

Original citation:

Bassett, Debra J.. (2015) Who wants to live forever? Living, dying and grieving in our digital society. *Social Sciences*, 4 (4). pp. 1127-1139.

Permanent WRAP url:

<http://wrap.warwick.ac.uk/76204>

Copyright and reuse:

The Warwick Research Archive Portal (WRAP) makes this work of researchers of the University of Warwick available open access under the following conditions.

This article is made available under the Creative Commons Attribution 4.0 International license (CC BY 4.0) and may be reused according to the conditions of the license. For more details see: <http://creativecommons.org/licenses/by/4.0/>

A note on versions:

The version presented in WRAP is the published version, or, version of record, and may be cited as it appears here.

For more information, please contact the WRAP Team at: publications@warwick.ac.uk

warwick**publications**wrap

highlight your research

<http://wrap.warwick.ac.uk>

Review

Who Wants to Live Forever? Living, Dying and Grieving in Our Digital Society

Debra J. Bassett

Department of Sociology, University of Warwick, Coventry CV4 7AL, UK;

E-Mail: D.J.Bassett@warwick.ac.uk; Tel.: +44-247-652-4771

Academic Editor: Emilie Whitaker

Received: 21 July 2015 / Accepted: 18 November 2015 / Published: 20 November 2015

Abstract: Almost ubiquitous hardware technology, such as smart phones, ensures that social networking sites are part of users' everyday norms and routines. However, some are now using these new communication technologies to deal with the issues of death, dying and grief. With the hope of being able to create digital memories to leave behind for future generations, the opportunity to “live on” and become digitally immortal is seen as empowering to some: but what about those left behind? Through a review of the current literature exploring how social media are being used as a new space to grieve and mourn, this paper contributes to the literature by arguing for the need for clarity in the lexicon being used by thanatologists and other disciplines. Furthermore, it introduces the term “digital zombie” to describe the dead who remain “alive” in our digital society. The paper concludes by joining the call for further research into the nascent phenomena being generated by human-computer interaction.

Keywords: thanatechnology; death; digital zombie; online grieving; digital immortality; digital afterlife; digital memories

1. Introduction

In 2007, Facebook dealt with the death of some of its users following the Virginia Tech shootings. At that time, relatives requested the pages of those killed, mainly young students, be left “alive”. Facebook decided to memorialize the accounts, rather than switch them off, enabling those left to write messages of support in their time of grief. Through the immediacy of Facebook, online obituary pages and memorial websites, such as Legacy.com [1], more people are grieving publically online via social media.

Companies, such as Eternime [2] and LifeNaut [3], both based in the USA, are launching new services that will enable people to control how they are remembered after they die. Eternime will take your digital footprint—tweets, online messages, vlogs and photographs—and, using artificial intelligence algorithms, create an avatar they claim will be a virtual interactive “you”. They maintain that your relatives will be able to visit you online for support and advice after you are dead, thereby offering digital immortality. Furthermore, they boldly state they are “Looking to solve an incredibly challenging problem of humanity”. Others seem to agree: Bell and Gray [4] of Microsoft Research suggest that the artefacts that make up a “cyberized” version of yourself will continue to learn and evolve (an interesting choice of words) and eventually “take on a life of their own”. Put simply, Eternime and other companies are offering to store your personality. The exponential growth of the emerging technologies needed to deliver and support these tools ensures that these services will be available in the not-too-distant future. However, this paper [5] is not focused on the emerging technologies involved in the creation of the cyberconsciousness, mindclones, mindware and mindfiles of Rothblatt, rather this paper is focused on the current technology: the platforms and services available and being used by a growing number of people as a new medium to deal with death and dying. How the dead will be memorialized and remembered in the digital world is a key issue, not only to sociologists, but to a wide variety of professionals, such as grief counsellors, palliative care givers, educators and those in other academic disciplines who are interested in thanatology (the study of death and the practices associated with it).

In her 1997 paper “Social support ‘internetworks’, caskets for sale, and more: Thanatology and the information superhighway”, Carla Sofka [6] coined the term “thanatechnology” to describe the bringing together of death and technology. More recently, in the 2012 book “Dying, Death and Grief in an Online Universe”, editors Sofka, Cupit and Gilbert continue the discussions by exploring how the Internet, via platforms like Twitter, Facebook, Skype and YouTube, has brought the previously taboo subjects of death and dying out of the closet, into our homes and onto our computer screens. These platforms allow for the datafication of end of life communications; moreover, the authors argue that the use of thanatechnology is bringing about fundamental changes to the traditional death systems of Kastenbaum and Aisenberg. Others agree that this could be the case. Brubaker *et al.* [7] argue that these new online practices are “new sites” of grieving and mourning, rather than just a disruption of the traditional systems. However, as Sofka *et al.* [8] argue, it should be acknowledged that the digital divide ensures that this new “thanatological death system” is not open to all.

