OMEGA, Vol. 64(4) 275-302, 2011-2012

DOES THE INTERNET CHANGE HOW WE DIE AND MOURN? OVERVIEW AND ANALYSIS

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ABSTRACT

The article outlines the issues that the internet presents to death studies. Part 1 describes a range of online practices that may affect dying, the funeral, grief and memorialization, inheritance and archaeology; it also summarizes the kinds of research that have been done in these fields. Part 2 argues that these new online practices have implications for, and may be illuminated by, key concepts in death studies: the sequestration (or separation from everyday life) of death and dying, disenfranchisement of grief, private grief, social death, illness and grief narratives, continuing bonds with the dead, and the presence of the dead in society. In particular, social network sites can bring dying and grieving out of both the private *and* public realms and into the everyday life of social networks beyond the immediate family, and provide an audience for once private communications with the dead.

doi: http://dx.doi.org/10.2190/OM.64.4.a
http://baywood.com

INTRODUCTION

Death is irreducibly physical, but it is also social. Getting frail or terminally ill and then dying disrupts social networks; bereavement entails a restructuring of social engagement, with both the living and the dead. The internet is also, and increasingly, social, so much so that the term "social networks" is nowadays as likely taken to include online as well as offline networks. So it is reasonable to ask whether, and if so how, the internet changes the experience of dying, and of grieving.

A second reason to ask this question derives from the need for information. We die only once, so dying presents an entirely new situation for each individual who faces it, and possibly also for their close kin. They have a lot to learn, and fast. Most knowledge about dying, however, is tied up in the heads, textbooks, and procedures of health professionals, so the ordinary family faces, at the very least, urgent information needs. The internet is fast replacing books (which in turn replaced orally transmitted knowledge) as the main way in which modern people search for information, so we may predict that the internet will be increasingly significant for dying people and their carers, and especially those dying at home.

In this article, we examine a range of research literature about the internet in relation to the whole span of mortality—from increasing frailty through death to bereavement and eventual archaeology of what is left behind. The literature comes from many disciplines and interdisciplinary fields, including death studies, journalism, media studies, cultural studies, memory studies, computer mediated communication, human computer interaction, sociology, psychology, medicine. Though there are many studies of particular facets of death and the internet, often focusing on one or two websites, no-one has reviewed overall how the internet may affect dying and mourning. The literature relates primarily to advanced industrial societies; this review is likewise restricted to these, mainly Western, societies.

We suggest that if the social interactions of dying or grieving people change, then the experience of dying or grieving may well change. Some of the studies reviewed focus on interactions, some on experience, some on the relation between the two. We argue that the evidence so far indicates that the internet has significant implications for many current concepts in death studies; in turn these concepts illuminate what is going on online. These concepts are: the sequestration (or hiding) of death and dying; disenfranchisement of grief, private grief, social death, illness, and grief narratives; continuing bonds with the dead; and the presence of the dead in society. Several of the implications of the internet for dying and grieving date from the development in the 2000s of Web 2.0, which refers to the internet's increased interactivity and the ease with which non-experts can upload text, pictures, and sound, and continuously modify these collaboratively—illustrated by, but far from confined to, the rapid development

of social network sites (SNSs) (boyd & Ellison, 2008, Kaplan & Haenlein, 2010; O'Reilly, 2010).[1]

The article is in two parts. Part 1 is descriptive, looking at dying, funerals, online memorialization, digital assets, and digital heritage, sketching some new practices enabled by the internet and the kind of research that has been done on them. Part 2 is analytical, asking how this research informs concepts within death studies, grouping them within the overall headings of sequestration and social death. Because the internet is increasingly social, our approach is predominantly sociological.

