



Selina-Ellis-Gray

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# Remains in the Network

Reconsidering Thanatosensitive Design in Loss



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**Selina-Ellis-Gray** This thesis is submitted July 2015 in partial fulfilment of the requirements for the degree of Doctor of Philosophy.

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## ABSTRACT

In the end, we are all dead. But for some of us, our deaths become entangled online. Our vast data legacies and the appropriation of social media by the bereaved can result in online networks being used to mediate loss, mourning and memory in the event of a death. Recognising this phenomenon between death and technologies has resulted in researchers and designers being asked to become ‘thanatosensitive’, or death-sensitive. In particular, designers have been presented with Thanatosensitive Design [TSD] as an optimistic and non-prescriptive design methodology, devised by Massimi, for researching, designing and developing thanatosensitive technologies within sensitive end-of-life contexts (Massimi, 2012).

This thesis is an invitation to reconsider TSD, to rethink what sensitive design practice could look like and the kinds of commitments and claims it is making to bereaved people. This reconsideration takes place through the development of an interdisciplinary conceptual framework that supports ‘thinking with’ and ‘caring for’ other elements in a situation of inquiry (Diprose, 2009; Puig de la Bellacasa, 2012; Puig de la Bellacasa, 2011). Empirically, this exposes a messy human landscape of loss, non-living ‘ghosts’ and non-human networks, the presences and agencies of which unsettle the human-centred ethico-political assumptions that lie within the TSD agenda.

This thesis embraces the disturbances that have arisen from empirical and theoretical commitments and uses them as a way to reconsider what thanatosensitivity looks like when it embraces a more inclusive ethico-political landscape that decentres the human. Therefore, this thesis contributes to emerging literatures at the recent intersection between death and technology studies, firstly, by exposing a complex and previously unaccounted for messy ecology of loss across networks online, and, secondly, by reflexivity, exploring how this messy ecology disturbs the centrality of the human in TSD framings.

These contributions cumulate in a reconfiguration of TSD that draws out an alternative approach and considerations for practitioners interested in designing sensitively for the end of life. This reconfiguration aims to be socially responsible, inclusive and ecologically sensitive in ways that set it apart from Massimi’s original concept of TSD. This new vision of sensitive design is summarised into a design statement and a polemic design manifesto to aid practitioners who wish to sensitively design for the end of life. The thesis leaves us with a speculative afterword, to consider future work and envision what other forms designing for death might take if we continue to push at the human-centeredness within design ecologies in light of the apocalyptic shadow of the Anthropocene.



## Remains in the Network: Reconsidering Thanatosensitive Design in Loss

Selina Ellis Gray

@nina ellis  
selina@digitalloss.net  
www.digitalloss.net  
www.lossmedia.co.uk

HighWire  
Lancaster University  
Research Councils UK Digital Economy Programme



For the Boss, Floss and the Jones's

I declare that this thesis is my own work and has not been submitted in substantially the same form for the award of a higher degree elsewhere. To the best of my knowledge it does not contain any materials previously published or written by another person except where due references is made in the text

Selina Ellis Gray

July 2015

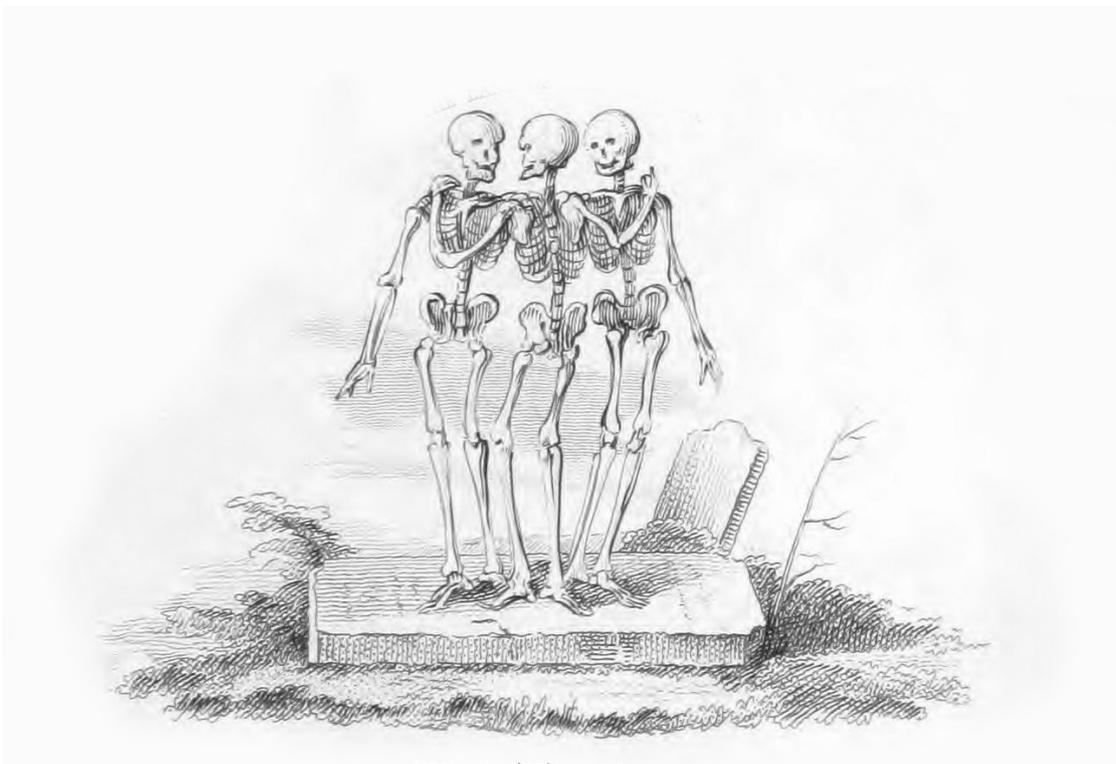


“ No matter how careful you are, there’s going to be the sense you missed something, the collapsed feeling under your skin that you didn’t experience it all. There’s that fallen heart feeling that you rushed right through the moments where you should’ve been paying attention.

Well, get used to that feeling. That’s how your whole life will feel some day.

This is all practice. ”

Chuck Palahniuk, *Invisible Monsters*



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## PERMISSIONS

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Chapter Two contains excerpts originally used within the journal article Ellis Gray, S., 2014, 'The Memory Remains: Visible Presences within the Network', *Thantos*, Vol. 3, no. 1, p.127, and also the conference paper Ellis Gray, S. and Luján Escalante, MA 2014, 'Digital Dead Remains: Exploring material and in-material legacies', *Death Online Symposium*, Durham.

Chapter Four contains excerpts originally used within the workshop paper Ellis , S., 2012, 'An Interdisciplinary Lens: Design Challenges in Bereavement Support', *Memento Mori, Workshop: Technology Design at the End of life, A workshop held in association with ACM SIGCHI 2012*, Austin, Texas, and also the conference paper Ellis Gray, S., 2012, 'The Diversity of Mourning Practices Online', *Digital Futures 2012*, Aberdeen.

Chapter Five contains excerpts originally used within the book chapter Ellis Gray, S. and Coulton, P., 2013, 'Living with the dead: emergent post-mortem digital curation and creation practices', in *Digital legacy and interaction: post-mortem issues*, 1st edn, Springer, Berlin.

Chapter Six contains excerpts originally used within the journal article Ellis Gray, S., 2014, 'The Memory Remains: Visible Presences within the Network', *Thantos*, Vol. 3, no. 1, p.127.

Chapter Seven contains excerpts originally used within the workshop paper Ellis Gray, S., 2012, 'The Ethico-political Dimension of Thanatosensitive Design-orientated Research', *Proceedings of HCI 2012 The 26th BCS Conference on Human Computer Interaction*, Birmingham, UK, 12 - 14 September 2012.

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“All God does is watch us and kill us when we get boring  
We must never, ever be boring”

Chuck Palahniuk

# CHAPTER ONE

## INTRODUCTION

This thesis is an invitation to reconsider Thanatosensitive Design [TSD],<sup>1</sup> to think about what other forms TSD could take and the kinds of commitment being made to potentially vulnerable people. This thesis is interested in the voices and elements that are on the margins or silenced in current TSD framings and within the death and technology studies intersection. In this reconsideration, the centrality of the human comes under scrutiny, due to the way it obscures the presences and agencies of other important elements that are present within an ecology of loss online. Not recognising these different elements has important consequences for research and design practice due to how their presences and agencies can trouble and disturb the promises being made to support people at the end of human life.

This study turns to online networks and undertakes a process of acknowledging humans but moving to decentring them in order to inclusively bring in other non-living and non-human presences that are missing within the

TSD agenda. My approach is not intended to diminish the important human component or to depreciate the TSD agenda. Rather, the human decentring that lies at the heart of this thesis takes very seriously the political commitments and ethics of care that underpin the vision initially expressed by Massimi (2012). The rationale and motivation behind this reconsideration lies with how decentring the human welcomes



<sup>1</sup> *Thanatos originates from the Geek mythology personification of death. 'Thanatosensitivity', as coined by Dr Michael Massimi, is asking us to be death sensitive in the design and development of technologies for the end of life.*

other presences that rely on a more distributed understanding of agency. These elements collectively work to mediate loss, mourning and memory in the event of a death online and I argue that, together, this collective of different elements constitutes an important ethico-political landscape that that is currently at work but presently unacknowledged in TSD.

Changes to the centrality of the human and human-centred agency profoundly destabilise how designers aligning with TSD can understand its role and capabilities at the end of life. This opens up a different vision of what sensitive design practice at the end of human life looks like and what its capabilities are for intervention when we take seriously other elements in ‘framing’ a situation for research and design inquiry (Stolterman, 2008; Schön & Rein, 1995).

This reconsideration of TSD and its ethico-political landscape unfolds through interdisciplinary channels, both in terms of where TSD is situated at the intersection between death and technology studies, and also in relation to the bodies of work upon which this thesis draws. It is for this reason that this introductory chapter clarifies key intersectional terms. With the terminology explained, the reader will then move on to gain an understanding of the issue of interdisciplinarity itself and the ways in which I understand and approach working across different disciplinary locations. I present a type of interdisciplinary ‘mode’ characterised by a critical and antagonistic engagement with the various literatures that have consequences for the thesis moving forward.

This introduction then moves on to explain my location and addresses my professional journey as a digital designer. I contextualise my encounter with TSD in order to draw out the elements of academic inquiry around death-sensitive design that have captured my interest, presenting my personal motivations by relaying more intimate experiences with loss that have undoubtedly shaped my approach to this study. I account for engagement with TSD as a ‘labour of care’, which has conflicts and struggles, before I finish this chapter with a detailed thesis structure that has been shaped by my practice as a designer.

## CLARIFYING INTERSECTIONAL TERMS

This research speaks to an emerging interdisciplinary space between death and technology studies. Spanning Human Computer Interaction [HCI] and the multidisciplinary arena of Death Studies, this very recent intersection has been developing since 2009 and is characterised by a small but growing body of literature. This inquiry is concerned with the research and subsequent influence on design in this arena. However, it is informed by my personal location and motivations as an interdisciplinary design practitioner and researcher drawing from New Materialist philosophy, Science, Technology and Society<sup>2</sup> [STS], New Media Studies and Critical Design Studies<sup>3</sup>. There is the potential for different readings and misunderstandings to arise; therefore, there are a number of key terms and phrases that I would first like to clarify.

To begin, when I talk about ‘sensitive contexts’,<sup>4</sup> I am referring to inquiry within taboo or difficult, unfolding research landscapes; for example, political instabilities, regimes, war, death, suicide, dying, chronic illness, sexual abuse, rape, violence, drug use, homelessness, prostitution and murder (Lee, 2000a; Liamputtong, 2007; Dickson-Swift et al, 2008). The ‘end of life’ is a specific sensitive area used to denote the academic study of death and its subthemes of mortality, dying and bereavement. Approached by numerous disciplinary fields such as psychology, sociology and anthropology as well as clinical health and medicine, the end of life is a highly interdisciplinary research field.

TSD has been focused on technologies that intersect with this end-of-life arena, yet the overwhelming focus has been the phenomena of ‘bereavement’ and the bereaved. From my engagement with this scholarship, I have come to consider bereavement as a term people identify with when they are living with loss, while “loss” itself is an “ontological dilemma” that the living face when a relationship is ruptured through death. Loss is the perpetual absence left behind by death. It denotes a need to hold

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<sup>2</sup> Also known as Science and Technology Studies.

<sup>3</sup> Also scholars who are working out of interdisciplinary spaces.

<sup>4</sup> Contexts is not referring to the representational view but to where content and context are mutually constituent, as explained by Paul Dourish (Dourish, 2004).

on, comprehend and remember while similarly to recognise the permanence of the absence and remake lives in the face of loss (Lunghi, 2006; Stanley & Wise, 2011). This dilemma of loss is a complex and messy phenomenon experienced within a wider cultural and historical framework (Small, 2001), a framework that is considered mutually to penetrate, influence and shape our inner emotional experiences of loss (Walter, 1994; Davis, 2002).

Academically, loss can be divided into the inner world of grief and the outer world of mourning. These delineations have arisen from particularly disciplinary approaches, such as the inner world of grief being of interest to a field such as psychology and the outer world of mourning being of interest to anthropology. However, I do not abide by these distinctions of loss. Rather, I use the word loss very deliberately to invoke something broader, a 'constellation of affects' of bereavement: the entanglement of the individual, collective, material, spiritual, psychic, social, aesthetic and the political (Eng & Kazanjian, 2003). To account for this constellation empirically, loss connects to the performative nexus of doings and sayings within practice theory. Documenting 'practices of loss' works inclusively to account for the phenomenon of loss in ways that do not delineate the inner and outer worlds in ways that address the materiality of these doings (Schatzki, 1996; Reckwitz, 2002).

This word 'entanglement', borrowed from the work of Barad and STS (Barad, 1996), helps to envision the inseparability of the phenomena of loss rather than reinforcing the traditional academic boundaries that typically delineate the emotional from the social or the individual from the collective, which can be found around terms like 'grief' or 'mourning' (Small, 2001; Barad, 1996). My rationale for this comes through an appreciation of Continuing Bonds theories that emerged in Death Studies in the late 1990s, which, methodologically, have pushed towards different understandings of loss outside of rationalised or normative frames of closure (Klass et al, 1996). Rather, Continuing Bonds works to acknowledge the differences that can be found in loss and to respect these differences with regard to how the living work with the inherent

presence of the dead within their lives.

In subsequent discussions around this idea of entanglement, the reader will encounter a more subtle and nuanced way of gesturing towards this sensibility. The removal of hyphens signifies the move away from dualistic pairings. Therefore, 'socio-technical' moves towards the 'sociotechnical' and the inherent inseparability that I consider to be at work.

## ADDRESSING INTERDISCIPLINARITY

This thesis speaks to designers and researchers within the recent interdisciplinary intersection between death and technology studies, by drawing from New Materialist philosophy, STS, New Media Studies and Critical Design Studies<sup>5</sup>. I consider Critical Design Studies as the home of my intellectual practice. This location encourages its practitioners to draw inspiration from unusual and even speculative spaces in order to think about the big and even global challenges facing design practice (Dunne & Raby, 2014; Ferri et al, 2014; Bardzell & Bardzell, 2013). My current focus in TSD and the space between death and technology studies comes out of this location and draws upon interdisciplinary scholarship as theoretical inspiration. These other stimulating disciplinary spaces, that I turn towards and draw upon, help me undertake the process of reconsidering TSD and to think differently about framing a situation for TSD research and design inquiry. Firstly, I draw on STS and New Materialist philosophy as I have found both generative for decentring the human and human-centred framings of agency that are a key to my reconsideration of TSD. Secondly, I draw upon New Media Studies as a companion to develop my understanding of social networks, which are the key empirical focus of this thesis. New Media Studies specifically helped me to stay with the themes of entanglement and materiality when turning towards digital networks and media.

The initial engagement with these different bodies of literature prompted my research questions, which are introduced together in the interdisciplinary literature review. Their

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<sup>5</sup> Also scholars who are working out of interdisciplinary spaces.

influences can be felt within my methodological commitments and I return to consider them together within the concluding sections of this thesis. The ongoing themes of human-centredness, agency and intervention that are discussed in these chapters bring very different disciplinary understandings of what constitutes knowledge and understanding of practice, particular protocols, and conventions together. This can be a transgressive act and can make scholarship appear undisciplined in nature. These differences are part of the inherent difficulties that I have experienced at work as an interdisciplinary scholar.

Scholarship that attempts to define what exactly interdisciplinarity is and what work interdisciplinarity does, has a rich history (Lattuca, 2001). My understandings contrast with mainstream interpretations of interdisciplinarity, which discuss traits of disciplinary integration, unity and cohesiveness (Lattuca, 2001; Barry & Born, 2013). Interdisciplinarity itself can invoke a method or problem-solving approach that builds a synthesis or creative fusion out of different disciplinary perspectives and integrates them into a unified whole (Barry et al, 2008). Other terms have also emerged to signal these promising synergies or fusions, such as pluridisciplinary, crossdisciplinary, transdisciplinary or postdisciplinary (Lattuca, 2001). Along with the term interdisciplinary, these labels collectively gesture towards the transcendence of disciplinary world views and suggest interdisciplinary problem solving (Barry et al, 2008).

While this friction-free dream of an interdisciplinary space that solves complex problems and breaks down disciplinary boundaries dominates academic understanding, there are other readings of what interdisciplinarity can mean (Lattuca, 2001; Barry et al, 2008; Barry & Born, 2013). Barry (geographer), Born (sociologist) and Weszkalnys (anthropologist) (2008) have presented three contrasting modes of interdisciplinarity (Barry et al, 2008). I will draw upon Barry, Born and Weszkalnys's 'agonistic-antagonistic' mode in order to better outline my understanding of interdisciplinary work. This 'agonistic-antagonistic' mode is described by Barry, Born and Weszkalnys,

As driven by an agonistic or antagonistic relation to existing forms of disciplinary knowledge and practice. Here, interdisciplinarity springs from a self-conscious dialogue with, criticism of or opposition to the intellectual, ethical or political limits of established disciplines or the status of academic research (Barry et al, 2008).

Working from these more critically engaged perspectives, interdisciplinarity is not foreseen or positioned as a way of building synergies, but rather troubling, agitating and even dismantling disciplinary perspectives (Lattuca, 2001; Barry et al, 2008; Barry & Born, 2013). Interdisciplinarity then becomes a term not related to integration but rather a more transgressive mode of working across different disciplinary conventions, knowledge practices, power asymmetries and value systems.

## MY JOURNEY TOWARDS ENCOUNTERING TSD

As a professional digital designer, my understanding of knowledge construction is heavily informed by practice and my recent research experience within Participatory Action Research and Participatory Design projects. My location as a designer and my identification with critical design means that I am aware of the broader discussions in the discipline of Design around knowledge construction and the relationship between design practice and research inquiry. To navigate and signpost where I locate myself within these debates, I consider myself to be a practitioner-researcher and describe the style of my inquiry process as ‘Designerly’ and ‘Bricoleur’ in nature (Schon, 1992; Cross, 2001; Gray & Malins, 2004; Cross, 2006).

I identify as a practitioner-researcher, as a designer who has a professional practice and at the same time carries out inquiry that is of relevance to the job (Gray & Malins, 2004). I bring a ‘designerly’ reflective practice and tacit knowledge that is interested in ill-defined or ‘wicked’ problems, the material agency of things, objects and habitats, which, according to critical designers Jan Rod and Denisa Kera, ‘design practice so ceaselessly embraces and experiments with’ (Rittel, 1973; Buchanan, 1992; Cross, 2006; Rod & Kera, 2010). Cross argues that there is a distinct designerly form of activity that separates and makes it identifiable from scientific or scholarly activities (Cross, 2006). I identify this designerly approach as a process of bringing

together and arranging different elements in an emergent and responsive way that unfolds a situation at hand (Punch, 2006; Gray & Malins, 2004). To characterise this aspect further, Gray and Marlins connect this designerly approach with the notion of the Bricoleur or Researcher-as-Bricoleur (Denzin & Lincoln, 2008; Gray & Malins, 2004). They use it in the sense that Denzin and Lincoln (2008) outlined, but apply it to practitioner-researcher and the field of design: 'The researcher became a Bricoleur, learning how to borrow from many different disciplines' (Denzin & Lincoln, 2008).

The term 'Bricoleur', derived from French culture, is to denote 'someone who works with his or her hands and uses devious means compared to those of the craftsman' (Weinstein & Weinstein, 1991). According to Levi-Strauss, the Researcher-as-Bricoleur is working with and limited by the particular histories of where the 'bits and pieces' came from, and they need to pay close and careful attention to the objects of research while trying to 'get the job done' (Levi-Strauss, 1994). I identify with the Researcher-as-Bricoleur's sense of 'inventiveness, resourcefulness and imaginativeness', which manifests as a designerly opening up, breaking open, pulling apart and bringing together of new, experimental and even eclectic arrangements (Crotty, 1998; Gray & Malins, 2004; Cross, 2006). It is important to flag these aspects at the outset as they serve to highlight the situated perspective from where this reconsideration of TSD is emerging.

Since leaving full-time professional practice to undertake an MA in 2009, my efforts have been focused on participatory research and design methodologies, particularly in thinking through the power relations and the political implications when researching or designing. This interest arose to the notion of the 'user' that I encountered during my digital design practice. Since 2000, I have been undertaking professional work involving the design and construction of responsive and interactive elements, which inevitably began to introduce me to scholarship on usability, user experience and user-centred design. This scholarship on interaction design began to raise questions about the political process of design and how the user is considered and implicated with

in this process. I was interested in what happened when the passive framing of the user was troubled in ways that meant he or she became agential (Stolterman, 2008; Dourish, 2006). Similarly, I was interested in how this shift in agency from the passive to the active user signalled a change in the role of the designer (Cruickshank & Evans, 2008).

It was these interests that led me towards exploring the practice of Participatory Design (Schuler & Aki, 1993; Muller & Jacko, 2009) and Participatory Action Research (Heron & Reason, 2006). I gained particular interest in designing and researching with people who have had long history of being marginalised and voiceless within design activities (Druin, 1999; Leigh Guha DruinFails, 2008). In 2010, I moved into increasingly interdisciplinary theoretical philosophical spaces that were questioning and troubling the central human and subject during my time as a HighWire MRes student. It was through the final MRes project of 2011 that the topic and shape of this entire doctoral study arose, during the summer. Through this time period I was working closely with Esther Waite, Helen Pritchard and Hazel Bone as part of a participatory study that introduced me to STS and New Materialism, which began to trouble the user and my commitments to human-centred design in a more disruptive and irreversible way. These broader interests intersected with death through ongoing discussions with my now supervisor, Paul Coulton, who was working on a project called Rest in Pixels (Lochrie & Coulton, 2011). It was through this project that I discovered the Death and Technology Studies intersection and, importantly, TSD literature.

Figure 1.1: Participatory artefact from 2011. The theme of death can be seen in the illustration of a grave on the bottom right hand side





with, I began to notice the other elements at work in the situation of inquiry. Thinking about the materiality of practice and the other non-human elements that could be present, I recognised that internet research and accounting for the ‘lives’ of digital media could potentially offer a different insight.

## PERSONAL MOTIVATIONS

In terms of my professional background as a digital designer and my research interests in sensitive areas, I felt a strong affinity with the work that was starting to emerge around the sensitive context of loss, thinking about design and digital media use. Yet my academic interest did not come from a ‘god’-like,<sup>6</sup> rational or objective place. Gale Letherby argues that drawing from feminist research traditions usually results in the researcher formally moving to acknowledge the contextually<sup>7</sup> located reasoning that is taking place (Letherby, 2003). Therefore, I was encountering this body of literature as a person, one interested in the dark side of life and one who is also affected by numerous losses.<sup>8</sup> Like everyone else, I am not loss exempt. I look upon bereavement with the knowledge that, ultimately, we will all experience loss and be implicated or belong to this community, even if these losses affect us in very different ways and we do not necessarily identified as being ‘the bereaved’ (Small, 2001).

From my own encounters with loss, I understand it to be something that shapes us rather than a phenomenon from which we necessarily recover from. This is a step away from scientifically inspired notions of grief and resolution and I believe this perspective is due to spending my formative years in the shadow of a deeply traumatic loss, one that has irrevocably damaged my family and shaped the



Figure 1.3: Discoloured home picture of Peter Gardening

<sup>6</sup> I am referring to what Donna Haraway considers as the ‘God Trick’, to do some form of objective distancing that makes it possible to see, but not be seen, to speak from nowhere (Haraway, 1988).

<sup>7</sup> Letherby is advocating using Liz Stanley and Sue Wise’s ‘intellectual biography’ approach (Stanley & Wise, 1993), which should provide readers with an analytically constructed account that brings insight into where the research design has arisen (Letherby, 2003; Stanley & Wise, 1993).

<sup>8</sup> Alongside losing people, there is also the loss of companions, the loss of love and even the loss of hopes and dreams (Eng & Kazanjian, 2003).

type of upbringing I experienced as a child. A difficult story to recount, and the true ramifications of which I cannot describe, on the maternal side of my family we are all missing and shaped by the loss of Peter. Peter Leedham was born on 14th December, 1929. He was a monumental stonemason, a single father to five children, a cyclist, a gardener and my grandfather. On the 20th October, 1981, Peter went to work and never came back. I was eight weeks old. His death left behind my aunt Janet (22 at the time), my mum Alison (20) and my uncles Andrew (21), Craig (19) and Martin (15). Due to the violent manner of his death, Peter had to be identified by his belongings. The young family faced a coroner's inquest and went through a lengthy seven-year court case (that was eventually settled through an out-of-court settlement).

Although I obviously have no memories of Peter, I have a fairly well developed sense of him as a person. I think this sense was developed in childhood through the deep grief of my mother. His death, just weeks after she became a mother, was a huge rupture in her life; but my mother ensured that his presence continued on in our lives. In my home and the homes of my relatives could be found a wealth of media that had been collected together and curated over my formative years, from a collection

of photographs, trinkets, birthday cards and formal records such as Peter's birth and death certificates and newspaper clippings. There were also frequent trips to the graveyard, particularly around family holidays and key dates, when my mother would clean his grave

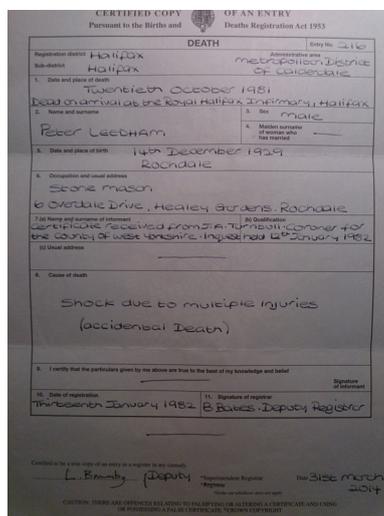


Figure 1.4: Newspaper clipping of Pete's death <https://www.dropbox.com/s/ck5rorhb0651530/newspaper.jpg?dl=0>

Figure 1.5: Peter's Death Certificate <https://www.dropbox.com/s/1ptaddkstvalk6a/cerificate.jpg?dl=0>

Figure 1.6 Oil Painting by Andrew <https://www.dropbox.com/s/caivnfvxji6ru7/painting.jpg?dl=0>

and talk to her dad. Even 34 years after Peter's death, my mother can still easily recount a detailed biography of her father and give life to his personality by sharing memories that invoke his vibrant presence.



The rest of my maternal family has been profoundly affected by Peter's death and it has marked not only their lives but also their relationships with each other (and our coherence as a family). The rest of the family also have their own individual ways of remembering, that differ between the siblings. These variations can be a source of comfort, derision and even discord, reflecting the vast differences in the social norms that can exist, even between relatives and families (Walter, 1994)

Above is an untitled oil painting, on canvas, created in the early 1980s by my uncle Andrew, who is a painter. Andrew has deviated away from his usual landscape work in order to capture a snapshot of family life after Peter's death that I find deeply evocative. The little girl in the white dress holding the radiator is me. Beside me is my mother, Uncle Martin and Uncle Craig. It seems to reflect the sadness, isolation and emotional distance between the family members that was particularly acute in the years shortly after Peter died. My mother's solemnness was particularly acute at this time because she experienced having her grief pathologicalised in the aftermath of losing her father. Now, over 32 years later, she still deeply resists notions of recovery that she was presented with at that time. Echoing Douglas Davis in 'Death, Ritual and Belief' (2002), my mother speaks of becoming a different person after her experience, of how some experiences affect life in such a profound way that people are never the same again (Davis, 2002). As Davis states, 'To speak of recovery is to talk about a kind of backwards change, an undoing of what has been done, an unliving part of a life, and this is impossible' (Davis, 2002).

## LOCATION STRUGGLES AND INTERDISCIPLINARY RIFTS

Within this reconsideration of TSD and its human-centred commitments is a collection of academic, professional and personal interests. In this thesis, these different aspects bring together scholarship and work with it in ways that may be provocative and wilful to encounter. It is certainly a struggle to undertake its process of inhabiting contrasting positions that often speak past each other. Yet this work provides a space to reflect and take seriously the balance of elements when framing a situation for thanatosensitive research and design inquiry. An aspect that is particularly important when considering design is making commitments and holding onto certain foundational assumptions when approaching particularly difficult circumstances.

The two main sources of tension can be found between the human-centred TSD frame and the Posthumanist space that open up from my STS and New Materialism engagement. To contrast these sources against each other, the TSD agenda aspirationally, even optimistically, envisions its role as a lens or process that can contribute to socio-technical improvement in the lives of the bereaved. For TSD, this process of improvement is occurring within a stable human-centred landscape, where a skilful and adept death-sensitive design approach is all that is needed to make a progressive step forwards in the design, development and improvement of existing socio-technical systems. For researchers and practitioners working within this thanatosensitive agenda, the aim is to engage in skilful practice that will work to favourably support people within the sensitive context of death, bereavement and loss. However, my engagement with New Materialist philosophy, critical feminist readings of care, and encountering of Posthumanism has deeply troubled this centrality of the human in the TSD agenda. Posthuman interests in more generative and collective life deliberately move away from human-centred and dualist frames in order to reposition the human as embedded within material networks from which they cannot be distinguished (Bennett, 2010; Dolphijn & Van der Tuin, 2012).

I am approaching this core tension from a humanities and human-centred background

while still being interested in other disciplinary spaces and scholarships. These other places prompt me to loosen my hold on my commitment to humans (and to the humanities). This light touch is undertaken knowing that I will eventually return 'home', to think about design frames in TSD differently, with the consequence that this home will look different. Therefore, part of this struggle is the experiential journey wherein I move to inhabit the different value systems that are at work, 'Rather than retreating into the secure position of an enlightened outsider who knows better' (Puig de la Bellacasa, 2012).

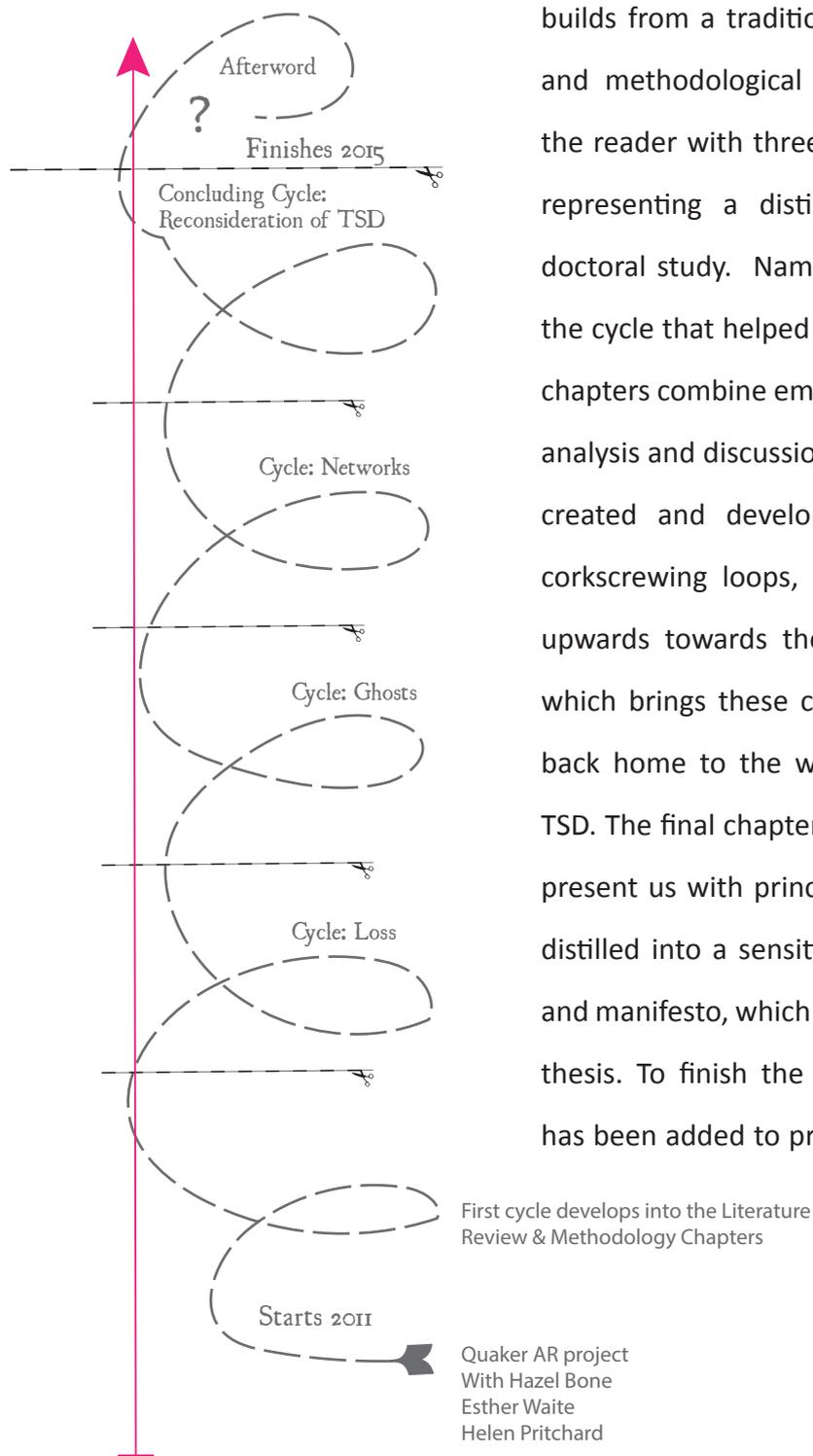
I carry out this work and inhabit these struggles because they can offer an insight into a more generative way of reconsidering TSD. My care for these commitments at the end of human life does not refer to a moral high ground or nostalgic idealised notion of caring about something or someone. Rather, when I talk about care and caring for TSD, I am gesturing towards the devalued labour of caring, as *an ethically and political charged practice* that lies at the heart of the doing of this study (Puig de la Bellacasa, 2011; Puig de la Bellacasa, 2012). To make an ethicopolitical commitment to neglected people and neglected things in TSD is to actively scrutinise and rethink the relationships within TSD as an ethico-political obligation (Puig de la Bellacasa, 2011; Puig de la Bellacasa, 2012). These are the struggles and rifts that lie behind the labour of this study, behind the term 'interdisciplinary' and behind my caring for TSD.

## THESIS STRUCTURE

The way I have approached this doctoral study, as someone shaped by loss, as a digital designer and interdisciplinary researcher who is questioning the relationship with the user, is reflected the shape of this thesis. Firstly, throughout the inquiry process I have used a number of professional design packages, including Adobe Photoshop to collate data together visually, Illustrator to analyse materials and InDesign to present the thesis. I have sketched, illustrated, visualised and diagrammed my way through the entire doctoral process and these are inserted in the document. This approach has been not only a way to capitalise on my visual literacy strengths but also strategies to

work around the disadvantages I have with being dyslexic.

Secondly, the background work in participatory research and design processes can be seen reflected within the core findings chapters of the thesis. Rejecting linearity and distinctive periods of research engagement such as data collection or analysis, this thesis does not have clearly delineated findings and analysis chapters. Rather it



builds from a traditional literature review and methodological chapters to present the reader with three core chapters, each representing a distinctive cycle of the doctoral study. Named after the focus of the cycle that helped to construct it, these chapters combine empirical vignettes, data analysis and discussion together. Originally created and developed as a series of corkscrewing loops, these chapters push upwards towards the end of the thesis, which brings these cycles of engagement back home to the work of reconsidering TSD. The final chapter and reconsideration present us with principles that have been distilled into a sensitive design statement and manifesto, which work to conclude the thesis. To finish the thesis, an afterword has been added to present an unfurling of

a potential future loop that shifts gear into a more speculative and practice-led space.

Figure 1.7 The PhD process that the narrative of this thesis moves to follow

Thirdly, my background in research with people means that I have strong politics of care that I bring to any situation or research and design inquiry. I take these research and design practices very seriously and, in turn, scrutinise the ethical and political landscape that I carefully chose to invest in. These ethicopolitical concerns are not just seen behind the motivations to reconsider the TSD agenda. They are also present in my shaping and presentation of the overall research inquiry, the methods I have employed and safeguarding techniques that I have used to protect those involved in this study.

To help present the shape of this thesis and prepare for the reader will encounter, an outline of each thesis chapter is presented below.

## CHAPTER TWO: LITERATURE REVIEW

This interdisciplinary literature review starts and finishes its journey with design. In between are a series of moves that guide us through the existing literature within the Death and Technology Studies intersection and a wider body of scholarship that feeds back into design. This chapter begins by thinking specifically about Massimi's vision of thanatosensitivity and his development of the thanatosensitive design agenda. I outline the ethicopolitical commitments that underpin TSD commitments before finishing with the small body literature that discusses death-sensitive design projects at the end of life.

From TSD and design, I turn to consider online networks and digital media and draw upon New Media Studies. This is a deliberate turning away from designing *for* people to instead designing *with* people. Drawing from Death and Technology Studies, this literature looks at social media appropriation and what people, themselves, are already doing at the end of life. To help frame the limitations and differences in how I understand networks and digital media, I draw on New Media Studies, thinking about networks and the materiality of digital media.

With the core TSD agenda laid out and literature addressing social media use framed by New media studies, I move on to outline where the roots of my materially informed

perspective arose through my engagement with New Materialism. I explain how this branch of philosophy was useful for thinking about the anthropocentrism in the humanities and reframing dualistic notions of agency. I continue this decentring of the human and human agency by also folding in STS in order to consider the different ethicopolitical landscape that this presents, shaped by who is visible, agential and who needs caring for.

Finally, I return home to thinking about design with these disturbances to the centralities of the human, human-centred agency and the different ethicopolitical landscapes. This home location of design inevitably looks different and I reflect on what these differences are. This activity prompts the unfolding of a set of research questions that the rest of the thesis moves on to address.

### CHAPTER THREE: METHODOLOGY

The methodology chapter presents an insight into my own ontological, epistemological, methodological framings, which have come together in order to give a methodical structure. Choosing sequentially to move down through each aspect of this chapter, I will open with the ontological layer and explain my preferences for critical paradigms of research. Then I will move on to discuss the epistemological layer and my understanding of knowledge creation as a politically sensitive, emergent approach with roots in Participatory Action Research. With these foundations in place, I will then open a space to expose my thinking behind the methodological selection, to help explicate the ethical reasoning that played a role in my moving away from the participatory research approach.

From these reflections, the reader encounters the methodological structure and my use of Situational Analysis in combination with unobtrusive methods. As a 'grounded' and STS framework, Situational Analysis has been designed by Clarke (2004) to deliberately work in a responsive fashion and supports its followers to pay attention to the much wider array of potential elements in a situation of inquiry (Clarke, 2005; Ramírez,

2009). I finish this layered discussion by reflecting on the ethics and limitations of the methodological structure.

After moving through the ontology, epistemology, methodology and limitations of the overall structure, I provide a pragmatic account of what I did within the methodological process between 2011 and 2015. This includes details of where and how I collected data, the kinds of analytical insights I had and, importantly, how each cycle prompted the movement towards to the next. These descriptions are aided by visual materials extracted from the process, which help to exemplify the different practices of data collection and analysis.

#### CHAPTER FOUR: THE DIVERSITY OF LOSS

Chapter four is the first findings chapter of this thesis, which brings together empirical vignettes, analysis and discussion work produced within the first cycle on loss in order to present a 25-year history of human practices of loss online. The first section starts in 1990 and moves to present the earliest accounts of death and loss that I found with the historical, archive and documentary sources. The second section moves on to the mid-1990s and tracks early examples of practices of loss on the World Wide Web, which emerged and are still active on the crafting HTML pages on user-generated web hosts. The chapter then moves on to the early 2000s and draws attention to the increasing complexity of these HTML sites, before addressing the migrations of data and practices onto social media networks. Finally, the chapter moves from early social networking sites to the contemporary landscape of loss that emerged across a diverse range of networks between 2011 and 2015. These contemporary accounts allow us to glimpse into the diversities, divergences and data of loss that can be seen online.

## CHAPTER FIVE: MANIFESTATIONS OF GHOSTS

Chapter five is the second findings chapter, which brings together empirical vignettes, analysis and discussion work using a characterisation of ghosts in order to make the dead visible and present the agencies of deceased individuals who have been sociologically living on within networks online. These findings ask us to take into account the presence of the deceased and the potential agencies of the dead that emerge if we consider death as a process, one that involves practices of loss and data remains.

I open these findings by drawing on data to exemplify how the deceased have been 'Created in Loving Memory' by the bereaved family, through creation and remediation practices. Then I turn to 'The Memory Remains' to discuss how ghostly manifestations can be created autobiographically in life, through intentional or more auspicious circumstances. In the third section, I address when 'The Social Afterlife Begins' and explore how remains are part of the ongoing relationships that continue to unfold within networks online. Continuing with this theme, the fourth section, 'Beloved by Family, Cherished by Friends', continues this work through recounting findings that speak about the obligations, commitments and moral duties the living uphold to the dead. Finally, I consider how the dead can become 'Dead Smart' through the computational ecology of the networks themselves.

## CHAPTER SIX: NETWORK ECOLOGIES

Chapter Six is the third findings chapter, which brings together empirical vignettes, analysis and discussion work from the phase on networks in order to turn towards the dark side of digital networks. This chapter has a shift in granularity, taking some time to think about this turn towards the dark side of network ecologies; therefore, I open the chapter to explain this shift and how the phenomena has been approached in order to ultimately prepare the reader for the materials about to be encountered. I then move to present two empirical examples in chronological detail, giving an account of

the phenomena as they unfolded and relating how both examples have proven to be of distress to the friends and family of the deceased. The first example follows the case of a woman who was murdered and whose post mortem pictures were uploaded and shared across a range of online social networks. The second example illustrates the use of Black Hat digital marketing to capitalise on a high-profile air crash. Both examples conclude with a reflective section that not only draws attention to certain practices at work but provides a moment to breathe before moving on. The final section continues to draw out the practices of sharing and tagging on a more detailed scale in order to draw out the computational ecology that is not only present but also is actively shaping how these remains persist and are accessible online.

#### CHAPTER SEVEN: WHEN DESIGNING REMAINS

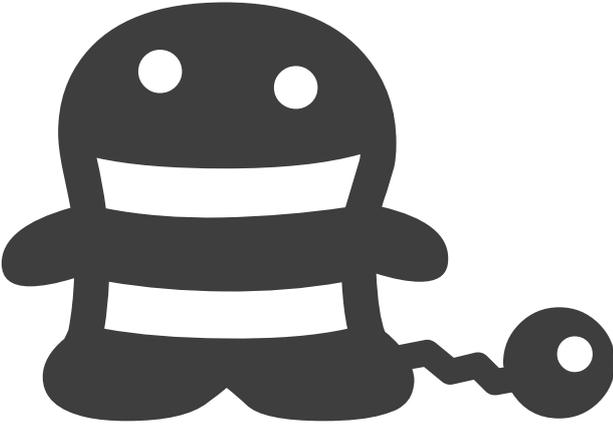
Chapter seven is a reflexive and conclusive chapter, which brings together analysis and discussion. I will begin by recapping the purpose of the study and the research questions that have set the trajectory of this doctoral project. Then I reflect on each of the findings chapters and what ‘thinking with’ and ‘caring for’ reading has uncovered in each findings chapter. I will first address the broader findings that reach out and contribute to the Death and Technology Studies field. Then I will turn to consider the elements and, importantly, the ethicopolitical implications in order to begin the process of reconsidering thanatosensitive design. From this ethicopolitical landscape, I will move towards outlining a set of principles to help rethink how TSD could frame approach practice further. These principals are followed by the intervention of a design statement and a design manifesto for sensitive design at the end of life.

The chapter then moves to address the limits of the thesis and the directions for future work. I explain the difficulties and limits of trying to decentre the human within a human-centred agenda. I emphasise how this thesis only manages to move towards more inclusive reading at the end of life. Yet these tensions and difficulties become a source of inspiration and designerly reflection, leading me to gesture towards future

thought with the concept of speculative 'Posthuman design' (kera 2013). Finally, this chapter concludes with a summary of contributions, making clear what I think this thesis has contributed to in both the death and technologies fields, and, more specifically, TSD.

#### AFTERWORD: DESIGNING FOR THE ANTHROPOCENE

Reflecting on the limitations of this study and thinking about future work prompted an afterword chapter. Rather than just dedicating a section in the previous chapter to writing about and gesture towards where my next cycle and future work might lie, I decided to explore this future work with a theoretical and practice-based afterword. This afterword felt important because my lenses to 'think with' and 'care for' came from a more non-anthropocentric or Posthuman place than I managed to employ. I wanted to have a space not connected to my commitments to human loss to move more towards a more speculative Posthuman way of troubling the user in design.



## CHAPTER TWO

### LITERATURE REVIEW

This interdisciplinary literature review contains New Materialist philosophy, Science, Technology and Society [STS], New Media Studies and Critical Design Studies. I begin by addressing TSD, moving through to New Media Studies, turning towards New Materialism then STS, and returning back to design and critically reflecting this theoretical journey. As a collective, the different bodies of literature either ignore or deeply resist each other, in ways that speak about the tensions and rifts that arise when different bodies of literature intersect. The purpose of the literature review is to draw out what TSD currently looks like and how its capabilities are understood, before pulling on the theoretical tensions to question this TSD framing. It is my designerly approach that gathers these theoretical spaces together, bends them into shape and creates intersections that eventually come together as a set of research questions.

Grappling with theory in this way has been a generative process but one that I recognise as being akin to building a monster. Encountering this Frankensteinian construction is a battle with the otherness that arises when we step into interdisciplinary spaces.



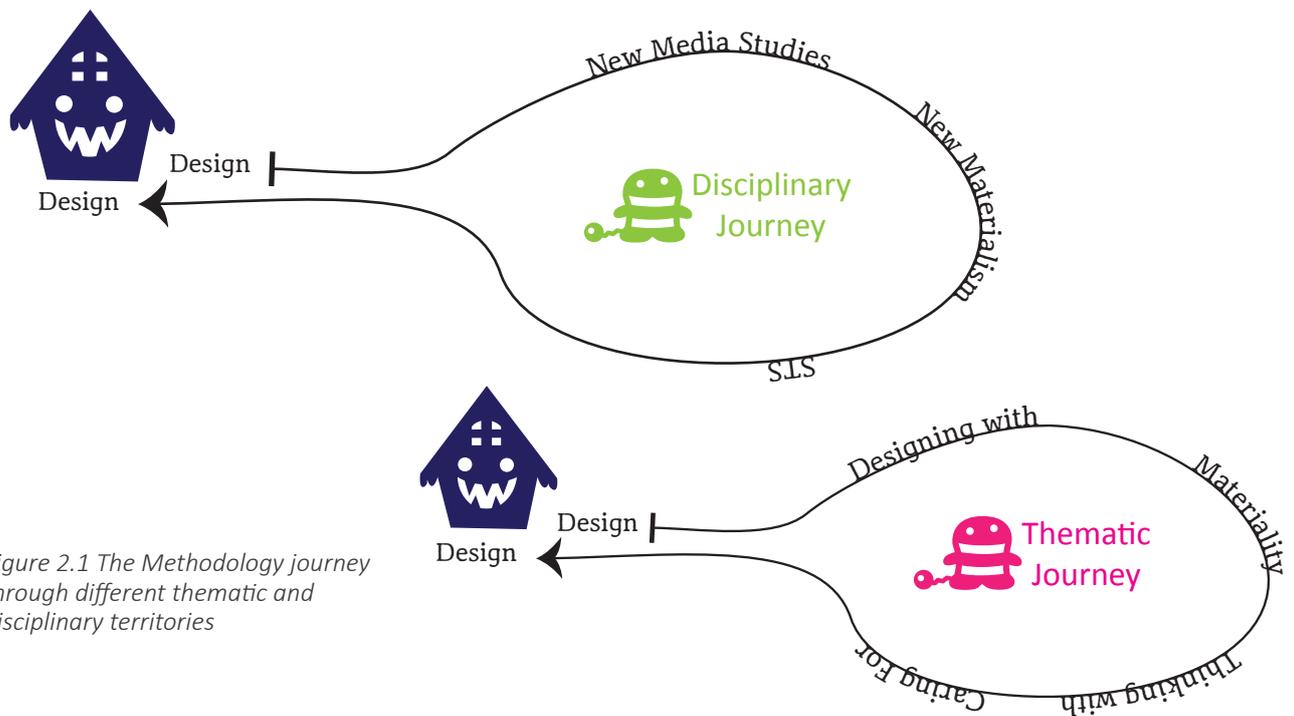


Figure 2.1 The Methodology journey through different thematic and disciplinary territories

Just as the monsters of science fiction and fantasy help us to reflect on what makes us human, interdisciplinary monsters help us to recognise our disciplinary location.<sup>9</sup> Therefore, my interdisciplinary engagements concentrated in this literature review hope to set free a monster with good intentions, one that is loveable rather than one that bursts out, terrorising academic populations. My main way of taming the behemoth has been to create a literature review that starts from a location, clearly moves through a series of locations and returns home, even if home looks different after it has been informed by the different bodies of work we have encountered on the way.

Therefore, the chapter begins at home, thinking about design by introducing Massimi's vision of thanatosensitivity and his development of the thanatosensitive design agenda. In this first section on design, I outline the ethicopolitical commitments that underpin TSD commitments before finishing with the small body of work within Death and Technology Studies that discusses death-sensitive design at the end of life. From TSD and design, I consider online networks and digital media and draw upon New

<sup>9</sup> *Monsters as an interdisciplinary PhD theme was discussed in a thesis whisperer blog, which helped me to explain the otherness that haunts this literature review. I use the concept of monsters from this post as it has been a useful device. The full post can be read at: <http://thesiswhisperer.com/2013/09/11/help-i-think-i-have-created-a-monster/>.*

Media Studies. This space opens by turning away from commitments to designing *for* people to instead designing *with* people. Drawing from Death and Technology Studies, this literature looks at social media appropriation and what it is that people are already doing to support themselves at the end of life. To help frame the limitations and the differences in how I understand networks and digital media, I have drawn on New Media Studies, thinking about networks and the materiality of digital media.

With the core TSD agenda laid out and literatures addressing people's social media use framed by New Media Studies, I move to introduce where the roots of my materially informed perspective arose through my engagement with New Materialism. I explain how this branch of philosophy was useful for thinking about the anthropocentrism in the humanities and reframing dualistic notions of agency. I continue this decentring of the human and human agency by also folding in STS in order to consider the different ethicopolitical landscape that this presents, shaped by who is visible, agential and who needs caring for.

Finally, I return home to thinking about design with these disturbances to the centralities of the human and human-centred agency and the different ethicopolitical landscape this presents. This home location of design inevitably looks different and I reflect on what these differences are. This activity prompts the unfolding of a set of research questions that the rest of the thesis moves onto address.

## INTRODUCING THANATOSENSITIVITY

TSD identifies itself as belonging to the HCI community. HCI is referred to within the TSD literature as the location in which it operates and contributes (Massimi & Charise, 2009; Massimi et al, 2011; Massimi, 2014). HCI is a complex field as it houses a variety of both academic and commercial practitioners who are thinking about the research and design (and development) of socio-technical systems or artefacts. According to Preece et al. (2002) and Saffer, this HCI community is part of a broader distributed population of researchers, designers, developers and engineers who are focused on socio-technical design and can be seen as part of a broader collective interested in

interaction (Preece et al, 2002; Saffer, 2007).

My understanding of what brings together TSD, HCI and this broader collective is their human- or user-centred<sup>10</sup> mutual focus when they frame a situation for research and design inquiry (Stolterman, 2008; Sas et al, 2014). This act of ‘framing’ or ‘to frame’ a situation is a term I borrow from Schön and Rein (1995) and Stolterman (2008), in order to refer to the kinds of implicit and explicit judgements and decisions that are made in a ‘socially situated’ design and development process (Stolterman, 2008; Schön & Rein, 1995). Stolterman specifically describes this framing from the perspective of a designer, arguing how, in the process of design, practitioners have to make decisions about who or what to pay attention to and listen to. Similarly, designers also make decisions about what to disregard from all potential sources at hand (Stolterman, 2008). Working from a similar ‘framing’ concept, technology philosopher Introna (2007) describes this process as one that is ‘socially situated’ in order to introduce the other people alongside the designers (Introna, 2007). Introna emphasises there are a diverse set of potential stakeholders such as funders, users and other practitioners who are also involved in the ‘framings’ where alternative options become *excluded or closed off* (Introna, 2007). Both Stolterman and Introna explain that there are important consequences for these closures, which can be made both implicitly and explicitly through the interests, values, assumptions and beliefs of a collective set of stakeholders (Introna, 2007; Stolterman, 2008).