Through a review of the current literature exploring how social media are being used as a new space to discuss the issues of death, dying and grief, this paper discusses the need for clarity in the lexicon being used by thanatologists and other disciplines. Secondly, it introduces the term “digital zombie” to describe the resurrected dead who remain “alive” and “active” in our digital society and crucially discusses how they differ from Internet ghosts. Finally, the paper calls for further research into the ramifications of computer-mediated communication technologies on the dying and the bereaved.

2. Terms and Definitions

In their 2011 paper, “Death, Social Networks and Virtual Worlds: A Look into the Digital Afterlife”, authors Braman, Dudley and Vincenti ([9], pp. 186–92) explore the online identities that are created by our interactions on social network sites (SNSs) and in virtual worlds. They suggest that “As

users live more as their ‘digital selves’, or live in ‘virtual life’, what we leave behind after our death can be important to consider and protect”. Each and every time we interact online, we create digital crumbs that can be thought of as our “digital souls” [10]. These “narrative bits” of information are what Mitra [11] calls “narbs”; he argues that, over time, these narbs describe a user and their interactions:

“The identity of an individual is eventually constructed by the combination of narbs that are available on a social networking site where different kinds of narbs work together to produce the composite narrative of a person at any moment in time” [11].

It is important to ensure that there is clarity and agreement in the terminology being used to discuss two very distinct categories: “digital data” and “digital selves”. Throughout the death and dying literature, the umbrella term “digital legacy” is used interchangeably to discuss different types of digital footprints. In their 2013 book chapter, entitled “What Role Does Digital Information Play in the Way We are (Re)Membered”, Pittslides, Waller and Fairfax [12] attempt to address the issue of terminology by including a “key terms and definitions” section. They use the terms “digital heritage”: “The accumulation and curation of digital data online, which could form the basis of an inexhaustible resource containing the exact documentation of our digital past”; and “digital historical artifacts”: “digital objects, which contain information for the building up of archives or digital heritage, for example Social Networks”.

When discussing the two distinct concepts, I suggest “digital legacy” should be used to discuss digital data: passwords, account information, digital assets and digital property; in essence, things that belong in a digital safe or vault that are static once the user has died. However, the term “digital memories” should be used for the digital selves’ category: personal videos, messages, photographs and blogs, which belong in a digital memory box. Walters’ term “durable biography” [13] is useful here since these biographies belong in digital memory boxes; they enable storytelling, on-going narratives, memorialization and “renegotiated” relationships with the dead in a digital afterlife. Although the categories of digital legacy and digital memories are often discussed alongside one another, or in some cases blended together [14], thanatologists and professionals need to adopt a common terminology that makes clear the concept being discussed, thereby providing clarity to users of digital legacy and digital memory service providers.

3. Service Providers

“The Digital Beyond” [15] is a think tank created by Evan Carroll and John Romano. It brings together digital afterlife service providers and other digital afterlife information. Some of the service providers listed on the site provide funeral planning advice, enabling people to plan their own funeral and leave instructions on how they want their digital legacy to be dealt with. Moreover, some of the service providers offer digital memory box creation, and some offer both: Infibond [16], founded in 2013, offers to “inspire people to turn their lives into a digital footprint: by uploading text, photos, music and videos, creating and sharing dynamic, engaging and everlasting life-stores”.

For those facing death, the ability to create and fill such digital memory boxes can be an effective and positive way to deal with their inevitable mortality [17]. Digital Dust [18], a blog and Facebook page by Vered (Rose) Shavit, aims to raise awareness of the importance of managing digital legacy

assets in a digital and virtual era. Although it is primarily interested in the way Israeli service providers are dealing with issues of digital legacy, it is a useful reference for other countries. The U.K.-based organization Dead Social [19] offers more of an “end user” planning tool and service. Working with hospices, charities and healthcare workers, the user-friendly website aims to empower those facing end of life decisions, by enabling the creation and future delivery of messages, including digital memories, to those left behind, as well as practical advice regarding digital legacy issues. The research opportunities created by such companies are discussed below.

4. Our Relationship with the Dead and Dying

The fact that we are all going to die is an undisputable reality of the human condition. Whilst the beginning of our lives are celebrated, discussed and chronicled, death and dying have become medicalized, sanitized and whispered about in many Western cultures. This hiding away and sequestration of death is intended to ensure that it does not interfere with everyday life [20]. However, there are signs that social media provide platforms where people can openly discuss death and dying [17]. Moreover, as a result of the hospice movement, many dying people have access to assistance that allows them to die in their own home and remain a part of society, rather than being removed from the everyday lives of friends and family [21]. Social media can also provide a space to debate what constitutes a “good death”, which, according to Whitaker, could be indicative of a “burgeoning public reclaiming of death” [22].