PART 1: PRACTICES, RESEARCH

Methodologically, research in this field is done most easily by going online and observing the sites in which dying people, their carers, and mourners participate. Ethical concerns have been expressed about researchers entering password-protected sites, and even in open group sites whose postings are public, participants may feel these are private and are offended should a lurking researcher make his or her presence known (Thomas, 1996). Some researchers, however, have interviewed site members as well as looking at what they produce (Massimi & Baecker, 2010; Nager & de Vries, 2004; Odom, Harper, Sellen, Kirk, & Banks, 2010; Roberts, 2004). We may here compare research into graves and roadside shrines, where it is much easier to observe and photograph their material culture than to find and interview their creators or those who object to them; or media research where it is much easier to analyze a media product than to observe the process of its production or audience responses. Online, however, contributors to death-related sites often do write about their reasons for contributing, so a certain amount about motives and responses can be gleaned just by observing what is being written online.

Dying

There is very little research specifically about online practices in relation to dying (compared, as will be seen later, with a lot about online memorialization practices). There are, however, areas of IT research—such as online health support groups (not least for those with life threatening conditions), digital inclusion, and blogging—which could be developed into productive research agendas illuminating the contemporary experience of getting to the end of life.

[1] Following boyd and Ellison (2008), we use the term social network site, rather than social networking site. Most SNSs articulate existing networks, making latent ties visible, rather than create new ones; relatively few people use them to meet strangers.

Online Support Groups

Research into online social networks is indebted to Granovetter's classic distinction between strong (close) and weak (peripheral) ties, and Putnam's related distinction between bonding and bridging social capital. Strong ties bond a person to a few close kin and friends, who are likely to be like oneself and hence provide emotional support but few new ideas, perspectives or resources; weak ties create a bridge to a diverse range of people offering a range of resources, which helps build social capital (Granovetter, 1973; Putnam, 2000). In online health groups, do members seek weak bridging ties as a source of information, or strong bonding ties with people like themselves who may provide emotional support (Wright, Rains, & Banas, 2010)? How does gender influence behavior and expectations online (Seale, Charteris-Black, & Ziebland, 2006)? Do those (often male) with instrumental approaches to problem solving go online for information, while those with affective approaches (often female) look online for emotional support (Doka & Martin, 2010)?

There has been considerable research on online support groups for people with life threatening diseases, especially breast cancer (Hoey, Ieropoli, White, & Jefford, 2008; Høybe, Johansen, & Tjørnhøj-Thomsen, 2009), with varying findings as to their efficacy both in providing social support and in influencing health outcomes (Johnson & Ambrose, 2006). Online support groups are easier to access, at any time, than face-to-face groups; a cancer patient who has just heard from her doctor that her prognosis has worsened does not have to wait for the next weekly meeting but can go online immediately and receive messages of support (Wen, McTavish, Kreps, Wise, & Gustafson, 2011). Night owls can discuss their health concerns online at any hour. Rare diseases, with only a handful of sufferers, can have online support groups comprising a very high proportion of all sufferers, at least within the West.

People may also go online to find fellow sufferers not because their condition is rare, but because it is stigmatized and/or they want a forum not dominated by medical narratives. Examples include mental health users (at increased risk of dying through suicide) and women with anorexia (at increased risk of dying through starvation). More directly concerned with dying are assisted suicide websites in jurisdictions where this remains illegal, and sites in which suicide is performed online. Health professionals and relatives may be concerned about the risky behaviors encouraged in sites not moderated by a health professional (Sofka, 2009), even in the absence of clear evidence whether such sites actually increase or decrease the likelihood of suicide, or of starvation. Meanwhile, users of these sites may value them as a sanctuary from professional or family surveillance (Dias, 2003).

Digital Inclusion

Most of those near the end of life are over 70, few of whom are online, and this is particularly true in the United Kingdom of women over 70. Over the past few

years, the U.K. and U.S. governments have been committed to digital inclusion (i.e., getting the whole population online). That primarily means getting the elderly online (Age Concern & Help the Aged, 2009; Dept. for Communities and Local Government, 2008; Ofcom, 2009). The inclusion literature understands the role of social networks in developing social capital, the influence of gender as well as age, and social exclusion.

The marriage of government and the IT industry that underlies this literature is very optimistic, gung-ho even, about the potential benefits for the very old (i.e., those approaching the end of life). Two questions, however, may be asked. First, might the digital inclusion agenda actually increase social polarization among the old, with those already well connected (e.g., with computer literate grandchildren and neighbors) being supported in their online endeavors, while those more socially isolated give up at the first attempt? What is needed is not only elderly-friendly technology, but for digitization programs to be community based, identifying who in the older person's existing networks might be readily on hand to help, and if there is no one, for helpers to be provided within the local neighborhood (or within a care home) (Independent Age & Calouste Gulbenkian Foundation, 2010).