The visibility of this political process and its understanding can differ greatly between the science/engineering understandings of design compared to the humanities/creative practice approaches. Ultimately, these differences speak about the underlying tensions and values at work beneath the ontological and paradigmatic commitments that underpin these approaches to design in HCI (Stolterman, 2008; Wolf et al., 2006; Zimmerman et al, 2010; Roedl & Stolterman, 2013; Zimmerman et al, 2007). While the users or, more politically, humans are usually the centre of these framings, exactly

<sup>10</sup> Sas et al. (2014) claim that the central tenet of HCI is that technologies should be user-centric (Sas et al, 2014).

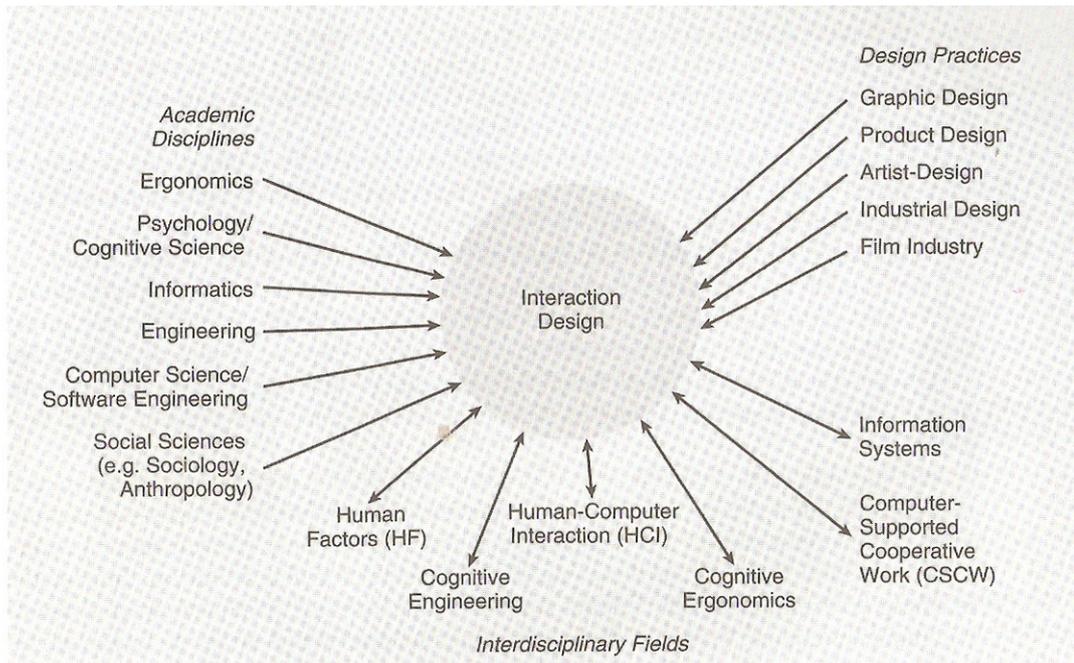


Figure 2.2: The interrelationships across Interaction design (Preece et al, 2002)

how the human user is considered and approached varies due to how processes are understood between a scientific, rationalistic and even authoritative position or, alternatively, as a creative, subjective and political process (Roedl & Stolterman, 2013; Stolterman, 2008).

The issue of framing and the political process at work when framing

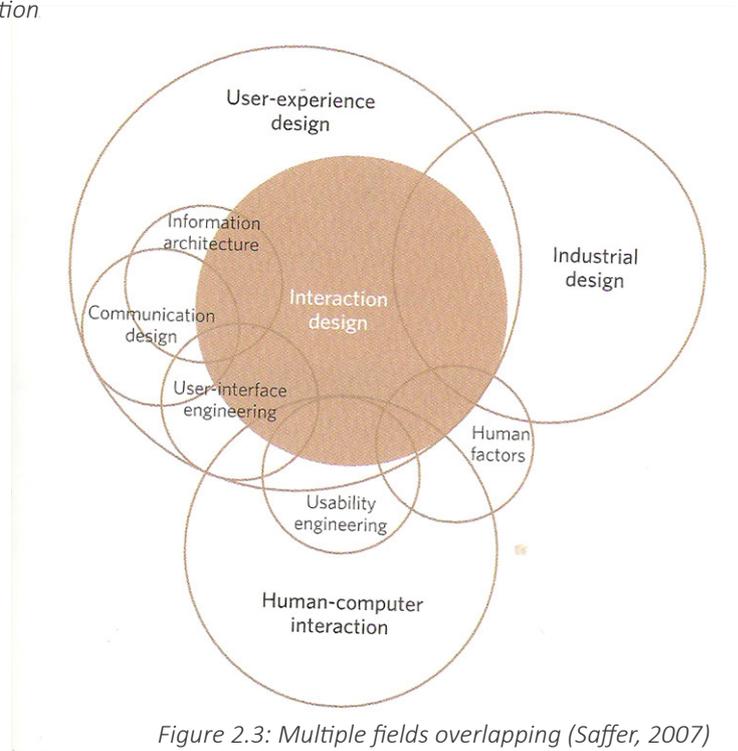


Figure 2.3: Multiple fields overlapping (Saffer, 2007)

a situation is at the centre of the TSD agenda, which wants processes to be death sensitive and consider that users face the end of life. In 2009, doctoral students Michael Massimi and Andrea Charise made a formal request for thanatosensitivity at The Association for Computing Machinery's (ACM) CHI conference in Boston, USA (Massimi & Charise, 2009). The paper 'Dying, Death, and Mortality: Towards Thanatosensitivity in HCI' (2009) argued for thanatosensitivity or death sensitivity from the significant

recognition that ‘human users’ of technologies die (Massimi & Charise, 2009). Michael Massimi and Andrea Charise claim that death had become mediated by technologies and, therefore, contend that the end of life is a sensitive area that deserves further attention within HCI research agendas (Massimi & Charise, 2009).

Massimi and Charise do not explicitly discuss design framings or the political process of design. Rather their contribution presents thanatosensitivity as a ‘critical tool’ or ‘lens’ to introduce the end of human life. The lens is aimed at encouraging HCI practitioners to be mindful or thanatosensitive in view of the fact that the users they are inherently interested in designing for will eventually reach the end-of-life period (Massimi & Charise, 2009). From examples that are only lightly drawn out, they give a tentative exploration into the difficulties that exist because mortality and the eventual demise of human life are not being taken into account within the design and development of technologies (Massimi & Charise, 2009). Massimi and Charise believe their ‘humanistically grounded’ concept of thanatosensitivity is a novel starting point from which to begin approaching the research and design of socio-technical systems that actively work with ‘mortality, dying, and death’ in the research and design of interactive systems.

The phrase ‘humanistically grounded’ suggests that Massimi and Charise are advocating for a thanatosensitive socio-technical practice that will draw upon the interdisciplinary bodies of scholarship emerging from the humanities<sup>11</sup> (Massimi & Charise, 2009). This turn towards interdisciplinary scholarship is in response to the extremely limited amount of literature on the intersection between death and technologies; they selected the Critical Humanist tradition of the humanities very deliberately (Massimi & Charise, 2009). Massimi and Charise argue that experimental lab work and traditional scientific computer science methods are too intrusive for end-of-life research. They argue that the deployment of lab-based methods is likely to raise considerable ethical concerns, as it can be inappropriate to ask potentially distressed people to test a prototype or undergo experimental lab conditions (Massimi & Charise, 2009). To mediate these

<sup>11</sup> While no definition of what the humanities constitutes is given, the author’s gesture towards arts, design, sociology and cultural theory.

limitations, Massimi and Charise turn towards the humanities as a ‘non-invasive strategy’ in light of the rich body of work around mortality and, what Massimi and Charise denote as, ‘the ‘importance of death, dying, and mortality in the minds of contemporary philosophers and cultural commentators’ (Massimi & Charise, 2009). Massimi and Charise claim that theoretical and methodological approaches that exist outside of technical disciplines can work to provide a ‘source of inspiration, elucidation, and evaluation’ (Massimi & Charise, 2009). Furthermore, existing scholarship in the humanities can support the identification of new avenues and directions for future work in light of the ‘paucity of research’ and understanding around sensitive contexts in the technical disciplines (Massimi & Charise, 2009).

As part of his doctoral work, Michael Massimi continued to develop this lens of thanatosensitivity but direct it into thinking about design, eventually comprehensively presenting Thanatosensitive Design or TSD in his doctoral thesis (Massimi, 2012).

In his doctoral thesis, TSD is a death-sensitive approach that helps practitioners to think through the design of social technical systems in the sensitive context of end of life (Massimi, 2012). It is presented as a series of problems and considerations that pragmatically work towards supporting designers approaching the context of bereavement (Massimi, 2012). Aspects of this TSD vision first began to emerge when Massimi returned to CHI in 2010 and presented the paper ‘Thanatosensitively Designed Technologies for Bereavement Support’ (2010). Within this paper, Massimi introduced a design arm to complement the original concept of thanatosensitivity, arguing how technologies are not being designed with what Massimi considers to be the ‘proper acknowledgement of the eventual death of their user’ (Massimi, 2010). He, therefore, introduced TSD as an approach that was intended to help practitioners work with mortality and the end-of-life design (Massimi, 2010).

As Massimi first began to present his work on TSD in 2010, it appeared that TSD was being developed as a structured methodological approach to design. That is, a prescriptive or systematic approach to a particular design situation, which can

be outlined as a step-by-step set of methods that are followed carefully in order to formulate thanatosensitive systems. Early work by Massimi focused on drawing out the technical challenges and problems. For example, Massimi's papers, 'A Death in the Family: Opportunities for Designing Technologies for the Bereaved' (2010) and 'Dealing with Death in the Design: Developing Systems for the Bereaved' written in collaboration with Baecker, undertook small-scale exploratory studies in order to open out a number of 'opportunities for design' (Massimi & Baecker, 2010) (Massimi & Baecker, 2011). It was in response to this exploratory interview and survey work that he was able to draw out problems that have pragmatic 'implications for design' (Massimi, 2012; Dourish, 2006; Sas, 2014). This set of problems helped to underpin Massimi's argument for building a bereavement support system (Besupp) and, consequently, working towards a set of design considerations that outlined and developed the Thanatosensitive Design approach (Massimi, 2012).

TSD emerged, interestingly, as a non-prescriptive design methodology. Rather than outlining particular formulaic steps or methods to follow for TSD, Massimi considered it to be a 'lens', a 'domain' and a 'tool' for thought, framing a potential situation, introducing considerations and making the end of life visible (Massimi, 2012). In his vision of TSD, Massimi argues that TSD can be combined with or folded into other established user-centred design methodologies (Massimi, 2012). In this sense, TSD was envisioned to help designers and developers to question and reflect on how 'systems might be used throughout, and beyond, a lifetime' (Massimi, 2012). The work of TSD and thanatosensitivity have, more broadly, become an important contribution that has been repeatedly gestured towards and explicitly cited by other researchers and designers interested in the design of technologies in sensitive contexts.

## THE ETHICOPOLITICAL DIMENSIONS OF TSD

Thanatosensitivity and the thanatosensitive design agenda, with its focus on bereavement, comes with a strong sense of care and commitment towards supporting bereaved people and making lives better through positive intervention in the context of

loss (Massimi, 2012; Massimi & Baecker, 2010; Massimi, 2010). In the thanatosensitive agenda, a lack of caring or commitment to the end of life when designing or developing technologies leads to technological systems of artefacts that continue to perpetuate the ongoing 'oversight' of technologies (Massimi & Charise, 2009; Massimi, 2010; Massimi, 2012). This oversight is in technologies that are not being 'designed with the proper acknowledgement of the eventual death of their users' (Massimi & Charise, 2009; Massimi & Baecker, 2010; Massimi, 2012).

When thinking about an intervention and making change, TSD brings with it a sense of care and a commitment to the differences that can be found in loss. The resistance of a prescriptive or formulaic approach to TSD reflects a broader resistance to not pathologicalising or medicalising grief (Massimi, 2012). Previous discussions of 'problems' in the design at end of life have been specifically challenged, as has the underlying problem/solution focus of design when approaching bereavement. To engage with notions of difference, Michael Massimi specifically refers to Continuing Bonds theories<sup>12</sup> within his doctoral study and his publications to reflect and respect the differences that can be found in loss rather than pushing for notions of closure and recovery (Massimi & Charise, 2009; Massimi & Baecker, 2010; Massimi, 2012; Massimi, 2014). Continuing Bonds respects that loss can be lifelong, that relationships with the dead can continue (or not) for differing lengths of time and that applying the notion of problems or solutions is an unhelpful way of considering death (Massimi, 2012; Massimi, 2014; Klass & Silverman, 1996).

Making commitments to support people and differences in loss comes with a political agenda for enacting intervention and change. This change is aimed at both existing systems that are not designed thanatosensitively with an awareness of the mortality of potential technology users, or alternatively, designing new interactive systems that are death aware (Massimi & Charise, 2009; Massimi, 2012; Massimi, 2010). When either

<sup>12</sup> As already stated in the introduction, authors in the Continuing Bonds tradition have tried to move understandings of bereavement and grief outside of the scientific and resolution-focused dichotomies (Klass & Silverman, 1996; Walter, 1994). Rather, their work discusses how relationships with the dead can continue over different length of time and with considerable variation. For this reason, practitioners in the end of life design should not be thinking in terms of normal or abnormal or in terms of 'recovery' and 'closure' (Small, 2001).

scenario occurs, TSD can be used as a critical tool to design new systems, evaluate potential design problems or identify opportunities for improvement, depending on the circumstances (Massimi & Charise, 2009; Massimi, 2012). Without the TSD lens, designers and their resulting socio-technical ideas could go on to produce technological designs that are not death aware, which could go forth to complicate and trouble bereaved family members (Massimi, 2010). Thanatosensitivity and the thanatosensitive design agenda, then, raise awareness of this end-of-life period, and provide a focal point for socio-technical design practice, to think 'optimistically', even aspirationally, through the potential spaces for socio-technical intervention and avenues that might lead towards bereavement support (Massimi & Charise, 2009; Massimi, 2010; Massimi & Baecker, 2010; Massimi & Baecker, 2011; Massimi, 2012).

Massimi contends that thanatosensitivity as a lens or critical tool can help formulate evaluations of existing systems or identify the possible design problems of existing systems in order to 'identify opportunities for improvement' (Massimi & Charise, 2009). Behind this claim is the notion that a likely source intervention can be attributed to a particular problematic location, framed dualistically across either the human or the technology (but usually the technology) and that these problems can be addressed through good design or redesign that positively affects the lives of potentially vulnerable and distressed people. This issue of good design is key to understanding agency and intervention, as, within socio-technical design, the issue of design intentions are inherently linked to the notion of agency and their outcomes (Introna, 2007). While Massimi does not discuss the issues of agency or intervention specifically in his outline of Thanatosensitive Design, he does introduce the notion of 'poor design', or when a 'system is poorly designed or conceived' (Massimi, 2012).

This belief in 'poor or bad design' in relation to agency has been discussed by Janet Murray. In the book, 'Inventing the Medium: Principles of Interaction Design as a Cultural Practice' (2012), Murray contends, in HCI, that agency is something that predictably 'results when Interactors'<sup>13</sup> expectations 'are aroused by the design of the

<sup>13</sup> 'Interactors' seems like Murray's attempt to be less passive in how she frames people who engage with technologies.

environment, causing them to act in a way that results in an appropriate response by the well-designed computational system' (Murray, 2012). For Murray, interaction designers are presented as practitioners who are 'providing agency' or 'creating the experience of agency' (Murray, 2012). In 'creating the experience of agency', Murray would consider 'bad design' as something that upsets a user through 'creating confusing or unsatisfactory expectations, or failing to anticipate actions by scripting the machine with appropriate responses' (Murray, 2012). Murray claims that the fault lies with designers: 'We create agency by scripting the interactor and the computer so that the human beings' expectations and behaviours elicit appropriate responses from the machine' (Murray, 2012). In this frame, the practice of design is the predictable wielder of agency and through its human-centredness somehow has the central ability to control and manipulate in ways that predictably speak about design outcomes being either good or bad or, in the case of Massimi, 'poor' (Murray, 2012).

Charise and Massimi claim that 'We are optimistic about how these technologies may improve quality of life for their users, gesturing towards what is known as the passive and promising character of technologies (Massimi & Charise, 2009). While technologies are presented passively within TSD frames, as an inert medium that can be manipulated, technological artefacts do have a 'promising character' that speaks about the potential for a better quality of human life as technologies are posed with the capability to liberate humanity (Verbeek, 2005; Massimi & Charise, 2009; Massimi, 2012). Philosopher of Technology Professor, Peter-Paul Verbeek, in his book, 'What Things Do: Philosophical Reflections on Technology, Agency, and Design' (2005), discusses how technology has been long positioned as something inherently connected to notions of the good life. He asserts that technological artefacts have a 'promising character' that speak about a better quality of human life, posed with the capability to liberate humanity with the aim to remove hunger, disease and toil in ways that enrich life (Verbeek, 2005). This 'promising character' that can liberate and remove suffering is present within Massimi's visions of thanatosensitive technological systems and artefacts, as he contends that,

Computing pervades many aspects of modern life, and continues to **improve the quality of life** for people across the world. Yet technology seems to offer little support at this critical time period in the human lifespan' (Massimi, 2010) [Emphasis added].

To rectify this, thanatosensitivity as a lens or TSD as a non-prescriptive approach to creating technologies for end of life 'may improve the design of personal technologies such that they remain *useful tools* for the bereaved, rather than sources of discomfort or confusion' (Massimi, 2012) [Emphasis added].

## DESIGNING FOR TSD

It is important to note that thanatosensitivity and TSD were not the first bodies of literature that discussed the issue of having to design for death. Through my literature review searches, I found the early work of Edwin Bos, who discussed designing for bereavement in 1995 for the SIGCAS journal (Bos, 1995; Bos, 1995). After Edwin Bos, Timothy Leary wrote a manifesto on designing for dying in 1997. It took another 11 years and 'SIMtech', and a mundane technologies event held at Microsoft Cambridge in November 2008, before the intersection between design and the end of life was reopened. Themes that Bos had introduced re-emerged at this event, such as thinking about material remains, memorialisation and remembrances practices (Foong & Kera, 2008; Kirk & Banks, 2008; van den Hoven et al, 2008).

The lineage of thinking about designing for death shares Massimi interest in bereavement when collectively drawn together. As a body of work, it typically focuses on positive interventions for those who have experienced loss or who would identify with bereavement. Furthermore, these themes of bereavement and loss stretch across and encompass a range of phenomena, as emphasised by Michael Massimi:

Bereavement is not simply the experiencing of grief (although this is a key part of it). Bereavement can include many different activities: taking on new roles, learning how to engage with outsiders, managing the deceased's assets, creating and organizing mementos, finding support, and so on (Massimi, 2012).

Considering this, designing for bereavement support involves thinking about ‘the unique needs of the bereaved’ and treating bereavement as a diverse but ‘viable and valuable site for technological intervention and support’ (Massimi, 2012). Along with Massimi’s emphasis on thinking methodologically about the process of ‘doing’ and designing for bereavement, there have been a number of other strands that have emerged through other related studies around design, such as designing for the presence of the dead or the digital afterlife,<sup>14</sup> designing for digital legacy or remains<sup>15</sup> and memorial and remembrance design.<sup>16</sup>

At the start of my PhD in 2011, there was a body of research and design literature that could be housed beneath this designing for bereavement umbrella. Firstly, there were practice-based studies of systems, artefacts or prototypes that aimed to support existing or new bereavement practices around the common themes of remembrance, memorialisation or legacy creation (Lochrie & Coulton, 2011; Kosem & Kirk, 2010; Kirk et al, 2011; Lindley et al, 2010; Uriu & Okude, 2010; Sandhaus et al, 2010). Secondly, there was a collection of non-practice-based studies, where empirical findings or discussions worked towards pragmatic recommendations or discussions around improving future technology design (Odom et al, 2010; Massimi et al, 2011; Massimi & Baecker, 2011; Massimi & Baecker, 2010; Foong & Kera, 2008; Kirk & Banks, 2008).

Literature continued to emerge that made recommendations or discussed the process of designing for bereavement and memorialisation (Maciel & Carvalho Pereira, 2012; Maciel & Carvalho Pereira, 2012; Mori et al, 2012; Moncur & Kirk, 2014). One paper that stood out as being considerably different from others in these spaces was authored and published by Denisa Kera in 2013. As a critical designer and philosopher, Kera’s article, ‘Designing for Death and Apocalypse: Theodicy of Networks and Uncanny’, sat uneasily in the mainstream design-HCI space. Rather, her contribution invoked the speculative work of critical designers, Dunne and Raby. Through speculative engagement, Kera makes an intentional jump in scale, using the apocalypse as way to think about the

<sup>14</sup> For examples of this theme see (Bos, 1995; Leary & Sirius, 1997).

<sup>15</sup> For examples of this theme see (Bos, 1995; Bos, 1995.; Kirk & Banks, 2008; Harvel, 2010; Sandhaus et al, 2010; Odom et al, 2010; Brubaker et al, 2014).

<sup>16</sup> For examples of this theme see (Foong & Kera, 2008; Kosem & Kirk, 2010; Lindley et al, 2010).

death of humans and end of life more broadly. This article and the concept of the apocalypse became an important reference for the second half of this thesis, as the empirical stage was well underway by the time I encountered it. I return to reflect briefly on the speculative and Critical Design home from which this work emerges in the final section of this literature review.

With the 'designing for' literatures now outlined, I stay within Death and Technology Studies, to think about designing with people. My turn towards this body of scholarship arose from my background and interests in participatory research and design projects. Rather than being interested in designing *for* people, I began to wonder what it was that people were doing already to support themselves in order to gain insight and think with these insights. However, there were a number of assumptions at work about the nature of these networks. To help elucidate these assumptions, I introduce New Media Studies scholarship as a way of illustrating how I understand these spaces differently.

## DESIGNING WITH

Due to my participatory background, I was interested in scholarship that can provide an insight into how people were already supporting themselves at the end of life and, importantly, think about the kinds of practice in which people were engaging. As outlined in my introduction, my interest in practice, in 'doings' with material things, came from not wanting to uphold the delineation between the inner and outer worlds of loss.

Recognising that the bereaved had begun appropriating technologies which had not been thanatosensitively designed, was first noted by death scholar Carla Sofka's 'Social Support Internetworks, Caskets for Sale, and More: Thanatology and the Information Superhighway' (2007). This seminal journal article noted the extensive appropriation of a wide range of existing technologies for bereavement and the end of life more broadly (Sofka, 1997). Twelve years later, this pattern of appropriation was reiterated by Massimi and Charise (2009) when their call for thanatosensitivity claimed that we needed to deepen the field's understanding of this phenomena (Massimi & Charise,

2009), particularly due to the awareness but lack of formal scholarship on what people were doing online and why (Massimi et al, 2011; Massimi & Charise, 2009).

Interestingly, this knowledge gap was approached by a collective of PhD students. Firstly, anthropology PhD student Anna Haverinen began to look empirically beyond just official memorial or remembrance sites into gaming environments and virtual worlds (Haverinen, 2010; Haverinen, 2014). Secondly, Informatics PhD student Jed Brubaker also moved towards undertaking empirical studies, but, alternatively, with a focus on identity and the use of Facebook and Myspace by the bereaved (Brubaker & Vertesi, 2010; Brubaker & Hayes, 2011). Thirdly, Interaction Designer and PhD candidate Joji Mori undertook a social networking study and gave a close reading of a Myspace account (Mori et al, 2012). The literature produced by these PhD students placed analytical emphasis on anthropological, phenomenological interpretations of ritualistic activities or content that looked discursively at death, identity and grief (Brubaker & Vertesi, 2010; Getty et al, 2011; Haverinen, 2010; Haverinen, 2014). Joji Mori, however, took a more 'designerly' approach through a multimodal analysis that accounted for both the discursive and the visual. His recommendations addressed digital designers of websites and social networks (Mori et al, 2012).

As I began my doctoral study in 2011, a number of conference papers and journal articles began to emerge that focused on Facebook (Cornfeld, 2011; Getty et al, 2011; Roberts & Hattick, 2011). This began, what I saw as, a Facebook trend, and research-focused scholarship throughout 2012 and 2013 turned to Facebook as, overwhelmingly, the primary site for empirical or discussion work (Kasket, 2012; Roberts, 2012; Stokes, 2012; Church, 2013; DeGroot, 2012a; Haverinen, 2014; Kern et al, 2013; Brubaker et al, 2012) (Marwick & Ellison, 2012; McCallig, 2013; McEwen & Scheaffer, 2013; Lingel, 2013). The studies looked at different themes of Facebook use such as memorialisation or digital legacy (Brubaker et al, 2014; Tsaasan et al, 2015). Outside of Facebook, there has been ongoing interest in the appropriation of broader gaming environments, virtual worlds and other social media networks, which were brought together through the

doctoral study of Anna Haverinen (Haverinen, 2014). Alongside Haverinen's doctoral dissertation, further studies that began to account for YouTube memorial videos and hashtag use on Twitter emerged in 2014 (Gibson & Altena, 2014; Carter et al, 2014).

## DRAWING FROM NEW MEDIA

When started my PhD in 2011, a considerable amount of the above mentioned literature was not present to draw upon. From the outset, I engaged with this literature with the intention of looking at people's practices of loss, looking to see what people were doing and with what. I was keen not to abide by existing disciplinary distinctions that broke loss down into the emotional or social, or the digital from the material. This theme around materiality became a huge part of how I framed my understanding of what was occurring. Therefore, from the outset, I could sense the disciplinarity others were approaching and the kind of difficulties my interdisciplinarity was already causing for how I would understand the field. My previous engagements with both STS and New Media Studies encouraged me to look for the entanglements and materialities at work. I recognised that I was approaching the area quite differently from the existing scholarship, a difference that continued to grow.

Explaining these differences begins with my critical gaze. From encountering literature on loss and bereavement, I was aware it was a highly complex phenomena where great differences in norms could be seen even across intimate family members (Walter, 1994). Therefore, I was troubled by the increasing focus on Facebook, when the complexities suggest that loss manifests in a range of diverse and divergent ways. Similarly, I noticed how the Internet or platforms such as Facebook had been framed. The literature spoke about Facebook as if it was a passive and homogenous tool that could support people at the end of life. This is perhaps best exemplified in the 2012 paper by Elaine Kasket, which labels Facebook as a modern-day medium (Kasket, 2012).

Academic fields such as New Media Studies tell us that notions of a singular network, a monolithic platform, whether framed as *The Internet* or Facebook, homogenises the massive interconnected web territory of linked nodes or elements (Mejias, 2013). This

monolithic framing does not reflect the material technological infrastructure, where digital information and communication technologies exist within multiple, overlapping and interconnected entanglements of digital networks (Gehl, 2014; Mejias, 2013; Lovink, 2011). In these entanglements, networks are not passive mediators, but fluid and complex digital networks that are composed of both human and technological actors that become linked by physical and social ties, which support, resist and mutually shape the transfer of data (Mejias, 2013; Boyd, 2010).

As well as breaking out of homogenising frames, Galloway and Thacker (2007) tell us that networks are not evenly distributed or inherently democratic (Galloway & Thacker, 2007). Still, the concept of social network use in death has become folded into the bigger discourse around the promise of connectivity (Galloway & Thacker, 2007). These bigger connectivity debates have proliferated alongside the development of the Internet, the World Wide Web and, more recently, social networks, which depict the rich potential networks can hold for democracy and the civic engagement of the commons<sup>17</sup> (Galloway & Thacker, 2007; Mackenzie, 2010). These debates have repeatedly positioned a network as a design that can overcome or transcend traditional hierarchies, gatekeepers and regressive structures (Galloway & Thacker, 2007; Mackenzie, 2010). An example is the technological deterministic writings of Howard Rheingold in the early 1990s, in which a network becomes an enabling 'tool' for human elevation (Rheingold & Weeks, 2012; Rheingold, 1993). More recently is Charles Leadbeater's vision of 'We-Think' and the concept of liberation and innovation through mass participation, in which people come together through digital networks and mass create through *collective creativity* and new forms of digital media (Leadbeater, 2005; Leadbeater, 2010; Leadbeater, 2008). On these frontiers, people can become empowered through accessing virtual worlds, *passive tools* and 'free' platforms for the commons, which supposedly aid people in coming together and transcending the dominant systems.

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17 By commons, I am referring to the resource as being depicted for all members of society

Studies by New Media theorist Christian Fuchs<sup>18</sup> and Tiziana Terranova<sup>19</sup> have disturbed this positioning of passive networks as something that can solve what Geert Lovink terms the 'longstanding shortcomings of the old democratic sphere' (Lovink, 2011). Similarly, Galloway and Thacker argue that,

To have a network, one needs a multiplicity of 'nodes' - Yet the mere existence of this multiplicity of nodes in no way implies an inherently democratic, ecumenical, or egalitarian order (Galloway & Thacker, 2007).

This prompts us to reflect on how networks and the 'multiplicity of nodes' do not necessarily mean that networks inherently support people at the end of life. Media theory tells us that they are not passive tools and they may come together to support some and yet work against others. However, in Death and Technology Studies, the literature overwhelmingly positions networks as a tool, one that supports positively. Therefore, this suggests that there is another side to networks that is not being accounted for, what Parikka and Sampson term the 'dark' side (Parikka & Sampson, 2009). By 'dark side'<sup>20</sup>, Parikka and Sampson are referring to the lack of scholarly attention and analytical light that are given to issues that have become the downside of the promised utopian potential of digital networks (Parikka & Sampson, 2009). In fact, digital networks have been described as spaces filled 'by digital waste products, dirt, unwanted and illicit objects' that are part of the 'expressive and material components of the assemblages that constitute network culture' (Parikka & Sampson, 2009). This dark side, then, suggests that there will be unwanted and illicit content, arrangements in networks that do not come together and support people, which we need to begin taking into account.

Another missing aspect to the discussions that I have previously touched lightly on is the materiality of digital networks and people's practices of loss. The field of Death

18 Fuchs critically addressed the notion of networks as liberators discourse in a review of Manuel Castell's book, *Networks of Outrage and Hope. Social Movements in the Internet Age* (Fuchs, 2012).

19 Terranova discusses 'free labour', i.e., 'forms of labour we do not immediately recognize as such: chat, real-life stories, mailing lists, amateur newsletters, and so on', which is in direct conflict with Charles Leadbeater's vision of 'We-think' and mass participation (Terranova, 2000).

20 While Jussi Parikka and Tony D. Sampson discuss this dark side in an analytical frame, for me it also invokes the work of Sara Ahmed's 'Strange Encounters', her description of meetings that invoke surprise and conflict, as well as reflecting on the term 'darkness' in relation to the 'heavy histories' of blackness and whiteness (Ahmed, 2000).

Studies well acknowledges the concept that loss itself causes the living to question that which remains, as 'Loss is inseparable from what remains, for what is lost is known only by what remains of it, by how these remains are produced, read, and sustained' (Eng & Kazanjian, 2003). As different authors in Death Studies tell us, these remains include what remains of us, our bodies, the clothes that covered us, the places where we lived and things that filled those spaces (Hallam & Hockey, 2001; Gibson, 2008; Seremetakis, 1991; Seremetakis, 1994; Richardson, 2014). Turning towards material remains in loss is a very old practice. Human cultures have long engaged in strategies and activities in the aftermath of death (Davis, 2002). Burial archaeologists claim that practices involving remains may in fact predate Homo sapiens and can be seen in our ancient ancestors (Sommer, 1999).

Death Studies scholarship reminds us that things, objects and material remains play a very important role within bereavement in mediating death, to help remember and be remembered (Hallam & Hockey, 2001; Hallam et al, 1999; Gibson, 2008; Hockey et al, 2010; Ellis Gray & Luján Escalante, 2014). While material legacies become abandoned in death and are left to the bereaved to manage, they also become a central part of the processes of remaking life and remembrance (Hallam & Hockey, 2001; Odom et al, 2010; Massimi & Baecker, 2011). The bereaved have to deal with the pragmatics these remains cause. The decaying, shifting, recasting, reorganising and the subsequent redistribution, discarding, and selling of remains, which is often managed in line with the perceived value by those left in control or the direct wishes of the dead (Hallam & Hockey, 2001; Hallam et al, 1999; Gibson, 2008; Hockey et al, 2010; Ellis Gray & Luján Escalante, 2014). Even HCI acknowledges that material remains can hold value for people in a multitude of different ways, including being prized for the capacity to provoke nostalgia, and helping the bereaved to reminisce about that which has been lost (Odom et al, 2010; Massimi & Baecker, 2011; Kirk & Sellen, 2010; Massimi, 2012; Odom, 2014).

The materiality of objects and things melts away as we move out of Death Studies

and into HCI. The supposed disappearance of materiality in relation to highly valued materials or possessions has perhaps been exemplified by Odom (2014), when he argues that,

People's practices have expanded and today they are amassing ever-larger and more diverse collections of virtual possessions. Virtual possessions include former material things that are becoming immaterial (Odom, 2014).

This immateriality has deep roots in discussions around networks and the Internet, due to the notions of cyber or hyper spaces that linger and, as a result, are causing digital remains to exist in some dematerialised form (Ellis Gray, 2014a; Ellis Gray & Luján Escalante, 2014). It seems that the remnants of the early 1990s utopian, friction-free and passive Internet has persisted, and, along with it, notions of disembodied minds roaming free from material concerns – like our decaying and dying material bodies (Ellis Gray, 2014a; Ellis Gray & Luján Escalante, 2014).

Paul Dourish argues that 'the digital is always, *inherently*, and inescapably material' (Dourish, 2014). The notion of data, of our media, remains as one without weight and size,<sup>21</sup> obscures the inherently in-the-material quality of data (Dourish & Mazmanian, 2013; Dourish, 2014; van den Boomen et al, 2009). The digital material is inherently in-the-material or 'In-material', and 'intrinsically embedded in physical carriers and containers' (van den Boomen et al, 2009). Our data that comes in the shape of media files and 'digital remains' are tied to our mobile phones, eBook readers, USB sticks, digital cameras, micro SD cards, tablet devices, unreadable floppy disks and obsolete zip disks. Therefore, alongside clothes, photo albums and jewellery, the bereaved can now find laptops, mobile telephones, back-up hard drives, games consoles, music players, Flash drives and tablets. The distributed data remains, in the files stored in the cloud, the last emails, logins, search histories, blogs posts, status updates and broader ghostly traces of people's engagement online. These things materially exist somewhere, just in places commonly out of our immediate (or accessible) reach,

<sup>21</sup> Dourish and Mazmanian note the problems faced by the US National Weather Records Center in storing meteorological data on punched cards in the early 1960s: 'Their concern was not that they had more data that they might be able to process; rather, it was that they might have more data than their building could physically support. One gigabyte of data on punched cards weighs over 35 tons' (Dourish & Mazmanian, 2013).

such as within servers, housed within data centres across the globe, existing across networks as a web of routers, cables, carriers and conduits like fibre optics, wireless signals, satellites and 4G towers (van den Boomen et al, 2009).

Therefore, what I refer to as remains are the data and files that persist and exist within the broader assemblage of networks. Technology engagement across networks means data remains can give us partial glimpses of a person, their lives and habits even after physical death (Balka & Leigh Star, 2011). Like material remains, digital in-the-material remains exist as another aspect of our legacies for people to turn towards in death.

The theme of materiality continues as we move forward into the next section, where I discuss my engagement with New Materialist philosophy and STS. In the timeline of my PhD process, I had encountered these bodies of literature before TSD. However, the presence and disturbances they create manifested after developing my understanding of thanatosensitivity. Confident that the tensions between them could prove fruitful, I continued to work with New Materialist and STS scholarship during the PhD process.

## ENCOUNTERING NEW MATERIALISM

Both STS and New Materialist philosophy have come together as a conceptual framework that supports the human decentring that is at the core of this thesis. Both STS and New Materialism are known to question the centrality of the 'user', anthropocentric framings of agency and notions of intervention that are built on dualistic subject/object foundations. They do this work alongside a richer lineage of philosophy that has 'severely contested' the unproblematic notion of the human and subject, such as through speculative realism, object-orientated philosophy or key scholarship by Martin Heidegger and Michel Foucault (Rod & Kera, 2010). The human and subject have also been contested through Posthuman critiques that later emerged by scholars such as Katheryn Hayles and Donna Haraway (Rod & Kera, 2010; Introna, 2007; Introna, 2014b; Miah, 2009). My engagement in this lineage places emphasis on Barad and Braidotti from New Materialism, and Latour and Puig de la Bellacasa from STS, as a way to explore the notions of material agency and care of things. Collectively,

these bodies of work and scholarship have become key agitators to the TSD agenda, troubling its human-centred ethicopolitical landscape.

New Materialist philosophy, which more broadly ‘focused on the material aspect of social life’, has become of interest and influential within technology fields, creative arts and design practice (Wiberg Ishii et al, 2013; Østerlund et al, 2015a; Bjørn & Østerlund, 2014; Barrett & Bolt, 2013). My engagement with this philosophical tradition has contributed to constructing a more nuanced and critically engaged ethicopolitical understanding of my own creative practice. However, Paul Dourish notes that while deploying the term materiality and signalling an interest in New Materialism might be becoming ‘all the rage’, it has led to discussions on matter and materiality without thinking on what these deployments may mean (Østerlund et al, 2015b). Dourish contends that ‘we need a better idea of what we’re talking about when we invoke words like “materiality”’ (Østerlund et al, 2015b). Therefore, I will distinguish approaches on matter and materiality from New Materialist understandings before moving on to discuss the work of Karen Barad.

Material feminist, Samantha Frost, says that, to understand the implications of New Materialism and its understandings of materiality and matter, it is helpful to distinguish New Materialist work to other approaches on matter (Frost, 2011). The first approach Frost invokes is the well-recognised Classical Materialism and the Cartesian approach, which accounts for matter as something essentially inert but subject to the law of physical cause and effect (Frost, 2011). As highlighted by Frost, this Cartesian understanding of passive matter has been lacking as it has been used to justify inequities in gender, race and class (Frost, 2011). An alternative approach to Cartesian deficiencies has been Historical Materialism, which presents matter as something less passive and malleable (Frost, 2011). Karl Marx suggested that humans have intimate relationships with the material world and, in his analysis of capital, commodities and the power relations, presented matter as political. In this tradition, Frost argues that ‘matter can be an agent by proxy, absorbing and translating the agency of individuals in ways that

exceed each agent's deliberate intentions' (Frost, 2011). Historical materialism has been useful in creating critical (constructivist) standpoints and in understanding matter as a constraining force on human activity (Frost, 2011).

Yet for Samantha Frost, the key divergence of New Materialism, in comparison to Historical Materialism and Cartesian approaches, is through its reconsideration of agency and its move to counter the assumption of matter as being agential through human agency. As Frost contends:

New materialists aim to counter the figuration of matter as an agent only by virtue of its receptivity to human agency. They try to specify and trace the distinctive agency of matter and biology, elucidate the reciprocal imbrication of flesh, culture, and cognition, investigate the porosity of the body in relation to the environment in which it exists, and map the conditions and technologies that shape, constrain, and enhance the possibilities for knowledge and action (Frost, 2011).

My first understanding of non-anthropocentric agencies came through a reading of Karen Barad's 'Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter' (2003). In this paper, Barad asserts how 'Language matters. Discourse matters. Culture matters. There is an important sense in which the only thing that does not seem to matter anymore is matter' (Barad, 2003). In this paper Barad contends how 'every turn every 'thing' is turned into a 'matter of language or some other form of cultural representation' (Barad, 2003). As Barad contends:

The belief that grammatical categories reflect the underlying structure of the world is a continuing seductive habit of mind worth questioning. Indeed, the representationalist belief in the power of words to mirror preexisting phenomena is the metaphysical substrate that supports social constructivist, as well as traditional realist, beliefs. Significantly, social constructivism has been the object of intense scrutiny within both feminist and science studies circles where considerable and informed dissatisfaction has been voiced (Barad, 2003).

Barad continues to take representationalism to task for its role in 'thingification' and the way 'things' or 'entities' have pervaded and shaped how people understand (Barad, 2003). In this 'thingification', the notion of interaction assumes that independently existing entities that pre-exist move to act upon each other (Barad, 2012). To trouble

this, Barad introduces instead 'intra-action', which 'queers the causality' and troubles the individualism through an Agential Realism (Barad also refers to this as an ethico-onto-epistemology) in which individuals do not pre-exist but materialise through intra-acting (Barad, 2003; Barad, 2012). From my reading of Barad, individuals only exist within 'phenomena' or the entanglement and 'ontological inseparability' of intra-acting agencies (Barad, 2012; Barad, 2012; Introna, 2014b). In this, agency is not a something someone (usually the human) has (Introna, 2014b). Rather there is an entanglement of intra-acting agencies and it is through these intra-actions that properties, boundaries or 'substances-in-becoming' within phenomena become determinate (Barad, 1996; Barad, 2012; Ingold, 2012; Ingold, 2013).

This representational and thingification may stem from the 'hylomorphic model', which outlines how a compound of matter (hyle) and form (morphe) are brought together in the act of creation (Ingold, 2012). To rethink the hylomorphic model, Ingold contends that we should attend to the histories rather than thinking about the properties of materials, as he claims that 'substances-in-becoming' overtake the designations and descriptions that become assigned to them (Ingold, 2012; Ingold, 2013).

## THINKING WITH AND CARING FOR

I came away from this engagement with a vastly different understanding of both materiality and agency. Shifting out of dualistic frames and out of the subject-object division had developed a new sensitivity and awareness to the dualistic framings in TSD. From a New Materialist perspective, this dualistic framing, like in TSD, where the human is privileged, means that it cares too much for its own sense of agency, which is a selfish arrangement (Dolphijn & Van der Tuin, 2012; Poe, 2011). Selfish because such arrangements are usually at the detriment of the 'object', which unfortunately positions non-human things in ways that keep them passive and subservient (Dolphijn & Van der Tuin, 2012; Poe, 2011). Therefore, I felt that the human-centredness identified at the core of TSD needed reconsideration, primarily due to the way current TSD framings seemed to be causing other elements to be missing or subservient when practitioners

were 'framing' a situation for research and design inquiry (Stolterman, 2008).

The timing of such reconsideration seems to be in harmony within the broader discussions that are happened across both HCI and New Materialism about our contemporary milieu. The differences between these conversations around themes such as sustainability, climate change and other complex global challenges are how the human is framed and understood. An insight into thinking about these complex issues outside of human-centred framings can be gleaned from philosopher Rosalyn Diprose, who claims:

We live in an age where rapid developments in technologies and environmental catastrophes increasingly question the limits and meaning of the human and human 'agency,' the inevitability of human 'progress,' and the capacity of humanity to control its world (Diprose, 2009).

Both Diprose (2009) and Miah (2009) claim that it is in response to the many catastrophic challenges and profound changes on a planetary scale that a number of differing ontological understandings around human-centredness have come through. One of these, Posthumanism, helps us to critique the notion of human agency and the sanctity of the human (Diprose, 2009; Miah, 2009; Gane, 2006). While the origin of Posthumanism is disputed and has been comprehensibly mapped,<sup>22</sup> my own understanding of it as a concept emerges from Donna Haraway's *Simians, Cyborgs, and Women: The Reinvention of Nature* (1991). Haraway does not identify with the term Posthuman, and even moves to distance herself from it; but her questioning of the boundaries<sup>23</sup> and sanctity of the human tells us that such boundaries are not secure (Haraway, 1991; Miah, 2009; Gane, 2006b).

Literature that reconsiders the centralities of the human, its boundaries and intra-relationship with others has been a very generative space, theoretically, which has intellectually disturbed the foundations and ontological assumptions at work within

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<sup>22</sup> Miah comprehensively documents the origins and the different ways in which Posthumanism is understood and has even been co-opted (Miah, 2009).

<sup>23</sup> Haraway discusses the dualism and boundaries such as those between animals and humans, or the physical and non-physical (Haraway, 1991).

TSD. However, I was keen to move out of what felt like very high-level theoretical discussions and, instead, look towards finding devices or theoretically informed lenses that could empirically support me to undertake a reconsideration of the centrality of the human in TSD. Science and Technology Studies and, specifically, Actor Network Theory offer a way to step outside of the security of human-centred framings in order to think ‘with’ rather than ‘about’ things (Diprose, 2009; Latour, 2005). This intention to ‘think with’ can provide a starting point for a reading that works to give ‘some kind of “agency,” to previously silent or passive elements’ (Diprose, 2009; Latour, 2005). This activity of thinking ‘with’ signals an opening to new collective ways of thinking that push at the default tendency to confine agency and consider it as something exercised by humans (Bennett, 2005).

Bennett claims that these more distributed understandings of agency, view agency not as human centred but through thinking about relationality, networks and ‘assemblages’ (Bennett, 2005). As she states:

A distributive theory of agency does not deny that human persons are capable of reflective judgments and thus are crucial actants in many political transformations. But it attempts a more radical displacement of the human subject from the center of thinking about agency. It goes so far as to say that effective agency is always an assemblage: even what has been considered the purest locus of agency—reflective, intentional human consciousness—is from the first moment of its emergence constituted by the interplay of human and non-human materialities (Bennett, 2005).

The interest, not on humans, but on relations, networks and assemblages are work comfortably with uncertain boundaries, rather than making distinctions that claim that agency is located somewhere or wielded by someone (Bennett, 2005). Agency is, therefore, framed as something considerably more nuanced (Bennett, 2005).

Being aware of the visibility and politics of different actants or elements, through the prospect of ‘thinking with’ them, prompted me to question the role of care and caring. Being aware and thinking ‘with’ non-humans did not feel enough unless the issue of care entered and brought with it concerns about the flourishing of these other elements. Making commitments to care in TSD was a considerable motivation that

lay behind taking the end of life seriously when ‘framing’ a situation for research and design inquiry (Stolterman, 2008; Massimi, 2012). TSD is asking for death sensitivity because it cares about people at the end of life (Massimi, 2012). I share Massimi’s commitments to care; however, my sense of caring deliberately wants to decentre the human, because I care about the broader array of elements in the ‘framing’ of a situation (Stolterman, 2008).

Puig de la Bellcasa has asked if ‘thinking with’ care can bring about a compassion and ‘caring for’ things that affect how techno-scientific agencies and elements are observed and presented (Puig de la Bellacasa, 2011). This act of caring for other elements opens a space that engages with feminist notions of care as a pervasive and often devalued act that is tied to the sustaining of life (Puig de la Bellacasa, 2011). To care for and to care about the survival and flourishing of others is only possible through a necessary and vital labour (Puig de la Bellacasa, 2011). Puig de la Bellacasa claims the need ‘to care’, to continue and to support an array of elements to be maintained, through doings, thinkings, interventions, activities of change and acts of repair, ultimately works towards generative pathways that support us to live well in our world (Puig de la Bellacasa, 2011). As Puig de la Bellacasa insists:

Caring constitutes an indispensable living ground to the everyday ‘sustainability of life’ (Carrasco, 2001) and for the survival and ‘flourishing’ of everything on this planet (Cuomo, 1997). This work is necessary and vital, but we predominantly continue to value more highly the capacity to be self-sufficient, autonomous and independent (Puig de la Bellacasa, 2011).

In this frame, caring for is underpinned by concerns not only for the presence of others but also the survival of others (Latour, 2004; Puig de la Bellacasa, 2011). Generating care is an ethicopolitical intervention that brings in those who have not or cannot ‘succeed articulating their concerns’ (Puig de la Bellacasa, 2011). Care then relates to the attention and worry for elements, recognising that they are not just present but can be harmed by an assemblage (Puig de la Bellacasa, 2011). This is asking us to pay attention to the voices and concerns that are less valued within existing arrangements, within our acts of caring for (Puig de la Bellacasa, 2011).

This worry and concern for other elements is not meant to become an accusatory or moralist undertone (Puig de la Bellacasa, 2011). As exemplified by Puig de la Bellacasa:

Caring should not become an accusatory moral stance – if only you would care! – nor can its knowledge politics become a moralism in epistemological guise – show that you care and your knowledge will be better (Puig de la Bellacasa, 2011).

Rather, caring about the different elements, different agencies and flourishing of others in TSD offers a generative way forward to scrutinise the moralism of human-centred care. While we talk about making commitments and wanting to support people at the end of human life, these human-centred framings rest on a moral high ground that privileges human life and end of life above all others and, possibly, to the detriment of others. This may be, in itself, a trap, one that leads us towards making TSD commitment that does not take the complexities of distributed agencies seriously and, therefore, creating much wider potential for harm from our limited and anthropocentric ‘framing’ of a situation for research and design inquiry. Therefore, I consider these processes of thinking with and caring for as a generative way forward to consider the survival and flourishing of others.

## DISSONANCE AND ‘CRISIS OF THE HUMANITIES’

These different theoretical encounters through New Media Studies, New Materialism and STS have left lasting impressions, which means that I return to TSD and Critical Design more broadly with different perspectives. On one hand, there is TSD and its commitments to human-centred design informed by a Critical Humanist tradition; on the other hand, there is New Materialist philosophy and distributed notions of agency (Massimi, 2012; Barad, 1996; Bennett, 2005). These different approaches are deeply uneasy when held alongside each other, due to their differing commitments and values. Therefore, there are no ‘synergies’ or ‘fusions’ at work here; rather, we have now to bring them together in conversation and acknowledge the differences and antagonism between them. Certainly, it would be much easier to retreat into the potion of an enlightend outsider, to sit firmly within one space or the other. However, the

uneasy conversation that I am now going to facilitate between them offers a different theoretically engaged frame for the practice of TSD. By bringing together the tensions and difficulties, we can explore what else TSD can look like and what its capacities are for intervention at the end of life.

My reading of New Materialism and STS literatures presented a different frame in which humans are no longer the centre and technologies are not passive or invisible elements. Rather, in this different frame, agency becomes distributed and the human exceptionalism becomes challenged through notions of Posthumanism, which trouble the very distinctions and boundaries of being human. The result was disturbances that resonate more widely, bringing forth the consequences of human exceptionalism as part of the justification for the commercialisation of the planet, global commodification of living organisms and the complex management of survival and extinction that is currently at work (Braidotti, 2013b). Therefore, moving to reject the anthropocentrism that pervades TSD is also connected to broader debates about how the privileging of the human above and to the detriment of the object is something that requires serious reconsideration.

There are, however, broader tensions that lie behind the rejection of this human exceptionalism and making an attempt to decentre 'man' as the former measure of things (Braidotti, 2013b). The loss of relevance and mastery of the human in academia profoundly affects the collective fields of scholarship that identify as being centred on the human – broadly known as the humanities (Braidotti, 2013b). While design, more broadly, has been aligned with the humanities and also considered a third space between the humanities and science, TSD is different in that it explicitly identifies with the humanities and specifically with Critical Humanist traditions (Freach, 2012; Cross, 2006; Massimi & Charise, 2009). Braidotti (2013) argues that ontological challenges like Posthumanism are causing 'a crisis of the humanities' by radically asking the humanities disciplines to think beyond human frames and limitations (Braidotti, 2013a; Braidotti, 2013b). For Braidotti, if we collectively want to embrace the planetary scale

of the problems, we are being asked to take 'Posthuman humanities' seriously, due to catastrophic challenges such as climate change or falling biodiversity (Braidotti, 2013a; Braidotti, 2013b).

This suggests that TSD, its human-centred commitments and preference for Critical Humanist literature, requires scrutiny, not only of its human-centred frame but also of its implications in what Braidotti considers as the broader 'crisis' of the humanities (Braidotti, 2013a; Braidotti, 2013b). While TSD is seemingly unaware of this 'crisis', it is interesting to note that TSD itself was a move to ask HCI and design to change their frames to include death as a complex problem (Massimi, 2012). TSD's call for death sensitivity arguably reflects design's interest in facing wicked, big, and planetary-scale challenges within contemporary life (Rittel, 1973; Massimi, 2012; Dunne & Raby, 2014; The Design Collaborative, 2014). The major difference between how TSD and design frame these big challenges primarily lies behind how they continue to frame these challenges as human centred.

This human centred framing is not unique to TSD and can also be seen within the recent thinking of critical designers Dunne and Raby (2014), who share a similar interest in design framings. In *Speculative Everything* (2014). Dunne and Raby recognise the complex challenges facing design in our contemporary landscape and are concerned with exactly how these challenges are being framed and considered by design practitioners (Dunne & Raby, 2014). For them, design's sense of optimism and need to fiddle is working as a form of denial (Dunne & Raby, 2014). To Dunne and Raby, this denial and fiddling is preventing practitioners from really engaging with how complex, serious and even catastrophic some of these issues really are (Dunne & Raby, 2014). They propose that designers approach or frame these challenges not as problems but as avenues to speculate and play with the framings behind design that address catastrophic challenges (Dunne & Raby, 2014). The role of the human, however, remains unquestioned in this framing, along with the designer's centrality as an agent of change (Dunne & Raby, 2014).