Many now live in a world where 24-hour rolling news channels ensure that the inevitability of death is brought into homes and onto screens. It should be acknowledged that the mass media have always reported on the dramatic and spectacular dead; however, the ubiquitous and embedded nature of social media engenders a re-surfacing of the non-spectacular dead: in October 2014, terminally ill Brittany Maynard, in conjunction with the organization Compassion and Choices, uploaded a YouTube video advocating assisted dying [23]. To date, the video has received over 11 million views and has succeeded in galvanizing debates and discussions about changes to the law on assisted dying. The case study of Brittany Maynard illustrates how social media can be used as crucial tools to galvanize support surrounding ongoing and important issues, such as the right to die.

5. Grieving on Social Media

Social media have an important part to play in changes to the way people grieve; mourning practices are changing [24], and there is a growing amount of research and literature dealing with these changes. In their 2013 paper, Brubaker *et al.* [7] conclude that social network sites (SNSs) provide a new space for grieving, which is socially situated in the daily lives of the bereaved. Carroll and Landry’s research [25] suggests that social networking platforms enable and empower those marginalized by traditional forms of grief to stay connected to the deceased. However, research is finding both positive and negative consequences of how mourning is experienced online: Marwick and Ellison’s paper [26] discusses issues regarding Internet trolls and the limitations of the “like” button being used on memorial pages. Likewise, Phillip’s research [27] examines the complexities of online trolls who target Facebook memorial pages and the impact these RIP trolls have on the bereaved.

In 2011, Walter *et al.* [20] examined the implications of online practices on the key concepts in death studies. They argue that their paper, “Does the Internet Change How We Die and Mourn? An

Overview”, is the first to summarize how this fast and dynamic phenomena is affecting dying and mourning. The desequestration and reclaiming of death, together with discussions on private and public grief, are recurrent themes in the current literature: Walter *et al.* [7,20] propose that there are three types of death: traditional, modern and postmodern. Traditional death takes place in the community, thus producing a bereaved community. The modern death happens at home or in a hospital, where the public and the private aspects of death and grief are “isolated” and produce “bereaved individuals”. However, in postmodern death, Walter *et al.* [20] suggest that the public and the private are combined: with SNSs, private feelings are expressed in public spaces, thereby creating a community of bereaved—a community of “diverse mourners”. In their 2013 paper, “Beyond the Grave: Facebook as a Site for the Expansion of Death and Mourning”, Brubaker *et al.* [7] consider how SNSs are producing new arenas for grieving and how “Facebook is associated with an expansion of death-related experiences—temporally, spatially, and socially”. They argue that these arenas create a socially-situated space where the bereaved can engage. Crucially, these new spaces are situated in their daily lives, thus ensuring that death becomes part of the everyday. However, Walter [28] argues that rather than just making grief public, SNSs are enabling grief to “become more communal, that is, shared within the deceased’s social networks”.

6. From “Moving on and Letting Go” to “Continuing Bonds”

Much of the current literature exploring digital death and dying online seems to be moving away from the letting go theories of Freud and Kubler-Ross in favour of Klass, Silverman and Nickman’s continuing bonds theory [28]. Although the paradigm shift is still in progress, the suggestion that relationships continue after death with the creation of virtual bonds is supported by research into online memorials [7]. In a 2013 research paper, Pennington found that Facebook users “don’t de-friend the dead” [29]. Instead, she suggests the living “renegotiate” their relationship with the dead, thereby redefining the bonds. The paper analysed grief communications on the Facebook profiles of college students. It found the majority of participants, the “silent majority”, did not actively engage with the site of a deceased friend, although most found support by “lurking” on the site. The “vocal minority”, those who did post messages on the site, addressed their posts directly to the dead, supporting Kasket’s [30] theory that there is a perception that “the dead are listening” online.

Pennington notes how participants make the distinction between sites that have been memorialized by Facebook and sites that are managed by the relatives of the deceased. She found that the sites controlled by others had a negative effect on the ability to cope with loss by those using the site. A clear distinction between these two types of “after death” sites would be useful here: I suggest a site where the service provider has been notified of the user’s death should continue to be referred to as a “memorial site”; whilst a site administered by others, where the creator of the site is dead, but still appears alive (the living dead), should be categorized by thanatology researchers as a “zombie site”. It is acknowledged that the service providers themselves would not adopt this terminology, as it could offend users. However, adoption by researchers could be useful to make the distinction between these two different post-mortem sites.

