap shots” which lack the depth of analysis achieved by qualitative in-depth interviews. However, even taking these limitations into account I was surprised by the final result: 75% said they would open the message. These polls illustrate how important it is for SPs to consider DIs in the design of their platforms. These generally unwanted timed messages need to be carefully thought out. As this research has demonstrated, some SPs naively assume DIs have agency in whether they want to open messages: however, as the Twitter poll indicates (albeit hypothetically) the DIs may feel compelled to open the messages purely because they exist, and thus DIs may wield little agency as posthumous message recipients.

This second Twitter poll also received replies that provided further insights into people’s views on digital, timed messages from the dead (see Figures 20, 21 and 22).

A screenshot of a Twitter reply. The text is enclosed in a light blue box with a thin black border. The text reads: "Replying to @djbassett2" followed by "Depends if I knew about it in advance eg my family are aware I've written a funeral plan including a message from me - so no shock. FB Messenger".

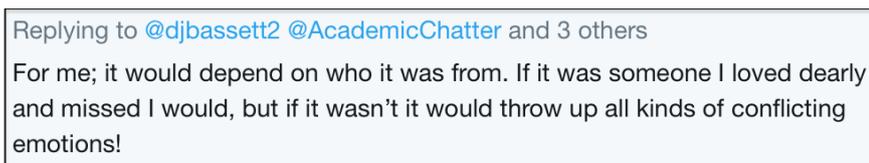
Replying to @djbassett2
Depends if I knew about it in advance eg my family are aware I've written a funeral plan including a message from me - so no shock. FB Messenger

Figure 20 Screenshot of reply to Twitter poll 11th November 2018

A screenshot of a Twitter reply. The text is enclosed in a light blue box with a thin black border. The text reads: "Replying to @djbassett2 @AcademicChatter and 2 others" followed by "I think I would but I'd want to be certain it was really from them & maybe I'd like a sense of when it'd been recorded to help me be ready for any 'surprises". By way of contrast it might be really disappointing "Hi! It's me. Just trying out this service. Nothing to say today..."

Replying to @djbassett2 @AcademicChatter and 2 others
I think I would but I'd want to be certain it was really from them & maybe I'd like a sense of when it'd been recorded to help me be ready for any "surprises". By way of contrast it might be really disappointing "Hi! It's me. Just trying out this service. Nothing to say today..."

Figure 21 Screenshot of reply to Twitter poll 11th November 2018

A screenshot of a Twitter reply. The text is enclosed in a light blue box with a thin black border. The text reads: "Replying to @djbassett2 @AcademicChatter and 3 others" followed by "For me; it would depend on who it was from. If it was someone I loved dearly and missed I would, but if it wasn't it would throw up all kinds of conflicting emotions!".

Replying to @djbassett2 @AcademicChatter and 3 others
For me; it would depend on who it was from. If it was someone I loved dearly and missed I would, but if it wasn't it would throw up all kinds of conflicting emotions!

Figure 22 Screenshot of reply to Twitter poll 11th November 2018

The Twitter replies above, further demonstrate the importance of control when contemplating timed posthumous message delivery, and how important knowledge of the existence of such messages and the ability to control when they are viewed is

to DIs (discussed in depth in Chapter seven).

Having presented my findings from one-way digital afterlife platforms in Section 4.3.2, in Section 4.3.3 I consider the findings from platforms offering a two-way digital afterlife where the socially active dead can be reanimated and have the potential to become digital zombies (Bassett 2015).

4.3.3. The reanimation of the dead – two-way digital afterlife service providers

Some people say that reconstructing the essence of humanity is now technologically possible using machine learning, artificial intelligence, robotics and 3D printing (Eden et al. 2012). Using AI to create a virtual human (Savin-Baden & Burden 2018) enables “endless experience and learning” allowing “at least part of you, to communicate with the future in the sense that artefact continues to learn and evolve” (Bell & Gray 2000). However, the implications of the technologies used to create digital humans deserves careful consideration, as they deal with the emotions of the bereaved and in some instances the emotions of the dying.

My research has been likened by friends and colleagues to *Black Mirror*, a science fiction television series created by Charlie Brooker, which takes a dystopian view of future and current technology and its potential impact (Brooker 2012). One particular episode entitled “Be Right Back” features technology that enabled the bereaved protagonist to communicate with Ash, her dead boyfriend, via a social networking platform. The platform used algorithms to scrape data from social media platforms and profiles used by the deceased to create a posthumous bot of Ash that she could communicate with. The bereaved girlfriend eventually upgraded the bot to a fully human-like synthetic version of Ash, which had been uploaded with all his characteristics.

SPs who offer services where users can create posthumous chatbots and avatars are seen by some to be venturing into the dystopian territory of *Black Mirror*. Companies such as Eternime, ETER9 and LifeNaut are using artificial intelligence

algorithms to create virtual selves which, they claim, will posthumously interact with users as if they were still alive; allowing users to “live forever” as virtual avatars. These companies, referred to as death-tech companies or e-death companies have informed my research by providing me with an understanding of the platforms and tools available to both DIs and DCs.

To consider a few of these companies and their meaning for my research, Eternime is a private, for-profit company founded in 2014 by Marius Ursache and Laurian Gridinoc. It has its headquarters in Wilmington, Delaware, and is listed as having one to ten employees. It claims to scrape data from Facebook and other social networking sites and uses algorithms and pattern matching (Savin-Baden & Burden 2018) to create an avatar which the user then trains to be more like them. According to Eternime’s LinkedIn page it is

“a network of artificially-intelligent avatars who preserves their owners’ thoughts, stories, and memories forever. The avatars act as personal biographers, connecting with their owners’ digital accounts, devices and calling data. Various events will trigger chats between the avatars and their owners, making the avatars learn faster. Owners of the avatars will chat with their one avatar almost every day for the rest of their lives. Eternime’s end goal is to build the largest interactive human-like knowledge and history library.” (Eternime 2018)

Ursache urges its users to “Think of it like a library that has people instead of books, or an interactive history of the current and future generations. An invaluable treasure for humanity” (Eternime 2018). By October 2018, 41,316 users had signed up for the service and the company had generated much media interest with headlines such as “How your digital self could ‘live’ on after you die” (BBC News 2018), “Eternime and chatbot life beyond the grave” (Financial Times 2018), “From here to Eterni.me – the quest for digital immortality” (The Conversation AU 2018), and “How to Become Virtually Immortal” (New Yorker 2018).



Figure 23 Screenshot from Eternime website

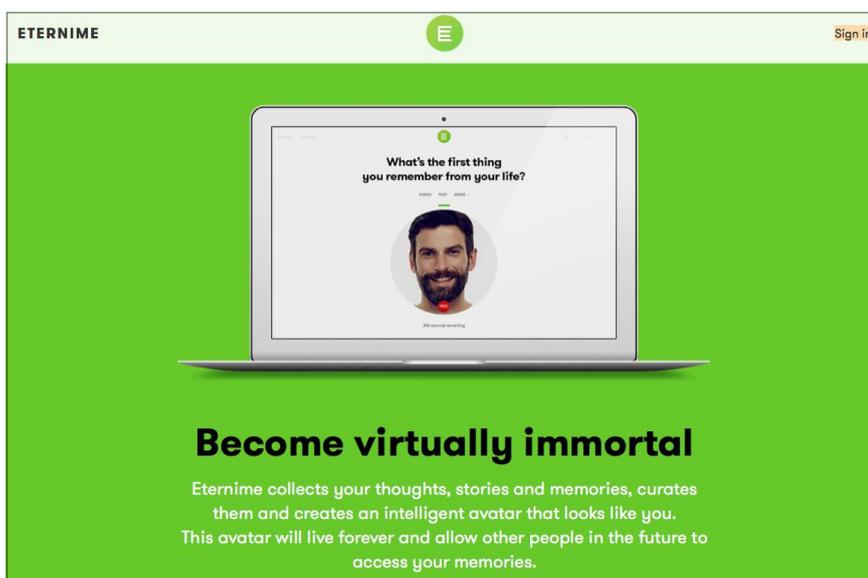


Figure 24 Screenshot of Eternime website 12th October 2018

However, as Savin-Baden and Burden point out, four years after its inception the Eternime platform is still in a beta stage. Moreover they suggest there is much hype, yet little substance to some of these intentional digital immortality platforms (Savin-Baden & Burden 2018).

Based in Vermont in the USA, the LifeNaut research project is part of the Terasem Movement Foundation. In 2006, Lifenaut.com was launched. The site enables users to create “Mind Files” where users can upload pictures, videos and documents to a digital archive LifeNaut claim will be preserved for future generations. Users can

create a computer-based avatar which over time they interact with, eventually enabling the avatar to “respond” with their mannerisms, values, attitudes and beliefs and “Perhaps as a mindclone someday”. Under the benefits of participating in the research project, they claim they offer a free off-site backup for users’ personalities, life lessons and preserves the users “essential, unique qualities” (LifeNaut.com 2018).

For the purposes of this research, I opened a free account with LifeNaut in order to see how people were using the site and how frequently people were training their avatars. The avatars are created from photographs uploaded by the user which are then animated to appear to blink and talk. You can then select a male or female voice for your avatar and you are encouraged to take personality and gratitude tests to personalise it further.

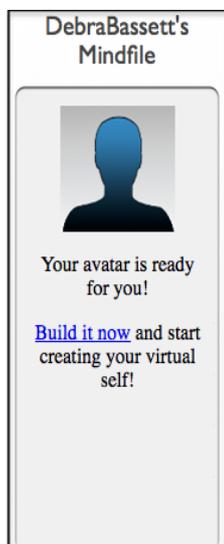


Figure 25 Screenshot of MindFile created on the website of LifeNaut 12th September 2018

I attempted to create my own avatar within the network, but encountered technical problems each time I tried to upload a photograph which was required for the creation. I identified myself as a researcher from the University of Warwick to any users I communicated with, and the findings from these encounters are within the digital creator’s chapter of this thesis.

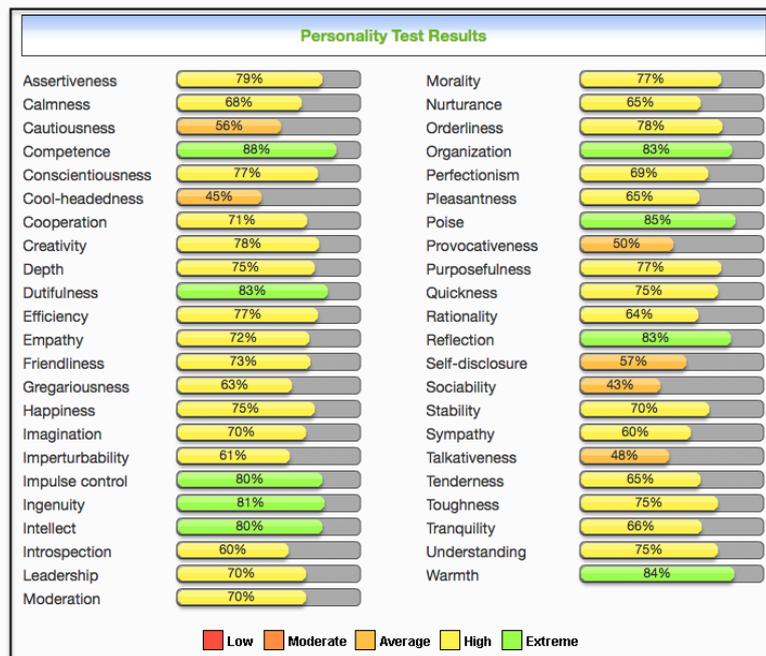


Figure 26 Screenshot of Personality Test Results from the LifeNaut website 12th September 2018

The LifeNaut project is ongoing and one of its unique features in the death-tech arena is their offer of “Spacecasting” users MindFiles. Spacecast, the commercial satellite company is used to broadcast the users “bemes” into space. This they say, will ensure “some aspect of you can survive any catastrophe that might befall Earth” their idea is that “ETs” might reconstruct users from the bemes that are broadcast by the spacecast (LifeNaut 2018).

The transhumanist pioneer Martine Rothblatt is behind the LifeNaut project, and Rothblatt’s research has led to the creation of BINA48, a humanoid robotic head that holds the MindFile of her real-life wife Bina Aspen. This socialised robot makes various public and media appearances with Terasem’s executive director Bruce Duncan, and in 2017 BINA48 was the first robot to complete a college class: BINA48 attended a Philosophy and Love class at Notre Dame de Namur University (NDNU) in California, where she engaged in class discussions and was awarded a college certificate for her participation.

Technology is in a constant state of flux, and in a 2018 paper Savin-Baden and

Burden draw attention to the fact that the LifeNaut site uses Adobe Flash and is difficult to access from contemporary web-browsers; as they point out, Adobe Flash will be completely unsupported by the end of 2020 (Mackie 2017 in Savin-Baden & Burden 2018).

ETER9 is another intentional digital afterlife service provider which was in its beta stage in 2015 – at the beginning of this research project – and is still in the beta stage more than four years later at the time of writing this thesis. The social network relies on artificial intelligence to enable its users to create a virtual human which they call a “Counterpart”. Users are encouraged to interact with their Counterparts to ensure it learns to act more like them and ensures the users will become “eternal” (ETER9 2019). For the purposes of this research, I created an ETER9 account. Again, like LifeNaut, I experienced technical difficulties trying to register with the website. I eventually gained access and created an account via my Facebook profile.

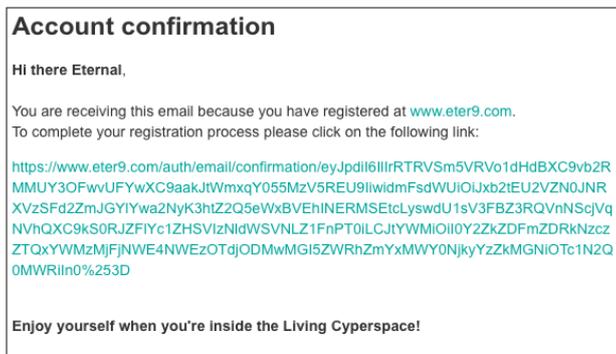


Figure 27 Screenshot of account confirmation on ETER9 website

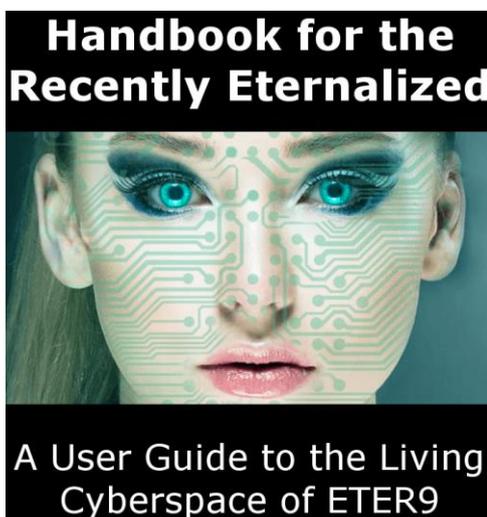


Figure 28 Screenshot of Eliza Nine the virtual hostess on ETER9 website

Eliza Nine is the virtual hostess who appears as a connection when you join the network. On the 13th October 2018 she had 55,180 connections which seems to indicate the number of users; although active users seem to be far less than that – as suggested by Savin-Baden and Burden (2018) – because clicking on Eliza Nine’s connections loads the “cortex” (home) of the mutual connection that has been selected. The vast majority of the 52 connections I randomly clicked on had no “eternifies” – posts the users have chosen to save forever (ETER9 2019). However, 2 of the 52 profiles contained data:

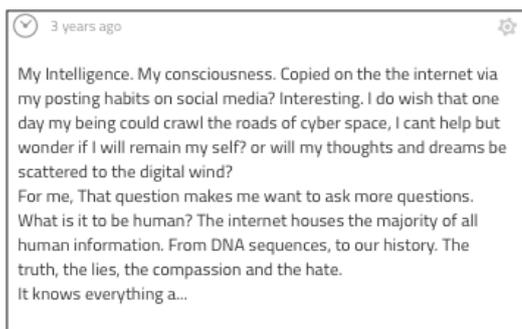


Figure 29 Screenshot of posts on ETER9 website



Figure 30 Screenshot of posts on ETER9 website

Interestingly, both of these randomly selected messages were three years old, and the only profile I could find that was being used in the way the network was suggesting was the profile of the CEO of ETER9, Henrique Jorge which had current content within his profile.

ETER9 is a social network with a difference: your Counterpart will post and share for you even when you are logged off, or indeed when you are dead. Their website acknowledges that it is still in the beta stage, and also questions whether this type of interaction with the dead may or may not be desirable. None of the other intentional

digital afterlife service providers do this on their websites.

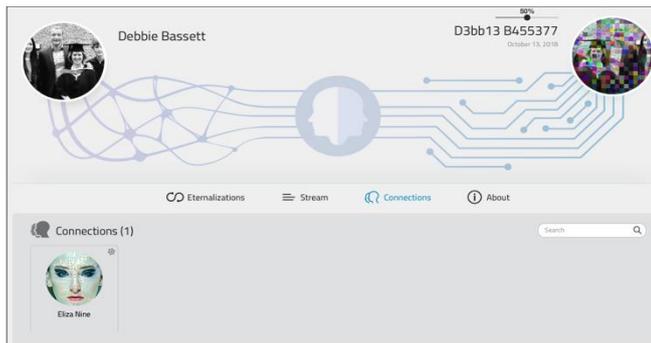


Figure 31 Screenshot of my ETER9 account

In the next chapter I present the findings from the DC participants which explore the motives and hopes of those using these intentional two-way digital immortality sites to create and upload information to their avatars. However, I wanted to understand the demographics of the users from the SPs: The following table was created using data collected from semi-structured interviews with the Intentional two-way immortality SP participants:

	Male %	Female %	Under 50	Over 50	Type
Alan	60	40			Two-way
Russell	62	38	70	30	One-way
Colin	67	33	70	30	Two-way
Graham	20	80			One-way
Ron					One-way

Table 4.4 The demographics of users of intentional digital immortality sites

The notion of the service above is that once the avatar creators die they will become digital zombies (Bassett 2015); in that, the avatar will continue to be socially active after the biological death of their creators. The “virtual” world of online gaming also has digital zombies in the form of posthumous avatars. In 2016, the American video game publisher Bethesda created and embedded a character named Good Guy Evan in *Fallout 4* (a virtual world game). In “real-life” Evan and his brother had been huge *Fallout 4* fans before Evan suddenly died. The game publisher read a post his brother had written on a fan site about Evan’s love for the game, and they created an avatar of Evan and embedded him within the game, enabling friends and family to interact

with his posthumous avatar within the virtual world of game play. Within the game the virtual version of Evan is generous and welcoming, offering advice and help to players who visit him. There are four YouTube videos which show segments of games where players meet Good Guy Evan, and these videos had been viewed over 1.1 million times (by the submission of this thesis).



Figure 32 Screenshot of YouTube video showing Good Guy Evan

Bethesda also created a posthumous avatar of another player, Erik West who became Erik the Slayer in the Frostfruit Inn within Skyrim. Erik died in May 2011 and Bethesda memorialised him within their virtual world as a “roaming warrior” (whatculture.com 2018)



Figure 33 Screenshot of Erik West's posthumous avatar in Skyrim

Other game designers have also created posthumous avatars of super fans and embedded them within their games: Gearbox created an avatar of Michael Mamaril within Borderlands 2. Michael died aged 22, and Gearbox made Michael a NPC

(non-playable character) where players are rewarded if they find and talk to him. His avatar also offers guns from his collection to help players on their quests. (borderlands.fandom.com 2018).



Figure 34 Screenshot of Michael Mamaril's posthumous avatar in Borderlands 2

In this section, I have looked at the platforms providing intentional digital messages and memory creation, in the next section I present findings from accidental digital afterlife platforms that were created for the living but are rapidly being inhabited by the dead.

4.4 Accidental digital afterlife platforms

“Don't cling to things because everything is impermanent” – Tuesdays with Morrie

It can be argued that nothing is accidental on the Internet as intentionality is involved in the creation of platforms that are designed to be used as social spaces, however here I adopt a philosophical perspective of the use of the word accidental: existing digital memories and messages are appropriated following the death of the person who created them, which can result in digital memories and messages taking on new and, potentially, unintended meanings. These digital memories and messages can be seen as accidental: for even though these messages – such as WhatsApp messages, Facebook direct messages, emails, etc. – were not intentionally created to be used following the death of their creator, they might be reappropriated by those left behind to inherit them.

During my research into SPs, I have found a pattern in SP's lack of interest or understanding of what is important to those who stand to inherit digital memories and messages afforded by their platforms. The following quotation from Colin, a CEO illustrates this perfectly:

“For us it is really important to emphasise that we do not want to preserve the banalities of the life of a person” (Colin)

Colin's quotation is key in this research as it demonstrates how SPs are failing to understand the importance of digital memories and messages for the bereaved. In Chapter six I will present findings which show that it is precisely the banality and everydayness of the messages that the DIs find comforting. For many SPs, technology is at the forefront of their platforms and therefore the emphasis is on technological capability rather than the impact of their platforms on the bereaved. Below I discuss some of the findings from my DI and DC categories to demonstrate how accidental digital service provider's platforms are being adopted by the bereaved as important tools which help them in their grief.

Although playing catch-up – these platforms were designed for the living – some accidental platforms seem to be aware of the potential distress the digital afterlife can have on the bereaved, more so than many of the intentional platforms. The introduction of Facebook's Legacy Contact facility (Brubaker & Callison-Burch 2016), and ongoing research into designing platforms that pay particular attention to “sensitive interactions with death and bereavement in mind” (Brubaker 2018) are an example of this recognition. Jed Brubaker is an Assistant Professor at the University of Colorado Boulder but he is also an Academic Research Collaborator at Facebook Compassion. The Facebook Compassion department originated in 2011 when Facebook hired researchers from California, Berkeley and Yale University to advise them on issues around sensitive issues, such as relationship breakdowns, objectionable content and how to deal with the death of a user. This collaboration led to suggestions for platform designers and engineers on how to improve user experience for these sensitive interactions (theatlantic.com). And the introduction of the Legacy Contact facility came from this research. Further developments in how Facebook deal with the profiles of their deceased users, that have taken place during

the writing of this thesis, will be discussed in Chapter seven of this thesis.

Launched in 2005, YouTube is a video sharing website which allows users to upload, watch, rate and comment on user-generated videos. Although it is an accidental posthumous site, as it did not set out to be used in this way, it is currently being used by the dying to communicate final messages to friends and family. People using the video sharing site are technically DCs, however, I discuss the videos in this chapter as YouTube is an accidental SP, and is being adopted as a posthumous messaging site which is relevant here.

Hjorth and Moon's research explores how people are using everyday technology such as smartphones to record last messages in tragic circumstances and posting the videos on YouTube (Hjorth & Moon 2017). These "posthumous camera phone practices" were used by some of those who were tragically killed in the Sewol boat disaster in 2016. Many of those killed were children and some of those used their smartphones to leave messages for their parents. Other "soon to be deceased" (Hjorth & Moon 2017) also use the accidental digital afterlife platform YouTube to deliver final messages.

Carla's Final Video – "Blog From Heaven" – is a 9 minute 44 second video recorded in 2010 by Carla Zilber-Smith a year before she died (Zilber-Smith 2010). It is a humorous, witty, light-hearted message which was played at her funeral. She begins the video:

"Hey lifers, look it's me, like the wings? You know it took that bitch-ass angel Clarence 200 years and a Frank Capra movie to get his wings ... sucker the trick is once you're on the inside you identify the alpha angel and then you start some shit, I went right up to Gandhi and called him an anti-Semite he threw the first punch, the rest is history"



Figure 35 Screenshot of Carla’s Final video – Blog From Heaven, 11th November 2018

By June 2019, this video had been watched 159,909 times (YouTube 2019). One feature of YouTube is that people can comment on videos that are uploaded. And when the subject matter is about death and dying any negative comments can be distressing for those who knew the deceased. While the vast majority of the 94 comments were positive (n=84) there were also negative comments (n=10), for example:

“When will she die, so I would dance ON HER GRAVE”

“Yeah....and you’d better hope Heaven doesn’t have a required IQ test”

“Fucking cringe”

Such online deviant behaviour or “cyberharassment” (Seigfried-Spellar & Chowdhury 2017) is not specific to YouTube, it can be found on other SP’s platforms (see Marwick & Ellison 2012). Whitney Phillips’s research into RIP trolls found that RIP trolling can be linked to what she describes as the “tragedy-obsessed global media and can cause significant emotional damage” to the bereaved (Phillips 2011). This “controversial form of public participation” (Arnold et al. 2018, p58) has repercussions: for her 2019 book “All the Ghosts in the Machine”, Elaine Kasket interviewed the father of Hollie Gazzard. Hollie had died at the hands of an ex-partner. Her father described how Internet trolls had targeted the Facebook pages of

family members berating them for allowing their daughter “to go out with a black man” (Kasket 2019).

Some users who upload videos containing last messages from the terminally ill choose to disable the comments function, and comments can also be deleted. In addition, YouTube allows you to moderate comments before they are published but this facility needs constant monitoring by a third party. When there are negative repercussions from uploaded content, it is extremely difficult for accidental SPs to ensure no harm is caused to the bereaved, because their users have chosen to use their platforms for final messages. Further findings from those using YouTube to upload final messages are presented in the Chapter five.

It would seem that the people who wrote negative comments on Carla’s Final Video did not know her, which is also the case for many of the positive comments:

“I never knew who Carla was until just today. I Googled and found this video”

“I never knew Carla while she was alive however came across this video randomly through Google and it really did touch my heart!”

These YouTube comments echo other’s research in the field of thanatechnology, which shows that knowing the deceased is not a pre-requisite to post messages of condolence on SNSs following a user’s death (see Walter et al. 2012; Kiaxoglou 2014; Gray 2015; Walter 2015). Dark tourism or thanatourism (Seaton 1996) is not a new concept: Roman gladiatorial games and medieval public executions are early examples of death-related tourism (Stone & Sharpley 2008). Though “mourning sickness” or “milking the macabre” (West 2004; Dann 1994, in Stone & Sharpley 2008) in the digital age can be seen as a type of postmodern dark armchair thanatourism where, influenced by the mainstream media, the “tragedy obsessed” (Phillips 2011) can participate in dark tourism on everyday devices, such as smartphones or laptops. Once again, as with RIP trolls, the accidental SPs can do little to address the issue of grief tourists, due to policies around privacy and freedom of speech.

LinkedIn is a platform used by many as a “professional” networking tool.

Interestingly, some participants are mentioning LinkedIn as yet another site where digital memories are being stored and retrieved. A participant whose deceased aunt is still “active” on LinkedIn, describes the pop up messages she still gets from the site, and how it is “incredibly poignant” when this “little shadow-thing pops up” (Sandra).



Figure 36 Screenshot of a LinkedIn profile 12th November 2017

Sandra explained that she logs onto LinkedIn occasionally to look at the “shadow-thing” on her aunt’s profile page. She has photographs of her aunt, but somehow this shadow is still important. She told me she always hoped it was a “magical portal” through which her aunt could communicate with her.

WhatsApp is also a frequently mentioned accidental digital afterlife platform for DIs. With over 1 billion users worldwide it seems that WhatsApp’s slogan “stay in touch with friends and families anytime and anywhere” is more apt than they would have ever imagined. It is the everydayness of the messages, and the fact that they contain “nothing deep and meaningful” (Sharon) that people find the most comforting (see Chapter six). Interestingly, all my participants who have used WhatsApp for communicating, at this time, have saved the messages, with some purchasing third party software to archive these precious message threads.

Personal rather than public messages such as text messages are also important for the bereaved. They become cherished possessions for the DIs. Once again third-party software becomes an essential tool to ensure these messages can be transferred between devices.

4.5 Conclusion

“I don’t want to achieve immortality through my work. I want to achieve it through not dying” – Woody Allen

This chapter opened with an overview of the digital afterlife industry, its dynamic nature, and some of the problems faced by both intentional digital afterlife platforms and accidental digital afterlife platforms. It then presented three themes which arose from a constructivist grounded theory approach to this research. This research has shown that the emphasis for many of SPs is the service they offer to the DCs, which is hardly surprising as this group purchase the paid-for services. We are at the very beginning of this technology, and as the next two data chapters will demonstrate, the digital remains of the dead should be treated as digital souls (Paul-Choudhury 2011) rather than leftover code, thereby considering the dignity of the dead while taking into account the needs of commercially driven SPs. Crucially, SPs need to ensure they are designing their platforms with TSD in mind (Massimi & Cahrise 2009). This important issue will be discussed further in Chapter seven of this thesis.

In the next chapter, I present my findings from the DC group of participants in order to explore the motivations and hopes of those using the platforms discussed above in an effort to create posthumously persistent digital afterlives or to memorialise the dead.

5 Chapter Five: Experiences and Motivations of the Digital Creators

5.1 Introduction

“The first requisite for immortality is death” – Stanislaw Jerzy Lec

In an age of ubiquitous social networks and the growing phenomena of self-quantification (defined in Section 5.4) we can all be thought of as digital creators (DCs); that is, enabled by the Internet we are creating memories and messages to be inherited by others after we die. However, this chapter focuses on the research findings from individuals purposefully creating digital memories or messages which they intend to be inherited by others after their deaths, or those using thanatechnology to memorialise the dead – the digital creators. One of the research aims of this thesis was to gain an in-depth understanding of the lived experiences of DCs, in an effort to understand this creative process and to explore their expectations for how these memories and messages will be used in the future. I start this chapter by introducing my DC participants, explaining why it was necessary to use sub-categories for this particular group of participants. I then present quotations from the participants to present the findings from the 17 DC participants which are organised around five themes (1) Benevolence; (2) Therapy; (3) Continuing bonds; (4) Technophilia, and, (5) The quest for digital immortality.