Second, for those elderly and those nearing the end of life who do succeed in going online, will this necessarily help them? Libertarians argue that digital inclusion should mean not only everybody getting online, but also moving from commercial to open source software; otherwise, getting the elderly online means getting this comparatively poor section of the populace to buy expensive software from multinationals such as Microsoft (Stevenson, 2009). The internet is particularly good at mobilizing weak ties, but there is some evidence that those at the end of life are looking not to enhance social capital by extending their weak ties but to capitalize on already existing strong ties (Wright et al., 2010). One study of 63-86 year olds who were already online found high resistance to joining Facebook (Gibson, Arnott, Moneur, Martin, Forbes, & Bhachu, 2010), not least because of concerns about privacy; compared to young adults, they were extremely reluctant to disclose personal information to online "friends" who offline would be mere acquaintances. Privacy settings need to reflect the various levels of disclosure that humans desire with different groups of family, friends, and acquaintances (Stiller & Dunbar, 2007). Online, older adults seem much more concerned with these distinctions than do young people.

At the very least, consideration needs to be given to what those toward the end of their lives might wish to gain from the internet; it will almost certainly differ from how younger generations use the internet (Sum, Mathews, Pourghasem, & Hughes, 2008). If other family members use the internet to help them care for an elderly member at the end of life, does it matter if the old person him or herself is not included in these online conversations? Is this vicarious inclusion? Or exclusion? (In a later section, we consider a similar post-mortem issue, namely

when a web memorial is created and maintained by someone other than the deceased's next of kin.)

That there is little research on such matters (compared, for example, with online groups for less than elderly cancer sufferers), reflects not only the lack of digitally connected elderly, but also the lack of research into the social networks of those who are dying. Even holistic palliative care that focuses on the dying person's family tends to ignore his or her social networks and the resources they can bring; the hospice model is typically of a patient in a family relating to the health services, rather than a person within a social network (of which health services form only a part) (Bowra, 2010). Given this lack of clinical and research interest in patients' social networks, it is not surprising if this lack of interest extends to online networks.

Blogging and Other Practices

A number of people now write blogs about their experience of life threatening and terminal illness. Whether, and if so how, these differ from pre-blogging print illness autobiographies, or pathographies (Hawkins, 1990), has yet to be researched. Does dying become less isolating when the dying person is either writing a blog or reading the blog of another dying person? One might expect rather more raw immediacy from the blogger, while readers' experience of logging in daily to see how the blogger is getting on seems different to reading a print autobiography after the person has died.[2]

The ease with which photographs may be taken with mobile phones and then uploaded to the internet means that pictures of the dying and dead in war zones are now readily accessible to anyone (Whitty, 2010), the execution of Saddam Hussein being the best known.

A possibility, which we have yet to see discussed in print, is to use digital technologies for recording and accessing advance directives. This could be done either via a dedicated website or by inserting a radio-frequency identification (RFID) tag under the skin, and then require emergency and intensive care staff to check the website or tag for instructions. (Tags are already used, for example for nightclub membership.)

Funerals

Since the funeral is one of those rare occasions, for some people the only occasion, when their various social networks gather together in one place, one might expect online networks not to be so important at the funeral as at other times. There are, however, a number of ways in which online facilities are

[2] Some newspapers, however, have serialized print pathographies during the dying person's life (Walter, 2010).

becoming part of the funeral. What follows relies on anecdotal observation and experience, for there is virtually no academic research into how the internet is affecting the contemporary funeral.

In English speaking countries, and in some others, the funeral is becoming a celebration of life (Co-operative Funeralcare, 2011; Garces-Foley & Holcomb, 2005). Funeral celebrants increasingly use Facebook to understand the deceased's character and networks, and use e-mail to check the wording of their eulogy with family members. Although the personalized funeral (in the United Kingdom, from the late 1980s or early 1990s) predates the dominance of the internet, electronic communication certainly facilitates its spread and its evolution into a co-production between family and celebrant.