Although Dunne and Raby do not question the human in their ‘framings’ for design, they do encourage that designers should go beyond their own field to other ‘methodological playgrounds’ in order find sources to inspire their speculative framings (Dunne & Raby, 2014; Stolterman, 2008). While our human-centred commitments may differ, I have found their suggestion useful to situate exactly the type of space that I open with interdisciplinary literatures. In Dunne and Raby framing, my engagement with other bodies of literature is connected to this ‘designerly’ pattern of designers gathering together inspiring and evocative things, in order to rethink or reconsider an existing design approach (Dunne & Raby, 2014; Cross, 2006), thereby constructing a theoretical ‘playground’ that helps me to explore these ontological disturbances and eventually draw them back home to the field of design (Dunne & Raby, 2014).

In this designerly mode, I consider the broader global challenges and ‘crisis of the humanities’ as a powerful motivator that further supports the need to question the centralities of the human in framings for design practice more broadly. They also lead me to question how commitments to other presences and agencies of other elements can trouble and disturb the promises made to support people at the end of human life.

Speculating with these theoretical sources led me to reflect on how TSD’s capability to intervene also helps us to understand its limits with regard to how it can positively support people at the end of life. In existing framings within TSD literature, how intervention is understood is built on the assumption that designers can locate where agency lies within a socio-technical arrangement (Massimi, 2012). TSD currently makes commitments to change and innovation because it leans on a dualistic understanding of agency between the human and technology that assumes it can locate a problematic source between them – usually framed as a problem with the technology (Introna, 2014b; Massimi, 2012). However, when agency is understood as distributed, it makes finding a singular source for intervention ‘impossible’ in any precise way (Introna, 2014b). Therefore, the capabilities of TSD, its promises and commitments become troubled when the other elements in ‘framing’ a situation for research and design

inquiry are treated with care (Stolterman, 2008; Puig de la Bellacasa, 2012).

Collectively, this space of dissonance prompts me to envision or speculate on what else a TSD framing could look like and what the capabilities for intervention are within more nuanced understandings of agency (Stolterman, 2008; Cross, 2006; Braidotti, 2013b). These speculations became something I wanted to explore empirically, knowing that there was a potentially complex empirical landscape to explore through interdisciplinary framework that was considerably different to existing literatures in the field. Through my interdisciplinary engagements, I was keen to look at a broader range of networks and account for the divergences around practices of loss. Considering an array of networks could introduce a collection of previously unaccounted for elements that would likely cause the assumed stabilities behind locating a source for intervention to be troubled. Collectively, these troubles were expected to prompt an empirically led reconsideration of TSD and reflection upon the commitments practitioners could make at the end of life.

## RESEARCH QUESTIONS

With the former tensions in mind with regards to the centrality of the human within design framings and human centred agency, I was interested in looking at this empirical landscape, where people had been turning towards social networks in loss in order to ask:

Can 'thinking with and 'caring for' an array of elements in a situation of inquiry present a more complex ethicopolitical dimension and prompt a reconsideration of the thanatosensitive design agenda? If so, what would this reading say about envisioning designing thanatosensitively and its commitments to positive intervention? Could it lead to a different understanding of what designing for death could mean?

## CONCLUSIONS

In this chapter I have brought together interdisciplinary literatures and opened a speculative space to consider TSD. I have taken the reader through TSD, its current

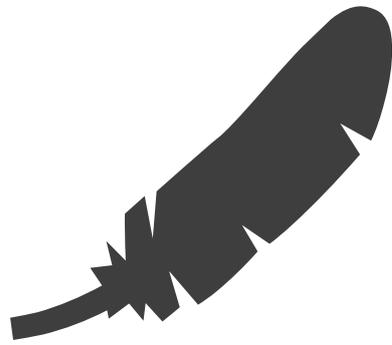
agenda and the human-centred ethicopolitical landscape upon which it rests. I then moved on to explore the literature in Death and Technology Studies, which fall into a division of designing for or designing with people. This latter designing with section, of turning towards what people were already doing, connected to my own sense of participatory politics as a designer and offered a potential site for future empirical focus. However, to draw out the differences between my consideration of this landscape in comparison to existing literatures, I introduced New Media Studies and, specifically, the theme of materiality.

This conversation about materiality continued, through New Materialism and the work of Barad. I explored how this philosophy troubles human-centred agency and the privileging of humans, which seem in sync with attempts to understand the complex challenges now facing our contemporary milieu. From this high-level engagement, I moved towards STS, Actor Network Theory and provide a more distributed notion of agency. I felt this offered a lens to pragmatically begin 'thinking with'; the issue of care was introduced due to it being an important component and motivator at work within TSD and my own commitments to sensitive contexts. This interdisciplinary journey then turned back to design, to reflect and later speculate on what TSD would look like and how it would operate when its foundations become troubled. This speculative space prompted the set of research questions that then go on to underpin this study.

The questions that I draw from outside of the Death and Technologies intersection are deliberately introduced to trouble and disturb TSD and potential empirical framings. The disturbances that I experienced have radiated out in ways that go beyond just identifying a gap in the literature. While there is certainly the empirical territory around online networks that this doctoral study can contribute to by just considering a broader array of networks and practices of loss, the literature review has also operated on an ontological level. It has presented challenges to existing assumptions around human-centred design framings, and also explored why these difficult disturbances matter to design in the light of complex challenges. Therefore, this literature review

pushes us towards a set of research questions that are interested in reconsidering the existing theoretically engaged frame for the practice of TSD. The questions I ask and their speculative nature lead me to trouble TSD and push towards a reconsideration that reframes what TSD look likes and how it operates.

To undertake this process of reconsidering TSD, I need a methodological structure capable of supporting the ontological and empirical framings of these questions, one that can generatively work with the notion of 'thinking with' and 'caring for' the different elements that TSD and Death and Technology Studies do not currently account for. I turn to address these aspects in the next methodology chapter by bringing together STS and design.

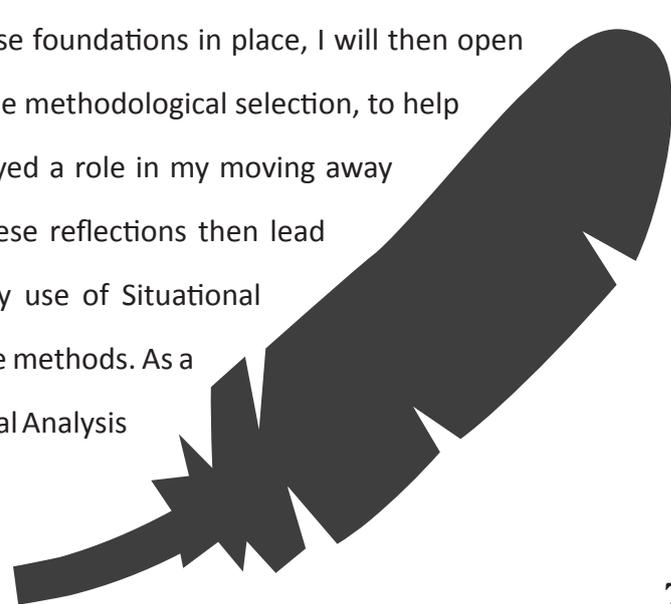


# CHAPTER THREE

## METHODOLOGY

**G**ray and Malins (2004) contend that design practitioners should extend reflexivity and help readers to be aware of how the methodological structure is a consequence of the ontological, epistemological and methodological reflections (Vasilachis de Gialdino, 2009; Clarke, 2005; Gray & Malins, 2004). This is particularly important due to the acknowledgment that design is known to borrow from more established research traditions and, therefore, needs to bring reflexivity to where the bits and pieces come from and how they hang together (Gray & Malins, 2004). Therefore, the focus of this chapter is to present an insight into my own ontological, epistemological and methodological framings, which have come together in order to give a methodical structure that can support a practitioner-researcher process of empirically 'thinking with' and 'caring for' an array of elements in a situation of inquiry.

Choosing sequentially to move down through each aspect of this chapter, I will open with the ontological layer and explain my preferences for critical paradigms of research. Then I will move onto discuss the epistemological layer and my understanding of knowledge creation as a politically sensitive, emergent approach with roots in Participatory Action Research. With these foundations in place, I will then open a space to expose my thinking behind the methodological selection, to help explicate the ethical reasoning that played a role in my moving away from the Action Research tradition. These reflections then lead on to methodological structure and my use of Situational Analysis in combination with unobtrusive methods. As a 'grounded' and STS framework, Situational Analysis



has been designed by Clarke (2004) to deliberately work in a responsive fashion and support its followers in paying attention to the much wider array of potential elements in a situation of inquiry (Clarke, 2005; Ramírez, 2009). I finish this layered discussion by reflecting on the ethics and limitations of the methodological structure.

After moving through the ontology, epistemology, methodology and limitations of the overall structure, I provide a pragmatic account of my methodological process between 2011 and 2015. This includes details of where and how I collected data, the kinds of analytical insight I had and, importantly, how each cycle prompted the movement towards to the next. These descriptions are aided by visual materials extracted from the process that help exemplify the different practices of data collection and analysis. These maps and illustrations supplement the textual account with a visual narrative that tries to relay the emergent, messy and unfolding nature of the cycles. These qualities are difficult for a textual account to really capture without becoming un-cohesive, yet together they relay the process that went on to formulate the shape of the ensuing chapters and the overall thesis.

## THE ONTOLOGICAL WATERS

In 2005, the late American author and professor, David Foster Wallace, gave a commencement speech that contained a ‘didactic little parable-ish’ story about fish and water. Wallace tells us that ‘There are these two young fish swimming along and they happen to meet an older fish swimming the other way, who nods at them and says “Morning, boys. How’s the water?” And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes “What the hell is water?”’ (Wallace, 2009). Wallace says the point of the fish story is ‘that the most obvious, important realities are often the ones that are hardest to see and talk about’, a point he considers to be both banally obvious and yet profoundly important in the ‘day to day trenches’ of our existence (Wallace, 2009).

Creative practitioners and designers have been encouraged by creative research theorists Carol Gray and Julian Malins to acknowledge our ‘water’ or social realities

and not begin by looking down the wrong end of the telescope at the methodological universe (Gray & Malins, 2004). This need to make the way we see the realities we are operating within as explicit as possible is important if we are going to take seriously the notion that our methods do not just describe social realities but create them (Law, 2004).

As I draw towards the end of the research process and have become more adept at describing my location, I recognise that, in terms of research discourses, I have been always drawn towards critical approaches to inquiry. As noted by designer, Otto Von Busch, 'While some types of research are based on distanced observation and non-intervention, others claim agency, action and a will to intervene in the world in order to change it' (2014). He continues, 'for critical research the task of knowledge production is to change the world' (Von Busch, 2014). By critical I am referring to the tradition of Karl Marx, of Critical Theory and inquiry that work towards an awareness of various cultural, social and historical conditions for emancipatory or transformational purposes (McNiff & Whitehead, 2002; Von Busch, 2014). I understand that this relationship with critical approaches to inquiry has developed due to living with what feminist theorist Sara Ahmed calls a 'failure to fit',<sup>24</sup> which has made issues of inequality and social justice salient concerns within daily life (Ahmed, 2015b).

I believe this 'failure to fit' is because my outlook on life is stained by my background. Being formulated in difficult circumstances has sensitised me to be aware of privilege, norms and the resulting discomfort that is invoked 'when we do not quite inhabit them' (Ahmed, 2014). I try to hold onto this awareness in a way that does not become diminishing, through an ongoing interest in projects that aspire to change and transformation – even though this transformative 'emancipatory' notion has itself become a source of critique (Clarke, 2005).

I contend that it is these sensitivities that have long guided my anti-positivist stance. I

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<sup>24</sup> In thinking about living a feminist life and diversity in work, Ahmed uses this phrase in her discussions on entering a room: 'They are not expecting you. Discomfort involves this failure to fit. A restlessness and uneasiness, a fidgeting and twitching, is a bodily registering of an unexpected arrival' (Ahmed, 2015b).

am suspicious about objectivity, neutrality and the 'universality of scientific knowledge'. I resist grand theories and the deployment of 'truth' that serves to legitimise some and successfully silence others. I am deeply resistant to academic approaches that emphasis neutrality, universality, generalisation, simplification, stability, rationality and homogeneity (Benton, 2001; Clarke, 2005). Rather, I align myself with inquiry that values the relationality, partialities, situatedness and the heterogeneities of knowing that reject a 'unified system of beliefs and assumptions' (Clarke, 2005).

Undertaking interdisciplinary work is a part of this rejection of a unified system of beliefs. I consider disciplines as power structures that contain their own values, practices, conventions and protocols; my interdisciplinarity is a continuing project that unintentionally and intentionally disturbs these. I make these disturbances (and the resulting messiness) by taking a practitioner-researcher and unfolding his or her approach to research (Gray & Malins, 2004).

## EPISTEMOLOGY

Like design practitioner-researcher, Ramirez (2009), I sit in space where, as a designer, I want to engage in doings and interventions, and, as a researcher, I am interested in constructing knowledge that helps me to find out more about practice and realities (Ramírez, 2009). Therefore, my approach to any research avenue is always from the perspectives of both a digital media researcher and a designer and is, concerned with the mutually informative relations between research and theoretically engaged practice. How I understand knowledge from this location is through thinking about it as a process of construction. This understanding has developed through my background in Participatory Action Research [PAR].

As Judi Marshall tells us, in PAR, research is a 'political process' and 'creating knowledge is a political business' (Marshall, 1999). In this landscape:

Who researches and how; whose experience is researched and how that is named or categorised; what discourses gain currency and hold power; what forms of inquiry and writing are favoured by 'mainstream' power-holders; and much more are

political issues (Marshall, 1999).

In this description, Marshall gestures towards the way in which politics and democratic approaches to inquiry play a central role in understanding knowledge production (Marshall, 1999). Politics are an aspect that PAR tries to attend to through its commitments to working with people and invoking a sense of ethics, reciprocity and care within an inquiry process (Stringer, 2013; McNiff, 2013).

Alongside paying attention to the politics and care within PAR is the important role of thinking about practice. PAR projects typically make commitments to some form of practice, action or intervention while simultaneously making a contribution to knowledge within its collective processes (Stringer, 2013; McNiff, 2013; Ramírez, 2009). It values practice and intervention alongside knowledge creation that is comfortable with different understandings of knowledge or 'knowing' as a tacit or embodied quality (Seeley & Reason, 2008). Bringing together different ways of knowing and creating new knowledge are part of the politics of PAR, which involves different people who can contribute to the process from very different locations and educational backgrounds (Seeley & Reason, 2008). Therefore, in this space different ways of knowing are welcomed and valued.

The process of PAR as an iterative, responsive and cyclic endeavour is a process that is recognisable to designers (Ramírez, 2009; Gray & Malins, 2004; Godin & Zahedi, 2014). Designers can relate to the cycles and emergent nature of a PAR process in relation to their own and, therefore, the tradition of PAR becomes a 'fruitful' way of designers framing their relationship with practice in academic inquiry (Ramírez, 2009; Godin & Zahedi, 2014). This is particularly useful due to how contentious<sup>25</sup> the role and doing of practice within academic inquiry can be within the discipline of design (Ramírez, 2009; Godin & Zahedi, 2014). It can also help address the contentious issue that the approach a designer takes to inquiry and knowledge creation is often carried out with a practitioner-research approach that makes replicating the process particularly difficult

<sup>25</sup> *What constitutes research in design is a subject that is touched on frequently by Ken Friedman, Don Norman, Terence Love and other well-known academics on the 'PhD-Design' mailing list: <https://www.jiscmail.ac.uk/cgi-bin/webadmin?AO=PHD-DESIGN>.*

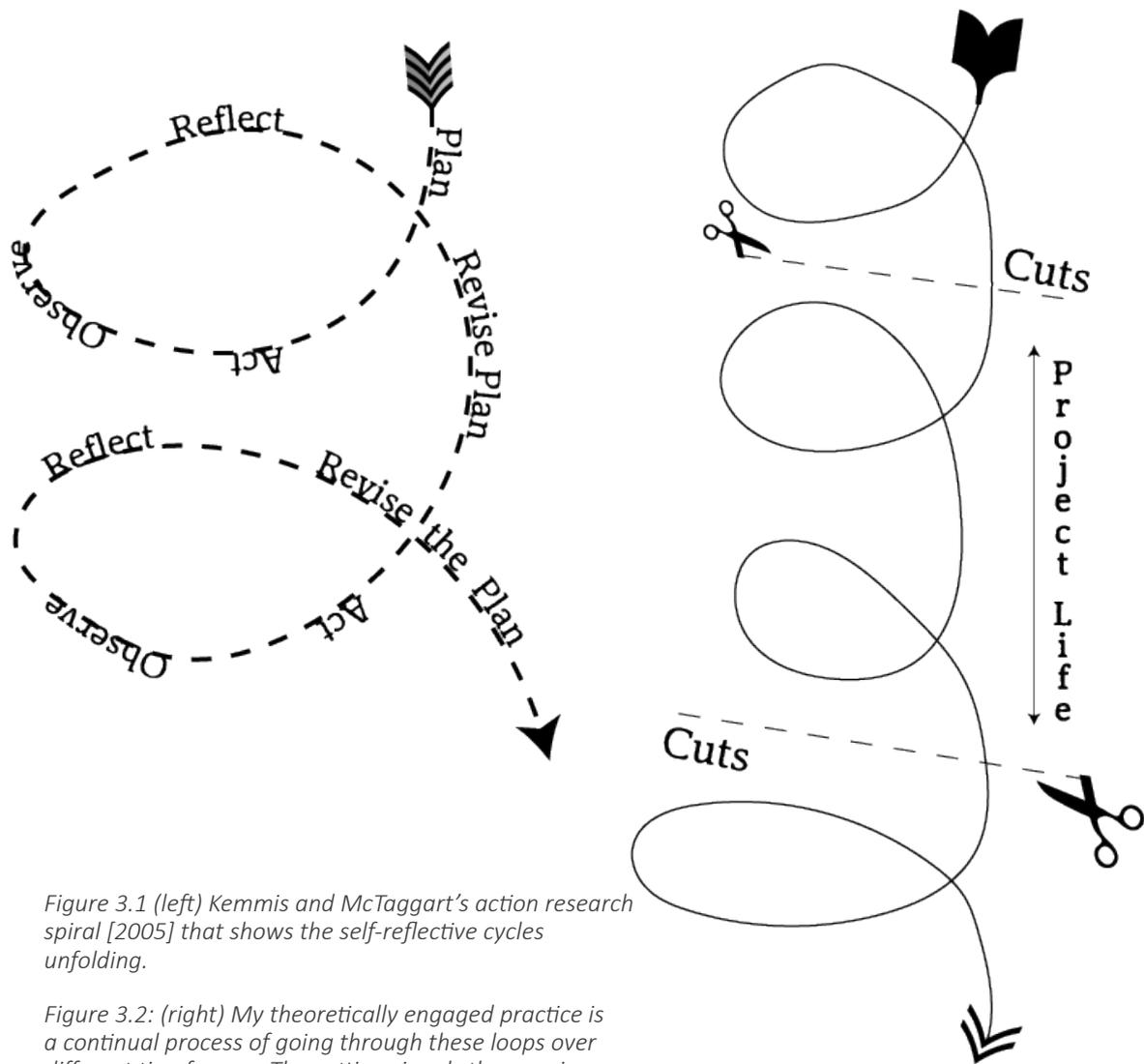


Figure 3.1 (left) Kemmis and McTaggart's action research spiral [2005] that shows the self-reflective cycles unfolding.

Figure 3.2: (right) My theoretically engaged practice is a continual process of going through these loops over different timeframes. The cutting signals the opening and closing of particular projects and individual cycles. I find this corkscrew visual helpful in illustrating that I am always come from somewhere and these cycles will shape where I move onto next.

(Gray & Malins, 2004; Godin & Zahedi, 2014).

Within the PAR process an intervention or series of interventions are made through an ongoing methodological structure that loops back on itself as a reflective activity. These cycles typically move through indistinct phases of gathering data, analysing the data, planning action, taking action and evaluating, leading to further data gathering and so on (Stringer, 2013; McNiff, 2013). The desired outcome is not only a positive intervention or action but also some form of important learning outcome(s) that is typically seen as an intended or even unintended contribution to knowledge (Stringer, 2013; McNiff, 2013; Ramírez, 2009).

As a designer I draw from PAR and our shared interests in complexity, practice,

intervention and knowledge creation to help acknowledging the non-linearity of this process and the other ways of knowing that bring value to a process. I find PAR literature to be useful in explaining both my political sensibilities and also the unfolding and iterative 'designerly' ways of carrying out inquiry (Punch, 2006; Gray & Malins, 2004; Cross, 2001; Godin & Zahedi, 2014). The illustration that is used in PAR to exemplify the cyclical nature of inquiry is a useful reminder that we start a process by coming from somewhere, located by our previous experiences, and are moving towards future work that is reminiscent of framing knowledge as a lifelong endeavour.

The legacy of my own my engagement with participatory projects is that I hold onto a strong sense of politics. The emergence and unfolding nature of these processes leads practitioners to be comfortable with inquiry that works outside of pre-structured methodological frames. The politics, process of emergence, reflection and cyclical nature can all be seen in the methodological structure. This means that literature, data collection and analysis are not separate, sequential or even distinctive phases, but rather a process of going back and forth in order to develop themes. The development of themes and directing the overall activities are driven by reflexivity and the collective process of

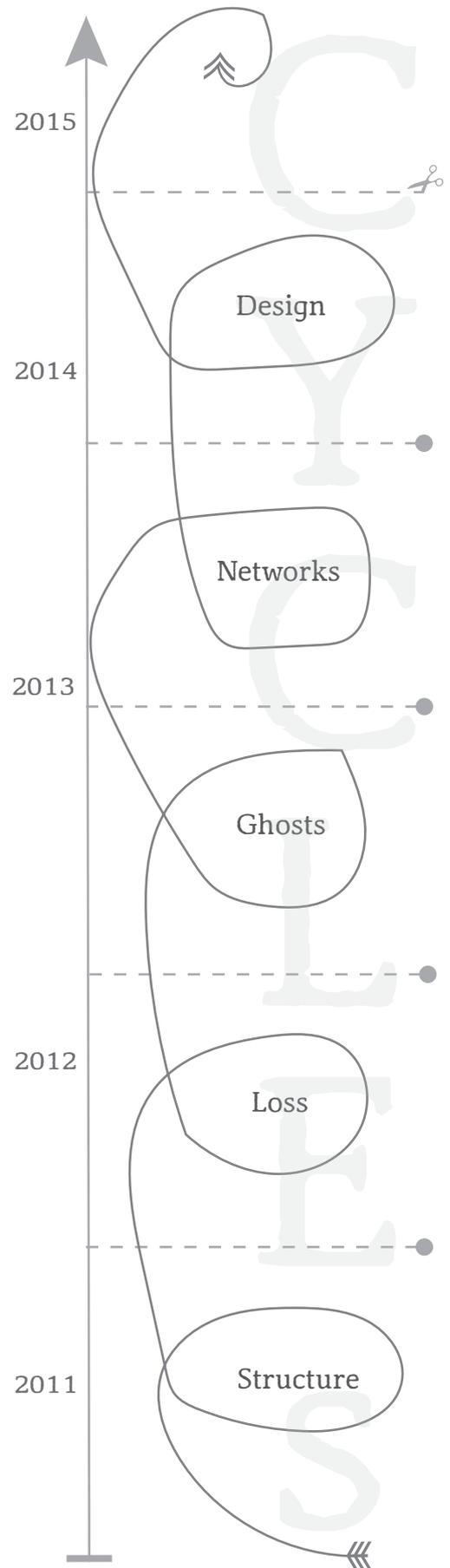


Figure 3.3: Core focus of the cycles I underwent through this study

supervision. This can be seen more within the central chapters of the thesis, which present the findings alongside the analysis, discussions and reflections.

## THINKING BEHIND METHODOLOGICAL SELECTION

From the outset, I recognised that I needed a methodology that could also underpin my research questions of thinking with and caring for different elements. Yet I also needed one that could work emergently, by supporting this kind of cyclical engagement that would be likely to involve my own practice to analyse and communicate findings. However, the selection of a methodology that could support my research questions and style of inquiry was only part of the rationale for the eventual turn to Situational Analysis and unobtrusive methods. It is this reflective dimension before the methodological structure was decided upon that I now move to explore, by taking a moment to consider the ethical concerns I had that have also fundamentally shaped my methodological selection.

Methodologies and methods employed in the end-of-life contexts are noted to demand a high level of methodological reflectivity and nuanced selection that is not just on the merit of the 'effectiveness' of a particular approach in relation to data collection (Liamputtong, 2007; Dickson-Swift et al, 2008; Lee, 2000a; Massimi, 2014). Partly, this is due to ethical concerns and an engagement with ethics that transcends the seeking of formal institutional ethical approval. It creates an ongoing and intimate relationship with ethics, which, from my experience, manifests as a day-to-day concern for the people and presences that were involved in my study. Therefore, the eventual methodological selection and methods choice came out of this responsible ethical engagement that was 'built on principles of care' (Boellstorff et al, 2012).

Although I have a preference for participatory work, there was very little scholarship in the Death and Technologies Studies intersection from which to draw for methodological insights when I began the PhD process. I recognised from the outset that I have had no formal training to work in the sensitive context of loss and I also have no official support in place to help guide and bear the emotional labour that has been recognised

in this kind of work (Moncur, 2013). I recognised I had to care for myself and a group of potentially vulnerable people if I opened an intensive participatory space. I also had concerns with trying to fit this type of subject matter and the potential for a participatory project into a PhD framework. I had reservations as to whether a PhD and its institutional requirements and limitations could foster the type of reciprocity I felt was important within participatory work. Conflicted by these tensions, I found that looking towards what people were already doing with existing technologies was the most agreeable way forwards, rather than turning back to designing for the 'user'. This led me to consider social networks as an avenue that became more favourable as I identified the limitations of the existing work in the field.

Not having a previous background in Internet research, I subscribed to the Association of Internet Researchers (AoIR) in order to help develop and guide my ethical engagement. The AoIR ethical guidelines were first written in 2001 and revised in 2012, offering Internet researchers an excellent resource from which to begin Internet research and consider the ethical treatment of people online (AoIR, 2013). The AoIR guidelines invoke a series of basic tenets, such as:

The fundamental rights of human dignity, autonomy, protection, safety, maximization of benefits and minimization of harms, or, in the most recent accepted phrasing, respect for persons, justice, and beneficence (AoIR, 2013).

The AoIR built from these tenets in order to present a set of guidelines, which became central to how I chose to methodologically approach my study and my day-to-day engagement. Two tenets in particular helped me to consider the shape of the methodological structure. The first of these claims the greater the vulnerability of those involved in the inquiry, the greater the obligation of the researcher to protect them (AoIR, 2013). The second tenet claims that the researcher must balance the rights and interests of the subjects involved with the social benefits of the researcher and their right to conduct research (AoIR, 2013). These two values stood out because they bring the rights of the research participants to the foreground and claim that these rights may outweigh 'the benefits of research' (AoIR, 2013).

It was by working with these values that I became acutely aware that, even outside of participatory research, the issue of reciprocity still exists. I could always see where I benefited by producing a PhD thesis. I could also see the academic benefits and the contribution to be made to a scholarly community. However, identifying and even predicting the benefits or value to potentially vulnerable people has been a difficult and uneasy task, particularly in view of the fact that research inquiry has the potential to be unpredictable. Similarly, research is known, in itself, to cause anxiety and even distress, affecting how people behave through a sense of surveillance and scrutiny (AoIR, 2013; Lee, 2000b; Liamputtong, 2007).

These qualities prompted me to consider a study style that was non-invasive and would not impinge upon people at the end of life. I felt uneasy at potentially intervening in people's loss and grief in relation to Internet research; I started to question if it was even necessary to explore my research questions. Internet research certainly offers researchers a landscape in which to explore methods that do not involve participants, where the researcher can engage in data collection through less intrusive research design. Turning towards Internet research and using online research methods certainly offered an array of benefits, not only opening a site for data collection, to begin 'thinking with' and 'caring for' the different agencies at work, but doing so using non-direct, less intrusive engagement and a more flexible research environment for the investigator.

Although not always prominent, both Lee (2000) and Hine (2011) note that research that does not need active participation has a 'respectable' role in the history of social research (Lee, 2000b; Hine, 2011). Unobtrusive and non-invasive research styles originate from the work of Webb et al. (1996) to refer to the any methodical style and methods for gathering data (Webb et al, 1966). Webb et al. (1996) argue that inquiry that does not actively involve the participation of research subjects can avoid the behaviour adaptation and scrutiny that can be caused by a researcher's presence and gaze (Webb et al, 1966). Unobtrusive methods are particularly valuable when dealing with sensitive or taboo topics that are difficult to get people to engage in and that

are likely to prompt emotional distress (Lee, 2000b; Lee, 2000b; Hine, 2011). Rather than actively seeking information from participants, Webb et al. (1966) encourage researchers to be reflective and pay more attention to the existing sources of data, such as the material traces left behind, non-participant observation and the use of documentary or wider historical sources (Webb et al, 1966).

Since Webb et al. (1966), and, in particular, Lee (2000), argued for unobtrusive research in sensitive contexts, the potential opportunities for gathering material data, engaging in observation and being able to access a wider array of multi-sited research sources has proliferated due to Internet research (Hine, 2011). Hine (2011) notes that people are engaging in social networking, uploading a variety of different media, tagging, reviewing, commenting, keeping blogs, creating search histories and leaving a wide collection of digital traces in the wake of their activities (Hine, 2011). This activity can occur over quite long periods of time, i.e., months or years, providing researchers with rich sources of data to gather in ways that are less intensive, not only on the researched but on the research (Hine, 2011).

Unobtrusive methods offer a way into the phenomena of bereavement and loss online, but through a style that reduces the scrutiny of this group. The bereaved are known to experience 'oppressive' and profound social pressure to conform to society (Harris, 2010). Furthermore, the phenomena of bereavement has been scrutinised by academics and people have found their experiences of loss medicalised and pathologically framed through this work (Harris, 2010). Unfortunately, this has led to research models and systems that have pushed concepts of closure and recovery upon them (Harris, 2010; Small, 2001; Walter, 1999). Being aware of this history, both academically and through my family's experiences, means that I am particularly sensitive and keen to explore the topic without adding further pressure to potentially vulnerable people.

There is a counter argument to the use of unobtrusive research and methods that can be described as 'covert' (Hine, 2011). Covert research can be seen to have a negative connotation within Internet research because it invokes an image of the

lurking researcher accessing data without informed consent or reflectively addressing whether it is ethical to do so (Hine, 2011). While I recognised this aspect, and I return to address it further in this chapter, I felt that unobtrusive research offered this study, myself and my participants a way for a research story to be told within the confines of a PhD with less chance of it intrusively intervening and causing unnecessary distress.

## METHODOLOGICAL STRUCTURE

By moving through the ontological, epistemological and reflective thinking work that has been carried out behind the methodical selection, I now move onto the structure of the methodology. From the outset, I knew that I needed a structure that could help me to ‘think with’ and ‘care for’ the potentially different elements within an empirical landscape in order to help address my research questions. Secondly, I needed a structure that could be responsive and support my cyclical patterns of engagement as a designer. Thirdly, I needed a structure that could support an unobtrusive research and methods, such as gathering existing data remains, engaging in long-term participant observation and drawing upon wider array of documents or historical sources.

These requirements, in relation to the limited bodies of literature that were situated in the Death and Technologies Studies intersection, led me towards considering Grounded Theory [GT]. This decision came from discussion with supervisors about taking a ‘data first’ approach to the situation of inquiry and through finding the work of Ramirez (2009) who discusses the favourable interconnections between the practitioner-researcher role and the traditions of PAR and GT. (Ramírez, 2009). Ramirez (2009) specifically argues for Situational Analysis devised by Clarke (2005) as a variant of Grounded Theory [GT] because it offers practitioners a home for their research through design practice and responsive and cyclical processes (Ramírez, 2009).

Alongside Ramirez’s (2009) recommendation to consider GT and Situational Analysis is a rich history of GT as a methodology design specifically for understanding the end of life. The origins of GT actually lie in how it was devised by Glaser and Strauss in order to find a way of carrying out a research study in light of the very limited bodies

of literature that are known to surround the end of life area<sup>26</sup> (Timmermans & Tavory, 2007; Timmermans, 2010). They used ethnographic methods in combination with GT to create one of the first qualitative studies to be undertaken at the end of life, now famously known as 'Awareness of Dying' (Timmermans & Tavory, 2007; Timmermans, 2010; Glaser & Strauss, 1966).

Since emerging out of Death Studies, GT has become a widely used research methodology capable of handling an array of data (Clarke, 2005). The variants and scope of GT are now so large that it has travelled out of its positivism roots and across a wide range a paradigms of inquiry and disciplines (Timmermans & Tavory, 2007; Timmermans, 2010; Glaser & Strauss, 1966). However, there were elements remaining in GT that made me concerned about whether or not it could really help to facilitate my aims to 'think with' and 'care for' other elements of a situation of inquiry. For this reason, I was quite sceptical when I approached Situational Analysis, which was compounded by Ramirez (2009) not drawing out its theoretical foundations.

My interest in Situational Analysis [SA], however, became more favourable when I began to understand the origins of it as a methodological structure (Clarke, 2005; Ramírez, 2009). Devised by sociologist and STS scholar, Adele Clarke, SA is a visual and cartographical approach to attending to humans and non-humans within a situation of inquiry (Clarke, 2005). Its interest in thinking about *the situation* aligns very well with my research questions and is sympathetic to my research style as a designer. Clarke devised SA because, in her view, 'positivist recalcitrances remain' in GT, even though it has been paradigmatically turned towards more constructionist and constructivist positions (Clarke, 2005).

Clarke was a student of Grounded Theory co-founder, Anselm Strauss, and her engagement with the Straussian style of GT has led her to believe that, while it has developed from positivism into constructivist positions, it still maintains a modernist world view, 'particularly by looking for a pure "basic social process" that does not take

<sup>26</sup> I recognised this characteristic of limited bodies of literature in 2011 when I approached the *Death and Technologies* intersection. I was literally working with a handful of papers and drawing in a broader array of interdisciplinary literature to help me contextualise and frame existing work.

seriously materiality or power relations' (Clarke, 2005). To address this, Clarke draws upon her influences from feminist techno-science and those 'emerging in part from feminism, antiracism, and related commitments to equality' in order to develop an approach that takes difference[s], power, contingency and multiplicity very seriously in empirical research (Clarke, 2005; Mathar, 2008).

This leads to a version of Grounded Theory that still begins by gathering rich data and working to analyse it through coding, writing memos and working in cycles in order to develop themes. Similarly, SA does not advocate a particular set of data collection methods, although Clarke does acknowledge that it works well with ethnographic and multi-sited research (Clarke, 2005). The focus of SA is rather on the analytic handling of this data, whereby it asks its followers to collect data that opens a complex situation of inquiry that is not human centred, but rather questions what different human and non-human, material, discursive or other elements are present (Clarke, 2005).

Clarke's reconsideration of GT is an introduction to the material and non-human elements and agencies she believes have been lurking in pragmatist tradition but without methodological reflexivity (Clarke, 2005). Clarke specifically draws upon Latour, Law and Actor Network Theory to introduce the human, non-human actors and consider more distributed notions of agency at work (Clarke, 2005). Yet it is Clarke's relationship with Foucault and his scholarship that prompts SA to begin asking 'what kinds of knowledge claims about whom/what and under what conditions', thereby taking power relations, silences and the issue of care seriously within the Grounded Theory framework (Clarke, 2005).

An SA approach can analytically support a wide variety of data types and Clarke outlines specific strategies for visual, historical and discursive materials (Clarke, 2005). Yet Clarke moves beyond just coding or memoing these data by encouraging followers to take heed of *ecologies and cartographies* (Clarke, 2005). By outlining cartographical methods in detail, Clarke encourages the construction of three kinds of map that help visualise the different elements and relationships that are a work (Clarke, 2005).

Firstly, there are situational maps, devised for capturing elements in the situation and prompting relations among them (Clarke, 2005). Secondly, there are social worlds/ arenas maps, devised to explore the collective commitments and relations (Clarke, 2005). Finally, there are positional maps, which are useful for mapping out where positions are taken or not (Clarke, 2005).

Comfortable with the visual approach that is built into SA, I spent some time returning to constructivist considerations of how to approach GT with Kathy Charmaz and her well-respected guidelines that laid the foundations for starting SA (Charmaz, 2014; Charmaz, 2011; Clarke, 2005). Charmaz's textbooks helped me get to grips with approaching GT through layers of coding, memoing and 'theoretical sampling', which, as an analytical tactic, pushes the research through phases of data collection and analysis that work to develop particular emerging traits or themes<sup>27</sup> in the work. Analysis is emergent and responsive to the materials at hand and allows the researcher to push through a multitude of lenses depending on those needed to help drive data collection and analysis towards the initial questions that emerged. The collective push towards finding and developing analytical materials that address the initial question is what supports SA to hit what is considered to be a 'saturation' point, where cycles are no longer presenting new insights or information related to research questions (Charmaz, 2014; Clarke, 2005).

Feeling comfortable with SA and the coding framework as outlined by Charmaz, I returned to thinking about methods. From the outset, I was interested in data collection methods that involve the researcher unobtrusively participating in participants' daily lives for an extended period of time.

I was interested in finding and working with sources of data remains in the long term, to pay attention, listen, and watch what was happening, begin analysis and ask further questions through the collection of artefacts and documents (Hammersley & Atkinson, 2007). This inevitably led me towards a style of unobtrusive data collection, drawing

<sup>27</sup> *Classic GT would claim that this is where categories and theory are generated. I refer to themes deliberately rather than categories because I feel they are a less violent way of thinking about groupings.*

from the tradition of ethnography (Hammersley & Atkinson, 2007).

Using ethnographically informed methods, I was interested in gathering data by engaging in long-term observation that was interested in following what it was that people were doing (Hammersley & Atkinson, 2007; Boellstorff et al, 2012; Hine, 2015). I also wanted to use methods that would help me capture the data remains I was observing through acts such as downloading or using screen shots and, finally, visualising or mapping elements (Gray & Malins, 2004). Finally, I also wanted to be able to access archive materials or a wider array of media sources such as newspapers or technical handbooks to help contextualise the area, an approach that Clarke considers as part of a multi-sited and mixed methods approach (Clarke, 2005).

I recognised that the data remains created out of these engagements, such as the media files or visual snapshots, to capture the practices and data involved were leaning heavily on my practitioner-researcher role. I felt that visual records could be kept for coding and comparison across long periods of time but that they also invoked my preference for visual analysis. To help balance this preference for the visual I followed the more conventional SA and GT approaches of keeping memos and handwritten field notes when observing practices, as a way of quickly capturing analytical insights.

Along with these specific methods for data collection, I also followed my usual practice of building an unbound sketchbook as a collection of A1, A2 and A3 sheets. This practice comes from my training in graphic design and is done in this way because large sheets of blank paper facilitate both textual and visual elements that emerged in the process of designing. I used this process to visualise and map out emerging themes. I also used them as a way of keeping sprawling notes, reflections and promoting relations. Sometimes I would also draw in Adobe Illustrator, printing

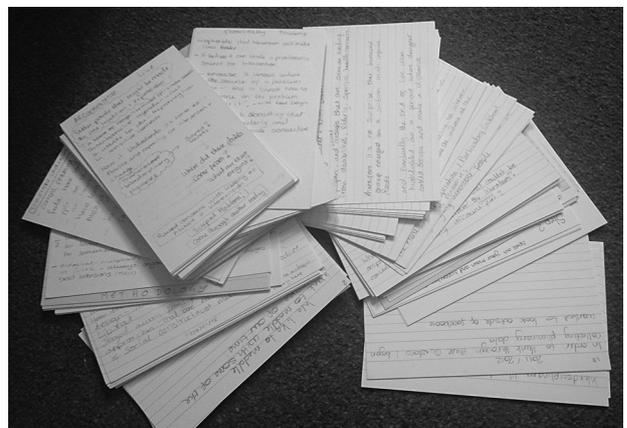
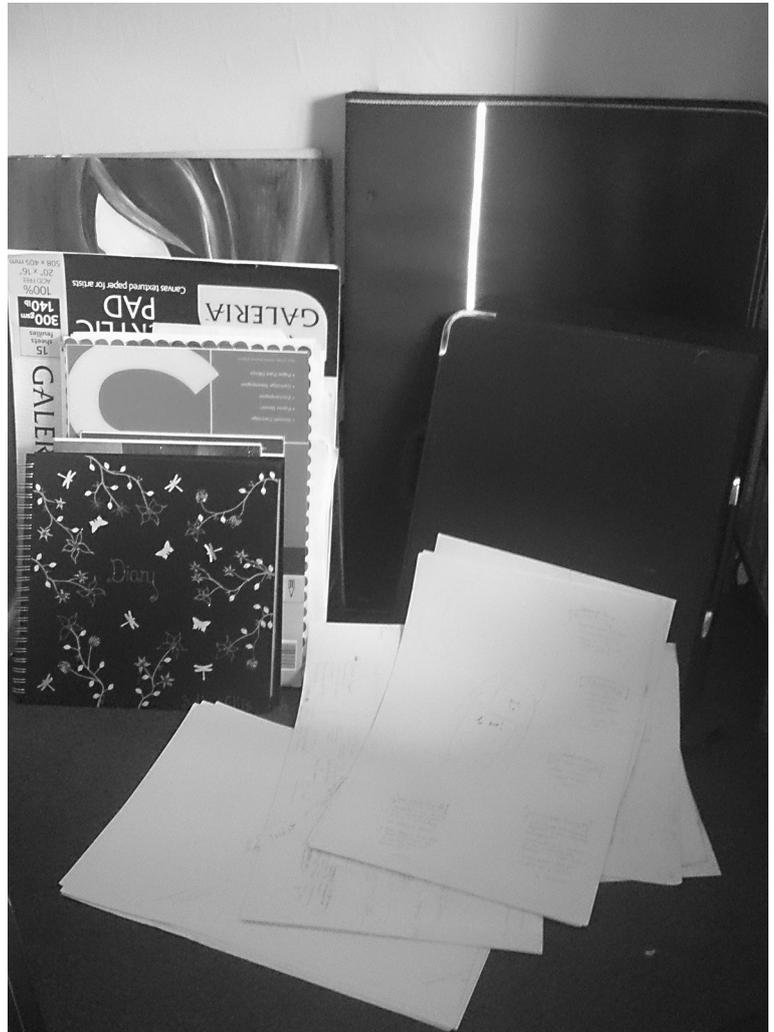


Figure 3.4 Sample of the note cards I carried around

out diagrams or collections of images. Over time these messy notes became less visual but their combined mixture of text and images would help me to think about the complex process at work, to help me orientate, analyse, construct and communicate ideas in supervision. When I could not carry these bigger documents with me I always had index cards in case I needed to keep working on the move.

## ETHICS AND LIMITATIONS

There are important consequences of bringing together these differing ontological, epistemological and methodical reflections. While they provide a methodology that employs an unobtrusive data collection style to SA as a way of supporting the research questions to begin ‘thinking with’ and ‘caring for’ within an emergent and cyclical process, there are limits to this approach. The first issue I want to return to is the lurking covert researcher who is a much discussed figure in Internet research (AoIR, 2013; Hine, 2015; Boellstorff et al, 2012; Markham, 2005). I have intentionally selected a methodological framework and methods that did not require me to directly approach or continually engage with participants in order to collect the empirical material. I could observe practices, take field notes, collect and save data remains, engage in visualisations and devise cartographies to build a contour of the terrain, moving across different networks without the participants knowing I was doing so.



*Figure 3.5 Selection of the portfolios and pads where they are currently housed at home*

Within Death and Technology Studies, Walter et al. (2011) comment that, 'Methodologically, research in this field is done most easily by going online and observing the sites in which dying people, their careers, and mourners participate' (Walter et al, 2011). Certainly, Internet research does have favourable capacities for the researcher such as high levels of searchability and accessibility, and the public, by the default logic of many social networks, make data collection relatively 'easy' across a number of platforms (Walter et al, 2011; Boyd, 2010; AoIR, 2013; Haverinen, 2014). Alongside this ease of engagement, methods for gathering data such as observation are considered to be fruitful because they allow insight into sensitive areas (Walter et al, 2011; Hine, 2015). As Hine argues:

Since almost every conceivable aspect of daily life is reflected somewhere online, and since the cloak of anonymity can lead people to a frankness they rarely show in face-to-face encounters, the Internet offers rich data for almost any social researcher and particularly those working in sensitive areas (Hine, 2005).

However, to participate covertly in Internet research and online ethnography and to extract data without participant consent invokes the uncomfortable figure of the lurking researcher observing people's daily practices without making themselves known.

In Internet research, the ethics of this type of covert research inquiry and ethnographic observation can invoke heavy criticism due to the lack of informed consent over long periods of time (Boellstorff et al, 2012; AoIR, 2013; Hine, 2015; Hine, 2011; Fossheim & Ingierd, 2015). From my perspective, an aspect to these debates that I came to recognise is that they do not often occur in research topics or contexts that would be considered sensitive. Research methodologies and methods within sensitive contexts bring with them their own sets of unique considerations and ethical dimensions (Lee, 2000a; Liamputtong, 2007; Dickson-Swift et al, 2008). These considerations have to play a large role in whether a study should even be opened and, if a study is opened, how it should take shape and operate on a day-to-day basis (Lee, 2000a; Liamputtong, 2007; Dickson-Swift et al, 2008). Sensitive research is directly confronting issues that are traditionally considered taboo or difficult; therefore, researchers have to take seriously

and balance the emotional harm to the participants and to the researcher with issues such as anonymity, consent, reciprocity, responsibility, legalities and understanding the potential for invasiveness through publication (Lee, 2000a; Liamputtong, 2007; Dickson-Swift et al, 2008).

This gesturing towards harmful consequences refers to the potential for distress, conflict or danger arising as a consequence of the inquiry or beyond the inquiry process through publication or the reporting of findings (Hammersley & Atkinson, 2007; Hine, 2015). Research can be a difficult process for participants and it has been noted in ethnographic studies that:

Being researched on can sometimes create anxiety or worsen it, and where people are already in stressful situations research may be judged to be unethical on these grounds alone (Hammersley & Atkinson, 2007).

Hammersley and Atkinson contend that the end of life is once such context the researcher needs to be very careful in approaching, particularly with ethnographic methods that traditionally would involve establishing some form of close relationship (Hammersley & Atkinson, 2007), primarily because there is the potential for a deep and ongoing emotional labour to arise out of this engagement, which can be taxing to both the participant and the researcher (Hammersley & Atkinson, 2007; Moncur, 2013). I was aware of this aspect from relationships with participants in other research projects. Thinking about my own self-care was important as I was acutely aware that I was approaching the end-of-life area as a neophyte, without being embedded in a department or surrounded by the disciplinary research environment where the histories, conventions and support of researching the end of life could be drawn upon.

While the positive aspects of this approach have been outlined, now I need to turn to the cautionary limitations that come with this unobtrusive methodological

**“Caring for myself is not  
self-indulgence, it is  
self-preservation, and that is an  
act of political warfare.”**

Audre Lorde

structure. When collecting both found data or ethnographic data, not all communities and cultures have Internet access, and those that do may be what Hine calls passive consumers of Internet information rather than active participants (Hine, 2011). Neither can we assume an overlap in language or network usages, as it is known that there are patterns of platform use that are connected to different communities or even countries (Hine, 2011). I am undoubtedly limited by my westernised approach, as an English speaker and influenced by the cultural preference for networks that feature heavily within westernised Internet research landscapes (Hine, 2011). This, in turn, shapes the kinds of network I visit, practices I will account for and my ability to attend to the kind of cultural nuances that I will encounter.

Then there are technical and legal constraints that emerge around data collection to consider. I will only be able to access data that is publically available. I also have to pay attention to the EULA and types of data I can legally download. Additionally, I am at the mercy of corporate decisions, which might revoke or change access to corporately owned material and remove my access to it at any time during the process (Hine, 2011; AoIR, 2013).

Finding these data streams does depend heavily on propriety algorithms that are obscure in how they operate. Examples of this are Google search or internal searches and tag functionality that lead to a particular portrayal of what is actually available. Similarly, my engagement can cause algorithms to respond to the types of search I do and the kinds of results I receive. Therefore, what I search for and find in networks may be intentionally targeted to me and my activities as a user of these places.

Another set of limitations and constraints arise from the lack of consent for this unobtrusive data to be collected. Engaging in Internet research through using unobtrusive methods that do build relations with research participants means that the responsibility of privacy and anonymity has to be taken very seriously and with professionalism (Beninger et al, 2014; AoIR, 2013). The NatCen Social Research (2014) argues that it is important to preserve and protect the privacy of the subjects of any

research study, but that this is especially critical if consent was not formally requested and received (Beninger et al, 2014).

This move to protect the privacy and lives of those who are already potentially vulnerable means that the findings of studies should deliberately work to avoid harm, ridicule and to protect the subjects' right to anonymity (Beninger et al, 2014). This is especially critical if consent was not formally requested and if the data streams are publically accessible and could potentially attract attention (Beninger et al, 2014). This is also especially important in view of the fact that, within Internet research, the impact is particularly difficult to foresee and predict (Beninger et al, 2014; AoIR, 2013). Over the course of my research, this aspect has become particularly salient around the theme of publication and presentation of the results.

I recognise that it is the sociotechnical arrangements that support unobtrusive methods, which can turn and begin to undo this work. As noted by Shklovski and Vertesi (2013), it is incredibly difficult to preserve anonymity and privacy online when using publically available and searchable data (Shklovski & Vertesi, 2013). Simply publishing findings or publically discussing results without a high level of anonymity and diffusion over the research sources can mean that this material, through the same mechanisms, can be searched for and found (Shklovski & Vertesi, 2013; AoIR, 2013; Fossheim & Ingierd, 2015). Preserving the integrity of sources from which materials have emerged can be incredibly difficult due to the capabilities of particular search propriety algorithms. Even small excerpts of texts, key words, phrases and images can easily be used to investigate, break open sources and remove the anonymity that is carefully built into the project (Shklovski & Vertesi, 2013; AoIR, 2013).

In practical terms, this has led to a series of decisions with my supervisory team around how to present the findings of this study, which include amending, editing, blurring and invoking techniques that add layers of difficulty to the 'searchability' and 'accessibility' of my data and its sources. This also includes traditional publishing techniques such as names being changed, details removed and the removal of identifiable features.

This process of obscuring details and removing identifiable features has manifested most visibly in my 'findings' chapters and the inclusion of data across the thesis. Only chapters Four, Five and Six will present a limited selection of what can be considered 'raw' data. There are empirical vignettes included in these chapters, but their presence is selectively used and details have been changed to reduce the searchability of the sources. This duty of care to remove specific details has only been carried out to dramatically reduce the identifiability of the subjects of my research. Some of these people have been living with loss for many years and I have been fortunate to gain insight into their practices and losses. I want to ensure, moving forwards, that this thesis does not interfere with them continuing these activities without interference.

Therefore, the data, analysis and discussion in the subsequent chapters have been very carefully attended to in order to ensure that the empirical data is not obscured for any reason other than to protect and respectfully conceal those whose difficulties, traumas and painful losses have provided the 'source' material from which this study is built. The issues of care, respect and reciprocity have to take precedence in sensitive research. Therefore, further references to the original 'raw' data can be requested and are available, but will not feature in this thesis.

By moving through the ontological, epistemological, reflective and methodological thinking that underpins this thesis, I have drawn out the limitations and ethical issues that are situated around this kind of methodological approach. I will now outline the key cycles and discuss the collection and analysis of data in detail. I will start with my entry point, which was to consider human loss across networks online. It was through this entry point that I moved to decentre the human and include the non-living and non-human elements.

## CYCLE ONE: HUMAN PRACTICES OF LOSS

This doctoral study has four separate cycles that respectively focused on human

loss, non-living ghosts and non-human elements, which come together and prompt reconsideration on thanatosensitive design.

Due to my literature review, I was keen to start outside of Facebook, even if I knew that I would inevitably end up moving into this network. I felt that the ever-growing focus on the Facebook network could be limiting the diversity and divergences in practices that might exist across people's practices of loss. Therefore, I began this empirical phase by approaching the contemporary networks of Twitter, Instagram, YouTube, Vimeo, Kickstarter, Just Giving, Tumblr, Flickr, Google blogger and WordPress sites that I encountered within the first six months of my PhD.

I approached the contemporary networks above and used their respective tag or search functions to systematically run through some common terms that are found around loss, similar to 'in memory of'.<sup>28</sup> This often resulted in considerable amounts of results in each network. Therefore, to focus and cut through these practices of loss I looked for the differences and divergences at work, such as types of loss, relationships to the deceased and the different sociological variables, such as age, ethnicity, gender, religion and so forth. I documented practices where people identified as being in heterosexual and LGBT relationships, intimate and distant relations, numerous death types such as suicide, accidental, chronic and terminal illness, both young and old, atheists, no denomination, Christian and so forth. Collectively, these variations were brought together by their differences, not their similarities.

At first I only documented a source location and jotted down what made it different from others in the network. Then, realising the amount of material I was facing, I began to gather data remains that documented these different practices of loss.

My favourite method was taking screenshots of pages in order to capture all the elements on the page. I would piece together the screenshots using Adobe Photoshop in order to build large static documents, which would contain multiple screenshots of one browser-loaded page. These were saved in date order, ready to access for

<sup>28</sup> *These are not included or listed here deliberately as I do not want to encourage people or expose my research sources.*

comparison and analysis. This visual collection and snapshots of practices of loss captured an overview of the multiple facets that were present such as the textual, visual, the design, layout and so forth. This offered a number of analytical approaches to get into the initial data, focusing on the text, visual elements and even the sites' design and layout.