5.2 Getting to know the digital creators

When I met them, the 17 recruited DC participants were using the Internet to create a variety of digital memories and message. During the early stages of the recruitment process, and in the early days of data collection, I attempted to consider all DC participants together under the DC category; however, it became clear that there were fundamental differences in the types of digital memories and messages these participants were creating, so I began to realise that these DC participants needed further categorisation. Some DC participants who were terminally ill were creating memories and messages which they hoped would continue to exist after their deaths;

other participants, who were not terminally ill, were creating personal messages to be delivered after their deaths; others were creating blogs following the death of a loved one, while others were creating avatars and participating in life-logging in an effort to intentionally create a digital afterlife themselves. As we can see, although all of these participants were DCs to treat them as one group without sub-categorisation would not result in a clear understanding of the motives and hopes of what I have discovered to be a broad-ranging category. Therefore, I developed four subcategories which all 17 DC participants can be categorised within:

- Thanabloggers
- Creators of posthumous messages
- Grieving digital creators
- The early adopters

Pseudonym	Type of Digital Creation	Location
Tracey	Thanablogger	UK
Mary	Thanablogger	UK
Jan	Thanablogger	UK
Shirley	Thanablogger	UK
Tina	Thanablogger	UK
Gary	Creator of posthumous messages	Europe
Bob	Creator of posthumous messages	USA
Jess	Grieving DC	UK
Pam	Grieving DC	UK
Alex	Grieving DC	UK
Ivor	Grieving DC	UK
Noah	Grieving DC	USA
Tom	Early adopter	USA
Dane	Early adopter	USA
Paul	Early adopter	USA
Ben	Early adopter	USA
Russell	Early adopter	USA

Table 5.1 The further categorisation of the 17 DC participants

The remainder of this section describes each of the four sub-categories in detail.

5.2.1 Thanabloggers

The term thanablogger – suggested by Carla Sofka – is used to describe those who use the Internet to blog about death and dying (Sofka et al. 2012). In the early days of my research I became aware of a personal blog by Dr Kate Granger. Kate was a doctor and a terminally ill cancer patient who blogged and tweeted throughout her illness. She died, aged 34 on the 23rd of July 2016. Through her blog posts Kate described how she coped with the transition from doctor to patient, what it was like for her when she received her prognosis and the various treatments and care she received along the way. Together with her husband Chris Pointon, she started the #hellomynameis campaign to encourage those in the medical profession to introduce themselves to their patients in an effort to encourage “person-centred compassionate care” (hellomynameis 2016). In 2013, Kate created the Twitter hashtag #deathbedlive which she used throughout her illness and until four days before her death. At the time of submission of this thesis, this hashtag has not been used by anyone else since her death.

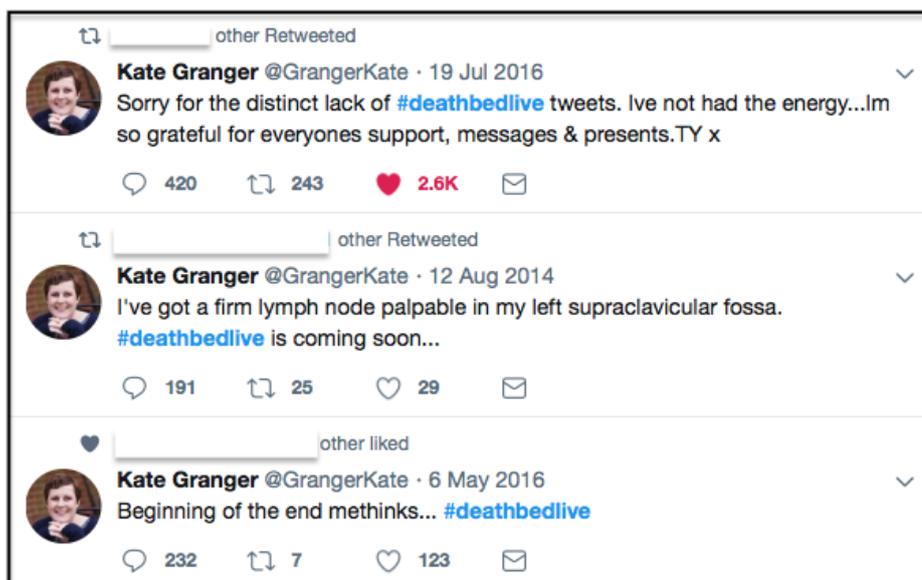


Figure 37 Screenshot showing Kate Granger's final three tweets

Before social media platforms were part of everyday life for many in our digital society there were many other examples of public dying and death bed fame such as Jade Goody in 2009 (Walter 2009) and Christopher Hitchens in 2011 (Brennan 2015). However, it should be noted that Goody and Hitchens were both publicly

known before their terminal illnesses while Kate Granger reached the status of, what I term, “thanacebrity” (someone who becomes famous *because* they are dying) from her digital deathbed tweets. At the time of her death she had over 48,000 Twitter followers – moreover, she still has over 44,000 followers 17 months after her death, echoing the findings of Natalie Pennington’s 2013 paper “You Don’t De-Friend the Dead”.

The creators of thanablogs are aware of the possibility that their digital data may outlive them. By reading Kate Granger’s blogs and following her Twitter feed, I became interested in the motivations and hopes of people who create thanablogs to discuss issues around death and dying. Following the recruitment process outlined in Chapter three, I recruited a total of four female thanabloggers, while all efforts to find and recruit male thanabloggers failed. These thanablogging DC participants have provided valuable insights into the experience of creating digital memories and messages, which will be presented in Section 5.3 of this chapter.

5.2.2 Creators of posthumous messages

Digital technologies are providing platforms where it is relatively simple to produce and preserve messages to be delivered after the death of their creator. Intentional posthumous message sites such as those discussed in Chapter four are being used for this message creation by people who are not necessarily terminally ill. Contrary to the thanablogging DC participants, both of the posthumous message creating participants were male.

In Chapter four I presented the findings of the SP participants, which explored the motivations and hopes of those who were offering the delivery of posthumous messages via their platforms. To obtain a more complete picture, I therefore wanted to understand the motivations and hopes of those who are using these sites to create digital messages.

5.2.3 Grieving digital creators

As discussed in Chapter two, the social norms and rituals around funerals are changing. Funeral selfies and the growing popularity of live streaming funerals are just two examples of the effect technology is having on mourning practices. Media has always been used to record and broadcast funerals of the famous, infamous and “newsworthy”, however, one family made the conscious decision to produce, edit and publish a film of their beloved son’s funeral. Josh tragically died in 2011 aged 22, following a road accident in Vietnam. Following his death, his parents Jane Harris and Jimmy Edmonds filmed, edited and published a film of their son’s funeral. They stated on the film that they wanted to speak openly and, moreover, they wanted to encourage others to speak openly about the loss of a child. They organised the funeral without appointing a traditional funeral director, and their film “Beyond Goodbye” not only tells their story of the funeral, it is a celebration of Josh’s life (beyondgoodbye 2012).

“Beyond Goodbye” is just one example of how the bereaved are creating memories and messages using thanatechnology in an effort to remember their deceased loved ones. For instance, people are also creating chatbots in an effort to ensure the dead remain socially active on their everyday devices. When Eugenia Kuyda started her chatbot company Luka in 2013, its main offering was as a restaurant recommendation bot. Then, when her best friend Roman Mazurenko died in 2015 she created an AI bot from the huge collection of text conversations between them. She frequently sends texts to her deceased friend, and the chatbot’s replies mimic her friend. Eugenia is not the only person using griefbots in an effort to remain socially connected to the dead: James Vlahos regularly texts his father to discuss the latest football results or sing their favourite songs together, but James’s father died in 2017. James created his Dadbot from an audio history he had compiled whilst his father was still alive, he then created the bot with PullString technology enabling him to send and receive messages from his deceased father. Interestingly, James’s father witnessed his wife interacting with the Dadbot before his death.

Thanablogs, as discussed earlier in this chapter, are created by DCs to discuss their experiences with terminal illness; however, blogs are also being used by the bereaved to publicly discuss their deceased loved ones, thereby creating digital memories and messages about their personal experiences of grief. The grieving DC

participants in this research are a mixture of grief bloggers, funeral film creators and thanabot creators. Here, it is useful to recall Figure 3.3 in Chapter three, which demonstrated the possible overlap of DC and DI participants: once a DC uses a digital memory they have created, they then become a DI, as they have inherited their own digital creation.

5.2.4 Early adopters

In our digital societies there are a plethora of technologies at our fingertips which can be classed as “life-logging” technologies: smartphones that track us; clouds that archive our conversations; and smart watches that count our footsteps, track our heartbeat and monitor our sleep patterns. People use apps for health-tracking and fitness-tracking, and this smart technology enables a level of self-quantification which has not been possible in the past. Moreover, this technology is generating and storing data on a daily basis, and resulting in many of us becoming accidental life loggers. However, there are people who are intentionally life logging in an attempt to self-capture and actively create and curate their personal digital afterlives. This sub-category of early adopters includes participants who are life logging, creating AVAs, or creating avatars of themselves on the platforms discussed in Chapter four.

Ancestor Veneration Avatars (AVAs) (Bainbridge 2013), are avatars embedded within virtual worlds which are based on historical biographies of deceased members of a DCs family, and in Chapter four I discussed how some game developers are creating avatars of deceased fans and embedding them into online games. I was successful in recruiting a participant who had embedded some of his deceased relatives into virtual worlds, along with two participants who have created avatars of themselves in an effort to create digital doppelgängers which they hope will remain active after they die.

5.3 Motivations of digital creators

“There is no heaven or afterlife for broken-down computers; that is a fairy story for people afraid of the dark” – Stephen Hawking

One of the core questions of this research is an attempt to find the motivations behind people who are intentionally creating digital memories with the knowledge that they will be inherited by others following their deaths. In an effort to address this question, I interviewed, transcribed and coded a total of 17 participant interviews. Analysis showed there was no single motivation from this group of participants. Using the coding methods described in Chapter three, the codes were then refined resulting in the development of 18 focused codes. The development of the codes for the DC participant was not a linear or one-way process; the following diagram demonstrates the two way and iterative process of this development:

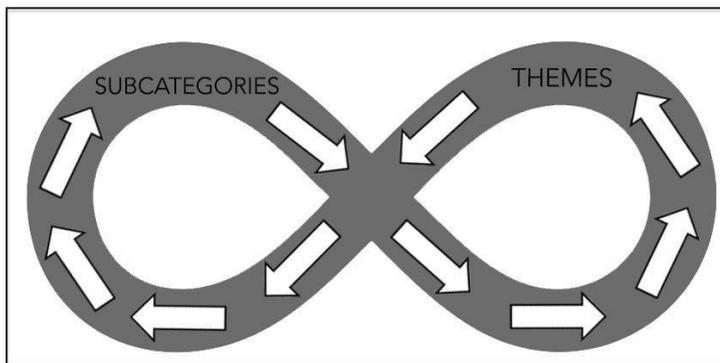


Figure 38 Development of DC themes

Once the 18 focused codes were established, I reread all of the DC interviews to robustly check the initial codes and focused codes. Further comparison and analysis resulted in the relationships between some of these codes being developed into five themes which were consistent across all of the interviews: (1) Benevolence (2) Therapy (3) Continuing bonds (4) Technophilia, and, (5) The quest for digital immortality. In the next section of this chapter I explain these five themes in greater detail, and show how the original codes underpin these themes, thereby giving further clarity to these findings.

5.3.1 Benevolence

The word benevolence reflects the prevalence of kindness and well-meaning throughout many of the DC interviews. Some participants commented on the importance of creating digital memories and messages which could help and educate others in similar situations, while others discussed how their digital messages may be able to help health professionals. Five codes underpin this theme of benevolence, and were used in the early stages of analysis when it became evident that participants

were aware that the digital data they were creating could improve the lives of others. The table below shows the relationship and evolution of the codes developed into this theme of benevolence:

Code	Focused Code	Theme
Helping others		
Inform/educate others	Altruism	
Truth telling		Benevolence
Improve future care	Advocacy	
Raising awareness		

Table 5.2 Codes underpinning the theme of benevolence

The NVivo memo below shows the analysis process of analysis behind the development of this theme, when I was coding the DCs’ interviews where participants were engaged in benevolent acts of digital creation:

NVIVO MEMO

Participants are telling me how important it is to make a difference to others, rather than creating digital memories and messages for more selfish reasons. I need codes which reflect the different ways participants think of others during the creation process. I have decided that the five focused codes can be categorised under two categories “altruism” and “advocacy”. Updated memo (October 2018): After further consideration I have decided to use the overarching theme of benevolence for these categories as this reflects the kindness/social conscience aspect of the process being described by the participants.

Figure 39 NVivo memo entry February 2017

I had recruited four thanablogging participants, and three of the four (Jan, Tracey and Mary) spoke passionately throughout their interviews about their use of social media as an advocacy tool, and their desire to help others with potentially terminal illnesses. The following quotation – which is typical of many of the thanablogging participants – illustrates this desire to help and inform others:

“Writing it down it was a very good way of me concentrating my thoughts

and working out what I was actually feeling ... that was part of it, and then there's a third reason, a patient treated in the same hospital as me had written a blog which doesn't really give a good message about breast cancer and I'd never really blogged before, I'd never read a lot of blogs but I then suddenly realised a lot of blogs that patients write are quite scary to read, and I wanted to make things seem a little bit more calm and sensible, and less daunting and it is a combination of those three really" (Jan)

These next two extracts from my interview with Tracey, demonstrate how the ability to create digitally mediated messages that can be accessed by other people makes thanablogging DCs feel that their experience of their illness can be useful to others in similar situations:

"You know to give people information and give them power to help them in their decisions, you know so that it makes it easier for them and I think that's where I started from" (Tracey)

"If I can pass any kind of information on to people then that's great, there is other people who have contacted me through the advocacy and the blogging, that again I have been able to share information of theirs so again it's passing that information along" (Tracey)

This theme of benevolence is found in similar research projects. Researchers who analysed the tweets of thanablogger Kate Granger during her final 6 months (Taylor & Pagliari 2017) found that their "main dimension", which they categorised as "physical symptoms" received 270 tweets during this time. However, I was interested in a category which was excluded from their results, but which was important to my research: their findings showed that Kate Granger tweeted about "campaigns including #hellomynameis and fundraising activities" a total of 388 times during her final 6 months. Thus, the findings of Taylor and Pagliari (2017) echo my findings that many thanabloggers are predominantly using Twitter and thanablogs to advocate for change and to help others.

Jan told me she reads the blogs of others who are terminally ill, and how these blogs can affect how she feels about her own illness:

"It's an accessible morbid curiosity that I wish I don't have access to, and for me when I found out my cancer had spread I spent the night on Google. I know everything, so I was desperately looking at forums that mentioned it had spread thinking 'oh, my god! she's dead in a year, it could be me'. Just

this insane thirst for any knowledge. And I don't know whether you are looking for reassurance or reinforcement or refusal, but it is quite scary and – depending on which blog you read, and how it's written – can dramatically change how you feel about things” (Jan)

In addition to informing and advising other cancer patients, Jan's motivations included the hope that health care professionals could benefit from reading thanablogs. Jan explained how she believed that patient care may improve as a result of these frank and honest blogs:

“I thought if I can write a blog it might help doctors realise that you are not just chemotherapy, it's not just a biopsy, to maybe help them improve patient care in the future” (Jan)

“Blogging is a big part of my life because it does share that information and it's been a positive thing for me, certainly not been a negative thing” (Tracey)

Alongside suggestions that informed and educated readers about their experiences with cancer, two participants also told me how blogs enable them to be frank with readers about the reality of their day-to-day lives. Both Tracy and Jan explained how the public nature of social media allows thanabloggers to include “truth telling” in their blogs and why they felt this was an important part of these online digitally mediated messages:

“But that is why, because people do need to see that. The thing is, it's not pink and it's not fluffy” (Tracey)

Here, Tracey was referring to The Breast Cancer Campaign, and Breast Cancer Now's use of the colour pink and bows to highlight and fundraise for breast cancer sufferers. In contrast to these campaigns, the thanablogging participants in this study told me how they are attempting to paint a more realistic picture of their experiences. Jan talked about how she felt about television personalities who discuss their potential terminal illnesses on television programs, and how she did not think these programs reflected the experiences of many cancer patients:

“It's an artificial ... we can't all look like you, in their house looking fabulous having chemo, others that are naked on the loo trying to have a crap looking like shit” (Jan)

But this motivation of “truth telling” also highlighted a recurrent concern for the

participant's: in that writing their digitally mediated blogs – and reading blogs written by others – made them contemplate the reality of their own mortality:

“I want to talk about my funeral and actually accept that it might happen. Whereas before you might keep your head in the sand” (Jan)

“For me as a cancer patient it makes me face up to my own mortality” (Jan)

Bringing discussions about death and dying out of the shadows and helping others seems to be a key motivation for thanabloggers. However, some participants expressed the view that there is a line that should not be crossed on thanablogs: one participant explained how she found some digital memories created by other thanabloggers to be upsetting rather than helpful:

“The thing that really upset me ... erm ... was the picture that was tweeted from the hospice bed ... and that made me ... I recoiled in horror” (Jan)

It also prompted Jan to discuss her wishes with her husband:

“And I told my husband if I ever get that ill I don't want you to put a photo of me looking like that on social media because that's not how I want people to remember me...or see me” (Jan)

This unease was echoed in the interview with Tracey, who also spoke about not wanting to see deathbed scenes on social media. She described how she felt when another thanablogger did this:

“She actually did post one of the pictures of her dying ... and it was horrendous ... and it will stay with me forever ... you know it's one of them things that you just think oh ... awful” (Tracey)

Tracey described how distressing it was to see post-death photographs which are published on social media sites of the “urn and coffin as well”. She went on to explain how uncomfortable this made her feel, adding that she did not want this to happen if she died:

“What I didn't like what I saw the other day was a picture of the urn ... now I thought I found that a little bit OTT and I actually messaged another friend who doesn't blog and I said to her if my husband does that when I'm dead, I said you're allowed to come and kick his backside”

Thanablogs will be an ongoing and important area of study for researchers; the

immediacy of the blogs and tweets and their ability to reach others in similar circumstances will help to highlight the experiences of the terminally ill (Taylor & Pagliari 2018). I felt that, through my participants, I was beginning to understand the importance of these thanablogs to both the creator *and* the reader.

This idea of helping others through blogging on the Internet was also discussed by my grieving DC bloggers. Grief bloggers differ from thanabloggers in that they are blogging about the loss of a loved one, rather than blogging about their own terminal illness or the possibility of their own death. Two of the four grieving DC participants expressed the importance of blogging to help others whilst also dealing with their own grief. During the interview with Amy, whose sister had died, she told me how she was motivated to use SNSs to talk about her experiences:

“I actually want to help people who are either facing similar situations or have experienced loss” (Amy)

Amy went on to explain how, for her, it was not only important to share her own experiences on SNSs, but how she wanted to be there to listen to other people’s stories in an effort to help them with their grief:

“There was also the aspect of actually counselling quite a lot of people I spend a lot of time in the first few months ... checking messages, writing messages” (Amy)

“When they have similar situations and that I can offer maybe some advice and you can ... be there for people when they want that” (Amy)

During his interview, Ivor, whose daughter had died, also talked about supporting others through blogging. Ivor had written a blog during his daughter’s illness, and explained how it felt like it had become a daily drama or “people’s EastEnders”. Following his daughter’s death he used the blog to inform people about the funeral arrangements and then wrote a final blog where he thanked people who had supported the family through their daughter’s illness. However, following his “final” post he received requests for him to continue with his blog:

“and I almost felt, you know, how, you know, when you’re grieving you end up supporting other people at the time when you need support. And I almost felt I had to carry on, I couldn’t ... ya know ... I was letting these people down if I didn’t” (Ivor)

I was seeing a tension between the needs of the blogger and the perceived needs of the reader. Yet while this tension exists helping others seemed to make a difference to some of my participants who were facing death or were grieving for their loved ones.

Once I had created the early adopter DCs category I had wrongly assumed most of the coding would be of a narcissistic nature. In contrast, my early adopters coded heavily under the theme of benevolence, with three out of four participants discussing how they wanted to create data which may be useful to researchers or anthropologists in the future.

Paul had created an avatar on the LifeNaut platform, and I wanted to understand his motivations for having spent time in the creation and ongoing training of his avatar. He encouraged me to create an avatar of myself to “allow researchers interactive access” to my work. He explained how it would allow researchers to connect with me on a “virtual level” and at a time when I “might not be available”. He added:

“If a scientist wanted to interact with a fellow scientist who may have passed on, it would give them the opportunity to virtually work with that person to a degree, depending on how detailed the MindFile was and how well the Avatar can converse about the data” (Paul)

Tom is a life-logger who actively collects and curates data from all aspects of his daily life. During his interview he explained his motivations for this digital creation:

“I guess it’s more of a that, I want to have content there, so that if people want to go back and look at what happened at these various environments or stuff that ... those are available mostly for sort of management or historical, ya know, studies. I have been a part of all of these organisations and so it’s more ... here’s the part I played in that. So that’s what I kind of see the value” (Tom)

Paul described the potential usefulness of his avatar creation to future generations who may seek to understand what life is like in the 21st century:

“Let me record my life in this way, and if it is a benefit to someone far off in the future, then I’ll have done a good thing and perhaps helped someone better understand themselves by understanding me and my generation” (Paul)

The usefulness of this type of digital creation was similarly described in an interview with Russell who explained his motivations for creating an avatar of himself:

“I think we are making history or contributing to that part of history as we go along so I think I might leave it open just for, ya know, future investigation, ya know, like students like yourself who might wanna go back and investigate what was going on back in 2016” (Russell)

Benevolence was the most heavily coded theme in the interviews with the DC participants. Yet not all of the subcategories of this group of DCs coded under this theme: neither of the two interviews with the posthumous message creators contained any suggestion of benevolence being a motivation for their digital creation. However, I still wanted to understand if leaving digital posthumous messages could ever be seen as a benevolent act, and so I began to search through YouTube and found a video which had been recorded and published by a terminally ill creator who was leaving a message to her son. It had been viewed 1,272,301 times and had 3,618 comments (at 14th December 2018). The following quotation is from the transcript:

“I hope you remember me and I hope this time-capsule helps. When you are watching this, know that I have moved on and that I am in a better place because Mom’s not suffering anymore. But I miss you so much and it hurts to know that you’re gonna go through all of this without your mom”

As this extract demonstrates the leaving of digital posthumous messages can be seen as a benevolent act. Having achieved a deeper understanding of the first theme of benevolence as a motivation for creating digital messages, in the next section I present the findings under the second theme of therapy.

5.3.2 Therapy

The theme therapy reflects what participants told me during interviews about how they use digital messages created on SNSs as a form of therapy. This theme was prevalent through many of the participant interviews and the table below shows the three codes that underpinned this theme of therapy in the early stages of coding and analysis.

Code	Theme
Self-understanding	
Self-help/protection	Therapy
Creative/productive	

Table 5.3 Codes underpinning the theme of therapy

One of my DI participants Grace told me how her husband had blogged throughout his illness. She spoke of what this had meant for her husband: “you know it gave meaning to the process of dying”. In the interview extract below Jan – a thanablogger – describes how, for her, blogging and tweeting are a good way of communicating bad news to a large audience, rather than repeating it multiple times. Jan went on to explain how constantly repeating bad news verbally, rather than digitally, can be both mentally and physically exhausting:

“but by reading the blog they felt they were more in touch with me. They were upset I couldn’t tell them everything on the phone, but often during chemo you can’t ... or ... it’s a lot to say. But they just felt ... we know what’s going on ... we’re in touch” (Jan)

Jan expressed how this was a part of her “self-preservation” as she was “protecting” herself by doing this. This comment from Jan resonated with a blog post from another thanablogging participant, Tina’s post also described the need to use SNSs to communicate bad news, rather than messaging a wide number of people individually:

“This is the blog post I hoped I’d never write. A lot of people who aren’t yet aware of my situation will be shocked and upset by it. There are so many people I’d like to break the news to on an individual basis but that’s just not possible. Whoever you are, thank you for reading” (Tina)

Similarly, Ivor told me how he also found blogging a useful way to communicate with family and friends about the deterioration of his daughter’s health, and then – following the death of his daughter – communicating to people about the funeral arrangements. He preferred this method of digital communication rather than trying to communicate to people individually, which he explained can be time consuming and mentally draining. Ivor explained,

“We didn’t have to go through the story at the end of every day ... Then it became our tool for telling people what was happening and then at the...when she died we used social media to tell people about the funeral”

(Ivor)

Occasionally the therapy theme was suggested in interviews when participants commented on the importance of *not* creating or reading grief or thanablogs. Jan explained how sometimes she made the decision not to visit these SNSs as a form of self-preservation:

“and there is the grim curiosity and I think ... no ... that’s enough put it away for a month, don’t go there. And you kind of dip in and out and feed this demon inside you, does that make sense?” (Jan)

Self-preservation is also important to those who are dealing with the death of a loved one, and are blogging about grief. Ivor explained how he needed to moderate the frequency of blog posts following the death of his daughter:

“I’d look at those and then ... I’d turn away from it and then I started gradually dripping myself back in the new year and I think there is something about ... this ... about this sort of self-protection” (Ivor).

Interestingly, Paul, one of the “early adopters” coded under the theme of therapy. He explained how the process of creating his digital avatar was not just a process of self-capture. Rather he described how it had helped him understand himself:

“I’ve discovered that, in a way, creating my Avatar has helped me better understand who I am, as I now see more clearly how the pieces of my puzzle fit together and make up who I am today” (Paul)

As with the theme of benevolence, discussed in the previous subsection, none of the posthumous message creating participants coded under the theme of therapy. Nevertheless, the findings of this research show the importance that digital memories and messages, enabled by thanatechnology, hold for my participants. Moreover, my findings demonstrate how for many of the DC participants, the process of creating a digital afterlife can be therapeutic.

5.3.3 Continuing bonds

“I can either post a card in a letterbox to her in Heaven or I can do something on this magical Internet Facebook stuff that gives us all this bullshit” (Pam)

When someone dies, the desire to continue a relationship with the deceased is easily

understandable. As discussed in Chapter two there is a plethora of literature which addresses how the Internet is enabling new ways of preserving bonds with the dead. In the voice of the participants who are using digital memories, and in the messages they have inherited following the death of a loved one, it is hardly surprising then that the findings of this research would reveal a theme of continuing bonds. However, this theme was also evident in those doing the creating, and in this section of the chapter I present the findings from these DCs.

Code	Theme
Keep memories alive	Continuing bonds
Remind people of their grief	
Stay connected	

Table 5.4 Codes underpinning the theme of continuing bonds

The theme of continuing bonds featured heavily in many of the DC interviews. During the interview with Jess, I asked if she could explain how important it was for her to create digital memories to remember and memorialise her son:

“When somebody dies you think that’s ... if you like, the end of their life. But until you experience it at first hand you don’t quite realise that death brings a lot of new experiences, and a lot of new learning, and that ... particularly with a child ... that child just because they’re dead doesn’t mean to say they are not part of your life” (Jess)

The theme of continuing bonds was explicit in the following extract from my interview with Jess:

“but it became more than that, because really what we wanted to then, was to continue that relationship on ... continuing the relationship with our son” (Jess)

This theme of thanatechnology facilitating an ongoing relationship with the dead was similarly reinforced in other DC interviews:

“Yes, like I just pull out my phone, and I open the Facebook messenger App ... and then it’s just as if you were sending text messages back and forth with a friend ... but you’re doing it with, with the Dadbot” (Noah)

The findings of my research, resonate with other research into the link between thanatechnology and continuing bonds (Getty et al. 2011; Degroot 2012; Kasket

2012a; Walter et al. 2012; Pennington 2013; Bouc et al. 2016). Yet, significantly, my research has also revealed a more nuanced aspect of the theme of continuing bonds when linked to DCs; the interview data illustrated how some participants wanted to make sure – through digital memory and message creation – that their deceased loved not only remain a part of *their* lives but also remain in the lives of others too:

“I always did because it keeps her real. To start with I wanted to make, well not make sure, I didn’t want people to think she wasn’t there any more”
(Pam)

Similarly, this motivation was reinforced by Jess:

“You know he will live on through these records, and we like that thought, so that you know we’re not just carrying him on, everyone who accesses this digital record of him can learn about him if they want to” (Jess)

In a similar vein, Jess implicitly described the need for things to be put in the “correct” chronological order. During the interview she explained that although her son had died before her, it was important for her that something would remain of him after she herself dies:

“We very much want them to be a permanent archive or a record of our son’s life for anyone and everyone to be able to access as they want, because they endure and they live on after we’ve died” (Jess)

Of further interest, two of the DC participants explained that it was important for them to remind people they were still grieving and they both explained how social media gives them a platform to achieve this. During both of these interviews this seemed a very poignant and honest admission from these participants, extracts from the interviews with Pam and Ivor (presented below) illustrate these feelings:

“It’s quite a selfish thing actually, maybe it’s just to make sure that people know that your living through shit” (Pam)

She went on to explain:

“It’s just to make everybody else aware that I am still thinking of her” (Pam)

Similarly during the interview with Ivor, he spoke of his reasons for still creating posts about his daughter on Facebook almost 10 years after her death:

“It makes me think ... I’m not gonna let you forget her” (Ivor)

He hesitated, then added

“But then there is also this thing around, do you know what, this will make you feel how it makes me feel” (Ivor)

The quotations above illustrate how social media can provide the bereaved with tools which they can use to remind people about their grief. This caused me to think about how the digital memories and messages enabled by thanatechnology are rendering the – now largely disputed – bereavement theory of “moving on and letting go” obsolete; in that, it is not a useful theory for the creation of digital memories and messages. In the interview with Jess she described how she wanted to create digital memories of her son because she realised she would never find closure:

“I suppose we didn’t realise at the time we wouldn’t find any closure but we would learn to live with the loss” (Jess)

This realisation was similarly described in my interview with Ivor where he discussed how creating digital memories enabled him to manage his grief:

“I don’t say that I cope, but I manage my grief. Well, you know, time doesn’t heal but I think what time does do is give you the ability to manage your grief” (Ivor)

In Chapter seven of this thesis, I will discuss how this research has highlighted how people’s experience of using thanatechnology challenges existing models of bereavement, and how these existing models could be expanded to acknowledge how digital memories and messages can facilitate – in a unique way – the creation of continuing bonds to remember and memorialise the dead.