In the United Kingdom, it is now common for the funeral service sheet to have on its cover a photograph of the deceased, often in good health shortly before they fell ill—as mourners would like to remember them. Sitting looking at this picture, quietly before the service begins, can in my experience be a moving experience, and one that focuses the mind on what is about to happen. When the next of kin is elderly, the picture is likely to have been sent electronically by one family member to another with the knowledge and software to scan and edit photographs and create the cover sheet. (This can be an example of a young person's digital skills being used to include rather than to exclude elderly members.) Likewise, wakes may include a PowerPoint loop of photographs of the deceased over his or her lifetime.

Whereas early examples of this typically come from the family, the funeral industry is now investing in digital technology. A few British crematoria have the facility to display digital images during the service (rather than during the wake), while rather more have the Wesley music system which can download almost any music from the web. In the United States, some funeral homes have the deceased's Facebook site displayed on a screen.

The internet also enables virtual attendance at the funeral. Funerals may now be streamed via the internet to those not present (Pitsillides, Katsikides, & Conreen, 2009). This can enable those who cannot be present physically to attend virtually, and even to contribute virtually. It can also provide a ready excuse for those who do not want to make the physical effort to attend. Thus, this facility can either enhance or detract from the funeral (not unlike the way televising professional sports events can both undermine attendances and increase global interest).

There are also online funerals and memorial ceremonies for those who have only ever been known online, for example when a member of an online gaming community physically dies. A 13-year-old girl's role in an online game was a fighter pilot ace; when she died of leukemia, the other players enacted an online fly-past (Haverinen, 2010). This raises the question of the girl's offline mourners. Were they aware of her online friends? If not, it seems that two totally separate rituals were performed for her. Online and offline friends often

overlap, but in online gaming this is less likely. (It is also the case that co-players in face-to-face gaming, for example in a chess club or football club, may not encounter a player's other friends and family—but they are all likely to meet at the funeral. This may be unlikely with online gamers.)

Mourning and Memorialization

Online memorializing has been categorized in terms of grief-specific and non-grief-specific sites (Sofka, 2009), and intentional and unintentional memorials (Haverinen, 2010). We use these categories to map the terrain of virtual memorializing.

Intentional Memorializing in Grief-Specific Sites

Since the 1990s, cyber-cemeteries have offered their services to mourners, the earlier ones being considerably less interactive and participatory than more contemporary ones (de Vries & Rutherford, 2004). Many of them use cemetery imagery, for example clicking on a picture of cemetery gates into order to enter the site. As will be discussed in Part 2, cyber-cemeteries are particularly popular with, and some are exclusively for, specific types of loss that tend to be disenfranchised in face-to-face relations, such as pet grief, grief following AIDS (Blando, Graves-Ferrick, & Goecke, 2004), and grief for celebrities (Hall & Reid, 2009).

In addition to cyber-cemeteries that, usually for a price, will memorialize anyone, there are also memorial sites for ordinary people who died in specific historical circumstances. Formal American examples include the virtual patchwork quilts of AIDS victims [http://www.aidsquilt.org], the virtual memorial wall for American soldiers who died in Vietnam [http://www.thevirtualwall.org], and the United States Holocaust Memorial Museum, Washington, D.C. [http://www.ushmm.org/] (Sade-Beck, 2004)—each of which, interestingly, is a spin-off from a physical memorial. An Israeli example is the Yad Vashem site [http://www.yadvasem.org.il]. Many of these are highly political, as indeed are a number of quite elaborate tribute sites set up by a family for just one individual, including Shiri Nagari, "a proud Jewish Israeli young woman . . . murdered on Tuesday, June 18, 2002 by a Palestinian suicide bomber on her way to work" [http://www.shiri.us/eng-main.heml, and Trooper Marc H. Niab, "A Hero you were, and always will be . . . ," killed on duty in Afghanistan [http://www.marcdiab.com/index.htm]. Less political are many of the tribute sites set up, often by old media such as newspapers, for famous people, such as singer Michael Jackson or celebrity Jade Goody (Walter, 2011).