Quickly gathering numerous sources and data, I wanted to produce an overview or snapshot of the practices of loss that I was finding. This index and collection would provide a basis to work with, to seek out the other elements of situation and later be able to prompt a reading of relations between them. To document and 'collect data'



from the practices of loss that I initially began to find, I drew upon my professional background to build a series of landscape maps to simply document where and when the phenomena I had found occurred, under what terms and with some information about the example. Similarly, I brought together the screenshots and materials to begin building a data archive that corresponded to the individual data sources.

After constructing the maps that revealed multiple different practices of loss across multiple networks, I entered an interim analysis phase. I

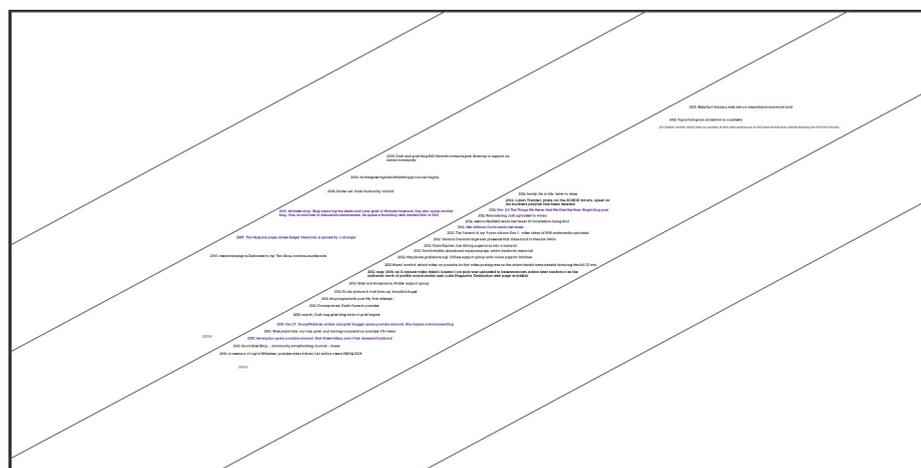


Figure 3.6 One large archive sheet shrank down. Unfortunately it cannot be full size due to it containing sensitive details

Figure 3.7 The A1 map as it first started out. Unfortunately it cannot be shown full size as it contains sensitive material

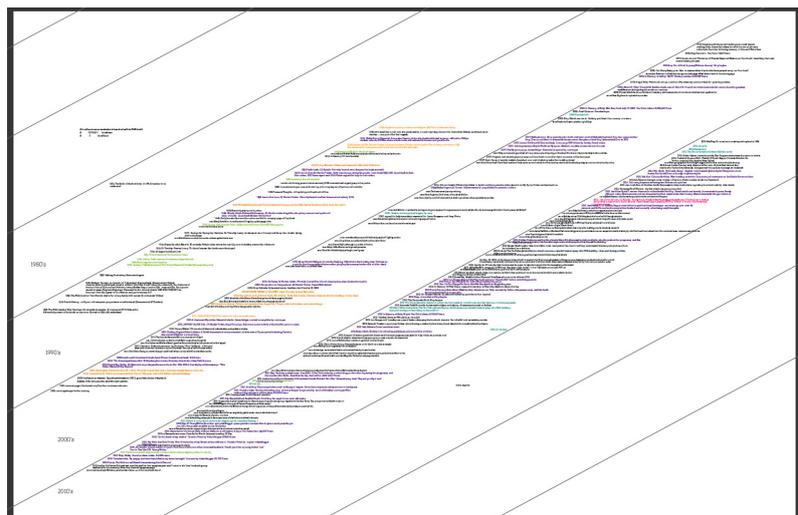
was curious about people's engagement in these practices, if they were contemporary or if there was a time dimension that I needed to pay attention too. I then began to run the details of certain kinds of loss through Google and Bing searches. Running preliminary searches around the name of the deceased was the most effective. I became aware that certain practices were singular events, while others belonged to patterns of longer-term engagement around certain deaths that actually spanned multiple networks.

This simple act of searching certain deceased names began to reveal that I was looking at practices that had occurred over a longer period of time than I expected. Furthermore,



Figure 3.8 Laying out prints of the visual captures and moving them around to prompt analysis

some examples of this phenomenon spanned a timeframe that dated back to a time before social networks and into early user-generated platforms. Therefore, my empirical phase began to take on a

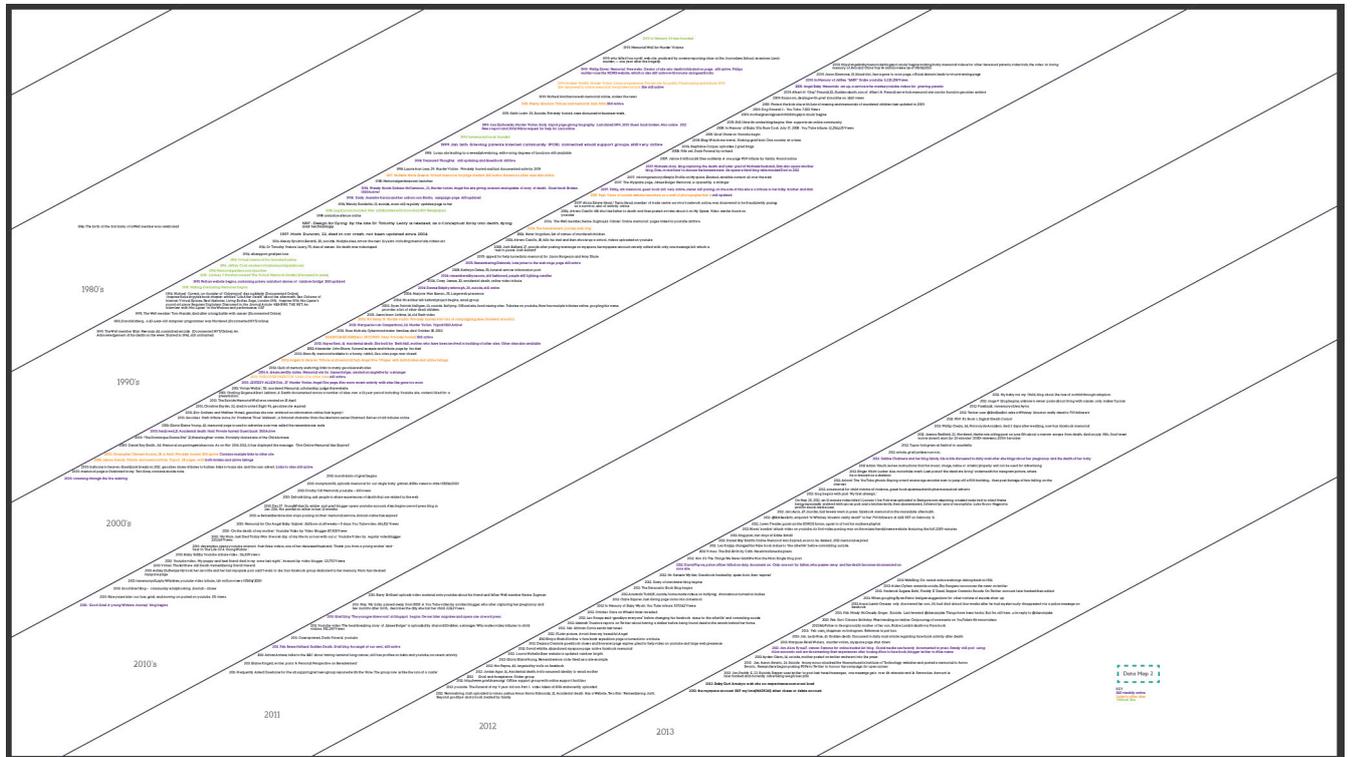


broader spatiotemporal

Figure 3.9 The A1 map shown on the previous page but in this version we can see the sources developing and being colour coded into themes

emphasis and older networks like Myspace, Geocities, Homestead, Angelfire, Tripod, Bravenet and early forums systems. Finally, archived secondary material was woven

Figure 3.10 The A1 Map developed over multiple decades



in. Maps were accordingly updating to incorporate the new data, revealing a growing archive that was spanning practices and sites that were between 15 and 20 years old and still highly active.

Analytically, this spoke of the potential for developing a historical frame to understanding loss online that had not been previously applied. I, therefore, returned to the literature in order to develop a sense of this long-term engagement while considering the need to archive the materials to be included. I began to run newspaper searches to see if loss had been discussed and found articles dating back to 1990, which discussed examples of people dying and the subsequent grief, recognising these archived and secondary data sources as adding a new dimension and previously unaccounted for landscape.

I had to develop my own technical histories to aid my understanding of what I was reading. Although I was using the Internet in the mid-1990s, I was unsure of the networks and technologies in any level of detail before this period. Therefore, I went through a period of developing a technical history. Interestingly, my engagement with New Media Studies meant that I increasingly grew to dislike this monolithic Internet history story. However, it did give me a basis to consider the practices within, what I began to deem as, a Silicon Valley history.

Within the first six months I also began to observe certain practices, keeping field



huge mind maps that developed themes and explored bodies of literature.

These themes developed and eventually formed the structure of Chapter Four. The focus of this chapter began and stayed with human loss throughout, documenting the practices that had continued to occur within what had become a diverse and divergent landscape. As a landscape, I began to realise that, collectively, this body of work – the source maps, the analytical maps revealing different layers



*Figure 3.12 One of many A0 mindmaps that I would piece together*

and the archive materials – laid out the foundations that supported the next phases. I was keen to go back to the data I had already gathered but also to begin to look for new elements and agential presences. The first of these elements to look for struck me when I realised that my maps referenced the name and details of a deceased individual.

## CYCLE TWO: THE NON-LIVING PRESENCES

I was aware that the word ‘ghost’ had been used by Brubaker, that Facebook had been called a ‘medium’ and people in the Death and Technology field understood the continuing relationships with the dead (Brubaker & Vertesi, 2010; Kasket, 2011; Getty et al, 2011; DeGroot, 2012a). However, the dead had only ever been discussed in research accounts in relation to the living and they have never been the focus of any empirical work in their own right. I recognised that these non-living elements had become a passive but present element in the situation of inquiry.

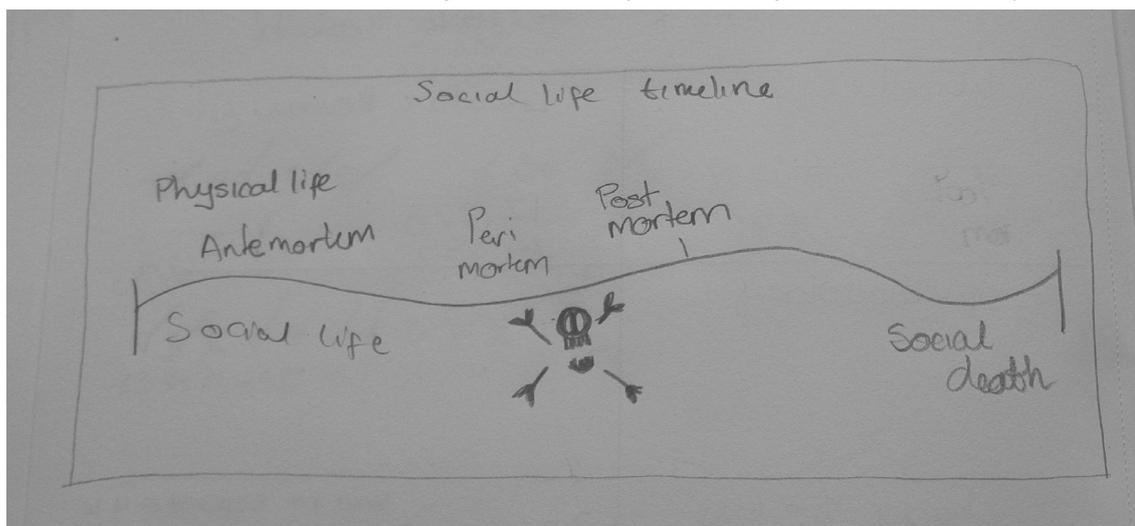
In some senses, the dead had already taken precedence and dominated aspects of my research inquiry. It was searching for the deceased on Google or networks that often brought through the sources for data collection. I got to know the names, dates,

locations, education, employment status and, sadly, how someone had died with very little effort. I believe that this was due to the sheer amount of work that was being invested into invoking these ghosts online and in making them become manifest by the bereaved. For this reason, I was sure that the dead needed to be removed from this passive frame and empirical work to consider how they have a sense of agency.

To do this, I built off existing materials and began another round of searches for deceased individuals on the Twitter, Instagram, YouTube, Vimeo, Kickstarter, Just Giving, Tumblr, Flickr, Google blogger and WordPress sites. Facebook had, by this time, moved into the empirical landscape, along with Bebo, Myspace, Reocitties, Angelfire, Homestead and Mysite. These older user-generated platforms, social networks and Facebook had begun to come through in my previous cycles. I also drew from the communities that were active around the presence of a ghost, noting that these connections could lead me out towards other deceased individuals. This turned into a second map dedicated to helping me index and oversee a landscape of ghosts.

This data collection and analysis used the same methods as the first cycle, preferencing the visual capture and construction of key pages with field notes. I would later use these visual records to code and make memos as part of an analytical process to draw out themes. The first theme I would develop would be to understand who the social presence was. I began to use more diverse codes than ghosts, such as angels or spirits, to help in this process. These terms came directly from the living and how they had chosen to characterise their dead. These codes helped me to understand how certain communities also named the types of losses they identified with and how they collectively considered their dead together. From these analytical themes of exploring the social presences of the dead, I began to dig down to see exactly how these ghosts were created and over what time periods. This inevitably led to me 'regularly' visiting certain sources of ghosts and practices of loss in order to see how the dead were being kept present over time. Some ghosts would appear and 'live' on through what I began to recognise as long-term commitments and obligations, while others would begin to

Figure 3.13 Social life timeline as first sketched out in my notebook



decay and become lost.

I recognised that ghosts were not just being created by their bereaved but also through their own day-to-day engagement with technologies. Therefore, ghosts actually emerged through a range of 'peri-', 'ante-' or 'post-' mortem periods. This timeframe, borrowed from forensic anthropology, helped me to denote the time periods of before, close to or after death when I was looking at the data. This meant that I had the date of death and the date when the ghosts emerged.

Through this process I noted how sometimes ghosts were emerging in more unusual ways that had become folded into practices of loss. Therefore, I began a final round of data searches and to look for data remains that had emerged close to the time of death or, more unusually, autobiographically. The focus of this work was across online media sources and the use of tags and searches that related to themes around death and suicide. I began to draw out these emergences, tracking how and when the dead had first appeared online and where they had traversed and travelled.

Through this engagement I began to encounter the potential for new sources of data collection. However, from what I had encountered through online media and tags, these would prove to be difficult sources of loss online that would feature the humans and non-living in more unfortunate circumstances. I felt that these sources began to relate to the 'dark' side of networks and tell a very different aspect of network use in

loss. This prompted me to consider moving into a third cycle, focused on non-human or entanglements seen in networks. These arrangements could be used to explore when things come together in ways that can begin to trouble and disturb both humans and non-humans in strange ways.

### CYCLE THREE: THE NON-HUMAN LIVES OF DATA

The third cycle began to document the presences of the non-human and the body of this work developed into Chapter Six, on the theme of 'Networks'. I began this cycle by working with the data sources that I felt captured the 'dark' side of networks. I coded and made memos to draw these details out and began to consider where media remains kept making appearances or reappearances cross spatiotemporal landscapes. These codes and memos began to speak about the networks themselves and entanglement between different elements.

During this period I took time to reflect and to rethink exactly how I could tell this entangled and human story of loss. Returning to my notes and visuals, core analytical themes became of interest in thinking about how to move forwards. The first was how the different elements of the network often did not become visible until something difficult or bad was unfolding. The second was how the different elements of the network would help facilitate and shape people's experiences of death within a much larger public frame. Both of these themes, unfortunately, connected back to how the entanglement of networks would become deeply distressing to bereaved families. I recognised that I needed new data that focused on accounting for these different elements as events happened. These would work to reveal the human story behind this 'dark' side but also highlight the array of elements that are present and unfolding.

Wanting to follow events more closely first hand, I began data collection in response to a number of unfortunate events and breaking news stories that emerged. Using the same methods of visual data capture, notes and observation, I stayed with an event as it unfolded and gathered data remains as they emerged across the Twitter, Facebook, Instagram and Tumblr networks. I would closely track a death or fatal event through

tags and searches that would enabled me to capture tweets, comments, posts and more media-related content.

As they unfolded, the events had an important account to give of the different elements that were at work and how these were coming together in complex arrangements that would impinge upon bereaved families. However, while I felt that giving insight into these kinds of events and making an account of them was important, there are difficult aspects to working with this kind of material in this 'real-time' way. I soon felt implicated in how these stories were unfolding. I felt uneasy searching for material or following trends or tags even for research purposes, as I felt implicated as part of the problematics at hand.

Within the period that the cycle was open, I managed to capture two key events like this, one of which was so big that it would be impossible to give an anonymised account. However, I felt confident framing the entire chapter around two examples because they were so rich and exemplified the two themes around network visibility and the appetite for this material. I had managed to collect so much data around the events in question that I gave attention to identify the different elements and thinking about how I could address these by discussing the features of sharing and tagging.

A considerable amount of reading was undertaken to help contextualise the media environment I was watching unfold. Similarly, I reached out to the SEO field in order to help draw out the digital marketing environment that was also implicated in this story. I was fortunate to have an SEO expert on hand who was willing to explain some of the tactics that, without insider knowledge, would not necessarily have been so visible. These aspects have to be interwoven into the overall narrative; therefore, Chapter Six approaches the story with a different granularity than the chapters before it, characterised by how the cycle itself, the data engagement and analysis were working to try to relay a difficult but important narrative.

## CYCLE FOUR: META-ANALYSIS ON DESIGNING FOR DEATH

With the elements of the human, the non-living and the non-human having their presences and agencies accounted for across numerous chapters, I began the final phase of drawing these elements together to construct a reconsideration of TSD. While this fourth cycle now exists as an analytical and concluding chapter in this thesis, the chapter itself was formulated through a meta-analysis with the analytical materials already created. This final cycle occurred late within the PhD structure, occurring just prior to and within the early stages of writing up.

To carry out this meta-analysis, I followed the Situational Analysis instructions for creating cartographical maps in order to open a space to draw out implications. The first type of visual analysis mapped the different actors, human, non-human, non-living, material, discursive and other elements in the research situation of inquiry. Then, using the 'position' maps that Clarke advocates, I laid out the major positions, taken or not, to reveal an axis of concern and controversy around the situation of inquiry. Although there were other maps to use that are part of the Situational Analysis family, these two maps were the most generative.

The process of compiling these maps was 'dirty and messy', a feature of analysis that Clarke encourages. I would use A3 or A2 sheets with multi-coloured pens and have my archive material close at hand. As I became more comfortable with scrawling them

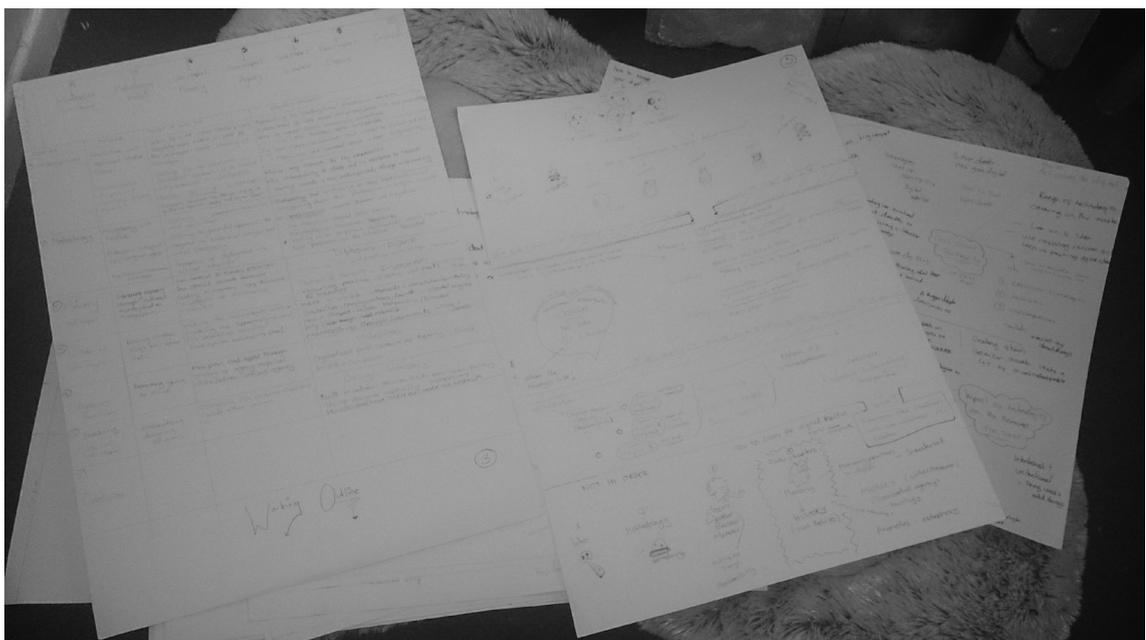


Figure 3.14 Analysis notes developing into provisional thesis structure

out, these maps became a quick way of catching the different elements, thinking with them, caring about the relations between them and, importantly, letting in the heterogeneity and mess. Organically, these maps began to develop into two forms of practice that I recognised as sitting alongside a more formal and academic contribution to knowledge. The first was a design statement on sensitive design, offering its viewers a visually informed way of thinking about design at the end of life. The second became the more polemic manifesto for sensitive, created as a series of sentences on what I thought a sensitive designer should pay attention to. Collectively, these became my 'interventions' or outcomes of the cyclical process to sit alongside the knowledge contributions that I explain in this chapter.

It was through these final cycles of reflection on the entire process within the last cycle that I recognised the limits of the current work. I speculated on a new avenue for future work and gestured towards thinking what else designing for death could look like. While this signalled the end of the lengthy analytical and empirical phases of the PhD study, it was also a creative cut that prompted me to think about future work. Musing in this space, I recognised the need for an afterword chapter, one that could start thinking about future directions in a more speculative and interesting way.

## CONCLUSION

The chapter takes the commitment to how research design constructs realities seriously. Therefore, I began by presenting the ontological framing of 'how I see the water', my preference for critical approaches to inquiry and where the desire to undertake interdisciplinary work originates. With the ontologically layer outlined, I moved onto to explore my epistemological understanding of knowledge construction. Drawing from the tradition of Participatory Action Research, I explored how knowledge is constructed through an ongoing political, iterative and responsive process. This attention to the politics and ethics that lie behind knowledge creation opened a space for reflecting about the methodological selection, before moving onto present the methodological framework. I then explained the selection of Situational Analysis in combination with

unobtrusive methods before concluding these theoretical discussions by addressing the ethics and limitations of this chosen approach.

The second half of this chapter then turned to describe the core cycles and doings that were undertaken between 2011 and 2015. In these interconnecting cycles I discussed the collection of data, the specific methods and analytical focuses I employed during this time. Although the process was an unfolding and overlapping process, I tried to draw out the linkages between each cycle so that the reader can follow the journey through the spiral. By including visualisations made during the process, insight is given into the designerly role that was involved in this kind of analysis.

This chapter has worked to not only present the methodical structure employed to support the research questions but also to explain the style of inquiry that is central to how I understand and 'do' knowledge construction as a practitioner-researcher. Using this located aspect has important consequences, not only for the 'replicability' of this kind of study but also to explain why the thesis is structured as it is, moving forwards to the empirically focused chapters of Four, Five and Six.



# CHAPTER FOUR

## THE DIVERSITY OF LOSS

**L**oss is a complex and messy dilemma which is experienced within a wider cultural and historical framework (Small, 2001), a framework that is considered to be increasingly fractious and continually oscillating (Walter, 1994; Hallam & Hockey, 2001; Davis, 2002). This findings chapter presents empirical vignettes, analysis and reflections that document a diverse and divergent range of practices of loss online. In order to break away from the contemporary spatiotemporal focus on Facebook, these practices are deliberately presented across a 25-year time frame in order to open a space for the complex and oscillating landscape to unfold. The historical framing allows the reader to move forwards in time towards an insight into the contemporary landscape of loss, which includes insights collated from a number of different networks, practices and entangled data remains between 1990 and 2015.

The first section starts in 1990 and moves to present the earliest accounts of death and loss that I found in the historical, archived and documentary sources. The second section moves onto the mid-1990s and tracks early examples of practices of loss on the World Wide Web, which emerged and are still active as the crafting HTML pages on user-generated web hosts. The chapter then moves on to the early 2000s and draws attention to the increasing complexity of these HTML sites before addressing the migrations of data and practices onto social media networks. Finally, the chapter moves from early social networking sites to the



contemporary landscape of loss that emerged across a diverse range of networks between 2011 and 2015. These contemporary accounts allow us to glimpse into the diversities, divergences and data of loss that can be seen online.

## 1990+ IN THE ARCHIVES OF LOSS

This first section presents the earliest found accounts of death and loss within online networks. However, before moving on to discuss the first death online, we need to keep in mind the notion of networks and the multiplicities of histories that this section is working across. The Internet is often historically presented as a kind of singular monolithic network with a singular history, which typically begins in the aftermath of WW2, and is jump-started through the threat of nuclear strikes.<sup>29</sup> This apocalyptic threat is said to have inspired RAND's Paul Baran to think about a distributed communication network of computers. This concept is what was eventually developed before manifesting as the Advanced Research Projects Agency Network or ARPANET (Ryan, 2010). This monolithic history of *the* Internet is often repeated and equally criticised for how it homogenises what, in reality, what was (and still is) a mass of overlapping and interconnecting networks, each with its own set of complicated histories (Mejias, 2013; Lovink, 2011; Parikka & Sampson, 2009).

Those interested in the intersection between Death and Technology Studies can find early accounts of human loss online rooted in different network histories. I draw from some examples to map out a 25-year history, through working archive material, historical and secondary data such as specialist computer or technology magazines, books and reports. There are undoubtedly other histories to be made that will differ from this one, but which will still likely note the consistent themes of social interaction and 'living on' in cyberspace that pervade these sources.

These were two themes I consistently encountered in archived materials and, in this history, are perhaps best exemplified through ARPANET and Timothy Leary. In terms of social interaction, the much-publicised ARPANET implemented email in 1971, and it

<sup>29</sup> For alternative histories that complicate this monolithic story, see (Jordan, 2003; Hafner & Lyon, 1996; Galloway & Thacker, 2007).

Figure 4.1 Technical timeline A1 Map. As first seen in methodology <https://www.dropbox.com/s/q1znwftkro1z10a/Technical%20timeline%20%28V3%29%20A1%20copy.pdf?dl=0>



was believed to have consumed almost two-thirds of the bandwidth as soon as it was implemented (Ryan, 2010). Similarly, in 1975, the first ARPA group email list called 'sf-lovers' again consumed so much bandwidth it was temporarily shut down (Ryan, 2010). In terms of living on, in the mid-1980s William Gibson's concept of cyberspace took hold, as did notions around downloading consciousness, themes that Timothy Leary began to advocate as he became terminally ill in the early 1990s. His eventual book *Designing for Death* told its readers 'IF YOU WANT TO IMMORTALISE YOUR CONSCIOUSNESS, RECORD AND DIGITISE' as a way to upload into the immaterial and friction-free cyberlands (Leary & Sirius, 1997; Ryan, 2010).

Therefore, it is not unexpected that death online and intimate communities of grief can be found within early accounts of networks. In terms of the focus of archive materials, Silicon Valley undoubtedly dominated these accounts of network use and development. For this reason, it may not be surprising to note that the first archival material that I uncovered that specifically discussed death and loss occurred within a network that developed and operated in the San Francisco Bay area.

The network known as TheWell had the first account of a death online that I encountered. It is the wealth of material published on TheWell, including by its own postgraduate and tech-savvy members, that helped it become well known as the first 'virtual community'<sup>30</sup> (Lewis, 1994; Ryan, 2010; Hafner, 1997). When TheWell opened in 1985, home computer ownership was considered to be limited, with systems that primarily operated with black and white displays and no internal hard drives (Ryan, 2010; Hafner, 1997). Even in the technologically comfortable San Francisco Bay area that TheWell came out of, modems were still a rare piece of hardware for computers and those that had them were only capable of 9.6kbp. At the time of opening, TheWell infrastructure itself consisted of a VAX 11/750 with only six modems and six phone lines that worked asynchronously.

Although the Macintosh had been released a year earlier, and the Graphic User Interface had signalled a huge shift in accessibility, TheWell was deliberately run using PicoSpan, <sup>30</sup> *Label given by author and TheWell member Howard Rheingold (Rheingold, 1993).*

which asked for programming knowledge of Unix arcana. PicoSpan was considered to be user-unfriendly conference software, which became the heart of TheWell's early infrastructure. It created an interface and operational style that Steve Jobs apparently denoted as being the ugliest he'd ever seen (Hafner, 1997).



Figure 4.2 Vax Machine. Sourced: [http://archive.computerhistory.org/projects/Visible Storage/AE/AE\\_foto project/500%20Club%20Sent%20to%20Aerin/Contents%20of%20Batch%201/no%20number%20VAX%2011-750.JPG](http://archive.computerhistory.org/projects/Visible%20Storage/AE/AE_foto_project/500%20Club%20Sent%20to%20Aerin/Contents%20of%20Batch%201/no%20number%20VAX%2011-750.JPG)

While it might be seen as the ugly duckling of 1990s networks, TheWell was claimed to be the first system accessible to anyone and not just researchers or corporate executives. Accessibility, however, is conditional as it undoubtedly took skill to use, and its functionality shaped member's practices. A well-known example was members' having to contend with their 'scribblings' or posts not expiring; that is, they didn't delete automatically after a certain amount of time as they did on other emerging commercial services or on Usenet newsgroups.

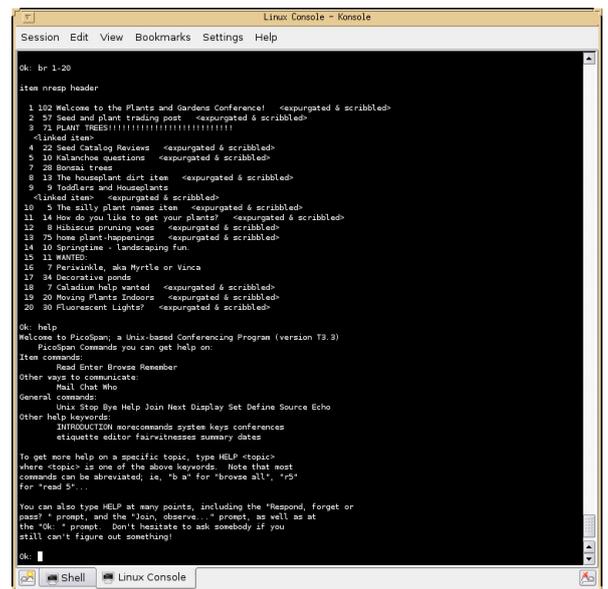


Figure 4.3 Picospan "ScreenCaptureOfPicospanBBSInKonsole" Licensed under Fair use via Wikipedia -

Still, TheWell is a richly documented network and, importantly for this thesis, noted for the lively relationships that were formed both online and offline. As a network, it was considered to support an 'intensity and intimacy' that notably spanned births, marriages, divorces and death (Rheingold, 1993; Hafner, 1997). The first encounter with death occurred when a highly active and long-term member died on June 1st 1990. As my earliest documented example of a death online, this death perhaps resonates through the way a member chose to commit 'Infocide'<sup>31</sup> by deliberately

<sup>31</sup> Term first used by Joseph Reagle in Reagle, J. (2012). 410 gone - Infocide in Open Content Communities. In F. Attwod (Ed.), Selected Papers of Internet Research AoIR13. Presented at the AoIR13,

erasing the 'scribbles' or posts he had previously written before death. Deletion of posts had become an act that was communally frowned upon as 'even one person's deletions left Swiss cheese-like holes in The Well's collective memory' (Hafner, 1997).

After exasperating fellow TheWell users, the member went on to commit suicide. This act of Infocide, then death, both shocked and deeply affected fellow participants (Rheingold, 1993; Hafner, 1997). From reflective accounts, people expressed regret about their interactions before death and how they had discussed this member prior to his suicide. He was well known within the network and topics were opened devoted to his death, including one requested by family for people to post eulogies. While this was known to offer comfort and support to some affected members, it also notably caused community tension. Conversations arose over what was considered to be appropriate etiquette with regard to how to behave (Rheingold, 1993). While TheWell faced having to mediate these conflicting tensions, news of the death travelled and was written about in the *New York Times* article, 'Programmed for Life and Death' (Markoff, 1990). The journalist noted that alongside the eulogies and outpourings of grief, the 'virtual friends' at the time chose to come together to create a new computer file to collate the deceased's previous writings, and back them up on a floppy disk. Although this member never used the WWW, a memorial page was later set up in 1994 to help memorialise his death and it still remains present today. In trying to summarise the loss, the *New York Times* article claims 'others see the experience in a different light, as a glimpse of a future in which computers change the way people live and work, and ultimately the way they die' (Markoff, 1990).

Following the loss of a member of TheWell in difficult circumstances, the next documented case of death online that I uncovered occurred in late 1993 when a computer programmer and online Ziffnet member was murdered by being shot in New York City (Seymour, 1994; Lewis, 1994). At the time of the death, Ziffnet was a forum-based service that operated via the CompuServe network<sup>32</sup>. To access Ziffnet, a

CompuServe member would connect from a home computer with a dial-up modem via Association of Internet Researchers.

32 ZiffNet transitioned onto the www and became known as ZDNet – a site still operating today

a home telephone line, paying an hourly rate for the connection (Ryan, 2010; Seymour, 1994). At the time of death, the Ziffnet member in question had been involved in an ongoing online discussion about gun control within the Ziffnet forums (Seymour, 1994; Lewis, 1994). Therefore, his type of sudden and violent death, that of being shot, profoundly affected the online community he left behind. Fellow Ziffnet members based in the US and the UK knew the victim well enough to be aware that he had been unemployed at the time of his death, and, therefore, chose to compile recipes for an electronic cookbook to help raise money for his now struggling relatives. 'The Ziffnet Cookbook: Recipes from the Digital Diner' was created, and members just had to type GO COOKBOOK in the Ziffnet search area to find and purchase the cookbook in a choice of ASCII or illustrated Windows Help format. The money collected from sales were substantial enough to support the creation of a trust fund for the bereaved family (Wellman & Gulia, 1999).

Similar to the attention that arose around the death of the TheWell member, the murder of a Ziffnet user attracted the attention of the press (Lewis, 1994; Seymour, 1994). The *New York Times* article, 'Strangers, Not Their Computers, Build a Network in Time of Grief' (1994) noted:

Although most of them had never met him in the real world, his cyberspace neighbors from around the nation mourned ----'s death with an on-line wake that lasted weeks, commiserating through their personal computers ... In a world where physical contact is impossible, ----'s cyberspace neighbors consoled each other over the senseless loss of a mutual friend. And in their collective grieving, they demonstrated an impulse for togetherness that is as modern as the digital age and as old as humankind (Lewis, 1994).

This newspaper excerpt highlights this immateriality of cyberspace and also the intensity of people's reactions and connections with each other. Personal reflections on death around this era notably discuss how deeply affected people had been by experiencing the sudden cessation of the person's involvement within their network.

From 1993-1994 onwards, I began to find archival references to numerous losses across a number of networks. Typically, these were young men who had died in

what I would call sudden or traumatic circumstances. Specific deaths of people also resonate throughout materials, like the high-profile death of a founding member of a well-respected mid-1990s mailing list. Similar to TheWell account, in the weeks leading up to his suicide, this founder had been involved in tense online discussions, which, after his death, intensified the reactions to his loss.

Yet the material in this period is not just focused on sudden death. There are community members who began to suffer with terminal illnesses whose chose to use their respective networks in order to discuss their diagnoses and eventually leave last posts. In March 1995, one member of TheWell who was diagnosed with cancer logged on for the final time:

It's bad luck to say goodbye before it's time to do so and there's no point in embracing death before one's time, but I thought maybe I'd sneak in a topic, not too maudlin I hope, in which I could slowly say goodbye to my friends here, curse my enemies one more time, well, not really worth the trouble, actually, and otherwise wave a bit at the rest of you until it's just not time to do so any more.

Dying only a handful of days later in April, this member had devised a social bot or programme to post quotes and references in a way that would help them to 'live on'. The cleverly devised social agent was designed to pop up randomly and to post 'prefabricated, entirely characteristic quotations' to help them be remembered (Hafner, 1997). This 'bot' is an early precursor of technological arrangements that are designed to help people have a form of digital afterlife, a theme I return to in the next chapter.

Alongside these accounts of deaths online are examples of practices migrating and also withering away. One practice that was occurring pre-WWW was the Monday night candle service that originally began on the Prodigy<sup>33</sup> network. This service for bereaved pet owners encouraged people to come together at the same time and light a candle in early 1993. These practices transitioned onto a well-known pet loss website, which still organises weekly services that are proudly advertised as those that started 22 years ago. Alternatively, there is the Usenet newsgroups that were considered the precursor to Internet forums such as [Alt.support.grief](#), described by a SysOp to be 'like the ruins

<sup>33</sup> *Prodigy was an online service in the US.*

of a castle, roofless and tumbling and gone to weeds'. But the SysOp emphasise that 'once there were real people here. Once there was love and affirmation'. In response, a former member replied, saying, 'A lot of us oldies are on Facebook now'.

## 1995+ DISCOVERING COMMUNITIES OF INTEREST

This second section now moves on to discuss the appropriation of personal HTML sites and web-hosting networks that supported user-generated content. These HTML coded pages undoubtedly took a degree of access, technical skill and knowledge for the user to be able to engage with them meaningfully. Therefore, it is possibly not surprising that my earliest found user-generated site for loss was authored by the technologically inclined. Hosted on a university server, this multiple page HTML site was created by a computer professor and dedicated to his son who died in 1996. This personally crafted tribute has come to exist and complement the more 'official' memorial sites and, more recently, appropriation of contemporary social media networks. Although I attribute this initial page to the mid-1990s, it seems that activities by the professor and friends of the deceased have meant that the deceased has continued on.

This circa-1996 personal tribute is not like the restrictive official memorials, which are primarily text based and operate around a certain constricting format. Rather, the deceased's memorial and 'homepages' contain scanned and digitised images from the son's childhood right through into his adulthood. The age of these images can be seen through the small pixel size, the grainy, low colour depth and low-resolution format. These images are presented on the father's personal homepages in a chronological theme that contribute to telling the visitor a visual 'life story' of his son, from his birth and his academic life, up to the circumstances that surrounded his death. These images have travelled and can be observed across other networks and within his later created 'Virtual Memorials' <sup>34</sup>site (circa 1998).

Like the scanned and digitised images, there has been the movement and displacement of his son's poetry. These have been placed online through scanned images of notebooks

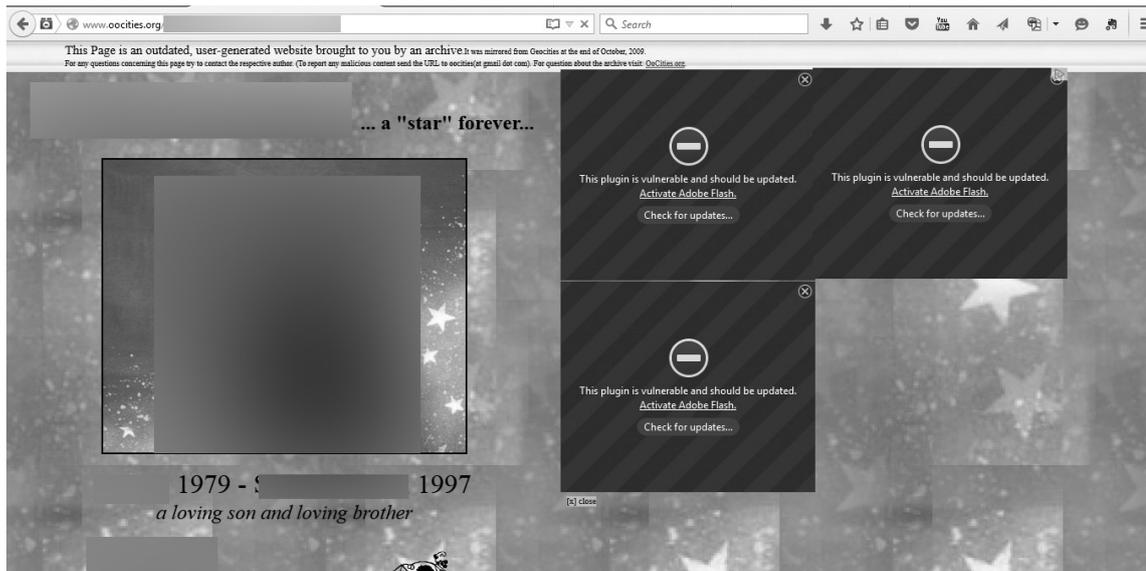
<sup>34</sup> *Virtual Memorials is a free site, but like other later, larger memorial sites, it soon began to offer paid services that provided more functionality and longevity of tributes created.*

and handwritten documents that have become transcribed and typed out for readers. One such poem was recently used as the basis of a song that a friend of the deceased played live and uploaded to YouTube in 2011. Poetry has also moved across array of memorials created by his father. He is also still amending the operational dates on the personal tribute from '1996-2013', and more recently from '1996-2014'. He has also dated when new content has been added so that there is a chronology of posts that can be seen spanning from 1996 onwards without any additions since the early 2000s. More recent postings can be seen on external memorial pages and comment areas that become active around the anniversaries of his son's birthday or death.

The practice of opening a space for loss seems to have grown with the first wave of user-generated networks and free web hosting on the WWW. I say this due to encountering an increasing quantity of these spaces for loss and remembrance across still-existing free hosting sites. In comparison with finding private and personal hosts, the free hosts that date back to this period began to dominate my findings originating in this time period. Empirical examples that I uncovered from 1995 onwards were typically found on Geocities (in its limited archive form through ReoCities) (circa 1994), Tripod.com (circa 1995), Angelfire (circa 1996) and Homestead (circa 1998), as free hosts that emerged just after the mid-1990s. These sites were considered to be a front for what are now known as user-generated sites, and were part of a broad range of sites that supported people to generate their own content for different means such as Craigslist (1995) or eBay (1995). They were free to use but would feature banner advertisements as a way of monetising and making these 'free' sites profitable for the companies involved.

These free sites still exist as shrines, eulogies, obituaries, memorials, tributes and spaces for remembrance and mourning practices. The most defining and consistent aspect of these sites is their characteristic look of the mid-1990s era and the technological constraints that highly shaped the sense of aesthetics and functionality. Often, on loading, a homepage would contain gifs or begin playing looped midi files to welcome people. Later 1990s sites might have a landing page and ask the user to 'enter'. Visitors,

Figure 4.4 an example from 1997. The content only fills half the screen which is representative of the screen resolutions being 800x600 or lower



who were tracked by counter, were also asked to sign guest books, view web awards and to browse very low resolution image galleries. Undoubtedly, they are sites that were designed to be accessed by slow dial-up connections. Functionally, they were a carousel of pages of basic hyperlinks with forward/back arrows that offer transition between handfuls of coded pages. Text, which was the bulk of content and the mainstay of these pages, seemed to be endlessly centralised, grouped through themed pages, and read by endlessly (it seemed) scrolling through pages.

The visible remains of community interaction were found through web rings, html links and guest books that were in various states of disarray. The location of a person was made explicit in community interactions, emphasising how on these free host sites' communities are built around interests and not proximity. From the sources within this time period, the US dominated results with a smaller collection of UK and European

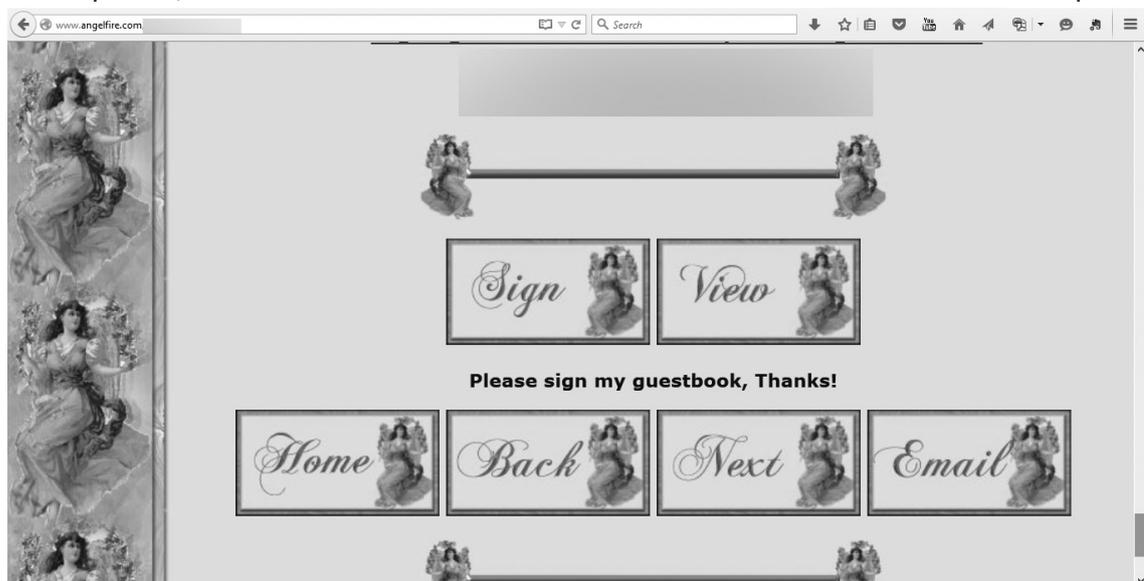
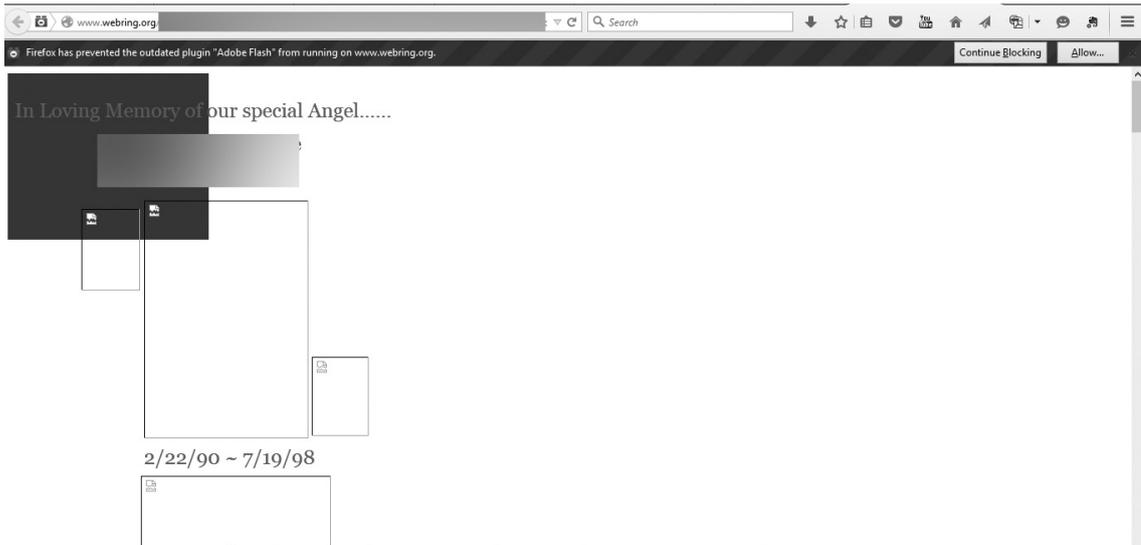


Figure 4.5 An example of the simple back/forwards navigation system

Figure 4.6 The decay exemplified here as missing images



sites. The difficulties of working with these sources are that some are almost 20 years old and built within commercial sites that have undergone changes or, in the case of GeoCities, are now gone. The consequence of this is a data corpus that appears to its visitors in various states of ongoing decay and disarray.

Often pages would be missing, links would be broken, images would no longer load, guest books had been retired, GeoCities mirrors would go dark, code would be interpreted as malicious and music files would no longer work. Interestingly, in the midst of this decay, the gifs would continue to flash away. Through the archiving and documenting of these spaces, I would repeatedly encounter GeoCities links that would no longer work due to the site being retired in 2009. Therefore, within my data corpus, decay and digital loss was something I was continually working with and against. If a site would begin to load content, I would often be trying to work around the later implementation of banners and advert videos displaying in ways that would make the sites unreadable. Personal shrines and sites for commemoration were often decaying in ways that meant, initially, I regarded these older spaces as relics of a previous era of the World Wide Web.

Therefore, it was a surprise to begin finding active web rings and user-generated sites, and to observe the subtle signs that a number of ageing sites were still active amongst the decay. Like the computer professor who updated his operational dates,

some of these changes were subtle. However, there was a selection that proved to be very active. One I recognised as active was the commemoration site of 'Willow', who committed suicide in 1996. Many pages dedicated to Willow are static accounts of her life and death written by her mother 'Sara'. Yet, on a single poorly displaying page is a collection of yearly letters addressed to 'forever 19' Willow. These lengthy letters are written directly to Willow on her birthday and the anniversary of her death. Within them Sara tells her daughter about what has changed since she left her family, and how her mother still misses her:

November xx, 2013,  
17 years and still overwhelmingly sad. Often times I think of  
how our lives would have been different if had you still been  
here and alive and kicking, but I don't go there many times, it is  
too painful.

Alongside these diligently posted letters to Willow, her mother has also kept a guestbook in working order, replacing one when it had reach the maximum number entries. With archives of older guestbook posts that Sara has received since Willow's tribute went live around 1998, these guest books offer an exceedingly rich insight into the interactions around Willow's site. They provide an insight into the continuing relationship Sara has with Willow and a wide range of geographically dispersed people. People continue to return to post on Willow's guestbook at times such as her birthday, the holidays or the anniversary of her death:

June 2015  
How did you find this Web Site? [Revisiting](#)  
Where are you from? [The Netherlands](#)  
Comments:  
[Hello Sara](#)

[Remembering Willow on her 38th birthday](#)  
[This time it's 19 years ago that she celebrated her 19th](#)  
[birthday on earth.](#)  
[But she will never be forgotten.](#)

June 2014

How did you find this Web Site? [revisiting as usual](#)

Where are you from? [The Netherlands](#)

Comments:

Hello 'Willow'

Happy 37th birthday . thank you for supporting so many

people including myself in my darkest moments, you are really an Angel.

Take good care of your mom and your family (I think you already do so).

November 2014

How did you find this Web Site? [Come back every year](#)

Where are you from? [England](#)

Comments:

Although I often think of you, today I think of you and the people you've left behind even more.

Your photo still sits in my lounge where I get to see you everyday.

"January xxth 2014

How did you find this Web Site? [Come back every year](#)

Where are you from? [England](#)

Comments:

Dear 'Sara'

Another year on but none of us forget 'Willow'"

June xxth 2013

Name: [Mom](#)

Where are you from? [xxxxx](#)

Comments:

Dearest 'Willow', Difficult day, 36 today but forever 19. Time flies and stands still all at the same time. We miss you and love you always.

Many of these dates coincide with 'Willow's birthday and death anniversary and their focus switches between leaving messages to support Sara and also talking directly to Willow. Some of these messages are from people who knew Willow in person, and then there is a proportion who are friends Sara has met through grief groups and other encounters online. As a tight knit community, these other parents who have lost their children to suicide reach out to Sara regularly. Their engagement leaves the reader with a sense of responsibility to each other and to support people to engage in acts of collective remembrance. In a postscript written in 2001, Sara posted:

I want you to know that I read every word that someone takes the time to share and after 5 years not a day goes by that I don't think of my darling, loveable, funny, only daughter. I am still on the net, not in a huge way as I used to be, but I keep in touch with so many from so many places.

While Willow's Site and Sara's dedication to it at first appeared quite unprecedented, in my observations of the community around this site I began to find references and links to a number of tributes, spread across free hosts like Homestead, Mysite, Tripod and Angelfire. This turned out to be the wider community that had supported Sara and had connected to her through loss. These other free hosts sites also revealed signs of activity within the last 12 to 24 months.

Through comparative work across my archives, the signs of activity I am referring to are updating pages, adding new content, fixing images and broken links and changing copyright information and dates. I was also able to see domains and subscriptions renewed, updates made and changes to guestbook software. However, it was the guestbook that were the most active locations and provided the most insight. They often revealed a number of long-term contact patterns between people who would reach out to one another. Frequency of these visible contacts varies, from people regularly returning on key dates to visits from people who have moved on to newer platforms

"November xxth 2013

How did you find this Web Site? from a post in a grief group on facebook

Comments:

Dear 'Sara' - I am sorry that I have not visited your memorial website for your daughter Willow in so long. I stumbled across it again just recently thru a post on a grief group that I just joined on Facebook. I wanted to again express to you how sorry I am for your loss of your daughter. My heart truly goes out to you.

love and hugs

Therefore, it was difficult through the course of the data collection and analysis to have a key piece of guestbook software – HTML Gear – retired in 2012. This retirement meant that I lost access to a wealth of historical material. Interestingly, the re-emergence of new guestbook software also then worked as an indicator of how active these sites could be. I observed how a number of sources replaced the broken links and guestbook through the maintenance of their respective tributes.