Those in control of zombie sites are defying the current rules of providers like Facebook, as they need passwords to access the profile pages [31]. A recent blog by Digital Dust “When Facebook Isn’t

Sensitive Enough” gives examples of why the policies pertaining to these sites need reviewing: “Look Back” is a service introduced by Facebook in 2014. The tool creates a one-minute video made from personal Facebook highlights. Following a request from a bereaved father, Facebook changed their policy to allow people to see Look Back videos of deceased users. However, in order to access the video, you need to inform Facebook that the user has died, which many do not want to do, as they want to retain access to the account [32]. Research into this issue is suggested below.

For some, social media may provide a space for a renegotiated relationship with the dead; however, it should be acknowledged that not everyone grieves in the same way. In their 2013 paper, Brubaker *et al.* [7,33] discuss the need for caution, explaining that for some, public expressions of grief are distressing, and others agree. Pennington [29] highlights how college students hide the posts of dead friends from their timeline, because they find them distressing. Sofka *et al.*'s discussions [8] around what Massimi & Charise called “thanatosensitivity” are useful here to ensure an awareness that, while death and grief may be more social and communal, each person’s grief is unique to them.

For some, a more tangible way of maintaining a relationship with the dead may be more valuable: The research into the design of a bespoke digital memorial, a tangible digital memorial, by Moncur and Julius [34] found that the ability of the story shell to “capture and replay stories” was successful in sustaining the continuing bonds of a bereaved mother to her dead son. A further example of the physical and the virtual combining to enable continuing bonds with the dead is the creation of Memory Art by the artist Nancy Gerhman, who works with end of life clients to collect stories, photographs and mementoes to co-create a “life affirming dignity portrait” or a “remember-me book”, offering a tangible object and a digital file [35]. Research by Michael Massimi [36] identifies opportunities for technology designers to support bereavement activities, by connecting bereaved people and providing ongoing social support-with a “thanatosensitive design”. His research into a system called “MyShrine”, a touchscreen with an “alter” underneath, is ongoing and seeks to better understand the use of technology by the bereaved.

Arguments supporting the continuing bonds theory are compelling; however, the dichotomous nature of letting go *vs.* continuing bonds suggests a “one size fits all” model of grief, which is unhelpful. Rather than relationships with the dead being static and unchanging, they are dynamic and change through what Neimeyer describes as a process of “meaning reconstruction”. This meaning reconstruction allows a continuation of the relationship with the dead whilst the bereaved are still able to move forward and restructure their lives [37].

In 1999, Stroebe and Schut proposed a dual process model (DPM), which supported the idea of moving away from the more traditional approaches of “grief work” by suggesting that healthy grieving involves an oscillation between “loss orientated grief” and “restoration orientated grief” (confronting *vs.* avoiding grief) [38]. Although Christensen and Sandvik [39] do not mention the DPM in their 2014 paper “Death ends a life not a relationship: timework and ritualizations at Mindet.dk”, their research provides an example of this “oscillation” being played out in an Internet space. The research explores the Danish website Mindet.dk, which is used by parents of children who die at a very young age or are stillborn. They argue that the website creates a space for a ritualization of grief work through performances, such as lighting a candle and writing messages to the child they have lost, and crucially, it engenders a supporting community of mourners. This “parallel existence” enables the parent to move on with their lives whilst maintaining a relationship with their dead child by continuously keeping hold (Walter in [39]).

It is becoming clear that online resources offer the bereaved new ways to remain connected with the dead, and further research showing how the DPM relates to grief work that occurs in the technologically-mediated space created by the Internet would be useful. However, in order to ensure these new opportunities are incorporated into existing theoretical frameworks, careful modification is needed.

7. Digital Immortality: Intentional and Accidental

The notion of digital immortality can be seen as a relatively new variation of what Robert Jay Lifton [40] described as a symbolic immortality: the need to pass on memories and attempt to remain influential to future generations. However, this quest for immortality is nothing new: in his 2007 text, Robert Kastenbaum [41] illustrates how the promise of an afterlife is woven through the world's main religions and how people have attempted to continue their relationship with the dead throughout history. Kastenbaum describes how people have pursued immortality in various ways, from stone monuments and time capsules to cloning. Since the invention of the radio, technology has been used to facilitate what he describes as "assisted immortality" (or assisted survival). However, recently, new technologies available in the digital age give us perhaps the greatest opportunity to explore the possibilities of assisted immortality.

As noted by others, users of thanatechnology often adopt the Christian notions of heaven and angels in their communications with the dead [7,20]. As Walter *et al.* argue in their 2011 paper,

"The digital revolution enables a plausible geography of the dead residing in cyberspace."