One type of website that intentionally commemorates the dead but does not usually involve grief are genealogy and historical sites.

Intentional Memorializing in Non-Grief-Specific Sites

As more and more people spend time interacting with each other online, physical death is now being marked in all kinds of everyday online social network and gaming sites. This occurs for two reasons. Either, a participant in an interactive site dies, and the site then becomes a place in which its still living members commemorate the deceased and share their feelings of loss. SNSs such as Facebook are now developing policies on what to do with deceased members' pages, whether they should be closed, turned into memorial mode, archived, etc. (Faure, 2009; Fletcher, 2009). Or, a living participant in a SNS may wish to indicate his or her status as a mourner, for example by adding an "RIP Granny" flag to their page, or by adding a picture of a deceased loved one, or linking to a memorial site. Some online groups have an increased likelihood of members dying—of suicide in mental health groups (Hsiung, 2007), of starvation in pro-Ana anorexia groups, of cancer in cancer groups (Wen et al., 2011)—so are likely to display memorializing and other grief-related postings. Even outside of social network and gaming sites, death is acknowledged in other group websites. My own university home page not infrequently announces the death of a retired staff member, and infrequently of a current staff member or student, with information about their life plus a funeral or memorial service announcement.

Unintentional Memorials in Non-Grief-Specific Sites

Though a dead person's material possessions are willed to specific recipients, or are sold in the impersonal market (thus detaching the object from memory of the deceased), a person's digital works can hang around in cyberspace indefinitely. Just because material is no longer visible on its original site does not mean it may not be found by unknown others, pre- or post-mortem (Donath, 2004). Even material that has been removed from the internet may have been downloaded by persons unknown and thus persist on their computers. Cyberspace is thus full of deceased persons' digital bits (Pitsillides et al., 2009). Though some of this digital material may become part of a formal or informal online memorial, much may just float around in cyberspace, to be accessed randomly by unknown surfers. This brings us to the final stage in online mortality: digital assets, digital heritage, and digital immortality.

Digital Assets and Digital Heritage

The question of the mortality or immortality of digital data is one discussed more by computer scientists and media researchers than by thanatologists, though there are exceptions (Aitken, 2009). Is digital data more or less mortal than

the products of previous communications technologies? Digital data certainly can be immortal. Once online material is copied by others, the author cannot retrieve ownership; the material may continue in cyberspace even if the original site is removed. Like a virus, once someone else has it, they may pass it on to others without the author's permission. Whether, and to whom, it is accessible, especially in the long run, is another matter. Paper, for example, is easily destroyed, but if it survives can still be read, even centuries later. Digital data is less easily destroyed, but whether future generations will be able to read it is less certain (Gibson, 2007; Jones, 2004). It is nevertheless clear that archaeologists in future centuries will be searching digitally as well as physically for traces of the 21st century; and what they will find on the internet will resemble what they find under the ground: mainly garbage, and graves (Pitsillides et al., 2009).

Returning from the distant future to the present, a number of questions may be asked about control, power, and privacy. At what point should a deceased person's Facebook site be closed, or what protocols should be followed for its memorialization (Walker, 2011)? If a deceased employee included personal messages in his work e-mail, will the employer allow family members access to these messages? Would the deceased wish family members to read such e-mails? Did the deceased leave details of passwords so that family members can access not only e-mail and SNSs, but also commercial sites and (for the self-employed) business accounts? Apart from convenience and privacy, other questions about the distribution of digital assets within families, both pre- and post-mortem, may be asked (Pahl, 1999).

It has been suggested that people should make digital as well as more conventional wills, providing not only passwords but instructions as to what to do with these assets (Walker, 2011). Digital technologies for archiving family material for future generations are being developed (Kirk, Izadi, Sellen, Taylor, Banks, & Hilliges, 2010). There are also services that scan a customer's online activity routinely, and if this ceases for a specified period, the customer is notified and asked if they are still alive; if after repeated inquiries there is no response, then friends and websites can be notified. A number of online providers are offering post-death digital asset management services, but take-up is reportedly not as high as had been predicted; possibly mortality is beyond the horizon for many members of the internet generation (Neild, 2011).