Guest books were not the only sight of interaction that I observed. Key community members were sometimes thanked for helping to maintain or create new pages for a site. Collectively, people also engaged in the practice of creating and gifting each other with graphics. These would be added to the site through the guest books, existing pages or even dedicated pages that are created as gifted image galleries. Their construction would involve an existing picture of the deceased that would be copied and saved from a memorial or tribute site. The picture would then be edited and repurposed

into a new montage for a holiday such as Christmas or birthdays. I observed deceased individuals being manipulated in photographs and given wings, surrounded by Christmas trees or other holiday-

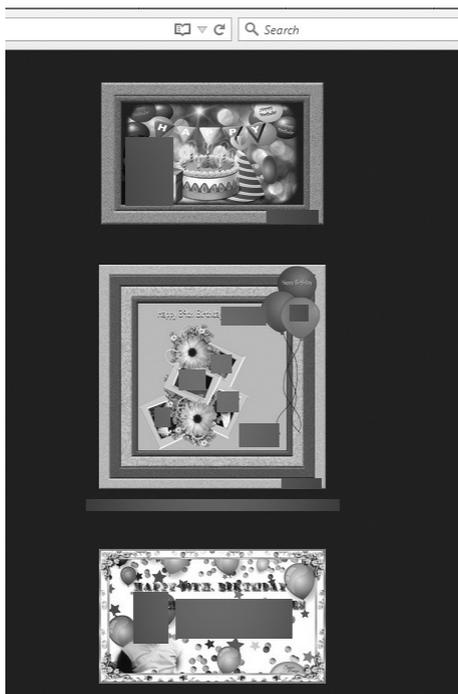


Figure 4.7 A collection of images created by the bereaved as a gallery. These images all contain appropriated images of the deceased which have been manipulated and then 'gifted'. <https://www.dropbox.com/s/3oqu4zjub526cif/image%20gallery.jpg?dl=0>

Figure 4.8 A deceased individual having wings added to his photograph <https://www.dropbox.com/s/8oedda7mr56pagv/added%20wings.jpg?dl=0>

related paraphernalia.

Deceased individuals could also be subject to being manipulated by the bereaved themselves to appear in family pictures, creating new ones or to depicting the dead as still present and socially active. The quality and aesthetics of these images certainly are affected by the technical skills, types of software and image qualities people had to work with. Sometimes the low-resolution graphics and cut and paste skills of particular makers could be quickly identified, speaking about the relations between how the practices, data and the technological landscapes shaped and formatted the types of materials and interactions around these materials that were occurring. For those who struggled, particular members had been seen together to 'gift' new pages or elements such as photographs.

With the broader set of user-generated sites I eventually collected from this area, I noted pages maintained for parents, siblings, cousins, partners, grandparents, unborn babies and pets. The deaths of these relations were sudden or what might be deemed as 'difficult losses', such as accidental deaths, suicides, murder and chronic to terminal illness. Overwhelmingly, in the active communities, it was members who identified as female that made the bulk of participants. There were accounts made by people who identified as men and these were dedicated to uncles, fathers and lost children; however, they made up only a small amount of sites.

Singular sites on these user-generated hosts often only revealed partial insights into the bereaved practices. I found myself curiously running details of particular deaths through search engines to find links to secondary material. One account dedicated to the accidental death of a young boy, 'Charlie', has numerous sites that have been created and updated sporadically over a number of years since his death in 2000. Operated by different members of his family, these sites cross more 'official' spaces for loss, like Memoriam.org, but are mainly linked together on a personal homepage, hosted by Mysite. The bereaved family has also bought a domain name and used it to frame the Mysite with a .com domain. From the personal and 'official' memorials there

is a collection of social networks involved such as Charlie's Myspace account, Facebook profile and a number of short YouTube videos.

A selection of pictures of Charlie that are based on his Mysite page are also found as his profile picture in 2013 or animated in his YouTube video. Similar to the images is the biographical text that meticulously presents his life and death. These have been reused in edited, lengthened and shortened versions across his many sites. This material has been created and remediated across different networks to portray the loss of Charlie as a close relative, while simultaneously portraying Charlie's death as a warning in relation to his accidental deathstyle. The narrative around the death of Charlie and the ongoing bereavement of this family has unfolded through these networks. They speak about the persistence of loss and the need to remember and, equally, to let go and move one. This leaves behind a trail of sites or pages that stand as a testament to engagement in different network eras since Charlie's death.

While Charlie's story speaks about the longevity of practices with data that were evident across certain losses, this was equally a story about the data loss that was

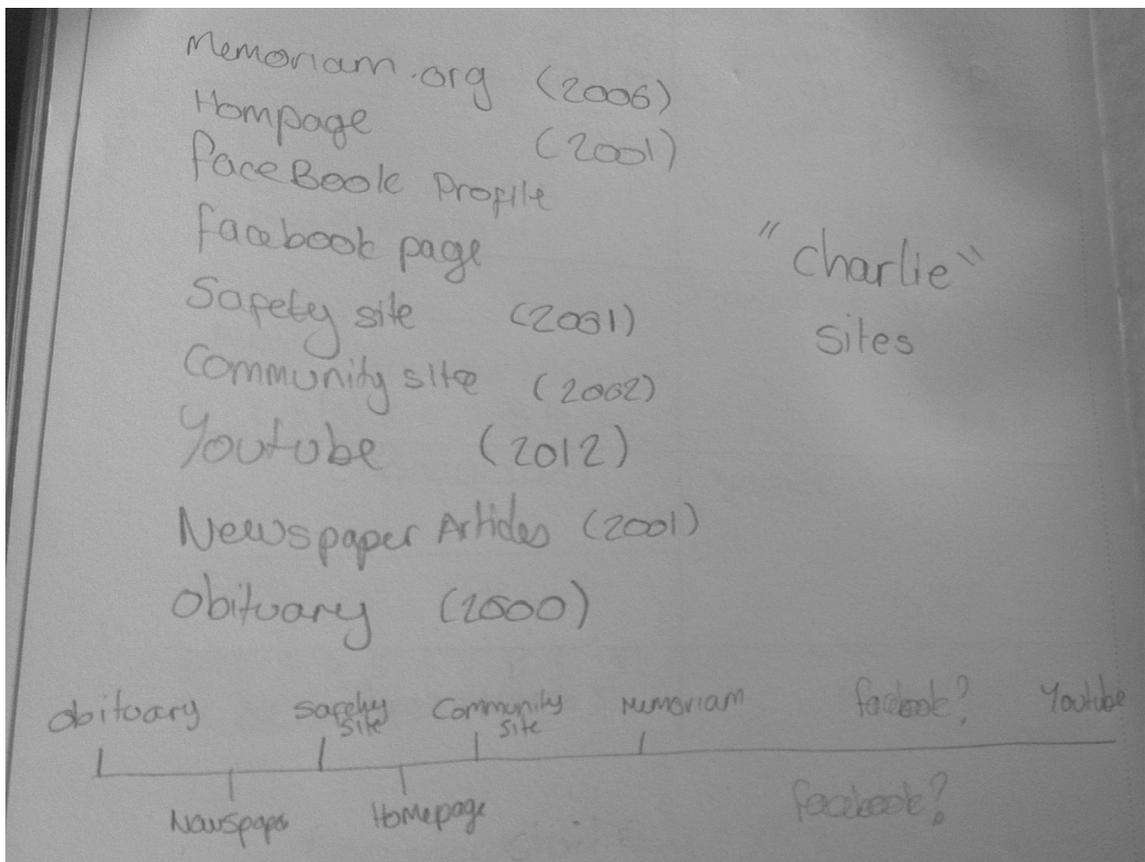


Figure 4.9 Charlie helps us recognise that the bereaved can create multiple sites for loss and these can occur across a number of years. Image taken from notes.

occurring concurrently. Charlie's family used particular pages for short periods of time before moving on. His sites and pages remind us that, while there are active sites to account for, there is also a considerable amount of loss.

Amongst the ruins of former memorials and tributes to the dead were those that began to wither away as I started my empirical work in 2011. I observed sites go dark, become disabled, deleted or blocked due to subscription. In turn, data would become inaccessible or become lost. This would mean that I would see a site that had been active just stop. While it was difficult to determine why, I could not help but revisit certain sites and wonder if it was a technical issue. I wondered if, like Charlie, people had moved on to newer spaces or found they no longer needed to visit these sites. Rarely would I find explanations, but I did find two notable examples. One was related to a person finding themselves locked out of an account:

I think of all you sweet ladies and your angels I lost my computer 2 years ago and all my info in it, but just know I think of you all and wish I could get back in, I know you guys all think I don't care but I do and miss you all very much...

The second example was on Markus's tribute pages, created in 1997 by his then fiancée and his mother after he died in an accident. His overall site had a strong religious overtone that presented Markus with angel wings, and his photographs had been edited to show him now to be standing alongside pictures of Jesus. Markus's mother



Figure 4.10 The now abandoned tribute to Markus

was leaving posts and messages to her son, and these posts appeared to be more intense within the early years of her loss.

Yet when, in 2012, the guestbook no longer worked, Markus's site was an example of those that were never fixed. I continued to periodically visit Markus's site and search for the emergence of new sites elsewhere, until, during one of my searches of 2013, I discovered that his mother had died through an online news source. In the overall body of data, she is the third bereaved individual who died between 2011 and 2014 and left behind a memorial as part of her own digital remains.

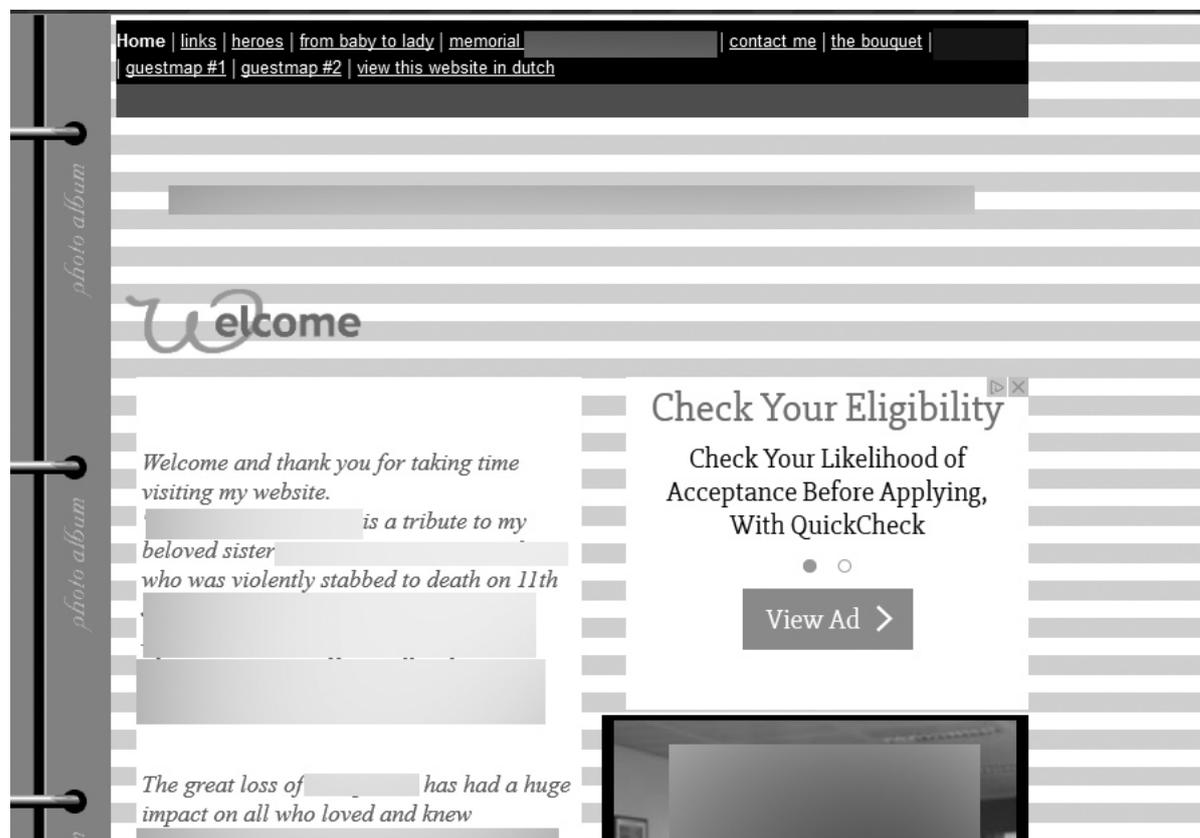
## 2000-2005 USER-GENERATED AND SOCIAL NETWORK REMAINS

This section documents the shift from the personal and free hosted user-generated networks to the early social media networks. Through empirical work, I noted that the creation of user-generated sites for loss, memorials, shrines and tributes continue to appear from the late 1990s onwards until the mid-2000s, then the frequency of new sites begins to drop. While there was a continuation in the practice of creating HTML pages, there were changes that visually almost signalled a different time period at work.

Analytically, their design and content became more technically sophisticated in terms of their layout and style, due to the WYSIWYG web design tools and editors built into free host sites. There is clearly a wider shift towards being able to support more visual content too, with further increases in the amount of quality, type and amount of images that begin to arise. Alongside a wider collection of photographs I also saw scans of news stories related to a deaths and suicide notes.

This increased visual sophistication was exemplified on a site for a UK child who died from a terminal illness in 2001. This site has become connected to an older community around child loss that dated back to the mid-1990s. Yet, unlike the mid- to late 1990s sites, this memorial stood out through the better layouts, colour schemes, newer guestbook features and content such as higher resolution images.

Figure 4.11 Mary's site helps illustrate the change in navigation system seen within a broader selection of HTML sites of this period



The technical capabilities were also starting to invoke more sophisticated interfaces. I first noted this in the Danish bilingual Tripod site of Mary, who was murdered in 2002. The site created by her sister incorporated new features that included navigation that moved away from a back and forwards system to an early style of 'framed'<sup>35</sup> menu bar. Rather than a guestbook, there were guest maps that visualised and showed the visitor location across a global map.

The creation of navigation bars and menus within frames, presented more structured content and regularity with 'top-level' pages such as 'homepage', 'about', 'contact us' and 'site map' was characteristic of these newer spaces. One such



Figure 4.12 Guest maps as an alternative to guest books

top-level page, 'Links', offered an insight into the communities and connections that were at work. As in these newer designs, without guest books or spaces dedicated to ongoing dialogues with the bereaved or deceased, it was hard to observe interaction.

<sup>35</sup> Frames are a section of a webpage that loads independently from the rest of the page or other frames

I would have to carefully monitor for the changes that could reveal whether or not a site was being actively cared for or updated. Like the earlier sites, these could be new post or content added to the site, changes to site date or if the person was still active but making a new memorial or account elsewhere.

A notable feature of these early 2000 sites was how images had increasingly become more frequent and of a higher quality. Rather than just picturing the deceased, or new pictures of graves, grave furniture or personal items left behind, post mortem images began to be posted, particularly of children and babies. Babies and children who had died began to feature heavily in my results, as well as older children who had died from accidents or as a result of suicide. One shrine dedicated to a premature baby contained an arrangement of materials that had been collated together, such as finger and hand prints and post mortem and coffin pictures. Another documented the short life of a chronically ill baby, with images of the baby with his siblings, capturing his eventual deterioration in health and post mortem materials. The deaths of one boy to illness and another adult son to suicide were documented by one mother who scanned and uploaded not only pictures of both of her children but also the suicide note. This narrative was revealing a different balance between the graphical and the discursive and textual content that was now possible.

I noted considerable variation around the time and type of loss as I moved on towards the mid-2000s. This included people who had died years previously but who had now been given a tribute online, such as the memorial of Victor, who died in 1990, or Dom, who died in the early 1990s, but whose tributes both emerged in 2004. This broader inclusion began to feature Tripod shrines set up for TV characters who died. Angelfire dedications were set up in honour of a tragic murder such as that of Jamie Bulger; memorials were set up for celebrity deaths and remembrance sites for 9/11 victims. In terms of patterns, I found that the majority of the sites I had gathered were maintained by people who identified as women.

Like earlier spaces, a common theme that ran throughout these sites related to how

they had been complicated or difficult losses for people to learn to live with, particularly losses of those who had 'died before their time', young family members and relations like nieces and nephews, brothers and sisters, children, life partners, pre-term babies and, finally, pets. Within the broader array were also tributes set up by people who identified as male, for their relatives, partners and children. A site by Joshua had been set up to allow him, as a father, to have an open space to discuss his difficulties after the death of his son. These difficulties arose in his ability to express his feelings and finding that his grief was expected to take particular forms. Therefore, his tribute also stood as a testament to the memory of losing his child and his broader experience of loss. Similar to Joshua was the particularly detailed account of a father going through a still birth delivery with his wife. The story worked not only to remember his loss but also to relay what had clearly been a very traumatic experience with his partner.

Starting from 2005, I begin to find shrines, tributes and memorial pages set up on social networks. Like the earlier example of Charlie, Myspace accounts were appropriated by the bereaved alongside their existing tributes. This indicates, like the migration and cessation of the previous networks around the opening of the web, that there was a similar pattern of continuation onto Myspace as a social media network.

I began to explicitly look towards Myspace for practices of remembering or memorialising contemporary deaths of this period. Accounts had been found that had opened in the mid-2000s onwards. Three of these that I began to document were remembrance pages dedicated to Kay, Matt and Deen. The pages included phrases similar to 'In memory of' in their titles, with the profile pictures being set up as a montage or collage of pictures of the deceased surrounded by RIP or the birth and death dates.

The designs of these pages followed later Myspace interface overhauls. Myspace was known for allowing its members to customise the backgrounds of their profiles, adding in dividers and contact sections. Eventually, Myspace began to work with a formal menu selection and pages. The types of content themes within these pages were similar to

those I was observing on previous homepages or hosting sites.

I observed how pages on the Myspace structure, such as 'About', had become repurposed and were used to write about the lives and deaths of the deceased. I found blogs used as a diary spot, which was a way for the bereaved to leave messages to the deceased. Other previous practices around keeping photographs were replicated within photo sections used as memorial albums. I observed new forms of practice, such as status changes on anniversaries. The difference between the Myspace and older user-generated HTML sites was how the content had been subject to the format and design of the Myspace network. There were clearly delineated features that shaped exactly how content was presented with a degree of uniformity.

The issue I had when finding these sites to study and observe was that the communities and pages had already begun to have long periods of inactivity and non-use when I first found them. All three of the examples I studied had been last touched (that I could tell) between 2008 and 2009. There was not the same capability to edit or change the site and, therefore, I had less subtle indicators to follow other than last post dates.

Similar to Myspace remembrance pages were the memorial pages of Bebo, and my discovery of a ring of profiles of deceased people who had committed suicide. Bebo filed for bankruptcy and fell into a 'maintenance' state in 2013. Along with Myspace's reduced membership and activity patterns, both social networks found themselves subject to large corporate changes between 2012 and 2013. This meant that I was no longer being able to access many of the sources I had initially identified, as accounts became private during an update. Then Myspace went on to delete the content of an unknown but potentially large amount of memorials, sites of remembrance and previously active communities of loss. I was confident that these spaces could have offered a rich insight but the issue of decay and deletion deeply disturbed my engagement with these sites. I had a sparse collection of data and, rather, a much bigger insight into the loss that is at work and pushing against these ideas that we 'live on' online.

Before I finally retired my engagement in Myspace and Bebo, I had become aware of a case on Myspace when someone had left their last words on the network before committing suicide. It appears that alongside Myspace being appropriated for contemporary memorials by the bereaved in the mid-2000s, it had also become a platform that the living would turn towards before death. I know this because of the news media and a forum that specialises in tracking this kind of activity. The forum provides an ethically questionable database of social media accounts that relate to death. Some of its examples like to draw out the data remains of the people who die, particularly the last photographs, status updates, blogposts and so on, created in and around the time of death.

The interest of this forum is not entirely unique. The data remains and social media profiles of people who have died have been attracting the media since the mid-2000s. This is perhaps exemplified by the UK tabloid press, which I have observed to search and report on the social media accounts of the dead when a new story breaks. Profiles, or practices such as last words, or postings of suicide messages have received considerable attention and the forum has no problem linking together the manner of death and network remains. I bring attention to this because it reminds us that the dead are not just being remembered by the living after death. The living are autobiographically (intentionally or more auspiciously) becoming tangled into networks in and around the time of death too. These remains that are left behind become important when moving forwards, as the bereaved notably do not just create remains within their practices of loss, they are also curating them.

## THE CONTEMPORARY ECOSYSTEM OF LOSS

This final section now moves on to discuss contemporary practices of loss that were observed to emerge across a selected range of social networking sites between 2011 and 2015. Unlike previous time periods, so extensive and diverse are contemporary practices of loss that recounting findings can turn into a large collective list of things I have uncovered and studied intensively over a number of months. To break up this

list of phenomena from just a divergent mass, I turned back to the issue of remains: firstly, accounting for the practices of loss that create data remains about deceased people, and, secondly, looking at how the bereaved curate the data left behind by the deceased.

### CREATING REMAINS

YouTube and Vimeo are popular networks on which video blogs about grief, autobiographical and biographical stories, memorials, anniversary messages, song writing and performing can be located. The type and style of video greatly affects how the media files are constructed and what they contain. I have seen existing video bloggers post content about loss when a death suddenly occurs, such as in the case of a chronic illness sufferer who lost his adult son. Then I have seen new people join these networks and begin to post video blogs in response to loss, a phenomena I observed through a selection of young widowers.

Video bloggers have been seen to record themselves talking to camera, record a narrative off camera, use found film footage and create documentary style films. These videos or posts would recount the circumstances of death, the 'coping' with grief, and document the remaking of life across different time frames of engagement. One video blogger began to make an 'advice' video for others who would be searching around the keywords of grief and loss, and discussed her experiences of the 'pragmatics' of dealing with death and loss.

I encountered more sporadic and isolated material that had little reoccurrence or long-term commitments made to it by the bereaved. This material could be funeral footage



Figure 4.13 A YouTube vblog by a person who identifies as a young 'widow'

or funeral photographs that showed upper parts of the deceased within their coffins. As a collection of post mortem material, it captured miscarriages and stillborn babies, elderly parents, partners, siblings

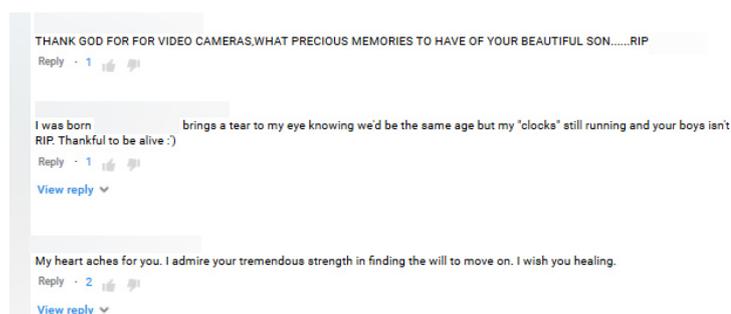


Figure 4.14 An open casket video

and pets. The footage or still images would often be collated together and animated by music, slide transitions or just edited digital video footage. Full funeral services can be watched on these video hosting sites, of pets, of children, of US military personnel, different religious denominations and black and minority ethnic communities. These contain a mixture of open-casket and closed-casket ceremonies.

The use of post mortem photographs or footage across image or video hosting sites invoked different kinds of response by the most anonymous viewers. Responses varied between the graphic nature of the material and how the material was handled. Glimpses of adults in coffins were the most common of these and they would involve typically less graphic post mortem imagery. The less restricted and graphic images that exposed more of the deceased on film always involved stillborn children and were very rarely contested by viewers. Commenters would be sharing their sympathy with the parents, and at times make remarks to suggest that they could empathise with them.

However, I noted that people would become uncomfortable with the material if the babies in question had been stillborn before being pre-term. It signalled a broader



unease with people seeing material that they considered to be graphic or distressing. Photos and video footage of early

Figure 4.15 Comments left on a video for a young child <https://www.dropbox.com/s/9nbd0qw6r2m6vgs/comments.jpg?dl=0>

miscarriages could make people uneasy, possibly because the babies were not always recognisable. The strongest reactions I witnessed were in relation to a child who had died in car accident in the mid-1990s. The reactions were in response to the footage of the boy's funeral that had been transferred onto digital video and uploaded as a three-part series. Sections of video showed the open casket, revealing the child's fatal injuries and what I presumed to be autopsy marks. His family who uploaded the video would argue with commenters who left remarks regarding not liking seeing this material, arguing that its purpose was to serve as a reminder and to prevent other children from being killed in similar circumstances. Eventually, the uploader posted a lengthy rationale for the video's presence, and moved to disable comments on the video series.

Outside of the solemn post mortem material create around the time of death was the creation of memorial or remembrance tributes, which characteristically used more creative collage, hobbyist and Bricoleur styles. As a mixed media, these memorial or tribute creations would contain still images, stock photographs, illustrations, pictures of the deceased, post mortem images, prenatal scans and animations. Text could be present to give key information, and kinetic typography could also be present dependent on the overall level of software and compositional skill that was brought to bear by the creators. Equally, the array of moving image material could be embedded with a host of different styles of music, over-narrated with explanatory texts and poetry or even left silent. In these creations I could see the operating systems reflected, the movie-making platforms used and the video-making skills with regards to video ration size, pace and aesthetic complexity. Default typography, screen transitions and automatic features of programmes like Windows Movie Maker were noted.

There was a series of feature length films that had been created in tribute to the life story and death of a young English man who had suffered a sudden and accidental death while travelling. The professional skills of family members had been deployed in order to make two separate videos about this death and the impact it had had on the

family. Weaving together footage of his funeral and subsequent burial, the film told an expertly constructed story that not only helped remember but also documented a contemporary and less sequestered approach to loss. These films have become embedded within a site dedicated to these films, reminding me that the potential of mobility of this material from these video hosting sites to external networks is always possible, and difficult to track.

Further investigation into memorial and tribute videos led me to identify the accounts of individuals who were creating content on a regular basis – that is, on key dates of death, birthdays and religious holidays. I noted the profile page of an individual who created memorials for other parents of pre-term babies too. I observed a single YouTube account that was dedicated to making memorial videos, birthday messages and hosting the funeral video of a ten-year-old boy. Similarly, two accounts were dedicated to video blogging and the remaking of life as single parents. The practices outside of creating video content centred on commenting and responding via the comments sections. On YouTube and Vimeo, the comments sections, video views and likes would reveal how regularly the site was being viewed and the bereaved were returning to these spaces.

I began to note the theme of child loss as one that heavily dominated activities, yet the types of loss and the ages of deceased children varied. In the case of children, these deaths could be through miscarriage, still birth, illness, accidental death, suicide



and murder. Going back through them as a collection, I observed that they were overwhelmingly being uploaded and taken care of by mothers. While young children featured most heavily, there were

Figure 4.16 Social life before physical life. The ultrasound scan of a baby that was later born 'still'

also examples of the deaths of pre-teen, teen and adult children who had been lost in ways that had been sudden, difficult or traumatic for the bereaved. I was also encountering a re-occurring song, 'My Precious Child' by Karen Taylor Good. I had noted a song on the midi players of earlier HTML sites but was unable to discover what it was until these YouTube videos also began using it as background music.

Alongside moving images were collections of photographs of still images of different networks. Single photographs and albums dedicated to a loss or deceased person could be found via tags across the image hosting sites of Flickr, Fotki and Instagram or as part of the profiles of other networking sites. Images were most commonly found to be organised biographically and grouped into collections that worked to document the lives of the deceased through particular time periods. Alternatively, I saw single images of the deceased deployed at key times or dates, and brought together through themes and tags within networks.

Flickr has groups and thereby communities around types of loss that can be very specific. For example, pet loss had divisions into the types of loss, such as cats, dogs and so forth. These communities were highly active and would 'gift' images and awards to



contributions that people made, leaving comments and engaging in dialogue with other members. These images have elements seen within the previous practice of gifting of photographs within the user-generated HTML sites, such as people or pets being supplemented with wings. Outside of these communities on

Figure 4.17 The early gifting and collaging of images can be now seen on Flickr



Figure 4.18 Open casket seen on Flickr

caskets and show the family around the deceased. The deceased featured in these collections were typically white, elderly or older deceased individuals. I uncovered no pictures of children or younger adults who might be identified as having 'died too soon' and I noted this in light of the amount of this type of material I had uncovered with older and more contemporary landscapes.

My experience of Instagram involved encountering singular shots that could be found through tags that would group together people's contributions. I did not find accounts dedicated to a particular person, but rather a diaspora of images brought together through tags such as RIP or In Memory. These tags would link together themes of remembrance, types of relationship and types of loss and present them as content that all belonged beneath that label. Therefore, the images on Instagram varied in terms of their content, as photographs could be substituted for messages or quotes or even 'selfies' that were posted in the immediate aftermath of a death.

Alongside the images and video-based tributes across Instagram, Flickr, YouTube and Vimeo were the sites and pages on Blogger, WordPress and Tumblr in tribute to a loss or a death. These sites were media rich and embedded with an array of external content into their posts. I observed numerous WordPress 'blogs' or 'memorial' sites dedicated to the loss of a particular relation. These blogs were still active or recently abandoned, but would go on to document the 'process' of moving on or remaking life with this loss

Flickr, I also found a wealth of photo albums with photographs taken at funerals of parents and grandparents. Found through relation tags such as brother, sister and so forth, some of these shots would include open

present. Text and the discursive elements played a heavy role in these spaces, with images and videos being embedded from external sites or uploaded internally. Working mainly with text, the focus on practices was in both setting up and maintaining these sites alongside the creation of posts. The broad discursive pattern of these posts would relay biographies, eulogies, memories and discuss life 'in bereavement'.

Blogs were not always created with loss in mind. A pre-existing blog dedicated a single post titled 'to dad' as a letter to a father after his death. After this 'to dad' letter was posted, the blogger seemed to take an uncharacteristic break before returning to post and getting back to the original theme of the blog. Similarly, there was a pregnancy and lifestyle blog of one mother, which changed quite dramatically when her pregnancy ended in a stillbirth. The mother began writing lengthy 'letters' to her child over a number of months. The intensity of these posts began to reach out to others who used her comments section to leave messages to not only the author, but to each other:

'My heart goes out to you.. Just knowing what a long painful journey you have ahead of you'

'You will never get over it, you just learn to get on with it. She's a big part of you'

'all these beautiful messages makes me realise just how many of 'us' there are out there'

This interaction between commenters can be seen to occur with people actually known in daily life to the blogger. One blog intensely documented the transition of a man from nursing his terminally ill partner from cancer to living through a deep period of loss and eventually opening a new blog that signalled a shift to a different phase in his life. These three blogs allowed his friends and family to receive updates on his partner's condition, and later acted as a way of engaging with him about his loss and eventual transition into meeting someone else romantically.

With blogs dedicated to a loss, I found that the frequency of posts would seem to

move from an initial period of intense engagement to a steadier and less frequent rate. If blogs had not been updated in a while, this could signal the end of engagement. Still, comparisons would show that 'gardening' activities could be taking place, such as keeping links active, changing dates, replying to or removing comments or messages. The bereaved may reappear on key dates or, alternatively, in the case of one blogger, return to post a final blog to signal the end of engagement.

In blogs people would express not just upset but also anger, resentment and a host of sentiments that allowed a snapshot into loss outside of a melancholic frame. I felt the resistance of certain typecasts explained in eloquent detail, a widow discussing her sex life and her irritation at when society deems it the 'right' time to move forward; mothers presenting graphic detail of miscarriages on labour wards, fathers expressing resentment at how they felt constricted by not being able to 'grieve'. The oppression of bereavement and the social conventions were interestingly being pushed against in these spaces. They allowed people to open a space for subjects like still birth be discussed and this inevitably would attract other people who related through similar experiences.

The final and least understood blogs I encountered were those dedicated to a form of creative practice of loss. By creative I mean that they contained discussions around hobbies or certain practices such as knitting, painting, woodwork, fundraising and paper crafts such as scrapbooking. These activities were claimed by the bereaved to be an outlet connected to expressions of loss. The practices could be dedicated to the deceased, even though the activities themselves focused on a particular hobby or practice that the bereaved individual had turned to in order to find comfort or some kind of solace. My encounter with these more creative practices was through a circle of painters and photographers, who turned out to be a group connected through their shared experiences of child loss. Alongside having singular spaces dedicated to their loss and practice, they also shared a group YouTube channel and blog.

Across all networks I did find numerous static sources for remembrance on

contemporary networks. By static I mean that someone created a single post or page, a single image or video that would stand alone and not seemingly belonging to a wider collection of material. These singular pages could appear on a fundraising site such as Kickstarter or Just Giving or be placed on Google Plus and LinkedIn. Similar to these patterns of isolated pages or profiles are the conversations dedicated to the dead on mailing lists, where people pass on a brief eulogy and share memories of the deceased before quickly stopping.

A network that seems to support singular posts well is Twitter. Within the limited character allowance, people post brief messages on Twitter about their losses on anniversaries, share remembrance practices, 'in memory of' messages and hashtags, and take pictures of final resting places:

I miss you mom and I hope I'm making you smile

Ill never forget xxx @Cemetery (Contained image)

Inmemoryof my dear friend xxx 1 year ago she went to heaven  
my mums flower bed at the xxxx gardens (Contained image)

Certain hashtags can be followed to bring together this singular diaspora of 140 characters for loss.

Finally, although I have not focused on Facebook, I have encountered numerous memorials, pages and profiles dedicated to the dead. In searching to explore the broader practices of loss related to a deceased individual, Facebook content would appear relating to people who had died years prior to Facebook existing, such as the profile of Charlie that I discussed at the start of this chapter. Similarly, there are the people who revisit older communities and mention how they are connected on Facebook. It appeared from my own empirical work that there was a richer history at work behind people turning towards Facebook in loss that is yet to be explored.

## CURATING REMAINS

So far, the emphasis on recounting findings has been on discussing how the bereaved

have been engaging in practices of loss and working to create data after the death of someone. However, data that emerges after the death of a deceased individual was not the only type of data the bereaved were engaging with in contemporary networks. When I looked at Myspace and Bebo, I noted the presence of autobiographical remains, or remains that people had created themselves before dying. To try and bring attention to these differing data types in my methodology, I borrowed from forensic anthropology the terms 'ante mortem', 'peri mortem' and 'post mortem', and applied them as codes to signify when remains emerged in relation to the deceased's time of death.

While post mortem refers to the data or sources that have been created and curated by practices AFTER death, the terms ante mortem and peri mortem are used to delineate before or near [or at] the time of death. I appropriated these terms from forensic anthropology to code remains that had been created by the deceased in the months, weeks or even hours and minutes up to their deaths. These remains had emerged through network engagement in the flow of daily life, such as Instagram pictures, Tumblr posts, tweets, status updates and so forth.

There was a major difference in how the ante mortem and peri mortem materials were considered and received by the bereaved. Data created in the acute peri mortem period, which is in the hours or immediate time running up to a death, was observed to have the potential to become the cause of trouble and distress to families. This distress unfolded in relation to how the material emerged or the auspicious timing of its presence. I documented examples of tweets by the victim of a shooting, an Instagram selfie taken before a motorbike accident, a status update before a fatal asthma attack and a Tumblr post before a suicide as examples that went on to upset or distress the bereaved.

This was heightened when people made last tweets, blog posts, status updates or changes to their profiles before intentionally committing suicide or intentionally killing others. This would leave behind cries for help, graphic or disturbing materials that are

implicated in people's deaths. I specifically return to address these types of auspicious remains in Chapter Six.

Unlike the *peri mortem* materials that could be potentially distressing and unpredictable, remains created in the *ante mortem* period have been seen to be welcomed. Abandoned remains were observed to become folded into the practices of bereavement through acts of appropriation, by the overtaking of accounts, copying, downloading and uploading, pasting and moving materials across onto other networks.

The remediation practices can be the management or caretaking of a space, gardening activities that would keep a source looking current and working. Therefore, it could be subtle and nuanced editing, updating and moving or replacing a picture to more obvious changes such as moderating or responding to comments, changing account statuses, fixing broken features, reclaiming hacked accounts, paying subscriptions and writing posts to the deceased and to other community members. The practices were highly dependent on the types of remains left behind as well as the skills of the bereaved. It depended on them engaging in practices such as saving, copying, downloading, reporting, deleting, uploading, pasting, embedding and editing.

I did document the bereaved taking over and overtly managing these spaces in the name of now deceased individuals. A heavy social media user and terminally ill woman left behind a Twitter account, a Tumblr blog and a Facebook page in her name. She had used these over a number of years and had a large following of people supporting her and following the progress of her illness. After her death, the family appropriated these accounts and continued to post in her name. At first this was in relation to telling the different networks that she had passed away and what the arrangements were. However, these posts continued in the aftermath of the funeral, giving updates on funds collected in the woman's name and how the family are managing without her.

On a smaller scale, I noted the photographs from one social networking profile being lifted out and used to populate a blog and create YouTube videos about the deceased.

Not all sources of remains, however, would stay active. Comparisons would not show any activity or gardening but rather decay starting to set in through aspects such as links and images breaking, spam advertisements appearing and even accounts being hacked. Through the course of my empirical phase, I observed profiles being deleted, pictures or albums disappearing and accounts being shut down or memorialised. The deletions would always serve as a reminder that the amount of material that has been digitally lost is unknown and that I was always presenting an account of what was present as a crystallised moment. My attempt at trying to describe these unfolding landscapes always gives only a partial glimpse.

## CONCLUSION

This chapter opened the landscape around loss online by presenting a mass of historically framed findings that discuss the diversity of loss within a range of networks online. The first section started in 1990 and moved to present the earliest accounts of death before moving on to the mid-1990s and tracking early examples of practices of loss on the World Wide Web. The chapter then moved on to the early 2000s and brought attention to the increasing complexity of HTML sites, bringing awareness to the examples that tell us of the migrations of data and practices onto social media networks. Finally, the chapter moved from early social networking sites to the contemporary landscape of loss that emerged across a diverse range of networks between 2011 and 2015. Different networks and practices were discussed alongside empirical insights to help understand the messy and diverse landscape at work.

In an attempt to present this messy picture, the chapter has touched lightly on a number of diverse practices with remains that have been presented within contemporary landscapes. These stories begin to trouble the notion of the 'user' in TSD as a contemporary passive consumer and one who needs socio-technical 'tools' and support to be designed for them. Rather, there is a relationship at work that speaks about practices shaping and being shaped around a multitude of networks, people creatively finding a way to do whatever it is they need to and for however long they feel it is

necessary. The diversity asks the designer and research practitioners to consider the bereaved as a highly diverse collective of people. In response, design framings need to respect and pay attention to the specificities within different networks. Therefore, the locations and situatedness of what it is people are doing, both alone and within small communities, in order to remake their lives is key to future framings and attending to the complex nuances at work.

Considering human and practices of loss with remains through a more diverse and divergent lens begins to gesture towards a situation for research and design inquiry that has started the process of troubling TSD. I will now move to continue this process in the next chapter, *Manifestation of Ghosts*, which turns towards an element never previously accounted for in TSD and *Death and Technology Studies* – the non-living.

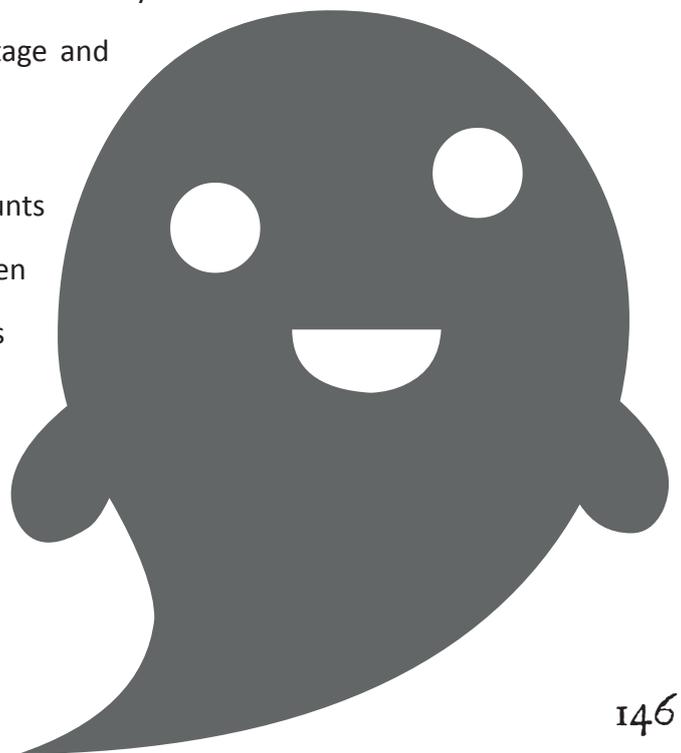


# CHAPTER FIVE

## MANIFESTATIONS OF GHOSTS

**W**e often phrase life or death as a binary position to inhabit, as a person being either alive or dead. It seems quite a simple distinction until death begins to be understood as a long-term process rather than a singular defined event. In this transition from event to process, the moment of death and when living stops can become more nuanced than previously thought. Thinking outside of binaries, anthropologist and theologian, Professor Douglas Davies argues that it can take much longer for a person to ‘die’ in a sociological sense than a physical one, as the dead can socially ‘live on’ after death for varying periods of time (Davis, 2002). This process of socially living on through reminiscing, recounting of memories, through photographs, the impressions left on furniture, scents on clothes and the material things the dead leave behind can be profoundly evocative to the living (Davis, 2002; Hallam et al, 1999; Hallam & Hockey, 2001; Gibson, 2008). It can invoke the deceased, provoke the living, mediate relationships and help life to be remade with the deep connections to the physically dead. As a phenomenon, these social lives of the dead can potentially continue for a generation or two until eventually a person moves out of the flow of social life or becomes notably folded into our histories and cultural heritage and continue to live on in history.

This findings chapter looks at and accounts for deceased individuals who have been sociologically living on within networks online. These findings ask us to take into account the presence of the deceased and the potential agencies of the dead that emerge if we consider death as a process,



one that involves practices of loss and data remains.

I open these findings by drawing on data to exemplify how the deceased have been ‘Created in Loving Memory’ by the bereaved family, through creation and remediation practices. Then I turn to ‘The Memory Remains’ and discuss how ghostly manifestations can be created autobiographically in life, through intentional or more auspicious circumstances. In the third section I address when ‘The Social Afterlife Begins’ and explore how remains are part of the ongoing relationships that continue to unfold within networks online. Continuing with this theme, the fourth section, ‘Beloved by Family, Cherished by Friends’, continues this work through recounting findings that speak about the obligations, commitments and moral duties the living uphold to the dead. Finally, I turn consider how the dead can become ‘Dead Smart’ through the computational ecology of the networks themselves.

## CREATED IN LOVING MEMORY – HOW THE DEAD EMERGE

When documenting human practices of loss I began to see the dead emerge. These deceased individuals, or ‘ghosts’ as I began to code them, would manifest through an array of practices, relationships and data remains. The first of these activities I noted were human practices of loss through the creation and curation of remains, and this is where I begin.

In terms of the bereaved creating media about the deceased, it was through these practices and data remains that the presence of what I coded as a ‘manifestation’ would occur. The dead manifested through the biographical details of names, dates of birth, dates of death and portrait photographs that were constantly seen. Similar to the epitaph and content of a gravestone, these persistent details would begin to tell the story of a life no longer lived. Where manifestations began to diversify lay within the broader and diverse collections of remains that to help expand these limited biographic stories.

In the mid- to late 1990s, the emphasis lay on expanding the core epitaph, firstly,

with texts containing detailed life biographies that would speak about the deceased's upbringing, educational history, hobbies, personality and partners. Detailed accounts that described the circumstances of death could be found alongside eulogies, reminiscences and memories that helped breathe life into a person.

The single or small collection of images that allowed viewers to see what the dead had looked like in life and often just prior to their deaths also began to grow alongside the gifs and illustrations being introduced. Images began to span the deceased's key dates and events and, through observation, I would see what the deceased look like as a baby, their first days at school, birthday parties, taking part in hobbies, leaving school and adulthood, depending on when they died. With the appropriation of social media networks from the mid-2000s onwards, opportunities began to open to embed video content, music files and, in one example, an audio recording of the funeral.

The practices of creating these fragments start to create rich manifestations of the deceased. This richness goes beyond name and age, and gives a broader insight into location, education, employment status, culture and hobbies. Readers of this material can get a sense of who the deceased was and now how they live on through an understanding of their personality, gender, friendships, life partners, pets, politics, religion, ethnicity and so forth. Created by the bereaved 'in loving memory', this collection of media that exists as shrines, tributes, memorials, sites of remembrance, eulogies, epitaphs, scholarships and charitable organisation's fundraising pages exist to invoke a presence and tell a particular partial and crafted story about a deceased to the living.

The level of detail about some individuals made me reflect on how I was possibly encountering manifestations that had been especially created for people who knew nothing about the deceased. In the case of Ralph, his memorial was created after his death on February 11th, 1997. There is an 'our story' page that documents Ralph's death from the perspective of the bereaved, and an 'About Ralph' page that documents his life and how he died. As a collection, these are written in manner that introduces

Ralph with a level of detail and specificity that would not be necessary if I knew who he was. There is a tone of explanation in the backstory, contextual information and subtle signs such as pictures carefully labelled. However, the community that surrounds this site are those brought together by interest and not proximity. The people who engage with Ralph's mother on his guest book exemplify this in posts from national and international visitors.

The public-facing nature of these pages or sites seemed to change when I began encountering more recently deceased individuals on social networking sites. The communities that surround these pages are not primarily communities brought together by interest but by location. This difference manifests in the lack of backstory and details given about the deceased. Pages or accounts are set up and constructed with the implication that readers knew the deceased and these details. I followed more recent accounts and realised that I did not know very much about the person who had died. In cases of media fragments such as singular photographs to Instagram or a singular tweets, I would never even know the full names or dates of birth and death of the deceased.

The presence of remains that emerge on social media networks can originate autobiographically but be quickly co-opted by the bereaved. I observed material across two social networks made by Jess before she was murdered and a fundraising page by Kim before she collapse and died. This material has been co-opted by the bereaved who have used these social media posts as a way to bring attention to their daughters' deaths. Although the families do not add to these remains, the remains in themselves give an insight into the lives of both of these women. I know what they both did as jobs, their relationship statuses, where they have travelled, their hobbies, their friendships and locations around the time of death. Then there are the types of clothes, shopping habits and music tastes of Kim. Jess enjoyed sports and we could see what games she had followed. These kinds of detail wove a more disjointed but intimate insight into the deceased.

Collectively, the remains that the bereaved create and curate together weave into a fragment or partial view of the deceased. These fragments help to manifest the dead and make them socially visible in death. Yet this is not the only way that the bereaved can manifest and become visible. There is a third way, through the wider collection of data remains that I found such as business networks and employment profiles, educational histories, news stories, court documents, driving offenses and missing persons requests.

I observed the case of Lee who went missing in the late 1990s. There are police requests for information about her after her initial disappearance, she emerges on missing persons directories, and then there are updates on her body being found in the press. In time, excerpts of court transcripts, tribute pages and memorials can be found presenting her broader biographical story. Her case is caught in a true crime documentary that can be located on YouTube. Depending on the presentation of Lee, she can be as described sensationally by the press or coolly detached by the police, which stands in contrast to the woman called Lee as described by her family. In the latter, Lee is much warmer, more personable and is not objectified as a 'victim' but rather as an intimate relation. This reminds us that there are multiple people creating media, busy pulling together, collecting and uploading remains, and not all of the people involved are invested or know the deceased.

It is only the bereaved that are manifesting the dead 'in loving memory' and working to speak about the deceased's life in order to remember them warmly and positively. Therefore, it is often the bereaved who are more invested in caretaking or stewarding<sup>36</sup> how the deceased are made visible. Having remains that are favourable or generous to the deceased's memory and presence is the undertone of this caretaking, as, to date, I have not observed ill-favoured social manifestations of the dead created by bereaved families.

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<sup>36</sup> Stewardship is a term borrowed from Jed Brubaker. See: Brubaker, J. R., Dombrowski, L. S., Gilbert, A. M., Kusumakaulika, N., & Hayes, G. R. (2014, April). *Stewarding a Legacy: Responsibilities and Relationships in the Management of Post-mortem Data*. In *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems* (pp. 4157-4166). ACM.

In this section we begin to see how manifestations and presences of the dead can occur and that there can be then multiple social presences that become visible. Yet these are not the only way deceased people can manifest. As touched upon in this section, we can create partial fragments through our engagements with technologies, and this is where we turn to look next.

## THE MEMORY REMAINS

People's engagements with technologies can lead to the creation of a social presence within networks. This can occur through the opening of profiles, accounts and the general day-to-day touches with different networks that provide content and active feeds. This engagement shapes how the living not only appear but how they continue to be presented online. Features like the character limits of Twitter, the filters that shape Instagram images or mobile photos taken in mirrored selfies speak about the ongoing relations between people and their networks that cooperatively shape how people are presented. They prompt us to think about how the weaving of technologies into the flow of daily life means that networks can go on to support and shape the types of social presence and profile we publically place.

Sometimes these ongoing relationships come together in strange ways, as in the case of Lee who posted a status update on Facebook saying 'goodbye everyone' and changed his location to the 'afterlife' before committing suicide. Frank used his heavily followed Twitter feed to post a series of 140-character tweets, including 'if there's a god then he's calling me back home. This barrel never felt so good next to my dome. It's cold and I'd rather die than live alone', before committing suicide. Charlie chose to post 'JUST LET MY KIDS KNOW I LOVED THEM DEARLY' via a mobile device before being murdered. Sean sent an SMS saying 'I can't breathe' and updated her Facebook status to 'feels like death' in an attempt to call for help before dying from anaphylactic shock.

The decision to turn towards technologies in the time around death is not as fleeting as the examples above suggest. Mark chose to create a detailed online chronicle and self-reflective account of his life and his rationale for death before ultimately committing

suicide. This HTML-crafted site using an unknown WYSIWYG editor, ftp, and image scanner may have taken a number of weeks in light of the fact that Mark created a total of 43 themed pages dedicated to his life, marriages, work and children. This extensive site is public facing and invokes the autobiographical epitaph of Mark, his upbringing, family, interests, personality, religious views, experiences of travel, musical tastes, favourite movies, general health, sport interests and food and drink preferences alongside his thoughts on life, death and suicide.

The site is extraordinary in its extensiveness and Mark shows a keen awareness and deliberate motives for it:

It's important for me to have written quite a bit about my decision to commit suicide because it's rarely been done. I assume the people I know would want to understand it better and I'm sure there are people out there who study suicide that would like to study mine – so I've left nothing to the imagination. It's all here.

Mark deliberately timed the release of the site and informing his relatives after his death. He chose to set up automatic method of contacting relatives post mortem.

Mark expressed his wishes for his site to be a permanent legacy: 'Today, is the first day

this site is active, but it will

be here for years to come'.

He had paid for a five-year

subscription and wrote a

'release of rights', opening

the site up and removing

any kind of copyright limits.

Unfortunately, the site host

took down Mark's site for

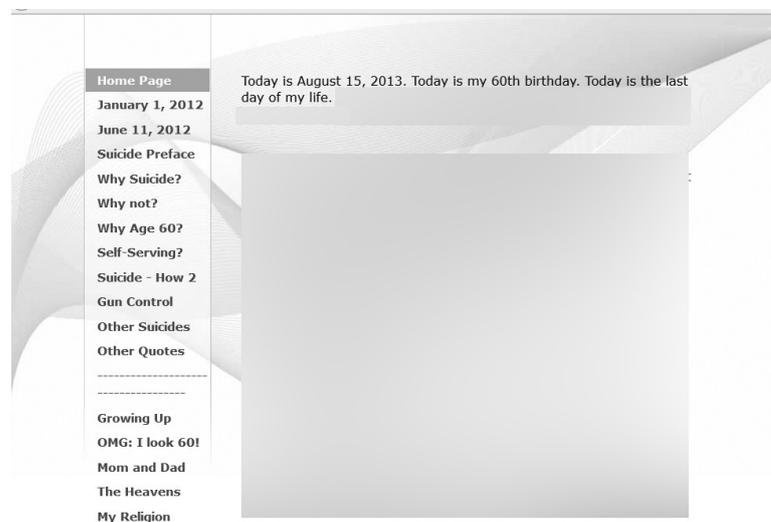
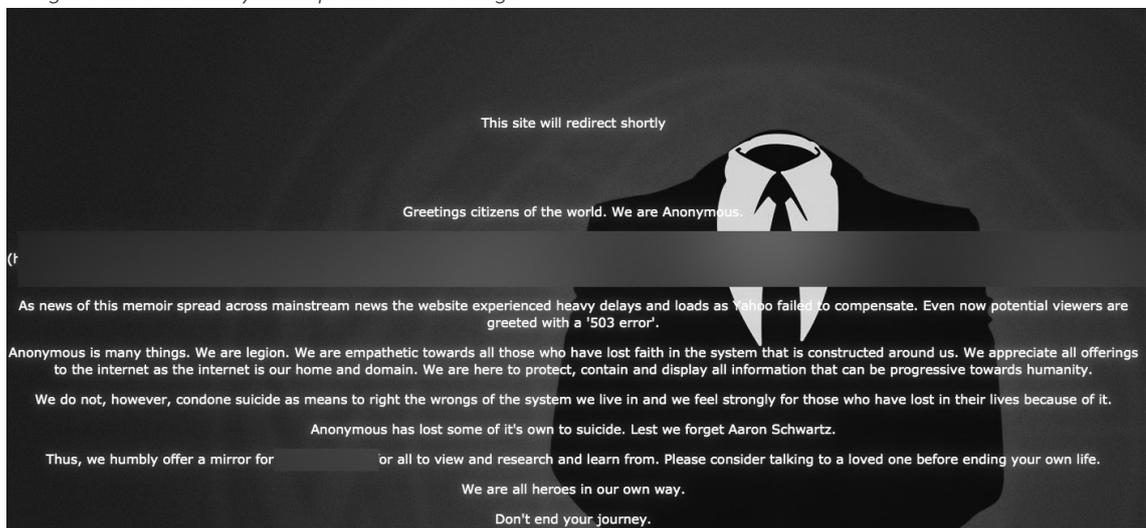


Figure 5.1 Marks memoir, the extensive list of content can be seen running down the left hand menu bar

violating its terms of service within hours of it being posted. Mirrors sprung up and the organisation Anonymous publically stepped in to create their own mirror of the site. They chose to preface Mark's self-created archive with their own political message and changed how Mark's site was first encountered. Similarly, my Internet service provider began to interfere with my access to Mark's site when it introduced the Sky broadband shield in January 2015, and elements of Mark's site linked to the web.archive.org known as the 'Wayback Machine' were 'blocked'. These help to remind us that things do not just 'live on' statically but are in fact always undergoing change and these are changes that Mark was not likely to have expected.