Since the Copernicus revolution, science and religion have been seen by some as dichotomous and competing; however, it could be argued that thanatechnology allows the creation of a "digital heaven" where "digital angels" exist, thereby entwining the two concepts. However, as Marwick and Ellison comment, "There isn't Wi-Fi in heaven!" [26]. Therefore, should the dead keep quiet?

Brubaker *et al.* [7] emphasize how "unexpected encounters" with the dead can be distressing for the bereaved. Those who have had telephone numbers of dead people re-appear from the cloud after deleting the numbers may relate to the distress caused by these "Internet ghosts" [24]. In addition, it is noted that the religiosity of heaven and angels on post-mortem posts makes some readers uneasy [7,20]. Walter *et al.* [20] point to other unexpected encounters with the dead, such as "spontaneous shrines" that appear at the roadside. These, they argue, allow mourning to "leak into the everyday life of passers-by" and caution against this mixing together of life and death. Crucially, the dead in these types of unexpected encounters remain dead; they may come back to haunt us, but they still remain dead. However, what about those who rise from the dead to once again become socially active?

Bollmer [42] suggests that it is not just the "presence" of the dead, but the "near full representation of the authentic identity of the human being" enabled by communication technology that causes anxiety, and as he points out in his 2013 paper, "networks have no way of distinguishing between the living and the dead".

These "restless dead", according to Nansen *et al.* [43] are "exhumed within a network of social and technical connections previously delimited by cemetery geography and physical inscription in stone". Here, I suggest an expansion of their notion of the "restless dead" by introducing the term "digital

zombie” to describe the resurrected, re-animated, socially-active “dead”. These digital zombies differ from Cann’s passive “Internet ghosts” [24], which she describes as glitches in social network programs. Nansen *et al.*’s distinction [43] between animation and repose when describing the dead is crucial here.

8. The Resurrection of the Dead: Digital Zombies

Four years after he died, Bob Monkhouse appeared in an advertisement to raise awareness for prostate cancer. In the video, he appears at his own graveside, discussing his own death. The video, which was recorded whilst he was alive, was edited with new footage, featuring a body-double and a voiceover by an impressionist, to create the final advertisement. Using this “modern necromancy”, or digital age communication with the dead [44], he was digitally resurrected from the grave, thus giving him digital immortality and turning him into an accidental digital zombie. Other digital zombies include Tupac Shakur and Michael Jackson, both digitally recreated to perform “live” on stage at concerts years after their deaths. In her 2013 paper, Alexandra Sherlock [44] discusses these “posthumous representations” and how dead celebrities being used in advertisements (e.g., Steve McQueen driving a Ford Mustang and Fred Astaire advertising a vacuum cleaner) add to what she describes as an advanced type of symbolic immortality. This paper’s term, digital zombie, is useful here to describe this dualism of being both dead and virtually alive; and crucially still being socially active.

The more we interact with technology, SNSs and virtual worlds, the more our digital selves evolve into realistic representations of our “real” selves. These interactions and the narbs they create are described by Kasket as “posthumously persistent” [30], thereby offering the promise of immortality by way of a digital afterlife. Such an afterlife can be empowering to the terminally ill, who may wish to fill their digital memory boxes with photographs, music, videos and messages to leave behind after their deaths.

The need to look at people as having lived and having a narrative rather than just becoming “the deceased” was once the job of clergy, obituary writers and eulogy writers. Respect for the dead requires remembering the dead [30]. The need to be remembered and the ability to pass on memories is an ancient need: from the first cave drawings and the magnificent mausoleums of the Egyptians, we can see that symbols of mans’ quest for immortality are well chronicled [6]. In his 2015 paper, “Communication Media and the Dead: from the Stone Age to Facebook”, Professor of Death Studies Tony Walter [28] posits that the “presence” of the dead is partly dependent on the communication technologies available in a given society. Undoubtedly, these communication technologies affect how we communicate with the living, and Walter considers how they affect the way we communicate with the dead. Furthermore, he argues that these technologies ensure that the dead are more “socially present”. The paper chronicles the use of communication media from stones and sculptures, which need mediating, to writing, music and printing:

“The presence of the dead within a society depends in part on available communication technologies, specifically speech, stone, sculpture, writing, printing photography and phonography” ([28], p. 1).

Walter noted that QR [45] codes on gravestones and memorials are just one example of this. When scanned, the quick response (QR) code takes you to a website containing the “story” of the deceased.

However, as Briggs and Thomas found in their study, older users were concerned about technological exclusion, business practice and digital vandalism, which surround this type of technology. Moreover, they felt that QR codes were exploitative and in “bad taste” [43]. In her 2014 book, Cann [24] discusses interactive tombstones, which contain barcodes allowing the living, through the use of a smartphone, to “interact” with the dead. She suggests that through links to videos, conversations, memories and pictures, the dead remain alive. I suggest these interactions are not unintended encounters with Cann’s “Internet ghosts”, but planned encounters with “digital zombies”, as this technology allows for a re-animation and resurrection of the dead. Importantly, the data can be amended and added to by whomever has control of the site, thus enabling the deceased to be socially active.