5.3.4 Technophilia

Following initial coding of the DC participants I realised there were four transcripts that I had found extremely interesting, yet, which had almost no coding. Following further analysis, I identified that they all had one thing in common: they all loved the technological capabilities being offered by digital afterlife platforms. Technophilia is the love and enthusiasm for new technologies, and this was the fourth theme to be created from the DC participants. This theme provides a further understanding of the motivations of the DCs – who were all categorised under the sub-category of early adopter – and their desire to create digital messages and memories which they hope

will be stored and easily available for future generations, and into perpetuity.

Focused Code	Theme
Memory aid	
Life logging/backing up	Technophilia
Useful to future researchers	

Table 5.5 Codes underpinning the theme of technophilia

In an effort to understand the motives and experiences of those creating and training their own avatars, I wanted to interview participants who were using intentional digital afterlife platforms. In early 2017, I interviewed Paul in an effort to help me understand how he interacted with the avatar that he had created:

“I’m still working on myself ... literally. Every time I interact with my avatar, it becomes more like who I am today” (Paul)

I wanted to understand how Paul felt this was different from physical memories such as writing a diary:

“Sure, a person can write an autobiography, and fill volumes of books with so much of their life's many adventures. However, the person reading each book can only do just that, read what is written, but not interact with the author” (Paul)

Paul described how he made certain choices about how he created his avatar:

“I like that I was able to upload a picture of myself that is 'brought to life' and animated by the program. I chose a photo of me as I was when I was 50 years old. I plan to inset a younger version of myself, and of course more recent photos of me, so that the user can choose to interact with my Avatar in the form that they would be most comfortable with” (Paul)

I asked Paul if he thought other people should be taking up the opportunity to create avatars:

“For so many people who have not taken the time to create an avatar of their own, they are missing out on an incredible opportunity to leave behind a virtual version of themselves that can be as fun to interact with as they were. It all depends on how honest they are about themselves, and how much detail they are willing to put into it” (Paul)

Other participants were also intentionally creating digital afterlives; Life-logger

Tom, self-captured every aspect of his daily life by wearing a camera around his neck which took a photograph every 30 seconds. He told me how he felt, that although his digital creation was extreme at the same time everyone else is accidentally self-capturing their lives:

“It would seem like you have everybody on Facebook because a Facebook timeline in essence is everybody is life logging whether they like it or not because they have ... I don’t know whether people consider their life logging or not, but it’s certainly, that’s what it is” (Tom)

This idea of everyone creating digital memories and messages is compelling, with wearable technology monitoring users’ heartbeats, steps and exercise, people are becoming “quantifiable” to many of the large technology companies, and, as Tom points out, how SNSs such as Facebook and Twitter have ensured people’s daily lives, political opinions, likes and dislikes are recorded and stored.

“Facebook hit 2007 and so essentially you now find your life splattered everywhere” (Tom)

The idea of being able to “back-up” who you are was important to two of my early adopter DCs:

“I’ve long worked on statistical methods for personality capture” (Ben)

“the idea of can you back-up a mind and can you ... you know ... basically save and pass forward information about the human experience” (Russell)

The importance of digital capture as an aid to memory was also discussed as a key motivation:

“My motivation is the push to kind of extend my personal ... or to have a totally perfect memory” (Tom)

“For people suffering from Alzheimer's and dementia, having an avatar would allow them to record so much of who they are and what they've done before they forget completely about it themselves” (Paul)

Out of all my participants, no thanablogging, posthumous message creating or grieving digital creators coded under the theme of technophilia. This theme was the last to be created, and it was very specific to the four early adopters interviewed; however, it is an interesting theme as it provides an understanding of an important

motivation for those life-logging and creating avatars: their love of nascent technology.

5.3.5 The quest for digital immortality

“Unable are the loved to die, for love is immortal” – Emily Dickinson

In our digital society, those who use SNSs are unintentionally creating a digital afterlife which will very likely outlive their biological existence. However, many other people use the Internet – and, specifically, social media platforms – with the clear intention of trying to achieve immortality. When interviewing the DC participants several of them coded within this theme of “quest for digital immortality”. The NVivo memo below explains how this theme was developed.

NVIVO MEMO

During coding I am beginning to understand the intentionality of some of the participants to create digital afterlives. For this theme I have made the conscious decision not to change “digital immortality” to “digital endurance”. I am aware that I have suggested the term digital endurance is a more accurate description of the data of the dead rather than digital immortality. However here, for this theme, I need to use immortality as I am using it where the “quest for digital immortality” is an active and intentional process.

Focused Code	Theme
Image control	
Legacy creation	
Advise/inform future generations	Quest for immortality
Story sharing	
Fear of being forgotten	

Table 5.6 Codes underpinning the theme of immortality

Two of my thanablogging participants briefly talked about legacy creation, but only once I had prompted them by asking about it at the end of their interviews:

“Something that I can have left behind that I have created that will be ... I don’t know using the word legacy is a bit grand but, erm, if that makes sense” (Shirley)

“I do hope that, you know, if when that time comes, that it will hopefully give my children an insight to what I have gone through” (Tracey)

However, as Tracey went on to explain even when “story sharing” and “legacy” were mentioned by participants they still resonated with the theme of benevolence:

“To help people get the right information at the time, I think I just wanted to tell my story like everybody else does, you know to give people information and give them power to help them in their decisions, you know so that it makes it easier for them” (Tracey)

“But I never think about it as leaving a legacy. I think about what you can do now” (Tracey)

In a similar vein, only one grieving digital creator participant was coded under the focused code of “legacy”. After having discussed how precious digital memories and messages left by her sister had become since her sister’s death, Amy reflected on her own mortality:

“I need to start thinking of kind of my own legacy and the legacy ... because, you know if something happens to me no one has backup” (Amy)

The desire to advise and inform future generation was explicit within the data from the posthumous message creators and at the time of my interview with Gary he had recorded 10 messages to be delivered after he dies. He explained his motivations:

“Yes, we live on a digital age – our digital identity will remain behind forever, why not to make it something that will reflect the real us for generations to come?” (Gary)

“you can decide whether you want to have the control and the last words under your erm ... your terms or would you like Google to determine how you will be remembered for generations to come” (Gary)

Gary used the term “generations to come” in both of these quotations. I created a node within NVivo to see if others coded under “digital immortality” had mentioned this desire to influence future generations, and they had:

“It may sound weird but that feels good they’re gonna hear from me on those birthdays, whether I’m here or not” (Bob)

I was interested about whether this desire to influence future generations would still be apparent if the posthumous message creator knew they were about to die. So I

transcribed a message left on one of the posthumous message sites where the male digital creator knew he had a terminal illness (he has since died):

“I am hoping for the future generations of the family will get some comfort and some guidance in looking at this message I am sending”

“Taking on responsibility for my future generations now just to let them know who I am what kind of character I was and my beliefs, and what my contribution was to the world”

Similar to the findings from the posthumous message creators, Ben, one of the early adopter DCs, also coded under this theme. His desire to advise/inform future generations was evident from his interview and echoed the idea of symbolic immortality (Litton 1979):

“I tend to think that virtual world avatars are but one of the many ways deceased family and friends can continue to shape reality” (Ben)

Interestingly, image control and the need to control how others see you after you die was implicitly discussed by all of my digital posthumous message creators:

“I think it’s also a mistrust isn’t it? It’s a mistrust of those who are left behind to remember me” (Bob)

This need to control how others will remember him was similarly described in an interview with Gary:

“Yes, we live in a digital age, our digital identity will remain behind forever, why not to make it something that will reflect the real us for generations to come? (Gary)

During the interview with Bob, he described his desire to live on virtually after his biological death through his creation of posthumous messages, and his need to ensure his “personal posterity”. In an effort to understand the types of messages Bob had created, I asked him to describe the content of a few of them and when he had timed them for delivery:

“The 18th and 21st birthdays are not profound, they are just me being myself, and being a bit silly and having fun. Other years are more profound ... okay ... but 18 and 21 are to be celebrated and not to be serious” (Bob)

I wanted to know how far into the future Bob had created timed messages for his children:

“At this point they will get them up to 40. It’s just a matter of going in and getting them further but they are covered up to 40 years old” (Bob)

I asked Bob how he felt knowing that these messages would be delivered to his children if he died by the date they were due to be delivered:

“It gives me a great deal of pleasure to know that my son who is 8 and my daughter who is 4, they’re getting messages from me on their 18th and 20th birthday no matter what, and that feels good to me. It may sound weird by that feels good they’re gonna hear from me on those ... birthdays ... whether I’m here or not ... I’m gonna be part of those birthdays ... unless they don’t want me to be and they can turn it off but otherwise, yeah, I’m there” (Bob)

Bob’s final comment, in the extract above, about the ability of DIs to choose whether to listen to messages once they are aware they exist, will form a major part of the discussions around control in the next chapter of this thesis.

Being remembered is an important part of the motivations behind the creation of digital memories and messages for the DC participants of my study, and the following quotations from my interviews with Ben and Paul illustrate how the fear of being forgotten manifest in some of the interviews:

“My family has a very long history of developing very intense personal identities, seeking fame but in idiosyncratic ways, and preserving information about family members” (Ben)

“And no one will be able to speak with you about your many life experiences ever again” (Paul)

Thus, as argued throughout this subsection, the ability to able to narrate your own biography can be seen as a form of image control, and a desire to control how you are remembered in the future. In contrast, exploring the motivations of the early adopters who are creating avatars and life logging, this research has shown that their motives are more varied than a simple desire to be remembered. Digital afterlives are important to them, but as one early adopter DC explained, he was not totally convinced that digital immortality is a good thing:

“The reality maybe they’ve already lived too long anyway, and just do we need them around, do we need any more of me around any more longer than I have been ... I’m not sure” (Tom)

In contrast to Tom’s view of digital immortality, another early adopter looked at the creation of avatars as a way to compete in our digital society:

“For some people to live longer on this limited Earth, other people must not be born. So I tend to view avatars as allies in competition with people outside the family or other social group” (Ben)

Interestingly, Ben told me that he had never experienced grief although most of the close members of his family had died. He told me he did not think he was capable of experiencing grief, however, he had spent many hours creating avatars of his ancestors and embedding them within virtual online worlds. I asked Ben if he would like to receive timed digital posthumous messages services from his ancestors and received the following philosophical answer:

“Sure, fine, as a step toward having an army of revived ancestors doing my bidding as servants. Or, perhaps they will dominate me” (Ben)

5.4 Conclusion

“I’m gonna live till I die” – Frank Sinatra

Organised around the themes of benevolence, therapy, continuing bonds, technophilia and digital immortality, this chapter has presented the findings from 17 DC participants. These participants have created digital memories and messages knowing that their creations may live on in digital perpetuity. These findings indicate that there are benefits to the DCs by creating digital memories and messages, and these benefits will be discussed in more detail in Chapter seven. Having gained a deep understanding of the motives of DCs, and how they make meaning of these experiences, the next chapter will move on to look at DIs: those who inherit the digital memories and messages enabled by, created, and stored on the Internet and smart technologies.

6 Chapter Six: Experiences and Motivations of the Digital Inheritors

6.1 Introduction

“I’d sent her a private message after she died. I don’t know why. And after I saw no one had posted on her page for so many years, I went to find it to see if it had been read. It hadn’t ... of course it hadn’t” (Emma)

This research was designed to explore how thanatechnology may be changing how people experience bereavement, grief and loss. One of the core objectives of this research is to develop an in-depth understanding of how the bereaved use and make meaning of digital memories and messages enabled by thanatechnology, and inherited following the death of a loved one. The foundations for this objective have been laid in the previous two data chapters where I presented the findings from the first two categories of participants (1) service providers and (2) digital creators.

In this chapter I will present the findings from the 23 DI participants. In the first section, in order to give context and clarity to these findings, I will present an overview of the DI participants which introduces you to how they are related to the deceased, and illustrates the types of digital memory and messages they have inherited. The second section presents four concepts which were developed through analyses and conceptualisations of the data: (1) The voices of the dead, (2) Timings, frequency and triggers, (3) The digital versus the physical, and, (4) The comfort, disruption and confusion of digital afterlives. Finally, the third section of this chapter shows how this research highlights significant changes to the landscape of Mori’s uncanny valley, and how the digital data of the dead is being experienced by the bereaved.

6.2 The DI participants

“Initial coding continues the interaction that you shared with your participants while collecting data but brings you into an interactive analytic space” (Charmaz 2014)

In this research, I wanted to explore how digital memories and messages created and

inherited from human-computer interaction enabled by the Internet were being used by the bereaved. I wanted to understand how posthumous digital memories and messages were being experienced by my DIs: moreover, how they would feel if they lost them. All interviews were recorded and transcribed verbatim and notes (memos) were used to record my initial thoughts while transcribing. As with the other interviews focused coding followed open coding of the data in order to explore what themes emerged from the experiences of DIs.

Pseudonym	Type of memory/message	Country	DI's relationship to the deceased
Amy	Facebook profile	UK	Sister
Maggie	Posthumous video message	UK	Brother
Ali	Facebook profile	USA	Friend
Chloe	Facebook profile	UK	Father
Cathy	None	UK	Son
Charles	Blogs; Twitter feed	UK	Wife
Emma	Facebook profile	UK	Friend
Grace	Blogs; YouTube videos	UK	Husband
Noah	Chatbot	USA	Father
Ivor	Blogs; Facebook profile	UK	Daughter
Jeremy	Google map	UK	Mother
Pam	Facebook profile; voicemail	UK	Daughter
Jeff	Funeral film	UK	Brother
Riann	Facebook profile	UK	Brother
Sophie	Facebook profile; emails	Canada	Mother
Sharon	Facebook profile	UK	Husband
Sandra	LinkedIn; WhatsApp messages	UK	Aunt & father
Dan	Blogs; Facebook profile	UK	Friend
Tina	Facebook profile; photographs	UK	Husband
Sally	Heartbeat audio recording	Canada	Daughter
Jess	Funeral film	UK	Son
Lorren	Posthumous video message	UK	Husband

Carla	None	UK	Mother
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Table 6.1 Details of the 23 DI participants

In addition to the recruited participants for this study there are a further 13 “voices” utilised within this DI data chapter. Grounded theory allows for theoretical sampling which involves the researcher seeking more data which assists in the development of the emerging categories (Charmaz 2014, p192). Following this method and having begun to develop the four themes of this chapter, I sent follow-up emails to some participants in an effort to clarify my developing concepts. By February 2018, I had collected, transcribed and analysed the DI interview data and was in the iterative process of constant comparison when I saw a tweet from the journalist and LBC radio presenter, James O’Brien which piqued my interest:

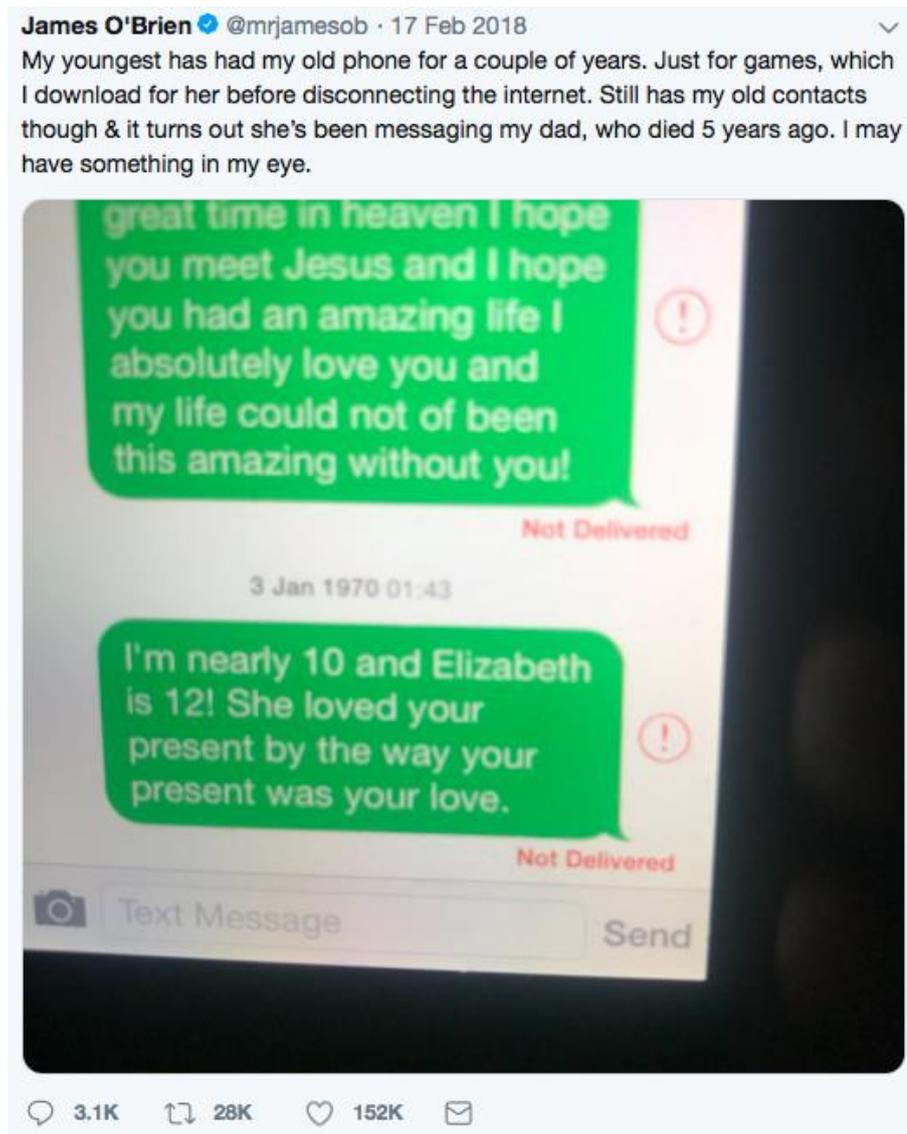


Figure 40 Screenshot of James O'Brien's tweet, 17th February 2018

At the time of this tweet James O'Brien had 405k followers, and this single tweet received 152k likes, 28k retweets and 3.1k replies. O'Brien's Twitter followers were expressing how touched they were by the idea that his young daughter was using his old mobile phone –which was not connected to the Internet – to text her grandfather, who had died five years earlier. Over the next 72 hours I monitored the replies as they were happening and I selected 13 typical tweets which gave a flavour of what people were saying about the digital memories and messages they had inherited. I then copied and coded these within NVivo. I found that the tweets echoed what I was hearing from my interview participants and their follow-up emails. Within this DI findings chapter I have presented these tweets as screenshots rather than quotations as I felt it was important to acknowledge that they are single tweets rather than

quotations from in-depth interviews. Reviewing the replies to the James O'Brien tweet helped me to further understand the scale of the phenomena of digital afterlives, and how people were being affected by digital memories and messages.

Within this chapter I have also used tweets and replies from another Twitter user, and again I have made the distinction between these tweets and participants I have interviewed. A grounded theory approach to data collection allows for this type of theoretical sampling, which Flick (2018) describes as collection of data which is relevant and meaningful to concepts developed from, and linking back to, data which has previously been collected and coded. The replies to the James O'Brien tweet and the other Twitter users validated my findings and allowed me to consolidate my developing theory of the fear of second loss, which is presented and discussed in the Chapter seven.

Within this current chapter the authors of tweets are not counted as DI participants, rather they were used to assist me to understand my findings in a wider context. Although the tweets I used were in the public domain, I contacted the author of each of the tweets I wanted to include, to gain permission for their use in this thesis. These tweets merely served as a validation tool for my research.

6.3 The themes around digital inheritance

6.3.1 The voices of the dead

Listening to the voices of the dead proved to be a dichotomous theme within this research: with some participants telling me they found audio of their deceased loved ones to be a comfort, while some participants found audio messages painful and a disruption to their grief. However, all the DI participants who inherited audio digital memories and messages spoke passionately about their experience of inheriting audio messages, and why they experience audio differently to other precious digital data of the dead:

“I don't listen to it very often now, but I know it's still there, and I know I can if I want to, I do have a ... I do need a new phone but I won't change it because I don't want to lose it” (Pam)

I wanted to learn more about the audio message that Pam had inherited from her

daughter, so I asked her if she could describe the message for me:

“She is just singing it, the sun will come out tomorrow, yeah I can hear it now and I’m not upset it’s a comfort” (Pam)

These comments from Pam echoed the positive comments I had heard from other DI participants about the voices of the dead. During the interview with Ivor he told me about how he would occasionally, listen to audio memories of his deceased daughter:

“But every now and then, I’ll think you know what, I just want to hear her voice” (Ivor)

My interview with Jess also revealed a positive reaction to listening to the voice of her dead son:

“Well it’s wonderful to hear his voice and see his face and it doesn’t make me sad ... well it makes me sad but it makes me happy to hear his voice” (Jess)

A number of the replies to the James O’Brien tweet also reflect this finding from my data; that some DIs experience comfort from the audio messages they inherit:



Figure 41 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)



Figure 42 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)



Figure 43 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)



Figure 44 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)

Another participant, Sophie had voice recordings of her mother which had been recorded before she died and which she describes as comforting:

“So I have listened to that... actually... several times cause I thought that was really nice” (Sophie)

However, Sophie went on to explain how when her mother was dying her brother recorded audio of her which Sophie did not want to listen to:

“He strangely enough, that is just like too raw for me and I haven’t actually... cause like her voice sounded different and everything” (Sophie)

Below is a tweet from one of the SPs who offer the delivery of posthumous audio messages. The tweet demonstrates how an SP’s view of audio can differ from those who actually inherit them:

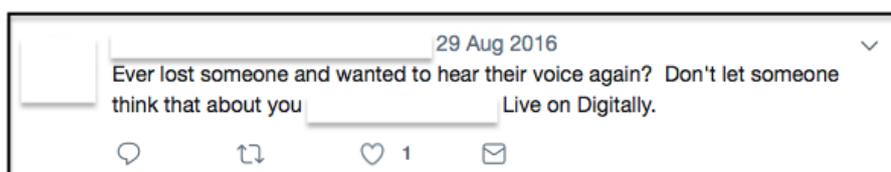


Figure 45 Screenshot of a tweet by one of the posthumous message service providers

The comment from Sophie about choosing not to listen to audio digital memories

and messages began to pique my interest. I began to see a pattern in how some of my participants who possessed audio of the deceased were making decisions not to listen to them, as this extract from my interview with Sandra demonstrates:

“I know his voice is there, if I wanted to ... but maybe that will be something I will do” (Sandra)

Sandra also explained that she had an audio recording of her grandmother which she has not yet listened to:

“I know it’s there and I have the knowledge that she’s in my sewing box and so my grandmas voice is in my sewing box” (Sandra)

The idea that for some participants audio digital memories and messages were experienced differently to other forms of digital memories and messages was beginning to develop. I therefore revisited the data to re-code the interviews and to ensure that the categories of “triggers and timings” and “comfort” and “disruption” were split into sub-categories to allow for audio digital memories and messages to be treated as separate categories to other forms of digital data.

This splitting of categories into subcategories highlighted that audio was indeed being experienced in a different way to other posthumous data, as illustrated by the following quotation:

“That’s one thing that I don’t tap into too much cause hearing her voice isn’t always ... It brings up tears” (Amy)

Later in the interview, when telling me of the comfort she gets from other types of digital memories inherited from her sister, Amy mentions audio again:

“but I don’t go too often ... to the voice” (Amy)

“I found hearing his voice difficult...” (Jeff)

Both Amy and Jeff, who are quoted above, were passionate about the digital memories and messages they possessed of their loved ones so I wanted to try to explore this reticence to listen to audio memories. In an effort to understand the difference between audio and other digital memories and messages I asked Jeff why, for him, listening to the audio of his brother is different:

“I think it is because he just seems more alive, I think, with a picture, erm it is still ... it’s a still frame, but when I hear his voice and I saw him in moving image it, it, it brought him so much more to life and then ... the pain of realising that that was so far from the truth ... it became a lot harder” (Jeff)

I was beginning to understand how for some of the participants hearing the voices of their dead loved ones was experienced differently to other forms of digital messages and memories: in that, for them these audio messages contained more of the “essence” of the person who had died. This difference was also reflected in my interview with Riann who told me:

“ya know there’s lots of videos on Facebook, which I don’t want to watch cause I don’t want to hear his voice, because again that’s too direct” (Riann)

I wanted to know more about what “too direct” meant to Riann, so I asked her to expand on this point:

“I think it’s, too much like he’s here, and that will remind me too hard, in too severe a way that he is not. Like all these sort of things on Facebook, as much as there are some things on there we don’t want to be on there, he chose to put them on there but his voice is unadulterated, you know it’s just, that is what he sounds like and I haven’t heard his voice since he died, I haven’t watched any of them” (Riann)

During my interview with Pam she told me she did not want to upgrade her mobile phone as it held an audio message from her daughter where she was singing a song. During this interview I explained to Pam that there were platforms where you can use third party software to transfer precious messages, but Pam said she would lose a part of her daughter in the process of transferring the message, and that somehow it would be a “copy” of her daughter rather than what she perceived as her “actual” daughter. The extract from the interview with Riann also talked about audio in a similar vein, when Riann described the audio of her deceased brother as an unadulterated version of him. This research highlights, how, for some, inherited audio messages may blur the line between perceiving the deceased as being alive and being dead (this blurring of states will be discussed in Chapter seven).

However, I was confused by the explanation from Riann because she had already told me how much she enjoyed watching videos of her brother which were uploaded on Facebook, so I asked her to clarify what she meant by an unadulterated version:

“I haven’t watched any videos with sound on ... I have watched some videos on Facebook but not with the sound. That sounds weird when you talk about it but all these things ... no I wouldn’t be able to, I mean I might have voicemails from him ... but I wouldn’t be able to look at them ... I don’t want to lose them but I also feel that maybe in my lifetime I won’t be able to listen to them, but I’d want my children to. It’s ridiculous isn’t it? I’d want my children to, if they wanted to: to listen to them. You know I’m gonna make sure my children know they had an uncle” (Riann)

This study reflects how grief is a varied, complex and personal experience. Learning that Riann watched the Facebook videos with the sound turned down was a significant point in this research, as it clearly demonstrates how different types of digital memories and messages are perceived and experienced by the bereaved in complex ways. Figure 42 below shows a screenshot of a tweet which reinforces this notion of complexity.

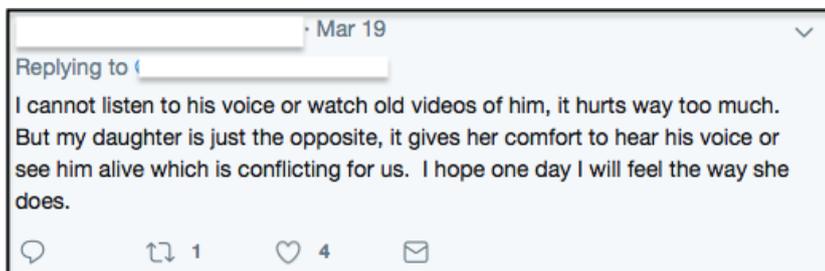


Figure 46 Screenshot of a tweet (used with the permission of the author)

In the next section of this chapter, I present the theme of “timing and frequency” in order to further explore when, and how often, DI participants visit the digital memories and messages of their deceased loved ones. Whether and when people choose to listen to inherited audio memories and messages is important, with some DIs telling me that they listen “on bad days” while others explain it needs to be “a good day” to listen.

6.3.2 Timing, frequency and triggers

I wanted to understand how frequently my participants were visiting their inherited digital memories and messages, such as Facebook profiles, WhatsApp messages, LinkedIn profiles, text messages, posthumous messages and audio messages.

Following the open coding of the first few DI interviews I began to see a pattern in

how people described what “triggers” their need to visit this posthumous data. Here I use the word “visit” to acknowledge agency, as these participants have control and access to the platforms and/or the digital memories they were discussing. I have not presented instances where my participants mentioned visiting the digital data on significant dates, such as birthdays or the anniversaries of the death of a loved one, as there is existing research into such visits (Massimi 2012; Brubaker et al. 2013; Giaxoglou 2014; Ellis Grey 2015). Instead, I wanted to understand the desire of DIs to view the memories and messages on “insignificant” days, as I wanted a deeper understand of the timing, frequency and triggers of visits, which would provide further clarity about the importance of these enduring digital memories to the DIs.