Figure 5.2 The anonymous precursor message



There are circumstances where the death is not considered imminent or planned when people have been using social networks. Unlike the cries for help or final words, these posts work as memento mori devices to remind us of the unexpected nature of death. Mike dressed as a Día de los Muertos-style skeleton for Halloween and took a 'selfie' photograph at home using his iPhone and mirror just hours before he was killed in a motorcycle accident. With a title that discussed how the dead are now living, Mike's picture and last post words are not an unusual contribution for the time of year. However, hours later Mike was involved in a fatal road accident and this Instagram picture and tweet is now a macabre shrine and memento mori device.

Similar to this are the last Instagram pictures taken of aircraft or aircraft tickets before major air disasters; drivers taking selfies before crashing their cars prior to

dying in automobile accidents; blogs written about near-death experiences and posted in the weeks before the writer is murdered. Such is the array of these types of eerie

Figure 5.3 Image taken by a passenger before the fateful MH17 flight and uploaded to Instagram



presence that Project 'Tweet Hereafter' capitalises on them on Twitter. It is a publically accessible account that works as an archive to bring together the last 140-character posts that people make before dying in sudden and shocking circumstances.

Through my data collection I noted presences that connect violent and traumatic circumstances. Technologies such as smartphones have an immediacy and ability to record and upload materials that are not always welcomed. Rape victims have had their assaults filmed and uploaded to video sharing sites, which has resulted in online harassment and bullying to such an extreme that the victims have committed suicide. Photographs taken by police officers in the aftermaths of violent accidents, films of car crashes and people being murdered and even dismembered can be found online, much to the distress of the bereaved who do not want to remember or engage with these representations of the dead.

There are increasingly strange ways that technologies can signify and shape death, such as when the living are not dead. An example is Tom, who had a mischievous friend with an idea that cam about after reading a post on how to memorialise an account on Facebook. Using Tom's details, his friend used the memorialisation channel on Facebook to claim that his friend was dead. As a practical joke, Tom attempted to sign into his account to find that he was locked out. With the help of another friend, Tom managed to view his Facebook wall and see that Facebook had declared he

had died to friends and family. Through memorialising his account, Tom observed a number of his contact's post messages of shock and distress at his sudden demise.

In similar but stranger circumstances is the online urban legend and curious case of 'Dave on Wheels'. Dave on Wheels was the online pseudonym for Dave Rose, a paraplegic blogger, who documented his ill health via a blog and Twitter account. Dave's online presence went viral and shifted from just 8 to 7,500 Twitter followers in 24 hours. Dave became rapidly championed as an inspirational figure by online celebrities and charitable organisations, which made his very sudden demise all the more shocking. Soon after Dave's death came an exposé that Dave was in fact a hoax. Dave was a fictional creation, devised from the downloaded image of a paraplegic male taken from a charitable site in the US.

Within these accounts I give a glimpse into the relationships unfolding between the living, ghosts and the networks. From Mike's iPhone selfie in the mirror, the opportunities arising out of the memorialisation form on Facebook and the downloading of Dave's charitable picture, these start to gesture towards a broader collective at work. They also gesture towards how these presences do not just emerge but continue to unfold. In the case of Mike's personal chronicles, we see how his intentions of living on have already been changed and interfered with. Therefore, this is where we now turn, after a presence becomes visible.

## THE SOCIAL AFTERLIFE BEGINS

Within the previous two sections I have outlined how the dead manifest through practices of loss and through ongoing relationships with technologies. While these help to recognise that the dead emerge or manifest, these manifestations do not exist as static presences. In this section, I will discuss how the dead can not only manifest and be present but can also have an active social 'life' with the bereaved after death. By active I am referring to the ways in which these presences are always undergoing changes across spatiotemporal landscapes, with new manifestations and dialogues occurring.

I use to term 'social' to discuss the social nature of these presences, the community interaction and the social agency that is given to the dead by the living. This liveliness can be a difficult phenomena to capture as it is difficult to know if a site is still being visited. Although the living may be returning and engaging with these presences, this interaction is not always visible or immediately noticeable. I suspected that this phenomena may be best understood through the absence or lack of phenomena such as the resistance to delete, remove or close accounts relating to the deceased. While there is a considerable amount that may have been lost that I am unable to grasp or study, I am aware of the collection of things, remains, memorials and fragments that have managed to live on in various states of decay rather than being deleted.

It was through studying the decay or what I thought were abandoned sites from the mid-1990s that I observed the subtle signals of gardening or caretaking activities. Part of these would do the work of making sure a site or fragment would live on. On html sites, this is about fixing the elements that are no longer working or subtly changing details such as the dates on a site. I noted that spam was an issue in the older html pages that were using guest books. Posts particularly about prescription drugs would begin to appear and clog up guest book feeds. The bereaved would begin to heavily moderate and remove content in order to keep the manifestations intact.

I did find a more explicit insight into the more subtle undertow of activities. I found a post on a forum related to an online music streaming service. A new member joined and made a single post that discussed how recent changes to the streaming system had disrupted his engagement with his mother's music playlists. As he explains:

I took on a subscription and stayed for the past few years. My reason was that we found fairly obscure French tracks from the 1940s for my Mother, who did a Playlist shortly before she died. I have downloaded the software and I have tried to help with and upgraded my controller, but hardly any of the tracks on my playlist appear and nothing at all of my Mother's playlist is there. I just wanted to share how sad I feel. I don't know if there is any hope that in time the tracks might be found, but I have found it quite hard to 'lose' the music my Mother selected. I listened to it a lot.

Infringements of data remains that impinge upon the deceased's character can be very upsetting for the bereaved. Like the account above, there was a family who was distressed by having the social presence of the son, John, targeted. Although I do not know why, John's death attracted the attention of Internet 'trolls' who proceeded to open up a social media account in John's name. Setting up profiles on Facebook and an account on YouTube, the trolls began to use John's account to post messages and video content. A message gathered the attention of the press when John messaged his mother telling her that he wasn't dead. Doctored images of John in relation to his cause of death were found along with messages such as 'Help me mummy'. John's case was eventually resolved through these accounts being closed and the perpetrators eventually being identified.

Presences of the dead do not just work as positive or negative forces, they can also be used by the bereaved to seek help or information. Emma, who was found pregnant and murdered in the late 1990s, is invoked across a memorial, an institutional police force page and missing persons sites with requests for information relating to her death. Her case is still ongoing, so there are numerous requests for help that invoke Emma's presence, telling us how wonderful she was and how she is missed alongside requests for information and witnesses relating to the circumstances of her death. Furthermore, Emma's collective remains invoke the presence of her unborn child too, using stock photographs and gifs to try and invoke some kind of manifestation for a life never lived. The baby was unnamed at the time of death, but the flashing winged cherub is often used to symbolise this life in Emma's memorial pages.

Similar to Emma is Dee, who went missing in the late 1990s and can be found memorialised on Tripod, even though no body has been found or actual confirmation of her death. She has a more recent site built in WordPress and a Facebook page that uses her image and biography as part of the overall materials asking for help. Ken, who has a memorial tribute, also has a scholarship fund and his biography is used as an anti-suicide message within a number of suicide awareness sites that spread from the

late 1990s. Finally, there is Charlie from the previous chapter. He died in an accident on a lake involving a boat in circumstances that the family have worked hard to relay to others. Included in the links on his Mysite homepage are some that direct visitors to learn more about the circumstance of his death. The bereaved want to educate others about simple safety measures and bring awareness to the preventable nature of his accident.

Within social media network feeds, the immediacy of these manifestations and their continuing presence can be heightened. Ghosts can suddenly appear in the immediate aftermath or in 'real time', like Don who, after being found dead in suspicious circumstances, began reaching out. Police and press posted Don's photo and a short biographical story alongside his last known movements, asking for witnesses and information to solve the mystery of why he was found deceased. His family used his very active Facebook account to ask his friends and work colleagues for further information. His family took to using his profile timeline on a daily and then weekly basis after his death, signing into his account and making posts that looked like they had been written by Don. Documents pertaining to the results of his coroner's court outcome also emerged online and his family continued to use Don's account to inform friends and family about his service and upcoming wake. These emergences speak about presences that manifest and continue to develop and become more multifaceted across different periods of time.

### BELOVED BY FAMILY, CHERISHED BY FRIENDS

Working closely and observing Don's emergence, I began to consider other deceased individuals who have continued to emerge over a longer span of time. Wyn, who died at 19 and is 'forever 19', becomes transformed on key anniversaries and her birthdays into an online presence who is [sadly] congratulated for her ongoing birthdays, not as a teenager but as grown woman who, through time, is subject to growing up and growing older.

She was a caring, loving, sometimes cantankerous young lady that will be forever 19, even though today she is 27

I know that Wyn and Dan are celebrating today, along with (sadly) many others

Wyn would be 33 years old tomorrow.....time flies/crawls all at the same time

34 years old today.....you have no idea how much we miss you and think of you all the time

Dearest Wyn, Difficult day, 36 today but forever 19. Time flies and stands still all at the same time

38 years ago you were born and 19 years gone this November. We miss you darling, so do others!

Ralph has yearly letters written to him and images made by the broader community wishing him 'happy birthday'. These are indexed by his Mother (see figure 5.4)

Time was an obvious indicator that signalled and discussed the social life or living on of the deceased, often through a dialogue that would signal how the dead were continuing

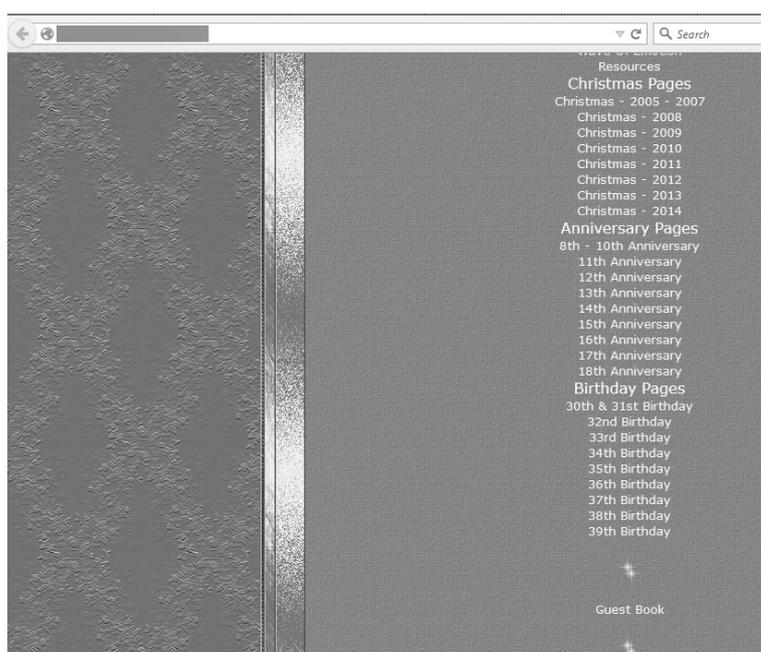


Figure 5.4 The list of pages that are being added yearly for Ralph

to grow up or grow old.

However, there was one type of deceased group that appeared to be frozen in time. Typically referred to as 'angels', these were the social presences of very young children or babies that appeared through the autobiographies of pregnant woman. They are consistently represented by

photographs of the pregnancy, images of ultrasound scans and post mortem images. These remains are also usually framed in this order too. As a collection of materials, they reflect the growing social presence of the baby within the lives of their parents and families before being crystallised at the age of death. From this point, different versions of an afterlife begin and their presences is frozen as babies and depicted to be living on elsewhere within some other dimensional or religious plane of existence.

Encounters with angels are likely to be out of the experience of the majority of web users; however, such presences and 'Angelversaries' of children date back to the early user-generated content sites. They are a part of a culture that is persistent and angels go on to reappear within new social media platforms. YouTube in particular gives an insight into the popularity of engaging with these angel presences, which is seen through the regularity of comments and views, with one video, uploaded in 2012, observed as having 9,335,089 views by October 2013 and climbing to 11,409,593 by October 2014.

I observed comment sections on YouTube posts as places where people would go to engage in 'dialogue' with the deceased and keep their relationships active. There was no specific network or time frame where these activities happened more than others, as it was a common and constant feature of a much wider public engaging with the social presences of the deceased online.

This engagement, both with more contemporary and older sites for loss online, provides fascinating insights into how 'alive' the deceased was thought to be. One parent writing to her teenage daughter asks her to make time to do something:

13 long, lonely years without you! This year has been particularly hard as the economy has hurt us more than you can imagine. But I count ourselves among the more fortunate ones. Once again this is not how it was supposed to be, but day by day we go on. We miss you always, and never forget. Too many have forgotten :- ( I have added a story written by another grieving parent called the GAP, it is listed on the Poems & Prose page, please read it if you can

Dear x,

I'll never forget those few happy hours where everything was ok and happy and the future was bright

In the immediate time after death, these dialogues would be intensely sorrowfully or emotional, discussing how much the bereaved missed the deceased and wished things were very much different than the circumstances they had found themselves in.

Some posts I encountered were less sorrowful and more filled with passing comments about everyday life. Amongst this dialogue, the bereaved included photos, sharing

their experiences and places they had visited.

The kick-smoking habit is still here, which is good, but so is the food that I eat now, and I know the metabolism has changed and with it and age I have gained a few pounds. I walk most nites in the back of the property and he is maintaing walk paths where once we rode the horses. It is pleasant and many days we see new and fun things that we did not know were there. This time last year we had just arrived on an ocean front beach to check in for a funtime week. I remember sitting on the veranda giving a toast to your b-day.

today you would be 31 and that rascally cat, xxxx is 12, hard to believe. That silly cat was not supposed to be with us any longer, he was supposed to be living with you. Life sure does take twists and turns

One poster liked to include pictures of her memorial garden so that her deceased family member could see it growing and developing. This continuing dialogue spoke about the moral commitment the living person had made to maintaining the garden for the deceased.

This duty of care and tending prompted me to reflect on the levels of commitment, maintenance and respect that was held for people to repeatedly return and invest time and effort. From my reading, the bereaved and wider public visited these manifestations due to a connection to them or the spaces they opened. As the examples show, these visits speak about the obligation at work. People would return on key dates, such as the birthday, anniversary of death, religious festivals and key holiday dates. This was an observable pattern that could be seen, spanning from the earliest html sites across to more recent social media networks.

## BEING DEAD SMART AND ZOMBIFICATION

During the course of observing the relationships, dialogues and practices between the living and the dying, I noticed a period when the dead began to reach out to the living. Unlike the dead we have previously discussed, these dead became active and almost reanimated.

I began to gesture towards these phenomena when I earlier discussed how Don's family began using his Facebook account to asking for help and information. While Don's family were manifesting his presence in 'real time' and asking for help, they were also taking over his account and repurposing it to discuss his death. In Don's case, his family continued to post in his name and use his timeline to ask for help and to give updates regarding his funeral. Observing this phenomenon, it was like Don himself asking for information about his own death and later discussing his impending funeral.

By using Don's profile and not always flagging up who else was posting made it difficult to get a sense of another person behind this ghost. Things then became more disjointed and strange because I noted that Don would be active on chat around the time of his death. These sporadic online/offline signals would eerily bring Don back to life for his broader contacts. In a similar fashion, in the weeks shortly after Don's wake I observed that he had been playing a Facebook game and posting the results to his wall. While I know this was undoubtedly a mistaken case of a family member being logged in to the wrong account, and the posts were later removed, for a short period of time it was like the death of Don had not occurred. He had just re-entered the flow of everyday life and connected back into the games he was frequently seen playing.

Similar to Don's Facebook account has been the continuation of numerous feeds by family members. What is strange about documenting these cases is watching the deceased come back to life across a number of social media channels. Alison, a UK teenager who died after a long illness, used a collection of sites to document her illness and raise money in relation to her illness type. After death, her family chose to continue this work and use her Twitter account and blog in order to give micro updates and blog posts about the work they were still doing in her memory. These posts would be undertaken using the login details and existing channels that Alison left, thereby invoking the presence of Alison who would begin to speak about how well things have been going since her death.

On Twitter I have seen the last tweets of a suicide victim replaced when the bereaved

have logged into accounts in order to leave messages of thanks or to reply to comments. I saw one Twitter feed, which was used to post the final words of a young male who committed suicide, taken over and the feed begin to fill with spam advertising prescription drugs. An unknown family member gained access to this account and removed the spam. They left behind a message that made the deceased look like he was thanking people for the thinking about him at this difficult time.

Due to the computational ecology of software, middleware and hardware that collectively house, manage and deploy data fragments, ghosts can be reanimated in other ways too that begin to disturb the living. Shock can arise from not expecting a deceased person to begin reaching out. Through my data collection I have noted that news stories and online media can project and house the dead under hashtags. In this way, the deceased become part of news algorithms, social media feeds, trends, tags, alerts and mobile notifications. *The Guardian* app that I use on my Android smartphone has regularly informed me of mass casualties and high-profile cases of beheadings, murder victims, earthquakes, air crash tolls and so forth.

Yet, as days turn into weeks, the difficulties and tensions found around still encountering particular deaths can increase, especially when the deceased is known more intimately. These are compounded by the unexpected and unseemly nature of these manifestations, such as when the dead have reached out to ask us to be friends online or to reconnect with them on platforms such as LinkedIn and Facebook. LinkedIn likes to also remind us of the birthdays and work anniversaries of people, including one person in my LinkedIn network who I know committed suicide while undertaking a PhD at the same institution as myself. PhotoBox, the photograph printing service, can automatically make up photo album books or use pictures as part of its marketing, which can include random selections of photos, including those of the dead. I know this through my Instagram picture feed, which brought in pictures of my deceased pet. Photobox offered to print this album at a reduced price for me, which, amongst my holiday photos, contained pictures of my deceased pet.

Some ghosts have been seen to like products and companies on Facebook. In September 2014, comedian Joan Rivers placed sponsored posts across Instagram and Facebook telling her followers 'I've just bought an iPhone!' nearly a week after dying. Scrapped photographs have been folded into dating adverts, including the profile picture of a well-known rape and suicide victim in the US. The use of the picture was highly distressing for her family as it was photographs of her rape circulating online that led to her eventually choosing to take her own life. These examples highlight that, online, the social remains of the dead do not just appear but are continually reloaded, reanimated and even co-opted to do the bidding of others within networks.

The deep tensions around our dead coexisting online with the living is only heightened when the dead seem to deliberately reach out, through well-crafted forms of digital afterlife. In the first chapter, I discussed the social bot that was created by TheWell member who wanted his comments and posts to carry on after his impending death. In a similar vein, there are now numerous services that can help people do this as well as craft their own remains. Since the emergence of the death bot on TheWell in 1995 and Finalthoughts.com in 2000, there has been a variety of 'afterlife' services appearing that require a degree of engagement from the living before death. This engagement needs the living to organise and make content in preparation for post mortem use, be that simple content that helps pass on passwords or login details in a similar fashion to basic end-of-life planning, or, alternatively, more intensive 'living memorials' for reaching out after death. These tap into the 1990s techno utopian dreams and Timothy Leary's transhumanist vision of escaping the material world in order to download the mind and upload the consciousness in ways that attempt to support us to live on or transcend death. The more recent examples, such as DeadSocial, ifidie and LivesOn, can support people to continue posting across a number of social media channels after death. LivesOn specifically claims to be constructed using an 'AI' that can help analyse your Twitter feed, learn the likes of a person, tastes and syntax in order to replicate these characterisations in future after-death posts.

Yet this notion of 'living on' and the assumed longevity of the digital afterlife is troubled by the story of Finalthoughts.com. As a pioneering emailing service that began in 2000, it offered the first automated 'afterlife' messages to be sent out to the living, via email, after a registered user had died. It was useful for helping people to plan their death, send out last wishes, funeral arrangements, organise finances and deliver the poignant last messages on behalf of the deceased. Yet the pioneering Finalthoughts.com lasted less than three years before it closed down. In a similar unpredictable fashion, Mark created his own extensive legacy and used after-death services for after-death messages before committing suicide. As already outlined, his extensive legacy meticulously documented his life and rationale for death. Mark envisioned his legacy lasting at least five years, which was as far into the future as he could buy his webhosting; but it did not last for more than one week. The service provider he had selected to buy his webhosting and domain name from claimed that the site breached its terms and conditions.

This idea, then, of the dead reaching out beyond the grave can be contentious. There can be great variation in how these reanimated ghosts are received. Post or emails can potentially be both very unnerving and yet welcoming for the living to encounter. This was the case for John who had similarly chosen to use an email service for after his death. His family began receiving emails five months after John had died, addressed as if John had just sent them. These messages spoke about things that needed doing or had occurred within people's lives. As one family member said:

I thought they were fantastic, they were good. They made some people happy, they upset some people - but to me, that's keeping people talking about him.

In the media there are numerous cases of email accounts being hacked and spam being sent out to families, who, regardless of complaining, have struggled to reclaim and shut these accounts down. Similarly, a woman in the UK who was buried with her mobile phone shocked her family by texting back three years after her death. When the family called the number, a person answered. He explained that he had recently acquired a mobile phone, that the service provider had put the telephone number

back into a pool and that he had unwittingly received it on reassignment.

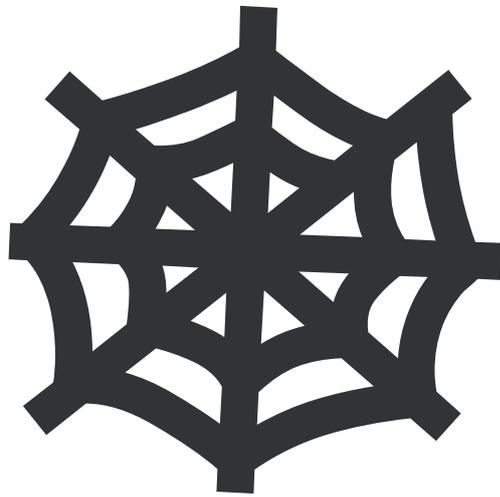
Mobile and smartphone devices have also played a central role in the living trying to find the presumed dead. After the disappearance of flight MH370, relatives of passengers relayed that they tried to connect with the missing people by calling their mobiles, which, according to reports, managed to start ringing. Smartphone devices began to suggest to relatives that their missing family members were 'online' in the immediate days after the crash. These devices, like previous technologies before them, become known by their capacity to support and manipulate how the presence of the dead reaches out.

## CONCLUSION

By framing death as a process rather than an event, this chapter has begun to explore when and how the dead can live on socially online. Attending to the social life of the dead after physical demise has been done by framing the deceased as ghosts and presences that manifest. In this chapter, I first presented how ghosts have manifested 'in loving memory' and through the remains that have been created autobiographically. I then moved on to give my reading of how they do not just manifest but in some cases begin to live on and age. I explained how this living on and agential force can be seen through the long-term commitments and duties that the living can make to the dead online. Finally, I discussed accounts where ghosts have slipped back into the flow of online social life and have reached out to the living through the relations between the computational ecology.

In an attempt to make the dead visible and to draw out the forces they can extend, I have provided empirical vignettes that explore the presences and their effects in the lives of the living. These accounts bring attention to a dimension that is currently diminished in TSD human-centred framings. Although references to the dead are made, the level of commitments shown by the living and potential agential force of the dead in networks have not been previously explored in TSD and the Death and Technology Studies intersection. These complex social presences demand further attention within

our situations for research and design inquiry moving forwards. The ghosts themselves have begun to tell us where to look next, towards the networks and computational ecologies. The relations between the living and the dead are asking us to attend to when the networks themselves begin to push back and interfere. Therefore, in the next chapter, 'Network Ecologies', I turn empirically towards ecology of elements that are part of this conversation and the relationship between the living and the dead.



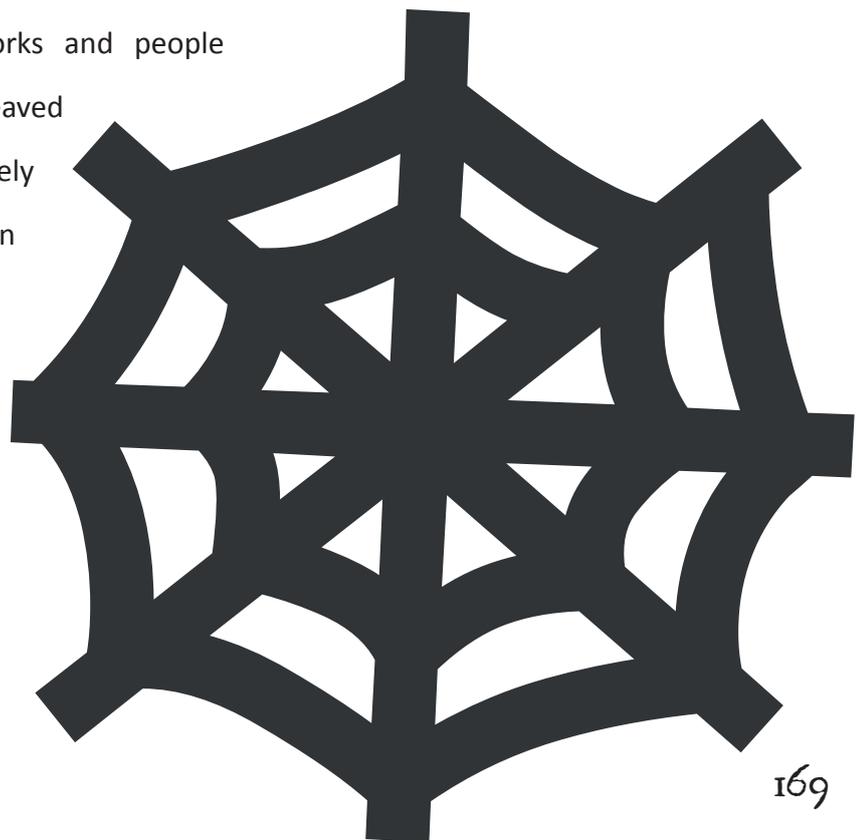
## CHAPTER SIX

### NETWORK ECOLOGIES



In 2014, an estimated 100,000 ‘content moderators’ – twice the headcount of Google – were thought to be at work on monitoring and regulating online services and social platforms (Chen, 2014). These moderators are facing and managing digital material that reflects the more difficult aspects of humanity. The media being moderated is known to contain racist, sexist and homophobic messages, threats of physical violence, verbal assault, physical assault and rape. Amongst this collection is also an array of death-related content such as suicide notes, suicides and suicide bombings, animal torture, beheadings and even murder. If we begin to think about the person or victim at the centre of these data remains and the wider circle of bereaved who are also implicated, these prompt us to consider when networks online might not be working as a positive focus for loss.

Behind this material lie the experiences of the bereaved who find these kinds of media potentially distressing. In response, this final findings chapter is turning to consider when ghosts, networks and people begin to work against the bereaved that TSD would want to positively support. This is a deliberate turn to the ‘dark side’ of online networks, to look towards when arrangements and elements come together and crystallise momentarily in ways that give us an insight into



the distress of the bereaved.

This chapter will next take some time to think about this turn towards the dark side of network ecologies. It is through my commitments to care that I use this space to reiterate why there has been a required shift in empirical granularity, how the phenomena has been approached and to ultimately prepare the reader for the material that is about to be encountered. I then move to present two empirical examples in chronological detail, giving an account of the phenomena as it unfolded and relaying how both examples have proven to be of distress to the friends and family of the deceased. The first example follows the case of a woman who was murdered and whose post mortem pictures were uploaded and shared across a range of online social networks. The second example follows the use of Black Hat digital marketing to capitalise on a high-profile air crash. Both examples conclude with a reflective section that not only draws attention to certain practices at work but also allows a moment to breathe before moving on. The final section continues to draw out the practices of sharing and tagging in a more detailed scale in order to draw out the computational ecology that is not only present but is also actively shaping how these remains are persisting and accessible online.

## DELIBERATELY TURNING TOWARDS THE ANOMALY

During the course of data collection I found numerous examples of networks and media arrangements coming together in ways that move to distress families, particularly when involving gratuitous, distressing, uncomfortable, disrespectful, explicit and embarrassing elements. This would often first emerge through highly harrowing circumstances, such as the recent pattern of perpetrators of crimes, such as murderers, serial killers and political groups, turning towards online networks in order to share and draw attention to their actions (which can be horribly graphic), to discuss their motives, bypass news outlets, build notoriety, make demands and more. I would observe the movement and mobility of this content through the practices of posting, sharing, searching, commenting, tagging and favouring material, causing it to publically

persist. it can be fairly easily sought out, further aided through algorithms and software that respond to these practices and also by the increasing professionalism of groups like ISIS and the high-quality production and marketing techniques that are at work.

As the 2015 article 'The Moral Dilemma of Death on the Internet' by Paul Smith pointed out, 'Content can be found in numerous locations on the internet and their popularity suggests it is not just the lunatic fringe of society logging on' (Smith, 2015). The hanging of dictators, the murder of strangers and the very high-profile video releases of militant's beheadings can be easily found on YouTube and Twitter (Smith, 2015). Smith notes that there is an open, even eager, interest in the macabre, destruction and death, a facet that works like a public invitation to think about life's meaning, to serve morbid curiosity, the Schadenfreude pleasure in the misfortune of others or to engage in a type of thanatophilia (Wilson, 2012).

Social networks such as Twitter or Facebook have become associated with notorious cases of hostage situations and terror groups through their use by perpetrators, victims and bystanders at high-profile events<sup>37</sup>. Recognising this dark side of digital networks has led to them being described as spaces filled 'by digital waste products, dirt, unwanted and illicit objects' that are part of the 'expressive and material components of the assemblages that constitute network culture' (Parikka & Sampson, 2009). In this framing of the 'dark side' of digital networks, analytical light has been deliberately shed on the 'anomalous' presences or the objects considered to have deviated away from the norm in ways that can prove to be *unconformable, dissimilar, and incongruous* (Parikka & Sampson, 2009). Therefore, looking at the dark side of networks and anomalous presences is not considering the anomaly as something abnormally unique or unusual, but rather as something that invokes strange, uneasy encounters. While it might seem tempting to frame these anomalies as being the exception, the regularity and wealth of distressing content means this characterisation would be incorrect.

It is worth keeping foregrounded that, regardless of the wealth of material to draw

<sup>37</sup> *The Sidney siege; social media was used in this way when the hostages were forced to use their own social media accounts, although it was the siege selfies that caught the attention of the media: <http://nypost.com/2014/12/15/shameless-selfies-being-snapped-outside-sydney-siege/>.*

together, the difficulties in approaching this material, both as a researcher and as a reader, should not be underestimated. This is why there is now a shift in granularity in how I bring together the empirical findings. I stay with this 'dark side' of digital networks by presenting two detailed empirical accounts of anomalies I encountered rather than focusing on presenting heterogenous range. I approach these examples carefully, reflectively and visually. Drawing out this issue rather than moving immediately into empirical material is my way of trying to navigate and prepare readers for this chapter.

## BECOMING DEAD FAMOUS

In 2013, a woman stood in her kitchen in the process of washing kitchen utensils and cutlery. Her partner entered the room and an argument broke out between the couple. After a physical struggle, the partner moved away, left the room and returned with a gun. The woman was then shot dead in the kitchen of her home.

Her partner, now a perpetrator of murder, calmly moved away from the scene, with the murder weapon, and then returned to the kitchen two minutes later. He lifted his hand, which was now holding a mobile phone, and deliberately captured photographs of the woman's body in the kitchen, before walking out of the room to go and retrieve his coat. He then immediately moved to leave the house, glancing at the body and the murder scene on his way past the kitchen to the doorway. Within an hour the police broke into the residence and a number of officers moved inside the home to find the scene and the woman's daughter still in the home.

How do I know this? Surveillance cameras installed on the premises were running on the day of the murder and the footage taken on that fateful day is now uncensored and available to watch on YouTube. Although the murder occurred just off camera, people can watch the publically available footage and see the flash of gun fire along with gunshot residue moving past the camera.

While the surveillance footage gives us an insight into what occurred, the first media to emerge online was not this video. Rather, this footage and the interest that it drew

online came in response to the photograph that the murderer took of his dead wife at the scene. Some time shortly after leaving the home and the crime scene, the perpetrator is described on police reports (that can be also found online) as choosing to login to Facebook in order to share the photograph and his confessional status update:

I am going to prison or death sentence for killing my wife. Love you guys and miss you guys. Take care Facebook people you will see me in the news my wife was punching me and I am not going to stand anymore abuse so I did what I did. I hope u understand me

People began commenting below the status update with comments such as, 'what??', seemingly confused by the statement and seeking further clarity. It was at this point that the perpetrator uploaded one of the post mortem photographs he had taken of his deceased wife to Facebook with the title 'RIP \*\*\*\*\*' (the name of the victim was written beside it).

The graphic image clearly shows the dead body of the victim crumpled back into the kitchen cupboards; she has been shot in the face and can be seen to be surrounded by her own blood. It is a highly graphic picture and it was posted on the murderer's public Facebook timeline. People who were likely to be already following due to the confessional status update began to comment on the photograph and ask what happened. One commenter said, 'That's my friend there' and tagged in the name of the victim, thereby linking the victim's similarly public Facebook account to the post mortem picture. Both the status and photograph were highly commented on, flagged and shared while they remained on the perpetrator's Facebook profile for five hours. Until the profile was disabled by Facebook, the photograph was shared internally on the site over 170 times, causing it to not only link in the victim's profile but also begin moving across Facebook.

Unfortunately, by the time Facebook removed the post mortem image, the photograph had already begun to migrate outside of the Facebook network. The image of the body and screenshots of the perpetrators profile, confession and post mortem image (turned into .jpeg or .png files) within 48 hours were observed circulating across Instagram,

WordPress blogs, Tumblr, YouTube, Twitter and Facebook accounts.<sup>38</sup> I first observed the perpetrator's confessional post and profile as it emerged on my Twitter feed. It was by following a singular tweet, a screenshot and gathering the details it contained that I found the Facebook profiles and watched the story unfold.

Even though the profile and post of the body had been removed from Facebook, duplicates of the original image and screenshots of the perpetrator's Facebook profile continued to circulate, particularly on Twitter, the day after the killing. Screenshots emerged that had been taken on mobile devices showing the different time periods when the material had been captured.

observed the image begin to appear with comments, such as on Tumblr, and the addition of social commentary tags like 'dreadful behaviour' and 'smh' (shaking my head). These expressions of shock came with links to or screen captures of the original content attached to or inserted within the posts.



Figure 6.1 Images of the deceased on twitter



Figure 6.2 Images of the deceased found in timeline

The day after the murder, the image began to gather broader public interest. I saw

<sup>38</sup> I am also part of this practice, taking screen captures of what I was observing and documenting the material circulating and being contained.

this through the amount of content related to the victim's name and the newer people who were discussing her death. The image and screenshots become a focal piece that people and independent bloggers, or online media and news organisations wanted to broadcast and

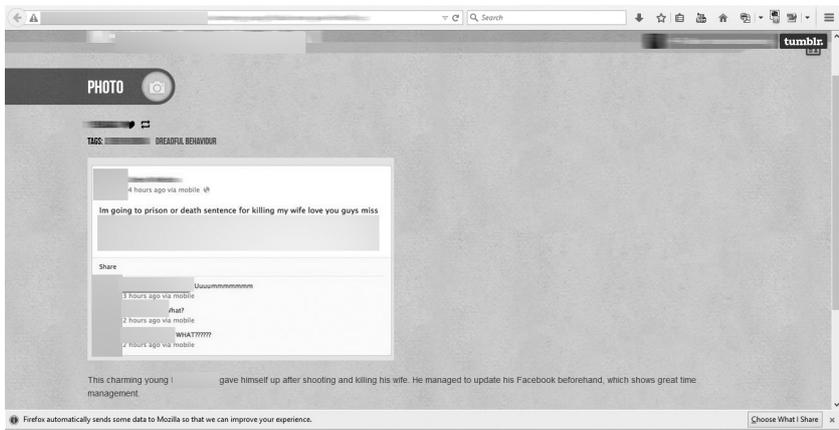


Figure 6.3 Images of the deceased on Tumblr

Figure 6.4 discussion of the 'overshare' while sharing the images

video blog about. On YouTube this encouraged others to begin leaving messages of respect and shocked reactions, such as 'tragic and sickening', 'omg', 'wow', 'so sad' and 'sick...'. Similar posts, status updates and tweets began to emerge across other networks, with tags or hashtags involving the name of the victim, the perpetrator and identifiable phrases.

I found content appearing through posts and then disappearing and being removed

Unlike Twitter and Tumblr, Instagram and

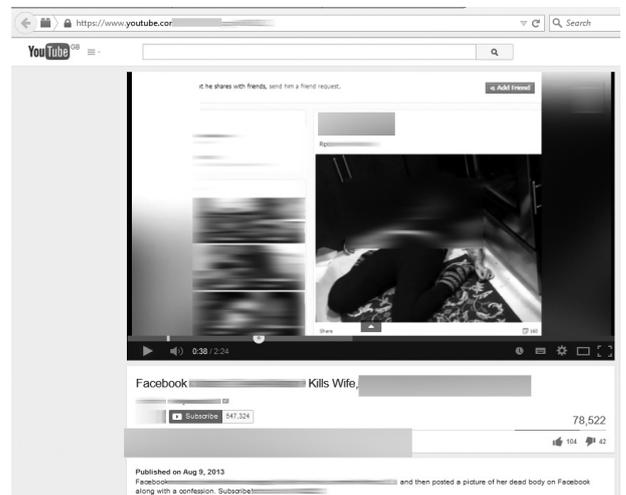
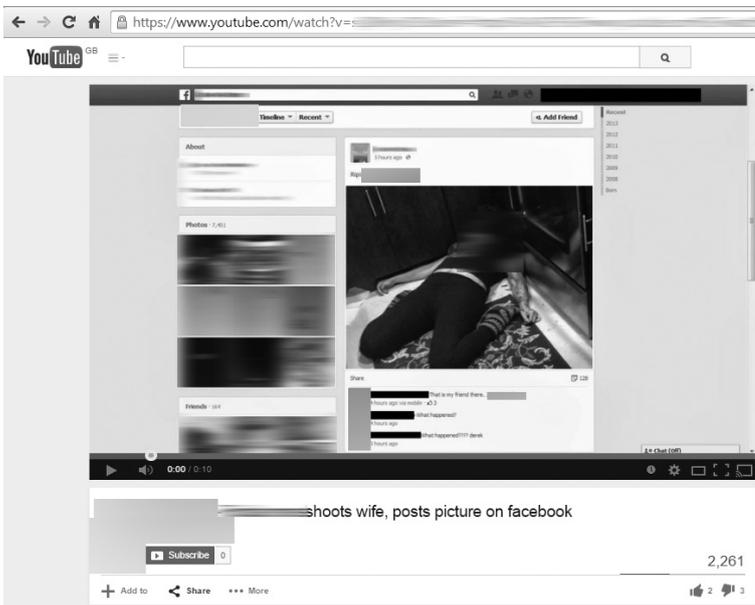


Figure 6.5 Screen footage of the profile being search

Figure 6.6 The images being discussed on YouTube blog

Facebook seem to have processes at work that remove content more quickly (even at the time of writing, within Twitter and Tumblr these types of post and content are still easily found).

Amongst this mass of activity that was unfolding, the content that was not trending and was not popular were the sincere tributes and messages from friends and family. These were difficult to actually locate amongst

the post mortem material that had begun to saturate tags and searches related to the victim. Searches and, therefore, search algorithms were already resulting in the post mortem content and media that related to the circumstances of the victim's death, rather than anything relating to her life and her own presences and activities online. Her leading 'ghost' had become formulated by the way in which she was killed and the macabre last media that captured the image of her body.

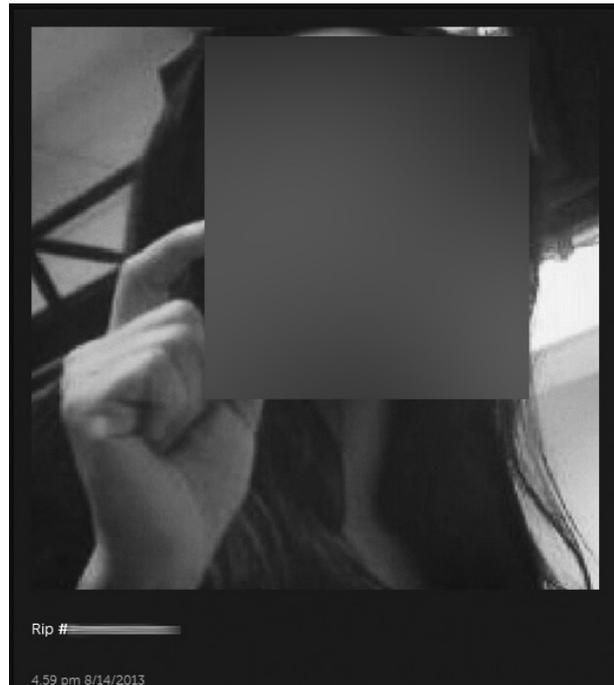
It was interesting to observe how the post mortem images gathered a considerable amount of commentary by people, including from friends and family, who left messages and comments beside different versions that emerged across different networks. These would express their relationship to her:

I can't believe this, this was my childhood bestfriend. He deserves everything that's coming to him. Rip \*\*\*\*\*

She was a great friend and everything a mother should be for her daughter. I wish I could have seen her one last time...

In tracking the image as it circulated, I overwhelming found people sharing who did not know her personally but felt compelled to comment due to a number of different

Figure 6.7 An image of the deceased as posted by a close friend in 'RIP'



reasons, including requests for censorship and anger at the image being posted:

SMH (shake my head)

I hope that God will bring all of the people who knew \*\*\*\*\* peace and understanding. I am so sorry for your loss.

Only a monster would post a picture of his dead wife on Facebook.

People have really gone crazy to do such things and then calmly post pictures about the murder they committed on Facebook!

It's exceedingly disrespectful to the victim and her family to show her death photos.

I don't have any words other than I'm so sorry for her friends and family to now be able to view this picture online. I'm sorry that she has been disrespected even in death to have this picture available.

Certainly the digital media environment was involved in supporting the circulation of these images. Press stories could be seen to contain galleries or include screenshots of the original image and profiles. The sharing and tagging systems of these pieces only further added to circulating capabilities.

Ironically, comments and posts on news stories were found discussing how distasteful it was that these images were now trending, while, at the same time, these posts were

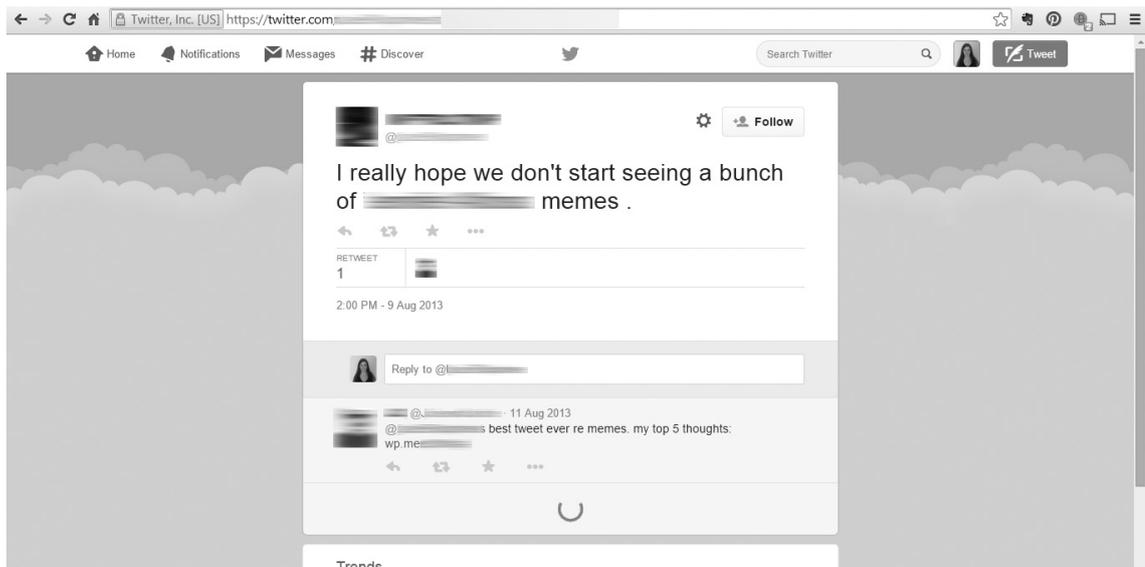


Figure 6.8  
A person expressing hope that the images won't be seen as 'memes'

attached to the content or news stories that contained the images.

In the immediate aftermath of this murder, the popularity, macabre interest and



case:

I was just looking for the knife he said she was coming at him with....not in the photo, hmmm.

sure looks like she was on her knees when she was shot and fell back. I don't see abuse by her here at all...I see a murder.

I read the police report and it tells a different story even to the one he posted on Facebook.

It was by staying with the case that I began to gain a small insight into how the death and the resulting images caused the family of the victim much distress, particularly to the victim's daughter who was in the house at the time of the murder. In response to people sharing the image internally on Facebook and externally on other social networks, a person close to the family requested that people stop sharing the image. They asked people to show respect for the victim's daughter and the family. By returning to Facebook and publically posting the status:

I have been flagging and reporting as many pictures of \*\*\*\*\*'s body. Whoever continues to repost these, please stop and respect. You're only hurting her daughter more than anything.

In response to this request, screenshots of the plea to stop have been taken and included into the latest news articles, thereby becoming ensnared and folded into the overall narrative about the victim's death and how shocking and distressing it is proving to the families. The text only seems to be used sensationally within new stories to confirm how shocking and harrowing the images actually are. Sadly, the sharing of the images is only part of the story about their persistence. A search for the victim's name seems to have unfortunately tapped into the fact that search rankings are based on factors such as popularity. Therefore, Google now presents the victim based on how she died.

I focus on Google because it allows us some insight with Google Trends. The victim's name brings up identical results but with different arrangements, as shown by the screenshot of Bing. Google Trends places the victim's name as a rising 'Breakout' search

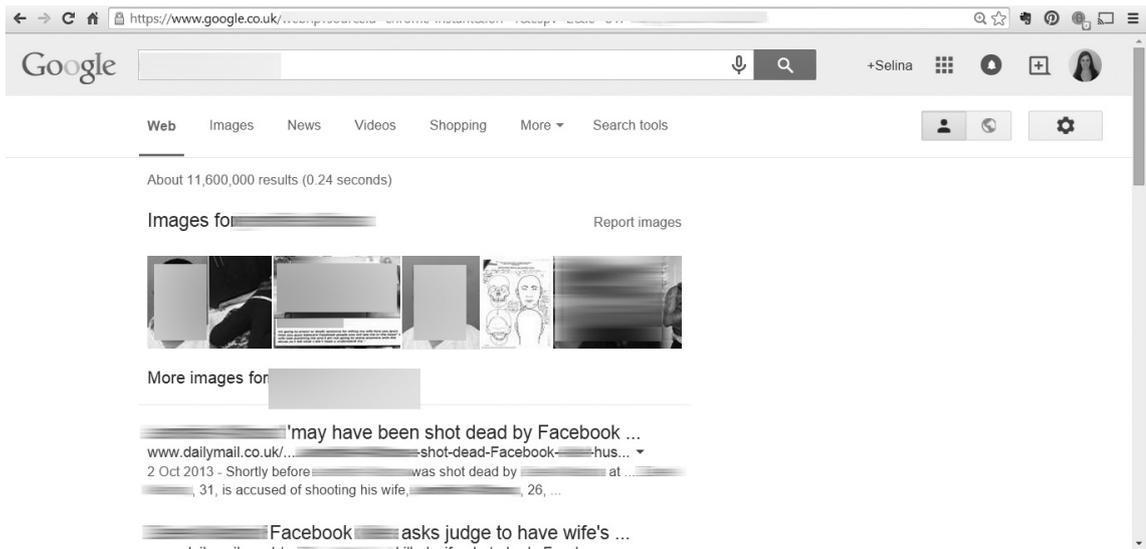


Figure 6.12 The deceased as found through google search

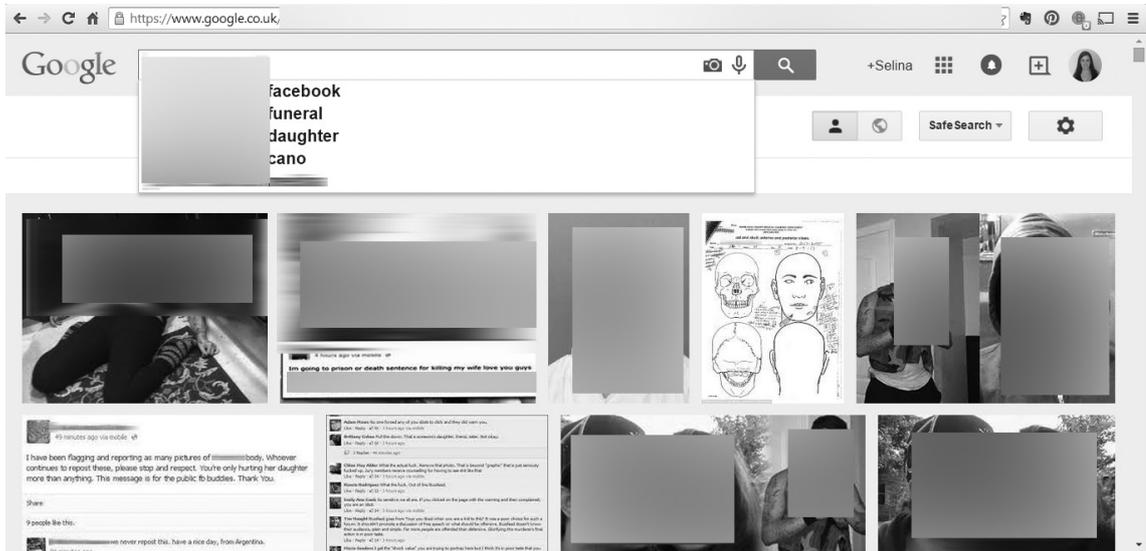


Figure 6.13 Suggestions by google that are offered in response to the deceased's names

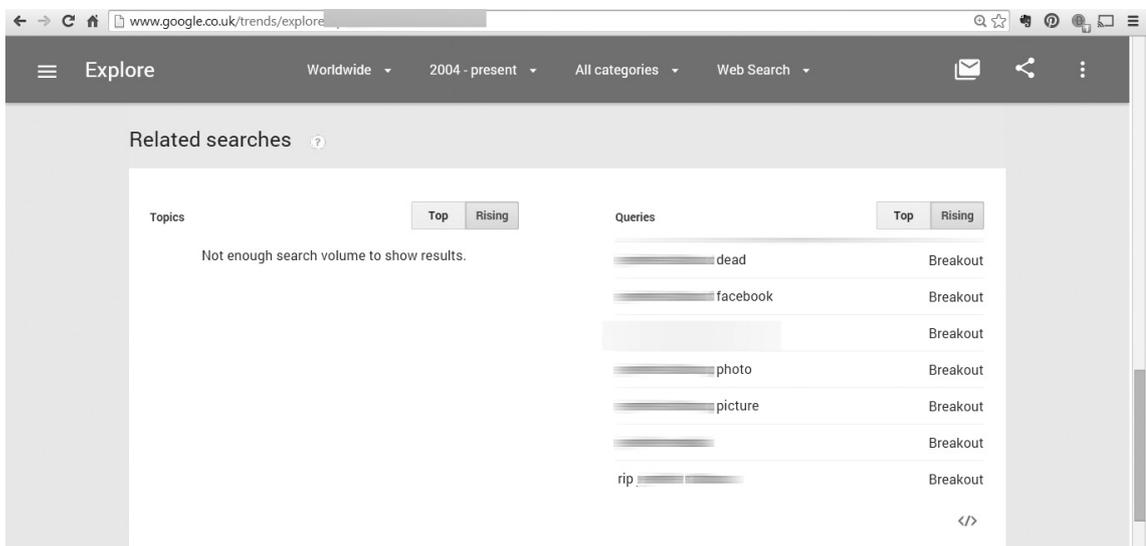
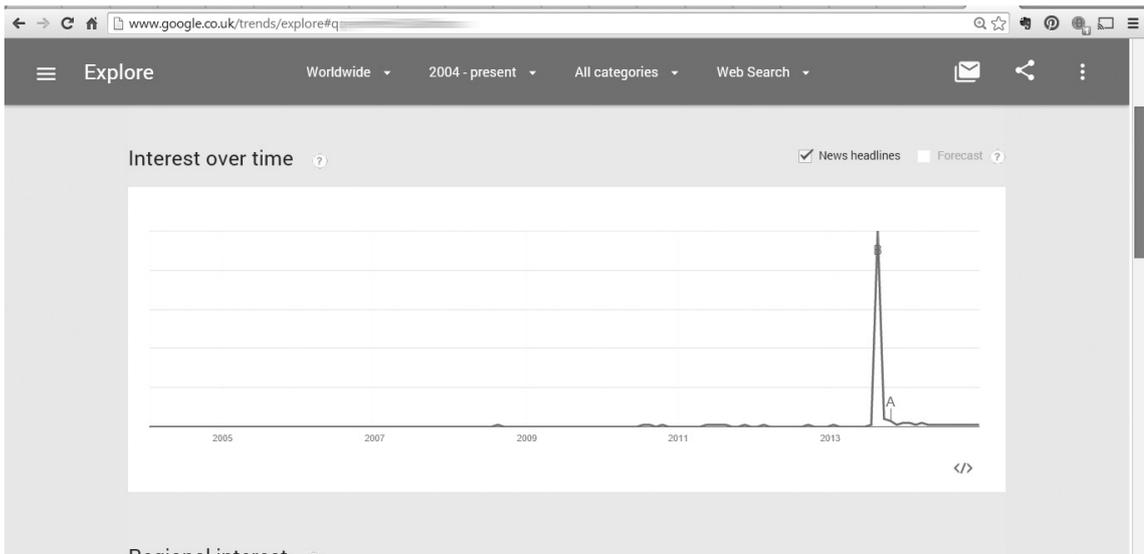


Figure 6.14 Google Trends 'breakout' terms

Figure 6.15 Google Trends over time



term around the month of her death. According to Google Trends support information, rising searches are searches that have grown significantly in popularity over a given time period when compared to previous periods, called breakout periods. Giving the term breakout, rather than a percentage, means that the search term experienced growth of more than 5,000%. Google Trends show an initial spike with low-level interest continuing and additional search terms that are being used around the victim's name. These additional search terms related to her death indicate the ongoing interest in the post mortem photographs. When searching for the victim on Google, the first thing that appears on the search result pages is a copy of her uncensored post mortem picture followed by images of the confession and screenshots of the Facebook accounts in question.