9. Thanablogging

The contemporary available technologies, together with platforms, such as Twitter, Facebook and YouTube, allow ordinary people to create their own digital narratives by writing, filming and publishing details of their lives. These blogs, tweets and videos then build into a collection of enduring digital memories. In their 2014 paper entitled “Palliative social media”, Taubert, Watts, Boland and Radbruch [17] explore how these thanatechnologies and social media platforms offer both challenges and opportunities to the terminally ill and medical professionals involved in end of life care. Taubert *et al.* discuss how microblogs can provide professionals with an alternative space to discuss media health scares and openly debate controversial end of life issues, such as the Liverpool Care Pathway. Technology also enables live feeds of conferences focused on palliative care allowing many to remotely attend such conferences. However, as the authors point out, the UK’s General Medical Council and the British Medical Association have urged caution about these open debates [17].

Until recently, the ability to be remembered and immortalized was the domain of the rich and famous. However, through recent communication technology, it is now possible for “ordinary” people to create and curate their own narratives, ensuring that they leave behind digital memories for others. In their paper, Taubert *et al.* [21] provide a list of example websites and blogs written and used by the terminally ill, illustrating how thanatechnology is now firmly rooted in the death and dying “arena”. These blogs, described by Sofka [8] in her chapter “Blogging: New Age Narratives of Dying, Death, and Grief”, as thanablogs provide the terminally ill with a space that enables them to take control of the finite time they have remaining. Thanablogger Dr. Kate Grainger blogs [46], tweets, makes videos and writes books about her experience with terminal cancer. The positive and direct way she confronts her situation (her latest blog is entitled “The things I love about life”) and the way she directly addresses some posts to “Dear Cancer” has earned her over 37,000 Twitter followers and illustrates a positive use of valuable and limited time to create a forum for open discussions of death and dying.

There is a growing number of examples of people using technology to demonstrate a positive and empowering attitude towards death. However, the capacity to face death whilst remaining positive and inspirational to others is perhaps best exemplified by the story of Stephen Sutton. This British teenager was diagnosed with incurable cancer at age 17. Stephen [47] started a blog in 2013, not to discuss his illness and care in detail, but to spread his “motivation and positivity”. His bucket list included the goal to raise £10,000 for the Teenage Cancer Trust charity. By the time of his death on 14 May 2014, he had raised over £3.2M. By using the computer-mediated communication of Facebook and Twitter, his

pragmatic and positive outlook on both life and death took on a digital life of its own. He had over 1M Facebook likes and 200,000 Twitter followers [48]. However, crucially, as a digital zombie, he is still very much at work. Although his Twitter followers have dropped by 8000, his Facebook likes have increased by 390,000, and donations to the Teenage Cancer Trust in his name sit at over £4.3M. Since his death, he has received a posthumous MBE and has been awarded an Honorary Doctorate of Science. Stephen Sutton was neither rich nor famous, but the digital memories he has left behind, in addition to his charity work, show the positive way he faced the end of his finite life in the real world by creating digital memories in the online world. Through these memories, he hoped to inspire others to live their lives in a positive way [47]. He became known for his thumbs-up gesture and even tweeted a thumbs-up photograph just days before he died. He summarized his mission as follows: “to spread as much positivity as possible, to show people what it’s like to have something go wrong in their lives but not to be defined by it”. He saw his impending death not as a threat, but as an opportunity to inspire and help others. He used the available technology to make this happen through the creation of a digital narrative, which has become an enduring digital memory box.

10. The Call for Further Research

An important element of any review paper is to identify gaps in the current research; however, the authors of the literature reviewed in this paper have identified many gaps themselves, and their calls for additional research echo throughout the literature. Some common themes for further research include:

- (1) The effect on and importance of traditional death systems [7,8,20];
- (2) Digital immortality creation: impact on the bereaved [8,29,30];
- (3) Thanablogging [8,20];
- (4) Impact of thanatechnology on the dying [17,20].

In addition, this paper suggests the following research topics:

- Exploration of “second death”: impact on the bereaved of turning off digital memories.
- The usefulness of digital memory boxes by health professionals dealing with Alzheimer’s patients.
- Exploration of zombie profile pages *vs.* memorial pages: why do some choose not to memorialize profile pages of the deceased?