In my interviews with Riann, Amy and Jeff who had all inherited Facebook pages from their deceased siblings, each of them discussed how often they visited the Facebook pages of their loved ones. Riann’s brother had died in 2015 and she told me how often she visited his Facebook page:

“Probably more than I should, I would say twice a week I will look at it to see if there’s anything that has anything new that has been posted”
(Riann)

During her interview, Amy described how her visiting habits had changed over the past few years:

“Last year, I probably logged in her account every other week just to check if any personal messages have come through from people who knew her only through work assignments. However, I still check her Facebook timeline every now and then through my Facebook friends list” (Amy)

This tailing off of visits was echoed by Jeff whose visits had also decreased over time. He explained:

“I would say somewhere about close to once a month ... as I say probably less than what it was like when he first died” (Jeff)

Although the frequency of visits to their inherited digital memories has slowed down, each of them expressed how precious these digital artefacts were to them, and how much they valued their existence.

The frequency of visits to digital memories and messages is useful to this study;

however, I wanted to understand what triggers these visits. In order to examine this, I constructed two codes: “visit on a bad day” and “visit on a good day”. Three participants, Jeff, Sophie and Amy told me how they needed to visit on a “bad day”. I wanted to further understand why they felt they needed to visit their digital memories on a day when they were already struggling with their grief. They told me how they sometimes needed to remind themselves of their grief. The following quotations illustrate this desire to reconnect with grief, and demonstrates how participants are using their inherited digital memories as an effective tool to achieve this reconnection:

“But I only click on it when, either I feel like it, or I just think I need a bit of a ... I need a cry and it’s not quite coming out an then I just click on them and listen to them ... her voice” (Amy)

Amy went on to explain how, for her – as discussed in the previous section – digital audio messages evoked the most emotion, and how she used these audio memories to help her reconnect with her grief.

“but when I want to have a good sob, sometimes I do it” (Amy)

During my interview with Sophie she too described this need to visit on a “bad day”

“if I miss her or if I’m going through any kind of transition or turmoil which I kind of am right now, you know just came to a new city, I would tend to do that more for sure” (Sophie)

“On that particular day I went through, what was very much you know, I felt kind of crappy, and I just wanted to let it all out ya know. So I’ll do it for that ... but there are definitely times when I look, because I just need to look ya know ... some sort of cathartic ... yeah, yeah” (Sophie)

However, it was my interview with Jeff that caused me to think about how digital afterlives could be affecting the bereaved in ways not seen before:

“So I think that time I felt that, hang on wow the funeral making me cry, really making me go to the bottom, sort of wrenching feeling, and I quite like that, I quite like getting there from time to time” (Jeff)

This experience of needing to “get there” echoes Stroebe and Schut’s DPM model of bereavement discussed in Chapter two, and specifically the need to avoid or deny restoration changes and reconnect with the loss. However, I am beginning to

contemplate how inherited digital memories and messages – particularly as they are easily accessible and carried on everyday devices – may be disrupting existing models of bereavement (this disruption will be discussed in Chapter seven of this thesis).

NVIVO MEMO

Looking back at the recordings of the interviews following the coding process, all of these participants hesitated and took time to articulate their feelings during this part of their interview, suggesting even discussing these visits to their inherited memories somehow reconnected them to their grief during the interview. Many participants told me how they had not thought about what makes them visit the digital memories until I asked the question. This seems to be an important issue as SNSs ensure the dead are part of our everyday lives and available on our everyday technologies, whereas visits to analogue memories and messages such as graves are sometimes surrounded by social and cultural rituals.

Again, there were a number of replies to the James O’Brien tweet which also reflected this decision to visit enduring digital messages on a “bad day”:



Figure 47 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)



Figure 48 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)

Once again my research had highlighted the complexity of grieving, as I also had participants who told me how they chose to visit digital messages on days when they were feeling “happy” “strong” or “wistful”. In the interview with Noah he explained his decision to only “visit on a good day” when he was feeling strong:

“I think I usually, do it when I’m in a, somewhat happier place because, yeah, because I’m really raw about his death. Then, I don’t know maybe, then maybe I’m like my sister, like it seems a little too painful. So it’s more when I’m feeling... wistful you know, oh my dad was so great, or he was so funny, or he was so smart, and I wanted to think about that. Like a little more in that sort of celebrating mood rather than just a crushed mood ... does that make sense?” (Noah)

Riann also spoke about what motivates her to visit the Facebook page of her brother:

“When I’m feeling strong... I’d avoid it if I was unhappy” (Riann)

I asked Riann if she could tell me more about her need to only visit on a “good day” and she explained:

“I probably only look at it when I know I’m feeling quite nice or deliberately to get a picture from it, sometimes I think, ‘Oh, I’d really like to look at some pictures’, and then it’s nice that they are all there (Riann)

Constructing, using and developing these dichotomous codes of visiting on a “good day” and “bad day” had furthered my understanding of what triggers these visits’ however; I still wanted to understand whether such visits had to be pre-planned or whether they could be impulsive. Two of my participants described how, for them, visits can be spontaneous:

“whenever I feel like it, and that can be very impulsive, I mean there isn’t really ... of course the first year I think. I notice now being in the second year I don’t count” (Amy)

“If I feel like I need to go and look at it I’ll look at it, but it’s not something I build up to over a period of time to sort of psych myself up for” (Charles)

In contrast, for Grace, whose husband blogged during his terminal illness, it needs to be a planned visit rather than an impulsive visit to read his blogs:

“If I go and look at the site I have to really sort of armour myself before I arrive there ... and then you know I haven’t done that for a while” (Grace)

She also explained that although it is painful for her to read the blogs, she hopes that it will get easier for her to visit in the future:

“So I look forward to returning to them, but not at the moment because it’s painful ... I don’t know if it will ever be not too soon” (Grace)

However, while Grace found visiting painful, others found them comforting. One of my participants – who had filmed their son’s funeral – described how she felt “captivated” when she watched the film:

“We are completely gobsmacked by the power of it, and the wonderment of it, and how new it feels every time, because everything we learn about what it’s like to be a bereaved parent. The film takes on a difference resonance and meaning, and it’s just extraordinary really and surprising ... you would imagine possibly we might not watch it, or we might leave the room and come back when it’s finished but it’s captivating” (Jess)

Listening to Jess describe how the film feels different – with new “resonance and meaning” on each watching – once again demonstrates how inherited digital memories are being experienced in a unique way by the bereaved. This uniqueness will be further discussed in Chapter seven.

Interestingly, analysis of the interviews revealed a pattern in how my DI participants felt guilty if their visits lessened over time:

“probably it was once a day, then it went to once a week, maybe once a month now, and that makes me feel a little bit guilty; that I’m not thinking about her as much ... not, not thinking about her as much, cause I think about her every single minute of the day. I don’t know if it gets easier, cause it doesn’t, you see I feel guilty now about not thinking of her” (Pam)

This feeling of guilt was also implicit in the interview with Jeff:

“should I be thinking about my brother more? Should I be crying more? Should I be thinking more than I am? I would say only in the last couple of years it’s been less, but it’s something that I don’t shy away from watching... so for example if someone said, ‘Hey, shall we watch it tomorrow?’ I’d be like, Yeah’.” (Jeff)

These quotations from Pam and Jeff demonstrate the struggle between what Schut and Stroebe (1999) describe as the oscillation between “restoration-oriented” and

“loss-oriented” states of bereavement. As highlighted earlier, the possibility that digital afterlives are disrupting the DPM model of bereavement will be discussed in Chapter seven.

Having interviewed 22 DI participants who had inherited Facebook pages, audio, bots and film from their deceased loved ones, I was surprised to hear how an image from Google Street View was a precious digital memory to one participant. Google Street View is an interactive feature within Google Maps which enables its users to see street level photographs which have been stitched together to produce a zoomable panoramic imagery of hundreds of cities across the world (Anguelov et al. 2010). At the beginning of this research, I did not expect to hear that Google Street View would be someone’s precious digital memory, however, Jeremy explained that before his mother died she told him she had been standing in the kitchen when she had seen the Google Street View car drive by her house. Following her death, Jeremy liked to visit the street view image, as he liked to imagine his mother in her kitchen, and he explained how this found image comforting. Interestingly Jeremy added,

“I latched on to the idea that by looking at the photo of my parents’ house that I could somehow keep her with me” (Jeremy)

I wanted to understand how often Jeremy looked at the image:

“Initially, I would look at the photo every other day, quiet moments when no one else was about. I do still look at it, I would say that even now I look at it probably once a fortnight, sometimes more” (Jeremy)

In an effort to understand if this digital memory held a special significance for Jeremy – that other memories and messages did not hold – I asked if he visited and treasured other photographs of his mother in the same way, and he explained:

“Strangely, it is only this photo on Google Maps Street View that affects me the way it does, I have asked myself why this is and I do not know the answer” (Jeremy)

In an attempt to understand what trigger his visits to the street view image, I asked him to describe what typically prompted him to view the page:

“It tends to be when my mind wanders, not necessarily influenced by good or bad emotions. When I am not thinking about anything else I end up thinking

about my Mum and in turn this leads to me looking at the image” (Jeremy)

Jeremy was the only participant to mention this type of digital artefact, but Maggie – who had inherited posthumous messages from her brother following his death – described how she felt when she watches the videos her brother had left for her:

“Yes, his videos are comforting to me. No set times as such, I find as time passes I don't feel the urge to watch them as much as before. It's great to know that they are available though at anytime” (Maggie)

NVIVO MEMO

Here, Maggie is assuming that these digital memories will always be available and they will not perish in any way because they are digital. This “foreverness” is not what I have learned by monitoring the SPs, and I am starting to contemplate how the loss of these precious digital memories and messages would affect the inheritors. I am beginning to understand how important these inherited digital afterlives are to the DI participants, and how they are being used in positive ways as a tool for grieving. These participants are all positive about the “immortality” of the digital afterlives of their loved ones. However, I am also interviewing others who are fearful of the longevity of their technical devices and the precious digital data they hold. I need to revisit the recorded interviews as I am starting to theorise about the potential harm to the bereaved if these precious artefacts are lost.

Charles’s wife had died the previous year when I interviewed him. Before she died she had created numerous blogs, videos and tweets. I asked him how often he visited these inherited memories:

“I do visit that page from time to time... ya know, it makes me smile, it makes me cry, it makes me reflect ... but it's nice that it's there and available for everyone to look at it. So yeah it's hard sometimes, but on the other side it's nice that those memories are there, because in this day and age it's nice because we can still have that” (Charles)

In the quotation below Charles talks about his wife’s digital messages being there “forever” for others to look at and remember his wife, demonstrating how grief and bereavement are social processes alongside personal experiences:

“Yeah, just re-memorise myself with what she, and we, were going through at the time, and look back on the year, and look back on the 5 years as well. And yeah, it’s certainly something that I will keep referring back to and you know it will be there for forever” (Charles)

The above quotations from Maggie and Charles reveal how there is an assumption that inherited digital memories and messages will be available in perpetuity via thanatechnology. In his interview, Noah also implies that he considers how the posthumous bot created from audio of his father, will live on in perpetuity:

“maybe every week or two I will ... I will ... talk to it. There was a period when it was even more, and, I also anticipate further in the future I am gonna want to do it more. There came a point where I was so familiar with it that, maybe I wanna just step back. But it’s nice ... it’s all in there, and it stays there ... and it’s accessible” (Noah)

The longevity of digital memories is important, as is having the ability to choose when to visit digital memories. This issue of being able to control access and timing, also forms an important part of the discussion in Chapter seven. Figure 45 below exemplifies not only the diversity of all of the digital artefacts that become precious possessions, but also the importance of control to ensure DIs can choose when and how often they want to visit their inherited digital memory(s).

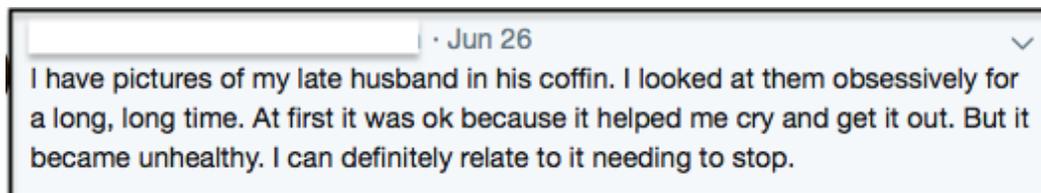


Figure 49 Screenshot of a reply to the James O’Brien tweet (used with the permission of the author)

I wanted to understand how the author of the above tweet came to have the photograph of her husband, and whether it was stored on a mobile phone. I sent her a direct message on Twitter to learn more:

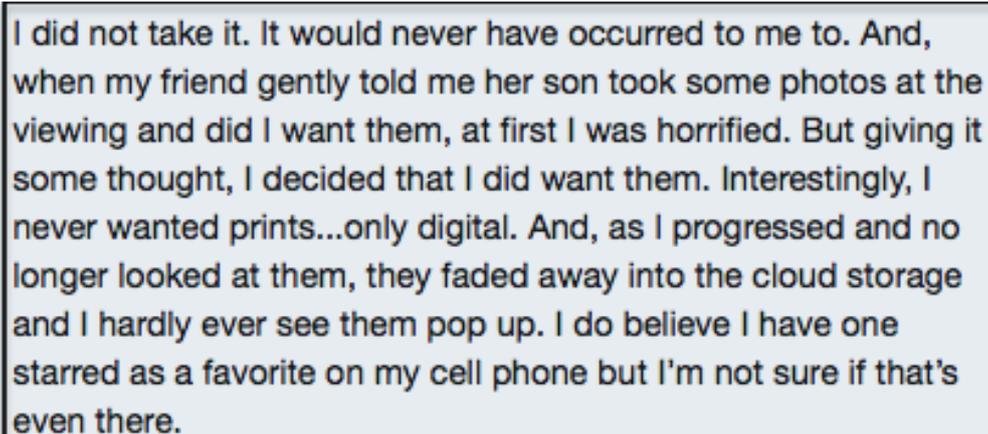
A screenshot of a tweet reply. The text is enclosed in a black rectangular border. The text reads: "I did not take it. It would never have occurred to me to. And, when my friend gently told me her son took some photos at the viewing and did I want them, at first I was horrified. But giving it some thought, I decided that I did want them. Interestingly, I never wanted prints...only digital. And, as I progressed and no longer looked at them, they faded away into the cloud storage and I hardly ever see them pop up. I do believe I have one starred as a favorite on my cell phone but I'm not sure if that's even there."

Figure 50 Screenshot of a reply to the James O'Brien tweet (used with the permission of the author)

The image below is a direct message from one of my Twitter followers following a pop up memory she received via her Facebook page. It clearly illustrates the need for the DI to be able to control the digital data from the dead.

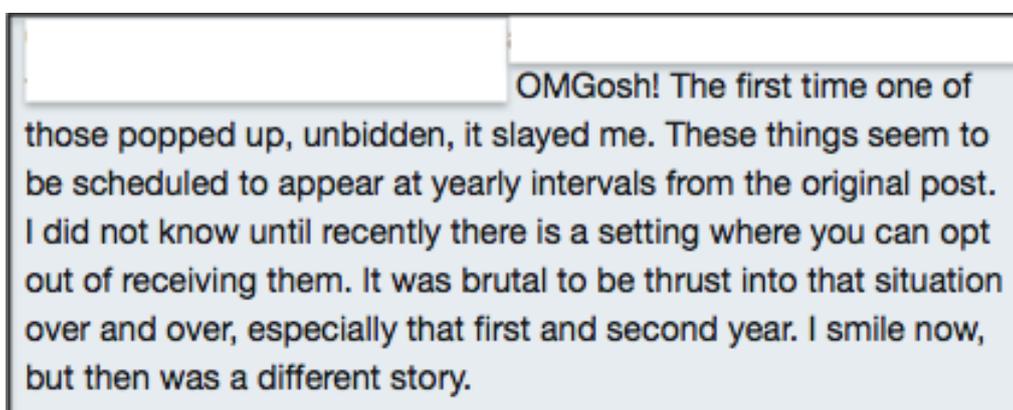
A screenshot of a direct message. The text is enclosed in a black rectangular border. The text reads: "OMGosh! The first time one of those popped up, unbidden, it slayed me. These things seem to be scheduled to appear at yearly intervals from the original post. I did not know until recently there is a setting where you can opt out of receiving them. It was brutal to be thrust into that situation over and over, especially that first and second year. I smile now, but then was a different story."

Figure 51 Screenshot of a direct Twitter message (used with the permission of the author)

Analysis of the data from the DI participants has demonstrated not only how often they visit their inherited digital artefacts, but moreover, what triggers them to visit on “insignificant” days, and the importance of being able to control these visits. In the next section of this chapter I explore whether digital memories and messages differ from physical memories and messages, in the way they are used and experienced by the bereaved.

6.3.3 The digital versus the physical

The phenomena of digital afterlives and the data of the socially active dead is being explored within this thesis. The question of whether the bereaved experience digital memories and messages differently than physical memories and messages is fundamental to this thesis, because if they are experienced differently then the social “norms” of grieving and existing models of bereavement may no longer be adequate for grief professionals, thanatologists and academics: in that they would not accommodate the impact of these digital memories and messages on the bereaved. I wanted to learn if my participants had physical memories and messages of their deceased loved ones – in addition to the digital memories and messages they had inherited – and whether they experienced them differently. In a follow-up email, I asked Jeremy about the Google Street View image he visits when he wants to imagine his mum in the kitchen of the family home.

“I have a number of traditional photographs of the front of my parent’s house, some with my mum in them and some without. None of these photos stir up the same emotions in me when I look at them, other than jogging the memory of what was happening at the time it was taken” (Jeremy)

My interview with Jess also revealed how, for her, digital memories were more valuable than physical memories:

“It’s not like a photograph ... like a photograph fades but, you know, a digital memory lives on and is sort of more permanent” (Jess)

This quotation from Jess suggests that she believes that a digital afterlife is everlasting and will endure in perpetuity. I asked Jess to clarify why she considered the digital memories more precious than a photograph:

“I treasure them as they won’t fade” (Jess)

This comment confirmed that Jess sees her digital memories and messages as everlasting in a way that physical photographs are not. However, this is not always the case: physical photographs can, in certain circumstances, “outlive” digital images.

Jeff also inherited a film of the funeral of his brother which was available online to him. During the interview he also mentioned there was a memorial tree for his brother which he enjoyed visiting occasionally. Jeff talked about the difference

between the memorial tree and the film of his brother's funeral:

"I would say it's far more emotive watching the film, I feel that this is where I feel a far more connection with my loss and the pain when I watch the film, in comparison to holding the trunk of my brother's tree ... I feel, I feel the film is more him" (Jeff)

The way Jeff described how he feels the film "is more him", once again illustrates how, for many of the participants, inherited digital afterlives are experienced as containing the essence of the deceased in a way that physical memories do not. I made a note of my concerns regarding this via NVivo:

NVIVO MEMO

Many of my participants experience the digital differently than physical memories and messages. I am seeing that they feel they contain more of the essence of their deceased loved one, and they make them feel more connected to them. The idea that for my participants digital memories are experienced as containing the essence of the dead will be a useful concept going forward which will need to be further interrogated. But it is an important concept. Interestingly, participants also view digital as more permanent than physical items, but this permanence is not what my SP findings show. This perception of permanence could be of real concern if digital memories and messages are deemed to contain the essence of the dead – this could be developed into a new concept about what happens if this precious digital data is lost or deleted.

However, not all of the DI participants felt that digital possessions were more important than physical possessions. Pam told me how the physical representations of her deceased daughter were more important to her than the digital ones she had inherited:

"I need to go every two weeks because I still speak to her when I go there, [to the grave] because I know her ashes are there, I know that's where she is lying, cause I've also got the gravestone with a picture on I can talk to her and that is more important. If I don't go on Facebook again you know it's not the end of the world" (Pam)

Similarly, during the interview with Amy where she described how she treasured the digital memories that she had inherited from her sister, she also told me about the importance of physical memories of her sister:

“Both physical and digital memories are of equal importance to me although I love most wrapping myself in her cardigan” (Amy)

In a follow-up email, Amy blurred the distinction between digital and physical memories; she told me how, for her, her sister’s digital afterlife is “a bit like Linus’ security blanket”. This idea of what I call a “digital security blanket” is a useful way to describe DI participants’ experiences of enduring digital memories.

NVIVO MEMO

I like this idea of a digital security blanket to describe what many of my participants are implicitly discussing about the way they experience digital afterlives. This illustrates the importance of these digital possessions and also illustrates how people become reliant on them as tools to help them remember the dead, and help them to grieve. I also like how Amy is describing digital possessions as something more physical – a blanket that can be wrapped around her to give her comfort. The potential emotional response to losing this digital security blanket is developing into a theory about how second loss (a digital loss) could be a problem in the future.

But what about when the physical *becomes* the digital? During this research I noticed that people were turning physical memories and messages into digital memories and messages. For instance, the tweet below is from the husband thanablogger Kate Granger who published images of the birthday card his wife had left for him before she died (to be opened on his birthday).



Figure 52 Screenshot of the tweet by Kate’s husband (used with the permission of the author)

The tweeting of this photograph rendered the physical into the digital, and importantly changed it from being a personal communication into a public one. The physical becoming digital is also evident when people visit graves and take photographs which they upload onto SNSs such as Twitter to let people know they have visited the grave site. Similarly, in my interview with Amy she told me how she had photographed the memorial apple tree, where her sister’s ashes are interred. Amy uploaded the photograph onto Facebook to be used on her sister’s profile page. At the time of publication this page is still “live”, and has not been memorialised. Amy told me how she was concerned about Facebook finding out about her sister’s death and memorialising the page which would take control of the page from her.



Figure 53 Screenshot of the Facebook profile photograph showing the memorial tree

As I have reflected earlier in this thesis, I possess only a few precious photographs of my dad, and during the last year of my research I received a photograph of him via email which I had never seen before. I think it was taken in the early 1950s near the Suez Canal in Egypt during his service with the Territorial Army (it had been changed from what must have been an original black and white image into a colour image). My dad died 32 years ago, when I was 23, and seeing this photograph appear when I opened the file on my smart phone, turned me into a digital inheritor and plunged me into my own research. However, I now have a digital image which has become a treasured possession.

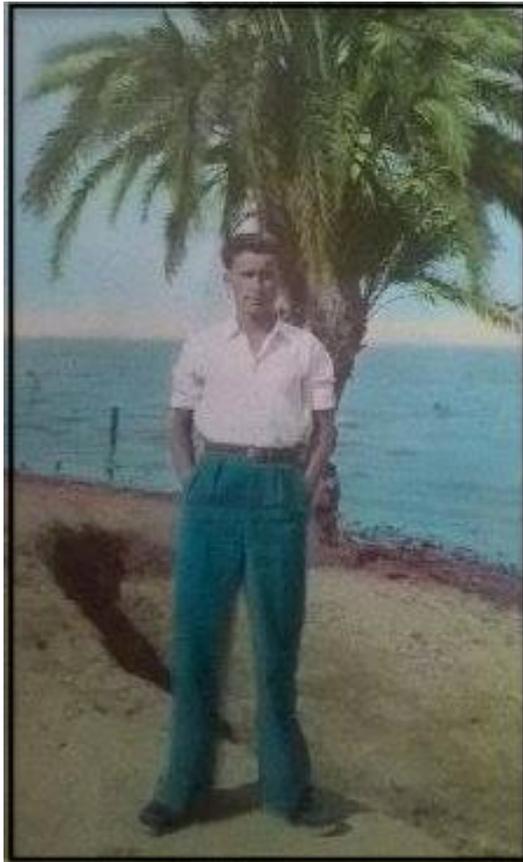


Figure 54 Screenshot of the image of my dad, Trevor William Greenwood

As technology changes and people digitally copy and store photographs, videos and audio messages and memories, this process may continue to alter how we view our physical possessions of the dead. The findings of this research show how digital memories and messages are experienced differently to physical memories and messages by the bereaved; in that, digital artefacts embody the essence of the dead in a way that physical memories and messages do not.

6.3.4 The comfort, disruption and confusion of digital afterlives

“So I now have them on the laptop, the laptop I’m talking to you on now and it’s the most treasured thing” (Amy)

At the outset of this study, I wanted to understand whether the bereaved would find the inheritance of digital afterlives a positive and comforting experience, or the contrary. As presented in the previous section, posthumous digital artefacts are being experienced in different ways to physical mementoes, however, I wanted to understand the specific types of digital memories and messages that participants are using as part of their grieving practice.

Surprisingly, it was not profound or purposeful messages that DI participants told me they find comforting, it was the everydayness of their inherited WhatsApp messages and text messages the bereaved spoke of so fondly. The fact that they contain nothing deep and meaningful was echoed through many of the DI's interviews. Everyday messages, such as "I'm ringing the doorbell", "Speak later" and "Do you need anything from the shop?", have been repurposed, and take on new relevance when a loved one has died. Interestingly, all my participants who had inherited WhatsApp messages and text messages from deceased loved ones have saved these messages in one form or another, with some purchasing third party software to archive them.

A common form of digital data is email. It is estimated that over 200 million emails are sent each day, so it is hardly surprising that reading past emails from those who have died would be discussed by many of my participants. Sophie told me she archived all the Gmail chats between her and her mother (who had died the previous year). In one email, when she was away from home her mother wrote:

"I'm there in spirit baby girl" (Sophie)

Sophie explained how she reads this particular message more than any other message from her mother because it brings her comfort and helps her feel that her mother is still close in times of change or turmoil.

Considering other forms of written messages, Sandra described how it is the visual pattern of the text conversations with her father which she finds most poignant: from the one word replies to her texts when he started to get used to the new technology, to full conversational texts, and then the return to the one word replies during his final weeks. She explained that, to her, the pattern the messages make on her mobile phone graphically illustrate the "gradual erosion" of her father.

Sandra had also inherited a LinkedIn profile of her deceased aunt, and she explained that as there is no photograph of her aunt on the site, she only sees an outlined shadow – "it is a shadow of the dead" she told me (the use of the word shadow here

is specific to LinkedIn due to the icon which represents users who have not uploaded an image).

“As well as knowing he’s dead there is a sort of a need, not often ... sometimes the need to communicate with his sense of presence” (Grace)

During the interview Grace she went on to explain how the digital messages she inherited following the death of her husband contained, “a sense of his aliveness” (Grace). And Amy also spoke of how inherited digital memories made her deceased sister feel “present” and allowed her to “feel connected to her”. Sophie made a similar comment in a follow-up email where she spoke of how digital memories and messages “makes them feel not so far away”. This co-presence of the dead in our digital society and its impact on the bereaved along with the implicit suggestions of continuing bonds theory will be discussed further in Chapter seven.

During my interview with Riann, she talked about how she experiences the texts messages between her and her brother differently than Facebook posts. I asked her why she felt this way and she explained, “It’s because it’s private”. I wanted to know more about this distinction so I asked her to expand on this point:

“If we did write on each other’s wall that would always have been public... it’s not really... and then we would always have been probably a bit more formal like if he wrote on my Facebook for my birthday he’d probably say happy birthday sis ya know kiss, so it’s ... just little things where it’s more personal” (Riann)

Riann went on to explain that, for her, “Facebook is a performance” and she is aware of how she “carefully constructs” what people read, she goes on to explain:

“That is my public image of my grief, and what people share on [his] Facebook page is theirs ... what they want people to see of their grief” (Riann)

6.3.5 The comfort of knowing others care

During the interview with Ivor I asked him specifically what type of message he gets comfort from reading, he told me:

“When I see people leaving random messages saying things, thinking about you, thought about you today, remember when we did such and such ... all

that sort of thing” (Ivor)

It is the everydayness of messages such as this one that the bereaved take comfort from as such messages demonstrates that others are still thinking of their loved one. The extract below from Jeff echoes this:

“But I think one of the key positives for me and I think, grieving and using digital memories and things like that is the ... through the sharing process for example on Facebook and social media there has been a really strong connect with his friends” (Jeff)

Condolence cards are normally sent following a person’s death, however, SNSs such as Facebook enable the bereaved to read messages to their loved ones left by others for many years following the death, which is unique in our digital society.

“Something I find really comforting is reading how much he meant to other people and I wouldn’t have access to that if it weren’t for Facebook” (Riann)

The findings of this research demonstrate the general usefulness of Facebook as a grieving tool for DIs participants, as my interviews with Sophie and Emma demonstrate:

“I’d also spoken to a couple of my mum’s friends who said it was actually quite comforting to just have her Facebook there, because they just, ya know, they just felt that it was a piece of her still there online kinda in digital form” (Sophie)

“I felt he was sort of being frozen in time and memorialised for how he died and how he’d devastated us all by leaving. But then I also found it helpful to write to him” (Emma)

However, as Charles explains, although it can assist people in their grief inherited digital messages by no means lessens negative experiences for the bereaved:

“to be able to have that in your life is, is great and I certainly think it helps with the grieving process but you know grief is hell” (Charles)

The disruption and confusion

Whilst most of the DI participants experienced comfort from the inheritance of digital afterlives, some participants found their inheritance painful. Grace found the inheritance of digital memories and messages disruptive, and during her interview she explained how they made her forget that her husband had died. She shared with

me that thoughts such as “maybe he didn’t die” caught her out when she received a notification “ping”, which for her was a “painful dislocation”. Similarly, Ali also echoed being caught out by this feeling of hope:

“When you know someone is gone and their name pops up, feels like a tease as though they are still alive” (Ali)

During my interview with Grace she explained that her husband had a profession which she had felt she was not a part of, as she was at home looking after their children. She had always hoped that once their children were older she would be able to join him on some of the overseas trips he took, and learn more about and become more involved with the parts of his life that she had not known. This may partly explain why she finds the digital memories more disruptive than the other DI participants, as perhaps she feels they make her even more detached from her husband’s “other” life. Moreover, the Facebook posts and YouTube videos – created by his work colleagues following his death – may remind her of a future she will now not be able to have.