Two studies, one Canadian and one British, have interviewed people about their experiences of both material and digital inheritance. Digital hardware (laptops, mobile phones) was more easily inherited than digital data, which often could not be accessed or were destroyed. Because digital information, unlike paper diaries and letters, is not clearly labeled, people often came across personal information when they were not expecting it. And people could feel burdened by the volume of digital data they had inherited (Massimi & Baecker, 2010; Odom et al., 2010).

PART 2: ANALYSIS

A Challenge to Sequestration?

It has been argued that in modernity, the dying and dead are sequestrated—secluded within special places such as hospitals, hospices, and cemeteries—where they will not disturb the everyday flow of modern life (Giddens, 1991; Mellor & Shilling, 1993). And although bereaved people are expected in most modern societies to continue their everyday activities, at least in Anglophone societies they are expected to keep their grief to themselves, and without visible signs such as mourning dress their status as mourners is hidden (Walter, 1999). Arguably this sequestration or hiding of death, dying, and grief continued with the online developments of the 1990s. Online support groups for particular categories of ill, dying, or grieving people (Seale et al., 2006; Sofka, 1997) replicate non-digital support groups in that they continue to keep death and life threatening diseases such as cancer out of everyday public view; cancer sufferers talk to each other in such groups, perhaps even reducing their need to talk to people without cancer. And just as one has to choose to enter a physical cemetery, so one normally chooses to enter a digital cemetery—though the ease of linking between websites means that it is possible to chance into an online cemetery (Walker, 2007).

In the new millennium, specialist memorial sites have continued, but are now greatly outnumbered (in terms of the number of people and connections made) by general SNSs such as MySpace and Facebook. In these sites, pictures of the dead, conversations with the dead, and mourners' feelings can and do become part of the everyday online world. A digital RIP on one's Facebook indicates one is in mourning. The dead and their mourners are no longer secluded from the rest of society. Though the mass media have long brought death into the living room, audiences are unlikely personally to know these media dead: politicians, celebrities, victims of murder and disaster, and fictional characters (Hanusch, 2010). Web 2.0, however, has brought the personally known dead and dying onto the computer screens, mobile phones, and iPads with which many people now spend more time than they do watching television.

On the face of it, this may seem similar to roadside and other spontaneous shrines in public places which bring death and mourning out of the cemetery and into the street (Santino, 2006; Walter, 2008a). These shrines divide public opinion between those who contribute to them and value them, and those who consider that death should remain within the clear walls of the cemetery and that it is indecent to display grief in public (Petersson, 2010). But is there a difference between laying flowers at a shrine in the street for anyone to see, and grieving on a Facebook site where—depending on your privacy settings—your grief may be witnessed mainly by others who knew, or at least had an interest in, the deceased? We will explore this shortly.

We will now look at some specific areas where it seems that the internet is indeed bringing death, dying, and mourning out of the protective box within which modern society is considered to have located them.

Enfranchising Narratives of Illness and of Grief

One of the main ways in which the dying have been separated from everyday life is through the definition of their condition as primarily medical; even if they are not hospitalized, their dying has become a medical matter. Even accounts by friends and family of their condition are more likely to be in medical terms ("her cancer has spread to her lung") rather than in social, familial, or spiritual terms. Frank has written about the possibility of medical narratives of illness being challenged by other kinds of narratives (Frank, 1995), so the question arises whether the online environment facilitates a wider range of accounts of illness and loss.

That online cemeteries are more likely to attract griefs (for pets, AIDS, celebrities, etc.) that are disenfranchised in face-to-face society (Doka, 1989) has been noted by a number of researchers. The editor of a special journal issue on online grief argues that many kinds of grief in modern America are disenfranchised and that the internet provides a new place for mourners to find a voice (de Vries & Rutherford, 2004). A postscript to this collection wonders whether all grief becomes disenfranchised after a while, since friends think "you should be over it by now," hence the demand for indefinite online memorialization (Moss, 2004).