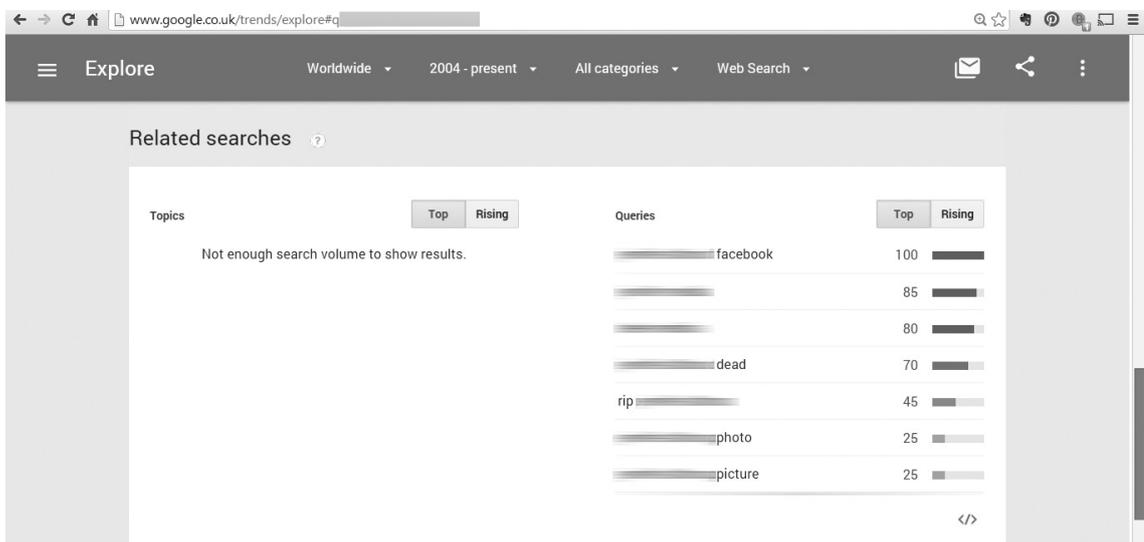


Figure 6.16 Google Trends Related searches

## REFLECTIONS

In this first empirical example, 'Becoming Dead [in]Famous', rather than following collaborations and positive arrangements, the contestations, disorder and unplanned arrangements that are emerging from network arrangements to upset the bereaved are focused upon. The motive here is to give an insight into when arrangements between the living, the hardware and software and the non-living come together in ways that prevent the dead from being able to 'rest in peace' and prevented the bereaved from finding solace or a positive focus for their loss.

In this example, a series of post mortem productions, through the creation of .jpg or .png files, from the initial photography, image copies or screen captures are still in motion and circulating in ways I can only begin to give insights into. There are numerous social networks involved in this movement, with origins that seemingly start from the network infrastructures of Facebook and their data centres, servers and software that help to shape and support a range of practices. These practices, such as copying, screen captures, downloading, renaming and saving of these images, previously denied as being used by the bereaved, are appropriated by a wider public in order to begin the process of remediating and making mobile disturbing content that now works against the bereaved.

Network ecologies can work to cut into and shape practices, that which is shared, tagged, searched for, commented about, linked to, liked, re-posted and, in the case of the bereaved and social network moderators, flagged, reported, removed and deleted across different social networks. These are only the observable aspects I managed to document. Certainly, there were multiple people engaging in these practices, including perpetrators, bereaved individuals, journalists and even myself as a researcher. Finally, there is also a mass of non-human material and computational infrastructures present too, that was not always easily observable but resisting and interfering in processes, from the often forgotten hardware of conduits and software technologies of search algorithms, tags and share functions.

These features then begin to exist simultaneously to support and push against the bereaved, to support practices of loss and simultaneously work against them. The contagion of these cascading and unfolding phenomena is moving and emerging as an ongoing and unfolding set of arrangements, across bodies, elements, practices and productions that gesture towards the multifaceted nature of networks. In the next empirical example, I want to turn towards presenting empirical phenomena and thinking with the material in order to consider the elements and people invested in these types of content, in capitalising on these types of contagion and cascading events.

### TRENDING #DEATH

The shifting nature of the news across digital networks, including its more recent linkages to social media and digital marketing, are an inherent part of the understanding of what emerges empirically within this section. News consumption is considered to have changed considerably within recent years, particularly in relation to accessing and engaging with news content due to the emerging 'digital news environment' on digital networks by news consumers in the west (Reuters Institute for the Study of Journalism, 2014; Pew Research Journalism Project, 2011). News content and unfolding stories have become a source of content for user-generated sites and social networks, meaning that there are a wide-ranging number of digital networks that news consumers can access, often freely and in what is deemed to be 'real time', as opposed to traditional media and news outlets, such as broadcast and print media. This has resulted in news outlets not only fighting to secure revenue streams but also to catch people's attention (Reuters Institute for the Study of Journalism, 2014; Pew Research Journalism Project, 2011).

News stories are a widely accessible resource online through search platforms such as Google, Yahoo and Bing, which can be found offering the latest news stories 24/7. Social networks have also become strong, trusted presences in how digital news content is being accessed, shared, liked and linked to, with Facebook, YouTube, Twitter, Google+, WhatsApp, LinkedIn, Instagram, Pinterest and Reddit all being flagged as popular

sources<sup>39</sup> (Reuters Institute for the Study of Journalism, 2014). Individual personalities and independent reporters have become key and trusted sources for news content that people have become loyal to rather than just being reliant on traditional news organisations. Notably, these independent and/or individual identities operate profiles across social networks, through Twitter accounts, Facebook pages and Google+ profiles that support them in reaching out to audiences.

Like networks, the digital news environment has, therefore, been described as a 'democratisation of distributions' away from traditional gatekeepers of news or mainstream news press organisations (Ingram, 2014). Yet the technologies and networks involved in distributing emerging newsworthy content and stories online have been noted to not work equally. There are differences between the ways key platforms handle the news content that Bing highlights on social networks. For example, Twitter is referenced as a platform where 'breaking' news can occur. This is partly due to its microblogging and importantly algorithmic design, which is thought to be based on who a person follows and chronology. Whereas Facebook's limited newsfeed algorithm is thought to be dictated on what the company curates and deems as newsworthy (Olmstead et al, 2011; Naughton, 2014; Ingram, 2014).

This changing digital news environment has become of interest to digital marketing, search engine optimisation [SEO]<sup>40</sup> and public relations [PR] as a set of fields. In the industry, they are increasingly sharing remits across creating, developing and publicising brand presences across search and social media networks. The industry term used for specifically leveraging mass interest in topical and breaking news stories online is known as 'newsjacking'. Popularised by David Meeman Scott,<sup>41</sup> the practice of newsjacking draws on the much older (often unnamed) technique of drawing off the popularity and content of mass and broadcast media in order to draw attention

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39 *Patterns of access and use vary across different countries and regions, with the example of WhatsApp being an important network used in India during the recent Indian elections (Barot, 2014).*

40 *SEO, as defined by Search Engine Land, 'is the process of getting traffic from "free", "organic", "editorial" or "natural" search results on search engines' (Search Engine Land, 2014). Moz considers it to be 'the practice of improving and promoting a website in order to increase the number of visitors the site receives from search engines' (Fishkin, 2014).*

41 <http://www.newsjacking.com/>

to clients or generate content that is topical, fresh and reflecting current trends in popular culture.

As an overall approach, newsjacking is considered to be a positive technique for digital marketing and overall brand awareness as it can help to build a quirky, memorable reputation. In relation to PR and SEO, newsjacking can increase a website's visibility and contribute to developing positive traits that link

into search engine ranking facts and contribute to

developing desirable search engine results. According to a leading online resource used by professional industry marketers Search Engine Watch, 'smart marketers know there is extremely high demand for breaking news stories and use this to their advantage' around online marketing strategies (Stetzer, 2013).

However, newsjacking is known to be a tricky and perilous business, one that is littered by examples that raise ethical and moral discussions about what types of newsjacking can be considered as fair game or out of bounds. These boundaries often relate to what digital marketing and SEO professionals identify themselves as. Marketing has repurposed the terms white, black or gray hat from their original use within definitions of types of hackers or hacker communities. These shades help professionals in the industry to identify exactly how they align their practices.

Mainstream Whitehat<sup>42</sup> or even Grayhat<sup>43</sup> marketers are known to follow a code of ethical practice and self-regulation that typically tries to avoid material that is considered highly controversial, distasteful, unseemly, unethical or immoral (including content or themes that potentially cause harm, negative impact or damage to reputations and trust). While popular culture is considered safe material for digital marketing firms, the more difficult material that involves large-scale socioeconomic or geopolitical political events, particularly those involving mass human casualties, are avoided. Whitehat

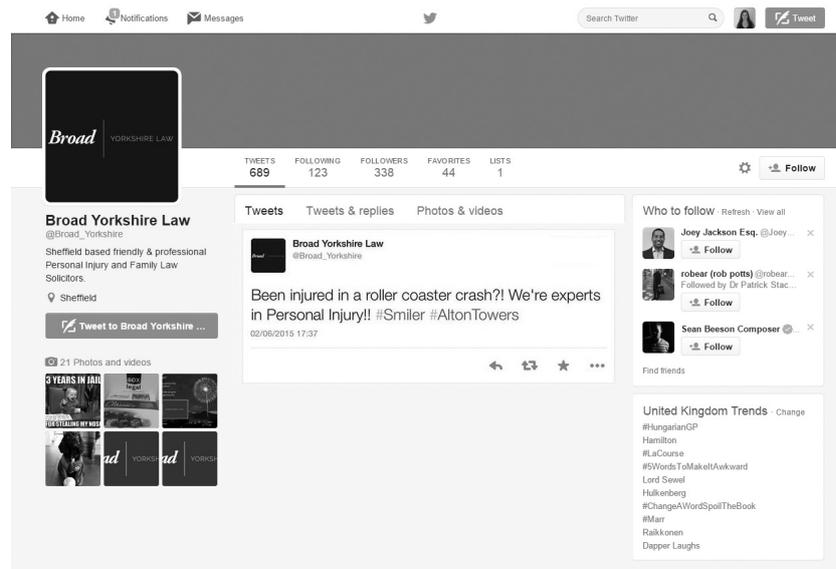


Figure 6.15 Margaret Thatcher: the Marmite PM. 2013. BBH Creative Teams

42 The term Whitehat refers to marketers that follow best practices and content guidelines, and as a term in digital marketing it can be annexed into a wide range of digital marketing sub-specialities such as SEO or SEM.

43 Grayhats are seen to be more risky and questionable in their approaches to their specialty practices or linked to particular agendas and ideals that maybe more politically orientated than commercial mainstream practices.

Figure 6.16 Recent capture of a news jacking that was poorly received



practitioners follow the mainstream and industry-wide culture of wanting to produce good, reputable and visible strategies that ultimately are a less risky approach for their clients.

However, the types of client that Whitehat practitioners work with are those that in themselves are not considered controversial or difficult to market for. Practitioners who are working with clients who may have products and services based around, for example, pornography, gambling, prescriptions drugs, plastic and cosmetic surgery or weight loss products, thereby highlight the difficult territories some marketers have to engage with.

SEO in particular struggles due to search engine ranking factors and guidelines that do work against these types of 'spammy' content and make gaining links and achieving high ranking very difficult. Alongside discouraging more questionable content related to spam, search engines regularly update guidelines that impart how SEO professionals should conduct their practice, an aspect that can draw derision in Grayhat and Blackhat communities, due to not wanting the big search engines like Google or Bing to be dictating and shaping practice.

To work around the guidelines<sup>44</sup> and the updating of the algorithms of search engines,

a range of Blackhat techniques (often frowned upon by Whitehat groups) are used  
<sup>44</sup> Examples of key speakers reaching out from search engines, such as Google's Matt Cutts, imparting what Google consider to be good SEO practices and thoughts on 'spammy' content: <https://www.youtube.com/watch?v=IFaP5huV5XI&feature=youtu.be>.

such as buying links, unsolicited email marketing, link exchange programs, spamming blogs, creating deceptive titles, buying followers and keyword stuffing. These tactics go against guidelines and written/unwritten codes and ethics that reputable industry aligns itself with. They are also considered unethical, possibly illegal and lead to penalties with regards to main search engines such as Google. In return, Google updates its algorithms to specifically address certain tactics that Blackhat practitioners have developed such as updating to 'penguin' and 'panda' (notably, they are black and white).

Blackhat professionals specialise in these and alternative approaches due to the difficulties that arise in using mainstream methods with difficult-to-market content. In return, there is good financial compensation that behind unethical and illegal techniques. While these activities may have similar goals and conversions in mind to Whitehat practices, they are situated around very different types of client whose services and products may not fit mainstream approaches and in themselves may be controversial.<sup>45</sup>

Within Blackhat circles, newsjacking is considered to be a way of tapping into topical, relevant material that is attracting widespread attention for these hard-to-reach groups. However, they approach news content with the opposite intentions of Whitehat marketers and instead deploy manipulative, deceptive and misleading practices. In this sense, Blackhat are seen to be the opposite of Whitehat practitioners. They capitalise on the nature of the news stories in order to meet a different, even malicious but still profitable set of conversions.

The detailed account I begin next involves observing the Blackhat newsjacking practices as they unfold. It is a broader pattern of Blackhat marketing activities that have been noted to emerge around high-profile events that involve mass casualties. Patterns of Blackhat activities have been previously documented around missing flight MH370, the

Boston marathon bombing, the Japanese earthquake and tsunami, Typhoon Haiyan,

<sup>45</sup> There are a number of forums and sites dedicated to Blackhat practices, which, in light of the way mainstream Blackhat is regarded, have been the best sources for looking into Blackhat practices, such as: <http://www.blackhatworld.com/> <http://www.blackhatunderground.net/forum/>.

the Sidney hostage siege and, more recently, the beach shooting at Sousse in Tunisia. Becoming aware of these activities and patterns occurring through the disappearance of MH370, I followed the unfortunate breaking story of the crash of MH17 on both Facebook and Twitter to see if any newsjacking activities emerged. I was specifically looking for tactics that would drive traffic or bring attention to any types of brand or service off the back of this tragic event.

## BREAKING NEWS

Malaysia airlines flight 17 (MH17) was a scheduled passenger flight that crashed on July 17th, 2014, after breaking up over the Ukraine/Russian boarder while on its flight path from Amsterdam to Kuala Lumpur. Assumed to have been shot down by a surface-to-air missile, the crash caused the death of all 283 passengers and 15 crew. The plane debris came down around Torez, Ukraine, which is a tense and conflicted political boarder due to the presence of pro-Russian forces and the ongoing Crimean Crisis in the region.<sup>46</sup> In the immediate aftermath of the disaster, gaining access and securing the crash site became an unfolding scene of tense negotiations. Within the first seven days, a range of news sources not only followed the unfolding story of a second Malaysian airplane being involved in a crash but also documented the controversial looting and removal of valuables that began within hours of the crash. It became known that local residents, armed separatists and journalists were able to walk around freely amongst the unsecured debris, bodies and wreckage, in a scene that was described as both a 'butchers yard' and 'hell'<sup>47</sup> (Deans, 2014; Waldron, 2014; Grabovo, 2014). Stories of the seeming desecration prompted Ukraine's National Security and Defence Council spokesman, Andrei Lysenko, to confirm reports that people were not just handling debris but heavily looting the crash site for valuables, particularly focusing on cash, credit cards, passports, mobile phones, cameras and jewellery. Through Facebook, Ukraine's interior minister requested that bereaved families cancel credit cards and the Dutch prime minister, Mark Rutte, released a statement to say:

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<sup>46</sup> *The Crimean Crisis is an ongoing dispute over the control of the Crimean peninsula between Russia and Ukraine that unfolded in February, 2014, in the aftermath of the Ukraine revolution.*

<sup>47</sup> *'This is not a disaster. It is Hell' (Grabovo, 2014).*

I am shocked by the images of utterly disrespectful behaviour at the crash site ... There are people fooling around amongst the debris with personal and recognizable items of the victims. This is utterly disgusting.

This intense initial news of the crash was soon followed by stories that surrounded the securing of the crash site, looting and, ultimately, speculation on the cause of the crash. A range of media outlets and independent journalists reported on trending #MH17-related material such as satellite images that eventually went on to become Internet memes (BBC News, 2014; Shevchenko, 2014).

I first connected with this story in the immediate aftermath of the crash. Malaysian Airline tweeted on July 17: 'Malaysia Airlines has lost contact of MH17 from Amsterdam. The last known position was over Ukrainian airspace'.

This tweet was retweeted and became part of my Twitter feed in the hours after the disappearance of the aircraft. While watching the news stories discussing the confirmed crash unfold, a Twitter spam campaign started shortly after MH17 has been reported



Figure 6.17  
Announcement  
on twitter

missing. Mixed amongst the condolence messages, prayers for victims, speculation and later graphic images was a mass of spam content that could all be coherently channelled together through the hashtags related to the event or #prayfor. By following the Twitter hashtag feed, I observed this occurring across a number of languages that included Malaysian posts.

Those posts that I could follow in English had shortened URL links that led off to masked or hosted links that redirected to sensationalist magazines. Others directed the viewer to a considerable number of provocative images related to pornography sites and also text-based posts that linked to gambling sites. Some tweets were observed to be posted

multiple times by different accounts, with identical content and links to external pornography sites. There were also examples of tweets written in garbled English that seemed suggestive of text that had been scraped or deployed by social bots but



Figure 6.18 Advert for pornography on Twitter

through correct tags, which had been placed into trending tags on Twitter.

Finally, I encountered a range of tweets that had been cleverly and deceptively written. These tweets claimed to be ordinary posters who had links containing genuine footage of the crash, particularly in relation to footage of the aircraft being

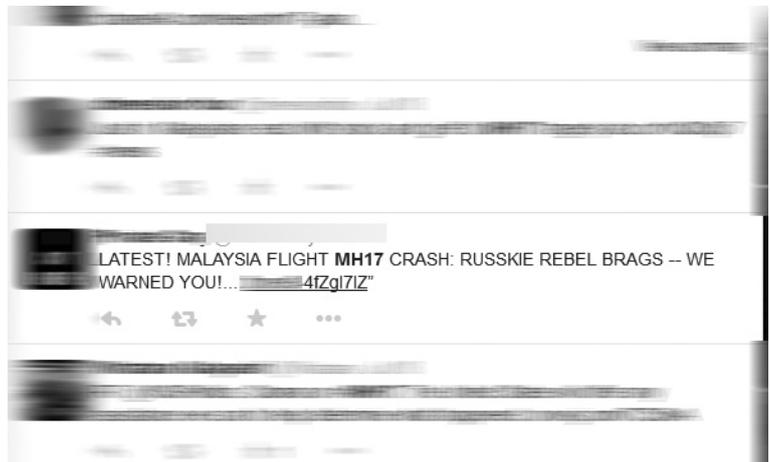


Figure 6.19 Luring links to fake content

hit or exploding in mid-air. Video links would never play, only redirecting people to a browser extension that could act as a method of delivering and encouraging people to download some kind of malicious payload.

There were tweets by other Twitter users warning of payloads of keystroke loggers. Equally, Twitter users would protest that the hashtags and news stories were being hijacked for what were deemed to be poor



Figure 6.20 Spam activities amongst messages of condolence

intentions and to share malicious links and deceptive content.

Although the story of MH17 appeared on Facebook's 'trending' section as the news story of the crash emerged, it did so at a slower rate. I believe this is related



Figure 6.21 Spam and luring links dominating much to the dismay of other posters

to how the algorithms for my newsfeed operate and also in relation to the slower emergence of breaking news on Facebook in comparison to Twitter. The interesting aspect to Facebook was not the newsfeed, but the way in which the network was appropriated when the passenger list of victims emerged after the crash had been confirmed.

After the passenger list had been disclosed, Facebook was used to host a number of identities of passengers. This included the creation of pages for children who had died



Figure 6.22 Lure video that wants to deliver a malicious payload

in the crash. However, these pages had not been set up by family members or friends as tribute or memorial pages; rather, they were created by Blackhat individuals or organisations using the names of the deceased in order to create a public page for

the dead that would be available in the Facebook search listings. Although they were relatively short lasting, it seemed that a pattern emerged around how these pages were set up. An image of the victim found on an online news source would be

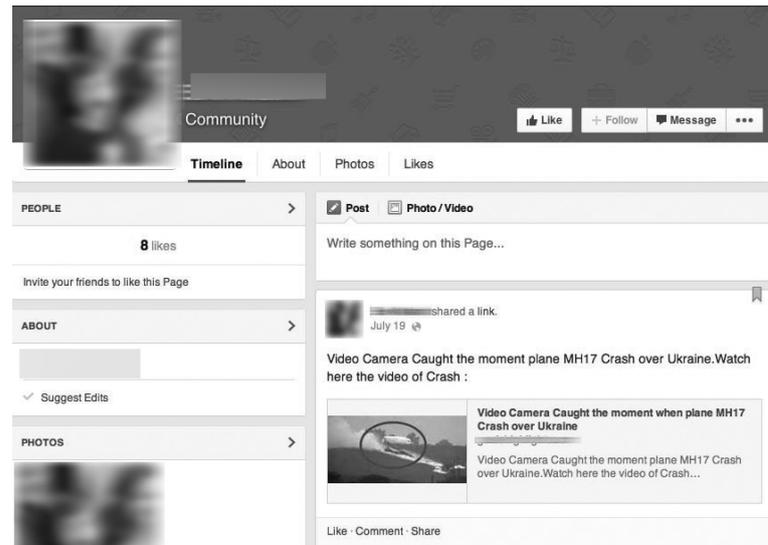


Figure 6.23 Fake Facebook profile

appropriated and set as a profile picture. The timeline of the community page would be black, aside from just one video and a link to 'footage' that supposedly caught the MH17 crash as it occurred in mid-air.

These pages would suggest that people may be searching for the names of victims online. Likewise, the videos titled 'Video camera caught the moment plane MH17 crashed over Ukraine' also suggest that there is an interest in seeking out photographs or video media that show the crash as it happened or the aftermath of the crash. Inevitably, however, the links did not lead to a video but to a series of pages that worked to lure people into imparting personal details, particularly using the scam of needing to verify age in order to access the promised content. Saturated by advertisements for gambling and pornography sites, these pages would also try other tactics after details were provided, such as encouraging visitors to download video players or updates for video players. While the media discussed how families of the victims felt compelled to close down official Facebook accounts, those that persisted began flagging the presence of fake pages that were emerging.

While tweets were archived and Facebook content was removed, variants of the videos have survived on YouTube. Although production is crude, their lure is always a very well-made photo composition of the crash and headers or titles that hold the

promise of lurid footage. Interestingly, not only have these videos survived, they have also come to list high across Google search listings. These suggest that, at the time of writing, Blackhat SEO have managed to bypass algorithm updates and capitalise on Google's



Figure 6.24 Distressed and angry family

ranking structures by using YouTube as a way of building deceptive and misleading content that lasts. Keyword stuffing, a technique generally targeted and penalised by Google, seems to be a feature present in these video descriptions. Repeated or garbled key words can be seen alongside groups of hyperlinks that contain different links to pornography, gambling or prescription drug sites.

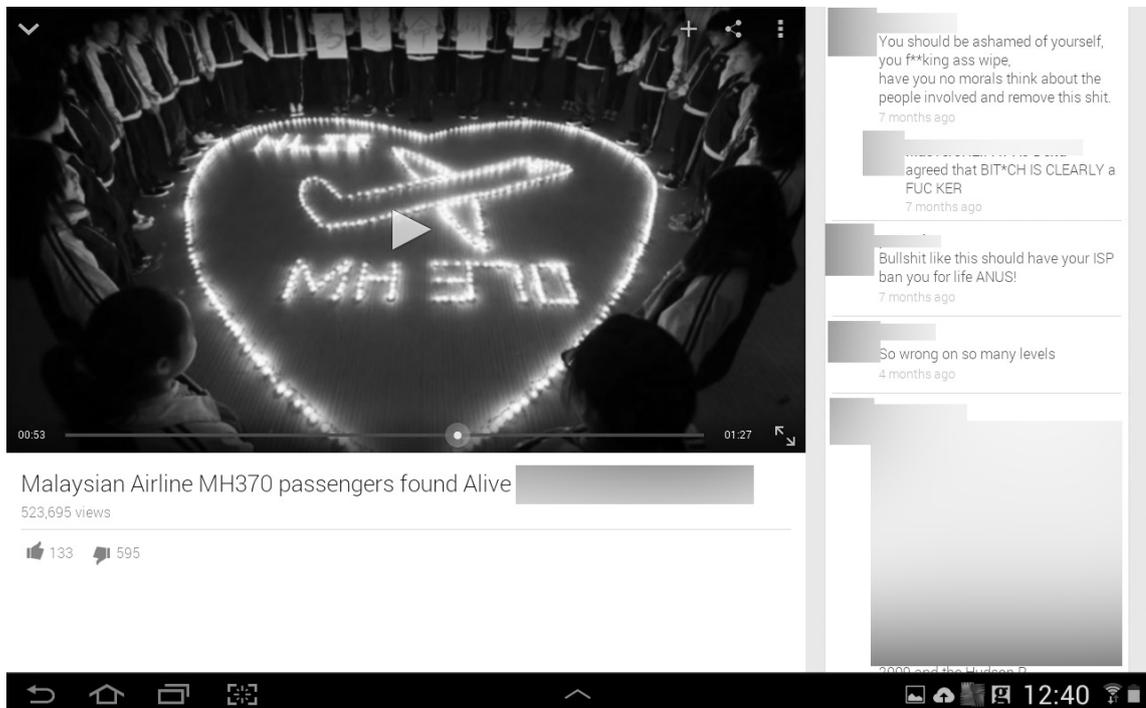
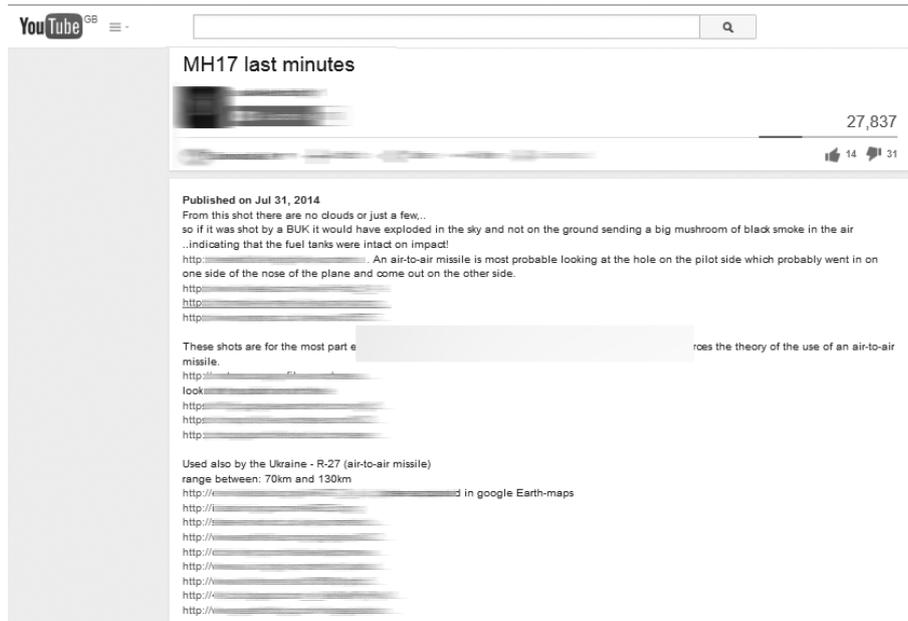


Figure 6.25 Distressed and Angry Public. The image above is taken from another recent flight MH 370 and I have used it to illustrate that it is an established practice

Figure 6.26 YouTube content describe bas being filled with 'keyword' stuffing in order to capitalise on the search rankings



These videos are not well received by YouTube visitors, either due to their deceptive nature or the tense debates around taste and decency. Yet these videos are multiple and also highly visited, with visitation ranking into the millions across certain videos. A tension is revealed between leveraging on the interest and desire for these types of material and how this is at odds with public perceptions of their presence.

## REFLECTIONS

Through this empirical account we are again introduced to a complex range of elements and relations at work within a complex ecology of loss, similar to that which we saw within the first empirical account. Similarly, I have shown that the transgressive practices of Blackhat SEO and digital marketing practitioners can begin to upset and not support people affected and having to face difficult losses.

Within this account there is a range of elements and practices that gesture towards the multifaceted nature of networks. As, in the previous examples, we saw the tension in arrangements being capable of working against the bereaved, we now see these similar arrangements being used to lure in the public and further capitalise on these kinds of graphic content and curiosity. In terms of specific practices, I coded multiple examples

of click fraud,<sup>48</sup> scraping content, sock puppets,<sup>49</sup> cookie stuffing,<sup>50</sup> URL redirection,<sup>51</sup> data gathering, keyword stuffing,<sup>52</sup> cloaking of text,<sup>53</sup> pop-ups and leveraging the trust and authority of social networks. These are aspects I have come to recognise from my own experiences and from drawing on insight and expert knowledge. Otherwise, being able to see them, give these practices a name and understand their different tactics would not have been possible.

Investigating these different practices and the Blackhat figures potentially working behind them, in turn, revealed a large industry deliberately working outside of guidelines and best practices. Rather their operational style as practitioners lies within the deceptive and manipulative approaches that leverage morbid curiosities and the ability to drive traffic from trending and topical themes surrounding death. There are clear financial rewards when this works, even though these practices are directly capitalising on the dead and the bereaved families.

These insights not only allow us to think about the public nature and accessibility of this content but also how thanatosensitive design is only one form of practice interested in this ecology. There are multiple other practitioners, including designers, who may identify themselves with other values, agendas and be engaging in practices that are working towards creating different types of arrangement.

I uses these practices to begin thinking about the practitioners and numerous other designers, developers or originators that are engaging in practice in ways that overlap, support and resist each other. I have appropriated the term 'originators' from Mackenzie (2006), who uses it relation to the numerous practitioners and makers that may be found operating around software (Mackenzie, 2006). I think it serves to situate the designer as one figure amongst many. As a term, it prompts designers interested in

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48 Click Fraud techniques explained: <http://archive.wired.com/wired/archive/14.01/fraud.html>.

49 Insights into online sock puppets: <http://www.wired.com/2014/07/virtual-unreality-the-online-sockpuppets-that-trick-us-all/>.

50 Cookie stuffing explained: <http://www.esrun.co.uk/blog/cookie-stuffing/>.

51 Understanding redirects: <https://securelist.com/analysis/57924/redirects-in-spam-2/>.

52 Google's Matt Cutts explains keyword stuffing: <https://www.mattcutts.com/blog/avoid-keyword-stuffing/>.

53 Cloaking or hiding text explained: <https://support.google.com/webmasters/answer/66353?hl=en>.

thanatosensitivity to think through the other figures that might be practicing, like the Blackhat marketers, SEO practitioners, malware developers, communication designers or even copy writers.

## TO SHARE AND TO TAG

When I chose to write the empirical findings it was important to give an insight into the stories of loss and events as they occurred chronologically. However, amongst these human stories and contagion events, it is important to draw out how the network elements involved are not passive. Rather, there are databases, servers, clients and interfaces that are responding, engaging and shaping how these events unfold. Therefore, in this final section I am going to move in closer to the material and consider in some detail the practices and elements that lay at the heart of the phenomena that I watched unfold.

When share buttons are selected or tags, hashtags and @tags are written in around photographs within Facebook, Instagram, Twitter, Tumblr and WordPress, certain actions would start, content would be displayed, collated, become connected and laid out in particular ways. These features were not just responding to what people were doing, but actively shaping how we see, engage and think about the remains at hand.

In the case of the photographs of the victim being uploaded to Facebook, depending on Facebook account settings, tagging in a name could place the content onto another profile, including a picture of the deceased onto her own profile. Similarly, sharing the image could mean that it would be placed or be awaiting approval on other people's accounts. Both sharing and tagging make content become more become visible across a wider newsfeed.

Facebook's news algorithm, which is involved in how data remains are visible on newsfeeds, is something that is always undergoing change. Facebook does draw attention to certain of its new algorithm features, rules and protocols that are rolled out every year. As it is proprietary and, therefore, not available for scrutiny, I cannot say

how it would have operated in our two examples. I do know, however, that Facebook confirmed changes to its 2015 algorithm design. Prioritising certain friends' content, how likes are counted and the time spent viewing stories have all been new factors built into the current and latest algorithm.<sup>54</sup>

Popularity, according to Facebook's press release, has been an important facet for a while that is taken into account within algorithm design. Content with a lot of likes and comments is treated favourably. The algorithm reads this activity as a factor for higher placement consideration and uses it to determine how prominently the content is displayed on newsfeeds. Similarly, Facebook posts that receive a high volume of likes, comments or shares within a short time frame are also considered to be favourable factors that the algorithm 'likes'. In terms of the graphic post mortem picture, these factors will work in the same way on more mundane everyday images, quotes, cat pictures and so forth. The exact context of the data and how it is read and valued by the human viewers is an entirely different matter.

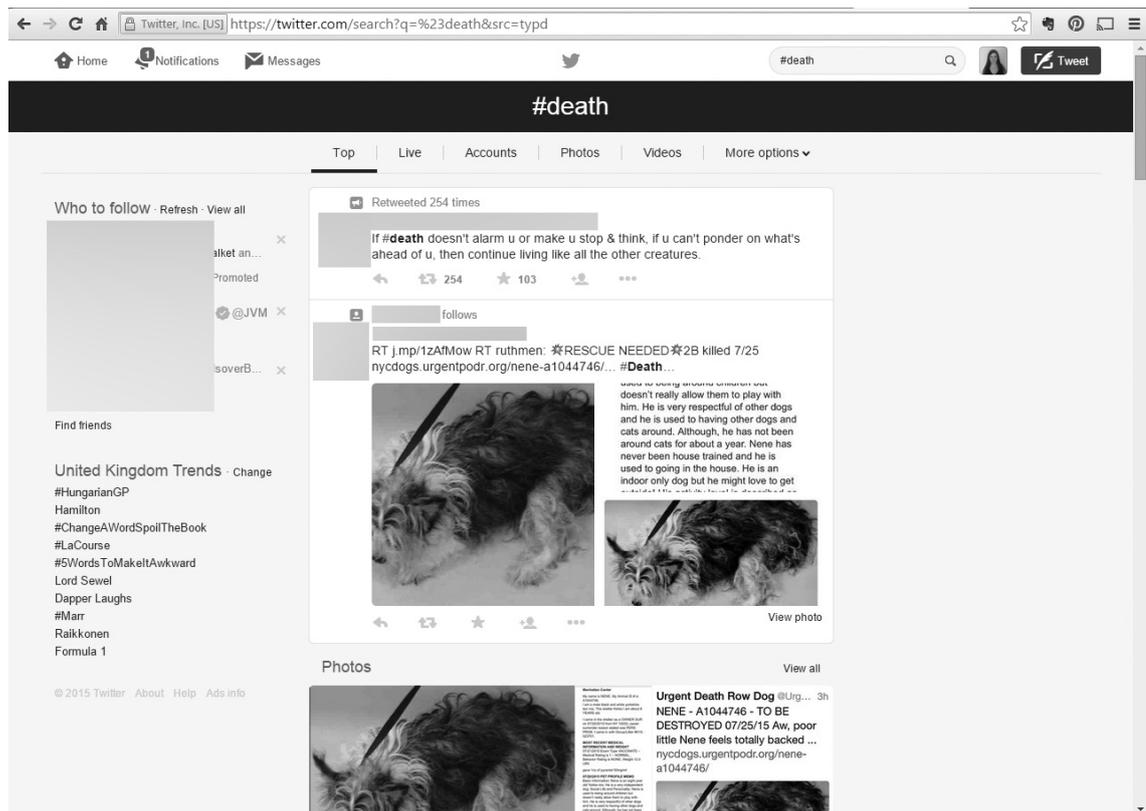
On Twitter, the use of @tags can highlight and draw attention to the content of friends or the wider network of Twitter users depending on who is linked in. Therefore, tagging a name on Twitter offers a similar mechanism to Facebook even if the way in which it is done and the hidden proprietary technical details of how it is done will undoubtedly differ. On both Facebook and Twitter, notifications are likely to be made dependent on settings and devices, such as notifications of activity within the web interface, through to email notifications and mobile push notifications. These notifications then become part of the mechanism behind people finding the materials. Already, then, we can see that Facebook and Twitter are not just the passive holders of content but, through developing mechanisms, are deliberately working to catch attention and bring in visits.

What these details draw attention to is how the algorithm design expects content to be about holiday photographs, pet photos and more mundane or humorous material. It

does not expect it to be graphic or distressing material that is shared amongst networks

<sup>54</sup> Both Facebook news and new sites cover these ongoing changes to algorithm design. For a recent example: <http://www.forbes.com/sites/amitchowdhry/2015/04/23/facebook-changes-news-feed-algorithm-to-prioritize-content-from-friends-over-pages/>.

Figure 6.27 Twitter Interface displaying 'default' results on #Death



in which the bereaved are involved. It is when potentially vulnerable people who are invested in or connected to this material that the difficulties arise. Sharing, liking, commenting or retweeting means that graphic or disturbing material becomes read as 'popular' and, therefore, more visible. An image then becomes read and its value

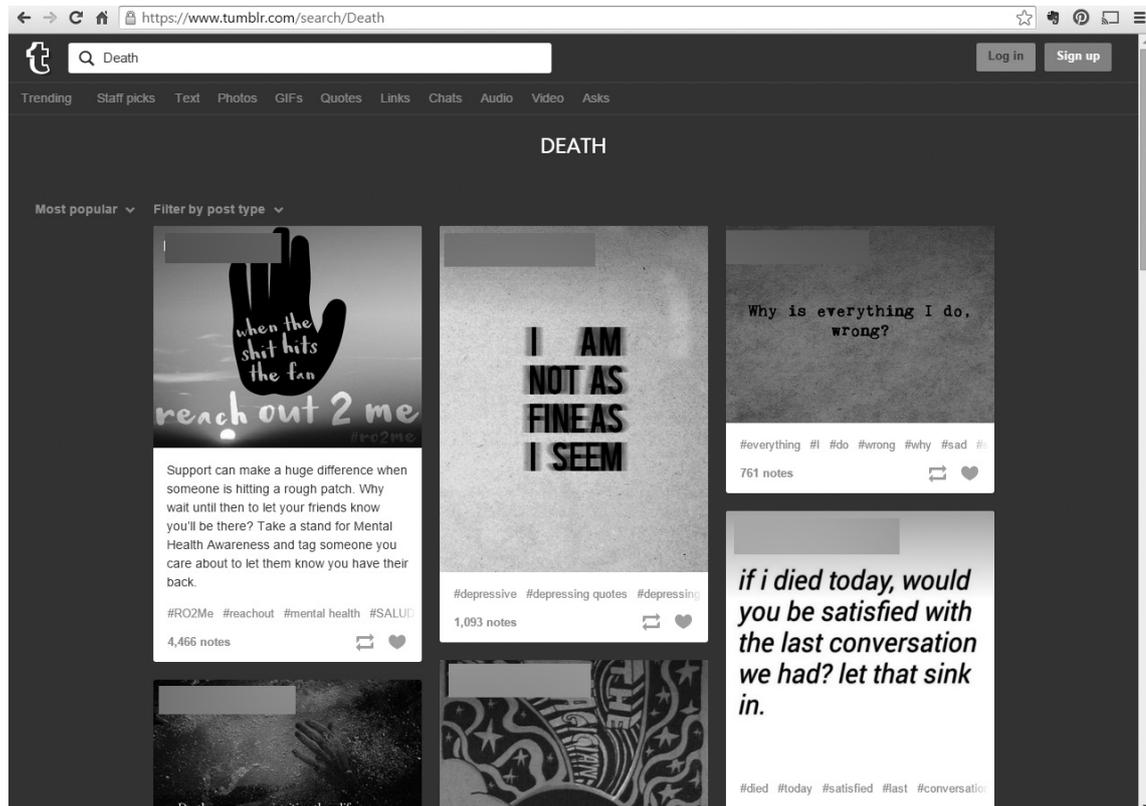


Figure 6.28 Tumblr Interface displaying 'default' results on #Death

in the network is particularly determined by the popularity that continues to push forward remains that can become part of the complex issue behind their mobility.

Therefore, the sharing and tagging of content brings awareness to the factors built into the design of proprietary programmes and algorithms. Thankfully, the SEO industry discussions and literatures are fairly sure that certain characteristics stay consistent. So alongside popularity mattering in algorithm design by big firms like Google, popularity sits alongside other ranking factors such as relevancy, quality and quantity. Popularity and relevance are features that can be closely observed through interface design and return of search results. For example, on Tumblr, tags help to categorise and theme content and bring together a wider array of material. These tags may relate to people or types of media that can be displayed via 'popularity' or 'recent' posts.

Similar to Tumblr is the use of hashtags on Twitter to help categorise and define for more nuanced and humorous labels. Hashtags become a way of finding and exploring content on the Twitter network. These hashtags can be displayed in lists, themed by 'top', relevance or chronology. 'Top' again seems to relate to forms of interaction

and engagement such as favourites and retweets, which are factors used by algorithms in both networks.

Therefore, to share or to use mechanisms such as retweets, notes and likes and to begin theming, categorising and bringing content together through terms or tags that describe, identify

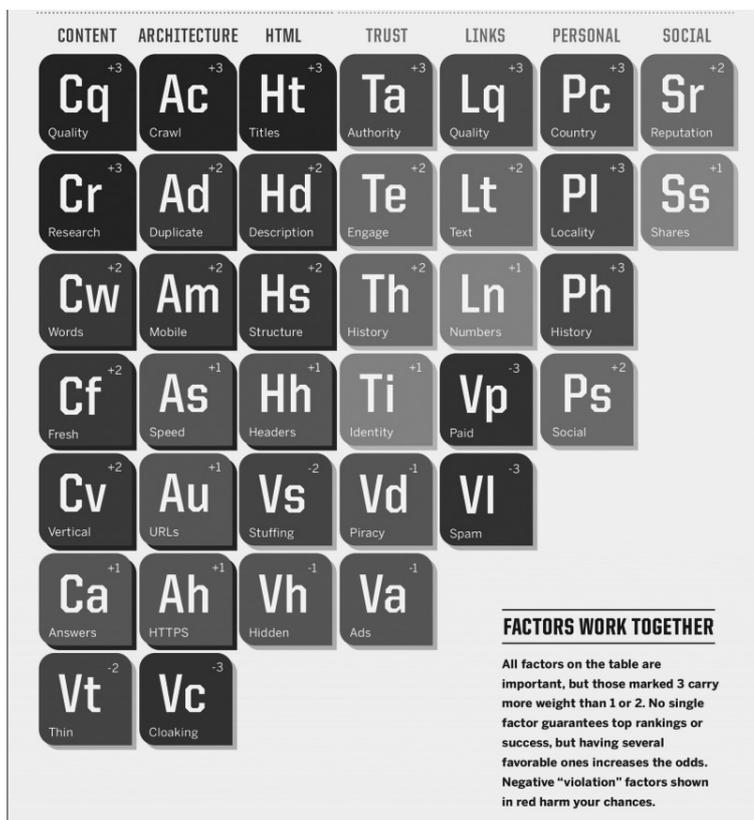


Figure 6.29 Search Engine Land periodic table of factors. Source <http://searchengineland.com/seotable>

and signify particular remains aids them in becoming findable and searchable. These relations and how they shape what people see are part of a broader collective of software and hardware storing, processing and uploading material that is handled through databases and software, which means it is presented to viewers in particular ways.

It is interesting to note how these themes of popularity, quality, quantity and relevance as examples of attributes are shaping how remains are sought and presented, and have been designed to work with a broad range of content. They help, on the one hand, to connect over terms related to bereavement and support practices, while simultaneously working against other bereaved individuals when remains emerge that have different investment and value systems at work around them. It is often not until they are seen as not working for a particular group that they are necessarily recognised as even being at work, shaping how people move and engage with remains online.

## CONCLUSION

This chapter opened by introducing the dark side of digital networks and the rationale for a shift in granularity. After this preparatory first section, the chapter then moved on to present two separate chronologies involving two different and difficult empirical examples. These opened to present a partial insight into the unfolding practices and activities that were implicated in the movement of remains. Unwanted by the bereaved, these remains circulated and persisted across a number of networks in highly visible ways that upset the families. The final section turned to draw attention to the practices of sharing and tagging, and the software and, specifically, algorithmic elements that are at work behind this kind of phenomena. I wanted to draw attention to a different logic at work around these remains, to highlight that the move to tag and share can lead to content being caught up and considered through a different set of factors such as popularity and relevance. This discussion gestured towards the inter-relations and the complicated array of network elements.

Engaging with this demanding empirical work helps to open a space for designers and

researchers to begin thinking about the ethically tricky and important 'dark' sides of networks that are missing within current accounts. It would be tempting to identify one element and single this out such as the human thanatophilia, practices of tagging, the ghostly victims or algorithms favouring popularity or the capacity to screenshot. I have instead tried to tell their collective story together. This is an intentional move to prompt thinking about the different relations and unfolding elements rather than attempting to focus on a single problematic source.

Along with the different considerations of diverse humans and non-living ghosts from the previous chapter, I want to now add into this frame the non-human network elements that have emerged. Thinking of diverse humans, ghosts and non-humans as part of a complex and interrelated ecology has important consequences for how TSD currently frames a situation of inquiry. Therefore, in the next chapter, 'When Designing Remains', I will consider what this ecology of humans, non-living and non-humans has to say on the practice of designing thanatosensitively for death.



# CHAPTER SEVEN

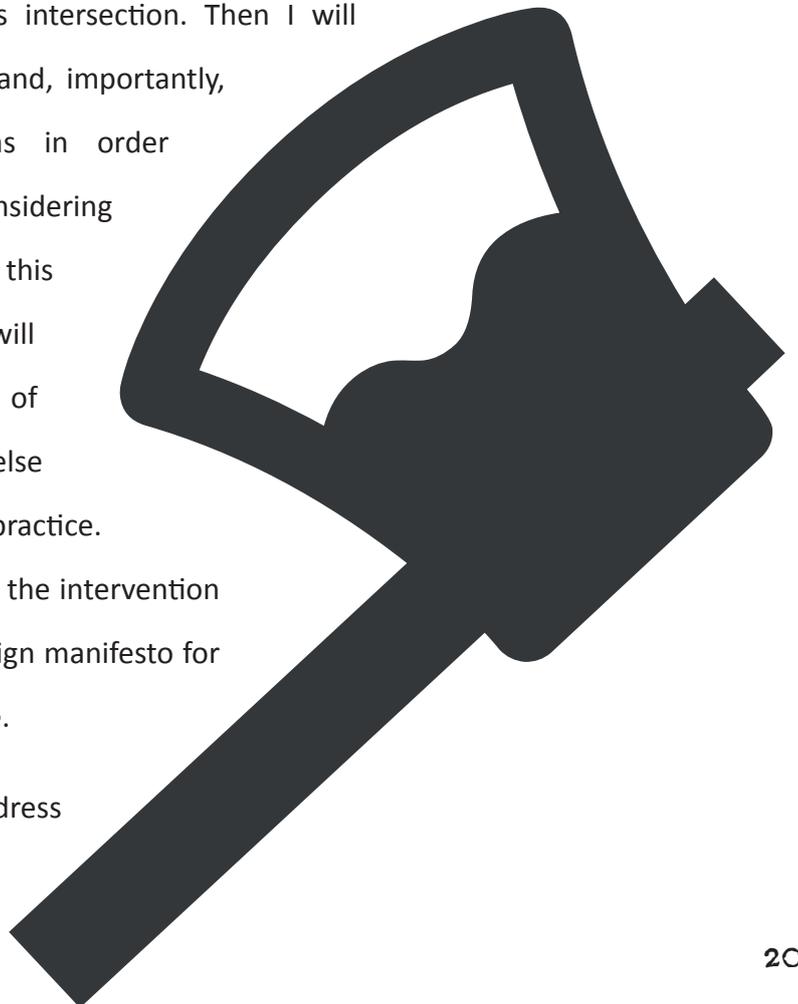
## WHEN DESIGNING REMAINS

**W**hat does TSD look like if we take into consideration the elements and implications that have emerged through the previous findings chapters? Reflexively exploring this question and the resulting ethicopolitical dimension is the focus of this final chapter. In this space, we are returning to the original questions in light of the empirical journey. We are considering how this journey has begun to reconsider TSD through troubling its commitments and notions of intervention within the agenda of designing thanatosensitively.

To set the scene for tackling this question, I will begin by recapping the purpose of the study and the research questions that set the trajectory of this doctoral project. Then I reflect on each findings chapter and what ‘thinking with’ and ‘caring for’ reading has uncovered in each. I will first address the broader findings that reach out and contribute to the Death and Technologies intersection. Then I will turn to consider the elements and, importantly, the ethicopolitical implications in order to begin the process of reconsidering thanatosensitive design. From this ethicopolitical landscape I will move towards outlining a set of principles to help rethink how else TSD could frame approach practice.

These principals are followed by the intervention of a design statement and a design manifesto for sensitive design at the end of life.

The chapter will then move to address



the limits of the thesis and the directions for future work. I explain the difficulties and limits of trying to decentre the human within a human-centred agenda. I emphasise how this thesis only manages to move towards more inclusive reading at the end of life. Yet these tensions and difficulties become a source of inspiration and designerly reflection, leading me to gesture towards future thought with the concept of speculative 'Posthuman design' (Kera, 2013). Finally, this chapter concludes with a summary of contributions, making clear what it is that I think this thesis has contributed to the Death and Technologies field and, more specifically, to TSD.

## RETURNING TO THE THANATOSENSITIVE AGENDA

I have been deeply sympathetic to the critical humanist thanatosensitive agenda and I have shared its commitments to supporting people at the end of life. However, due to my engagement with New Materialist philosophy, Science, Technology and Society [STS], New Media Studies and Critical Design Studies, disturbances arose that made me question if TSD could keep the commitments it was making to vulnerable people at the end of life. My concern about these commitments originated from questioning if TSD had an ethicopolitical landscape that was built on a dualistic and human-centred understanding of agency. If so, this frame and the simplistic notion of agency it draws upon may be underestimating the complexity and difficulties that lay behind locating a source for intervention.

Therefore, drawing from interdisciplinary scholarship, I began to question if 'thinking with' and 'caring for' an array of elements in a situation of inquiry could present a more complex ethicopolitical landscape. I wondered what this different reading could say about reconsidering TSD and its commitments to positive intervention. I turned these questions towards the empirical landscape of social networks online. As a new and still unfolding area of study, it offered gaps for new understandings and interpretations to emerge that aligned well with my 'designing with' political sensibilities.