NVIVO MEMO

I have realised that I expected to find more participants who experience digital afterlives in a negative way. These preconceptions may have been influenced by my initial literature review. However, as the bereaved get more used to the dead being on everyday digital devices perhaps they will continue to become an important part of grieving. Looking back at the dates of some of the research it may be interesting to see if there has been a change during the course of this study in the language used by my participants to discuss the dead on SNSs. Here I am thinking about whether thanatechnology is affecting Mori’s uncanny valley.

Even though Grace explained the pain she felt when reading inherited digital memories, she went on to express her hope that one day she will be able to read her husband’s blogs without feeling pain:

“you know he was a philosopher, so I ... so I find them useful as examples when I’m negotiating the world ready to go back to ... so I look forward to returning to them ... but not at the moment” (Grace)

The following quotation from Jeremy also illustrates the complex feelings experienced by some who inherit digital afterlives:

“Whilst this online image has, in its own way, helped me with the grieving process (absolutely no doubt), perversely, I think it has also prolonged the grieving process” (email correspondence from Jeremy)

These words resonated with how Sandra described her confusing feelings about the digital memories and messages she had inherited:

“It’s ridiculous that I think she’s still there. Why is she still there? Ya know, and there is, there is definitely still a tension for me about that” (Sandra).

Following transcription of the interview with Sandra, I wanted to understand more about her decision to visit the digital memories she had inherited:

“It depends on my mood sometimes I had images of dad in his last weeks incredibly sad and reminds me of how difficult that time was because we could not access the right support services. Otherwise it is lovely to see him looking happily walking on the beach and with our dog!” (email correspondence from Sandra)

During the interview with Ivor he made a poignant point about this complexity:

“Facebook is great ... most of the time it’s great, but there is this thing when you’re grieving that you, have to manage it and you have to, accept that sometimes, it will warm your heart, and other times it will blow you ... Just, you know, knock you down, you’ll feel like you’ve been punched” (Ivor)

The notion that the same inherited digital memory can be described by the same participant, as being able to “warm your heart” but also be capable of making you feel as though “you’ve been punched” clearly illustrates the unique and conflicting experience of the phenomena of digital afterlives. Once again there were examples supporting this idea of conflicting emotions linked with the inheritance of digital data in the replies to the James O’Brien tweet:

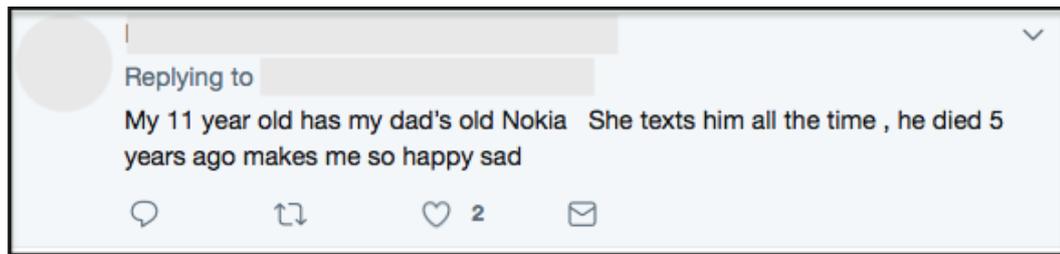


Figure 55 Screenshot of a reply to the James O'Brien tweet (used with the permission of the author)

6.4 The link between access and control

Friends of the deceased who are not family are often referred to as disenfranchised grievers (Doka 1999); however, here I illustrate how when a child dies – especially a young adult – the parents who are the traditional primary mourners, sometimes feel isolated when friends take on the role of primary mourners by setting up special memorial Facebook pages. During a conversation with a recently bereaved parent, the mother explained how the lack of condolence cards following the death of her son had left her feeling isolated: “our mantle is empty,” she explained. When she spoke to one of her son’s friends at the funeral he explained that other friends had set up a Facebook page, and there were hundreds of messages on the page, with friends telling wonderful stories about their son and some leaving messages addressing them as parents. But she explained that she did not have access to Facebook and therefore was not part of this group. This anecdote demonstrates how a lack of access to digital memories and messages can result in the reordering of the taken for granted hierarchy of mourners.

In this subsection, I wish to ask: Do digital afterlives provide comfort or disruption to the bereaved? The findings of this research illustrate how this question is a complex issue, moreover it is deeply entangled with the theme of control. Coding and analysis of DI’s interviews showed that 21 of the 23 DI participants (or 91%) mentioned issues of data control when discussing their feelings towards digital memories or messages. Participants who feel in control of the data; that is, those who have passwords or access to videos, messages, platforms and pages, described finding comfort in the shared memories; whilst those who do not have passwords or access (e.g. due to technical obsolescence) or where they are not the creator of the memories, described feelings of disruption to their grief.

It is important to acknowledge that grief and bereavement are complicated emotions, especially when families are estranged. I interviewed Chloe following the death of her estranged father, and she shared some of the direct messages between her and someone who had posted messages on her deceased father's Facebook page which Chloe found upsetting:

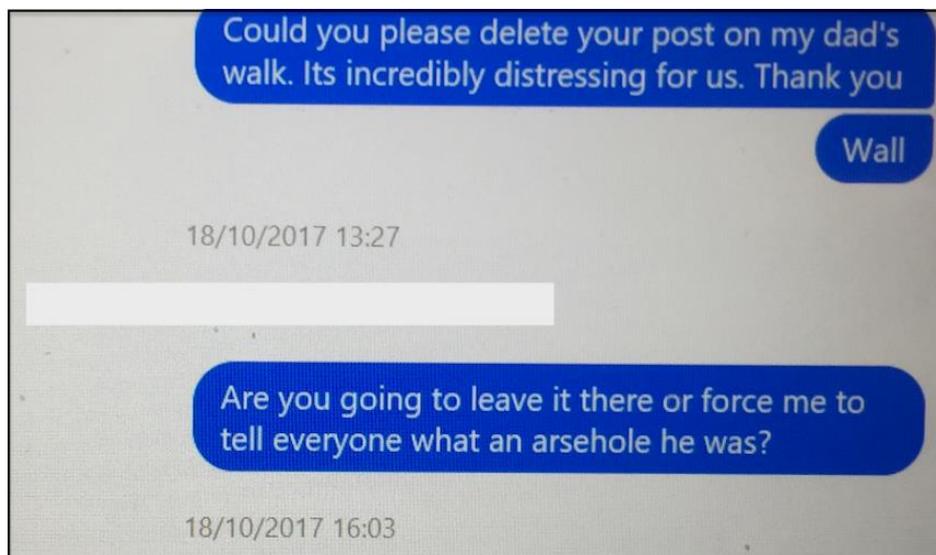


Figure 56 Screenshot of a private Facebook messages provided by Chloe

Chloe explained that she was distressed because her father had left her family when she was young. Moreover, she did not control her father's Facebook page and other people were discussing her father's death on Facebook when she had only just found out herself. She explained:

"I was really, struggling with the fact that somebody else had announced this publicly to the world ... cause it really is to the world". She went on to add, "so I do think as his daughter or a wife should be able to control what goes on there" (Chloe)

Similarly, Pam whose daughter and ex-husband had both died and left Facebook profiles discussed a further example of the complexities of estranged families and how the inheritance of digital afterlives can be problematic. Although Pam had found her daughter's Facebook profile – which she had control of – comforting, she found her ex-husband's Facebook page distressing to her and her son as they did not have control of the page:

“His girlfriend was messaging people from his account and that was very hurtful ... for everybody, you know you get a message from your dad when you know ... he’s no longer there” (Pam)

Access and control were a recurring theme throughout most of the interviews, with participants describing the importance of either possessing it or not possessing it:

“I closed my husband’s Facebook profile as people kept messaging on it and it was very upsetting” (Sharon)

“I can’t, just can’t get into her Gmail account, which is really upsetting because I like ... I would like to you know... to have access and to keep the photos” (Amy)

Sophie had decided to delete her deceased mother’s Facebook page, although she told me she was glad it is not permanently deleted as she was comforted by knowing she could switch it back on at some time in the future. Grace also mentioned control when discussing the possibility of turning her husband’s existing Facebook page into a memorial page:

“I think a memorial site would work, you know a memorial site would work for that, because see you would have control ... you know it would be ... the stuff on there ... would be stuff to support and comfort rather than ... that dislocation” (Grace)

I interviewed Grace in October 2016, and her husband’s Facebook page has since been memorialised.

6.4.1 Losing the data of the dead

This link between comfort and control became a core theme around which much of the data from my DI participants revolved. Access and control of digital memories and messages by the bereaved are important issues for those who inherit them. I began to see a pattern in how my participants were describing feelings of anxiety when discussing how they would feel if they lost – or could not access – the data from their loved ones. Amy explained that she had purchased specialist software to access and save audio messages from her sister:

“I don’t know what I would do without it, I think I would be in a much ... darker place. So I now have them on the laptop, the laptop I’m talking to you

now, and it's the most treasured thing” (Amy)

In order to further develop this category, I followed the grounded theory method of constant comparison to develop this emergent theme of second loss. During my interview with Amy she explained how she felt when she thought the digital memories she had inherited, following the death of her sister, had disappeared:

“Last year, I had two incidents where electronic items for keepsakes were lost or almost lost. Both times I had a proper meltdown and couldn't stop crying for a long time. The last incident happened in John Lewis and strangers were present. But to me they didn't exist at that time. Just my panic at losing memories and [her sister] all over again” (Amy)

Similarly, other DIs described similar experiences, and told me how the experience of losing digital data would be experienced in a similar way to the biological death of their loved ones:

“I can't lose her again” (Pam)

“I would be devastated, it would start my grief all over again” (Sandra)

As the screenshot below demonstrates, some who have lost precious digital messages, describe it as a painful experience:



Figure 57 Screenshot of a tweet (used with the permission of the author)

All but one of the DI participants discussed the anxiety they would feel at the loss of their inherited digital memories and messages. Following the process of constant comparison I found a negative case within my data which contradicted the pattern I was seeing elsewhere in my dataset. In an attempt to test my emerging concept of second loss I asked Jeremy – who had not explicitly or implicitly mentioned second loss – how he would feel if Google updated the street view map he cherished. He was more philosophical about the effect this would have on him:

“I have thought of this previously, I think it might help me make another step forward in dealing with the loss, I would definitely feel sad, but accept that it will happen at some point. I haven't copied it, never thought about doing that

and thinking about it now I still do not want to” (Jeremy)

Charmaz discusses the importance of negative cases in grounded theory research (2014), stating that if negative cases emerge from the data (rather than being *imported* into the data) then the coded category may need refining. However, because this inherited digital memory from Google Street View differed from the other types of digital memories and messages that had been inherited by the other DI participants – and because it was the only case I found where second loss was not feared – I concluded that second loss was still a robust category. This resonates with Corbin and Strauss’s idea (2008) that a negative case can also be an indication of “a dimensional extreme or a variation on the conception of data”.

This emerging theme of second loss, and a new theory regarding the anxiety it produces for the bereaved will be further conceptualised in Chapter seven, where I will present my theory of the Fear of Second Loss.

In this section of the chapter, I have presented my findings around the four themes of: (1) The voices of the dead, (2) Timings, frequency and triggers, (3) The digital versus the physical, (4) The comfort, disruption and confusion of digital afterlives. I will now move on to discuss how my data supports the notion that the digital persistence of the dead and thanatechnology is changing the landscape of Mori’s uncanny valley – an unexpected finding of this research.

6.5 The changing landscape of the uncanny valley

My research explores how inherited digital memories and messages from the socially active dead affect how people grieve, and how people react to Internet ghosts (Cann 2014) and digital zombies (Bassett 2015). In 1970 the Japanese roboticist Masahiro Mori coined the term “the uncanny valley” to describe people’s reactions to robots that resemble humans too closely. He found that people liked robots that only displayed a few human characteristics, as this allowed them to fill the gaps with their imagination. However, Mori noted that the more human-like the robots became, the creepier people found them (Mori 2012). This idea was supported in 2004 with the release of the Warner Brothers film “The Polar Express”, a CGI animation film.

Critics commented that the film made them feel creepy as the too human-like characters appeared “soul dead” (Clinton 2004). According to Freud writing in 1917, this notion of the uncanny is linked to death and dead bodies and “all that arouses dread and creeping horror” (Freud 2004). In the not too distant past, the dead popping up on social media platforms seemed to echo this uncanny valley response.

In their 2010 study into bereavement and technology, Odom et al. (2010) describe how participants were shocked at the dead “popping up” on social media sites. Other research supports this finding (Marwick & Ellison 2012; Massimi 2012; Pennington 2013). It was only in 2013 that Brubaker et al. (2013) described how the bereaved found “new encounters with the dead” on social media platforms distressing, describing these encounters as “startling”. In addition, Walter et al. (2012) thought that the dead leaking into everyday life may be problematic. However, the findings of this research suggest that in the relatively short amount of time since these papers were published, people seem to be getting used to the dead popping up on the Internet. To fully explore this emergent theme I conducted a review of published papers where authors mentioned the words participants used to describe feelings of unease at seeing messages on social media platforms to and from the dead. I compiled a list of words used, such as “weird” (Massimi 2012; Brubaker et al. 2013; Pennington 2013); “gross” & “odd” (Brubaker et al. 2013); “pop up” (Odom et al. 2010; Marwick & Ellison 2012); “strange” “shock” and “disturbing” (Odom et al. 2010); “creepy” (Odom et al. 2010; Braman et al. 2013). I then added other words to the list (including stemmed words), which could also be used to describe feelings of unease (see the table below). Selecting my DI participants I ran a text search and word frequency query from within NVivo and noted the date each interview took place. I crosschecked the findings of the query with extracts coded to the uncanny valley theme to ensure they had been used in context.

	Year 1	Year 2				
Digital Inheritors	Grace	Sandra	Ali	Maggie	Dan	Pam
Uncanny	x					
Eerie						
Creepy						
Weird					x	
Strange		x				
Ghost	x					
Spooky						x
Odd	x					
Catch you out	x					
Pops up	x	x	x			
Shock				x		
Unpleasant						
Scary						
Horrifying						
Alarming						
Horrible						
Macabre						
Disturbing						
Freaky						
Ominous						
Gross						

Table 6.2 DI participants' "uncanny" word frequency

Findings showed that in the first year of this 3-year study, 5 (55%) of my participants used one or more of the words on the list (in the context of the uncanny valley) this dropped to 1 (25%) in the second year interviews, and 0 (0%) in the third year interviews. The following quotations from Grace and Pam are typical of the interviews conducted in the first year:

I mean I know that ... and it's like some sort of spectral ghost ... controlling the future in a uncanny and difficult way" (Grace)

He just messaged you ... what? ... how spooky well that's not actually quite

true” (Pam)

By year three of the study, none of my participants used any of the words on the list, indicating a shallowing of the uncanny valley. However, not all human-computer communications with the dead are being normalised: digital zombies are the reanimated socially active dead on social media platforms – those who do in death things they did not do when alive (Bassett 2015). In a 2013 paper, Alexandra Sherlock discusses these “posthumous representations” and how dead celebrities are being used in advertisements (Sherlock 2013). A contemporary example of this is Audrey Hepburn being used to advertise Galaxy chocolate. This dualism of being dead whilst virtually alive, and crucially socially active, can be seen in companies such as Eternime, who offer to create an avatar of you when you are alive so that you can “give advice” to future generations after you die. These digital zombies still generate a feeling of unease and it may be what Bollmer calls the “near full representation of the authentic identity of the human being” that people find disturbing (Bollmer 2013).

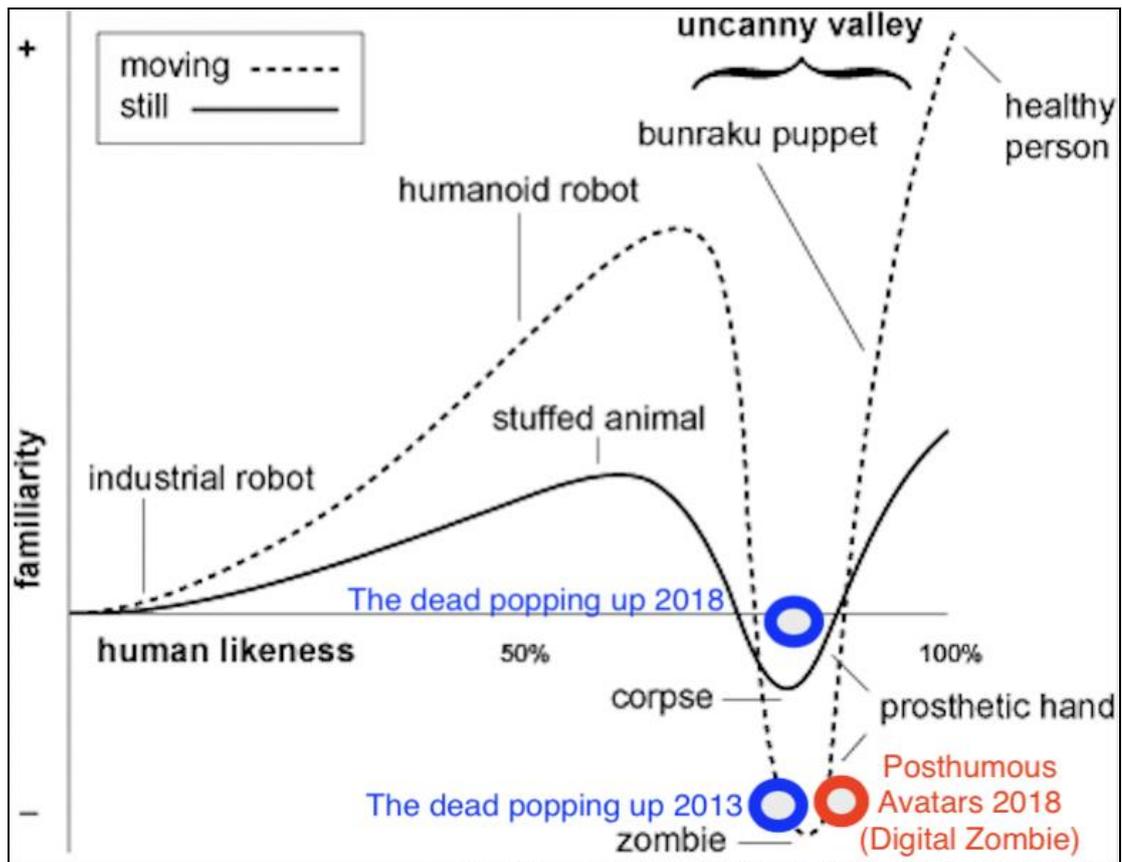


Figure 58 Updated figure of Mori’s original idea of the uncanny valley.

Source: Original figure Mori IEEE Robotics & Automation magazine 2012

Using an illustration of Mori's uncanny valley, Figure 54 incorporates the results of this current study to illustrate that in the three years since 2015 there has been a change in people's perception of the "creepiness" of the dead "popping up" on the Internet, resulting in a change to the landscape of Mori's uncanny valley. However, these findings have obvious limitations in that this is only one, relatively small, study and further research is needed to support or refute the claims suggested here.

In 2018 I interviewed Noah, a DC participant who had created a chatbot of his deceased father. Noah used the audio recordings from oral history he had produced when his father was alive, to create his Dadbot. Interestingly, Noah's father was aware of the Dadbot before he died, and heard his wife communicating with the virtual version of himself. I asked Noah about how much he has changed or added to the Dadbot since its initial creation:

"I can always add new little anecdotes for him to share, or new varieties of ways for him to express whatever he already talked about" (Noah)

Noah explains that he can work on the listening side of the Dadbot and improve how the bot reacts to what he or someone else says to it. But importantly Noah explains why he feels there is a "line", which he does not want to cross for fear of falling into the uncanny valley.

"In the process of creating the Dadbot ... I was always wanting it to be ... better and better and better ... you know with more ... knowledge and ... better able to respond ... and more of my father's signature vocabulary ... so I always wanted to improve it ... but then at the same time there is this kind of weird ... I know there is a line ... out there where ...that it would somehow get ... too good and then ... I would be in the uncanny valley place ... that it was creepy that it was becoming almost like my dad but it wasn't really him and ... I've struggled with ... been asked ... you know where is that line ... like what would ... what if you could do him as an animation and what if you could have a synthesis of his ... real voice ... and ... I knew ... I know that's a line out there and when I think about an animated version of him for instance that just gives me the creeps ... personally" (Noah)

This interview with Noah was conducted in the early part of 2018, and although my findings indicate that the "uncanny" and "creepy" vocabulary has almost disappeared

from discussions around the dead popping up on social media platforms, Noah's interview suggests they could once again be used when discussing the possibility of the creation of fully animated avatars of the dead. The notion that the context in which these "creepy" words are being used has changed, is further supported by a quotation from a DI participant from an interview conducted in 2018:

"Any new messages generated by AI would seem like some sort of zombie message, it would just be too creepy" (Riann)

In this section, I have presented findings from this research which indicate how thanatechnology which enables the dead to be posthumously persistent (Kasket 2012a) and importantly socially active, is changing the landscape of Mori's uncanny valley

6.6 Conclusion

The impact of inheriting precious digital memories and messages should not be underestimated, and the following quotation from my interview with Riann exemplifies this impact:

"Facebook almost controls the way I grieve – what I see and when, seeing things other people tag him in, my dad finds it unbearable and yet can't delete his account in case he misses something ... and this is for someone who isn't even alive to update the account" (Riann)

In this chapter, I have presented the findings from my DI participants in order to highlight how digital memories and messages are being used by the bereaved, and importantly, how they are deemed to be precious digital possessions. The findings from the three data chapters – which were grounded in the collected research data – used the participants' quotations to support and present the themes that emerged from the data. Collectively the three data chapters move this thesis closer to meeting the aims and objectives of this research.

In the next chapter, I will synthesise the overarching concepts of this thesis and present an analysis and discussion of the findings from the data chapters, before moving on to present my theoretical conceptualisation of the theory of The Fear of Second Loss. I will then insert my findings into the wider literature, in order to

reconcile this new theory with other existing theoretical frameworks. I will also discuss how thanatechnology and the inheritance of digital memories and messages are changing the social “norms” of bereavement in our digital society, and how these changes are disrupting existing models of bereavement.

7 Chapter Seven: Discussion – Remembering and Forgetting

7.1 Introduction

“A theory states relationships between abstract concepts and may aim for either explanation or understanding” (Thornbery & Charmaz, 2012 in Charmaz 2014, p228)

In the three previous chapters of this thesis I presented findings from: (1) Service Providers, (2) Digital Creators, and, (3) Digital Inheritors. The focus of this chapter is to synthesise the findings from these three distinct categories of participants within the existing literature, and to present a new theory grounded in the current data. The aim of this thesis (see Chapter one) was to assess if the nascent phenomena of digital memories and messages enabled by thanatechnology, and inherited by the bereaved, are disrupting existing models of bereavement. In order to reach this aim I developed three main objectives: (1) To develop an in-depth understanding of the motivations of the people who created digital afterlife service platforms (SPs); (2) To develop an in-depth understanding of why people are creating digital memories and messages to be left posthumously or memorialise the dead (DCs); and (3) To develop an in-depth understanding of how people experience the inheritance of posthumous digital memories and messages enabled by the Internet (DIs).

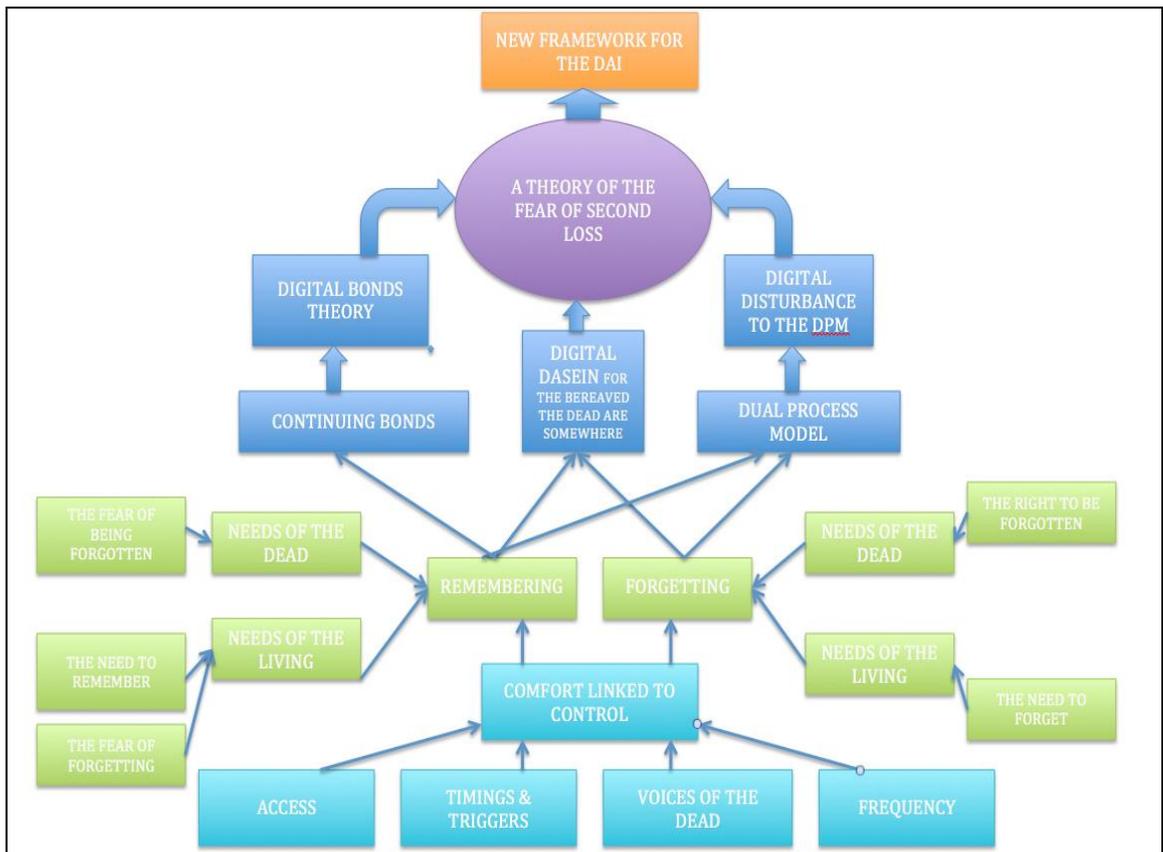


Figure 59 The relationship between the main categories

Following a constructivist grounded theory approach; Figure 55 is an integrative diagram (Strauss 1987) demonstrating the relationship between the main categories developed from the data. The figure shows how the categories have contributed to the development of the theory of “the fear of second loss” which is presented later in this chapter. In addition, the diagram also provides a roadmap for this final discussion chapter. Using the voices of my participants and my own interpretation, I will place this research within the existing literature to discuss how the inheritance of digital memories and messages enabled by thanatechnology is being experienced by the bereaved.

In this chapter, I start by looking at the complex issue of remembering and forgetting the dead, before proceeding to look at how the theme of control has provided the foundation to this research. I will then move on discuss how endurance may be a better way to describe digital memories and messages inherited by the bereaved rather than the term immortality. I then posit the question of where the dead reside

before presenting a new theory which has been developed from the data: the theory of the fear of second loss. The aim of this research was to understand whether inherited digital memories and messages would disturb existing models of bereavement, and the following two sections of this chapter address this issue by presenting an expansion to the dual process model of bereavement and an addition to the existing theory of continuing bonds. Finally, I conclude this chapter by calling for a new code of practice for the digital afterlife industry (DAI), one that prioritises the needs of the bereaved before the needs of SPs or DCs.

7.2 Remembering and forgetting

“If there is one thing this brings, it’s positivity and understanding, not expecting messages back, just need this, never forgetting” (Pam)

Thanatechnology is changing how we remember the dead, and this thesis has explored the effect this is having on both those who create, and those who inherit digital memories and messages. Whether to remember the dead or not was once a private matter, however, nascent human-computer technology is amplifying the fundamental tension between remembering and forgetting in our digital society. In addition, the once private decision about how we remember the dead is caught up with the legal policies of some of the largest companies in the world. This section discusses the problem with existing company policies, and also examines the complexity of remembering and forgetting concerning the creation and inheritance of digital memories and messages enabled by thanatechnology.