11. Conclusions: A Bright Future for Death?

As this literature review has demonstrated, the phenomena being created by thanatechnology have become the focus of many who are interested in the important issues of death, dying and grieving. The implications and ramifications, both positive and negative, created by these phenomena present huge opportunities for researchers, grief counsellors, death educators and palliative caregivers. The Digital Legacy Conference [14] is just one example of a collaboration across these disciplines and agencies. When discussing the issues of digital legacy and digital memories, the adoption of a clearer lexicon across agencies suggested by this paper could be beneficial: because only by continuing to work together to discuss and debate the issues can research keep pace with the exponential growth of communication technology and the plethora of data that it produces.

Perhaps the offer of digital immortality afforded by the creation of enduring digital memory boxes may prove pivotal in how people use their finite time to enable them to “live on” in a digital afterlife. This paper’s introduction of the term digital zombie could be useful to describe these socially-active, restless dead.

There is much research to be done; it has only just started. How this human-computer interaction will affect the bereaved is an important area of research. However, the need to be remembered is a powerful desire for some; the ability to curate and store memories and thoughts for future generations is a tempting offer, because, ultimately, you only have one chance to make a good last impression.

Conflicts of Interest

The author declares no conflict of interest.

References

1. Legacy. Available online: <http://www.legacy.com/ns/> (accessed on 5 September 2015).
2. Eternime. Available online: <http://www.eternime.com> (accessed on 10 February 2015).
3. Lifenaut. Available online: <http://www.Lifenaut.com> (accessed on 3 March 2015).
4. Bell, Gordon, and Jim Gray. “Digital immortality.” *Communications of the ACM* 44 (2001): 28.
5. Rothblatt, Martine. *Virtually Human: The Promise and the Peril of Digital Immortality*. New York: St. Martins’ Press, 2014.
6. Sofka, Carla J. “Social support ‘Internetworks,’ Caskets for sale, and more: Thanatology and the information superhighway.” *Death Studies* 21 (1997): 553–74.
7. Brubaker, Jed R., Gillian R. Hayes, and Paul Dourish. “Beyond the grave: Facebook as a site for the expansion of death and mourning.” *Information Society* 29 (2013): 152–63.
8. Sofka, Carla, Illene Noppe Cupit, and Kathleen R. Gilbert. *Dying, Death, and Grief in An Online Universe*. New York: Springer Publishing Company, 2012.
9. Braman, James, Alfreda Dudley, and Giovanni Vincenti. “Death, Social Networks and Virtual Worlds: A Look into the Digital Afterlife.” Paper presented at Software Engineering Research, Management and Applications (SERA), Baltimore, MD, USA, 10–12 August 2011.
10. Paul-Choudhury, Sumit. “Digital legacy: The fate of your online soul.” *New Scientist* 210 (2011): 41–43.
11. Mitra, Ananda. “Creating a presence on social networks via narbs.” *Global Media Journal* 9 (2010): 20–40.
12. Pitsillides, Stacey, Mike Waller, and Duncan Fairfax. “Digital Death: What Role Does Digital Information Play in the Way We are (Re)Membered?” In *Digital Identity and Social Media*. Edited by Steven Warburton and Stylianos Hatzipanagos. Hershey: IGI Global, 2013, pp. 75–90.
13. Walter, Tony. “A new model of grief: Bereavement and biography.” *Mortality* 1 (1996): 7–25.
14. Digital Legacy Conference. Available online: <http://digitallegacyconference.com> (accessed on 4 September 2015).
15. Digital Beyond. Available online: <http://www.thedigitalbeyond.co.uk> (accessed on 12 June 2015).
16. Infibond. Available online: <https://www.infibond.com/pages/about.php> (accessed on 28 May 2015).