Running as a series of cycles between 2011 and 2015, the results of this empirical work were collated and presented within the previous three chapters. Each empirical

chapter has dealt with its own theme, moving sequentially through loss, ghosts and networks. In each chapter has been the weaving together of empirical vignettes and material from data collection that have been framed by analytical insights and findings. This combination of empirical vignettes and discussion in these chapters opens a new situation of inquiry, one that not only brings forth the more diverse and agential human story of loss but also makes other elements visible and prompts reflection about the relationships between them. This was a deliberate move and an attempt to try to disrupt the human-centeredness of TSD through caring for the other human, non-living and non-human elements that are entangled within the ecology of loss.

Within the first findings chapter I focused on presenting the diversity of loss. I attempted to draw out the heterogeneity and messiness that had been missing within the contemporary spatiotemporal focus on Facebook. Rather than solely focusing on the emotional, affective and discursive dimensions, I tried to draw on the constellation of loss and a practice of understanding that invokes the material, histories and multiplicities of networks.

In turning to look at the appropriation of networks for loss, Chapter Four and the 25-year history touched lightly on a number of diverse practices with remains. These practices spanned a number of networks and moved across a linear timeline to finish with contemporary practices in social networks. The accounts I raised and the mass of practices they gestured towards trouble the presentation of the bereaved as a passive 'user' or just a consumer. Rather than considering the bereaved as users, the vignettes prompt a consideration of practices that are shaping and being shaped by elements and relationships in the network. Commitments to the non-living ghosts and people being formatted by network elements are present within these accounts.

People were creatively responding and reacting to these limitations in order to creatively find ways to support their individual needs. While these accounts depicted patterns, they also gave an insight into the personalisation and uniqueness of people's practices of loss. Therefore, the bereaved are a highly diverse and agential collective

of people, one that is extremely difficult to homogenise. This recognition begins to ask TSD to respect and pay attention to the specificities and differences at work, to commit to developing a richer situated understanding of the people it wants to work to support.

Within the second empirical chapter, I deliberately turned to consider the social lives of the dead through empirical vignettes and discussion presented through a framework of ghosts, manifestations and hauntings. References to the dead are made by both TSD literature and Death and Technology Studies recognising that the bereaved may wish to continue bonds with the dead. However, the depths of visibility and agency of these ghosts have been diminished through human-centred framings. Having the human element as the core focus of inquiry does lead to elements circulating and relating to this human centre.

The consequences of decentring the human and thinking with and caring for ghosts alongside the human elements is a more inclusive reconsideration of loss that allows the visibilities and agencies of the dead to come through. The implications of these findings firstly speak about how these complex social presences are demanding further and more nuanced consideration within our situations for research and design inquiry moving forwards. The obligations and abilities of the dead being able to reach back out into the flow of everyday life cannot continue to be overlooked. Secondly, these implications prompt reflection on what other elements are lurking around this human-centred framing, ready to be drawn out and cared for. In the case of this thesis, I turned towards the non-human elements found within the technological infrastructure of the networks.

The third findings chapter turned towards the dark side of networks and presented empirical vignettes and discussion related to when situations unfold that begin to work against the bereaved. This dark side of networks online opens a difficult but reflective space to capture the visibility of technologies that seem to increase and become heightened in these circumstances. I did this through a chronological

account that brought together different elements and practices such as sharing, tagging, thanatophilia, ghostly victims, other practitioners, algorithms, databases and interfaces. This collation was an intended move to work through the different relations and unfolding elements than focus on one source of interest or problematic source.

Therefore, alongside the ghosts of the Chapter Five that have become more visible and agential, other elements have also been able to emerge through a more inclusive reading that cares for the intra-relations. This consideration opens up a space where the different humans, including the bereaved, the non-living ghosts and the non-human elements of the network exist together within an ecology of loss. These findings chapters open an ecology of loss, and themes emerge that are of interest to the broader field of Death and Technology Studies as well as to the agenda of thanatosensitive design. Therefore, before I go on to discuss what the findings have to say for the thanatosensitive agenda, I will briefly discuss what they say to the broader field.

Firstly, to Death and Technology Studies, the findings chapters present practices online as much of a diverse, divergent and sometimes persistent phenomena as when they are considered in the current literature. These findings intentionally break outside the mainstream and contemporary spatiotemporal focus of Facebook to turn towards the messier constellation of loss online. Furthermore, these findings chapters do not abide by the existing distinctions in the Death and Technology Studies field between the topics of grief and mourning or memorialisation and digital legacy. These careful delineations between practices, discourses and the involvement of material remains are not replicated in these chapters as I want to take as seriously as possible the entanglement of the individual, collective, material, spiritual, psychic, social, aesthetic and the political (Eng & Kazanjian, 2003). The consequences of this approach to data collection, analysis and resulting chapters is a presentation of loss as a diverse and divergent nexus of doings and sayings with remains. In turn, these remains are not a static legacy of things left behind and abandoned, but rather a broader fluid collection

or arrangements created across different timeframes and networks. Paying attention to their movement was an important part of understanding the human, non-living and non-human elements at work.

Secondly, these findings and messier ecology of loss that opened up from this work were in part to my broader commitments and interest in decentring the human within this human-centred agenda. This decentring brings attention the commitments to the human that also lie within the heart of Death Studies and how that central human figure is the focus of scholarly attention. However, thinking with and caring for other elements that lie within a situation of inquiry can open out this framing in ways that, in the case of this study, support the dead. By drawing out these non-living presences, the non-humans in these findings have also become visible and agential. Their importance lies in how they open up a more complex view of loss outside of medicalised binaries, homogenised and disciplinary frames.

## TROUBLING ETHICO-POLITICAL IMPLICATIONS

Now that I have recapitulated the purpose of the research and discussed the findings in relation to the broader Death and Technology Studies intersection, I want to focus these findings specifically to address the TSD agenda and the ethicopolitical landscape.

The thanatosensitivity agenda and thanatosensitive design methodology emerged in response to the recognition that socio-technical systems were not being designed and developed with the eventual death of users properly acknowledged within their construction (Massimi & Charise, 2009; Massimi, 2012; Massimi, 2014). Drawing from a critical humanist tradition, TSD was presented as a non-prescriptive methodology that worked as a lens or reflective tool to prompt designers and researchers to consider the end of life (Massimi, 2010; Massimi & Baecker, 2011; Massimi, 2012).

TSD resisted following a prescriptive focus that would normalise or pathologically frame grief and loss with socio-technical design (Massimi, 2012). Massimi did not want design at the end of life to be approaching the bereaved through a problem/solution

focus (Massimi, 2012). His careful decision to not push out a prescriptive approach to 'bereavement support' was supported by my findings. Practices of loss online are diverse and divergent when we break out of the contemporary spatiotemporal focus of Facebook. The bereaved are busy doing things, as a nexus of doings and sayings, across a wide range of networks. These differences should not be diminished or placed across stigmatising or homogenising binaries of problem/solution or normal/abnormal framings. The messiness that emerges asks design at the end of life to be sensitive to the heterogeneity and the contrasts and tensions that are at work. Therefore, to design for bereavement is to become sensitive and responsive to the finer details, to the understated and sometimes elusive qualities that are at work.

It is from this point of synergy that the findings and reflective discussions within this thesis begin to deviate away from the TSD agenda and its human-centred ethicopolitical landscape. This point of departure starts with how differences are considered between TSD and my findings. Attending to differences in my findings relates to both the designer and the bereaved and to pay attention to the locations, histories and situatedness within a designer's approach to the homogenised group called 'the bereaved'. Furthermore, within this commitment to diversity, who or what is welcomed and differs. This study has produced findings through holding on to commitments to humans (and to the humanities) more lightly. Other elements, human, non-living and non-human, have been welcomed so that they are no longer invisible or positioned as passive presences within these accounts. Therefore, differences are not just different human elements in the situation, but also the designers and the array of other elements that can be reflexively drawn out and implicated for a situation of inquiry.

I consider the current invisibility of these elements and locations in TSD to be a result of the ethical and political commitments of TSD being human-centred. TSD does not recognise or attend to the non-living and non-human presences and agencies that have become visible through my findings chapters. Reflexively, my findings are asking designers to question this ethicopolitical landscape in order to pay attention to the

diverse and heterogeneous range of elements that are currently missing from the TSD frame. Reflexively, my findings are encouraging TSD practitioners to begin the political process of asking who or what is being included when it frames a situation for design inquiry. In the same vein, it is asking TSD to develop a more inclusive ethics of care in order to attend to those elements that have been previously silenced or muted in the existing agenda.

Yet making elements visible and accountable is only part of the troubling of the existing ethicopolitical landscape of TSD that I have reflexively drawn out in my findings. In my study there were multiple examples to illustrate that elements are not just passive within the situation at hand but are actually agential in different ways. For example, the dead are seemingly reanimated by algorithms and the humans have their practices shaped by commitments to the dead. These phenomena unfolded and my accounts captured the relations across different elements, prompting a different consideration of agency that is a more distributed framing. Therefore, these findings are reflexively troubling how TSD understands agency and its capacity for change. This challenge to agency is a profound shift because it disturbs the human-centred notion of agency that is at the heart of TSD political and ethical commitments.

This human-centred notion of agency and its capacity for change can be perhaps exemplified through my understanding of the ways in which TSD would consider the difficult dark side of networks. Through a thanatosensitive lens, the difficult and dark side of networks is likely to be a situation that has arisen due to networks and socio-technical systems not being designed with the deaths of its users adequately in mind. To address this aspect, a thanatosensitive approach could move to identify the source of the problem and make an intervention or change in order to address the issue at hand. The confidence exuded in the literature that a design 'expert' can intervene comes through an assurance that TSD can locate a problematic source and place to intervene. The designer imbued with agency steps in to make a 'good' design intervention to an identified problem. Through a 'good' design intervention, the problem at hand will be

resolved.

This notion of thinking that design can identify the source of a problem, define exactly where to intervene and the consequences of doing so comes from a human-centred notion of agency that I cannot honour in moving forwards. Rather, my empirical work has been drawing out the multiple agencies and messy displacements from the outset. In fact, the recognition that socio-technical arrangements unfold in planned and unplanned ways is perhaps exemplified by the appropriation and displacement of the very networks that have been studied empirically within the previous three chapters. While TSD itself does recognise that networks like Facebook have been appropriated and displaced from design intentions, there is no discussion around that the consequences of these intentions and displacements in practice. Rather, without reflexivity, they continue to obscure the question of what these intentions and displacements are saying to the complex and unstable nature of design practice.

Further points of departure and trouble to existing TSD ethicopolitical understandings and its commitments to intervention begin when we reflect on how, in the unfolding arrangements, networks can be appropriated to both facilitate and block inclusions. Networks can be appropriated and their 'functions' and capacities can equally work to support some bereaved people or, as we saw in Chapter Six, they can begin to work against people. This speaks about the multifaceted way networks can emerge and unfold in arrangements. TSD does not discuss how designed socio-technical systems can create contestations and collaborations at exactly the same time. Its ethicopolitical landscape, therefore, does not frame itself as a practice facing a hugely complex and unfolding ecology. Nor do its claims speak about making modest interventions that frame design more humbly in relation to this unfolding ecology. Rather, its sense of politics lead it to make claims of practice as a stable and even predictable transformational endeavour that, if done well, can have a positive impact.

Therefore, the TSD agenda is making promises to care and political commitments to change, which, while from good intentions, are not engaging with the emerging

and unfolding ecology that is continually shifting and transforming around practice. I would argue that TSD is making promises that are difficult to uphold. In TSD's defence, the more reflexive and complex ethicopolitical landscape that I am gesturing towards comes through opening up situations of inquiry from which to reflect. Long-term studies that open a space to do this kind of reflexive work were not present when TSD was first drawn together to bring attention to the area in the first instance. This undoubtedly affects how TSD was operationally drawn together and new studies will continue to draw attention to these issues as new empirical material emerges. However, recognising that the ethicopolitical landscape that TSD currently holds in esteem may transform in ways that work for some people and not others is a way of tempering the tendency to think of innovation in TSD while holding onto a more humble but altruistic sense of wanting to help.

In this section I have reflexively troubled and explored the key departures and differences that lie behind the TSD ethicopolitical landscape and agenda in relation to the findings of this chapter. I have done this to expose the divergences that have arisen within the current ethicopolitical frame of TSD. Responding to these divergences is what the next section is constructed from and I use these schisms to begin to reconsider what else designing for the end of life needs to pay attention to or consider moving towards.

## RECONSIDERING THE THANATOSENSITIVE DESIGN AGENDA

In my research questions I asked what a more complex ethicopolitical dimension would say about designing with thanatosensitivity and TSD commitments to positive intervention. In this section I want to draw out the core messages that have arisen when bringing together the divergences and complexities between my findings and TSD.

Overall, I want to reconsider design at the end of life as a responsible practice for sensitive contexts. This 'responsible' label signals a move to acknowledge the complex set of relations and how these fundamentally affect the capacities and claims that designing sensitively should make. Attending to these specificities and relations is

where this notion of being responsible lies, using John Law's phrase 'tinkering' within an unfolding situation rather than making bloated commitments and impossible promises (Law, 2011a). It is from this more humble place that consideration of how design can be more sensitive to the end of life begins.

#### BE WILLING TO APPROACH THE MESS

Thanatosensitive design is facing a diverse constellation of loss within networks online. In combination with the dynamic interrelations between human, non-living and non-human elements, these are prompting a reconsideration of design at the end of life that is willing to engage with the messiness and trouble. This engagement with the mess is a different way of thinking of caring.

Rather than caring with a sense of hubris, the labours of care become more visible when having to pay attention to the specificities, relations and flourishing between different elements in the mess. This care is a more political and transformational process because to 'care for' means to ask who or what is present. Attending other silences or passivities of design can inclusively work to pay attention to those humans and non-humans whose voices and concerns have been previously less valued within thanatosensitive framings.

#### BEWARE OF THE CRUEL OPTIMISM

Since highlighting the optimistic<sup>55</sup> nature of design within the literature review, I have been concerned with how this apparent optimism within design has become reflected in the TSD agenda and how design approaches designing the end of life. Empirically, when we look at a 'thanatosensitive' situation unfolding, we are getting an insight into when design and its intentions are become displaced and interpreted in often dynamic, unexpected and unintended ways. We see this when networks such as Facebook or Instagram become folded into the end of life, even if that was not their original design intention. We also see it when certain features become appropriated and displaced in unusual ways.

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<sup>55</sup> In the literature review I highlighted how Dunne and Raby claimed that design's optimism caused it trouble. This trait has also been flagged by Kolko (2013) who discusses the optimism of sociotechnical design (Kolko, 2013; Dunne & Raby, 2014).

These insights prompt us to think about how even technologies that are designed for end of life cannot expect to operate predictably or, importantly, as designed. This is not bad design but rather the deeply unstable nature of design practice that we are working with. Yet our ‘affective attachments<sup>57</sup>’ to progressive and inherently better socio-technical futures keep prompting design to make promises that we cannot keep because we cannot know the results of our interventions (Berlant, 2012). I want to claim that these ‘affective attachments’ are ‘cruel’, both to ourselves as designers and also in terms of the promises that we are making to potentially vulnerable people at the end of life (Berlant, 2012).

So while I share the aspirations of wanting to make the world and the end of life a better place, I believe that caution is needed when embracing the ‘inherent optimism’ of design and using these potential utopian framings as a lens through which to view design as having more capacity for change than it actually does.

#### BETTER FOR WHOM?

In thinking about this desire to put things right for people, Professor John Law invokes the figure of Englishman Sir Thomas More, who was the first in the western traditions of thought to write about a better world (Law, 2011a). Law discusses how Sir Thomas More’s notion of ‘utopia’ inspired a body of work around social, political and economic utopias (Law, 2011b). As idyllic visions, these utopias are typically places where humans become able to ‘perfect’ both themselves and social order through striving and achieving a kind of utopia (Law, 2011a). What Law reminds us is that we need to be cautious when driving towards some kind of progressive and perfect place. While it may seem to be progressive to move towards a better and perfect vision, we have to remember that one person’s vision of perfect is another person’s idea of disaster (Law, 2011a). As Law states:

The world has a nasty habit of being more complicated than is imagined by those who seek to put it right. It has a nasty habit of escaping our schemes to make it better. It

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<sup>57</sup> *Cruel optimism is a term I have borrowed from Berlant (2012), which she uses to refer to the double-bind in which attachments sustains that people, can at the same time be a threat to them flourishing (Berlant, 2012).*

even has a nasty habit of biting back at us. Just when we think we have got something that is beneficial working properly, we discover that it is all going wrong (Law, 2011a).

Law's thoughts here work as an antidote and can serve to remind design that our good intentions and best designs are subject to the unpredictable and unstable nature of practice. By keeping in mind that some designs and schemes fold in certain people and work for them, excluding others, it starts to help a practitioner interested in designing for the end of life to think about the specifics, to ask and question, better for whom and for what? Thinking about this question might lead practices away from the TSD optimism of framing design interventions as universally progressive.

### REMEMBER OUR HISTORIES

I explained in the literature review that technologies do not just appear, they open a situation of inquiry, framing the interests, values and beliefs of a diverse set of stakeholders. This framing closes in and folds out different possibilities, choices and people as part of its socially situated processes (Schön & Rein, 1995; Introna, 2007; Stolterman, 2008). Remembering that these processes occur is important because, if we forget that this political dimension has occurred, it has important consequences for how we consider the technologies that are now present (Introna, 2007).

Primarily, it reminds us that socio-technical devices are not 'tools' that sit apart from or impact upon the social worlds and people, because the technical is already part of the social through being the outcome of a socially complex process for the sensitive end-of-life context.

It is important to remember that these design framings and closures occur because, when design forgets, it can become a very powerful way of denying and obscuring the political endeavours that have been at work (Introna, 2007). Presenting technologies as passive tools for social means hides away the design histories that have been at work. Being aware of the design histories and having an openness to discuss political and ethical dimensions of practice becomes an important part of keeping the ethics and the politics awake and alive.

## RESIST ONTOLOGICAL SEPARATION

Resisting the separation between the social and technical worlds as tools that impact upon each other not only keeps the ethical and political dimensions alive but also returns design at the end of life back to the issue of agency.

The tool view of technologies tends to place agency in the hands of humans to wield or, in the case of practice, in the hands of designers and their intentions. Therefore, agency becomes an anthropocentric notion, similarly to the way it was reflected in the TSD literature review. Yet the empirical findings speak about a messy array of elements and a more distributed notion of agency at work. This different and distributed account of agency has been extensively discussed within the bodies of interdisciplinary literature that I draw from. As Introna highlights:

It seems clear that it is not feasible, given all the work that emerged from the STS tradition, and the philosophy of technology, to maintain a simple dualistic view of agency which claims that agency is located either in the human or in the artefact. It would be reasonable to say that there is a generally accepted view that agency is more distributed than such a dualistic view would suggest (Introna, 2014).

It is for this reason that Rod (2009) asked if contemporary HCI design theories on agency were 'outdated' even 'irrelevant' in light of contemporary scholarship in other traditions (Rod, 2009). I want to follow in the footsteps of Rod (2009) and Rod and Kera (2010) in order to question the role of agency in designing for the end of life as something that is located in either the human or the artefact. Due to the findings of this study, I believe it is important in moving forwards to begin considerations of agency that are ecologically sensitive and socially inclusive to the entangled co-dependences that are at play. In this space, design practice becomes sensitive to different agencies distributed within the ecosystem and rejects outdated notions of agency (Rod & Kera, 2010; Rod, 2009).

By embracing the relations and co-dependences that are play, design for the end of life can resist a human-centred notion of agency that creates an ontological separation between the human and technical worlds. While it can seem to be a pragmatic decision

to create this separation, resisting it ensures that sensitive design practices do not allow the important ethicopolitical landscape of political framings in design practice to become obscured or forgotten (Introna, 2007).

DESIGN STATEMENT AND MANIFESTO (ON PROCEEDING PAGES)



# SENSITIVE DESIGN STATEMENT

## APPROACHING THE END OF HUMAN LIFE DIFFERENTLY

Death Sensitive Design is a reflective practice which pays attention to the ethical commitments and political interventions into digital design at the end of human life. At this time people are increasingly drawn to online spaces where they find opportunities to remake life in the face of loss and trauma. In digital times many of these commitments or investments are expressed or played out via digital media.

Death Sensitive Design advocates that when Design practitioners approach what is thought of as the human-centred problem of a person at the end of human life, they need to consider the broader ecology of **GHOSTS**, **NETWORKS** and **HUMANS**. Death Sensitive design acknowledges humans but pushes to decentre them within this broader ecology.



**GHOSTS** are the social presences of the dead that reach out to humans by haunting the networks.



**NETWORKS** are the co-dependent collection of technical, social and material things that form a digital system. **NETWORKS** support and interfere with how the social presences of the dead live on.



**HUMANS** are the dying, the dead, the bereaved and the broader human public.

There is no clear binary between life and death. A human's digital death, social death and physical death are separate processes which do not automatically occur together.



### DEGREES OF GHOSTLINESS

There is a spectrum of life after digital death within **NETWORKS** which ranges from silence, decay, disappearance and deletion at one end and magnification, celebration, fetishization and reification on the other.



The **DEAD FAMOUS** draw public attention after death



The **DEAD SMART** are intelligently reanimated by network algorithms



The **DEAD HAPPY** are a positive presence in the lives of the living



The **DEAD SAD** are a negative presence which live as distressing ghosts



The **MISSING** are the dead that never live online

The dead can live on as more than one of these types of ghost as death gets tangled up in networks and generates different responses from humans. In this process the rupture of death radiates out in unknowable ways causing aftershocks in the network. Sensitive design is paying attention to these subtle and connected arrays of **GHOSTS**, **NETWORKS** and **HUMANS**



# SENSITIVE DESIGN MANIFESTO

A Sensitive Designer

faces difficult and complex issues

is situated

takes inclusiveness seriously

acknowledges the array of Non-living,  
Non-human and Human presences

is thoughtful and willing to scrutinise  
who or what is accounted for

makes responsible ethical commitments  
in raw Human circumstances

understands that things will escape their plans to

make things better

Avoids Hubris

What kind of designer are you?

[www.digitalloss.net](http://www.digitalloss.net)

## LIMITATIONS OF STUDY

To help me explain what I understand to be the limitations of this study, I want to return to the work of designer and philosopher, Denisa Kera, who I initially flagged in my literature review. It has been Kera's recent scholarship on designing for death (2013) and her collaboration with Rod (2009) around the theme of agency that have helped me define and understand the inclusive and human decentring limits of this thesis.

Within Kera's scholarly body of work critiquing the notion of user agency and design practice for death has been the developing concept of Posthuman design (Kera, 2013). To try to disturb optimistic user or human-centred framings in socio-technical design, Kera has begun to think about design's intersection with the end of life, scaled from individual deaths to cultural, collective, planetary and onwards to consider death as a force within the universe (Kera, 2013).

In her journal article, 'Designing for Death and Apocalypse: Theodicy of Networks and Uncanny Archives', Kera speculates about collective human extinction and our planet without the human species and turns instead to think about the other 'users', non-human, non-living or even alien, that will live on after we are gone (Kera, 2013; Kera et al, 2009). In this post-interactive and non-anthropocentric approach to design, Kera reduces design to the problem of theodicy.<sup>58</sup> Bad design in this approach would be any creation that does not relate to the ecologies and networks, the ecosystem and planet (she goes as far as transcendental entities) (Kera, 2013). She considers bad design to be 'egoistic, narcissistic, and anthropocentric'. Whereas good design is ecologically sensitive and sustainable and places the human within networks of relations and mutual dependencies (Kera, 2013). Kera argues that 'the goal of a good design not only as sustainability or some form of enhancement but also probing the limits of anthropocentrism and the possible post human future' (Kera, 2013).

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<sup>58</sup> For Kera, 'The obvious, teleological and theological connotations' of theodicy are 'less important than their actual consequences on our understanding of design'; rather, it is more important to consider 'design as a problem of theodicy, a process of justification but also doing justice, restoring meaning in a corrupt world by referring to a larger perspective' (Kera, 2013).

My reading of thinking with and caring for other elements within a situation of inquiry has brought forth a sense of inclusiveness, and prompted an approach to designing for death as a responsible, ecological and socially aware practice. In Kera's framing this reconsideration would be considered to be a 'good' frame. It is one that moves to decentre the human and open a more inclusive approach to sensitive design contexts. However, this thinking with and caring for would not be considered by Kera as a non-anthropocentric, nor would it be a move towards being Posthuman. Even though these notions to think with and care for are borrowed from non-anthropocentric and Posthuman theoretical places, there have been different choices made in regards to how Kera and I have held onto our commitments to humans (and to the humanities) when thinking about design.

My light touch of these human centred commitments has been undertaken knowing that I will eventually return 'home', to think about design frames in TSD differently, but will still crucially involve the sensitive context of loss and the bereaved as an important element in the design process. Therefore while attempting to decentre the human and to make ethicopolitical commitments of thinking with and caring for other elements, this ethical and political landscape is still intentionally anthropocentric and concerned with the broader ecology of loss.

What Kera's work helped me to reflect upon, was how a non-anthropocentric or Posthuman reading of thinking with and caring for a different array of elements would involve a more speculative Posthuman ethicopolitical dimension. I suspect that a Posthuman ethicopolitical landscape would not resemble my own, because my ethicopolitical relationship with the non-living or nonhuman others is always determined beforehand by me and my human value system (and is, therefore, anthropocentric). From the very outset, I have already chosen the framework of values that will determine the ethical and moral significance (Introna, 2014a). As Introna explains:

Non-human things are always and already, 'things-for-us'—in our terms. They are always already inscribed with our gaze—they carry it in their flesh, as it were

(Introna, 2014a).

To try to do anything more than an inclusive reading that decentres the human, would involve profoundly destabilising the human in my reconsideration of TSD. This destabilisation would occur to such an extent that I would lose the conventions and normative basis that underlie my own anthropocentric political and ethical concerns around the sensitive context of loss. Kera however, is not invested in thinking about design in relation to loss or the bereaved, and therefore her choices allow her to be more speculative in her own ethicopolitical framings. While other scholars like Kera (2013) and Introna (2014) are exploring ethicopolitical dimensions outside of the non-anthropocentric gaze, my PhD study was invested in an anthropocentric ethicopolitical dimension that was important to hold onto. Therefore, this thesis is an inclusive reading, one that moves to decentre the human in our framings, but is intentionally not a non-anthropocentric or Posthuman one, due to the broader set of ethicopolitical commitments that have been at work.

My move to think with and care for the different elements within a situation of inquiry has always occurred within a human-centred agenda and the human story of loss. This has resulted in a continual pulling and tugging between the different elements and how to engage and account for them while balancing the human story that contextualised and was my motivation for engagement. While I moved to allow other elements in and accounted for them, I did struggle to push the human story too far out of the centre of this ecology. It was a difficult balance, to push and see how far the human can be decentred out of this thanatosensitive design-orientated inquiry before loss and the agenda surrounding loss is troubled.

I think this need stay with the human story of loss while simultaneously trying to hold on to the human more lightly reflects my years of being disciplined by the humanities and working to produced user-centred designs. While I was keen to really push at the human-centeredness of framings, it was difficult not to get hung up and connected to the human stories that I was watching unfold. Similarly, approaching this entire

process as a designer, it was difficult to resist the temptation to begin thinking about practice and interventions, and to remain focused on longitudinally documenting and analytically opening up a situation at hand.

This was compounded by the privilege I detected within the thanatosensitive design agenda itself. I was aware of how thanatosensitivity is an agenda-framed particular kind of human backdrop. Typically, a privileged western human can have access to these types of network without necessarily having to face the critical and detrimental ecological costs for doing so. Conflicted by these tensions, I began to think of the humans who were missing from these stories, where would they be located, and what the ecological dimension of their stories would be likely to bring.

These lines of thinking were gesturing towards care and the consequences of networks, the flourishing of humans and non-humans alike who were not visible in the unfolding story. Similarly, my questions towards the end of the study began to take on a different resonance and ask, what might be the costs of current arrangements across the ecologies we are in? Is it ecologically sustainable? And if not, how can we be mindful and rethink our current ethical and political commitments within design frames?

These questions are well beyond what this PhD process could accommodate, but they have become the legacy of this process and reflect my own critical thoughts that began to emerge around the design of themes such as digital legacy and digital memorials. Interestingly, this ecological frame also connected to Kera's notion of the apocalypse and Posthumanism (2013), themes that I will return to in the afterword. First, I would like to succinctly summarise the contributions to knowledge this thesis has made.

## SUMMARISING CONTRIBUTIONS

As a practitioner researcher, I have emergently approached this inquiry through a cyclical engagement process that has a likeness to Participatory Action Research. Like the Participatory Action Research project, the desired outcome of engagement

in inquiry is both some kind of action or intervention alongside some knowledge contribution.

Therefore, the first contribution is a design statement and manifesto that live as a practice-based intervention both in and outside of this thesis. They are an important way of summarising what else designing for the end of life looks like and the important considerations to take forwards. These interventions become an important way to begin opening up a conversation about what else designing for death looks like with other practitioners who are not likely to have read this thesis. They may also work to bring disciplinary awareness to the topic of death in a design more broadly. These practice contributions are intended to be a positive and even polemic intervention that sits alongside the important knowledge that this thesis has worked to create and contribute.

Alongside this statement and manifesto, this thesis has made two different knowledge contributions. This first contribution I have made speaks to the broader Death and Technologies field. Firstly, it signals a different shift in perspective about how else loss can be thought of as an entangled constellation. Secondly, it contributes to the still emerging bodies of interdisciplinary literature around loss online. It does this by introducing a more diverse and divergent insight into the practices of loss, one I have intentionally moved to open up in order to explore the broader ecology of loss. This ecology, for the first time, includes the non-living ghosts, non-human networks and presences of remains within the nexus of the bereaved doings and sayings online.

The second contribution speaks to the mutually informative relations between research and theoretically engaged design practice for the end of life. By opening up a more diverse framing of loss, including non-living ghosts, and thinking about the complexities of non-human networks, this inquiry has gone on to prompt a reconsideration of TSD and, importantly, its ethicopolitical commitments. This reconsideration encourages practitioners to approach the mess, think about the specificities and situatedness and to reflect critically upon the kinds of optimistic promises that designing for the end of

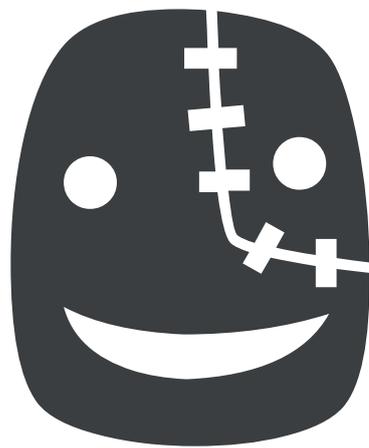
life engages with. This reconsideration asks us to resist the ontological separation or assumption that the technical and social worlds are separate realities that impact upon each other. Rather, by resisting or refusing to honour this distinction, a more nuanced and distributed framing of agency beyond the intentions of designers emerges. In this move, TSD is reconfigured to think responsibly about the doings and interventions within an ecologically and socially inclusive frame that is sensitive to the entangled co-dependencies at play.

## CONCLUSIONS

Alongside introducing a more diverse and divergent insight into practices of loss, this thesis has presented a broader landscape of elements and identified the ongoing entanglement of material remains within the nexus of doings and sayings. In thinking about these in relation to thanatosensitive design, it has prompted a reconsideration of thanatosensitive design that hopes to encouraged practitioners to approach the messiness of the situation, think about the specificities and to question who or what is within these framings and question the types of promise that are being made.

In this thesis, thanatosensitive design becomes reconfigured to think about doings and interventions within an ecologically and socially inclusive frame, which is responsible, sensitive to the entangled co-dependencies at play and interested in the specificities. This reconfiguration has been crystallised into a design statement and manifesto that hopes to engage other practitioners in thinking about designing sensitively at the end of life.

In my final move, I am now going to turn towards the afterword of the thesis and then pick up on the notion of the apocalypse and Posthuman design as a speculative but theoretical practice. This is what my work was moving towards when the main cycles of the thesis concluded and, therefore, I wish to use this afterword as way of thinking speculatively about future work. This afterword draws on my background as a digital designer and my speculative interest in the apocalypse to ask uncomfortable questions and present uneasy extreme scenarios to future trouble the human in design frames.

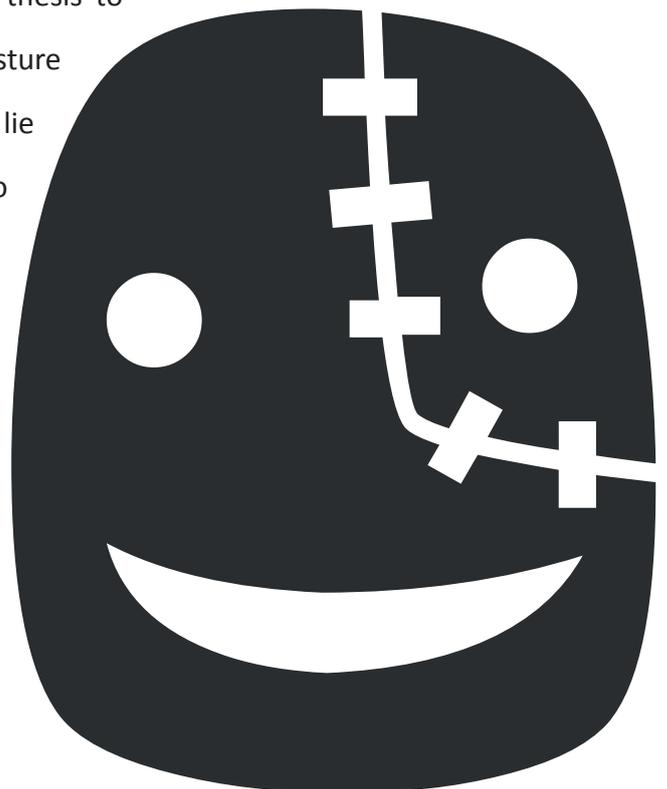


# AFTERWORD

## DESIGNING FOR THE ANTHROPOCENE

**A**fter encountering Kera's (2013) theoretical vision of Posthuman design and the apocalypse, I began to recognise my own human ethicopolitical commitments and reflect on where I had managed to take 'thinking with' and 'caring for' within the frame of human loss. However, in the process of reflection I also began to think about what my future work would look like if I was willing to loosen my hold on human users further. Reflecting on the choices I had made and thinking about future work felt important because my lenses to 'think with' and 'care for' came from a more non-anthropocentric or Posthuman theoretical place. In this place, the literatures I had engaged with were critical about what the effect of human centred commitments were doing in the face of planetary scale issues. Being aware of this tension prompted me to wonder what would happen if I had a space not connected to my commitments to human loss in order to speculate on what else designing for death could look like.

Rather than dedicating a section of the thesis to writing about this thinking and to gesture towards where my next cycle of work might lie in this more speculative place, I decided to explore this future work with a theoretical and practice-based afterword. This feels more in synergy with my home as a practitioner within critical design, and what it produces offers a speculative exploration of what the big challenges facing design can do to the designer's user-centred attachments.



## DEVELOPING A FUTURE DOOMSDAY DEVICE

Encountering Kera's vision of the apocalypse presented a non-anthropocentric and even Posthuman approach of speculating about extreme futures to think about user-centred commitments (Kera, 2013). I found Kera's contribution a source of inspiration because, not only did it trouble the scale of death, from human to planetary, but it also tapped into some of the sentiments I was beginning to have around the ecological sustainability of just thinking about a privileged human death.

Kera was exploring how to think about the human, but in relation to the complex socio-technical phenomena that moves beyond 'individualising' people's needs and goals (Kera, 2013). This need to move beyond human-centeredness prompted her to think about non-anthropocentric positions and develop her thesis towards Posthuman concepts for design (Rod & Kera, 2010; Kera, 2013). This theoretical framing of a Posthuman design approach introduces more complex notions and values that are sensitive to 'global challenges' at hand (Kera, 2013). Kera claims that this new sensibility is needed because the seemingly small and unimportant choices and decisions that are based around patterns of human-centred consumptions are operating within an ecology where flourishing depends on broader ecological sensitivities and commitments to care (Kera, 2013).

When I encountered Kera's work, I recognised that her thinking had moved in a more speculative and theoretical direction than my own, which had been anchored through keeping hold of the human story of loss through a PhD journey. Unlike my own thinking about design and death, which has been situated by ongoing commitments to loss, Kera's thinking about death troubles the entire human-centred frame and sense of scale until it reaches apocalyptic proportions.

This thinking about the apocalypse as a device for future work and to move outside of the limitations of the thesis really resonated as the place to which I wanted to move towards. As well as the apocalypse being extraordinarily useful to think about the choices of my thesis and reframing it within a broader ecological frame, it also

connected to bigger creative explorations of apocalyptic thinking within my practice. As a horror fan, a zombie aficionado and an admirer of the dark side of life, I find apocalyptic and end-of-the-world themes engaging. From disaster and apocalyptic tales at the cinema to survival guides for zombie apocalypses, creative fictions speak about humanity facing radically threatening futures full of aliens, genetic mutations, ancient monsters, wayward intelligent technology, inter-dimensional critters, meteorological and interplanetary destructions (Colebrook, 2014a; Colebrook, 2014b). At their heart are catastrophic tales of loss, redemption and the looming extinction of the human species.

Themes of death within ecologies and the apocalypse have been seen in a number of speculative art and design projects (Kera, 2013). For example, These themes are explored on a cellular level within projects such as 'NoARK' (2007) by Oron Catts and Ion Zurr, 'Continuous Bodies' (2010) by Maurizio Montalti, or 'Afterlife' (2009) by James Auger and Jimmy Loizeau. Alternatively, on a grander scale are the architectural preservation facilities like the Svalt Global seed vault, which aims to preserve the diversity in a potential future where there may be a nature disaster. Similarly, in nature are the Frozen Arc Project or the Frozen Zoo (and seed bank) in San Diego where collections of DNA material are kept.

These themes of survival, state of current ecological challenges and the capitalisation on living things have been themes within academic scholarship too. One well-publicised<sup>24</sup> discussion that arguably invokes the vision of an apocalypse has been seen in the debates around the Anthropocene. A proposed new epoch in the geological time frame, the anthropocene is seen as a 'geographic imaginary' that raises questions about how we imagine the current sustainability and longevity of the human species (Yusoff & Gabrys, 2011; Gabrys & Yusoff, 2012). Just as life itself has been recognised

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59 *The anthropocene as a topic has featured within a number of Ted talks, press and academic outreach venues, such as The Conversation : <https://theconversation.com/the-anthropocene-has-been-shaped-by-the-media-and-our-digital-lives-37124> .*

<https://www.youtube.com/watch?v=ABZjlfhN0EQ>.

<http://www.theguardian.com/science/2015/mar/11/was-1610-the-beginning-of-a-new-human-epoch-anthropocene>.

as a geological force, within discussions on the anthropocene, humans especially have been considered to be creating extreme geological forces, which is leading to questions about the extent to which humans have changed the planet through the human practices of terraforming the earth's surface, changing biodiversity, water courses and affecting sea levels, mining and the consumption of fossil fuels, which are considered to be part of the extreme geological forces (Yusoff & Gabrys, 2011).

Thinking about the anthropocene as part of the dialogue about climate change and the imaginary, geographer Kathryn Yusoff and STS researcher Jennifer Gabrys tell us that:

In short, the Anthropocene provokes us to imagine ourselves as a population acting collectively, reorganizing the conditions of life in terrestrial, atmospheric, and oceanic spaces; passing out of the territories of man and into the territory of earth as the organizing condition of earth systems. The age of the Anthropocene then invokes an imaginary that is also a cosmology, as it repositions humans as the driving force of change on earth, just at the point where philosophers were predicting the death of humanism and the relic of 'the human' (Yusoff & Gabrys, 2011).

In this frame, the anthropocene becomes a way of imagining, challenging and pushing at how we might want to frame the 'actuality' of the planet (Yusoff & Gabrys, 2011). Its debates allow us to think about other possibilities, to rethink certain commitments and understandings and creatively work with new notions (Yusoff & Gabrys, 2011).

This is why Colebrook discusses the anthropocene specifically as a 'doomsday device' because it becomes a compelling and evocative device to think about the interrelations and co-dependencies facing unsustainable ecological circumstances (The Anthropocene Project, 2013). Colebrook discusses the how the human act of intentionality or mastery of the earth ultimately comes to have a tragic quality within this anthropocentric device (The Anthropocene Project, 2013). The imaginary anthropocene provokes and prompts us to reconsider the human species as provisional, transitory and dire (The Anthropocene Project, 2013). As a device that can invoke these qualities, the anthropocene becomes a creative device for imagining, challenging and pushing design practitioners and their human-centred commitments.

## IN THE FACE OF THE ANTHROPOCENE

My interest in the anthropocene as a device in moving forwards is not only how it grounds Kera's notion of the apocalypse, but also in how it disturbs the centrality of the user in design when facing extinction. The anthropocene can disturb design's sense of optimism, stability, scale, time, continuity and progress and remind us that things are in flux. Planetary cues and their familiar patterns that provide stability, such as the sun setting, the moon rising and gravity being constant, all work to a timescale relative to the human lifespan (Brown & Hubbard, 2013). By being reminded of the instability, of how there was a deep time before the human user and that there will be a time afterwards regardless of the mode of human extinction, is a sobering thought.

These disturbing qualities also have an interesting effect if we bring them back around to the topic of designing for death. For example, the themes of digital legacy and memorialisation can be reframed from an issue just focusing on individual human legacies or remembering individual humans, to instead considering how we are leaving a legacy to be memorialised through consumption.

The planet, then, is archiving and holding onto a history of the human species, as one of many species that has consumed and left scarring on the planet's surface. Rather than thinking about your data after death and designing thanatosensitive networks to manage these legacies, our remains become the sociomaterial impact of this collective consumption, the waste and the fossilised remains that live on after human extinction.

It is from seeing these qualities that I felt that working with the anthropocene would be an interesting and fruitful future direction to think of working towards after the PhD, yet this has equally arisen out of the limits of the thesis and its human-centred ethicopolitical commitments. This interwoven crossover is what prompted me to want to engage in a different approach to moving forwards and to consider the theoretical messages of the anthropocene presented as visual devices that might work to disrupt others. Therefore, I opened Adobe Illustrator and began sketching ideas and slogans about how I would communicate this message. These soon turned into a developing

series of posters. Created as PDF files, I imagined them being printed out and through acts of guerrilla tactics these 'ads' could begin to infiltrate spaces like studios and labs, thereby spreading a provocative and curious message.

While developing these 'public service announcements' I recognised that their production had to come from somewhere. Therefore, at the bottom of any propaganda material posted will be a message declaring that these were created via the Antihuman Collective ([antihumancollective.org](http://antihumancollective.org)). What exactly the Antihuman Collective is, how it describes itself and what it envisions as its remit are still unfolding. I can say that it is influenced by the graphical styles of Barbara Kruger, Christopher Wool, Metahaven, Adbusters and the identity correction/hacking/bending techniques seen by art collectives such as e-toy or ubermorgen. Currently, it is emerging as a shadowy organisation, which is sponsoring or bankrolling the operations behind these 'public service announcements'. These posters that are directed at both designers and citizens—the two groups at the centre of this user-centred framing. They are deliberately trying to provoke, disrupt and garner reactions that hopefully work to raise consciousness and asks questions about design processes or user centred framings by presenting the anthropocene as the sixth great extinction event.

Prototype site running at: [www.antihumancollective.com](http://www.antihumancollective.com)

**FIGURE 8.1 POSTER1. TROUBLING THE SOCIO-TECHNICAL DESIGN THAT PERSISTENTLY STAYS WITH HUMAN-CENTRED FRAMINGS.**

Aimed at end of human life and legacy, this poster provokes viewers to think about digital legacy but through an absurd and Anthropocene lens that troubles the contemporary sense of time and stability. Designing for digital legacy in this frame is not about a person's individual data remains at end of life but rather our collective remembrance and what will outlive us.

The Antihuman Collective Presents

# *The Ultimate Legacy*



# *You shall live on!*

Our focus groups have told us that you have been worrying about your digital legacies and data. Have no fear! Here at the Antihuman Collective we know the topic of digital legacy is now obsolete. In the face of the Anthropocene, be assured that our collective human legacies have been taken care of. You shall live on through the mass of Radio waves, TV signals and even the capsule of voyager.

**We shall live on together!**

FIGURE 8.2 POSTER2. THINK ABOUT THE CONSEQUENCES OF SOCIO-TECHNICAL DESIGN FOR A PRIVILEGED WESTERN HUMAN ON AN ECOLOGICAL SCALE.

Aimed at the theme of memorialisation, this poster is prompting people to consider how they will be remembered across deep time and through our extinct fossilised remains. Designing for memorialisation in this frame is not about personal memorials but how we will collectively be remembered after our extinction.

**CITIZEN**

**YOUR ULTIMATE  
MEMORIAL  
IS IN THE STRATA**

**R.I.P  
HOLOCENE**

**SECURE YOUR FOSSILISED REMAINS**

This message was brought to you by the Antihuman Collective © 2015 *Abandon human futures™*

### FIGURE 8.3. POSTER 3. A CALL TO ARMS

An Invitation to designers who have user centred attachments. The message is asking them to think differently and even reconsider these attachments in light of the anthropocene and potential for extinction. It is trying to gesture towards how these attachments are implicated in the problematics without specifying exactly what in order to open a speculative space to think .

# DESIGNERS!

## PREPARE FOR THE ANTHROPROCENE



**GIVE UP YOUR USER CENTRED METHODOLOGIES IN THE  
FACE OF COMPLEX CATASTROPHIC GLOBAL CHALLENGES**

**JOIN US TODAY!**

## FIGURE 8.4. POSTER4. QUESTION DOGMA

A radical call to question the dogmatic approaches to formulaic design methodologies. Inspired by Historian Howard Zinn who argued the problem in society was people being obedient and not questioning the circumstances they find themselves in. This poster is asking designers to be disobediant, to provcatively question the authoritarian and dogmatic mindset that comes with aligning with particular design tradtions.

# FACING THE ANTHROPROCENE



**DESIGN DISOBEDIENCE IS NOT OUR PROBLEM,  
OUR PROBLEM IS DESIGN OBEDIENCE.**

**FORGET WHAT THEY TOLD YOU. FORGET GOOD AND BAD DESIGN.  
FORGET USER CENTRED METHODOLOGIES.**

**JOIN US!**

*Abandon human futures™*

This message was brought to you by the Antihuman Collective © 2015

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## FIGURES

Figure 1.1: Participatory artefact from 2011. The theme of death can be seen in the illustration of a grave on the bottom right hand side

Figure 1.2: Map of intersections I inhabited in 2011. The theme of death is also visible. Fullsize: <https://www.dropbox.com/s/euc4927a3fzkkog/process%20map.pdf?dl=0>

Figure 1.3: Discoloured home picture of Peter Gardening

Figure 1.4: Newspaper clipping of Pete's death <https://www.dropbox.com/s/ck5rorhb065l530/newspaper.jpg?dl=0>

Figure 1.5: Peter's Death Certificate <https://www.dropbox.com/s/1ptaddkstvalk6a/cerificate.jpg?dl=0>

Figure 1.6 Oil Painting by Andrew <https://www.dropbox.com/s/caaivnfvxji6ru7/painting.jpg?dl=0>

Figure 1.7: The PhD process that the narrative of this thesis moves to follow

Figure 2.1: The Methodology journey through different thematic and disciplinary territories

Figure 2.2: The interrelationships across Interaction design (Preece et al, 2002)

Figure 2.3: Multiple fields overlapping (Saffer, 2007)

Figure 3.1: Kemmis and McTaggart's action research spiral [2005] that shows the self-reflective cycles unfolding.

Figure 3.2: My theoretically engaged practice is a continual process of going through these loops over different timeframes. The cutting signals the opening and closing of particular projects and individual cycles. I find this corkscrew visual helpful in illustrating that I am always come from somewhere and these cycles will shape where I move onto next.

Figure 3.3: Core focus of the cycles I underwent through this study

Figure 3.4: Sample of the note cards I carried around

Figure 3.5: Selection of the portfolios and pads where they are currently house at home

Figure 3.6: One large archive sheet shrank down. Unfortunately it cannot be full size due to it containing sensitive details

Figure 3.7: The map as it first started out. Unfortunately it cannot be shown full size as it contains sensitive material

Figure 3.8: Laying out prints of the visual captures and moving them around to prompt analysis

Figure 3.9: The A1 map shown on the previous page but in this version we can see the sources developing and being colour coded into themes

Figure 3.10: The A1 Map developed over multiple decades

Figure 3.11: Technical timeline A1 Map <https://www.dropbox.com/s/q1znwftkro1z1oa/Technical%20timeline%20%28V3%29%20A1%20copy.pdf?dl=0>

Figure 3.12: One of many A0 mindmaps that I would piece together

Figure 3.13: Social life timeline as first sketched out in my notebook

Figure 3.14: Analysis notes developing into provisional thesis structure

Figure 4.1: Technical timeline A1 Map. As first seen in methodology <https://www.dropbox.com/s/q1znwftkro1z1oa/Technical%20timeline%20%28V3%29%20A1%20copy.pdf?dl=0>

Figure 4.2: Vax Machine. Sourced: [http://archive.computerhistory.org/projects/Visible\\_Storage/AE/AE\\_foto\\_project/500%20Club%20Sent%20to%20Aerin/Contents%20of%20Batch%201/no%20number%20VAX%2011-750.JPG](http://archive.computerhistory.org/projects/Visible_Storage/AE/AE_foto_project/500%20Club%20Sent%20to%20Aerin/Contents%20of%20Batch%201/no%20number%20VAX%2011-750.JPG)

Figure 4.3: Picospan "ScreenCaptureOfPicospanBBSInKonsole" Licensed under Fairuse via Wikipedia - <https://en.wikipedia.org/wiki/File:ScreenCaptureOfPicospanBBSInKonsole.png#/media/File:ScreenCaptureOfPicospanBBSInKonsole.png>

Figure 4.4: an example from 1997. The content only fills half the screen which is representative of the screen resolutions being 800x600 or lower

Figure 4.5: An example of the simple back/forwards navigation system

Figure 4.6: The decay exemplified here as missing images

Figure 4.7: A collection of images created by the bereaved as a gallery. These images all contain appropriated images of the deceased which have been manipulated and then 'gifted'

Figure 4.8: A deceased individual having wings added to his photograph

Figure 4.9: Charlie helps us recognise that the bereaved can create multiple sites for loss and these can occur across a number of years. Image taken from notes.

Figure 4.10: The now abandoned tribute to Markus

Figure 4.11: Mary's site helps illustrate the change in navigation system seen within a

broader selection of HTML sites of this period

Figure 4.12: Guest maps as an alternative to guest books

Figure 4.13 : A YouTube vblog by a person who identifies as a young 'widow'

Figure 4.14: An open casket video

Figure 4.15: Comments left on a video for a young child <https://www.dropbox.com/s/9nbd0qw6r2m6vgs/comments.jpg?dl=0>

Figure 4.16: Social life before physical life. The ultrasound scan of a baby that was later born 'still'

Figure 4.17: The early gifting and collaging of images can be now seen on Flickr

Figure 4.18: Open casket seen on Flickr

Figure 5.1: Marks memoir, the extensive list of content can be seen running down the left hand menu bar

Figure 5.2: The anonymous precursor message

Figure 5.3: Image taken by a passenger before the fateful MH17 flight and uploaded to Instagram

Figure 5.4: The list of pages that are being added yearly

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Figure 6.2: Images of the deceased found in timeline

Figure 6.3: Images of the deceased on Tumblr

Figure 6.4 : Discussion of the 'overshare' while sharing the images

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Figure 6.10: Comments left by the public in online media sites

Figure 6.11: Copies of the autopsy file

Figure 6.12: The deceased as found through google search

Figure 6.13: Suggestions by google that are offered in response to the deceased's names

Figure 6.14: Google Trends 'breakout' terms

Figure 6.15: Google Trends over time

Figure 6.16: Google Trends Related searches

Figure 6.15: Margaret Thatcher: the Marmite PM. 2013. BBH Creative Teams

Figure 6.16 : Recent capture of a news jacking that was poorly received

Figure 6.17: Announcement on twitter

Figure 6.18: Advert for pornography on Twitter

Figure 6.19: Luring links to fake content

Figure 6.20: Spam activities amongst messages of condolence

Figure 6.21: Spam and luring links dominating much to the dismay of other posters

Figure 6.22: Lure video that wants to deliver a malicious payload

Figure 6.23: Fake Facebook profile

Figure 6.24: Distressed and angry family

Figure 6.25: Distressed and Angry Public. The image above is taken from another recent flight MH 370 and I have used it to illustrate that it is an established practice

Figure 6.26: YouTube content describe bas being filled with 'keyword' stuffing in order to capitalise on the search rankings

Figure 6.27: Twitter Interface displaying 'default' results on #Death

Figure 6.28: Tumblr Interface displaying 'default' results on #Death

Figure 6.29: Search Engine Land periodic table of factors. Source <http://searchengineland.com/seotable>

Figure 8.1: Poster1. Troubling the socio-technical design that persistently stays with human-centred framings.

FIGURE 8.2: POSTER 2. THINK ABOUT THE CONSEQUENCES OF SOCIO-TECHNICAL DESIGN FOR A PRIVILEGED WESTERN HUMAN ON AN ECOLOGICAL SCALE

FIGURE 8.3: POSTER3. A CALL TO ARMS

FIGURE 8.4: POSTER4. QUESTION DOGMA