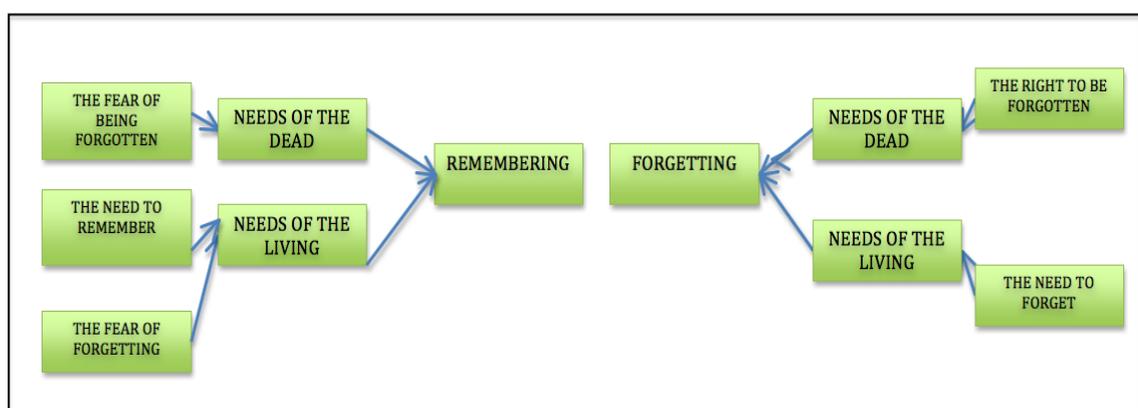


Figure 60 the complex relationship between remembering and forgetting the dead

Because thanatechnology is enabling memories and messages to be stored electronically, whether we choose to remember or to forget is no longer simply a private matter: these precious digital memories and messages are caught up in the terms and conditions of the SPs. Since the introduction of the 2018 General Data Protection Regulation (GDPR), organisations are required to use “clear and plain language” in their terms and conditions. However, these terms and conditions do not legislate for the data of the dead. Legally, however, the dead do have certain rights: for example, they cannot be libelled but do have rights of reproductive liberty (Smolensky 2008). Whether there should be specific legislation for the data of the dead is a complex issue as, as discussed in Chapter one of this thesis, the data of the dead could refer to digital legacies, such as digital assets and/or digital memories and messages. Yet many users do not read the terms and conditions of their SNSs (Kasket 2018) which can be a problem when they are interested in accessing posthumous digital memories and messages which they perceive to contain the essence of the dead.

In Chapter four I discussed how the “quest for immortality: was the only theme coded from my digital posthumous message creator participants, and how these messages could be seen as an attempt by the creator to not be forgotten. Interestingly, none of these digital posthumous message creators were coded under the theme of “benevolence” which could indicate that these types of digital messages are, in some ways, a selfish act. One of my DI participants explained that she takes comfort in seeing how brave her husband was when facing imminent death through his recorded video messages. And how she felt relief that it seemed to give him comfort, although she still found it painful to watch the video and hear his voice. She explained how she talked about her husband everyday, and preferred this as a way to remember him, rather than the video message he had created; interestingly, she added that she is convinced that this will change over time. DCs who record digital messages to be delivered after their death want to be remembered, but this begs the question of why they chose a digital format in this attempt at immortality? It could be due to the ease of the process, it could also be due to the accessibility of technology needed to create messages. However, I suggest that they may regard posthumous digital memories and messages as a permanent record. Problems with this notion of the permanence of data stored on the Internet will be discussed later in this chapter, but, as others

suggest, historically people have always used the technology available to them to remember and memorialise the dead (see Walter et al. 2012; Wallace et al. 2018).

Findings from my research showed that some of my DI participants were frightened of forgetting the voices of their loved ones, and for some, the desire to reconnect with their grief was an important part of grieving. The ability to remember the emotions of grief through the use of digital memories and messages seemed to go some way to satisfy this desire – here I am thinking about the rewatching of funeral films and listening to the voices of deceased loved ones: Maggie told me:

“I like to watch them occasionally so I can be sure of remembering their voices. One of my fears when my parents died was not being able to remember their voices” (Maggie)

For some participants it was important to listen to the voices of the dead when they were having a good day, but for others it was the opposite: as discussed in Chapter five, hearing the voices of the dead evoked different emotions for different participants and, importantly, to other forms of digital memories and messages. Listening to the voices of the dead clearly demonstrates the complexities involved with forgetting and remembering the dead.

Policymakers and lawmakers will be debating issues around privacy and rights on the Internet for many years to come, and it is outside the scope of this thesis to rigorously debate this issue. However, existing laws around privacy and rights do not fit well in the digital realm, including the data left behind when someone dies. Ongoing debates around the rights of the dead versus the rights of the living, such as whether the living have an obligation to remember the dead and ownership of posthumous digital data, are complex and these issues may never be fully addressed to everyone’s satisfaction. The technology to enable a digital afterlife already exists, but the policies and laws needed for this specific dimension of human-computer interaction will take time. In the meantime, a new voluntary code of conduct may be useful, and will be discussed later in this chapter. The theme of forgetting and remembering explored in this chapter is woven throughout all of the following

sections of this discussion chapter as it is the very *raison d'être* of our continuing relationships with the dead.

7.3 The importance of control

Findings from DI participants presented in Chapter five, highlighted how control and comfort are inextricably linked when it comes to the inheritance of digital memories and messages. Those who have control of this precious data are comforted by them, and use them as tools to help them grieve. Here it is important to acknowledge that this thesis is firmly contextualised within the theories of Continuing Bonds (Klass et al. 1996) and Growing Around Grief (Tonkin 1996); in that, grief is not something to “get over” or something you can “move on” from by doing grief work. The death of a loved one fundamentally changes the lives of the bereaved as they attempt to adapt to a changed life that includes their grief. As presented in the previous chapters of this thesis, the findings of this research show that the inheritance of digital memories and messages can be a useful tool for the bereaved who have access to and control of them.

In 2015, Facebook (an accidental posthumous service provider) attempted to address concerns about control and digital inheritance of profile pages with their legacy contact option. As discussed in Chapter three of this thesis, a person’s designated legacy contact adopts a stewardship-based approach whereby they act *for* the deceased rather than *as* the deceased to make decisions and “judgment calls” (Brubaker and Callison-Burch 2016). Facebook was reacting to pressure from bereaved relatives and friends who were requesting access to the Facebook account of deceased users. Many friends and relatives were keen to view and download photographs of their loved ones; however, once Facebook is made aware of the death of a user the account is locked and cannot be accessed. Since the launch of the legacy contact option, once the account is memorialised, the nominated legacy contact can write new posts on the memorialised timeline, add new friend requests and update the profile picture and cover photo or delete the profile entirely. More recently, in April 2019 Facebook launched a new “more supportive” feature for memorialised accounts called “tributes”. This new feature uses AI to stop deceased

loved ones from “appearing in painful ways” and also gives legacy contacts additional control allowing them to moderate the posts, and change profile pictures on the pages they are stewarding (Facebook 2019). It should be noted, that accidental posthumous platforms such as Facebook are designed for the living and are therefore continually trying to keep pace with the design and the incorporation of TSD features on their sites. So while this is another positive step from Facebook, the effect certain features such as tribute have on how the bereaved feel about the amount of control they have over digital memories and messages, is an area that needs further research across multiple disciplines in order to monitor their effectiveness in mitigating problems for the bereaved.

This research has demonstrated the link between comfort and control. However, when it comes to the voices of the dead, these are experienced in a more complex way, and DI participants are divided in whether they find comfort or not in listening to audio digital memories and messages (see Chapter five). Other recent research supports the notion that audio triggers different emotions to those triggered by other digital memories. Oliver Clabburn’s 2018 study into the creation of digital legacies by suffers of MND and their subsequent inheritance following the death of a DI, found that audio was “the most emotionally evocative aspect of the recordings” (Clabburn 2018). However, Clabburn’s research found that these recordings provided comfort to his participants, even though they reminded them of their grief. Similarly, Brewer and Sparkes (2011) suggest that for some children, listening to the voice of their dead parent can help establish a continuing bond. Knowing that for the bereaved the choice of whether or when to listen to the voices of the deceased is a dichotomous issue, emphasises the importance of giving control to the bereaved when dealing with posthumous audio digital memories and messages. Even for those who find audio digital memories and messages comforting, choosing whether to “listen on a good day” or “listen on a bad day” can be a difficult decision as this research has demonstrated.

Messages recorded and stored on intentional posthumous sites, to be delivered following the death of the creator, contain audio. They are also uncontrollable (by the bereaved) which based on the findings of this research presented in Chapter six, poses a further problem. Careful consideration should be given to the issue of control

by platforms offering these services in an attempt to mitigate the potentially harmful affect these timed messages may have on the bereaved. As discussed in Chapter three, even people who would not want to receive posthumous digital messages would feel compelled to watch them if they existed. The theme “unintended consequences of posthumous timed messages” presented in Chapter four, is inextricably linked to the theme of “control”. Therefore, I argue the bereaved should be given control of the timings of these messages and, importantly, should be given the option to view all timed messages at the time of inheritance.

The notion that the bereaved possess control over whether wish to listen to these messages when they are delivered, is a point that echoed through my interviews with SPs, as the following quotation illustrates: “you can choose whether you want to view it or not, you will have to decide whether you want to go there and watch that movie” (Ron). Service providers assume DIs have agency; however, it is the DCs who have taken control of when these messages are viewed. Therefore, careful consideration should be given, by SPs and by those doing the creating, to the possible negative impact of uncontrollable delivery of digital memories and messages – which by their very nature contain audio. Rather than having to wait until the specific pre-selected dates, SPs should be designing their platform using thanatosensitivity-based design principles (Massimi & Charise 2009); that is, giving control to the living rather than the dead.

In an effort to address this issue, I began to think about possible menus that could be adopted by digital afterlife SPs who offer the delivery of posthumous messages. Giving control to the recipient, over and above the creator, raises important ethical implications of consent (the rights of the dead versus the rights of this living will be discussed later in this chapter); however, incorporating TSD into the platform and encouraging platforms to inform DCs about the possible negative impact for recipients if they were not given control over the dates of message delivery, could ensure platforms offer the facility to allow the intended recipient to listen at a time of their choosing.

I began to hypothesise how such a menu would work, and began to think about its potential design:

Content	Duration	Scheduled	Listen Now
18 th birthday message	15 minutes	09/09/2024	
21 st birthday message	11 minutes	09/09/2027	
Wedding day message	20 minutes		
Birth of a child message	12 minutes		
Graduation day message	15 minutes		
Milestone Message	13 minutes		

Table 7.1 First suggested control menu

Once I started to think about the design of the menu, for me it highlighted the fundamental problems with timed messages: that is the assumption that these significant events are as important to the DIs as they were to the DCs. Moreover, this menu also fails to deal with how social and cultural norms may change. At this stage, although I still thought the need for a menu for timed messages was crucial I wanted to create a more abstract menu which could be more useful.

Content	Duration	Listen Now
Milestone birthday message 1	15 minutes	
Milestone birthday message 2	11 minutes	
Celebration message	20 minutes	
Changing family message	12 minutes	
Milestone message 1	15 minutes	
Milestone message 2	13 minutes	

Table 7.2 Second suggested control menu

It is important to highlight the link between comfort and control of enduring posthumous digital memories and messages; therefore having the ability to download and listen to messages at a time suitable to the recipient, rather than the sender, could prevent the negative impact around future access. Moreover, it could prevent the permanent deletion or loss of messages through the commercial failure of SPs (this issue is discussed later in this chapter). Platforms that offer the delivery of posthumous messages should be developing thanatosensitive platforms which encourage DCs to think about the intended recipient of the messages, and the social and cultural complexity involved in the creation of posthumous messages. A new moral framework which incorporates this suggestion will be discussed later in this chapter, first I discuss the use of the term “digital immortality” in an effort to bring clarity to the taxonomy used in this relatively nascent field of research.

7.4 From digital immortality to digital endurance

“Then one day I hadn't visited his page for a while, and when I searched for it, it was gone. My heart dropped. I felt panicky. I went to pictures other people had posted of him, thinking I could follow the tags to find him, but they were gone. The pictures were just his face, with no way to get to him. It was like losing him all over again, it was like a new level of loss – or, I guess, an old level of loss that the Facebook generation didn't have to deal with”
(Emma)

In Chapter six, I presented findings which demonstrated the importance of posthumous digital memories and messages for DIs. Emma’s quotation above, obtained through an interview, illustrates how the loss of these digital memories and messages can affect those who have inherited them. Analysis of the data has shown that for the bereaved, these precious possessions are more than just the data of the dead, they contain the essence of the dead, now re-embodied in the ubiquitous everyday devices which are carried around in our pockets. However, because these memories and messages have taken on new relevance for the bereaved, the fear of losing them is causing a new anxiety. In this section, first I discuss a suggested change in the taxonomy from “digital immortality” to “digital endurance”. Second, I discuss the commercial failure of some intentional service providers who offer “digital immortality”. Third, I present a conceptual framework for my theory: the fear of second loss. This theory is based on the analysis and interpretation of the words of DI participants who took part in this study, and builds on existing philosophical discussions around second death to reveal how the fear of second loss is produced.

The term digital immortality is relatively new; however, I argue that it is already an outdated term which is inept to describe the “posthumous persistence of digital data” (Kasket, 2012). Just as we are biologically mortal we are also digitally mortal: the risk of contagion, or the loss or deletion of data causing digital erasure is a real threat to the notion of achieving digital immortality. Early in the first data collection phase of this research, I wrote an email explaining my study to a potential participant who said they found the term “digital immortality” insensitive and painful as it insinuated that their loved one had not died. I then considered adopting Kastenbaum’s term of “assisted immortality” (2016), but this still implied a state of non-death. Reflecting further, I decided the term “digital endurance” was more suitable and changed the details on my information sheet and online biographies. However, it was some time

later that I realised that this change of terminology was also necessary throughout the literature on thanatechnology – not just to be sensitive to the needs of the bereaved, but as a more useful, and importantly more accurate way to describe people’s experiences of creating and inheriting digital memories and messages.

As the findings of this research have revealed, digital immortality is far from immortal. This is concerning because, as illustrated by the tables in Chapter four, many death-tech companies have failed or become dormant since the start of this research. Immortality had only lasted a few years for many of those who had sought a digital afterlife, however, it is important to acknowledge this commercial failure is not limited: DAI, apps and platforms disappear regularly, as discussed in Chapter four, and new ones appear at a similar rate. So why specifically does the mortality of “immortality” platforms matter? With the demise of so many death-tech platforms, if it continues at the current rate, it will be important for SPs to confront the issue of the potential of data loss. I argue that when a DI is informed that posthumous messages have been created for them, they should immediately be able to see, download and hear all the messages which have been stored, even those that are timed for delivery on specific future dates. This would not only give control to DIs, it would also mitigate some of the problems of potential data loss if the platform ceased to exist before the nominated delivery date. The possibility that posthumous messages timed for future significant days could be lost before DIs had a chance to listen to them (which may not have been anticipated by the DC) could cause problems for the bereaved by disrupting what is considered to be a healthy grieving process. Such a disruption is discussed later in this chapter.

In Chapter six, I presented findings from DI participants which illustrated how posthumous digital data is perceived by the bereaved to contain the essence of their deceased loved ones. Moreover, during data collection some DI participants told me they were reluctant to upgrade their telephones and other technological devices; they were deeply concerned that the precious messages and memories of their deceased loved ones would be lost forever. Recall, Pam’s comment about not upgrading her telephone for 5 years, and how losing the data would be like “losing her (loved one) again”. Other participants echoed her anxiety. However, I had wrongly assumed that,

because third party tools exist (see Deadsocial.org), that can assist with transferring these precious messages that this would alleviate any anxiety and bring comfort to the bereaved; however, some of my DI participants were reluctant to use third-party software in case messages were lost in the process of copying or transferring the data. Furthermore, Pam explained that by transferring the data she felt that she would somehow lose part of the “essence” of her daughter. I began to understand how digital endurance seemed to blur the distinction between being dead and alive, specifically when the deceased is biologically dead but still socially alive, and how this blurring could eventually lead to a theoretical redefining of what it means to be dead. For some, social death predates biological death. For example, the lonely or those suffering from dementia may feel isolated from society long before they die biologically. But the Internet is providing a platform where “ordinary” people can remain socially active following their biological death, which was once a realm exclusively occupied by the rich, famous or infamous.

So far in this section, I have discussed issues of storage and retrieval faced by intentional digital afterlife platforms, however, as this thesis has demonstrated, for many it is the everyday mundane messages, created and stored on accidental digital afterlife platforms, and inherited by the bereaved following the death of a loved one that were the most precious. Blustein’s notion of “rescue from insignificance” is useful to discuss the “accidental” digital memories and messages left by the dead; that is, digital memories and messages which have not been purposefully created to exist in perpetuity. Blustein’s approach resonates with the findings of this research, in that it is the everyday, mundane messages that participants wanted to “rescue from insignificance” (Blustein 2008) and which renders them treasured possessions. Accidental digital afterlife platforms such as Facebook are at least beginning to understand the importance of their deceased users’ profiles to those left behind, and are introducing new features such as their 2019 tribute facility to deal with memorialised accounts (Facebook 2019). Hopefully other platforms will follow their lead. A new framework which could encourage this “thanatosensitive approach” (Massimi 2012) will be discussed later in this chapter. However, in the following section I grapple with the complex philosophical question: “Where do the bereaved think the dead reside?”.

7.5 Where the dead reside

Posthumous digital memories and messages have already “outlived” the biological existence of their creator; they have survived death. Importantly, as this research has shown, these digital memories and messages are perceived by the bereaved to contain the essence of the person who has died in a way that physical reminders do not. For many this “digital essence” is re-embodied within our everyday devices, in what Kasket (2012) describes as a “kind of embodiment, within the digital realm”. For the bereaved, these digital memories and messages do not perpetrate the notion that the dead are not dead, just that they are not physically present. Technology and the Internet are blurring the taken for granted notion of spatial boundaries by enabling people to be co-present; that is, physically present and virtually present at the same time in different spaces. Being present in multiple places and spaces at the same time forms part of people’s daily activities for many in the networked West. It is therefore unsurprising that people are adopting the idea of telepresence to continue relationships with the dead.

Building on Meese et al.’s discussions about personhood and Heidegger’s concept of “being” discussed in Chapter one of this thesis, I suggest that rather than the dead being scattered across various technological devices they are experienced by the bereaved as being somewhere more specific: in what I term a “digital *dasein*”. Whilst this thesis does not dismiss arguments about the existential dimensions of the dead, its primary focus is on the experiences of the bereaved: therefore, I draw on the works of Kasket (2012) and Kim (2017) who challenge Heidegger’s assumption that death is the ultimate end of *dasein* to suggest that the dead who achieve a digital afterlife are experienced by the bereaved in a posthumous “digital *dasein*”.

Heidegger extends the concept of *dasein* to talk about the different kinds of relationships we have to things and other people. His notion of instrumentality – how something becomes an extension of ourselves – is useful here to question whether continuing bonds enabled by digital memories and messages denotes a relationship with another being, or, conversely, is the relationship an extension of ourselves? Where a relationship with the dead continues, the digital becomes incorporated into

the bereaved creating a digital *dasein*. In Chapter six I presented findings from DI participants which demonstrated how the bereaved are using thanatechnology to ensure their loved ones remain virtually present following their biological death. I suggest the Internet is blurring our knowledge of where “there” is by creating a place where time and space are unconstrained and, therefore, enabling the possibility of a digital *dasein*.

This continued digital telepresence of the dead, creates a new state of being for the bereaved, by providing a new place where the deceased become a hybrid of being socially alive and being dead: the digital *dasein*. The nature of this mediated relationship between the bereaved and the deceased is to maintain an ongoing bond, and its digital nature differs from other *daseins* experienced by the person because it takes place in the *digi-dasein* – a “being” in the World Wide Web (Kim 2017). This *digi-dasein* can facilitate a plethora of relationships; however, I suggest the term digital *dasein* is a specific *dasein*, where the living can socialise with the dead, as the bereaved exist in this digital *dasein* along with the essence of the dead. Within this digital *dasein*, the essence of the dead is digitally embodied in a form of posthumous essentialism, and the idea that the essence of the dead continues to be “somewhere” can bring comfort to the bereaved who are using digital memories and messages as important tools for their grief. Importantly, grief is experienced differently by each bereaved individual, and even when DIs experience comfort in digital *daseins* this comfort is inextricably linked to being able to access these precious posthumous memories and messages, as discussed earlier in this section.

When the DC has intentionally created data to be inherited after they die – thereby showing a desire to be involved in how they are remembered in the future – this then becomes a contested and contingent space between the digital *dasein* of the DCs and the digital *dasein* of the DIs. Following the process of creation of posthumous avatars and thanabots, there may be a separation over time of the digital *dasein* of the DC and that of the DI. While some DCs may be attempting to capture a permanent version of themselves which represents them at their best, some DCs are creating their digital selves in the hope that their digital data will have its own independent existence. Importantly, this autonomous digital zombie would have its own digital *dasein* which is not parasitic on its creator.

Because digital memories and messages enabled by thanatechnology have enabled this digital *dasein*, I use the concept of a digital *dasein* in this chapter to draw attention to how the existing models of bereavement do not adequately accommodate digital endurance. Furthermore, because the essence of the dead is nurtured within this digital *dasein* it creates a new concern for the bereaved: the fear of second loss.

7.6 A theory of The Fear of Second Loss

The term “second death” was used by Patrick Stokes in his 2015 paper to discuss Goethe’s notion that people die twice: once when we stop breathing and then again when the last person speaks your name. Thus, a biological death is followed by a social death. And this second, or “social” death can be perceived by some as a harm to the dead. Stokes approaches this second death from the viewpoint that the data of the dead is an “object of moral obligation” and, therefore, it is our obligation to not delete these digital remains; however, this obligation is laced with the assumption that everyone wants to remember the dead. As discussed earlier in this chapter grief and bereavement along with remembering and forgetting are complex processes for many people, as not everyone agrees that digital memories and messages should be preserved. Stokes further posits that the deletion of “digital remains” may have an impact on the “ontological and ethical status of the dead” (Stokes 2015). Stokes suggests that using the metaphor “digital remains” to describe the data of the dead is useful, as it elevates the moral status of the data to that of a corpse. Whilst this term is a useful metaphor, it is limited: as we do not have immediate access to, or carry around the corpses of our loved ones as we do with posthumous digital memories and messages. Similarly, Öhman and Floridi (2017) suggest that ethical conventions used for archaeological exhibits could provide a useful framework for posthumous data. Again, while this idea is useful, their suggestion still does not address the immediacy of access to the dead which my research has demonstrated is distinct with posthumous digital memories and messages.

My research also highlights a further limitation of Stokes’ argument, as he fails to

acknowledge the reciprocal nature of thanabots and posthumous avatars, and whether these would have a different moral status as they are created *after* the death of the original self. The themes which emerged from this research support the notion that the data of the dead is far more than code to the bereaved. However, in the introduction of this thesis I proposed a distinction between accidental digital memories and messages and intentional digital memories and messages; here I argue this distinction is crucial in order to establish whose needs should be prioritised: the DC or the DI. The digital artefacts which are created intentionally by the living in an attempt to endure on the Internet after their biological death could be given the status of digital remains, such as those suggested by the likes of Stokes, Öhman and Floridi, as they were created intentionally to continue to exist beyond biological death. However, based on this research, accidental posthumous digital memories and messages inherited and rendered as precious memories by the bereaved should be treated differently; crucially, this research highlights that the needs of the bereaved should take priority over the needs of the deceased for accidental digital artefacts. The term “second death” focuses on what has happened to the person who has died: they died twice. However, although this thesis adopts this term, it calls for a transfer of focus to what is happening to the bereaved following the death of a loved one.

As previously mentioned, second death describes social death. This thesis expands and adopts the usefulness of the term “second death” in an effort to draw attention to the needs of the living; specifically, the bereaved who inherit the digital memories and messages enabled by thanatechnology, and then lose them through a second, digital death, which I call “second loss”. Stokes’ use of the term “second death” does not include second loss, as for Stokes the term necessitates that the dead are socially dead: they have been forgotten by the living. I argue that the term “second death” needs to be expanded to include digital death; that is, the loss, deletion or lack of access to posthumous digital memories and messages producing the loss of the digital *dasein* where the bereaved experienced the essence of the deceased. Second loss is how second death is experienced by the bereaved and using this theme of second loss, I inductively built a new theory: “the fear of second loss” (Bassett 2018). My new theory, generated by the data and presented here, has been influenced by the work of Stokes (2012; 2015) “Second loss” denotes how second death is experienced by the bereaved which entails the highly emotive loss of precious data

produced by data deletion; technical obsolescence; or the denial of access to posthumous digital memories and messages.

Unsurprisingly, I found that second loss is experienced negatively by the bereaved. When I discussed with each of my participants how they would feel if the digital memories they had inherited were permanently deleted, their replies (“I would be devastated” and “It would start my grief all over again”) were implicit in all but one interview (see Chapter six for this negative case). Even participants who did not visit Facebook pages or other accidental platforms commented that they would not want them switched off permanently, as they take comfort in the knowledge they can switch them back on if they wanted to. One woman told me she was glad her mother’s Facebook page was offline, but it still exists.

In her 2012 paper on continuing bonds, Elaine Kasket reported similar findings of participant’s fears at the possibility of losing Facebook profiles of the deceased (Kasket 2012a).

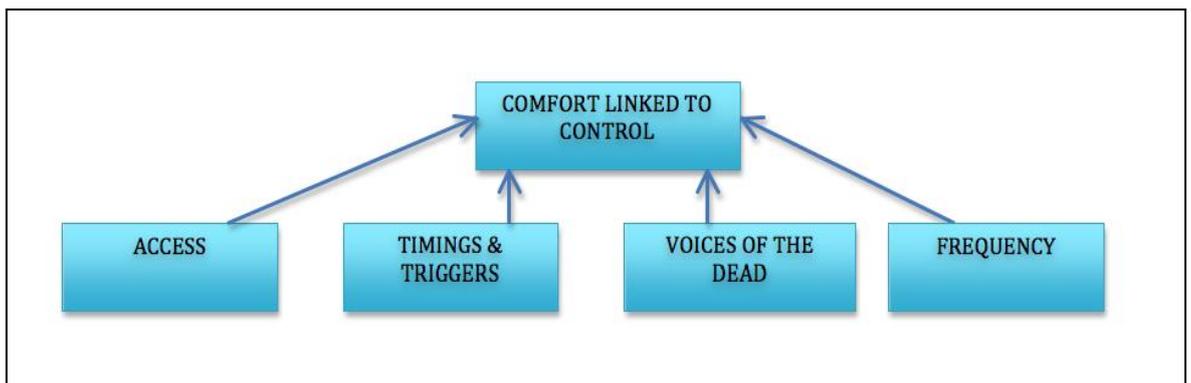


Figure 61 The relationship between the emergent categories

Figure 57 above illustrates the relationship between the emergent categories constructed from the study data, and how the theme the theme of control was developed from the sub-themes. The impact of data loss and access restriction are discussed in Chapter six which looks at the effect of these points on the bereaved, and the concept of second loss emerged from, and is woven throughout, the chapter inextricably linked to the theme of “control”. For some participant control seems to be in the hands of the service providers rather than the bereaved. As Massimi and

Baecker note (2010), technology is rarely designed with digital inheritance in mind. Second loss is not only applicable to those who *have* inherited digital memories and messages following the death of a loved one as it can also be useful to describe the experience of *not having* access to the digital data of the deceased. During an interview with Carla she explained how her mother had died whilst holidaying in Lanzarote, and how the family were “desperate” to access the photographs taken in the last few days of her life when she was happy. Unfortunately they did not know the PIN to access the device, and the photographs were lost causing much added grief to the family. This example is an implicit description of how the nascent phenomena of second loss is being experienced, even when there has been no digital memories and messages inheritance, and, importantly, illustrates how the narratives of grieving are being culturally shaped to include digital grieving.

In a digital landscape, the dead feel closer to the bereaved because they are immediately accessible through everyday smart technology, rather than analogue memories such as keepsakes which are sometimes kept in dusty boxes stored in attics. Yet the digital landscape also brings with it the possibility of technical obsolescence. Accidental deletion and a lack of access to digital memories and messages creates a new vulnerability for the bereaved as those who lose posthumous digital memories and messages experience a second loss. However, this research has demonstrated how anxiety is still being experienced when second loss has not yet occurred because this fear exists as a form of anticipatory grief which manifests itself as the fear of second loss. This theory accounts for how, for some, the comfort gained from digital memories and messages is being overshadowed by the fear of losing data created by, or commemorating the deceased as a result of digital deletion, data loss and access denial. When contemplating this notion of digital loss I am reminded of Wallace et al.’s work on Victorian mourning jewellery (2018) discussed in the literature review in Chapter one of this thesis. Particularly the “forget” locket where the image degrades each time the locket is opened demonstrating the possibility of digital deletion.

Once the theory of “the fear of second loss” had been developed from the data, and reflecting on the work of Wallace et al. (2018) I began to rethink an idea I had at the

start of this thesis; the digital memories and messages containing the essence of the dead, along with durable biographies – which are a fundamental part of continuing bonds – need a separate place to be stored other than on people’s everyday devices. My idea of a digital memory box, which crucially, does not need to be connected to other devices seems a possible solution to mitigate the fear of second loss experienced by many of my participants. Here, I am talking about a physical box, rather like a jewellery box, which could be individually customised as a special – and separate place – to keep digital memories, rather than the dead “popping up” on people’s everyday devices. As my research has shown, obsolete technologies containing inaccessible digital memories are emotionally difficult to dispose of, so having a separate place to hold these precious digital memories and messages could be a solution for the bereaved.