17. Taubert, Mark, Gareth Watts, Jason Boland, and Lukas Radbruch. "Palliative social media." *BMJ Supportive and Palliative Care* 4 (2014): 13–18.
18. Digital Dust. Available online: <http://digital-era-death-eng.blogspot.co.uk> (accessed on 19 May 2015).
19. Dead Social. Available online: <http://www.deadsocial.org> (accessed on 16 May 2015).
20. Walter, Tony, Rachid Hourizi, Wendy Moncur, and Stacey Pitsillides. "Does the internet change how we die and mourn? Overview and analysis." *Omega: Journal of Death and Dying* 64 (2011): 275–302.
21. National Association for Hospice at Home. "What is hospice at home?" Available online: <http://www.nahh.org.uk/about-hospice-care/what-is-hospice-at-home> (accessed on 2 July 2015).
22. Whitaker, Emilie. "The Year of the New Necropolitics?" Available online: <http://www.sociologicalimagination.org> (accessed on 20 February 2015).
23. Hoffman, Allie. "The brittany maynard fund." *YouTube* Video, 6:30. 8 October 2014. Available online: <https://www.youtube.com/watch?v=FLJ8yx7jcS4> (accessed on 12 March 2015).
24. Cann, Candi K. *Virtual Afterlives, Grieving the Dead in the Twenty-First Century*. Lexington: The University Press of Kentucky, 2014.
25. Carroll, Brian, and Katie Landry. "Logging on and letting out: Using online social networks to grieve and to mourn." *Bulletin of Science, Technology and Society* 30 (2010): 314–49.
26. Marwick, Alice, and Nicole B. Ellison. "'There isn't wifi in heaven!' Negotiating visibility on facebook memorial pages." *Journal of Broadcasting and Electronic Media* 56 (2012): 378–400.
27. Phillips, Whitney. "LOLing at tragedy: Facebook trolls, memorial pages and resistance to grief online." 2011. Available online: <http://firstmonday.org/ojs/index.php/fm/article/view/3168/3115> (accessed on 15 August 2015).
28. Walter, Tony. "Communication media and the dead: From the stone age to facebook." *Mortality* 20 (2015): 215–32.
29. Pennington, Natalie. "You don't de-friend the dead: An analysis of grief communication by college students through facebook profiles." *Death Studies* 37 (2013): 617–35.
30. Kasket, Elaine. "Continuing bonds in the age of social networking: Facebook as a modern-day medium." *Bereavement Care* 31 (2012): 62–69.
31. Facebook Help Centre. "How do I report a deceased person or an account that needs to be memorialized?" Available online: <https://www.facebook.com/help/150486848354038> (accessed on 15 September 2015).
32. Digital Dust. "When Facebook Isn't Sensitive Enough." Available online: <http://digital-era-death-eng.blogspot.co.il/2015/11/when-facebook-isnt-sensitive-enough.html> (accessed on 8 November 2015).
33. Balk, David E. "Dying, death, and grief in an online universe." *Death Studies* 38 (2014): 482–84.
34. Moncur, Wendy, Miriam Julius, Elise van den Hoven, and David Kirk. "'shell story' the participatory design of a bespoke digital memorial." Paper presented at 4th Participatory Innovation Conference 2015, Den Haag, Netherlands, 18–20 May 2015.
35. Art for Your Sake Storytelling Dreamscapes. Available online: <http://www.artforyoursake.com> (accessed on 1 July 2015).
36. Massimi, Michael. *Technologies for Supporting Bereaved Families*. Toronto: University of Toronto, 2010.

37. Neimeyer, Robert A. *Meaning Reconstruction and the Experience of Loss*. Washington: American Psychological Association, 2001.
38. Schut, Margaret, and Henk Stroebe. "The dual process model of coping with bereavement: Rationale and description." *Death Studies* 23 (1999): 197–224.
39. Christensen, Dorthe Refslund, and Kjetil Sandvik. "Death ends a life not a relationship: Timework and ritualizations at Mindet.dk." *New Review of Hypermedia and Multimedia* 21 (2015): 57–71.
40. Lifton, Robert Jay. *The Broken Connection. On Death and the Continuity of Life*. New York: Simon and Schuster, 1979.
41. Kastenbaum, Robert. *Death, Society, and Human Experience*. New York: Pearson Education, Inc., 2007.
42. Bollmer, Grant David. "Millions now living will never die: Cultural anxieties about the afterlife of information." *Information Society* 29 (2013): 142–51.
43. Nansen, Bjorn, Michael Arnold, Martin Gibbs, and Tamara Kohn. "The restless dead in the digital cemetery." In *Digital Death: Mortality and Beyond in the Online Age*. Edited by Christopher M. Moreman and A. David Lewis. Santa Barbara: ABC-CLIO, LLC., 2014.
44. Sherlock, Alexandra. "Larger than life: Digital resurrection and the re-enchantment of society." *Information Society* 29 (2013): 164–76.
45. Qr Memories, Preserve-Remember-Enlighten. Available online: <http://www.qr-memories.co.uk> (accessed on 25 June 2015).
46. Granger, Kate. "The things I love about life." Available online: <https://drkategranger.wordpress.com/2015/06/01/the-things-i-love-about-life/> (accessed on 24 June 2015).
47. Stephen's Story. Available online: <http://www.stephensstory.co.uk> (accessed on 14 May 2015).
48. Manse, Henry. "Stephen sutton campaigner, 1994–2014." *Financial Times*, 16 May 2014. Available online: <http://www.ft.com/cms/s/0/40ea8f30-dc3f-11e3-8511-00144feabdc0.html#axzz3rxosjUBYURL> (accessed on 3 July 2015).

© 2015 by the authors; licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution license (<http://creativecommons.org/licenses/by/4.0/>).