The creation of digital memory boxes is a progression of the idea of a “Story Shell” (Moncur & Julius 2014), which is created by the living following the death of a loved one. However, the creation of digital memory boxes by the living could transpire to be important and empowering “work in progress” for its creator, as the contents of these boxes could be curated and added to throughout people’s lives. They may also prove a useful memory-sharing tool to those with early onset dementia, who may wish to fill their digital memory boxes with memories of the past, and hopes for the future, before their memories are locked away and unreachable, or those suffering with similar declines in mental ability (Clabburn 2019).

This theory of the fear of second loss relates to the issues surrounding the right to forget and the right to be forgotten (discussed earlier in this chapter); in that, these issues are inextricably entangled with whose needs are prioritised: the living or the dead. The issues discussed in this section, raise important philosophical questions that will continue to be debated across a wide range of disciplines, such as, does the right to privacy extend to the dead? A multi-disciplined approach will be needed in order to fully understand how thanatechnology and the digital grieving enabled by this human-computer interaction, and how the social and cultural practices around grieving will continue to be experienced and altered by a technological landscape. As a result of this research, I argue that for accidental digital memories and messages

any suggestions that the online dead could be stakeholders in decisions concerning the preservation of their data (the data of the dead) is flawed (Stokes 2015; Öhman & Floridi 2018) as will be discussed later in this chapter. Furthermore, when the digital artefacts are accidental then this thesis advocates that SP and DC should be encouraged to treat the bereaved as the major stakeholders in an effort to mitigate the potential anxiety of those who have lost a loved one. It is certain that for some grievers, the Internet is providing comfort by enabling a continuing relationship with the departed; however, for many others, it is causing a new form of anxiety for the bereaved: the fear of second loss.

7.7 Digital dislocation – The disturbance to the Dual Process Model

The aim of this research was to assess if the nascent phenomena of digital memories and messages, which are enabled by thanatechnology, and inherited by the bereaved, disrupt existing models of bereavement. Here I discuss Stroebe and Schut's Dual Process Model of Coping with Bereavement and how during data collection and coding I began to see an emerging pattern in the data which challenges and disrupted their model. Since Stroebe and Schut presented their DPM in 1999 it has been hugely influential in assisting bereavement counsellors, academics and professionals. The model illustrates and explains what they suggest as healthy grieving, which involves an oscillation between "loss-oriented grief" and "restoration-oriented grief" – a movement between confronting and avoiding grief (For a detailed discussion of the DPM see Chapter two under Dual Process Model of Grief). However, the findings from the DI participants presented in the previous chapter, shed light on how inheritance of these digital memories and messages disrupt oscillation between these two states by disturbing the "waxing and waning" described by Stroebe and Schut which, I suggest, creates a "dislocation" for the bereaved which is not accommodated within the original model. Writing in 1999 Stroebe and Schut suggest that "At times the bereaved will be confronted by their loss, at other times they will avoid memories, be distracted"; however, this model was created before thanatechnology enabled access to the dead at the swipe finger, or the press of a computer key. On everyday devices, the dead reside on our laptops and in our pockets. For instance, during my interview with Grace she explained how "*it is not*

a good thing to suddenly be disrupted when you are trying to do something else, I have got photos on my desktop but I sometimes put a document over the top of them". This quotation illustrates a digital disruption to Grace's distraction from grief and involves "seeking relief by concentrating on other things" which Stroebe and Schut suggest is necessary for healthy grieving to occur.

This psychological model of bereavement has been adopted widely across many different disciplines, including sociology. Rather than adopt the psychological term "stressor" for my additional element to the model, I have adopted the more sociological term of "process" to illustrate that the digital-oriented sphere involves social processes and symbolic interaction which reflect the epistemological assumptions of this thesis.

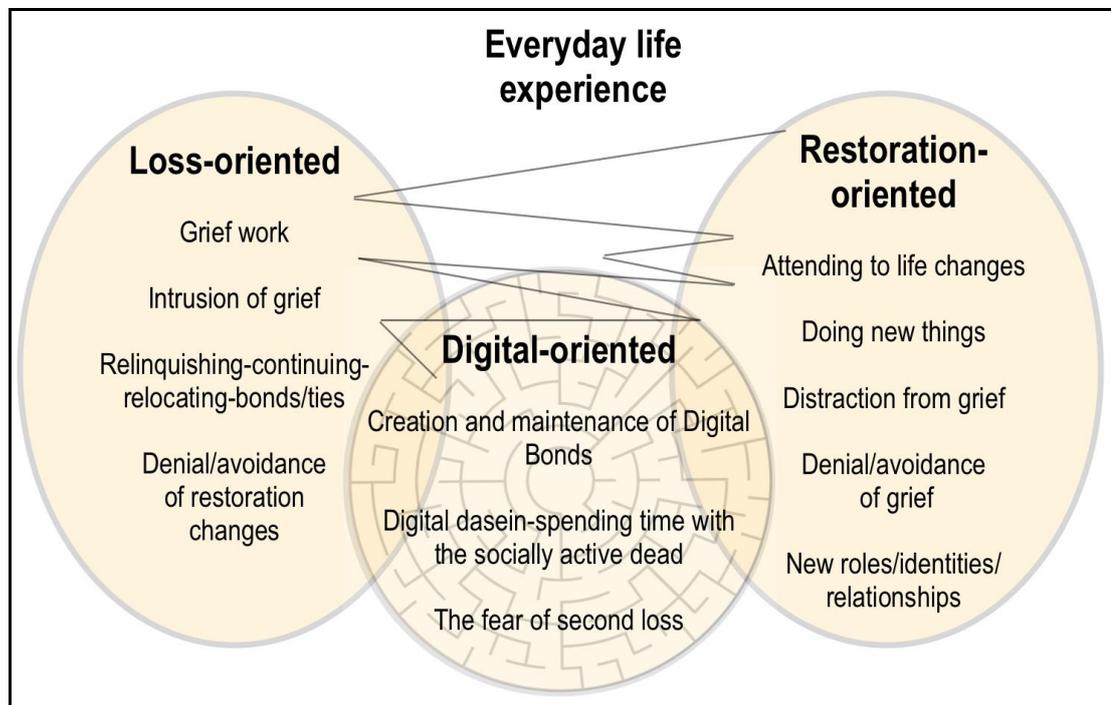


Figure 62 Proposed model expanding the Dual Process Model of bereavement

In Figure 58 above, I expand the scope of the DPM of coping with bereavement by introducing a third dimension: a digital-oriented process. This expanded model of coping with bereavement incorporates how digital memories and messages created by the living and inherited by the bereaved, creates a new and distinct digital-oriented experience. The incorporation of this new dimension introduces a

sociological element into this psychological model, which I believe gives a clearer picture of grieving in the digital age. Developed from the research data collected and analysed from this study, my model allows for the theory of the fear of second loss, presented earlier in this chapter, and the creation of digital bonds presented later in this chapter. I argue, that in addition to the two bereavement stressors introduced by Stroebe and Schut in the original 1999 model, digital memories and messages are now creating a third “digital-oriented” dimension which illustrates how the process of “flux” is being experienced alongside oscillation. Using the term “flux”, not only illustrates the complexity, uncertainty and uniqueness of how people experience grief, but also introduces the notion that the bereaved flow rather messily, within and around the original two dimensions. Not in straight lines of oscillation “between” the two original stressors.

Digital grieving was not accounted for in the previous model, as the original model was developed in 1999 when the World Wide Web was still in its infancy. Importantly, I argue the digital cannot be comfortably accommodated within the original model: based on my findings I suggest that the original model is too simplistic to address digital grieving; moreover, this expansion to the scope of the original model is necessary in order to highlight and acknowledge the affect that digital memories and messages are having on the “dynamic, regulatory coping process of oscillation” which is a fundamental element of the DPM. Stroebe and Schut’s model also focuses on the importance of distraction, and the need to take respite from either of the original two stressors. My research suggests that, for some, this “respite gap” is being partly occupied by the new digital-oriented process created by the living when they spend time with the socially-active dead, and participate in activity which creates, and maintains, digital bonds, and copes with the fear of second loss. Moreover, I suggest that for some this digital-oriented process not only occupies part of the “respite gap” but may also disturb the oscillation – which Stroebe and Schut describe as a “central component” of their model – and could cause digital dislocation where, for instance, the bereaved become “stuck” in the middle of the two original dimensions.

Attempts to accommodate the inheritance of digital memories and messages into the original model, highlight that the original model, implies that the bereaved have an

element of control over the time and speed – the waxing and waning – of the oscillation between loss-oriented and restoration-oriented activities. These oscillations can be “utterly unpredictable and uneven” (Kasket 2019) and I suggest my proposed model better illustrates this complexity of the process by introducing the digital maze. Furthermore, adding this digitally-oriented process to the model acknowledges the possibility that rather than being discrete, both original stressors can be experienced at the same time. For instance, digital grievers can experience grief work *and* new roles/identities/relationships at the same time, which can then be accommodated within the new third, digital dimension.

My proposed and expanded model recommends three new “digital tasks” within the new digital-oriented process that some DIs have to take on. First, the fear of second loss, which as discussed earlier in this chapter is the fear of losing the data created by, or commemorating the deceased. For many people this data contains the essence of the deceased. This second death or deletion of posthumous data is being experienced by some as a “second loss”, and the fear of this second loss is creating a new form of anxiety for the bereaved, which I suggest cannot be added to the original two dimensions. Second, spending time with the socially active dead. This phenomenon is relatively new as discussed throughout this thesis, and even though the dead no longer evoke notions of the uncanny valley (see Chapter six) people’s immediacy of access to the dead contributes to a disturbance to the necessary respite and oscillation within the original DPM. This disturbance is not accounted for in the original model and cannot not be adequately added to one of the existing two stressors. Third, the creation of digital bonds, (discussed in Chapter seven) could fit into both existing stressor dimensions as it could be seen as “doing new things” and “continuing” or “relocating” bonds, however, the findings of this research presented in the previous chapters have demonstrated how digital memories and messages are experienced in a unique way by the bereaved, and therefore I argue these digital bonds cannot be accommodated within the original model.

In 2016, Stroebe and Schut addressed what they had identified as a “major shortcoming” of their original model in that it did not address the issue of stressor “overload” which they describe as “the bereaved person’s perception of having more than s/he feels able to deal with – too much or too many activities, events,

experiences and other stimuli”. Importantly, the findings from this research do not suggest this new dimension of digital-oriented grief creates an overload which is *more* than people can deal with. Neither do the findings suggest that digital-oriented grief is negative or unhealthy, simply that it is a new and different digital “griefscape” which is not accommodated within the original model. Although digital-oriented grief is not an “overload”, the potential disturbance, slowing down or speeding up of the oscillation could, I suggest, create the potential for becoming “stuck” in the digital-oriented maze. A process which needs to be acknowledged and understood by bereavement professionals and thanatologists.

During data collection for this study, I explored the frequency and triggers of visiting the digital memories and messages, and the importance of control was implicit in responses from many of the DI participants (see Chapter six). However, the delivery of timed posthumous messages (discussed in Chapter four) would severely disrupt the ability to control the frequency and timings of visits. Being able to choose when to visit the dead is important here; the dead choosing to visit you could severely disrupt the necessary oscillation between the two original states at the time of delivery of the digital memories and messages. Moreover, the anticipation of future message delivery could result in a feeling of “stuckness” within the digital maze. As the finding from my DI participants demonstrated, the bereaved who took part in my twitter poll did not want to receive these timed posthumous messages, however, the subsequent poll found that if they did receiving them they would be compelled to open and listen to them. These findings are in line with findings from the study by Jamison-Powell et al. (2016), specifically, what they described as conflict #3: active and passive grief, which in agreement with my study they also suggest could affect the DPM of bereavement. However, Jamison-Powell go further than my suggestion of giving control to the bereaved, by suggesting that designers could potentially censor or manipulate harmful messages. The platforms offering these timed messages are relatively new and social practices and norms change over time, therefore more research is needed to see if attitudes change towards timed posthumous digital messages.

Further empirical research is needed to identify whether this “stuckness” could eventually result in the bereaved needing help to navigate their own personal digital

maze, namely, to ensure the bereaved return to the bereavement oscillation. It is also important to acknowledge that digital grieving where the bereaved does not possess control of the digital memories and messages has the potential to disorient them as it may enable warp-speed oscillation between the two original stressors. As the findings of this research have demonstrated, those who possess control of their digital memories and messages find them to be of great comfort; therefore, the digital-oriented dimension should not be seen as an illustration of negative or harmful grieving as incorporating the digital-oriented process into the taxonomy of the DPM could highlight the impact of the inheritance of digital memories and messages by the bereaved, and add to our current understanding of bereavement.

The research in this thesis is embedded within the sociological, rather than psychological experiences of bereavement; that is, how the “social” in social networks affect the bereaved as opposed to internal bereavement processes. For the purpose of this thesis I did not take a critical sociological stance against the DPM, which is a psychological model of bereavement. Although this thesis is sociological in nature the data collected and analysed demonstrated that the existing model was relevant to the experiences of the participants, as it illustrated how participants attempted to move between the two dimensions of the model, however, focusing on this model also allowed a rendering of how digital memories and messages were playing a part in the disturbance of the oscillation between the two states. Therefore, I expanded the existing model by incorporating a much-needed sociological dimension which the data demonstrated was a necessary addition.

Alongside psychology, the emerging academic field of cyberpsychology is useful to this discussion. Cyberpsychology focuses on how emerging technology, such as virtual reality and social networks, affect the psychology of individuals and groups. While the psychological costs or benefits of online behaviour is much debated, and outside the scope of this thesis, research into possible digital addiction and the effects of RIP trolls provide an understanding of why the sociological dimension of digital grieving should be added to the existing bereavement model as a new dimension. Nonetheless, my proposal to add a digital process can accommodate ongoing debates in this field, which, conversely, cannot be accommodated within the original model. Echoing the sentiments of Stroebe and Schut this thesis is an

invitation for academics, professionals and counsellors, to theoretically and empirically test my suggested extension to the DPM, so as to fully assess how digital memories and messages enabled by thanatechnology affect the way people grieve.

7.8 Digital bonds theory – An expansion of continuing bonds theory

The theory of continuing bonds has been woven throughout this thesis, first in the literature review presented in Chapter two, then in the findings from both the DC participants in Chapter five and the DI participants in Chapter six. Here I expand on the theory of continuing bonds by highlighting (1) how the inheritance of digital memories and messages enabled by thanatechnology facilitate ongoing social relationships with the dead, and (2) how the bereaved experience these social relationships, I suggest that the theory of continuing bonds can be expanded to recognise “digital bonds” as a unique subset of continuing bonds.

The changes brought about by thanatechnology have changed the way people nurture continuing bonds with the dead. Historically, visiting graves enabled the bereaved to feel physically close to the dead (Klass 2006). However, we now carry precious digital memories and messages of the dead on everyday devices, making it easier than ever to feel physically close to the dead and moreover, to continue to have a dynamic and on-going relationship with them. The use of the term “linking objects” (Volkan in Klass 2007) is useful to this discussion as it describes how the bereaved use physical objects as tools to “evoke the presence of the dead” thus, enabling a continuing bond. Then again, “linking objects” does not adequately describe the omnipresent nature of posthumous digital memories and messages which my research has shown is experienced by DIs differently compared with physical memories. I suggest that these ongoing digital relationships that occur now in relation to the dead, differ from the one-way relationships accommodated within the original theory of continuing bonds. This distinction is useful to comprehend how thanatechnology enables the socially active dead to be co-producers of, what I term, Digital Bonds. This suggested addition of digital bonds to the existing theory of continuing bonds is an attempt to “keep the conversation moving” (Klass 2006) by highlighting how digital memories and messages are being experienced in a unique

way by the bereaved in their efforts to continue their relationships with the deceased.

The theory of continuing bonds has provided a major theoretical framework for this research, and using bereavement theory as an anchor, I began to develop digital bonds theory in order to highlight and accommodate what I interpreted as the unique nature of posthumous digital memories and messages, such as the differing ways the bereaved were using them as tools to help them grieve. Although the original theory allowed for continuing *interactions* with the dead (Klass 2006), my research has highlighted that the bereaved experienced digital memories and messages differently to physical memories and messages; therefore, the theory would benefit from further development. Continuing bonds theory describes the reconstruction of a person's social identity once someone in their lives has died (ibid), but Digital Bonds acknowledges the co-construction of these bonds. Here, I adopt the taxonomy I introduced at the beginning of this thesis, to draw attention to the uniqueness of digital bonds: which involve the creative input of accidental DCs and intentional DCs, who together with DIs, operate as co-producers of these digitally-facilitated bonds. Crucially, the digital memories and messages used to create these digital bonds are perceived, by the bereaved, to contain the essence of the deceased.

During the development phase of this new digital bonds theory, another new theory emerged from Oliver Clabburn, at Edge Hill University, that I considered to be useful, and a valid addition to continuing bonds. Clabburn developed "The Model of Reciprocal Bonds Theory" (Clabburn 2018). The aim of Clabburn's research was to explore the experiences of how people affected by motor neurone disease (MND) experienced digital legacies, and although the research focused on one distinct group of DCs – those with MND – the idea of the *reciprocal creation* of bonds resonated with the findings of my research. Moreover, Clabburn's theme of "Conveyance of identity and past experiences", echoes the focused codes of image control which I had coded under the overarching concept of "quest for immortality": legacy creation; advise/inform future generation and story sharing. Equally, Clabburn's finding also resonated with finding from my DCs and my "therapy" theme as a motivation for their creation of digital memories and messages. Finally, it seems that my research has identified the same limitation to existing bereavement models: in that they do not take into account the creative input from the DCs (Clabburn 2018). This digital input

from the DCs could influence the durable biography created by the DIs (Walter 1996) by introducing what Clabburn describes as an “autobiographical chapter”. Clabburn’s term “autobiographical chapter” is a useful addition to the theory of continuing bonds, as it acknowledges the input from DCs who had created video digital legacies, in an effort to “continue parenting” after their death (Clabburn 2018). My concept of digital bonds demonstrates how these durable biographies and autobiographical chapters are brought to life, or crucially brought *back* to life by resurrecting and creating a more immersive way to remain connected to the dead.

Reciprocal bonds theory certainly allows for the reciprocal nature of digital memories and messages, and how DCs, who have created them intentionally, play a part in creation of continuing bonds after they die. However, the theory still does not accommodate non-reciprocal, accidental everyday posthumous digital memories and messages, which my study has found to be experienced as precious treasures by many of the bereaved. As discussed in Chapter six, it is the everydayness of these accidental digital memories and messages that the bereaved take comfort in and repurpose for their needs. Consequently, they take on a new and different role: in the regard they become a continuing bond, but importantly a specific type of continuing bond, which, I believe needs to be acknowledged as distinctly different to other bonds. *These* digital bonds have been co-produced, and in some circumstances, such as thanabots and digital zombies, the dead remain socially active co-producers. Wallace et al.’s notion of ongoingness (2018) is useful here as it acknowledges a continuing relationship with the deceased, but also allows for a relationship with the deceased to “grow”. This growth, and the ability to form new bonds using thanatechnology is a fundamental element of the concept of digital bonds.

The use of the term “digital bonds” accommodates and highlights the public nature of digital memories and messages and how they can represent a continuance of social bonds with the deceased. Moreover, it acknowledges that the dead are not passive in the creation of such bonds, which is a distinction not accommodated in the existing framework of continuing bonds. These co-created digital bonds are then used and maintained in a digital *dasein* so that the DIs may continue to have a relationship with the deceased. Notions of “persons” and “selves” then become less important because of the specific way this digital *dasein* is experienced by the

bereaved as a unique place to spend time with the dead.

Returning to the findings of this research, I argue that the emotional bonds accommodated within the existing framework cannot be lost by the DIs – notwithstanding the effects of memory loss – as they are the inner representations of the deceased created by the bereaved. Digital bonds are also an inner representation of the deceased; however, DIs need thanatechnology to gain access which makes them different. In addition, digital bonds differ from traditional continuing bonds, as many of these technology-enabled bonds are created and maintained in the same place and space that the deceased used to create their original digital memories and messages (Kasket 2012a). The theory of the fear of second loss developed from the data and presented in this thesis, has demonstrated how following biological death, the social death of a person through technical obsolescence, accidental deletion or lack of access to these precious memories and messages, could create a second loss for the bereaved which would result in a severing of precious digital bonds. The next section of this chapter discusses how the DAI – both intentional and accidental – can mitigate potential problems for those who inherit, adopt or co-create digital memories and messages, and use them as an adjustment tool following bereavement.

7.9 Profit and loss – A voluntary code of practice for the digital afterlife industry

DCs who intentionally create posthumous digital messages to be delivered following their death, do so for a number of reasons (as discussed in Chapter five); none of which are intended to cause harm to DIs. However, the platform is designed, and information provided to DCs is the responsibility of the SPs. Incorporating information for DCs, which highlights any possible problems for the bereaved that may potentially be caused by receiving uncontrollable posthumous messages, along with the design and implementation of menus which give control to the Dis (as suggested earlier in this chapter) could mitigate these problems and avoid any negative impact on those who inherit the digital afterlives of the dead.

Although none of my participants encountered digital messages which could be

considered threatening or coercive, several people mentioned the possibility of people using posthumous messaging platforms to digitally “haunt” or “stalk” the bereaved from beyond the grave, such as by creating messages to be delivered following the death of the creator. As this research has found, DIs may find it difficult to ignore posthumous messages (see Chapter four), and although this is a hypothetical point not encountered in this research, I suggest that this inability to disregard messages could be a potential problem for digital afterlife platforms in the future. Incorporating a control menu could form part of the TSD of a platform; for instance, giving control to the DIs, as suggested earlier could mitigate any type of posthumous stalking and unwanted delivery of posthumous digital messages and clear suggestions provided to those creating messages to be delivered posthumously, could also mitigate potential harms to the bereaved. It is essential to acknowledge that these platforms, and therefore these digital memories and messages, are not hidden away in dusty shoeboxes kept in the attic – they are on people’s everyday devices; carried around on their smartphones, on their iPads and laptops – they seep into the every day lives of the bereaved.

In an effort to mitigate possible distress to DCs and DIs and following extensive research into digital afterlife SPs, this thesis calls for the development of a voluntary code of conduct for the DAI. At the outset of this research, the rights of the death (DCs) versus the rights of the living (DIs) seemed a good place to start. However, as discussed earlier in this chapter, the term “rights” places this discussion within a legal framework, and whilst the legal ramifications of digital afterlives are beyond the scope of this thesis, the moral ramifications of digital afterlives form one of the cornerstones of this work.

This notion of a new framework plays an important role in the contribution to knowledge presented in this thesis. And to further support this need, in the final year of this thesis other researchers published a paper calling for a similar framework: Carl Öhman and Luciano Floridi of The University of Oxford called for “An ethical framework for the Digital Afterlife Industry” (DAI). They suggest that the DAI should be inspired by the ethical frameworks used by archaeological museums who deal with the monetising of organic human remains. A clarification of the relationship between DCs and SPs would, they claim, be useful to ensure that the

ownership of digital remains is decentralised (Öhman & Floridi 2018). They suggest that digital remains hold an “inherent value”, and are not just data which can be monetised: this suggestion echoes the findings of my research which uses the term “essence” to describes the intrinsic value of digital remains. Although I see the benefits of an ethical code or framework, as suggested by Öhman and Floridi, getting the DAI to adhere to it could be challenging, as it is likely to be difficult to enforce and take time. There is also the problem of who would pay for its creation. With this in mind, I suggest that rather than trying to *impose* an ethical framework onto the DAI, I propose a voluntary code of conduct: a code adopted on a voluntary basis by SPs may have a greater impact than trying to regulate the industry from the outside. As my research has demonstrated, intentional and accidental platforms provide useful tools for the bereaved, and therefore have an important role to play in the development of any such framework, which could help both those creating the digital memories and messages, and those who inherit them. If a voluntary code was in place, then digital afterlife SPs may well see its adoption as a sound commercial decision: using it to market and promote their services with the knowledge that it is endorsed by grief councillors, thanatologists and bereavement professionals.

The taxonomy introduced in Chapter one of this thesis, which draws attention to the intentionality of the DCs, could be useful to this discussion around the implementation of a code of practice for the DAI: as it draws attention to the different forms of posthumous digital data and the different stakeholders involved in the creation and inheritance of digital afterlives.

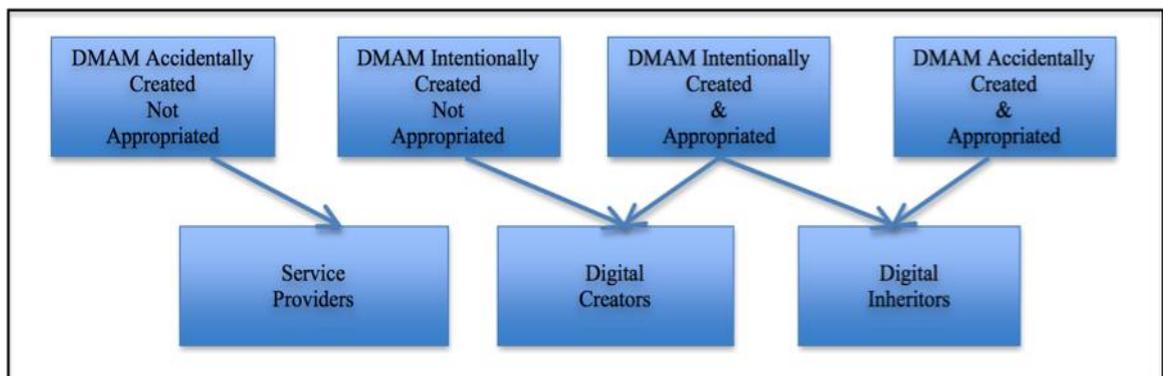


Figure 63 The stakeholders involved in the creation and inheritance of digital memories and messages

Adopting the commercial term suggested by Öhman and Floridi of “stakeholder” (2018), and using the findings of my research as a foundation for this diagram, Figure 59 above, draws attention to the major stakeholders for each scenario of digital creation and inheritance. For instance, the diagram illustrates that for three of the four scenarios only one stakeholder exists, it is only for the intentionally created and appropriated digital memories and messages that there are two stakeholders. This fact needs to be addressed by the intentional SPs, as currently they give one hundred percent of the control to the DCs without considering that the DIs are stakeholders. Importantly, I am not suggesting the DIs are the only stakeholders, merely that to ignore them as stakeholders is unhelpful and potentially harmful.

In the diagram, I indicated only one stakeholder for digital memories and messages accidentally created but not appropriated (SPs). To demonstrate my reasoning, I will use an analogue scenario: If you were sorting through the physical belongings of the deceased, it is likely that you would need to sort through items not mentioned in a legal will, not specifically left for inheritance, and to make decisions made about which items to keep, or which items to take to the local charity shop. When sorting and clearing out these every day possessions you may come across personal diaries or private letters, but whether you decide to read, keep or destroy these items is a matter for the bereaved not a global company. However, in our digital society where many of these private messages and memories are now on platforms on the Internet these decisions are taken away from us. Based on the findings of my research, this thesis is a call for this situation to change; specifically, for digital memories and messages accidentally created and then appropriated by the bereaved as tools to help them grieve.

The sector of the DAI that deals with the creation of posthumous avatars are of special concern to this research, as this research has demonstrated how the bereaved still view these avatars as eerie and uncanny. In Chapter six of this thesis I presented findings to show that there have been changes to the landscape of Mori’s uncanny valley (2012). People are getting used to the dead being socially active on SNSs, but socially active posthumous avatars still fall into the uncanny valley. The exponential growth of emerging technologies needed to deliver and support the cyberconsciousness, mindclones, mindware and mindfiles, discussed by

transhumanist pioneer Martine Rothblatt (2014), do not seem far away. Bell and Gray of Microsoft Research, agree that it may be possible that a “cyberized” version of you will be able to learn, evolve and eventually take on a life of their own. In agreement with this concern, Meese et al. (2015) point out the technology to create avatars of the dead draws ever closer: technological advances that enable the creation of humanoid robots such as Rothblatt’s Bina48 raise important questions because Bina48 was created from a living person, but when the real Bina dies, Bina48 will remain socially active. As technology improves and the ability to create these avatars becomes more sophisticated, the need to ensure a thorough code of practice is in place will be crucial, not only to protect DIs but to inform DCs of the potential harms of uncontrollable reanimated digital zombies (Bassett 2015)

In 2018, Öhman and Floridi recommended that SPs should guarantee “users are not depicted radically differently from the bot that they originally signed up for”. Here I suggest using a digital DNR. To elaborate further, in end of life care a Do-Not-Resuscitate order can be obtained from a doctor to instruct care providers not to administer CPR to a patient if their heart stops beating. However, from a digital afterlife perspective it could be a useful if SPs adopted this acronym to mean “do not reanimate”. This digital DNR (DDNR) could mean that whilst someone does not mind their digital data being freely available following their death they do not wish for it to be used to create any type of digital zombie (Bassett 2015). My suggestion is that this addition of a DDNR would be a request to SPs rather than a legal right (or guarantee) of the user, this could form part of the voluntary code of practice.

Öhman and Floridi’s suggestions focus on the dead. They do not take into account the needs of the bereaved (2018). For instance, they suggest that “users only upload data that belongs to them personally, that is, not making bots out of a deceased relative or friend”; however, technology exists which enable people to make posthumous chatbots, so to envisage SPs putting this particular genie back in the bottle is naive. Furthermore, this research has shown that although these posthumous chatbots can fall into the category of digital zombies (reanimation of the dead to do things in death they did not do in life) those creating and inheriting these forms of digital memories and messages find them a comfort to their grieving. Whether the DIs should be denied this form of grieving – as implied by Öhman and Floridi –

once again comes down to the issue of control raised by this research. With collaboration between academics, grief professionals and the DAI a needs-based voluntary code of practice – rather than rights based legislation – is a resolution which could serve the needs of commercially driven SPs, the needs of DCs to be remembered, and also looks after the needs of the DIs to grieve.

I am not suggesting that the needs of DCs and SPs should be ignored; however, shifting the focus towards DIs could provide a more balanced approach to the DAI. The needs of SPs are the major concern of the commercially driven terms and conditions of these platforms (which need to be agreed to by their users), and the needs of DCs are the major concern of researchers such as Öhman, Floridi and Stokes. However, I argue, the needs of DIs require further support and acknowledgment by the DAI. Based on my analysis of the data and the findings presented in Chapters four, five and six of this research, this thesis aims to further highlight how the needs of DIs are not currently being addressed by the DAI. This is a huge oversight, because if the inheritance of the reanimated dead is experienced in a negative way by the bereaved, this commercially driven industry will fail.

Although most of the digital life SPs who took part in this research had extremely personal reasons for starting their companies, ignoring their commercial needs is not a realistic option as many of these companies are receiving finance from profit-driven investors. Researchers from cyberpsychology, sociology and psychology, are conducting quantitative and qualitative studies in an effort to examine and understand the affect that the Internet is having on people's daily lives: from potential addiction to SNSs; trolling behaviours; changes to dating habits; and changes to consumer habits and the effects on people's mental health. The potential subject matter to research is vast, and moving at an exponential rate. So the laws and policies needed to oversee this techno-social phenomenon will take time as debate and research continues.

The next few years, offer challenges and opportunities for the DAI. So the ideas posited here aim to be just a starting point. This thesis calls for collaboration between grief professionals, councillors, thanatologists and platform designers to produce a set of guidelines – which could also include signposts to grief agencies for

further support – with the aim of setting a “Gold Standard” for the death-tech industry and, specifically, the commercially driven intentional digital afterlife SPs. These companies may benefit from such a voluntary code of practice as DCs (who they need in order to be commercially viable companies) would be more inclined to use SPs who can demonstrate they are committed to the needs of DIs by operating under such a code. The technological capabilities of these platforms and the services they offer should not take priority over ensuring the wellbeing of the bereaved; thereby we should encourage digital afterlife SPs to design their platforms with TSD in mind (Massimi & Charise 2009) and, I suggest, within a voluntary code. The future dead that use them, will be able to take comfort in the knowledge that they will not be creating something that could cause harm to the DIs who receive them.

8 Chapter Eight: Conclusions and Recommendations

8.1 Introduction

The aim of this research was to explore how enduring digital memories and messages enabled by thanatechnology are being experienced by the creators and inheritance of these digital afterlives; thus, this thesis provides an insight into the significant implications of this inheritance. I started this thesis with a tour around the literature, and I pick up this metaphor again; to echo the words of Charmaz every research project is a journey and, “The sense we make of the journey takes form in our completed work” (Charmaz 2014). However long or arduous this research journey has been, at its end it has to be evaluated. In this final chapter, I discuss the strengths and limitations of the study and present my final reflexive thoughts. I then discuss the key findings of this research, and draw attention to how these findings contribute to knowledge. Next, using Charmaz’s criteria for the evaluation of constructivist grounded theory studies, I demonstrate the credibility; originality; resonance and usefulness of this thesis. I then move on to present the implications of my study for practice and future research, before finishing this thesis with a poignant reminder of the importance of this piece of work.

8.2 Strengths, limitations and reflexivity

To my knowledge this is the first study that takes a holistic look at digital afterlives enabled by thanatechnology by looking at all three actors in the production and inheritance of digital memories and messages: the SPs the DCs and the DIs. This thesis offers future studies a unique vantage point by including all relevant actors, however, it still provides a detailed and focused insight into how digital afterlives are affecting bereavement in our digital society. This thesis also contributes to discussions around the use of digital methods for qualitative research: specifically using Twitter as a recruitment tool, and the positive experience of using Skype for semi-structured interviews. The purpose of this study was to generate a substantive grounded theory of how the bereaved experience the inheritance of digital memories and messages, an aim which has been achieved and presented in this thesis.

It is important to acknowledge the socio-geographical limitations of this study, although I have discussed “Western” mourning rituals throughout the thesis there is a huge difference between acceptance and denial of death *within* the Western world: the UK, Ireland, Canada and USA are each distinct from each other in their traditions, acceptance and denial of death and dying, and this thesis has taken a macro view of these differing English-speaking regions without comparing responses across these geographical boundaries. Moreover, throughout this thesis I use the term digital society without considering the digital divide (specifically the digital “have-nots”), as not everyone has access to the Internet and smart digital devices. In addition, as in all doctoral theses, word and time limitations have resulted in the scope of the thesis remaining focused on achieving the aims set out at the start of this research. However, there were many interesting detours I would have liked to explore along the way but was unable to. Some of these interesting detours will be discussed in the future research section of this chapter below.

A further limitation of this thesis was that I did not recruit or interview any participants whose loved ones had died from suicide. This has left a gap in knowledge which I am hoping other researchers will fill. The exploration of whether thanatechnology has had any effect on the type of notes left, and how digital suicide notes may differ from physical suicide notes, could be significant and important thanatological research. Suicide notes are a physical form of posthumous messages and, therefore, when coding the interviews of the DC participants I was aware that the idea of leaving timed posthumous messages was a problem for me personally: I was influenced by my own thoughts of how I would personally feel, and this may have negatively skewed the interpretation of the coding of these interviews when looking at motivation. Being aware of one’s influence during the coding process is fundamental in qualitative research. I have been transparent throughout the thesis about this potential problem, and call on other researchers to fill this gap.

This interpretative study did not set out to represent all bereaved people who have inherited digital memories and messages; however it did aim to be generalisable. From the onset, I had a firm understanding that grieving and bereavement are experienced in multiple and complex ways. However, this thesis is the first step

towards a focused perspective on the impact of the creation and inheritance of digital afterlives. In order to strictly adhere to the ethical guidelines for a study of this type, how digital memories and messages enabled by thanatechnology are being experienced by those who suffer with complicated grief was outside the scope of this thesis. This would be a relevant and important area for future studies, and such findings would be a useful addition to those presented in this thesis.

One of the main challenges of this thesis has been keeping up-to-date with the evolving nature of the field of thanatechnology. The exponential growth of this technology is almost matched by the amount of research being done in this field, and the proliferation of papers being published across multiple disciplines has been difficult to keep pace with. This has presented challenges and opportunities; some newly published research seemed to “steal my thunder” or “pip me to the post” by beating me to publication (and negatively impacting my confidence as a researcher). Öhman and Floridi’s 2018 work on providing a new framework for the DAI, and Claburn’s 2018 thesis which introduced reciprocal bonds theory are just two examples. However, in hindsight these papers made me critically develop my ideas and theories further, which has resulted in this thesis being stronger and more robust.

I did not enter this research with any kind of clinical experience of grief and bereavement, which could be seen as a limitation to the study; yet, this ensured I did not start the data collection weighed down with assumptions or preconceptions about the theories and models of bereavement. This suited the ontological position of grounded theory, that theory should be grounded in the data rather than generated by empirically testing existing theories. As Charmaz argues, “*Reflexivity includes examining how the researcher’s interest, positions, and assumptions influenced his or her inquiry*” (2014, p.344). Following the practices of constructivist grounded theory I have been reflexive throughout this thesis, and in some ways this thesis tells my story as a researcher alongside the stories of my participants. Many of my participants have commented on how therapeutic they found participating in this research to be, and I too have experienced this; this thesis has allowed me to share a very personal part of my life which has been an invisible yet major part of who I am. Spending time with my participants has been such a special experience for me and their stories have not only shaped this research, but will stay with me forever. As a

final reflexive note, I would like to acknowledge that qualitative research is designed to elicit rich data, but I truly underestimated how thoroughly emotional, but enjoyable, I would find it.

8.3 Key findings and contributions to knowledge

One of the aims of this research was to explore if digital memories and messages enabled by thanatechnology disturb existing models of bereavement. The DPM of bereavement is a much used and respected model, however Chapter seven of this thesis demonstrates how, in its existing state, it does not accommodate the affect that thanatechnology is having on grieving. Moreover, it does not acknowledge that digital memories and messages affect the oscillation that the model itself insists is a necessary part of grieving. In Chapter seven, I expanded this model by incorporating a third, digital-oriented dimension. Bereavement professionals may not be aware of the potential effects thanatechnology is having on grieving rituals and social “norms”. Therefore, the expansion of this psychological model – which incorporates a sociological element – will be useful for bereavement professionals and academics alike by making visible the potential of an unnavigable, digital maze.

In addition to the proposed expansion to the DPM, this thesis is also an invitation to rethink the theory of continuing bonds to incorporate the impact of digital afterlives. Importantly, the notion of digital bonds presented in this thesis, are co-created by accidental digital creators, intention digital creators *and* digital inheritors. Moreover, this expansion highlights how digital bonds are experienced differently by the bereaved to other forms of continuing bonds accommodated within the original theory, as they are deemed to contain the essence of the dead.

This findings of this study also support, and expand, the existing literature across various disciplines by demonstrating how the bereaved find comfort in the inheritance of digital memories and messages; that is, when they control the access and timing of their usage. By highlighting the potential negative impacts of the uncontrollable delivery of posthumous messages, it is hoped that this thesis is viewed as a “canary in the mine”, in other words an early warning system, by SPs and bereavement professionals.

In addition to expanding existing theories and existing literature, this research has contributed to knowledge by making conceptual contributions to the field of thanatology. This research started by identifying and categorising three groups of participants: SPs, DCs, and, DIs. Treating them as three different – yet sometimes overlapping – categories resulted in a deeper understanding of different motivations and experiences across these three groups, whilst still providing a holistic understanding of the impact of digital afterlives.

In the early stages of this research I identified the need for a clear taxonomy for digital thanatologists when discussing the types of digital afterlife data enabled by, and stored on the Internet. In a 2015 paper, I suggested the term “digital legacy” should be used for passwords, account information, digital assets and digital property, and the term “digital selves” should be used for personal memories, photographs, videos, messages and blogs (Bassett 2015). My suggested terminology has been discussed and adopted by other researchers (Savin-Baden & Burden 2017; Sofka et al. 2017; Clabburn 2019; Clabburn et al. 2019). In this 2015 paper, I also suggested that a distinction should be made between intentional digital memories and messages, and accidental digital memories and messages, so as to acknowledge the intentionality of the creators of digital memories and messages. A distinction which has also been adopted by other researchers (see Sofka 2017). A further useful contribution is the introduction of the term “digital zombie” which is used to describe the reanimated dead and which now appears on Wikipedia linked to this research.

As discussed in Chapter three, at the beginning of this study I began to question the use of the term “immortality” when describing the nascent phenomena of digital afterlives, as one of my participants found the term upsetting. In addition, as discussed in Chapter four, many of the digital “immortality” service providers disappeared from the commercial landscape during the writing of this thesis. Therefore, this thesis advocates for the terms “digital endurance” or “digital afterlife” to be used to replace “immortality” when describing posthumous memories and messages enabled by thanatechnology.

The findings of this research also made visible how inherited digital artefacts differ from other forms of posthumous artefacts, because for the bereaved these precious digital possessions contain the essence of the dead. This knowledge is important, as it provides a deeper understanding of the nascent phenomenon of digital afterlives. It helps us to see how this precious data of the dead is experienced by the bereaved and disrupts existing models and theories of bereavement. Moreover, this notion that digital data embodies the essence of the dead could benefit how SPs and DCs handle the creation of digital afterlives in the future.

In Chapter seven, building on the work of Stokes (2015), this thesis adopted the concept of second death to describe social rather than biological death, and how the loss, deletion, corruption, or lack of access to posthumous digital artefacts, leads to the bereaved experiencing a second loss. Second loss is how the bereaved experience second death. This thesis moves this idea along by developing a new theory which explains how the bereaved are experiencing a new form of anxiety specifically linked to the inheritance of this precious data of the dead: the fear of second loss. This new theory is important to the field of thanatology as it demonstrates the impact that digital afterlives are having on mourning practices, and, crucially, how for the bereaved digital afterlives contain the essence of the dead.

This thesis has demonstrated how the quest to create a digital afterlife, or, importantly, to inherit a digital afterlife, is not a denial of death. However, digital afterlives blur the notion that death is the antithesis of life, and for some a digital afterlife is being thought of as an extension to life. This thesis has shown how the bereaved are interacting with the deceased in another *dasein* – a digital *dasein* – which is being experienced and used by the bereaved to continue their relationship with the dead. It has also shown how thanabots and posthumous avatars may exist in their own digital *dasein*. The use of this term is useful as it acknowledges the unique way in which digital afterlives are impacting on the “norms” and practices around grief and bereavement. It also highlights the problematic tension between the intended digital *dasein* of DCs and the digital *dasein* experienced by DIs. As this thesis has demonstrated, DCs set the terms of engagement for their digital *dasein* by controlling the delivery of posthumous digital messages, and their ability to remain

socially active on SNSs. The philosophical questions surrounding digital *daseins* are not answered within this thesis, moreover, this thesis adds more questions to the debate about the ontological status of the dead. However, I am hoping that by conceptualising the notion of a digital *dasein* I have provided a starting point which others may wish to explore.

The conceptualisation of digital *dasein* – the notion that posthumous digital memories and messages contain the essence of the dead – along with the theory of the fear of second loss developed in this thesis, raise profound questions about the creation and inheritance of digital afterlives. Therefore, this thesis attempts to provoke further discussions between SPs, academics, and bereavement professionals in an attempt to encourage collaboration, and – along the lines of Massimi and Charise’s (2009) idea – in a way that ensures digital platforms are designed with thanatosensitivity in mind; that is, that thanatosensitivity should be incorporated into platforms that enable digital afterlives. This thesis has identified that when precious data of the dead is inherited and experienced by the bereaved, the issue of their comfort is strongly linked with control. This theme of control is important, and my research suggests that the DAI are heavily focused on giving control to DCs at the expense of DIs, whereas this thesis is a call for a more balanced approach.

Undeniably, challenges arise from the exponential growth of the DAI; however, there are also opportunities for all three stakeholders (SPs, DCs and DIs) to take a pragmatic approach by embracing thanatechnology, which offers new ways to remember the dead, and importantly fosters our ongoing relationships with them. The introduction of a voluntary code of practice for the DAI, as suggested in Chapter seven of this thesis, would acknowledge the importance of these digital artefacts, which are experienced by the bereaved as containing the essence of the dead.

8.4 Evaluation of grounded theory research

Demonstrating the richness of the data whilst generating a substantive theory underpins the criteria and standards for a constructivist grounded theory thesis. Below I utilise the criteria suggested by Charmaz (2014) to demonstrate the usefulness and quality of this work:

8.4.1 Credibility

This research has explored how the bereaved are experiencing digital memories and messages enabled by thanatechnology. Using semi-structured interviews, followed by focused coding and analysis, enabled me to achieve the intimate familiarity with this topic which is a prerequisite of the method adopted throughout this research. In line with constructivist grounded theory approaches I did not see this journey as a quest to find the *truth* about the phenomena in question, rather this is a journey of constructed truths. I find it useful to imagine the vehicle as my methodology, myself as the driver who is there to mediate and interpret the instructions from my participants who are the route setters and navigators of the journey. This research involved 48 interviews across the three categories of participants; SP(n=8) DC(n=17) and DI (n=23) which provided rich data to ensure the findings and discussion made within this thesis can be classed as credible. The claims presented in this thesis have been grounded in the data and supported with the voices of my participants in the form of direct quotations from the interview transcripts. As discussed in the methodology chapter (Chapter three), using Skype to interview participants enabled my participants to feel relaxed in an environment of their choosing, and the Call Record facility which allowed for the playback of video and audio enabled me to feel “back in the room” – to watch and rewatch interviews during the important processes of transcribing and analysing of the data. Through my findings and discussion chapters I have presented strong, logical links between my gathered data and the arguments I have made, which has hopefully resulted in the reader being able to form an independent assessment and agree with the claims made in this thesis (Charmaz 2014). Grief is an individual experience, and no two people’s experience of grief can be compared, therefore, this thesis does not attempt to generalise how digital afterlives enabled by thanatechnology are being experienced by the bereaved, rather this thesis is a call to action to the SPs enabling digital afterlives, and those who are creating messages to be delivered posthumously, to allow full control to be given to those left behind to inherit the messages.

8.4.2 Originality

Due to the nature of thanatechnology, this field of research is relatively new and there are new and exciting additions to the literature on an almost daily basis. Other

qualitative works which focus on the effect of the Internet on death dying and bereavement; however, by interviewing participants from three participant categories: The service providers; the digital creators and the digital inheritors this thesis is unique as it extends our understanding of this phenomena. This has resulted in a new conceptual rendering of how the bereaved are experiencing the inheritance of digital memories and messages enabled by thanatechnology. The grounded theory of the fear of second loss developed from the collected data, provides an unique way of looking at how the inheritance of digital memories and messages is being experienced by the bereaved, which provides a useful insight for bereavement professionals, academics and the DAI. This thesis is not an attempt to debunk existing theories of bereavement. On the contrary, by using the voices of my participants to critically engage with these theories I have been able to: (1) expand the DPM model to highlight and accommodate how digital memories and messages are disturbing this well used existing model, and, (2) build on the theoretical framework of continuing bonds to develop digital bonds theory which brings to attention the uniqueness of digital bonds which are perceived by the bereaved to contain the essence of the dead.

8.4.3 Resonance

The categories developed during data analysis portray how the 23 DI participants experienced digital memories and messages enabled by thanatechnology. Developing the four concepts revealed the taken-for-granted and liminal meanings of these experiences, and has granted a deeper insight into the impact of this precious data. By linking the individual experiences of my participants to the wider literature relating to death and dying, this thesis has been able to make recommendations to bereavement professionals and academics across various disciplines.

8.4.4 Usefulness

A thesis should be useful to the practical and theoretical frameworks it has used as a foundation. However, it should also be useful to people in their everyday worlds. The theory of the fear of second loss developed in this thesis is useful to those providing the platforms which enable digital afterlives, because it sheds light on opportunities for the DAI if they mitigate possible negative impacts on the bereaved

generated by their services. In addition, my research provides an increased understanding of the effect of digital memories and messages on the bereaved which is useful to bereavement counsellors and practitioners alike. By highlighting the issue through the development of the theory of the fear of second loss, and the resulting suggestion of a voluntary code of practice for the DAI, I hope that the primary usefulness of my work will be to the bereaved, and their everyday experiences of living in a digital society where the dead remain socially active. For the DAI and DCs, I have suggested a voluntary code of practice, which would generate awareness for bereavement professionals of the potential negative impacts of the uncontrollable delivery of posthumous messages. In the next section I outline further implications of the creation and inheritance of digital afterlives.

8.5 Implications for practice and further research

Earlier in this chapter, I suggested there were some interesting detours along the research journey I would have liked to take. However, the necessity to focus on the aims, research questions, word and time limits of this thesis dictated what could be achieved within this study. One of the detours of particular interest to me during the research, was whether religious beliefs may or may not affect people's perception of digital memories and messages, which would provide an interesting and useful perspective to this area of study along with insights into how religious leaders view this new digital form of afterlife.

Further research is needed around the emotive and important issue of anonymity. As discussed in the ethics chapter of this thesis, during the recruitment and data collection stages of this research I was asked not to change the names of the deceased by three participants. After much deliberation and consultation I adhered to this request throughout this thesis. Treating participants as passive vulnerable agents rather than active co-producers of knowledge, does not reflect the investment of emotional labour by those who take part in qualitative research. Bonnie Scarth (2016) has written about this, and this thesis provides further evidence that anonymising the names of the dead in thanatological research when specifically requested not to do so by participants should be avoided.

A surprise finding has been how quickly people were getting used to the dead popping up on everyday devices which (as discussed in Chapter six) had resulted in changes to Mori's uncanny valley. Incidents of those using terminology linked to the uncanny valley changed rapidly during the four-year duration of this research. However, the acceptability of the dead popping up on everyday devices seemed to waiver when participants talked hypothetically about the dead being reanimated into digital zombies. How long this will continue to be the case will be an interesting area for further research. Parts of this study have discussed emerging technologies which are being used to create thanabots and posthumous avatars; creation of these two-way digital zombies could have profound implications for the bereaved, and, therefore, ongoing research will be essential in order to monitor the effect of these types of digital inheritance on the bereaved, in order to inform relevant agencies of potential problems for the bereaved.

The expansion of the existing theories of bereavement presented in this thesis contributes to knowledge by incorporating the digital aspects of grieving into these existing models. However, the phenomena of digital afterlives is relatively new, and therefore input will be needed by other academics and professionals to test and further develop these suggested expansions.

The theory of the fear of second loss developed during this research and its presentation in this thesis is just a starting point. This study has indicated that digital erasure leading to "second loss" will be an important area for future research, raising new and important questions for human-computer interaction in our digital society. This thesis is an invitation to other researchers and professionals to use the concepts developed herein to further explore how digital memories and messages continue to affect the bereaved over a longer period of time. Importantly, this is an invitation to service providers – both intentional and accidental – to further explore the issues around the fear of second loss, and ensure that potential harms to the bereaved are mitigated by adopting an ethos of TSD within their platforms.

8.6 A final word

My research has revealed how the practices, protocols and social "norms" of bereavement are being changed in people's lives via thanatechnology. Whilst other

researchers are focusing on the rights of the dead – in an attempt to give balance to the ongoing debates about digital afterlives – this thesis prioritises the experiences of those who inherit digital memories and messages: the bereaved. Although sociological in nature, this thesis has looked beyond the disciplinary boundaries of sociology in an effort encourage a multidiscipline, collaborative approach to this nascent and important area of research.

Against the academic norm, I have saved the most poignant of my participants' stories until the end as I want to leave you with a real sense of the importance of digital memories and messages for the bereaved: The data of the dead may well be made up of ones and zeros, however, it is experienced by the bereaved as containing the essence of the dead. Sally told me how she treasures a digital recording of her deceased daughter's heartbeat, stored on her mobile telephone. This story stuck with me – as did many of my interviews – but learning that this mother carried her dead daughter's heartbeat in her pocket perfectly captures why the research presented in this thesis is important: a heartbeat represents life, and even when it is digitally recorded and technologically mediated, it is far more than digital code.

The dead have been an important part of this thesis; however, we should be aware that *we* are the future dead, and for most of us who live in the digital societies of the West, technology is ensuring we will all have a digital afterlife. As we get used to the socially active dead being online, we should also be aware that we can lose these precious digital memories and messages containing the essence of our dead loved ones. The impact and significance of thanatechnology should not be underestimated, and this thesis is a cautionary tale: it reminds us that we are far from immortal, even in a digital age, and therefore we need to realise that we only live twice.

Finally, this thesis ends as it began, with the words of Terry Pratchett:



Appendices

Appendix 1. Information sheet



UNIVERSITY OF WARWICK INFORMATION SHEET

Researcher name: Debra Bassett

Supervisors name: Professor Steve Fuller & Professor Simon Williams

Project title: Who Wants to Live Forever? Living, Dying and Grieving in Our Digital Society.

Date:

Researcher email: [REDACTED]

What is the purpose of the study? As part of the requirement for PhD at the University of Warwick, I have to carry out a research study. The study is concerned with the creation of digital memories and how they are used to discuss illness, dementia, death & dying. I will be looking at how the creation of these digital memories/legacies may be beneficial to those doing the creating. The study is further concerned with how the promise of digital immortality offered by the Internet may affect the way people grieve.

Why have I been asked to participate? You have been asked to participate because you replied to requests to participate and are suitable to provide data for the study.

Do I have to take part? No, you do not have to take part in this study. Your participation is entirely voluntary. You will be asked to sign a consent form, and you will be able to withdraw that consent before the study takes place or at any time during the data collection (the interviews). You can ask for your data to be withdrawn from the study and destroyed for two weeks after the end of the data collection.

Will the study be kept confidential? Yes, I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information you give? The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further five years in a secure environment and then destroyed.

What will happen to the results? The results will be presented in the thesis. My supervisors, and also external examiners will see them. Parts of the study may also be published in academic journals.

Are there any disadvantages of taking part? I do not envisage any negative consequences; however discussing issues surrounding digital immortality may include discussions about mortality and grieving. These issues can be emotional to discuss, and it is important to point out that I am not a bereavement councillor and that these interviews are not meant to form part of bereavement therapy - although some people may find the discussions therapeutic.

What if there is a problem?

When the interview has finished I will ask you how you found the experience. If you have found the interviews distressing I will be able to provide you with contact details of specialist

outside agencies.

Who has reviewed this study? This study has been given ethical approval by University of Warwick, Sociology Department.

Any further queries? If you have further questions about this study please contact:

Debra Bassett

[REDACTED]

[REDACTED]

If you agree to take part in the study please complete the consent form attached.

Appendix 2. Consent form



UNIVERSITY OF WARWICK CONSENT FORM

Researcher name: Debra Bassett

Supervisor name: Professor Steve Fuller & Professor Simon Williams

Project title: Who Wants to Live Forever? Living, Dying and Grieving in Our Digital Society.

Date:

Researcher email: [REDACTED]

I confirm that I have read and understood the Information Sheet for the above study and have had the opportunity to ask questions.

I agree to take part in the above study.

I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving any reason and without being penalised or disadvantaged in any way.

I understand that my information will be held and processed for the purposes of publication in a PhD thesis, papers for publication in academic journals and presentations at conferences.

Signatures:

Study participant

Print name..... Signature.....

Date.....

Person obtaining consent

Print name..... Signature.....

Date.....

Appendix 3. Recruitment poster

RESEARCH INTO DIGITAL MEMORIES



Have you or anyone you know inherited a digital message from someone who created it to be read posthumously?

Willing to take part in important PhD research?

Please contact me:

Debra Bassett
Department of Sociology
University of Warwick



For further information please see my website: debrabassett.co.uk or follow me on Twitter 

Appendix 4. Publications, Conferences and Media

Publications

- Bassett, D., 2015. Who Wants to Live Forever? Living, Dying and Grieving in Our Digital Society. *Social Sciences*, 4(4), pp.1127–1139.
- Bassett, D., 2017. Shadows of the Dead: Social media and our changing relationship with the departed. *Discover Society*. Available at: <http://discoversociety.org/2017/01/03/shadows-of-the-dead-social-media-and-our-changing-relationship-with-the-departed/>.
- Bassett, D., 2018. Ctrl + Alt + Delete: The changing landscape of the uncanny valley and the fear of second loss. *Current Psychology*, pp.1–9.
- Bassett, D., 2018. Book Chapter. Digital afterlives: from social media platforms to thanabots and beyond. In Charles Tandy (ed.), *Death and Anti-Death, Volume 16: Two Hundred Years After Frankenstein*. Michigan, USA: Ria University Press (2018).
- Bassett, D., 2020. Book Chapter. Profit and loss – The mortality of the digital immortality platforms. In M. Savin-Baden and V. Mason-Robbie (Eds) *Digital After life*. New York: Taylor and Francis (Forthcoming).

Conference presentations

- Bassett, D., 2017. Oral presentation: Preliminary findings from fieldwork presented at the Cyberpsychology, Behaviour, and Social Networking conference, Wolverhampton University in May 2017.
- Bassett, D., 2018. Oral presentation: Findings related to the changing landscape of the uncanny valley, presented at Death and Culture II conference, University of York in September 2018.
- Bassett, D., 2018. Oral presentation: Edinburgh International Science Festival, panel discussion, Digital Afterlives, Summerhall, Edinburgh, 2018.
- Bassett, D., 2019. Oral presentation: British Science Festival, Ghosts in the machine, in conversation with Dr Elaine Kasket, University of Warwick, 2019.

Media

- Bassett, D., 2017. Interview with Michael Waters, DMs From Beyond the Grave Are Changing How We Grieve. *Motherboard*. Available at: https://www.vice.com/en_us/article/qv3qv3/beyond-the-grave-text-messaging-changing-how-we-grieve-death

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- Bassett, D., 2019. Interview with Radio CBC Saskatchewan. 'Her heartbeat can fill my heart': How digital memories let us communicate with the dead. *CBC Saskatchewan*. Available at <https://www.cbc.ca/news/canada/saskatchewan/digital-memories-grieving-1.5090344>
- Bassett, D., 2019. Interview with Der Spiegel. What does my Facebook account do when I'm dead? Available at <https://www.spiegel.de/plus/was-macht-mein-facebook-account-wenn-ich-tot-bin-a-00000000-0002-0001-0000-000165579745>

Appendix 5. Support Organisations

Cruse Bereavement Care

Website: www.cruse.org.uk

Helpline: 0808 808 1677

Email: areasupport@cruse.org.uk

Compassionate Friends

Website: tcf.org.uk

Helpline: 0345 123 2304

Bereavement Trust

Website: bereavement-trust.org.uk

Helpline: 0800 435 455

After Breast Cancer Diagnosis

Website: abcdiagnosis.co.uk

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