However, the case for automatic online enfranchisement can be overstated. Sade-Beck's Israeli study found that:

> The departed commemorated in memorial sites usually have socially legitimate and acceptable reasons for their death, such as automobile accidents, terror attacks, incurable diseases, war, and the like; thus, there is no problem posed by telling the story of their lives and deaths in public. Accordingly, there are very few sites for people who died under controversial circumstances surrounding their death, such as suicide, murder, drug overdose, domestic violence and murder. (Sade-Beck, 2004)

Whether Israelis feel under more pressure than Americans to conform online, we do not know. But this study does suggest that the "enfranchisement" thesis may apply only to certain societies, or to certain groups. Or it may apply only to certain sites. For example, though serious and lasting grief for a pet may be totally accepted in pet cemetery sites, it may not be on an ordinary Facebook site.

The thesis that the web provides an arena where socially problematic grief or marginalized illness narratives may be more easily communicated is but one example of a much bigger thesis, namely that the internet provides an unprecedented arena for presenting alternative or marginal views and for resisting dominant media, political and medical cultures (Atton, 2002; Lievrouw, 2011).

This thesis is vigorously debated within cybersociology. Within undemocratic societies, the evidence is mixed. The Egyptian revolution of 2011 was facilitated by Facebook, though more traditional media such as the Al Jazeera news network were also significant. In China, certain websites are blocked, and some apparently free blogs have been flooded by undeclared state-sponsored contributors, so the internet can enable *more* effective state manipulation of popular opinion. Within democratic societies, the evidence is also mixed. One study of American political blogs found that they do not in fact provide alternative views to mainstream political journalism (Kenix, 2009), whereas another (Meraz, 2009) finds the evidence more complex. In the area of health, there is similar variation. Studies of pro-anorexia sites clearly demonstrate online alternatives to medical narratives, providing a sanctuary for women who feel their feelings about their body are not understood by others (Dias, 2003; Miah & Rich, 2008), even to the extent of sites being closed down because more powerful lobbies consider them dangerous. A study of the most popular British websites for breast and prostate cancer, however, found they replicated popular gendered discourse about how men and women cope with cancer (Seale, 2005b), and as with political blogs, there is much interchange between internet sites and old media (Seale, 2005a). And just as face-to-face cancer support groups vary as to the extent to which they enforce a group norm (such as "be positive") or provide a free space for any expression (Helgeson, Cohen, Schulz, & Yasko, 2000), it would be surprising if online groups did not also vary.

So what about memorial sites? Do they enfranchise not only the expression of grief, or of certain kinds of loss, but also the expression of feelings and experiences that may not be expressed elsewhere? An American study of a bulletin board for bereaved parents (Musambira, Hastings, & Hoover, 2006-2007) found that online there was some evidence of non-normatively gendered expressions. In a Dutch study of mothers whose child had died around birth, half the mothers interviewed belonged to an online group, *Lieve Engeltjes (Dear Angels)*; they found support there, which they often did not find with family or partners, suggesting their feelings were accepted online. This supports the enfranchisement thesis. However, half those interviewed did not belong to this group, for good reasons, not least because they felt that the group ethos that only a bereaved mother can understand a bereaved mother would further distance them from partners—this suggests that the online group had developed its own "party line" and was not a free space in which any view could be expressed (Peelen, 2011). This replicates the split opinion about face-to-face mutual help bereavement groups (Walter, 1999).

If one reason that grief is disenfranchised is that the type of loss is not recognized, another is that the griever is not recognized, because of very young or old age, or complex communication needs. Bereaved children and teenagers, who are nowadays "digital natives," are adept at using social network sites, not least in the very early hours and days after the death (Sofka, 2009). The internet may not so easily be adopted by other disenfranchised groups.

The jury is still out on whether cyberspace provides a free area, in this case for the expression of griefs that are stigmatized elsewhere, or by mourners who are stigmatized elsewhere. It may well vary by site, by moderator, by topic, by country, by age, and by individual.

Grief: From Private to Public?

In many modern societies, mourners are not expected to display their grief (Jalland, 2010), though since the latter years of the 20th century there have been moves toward more public expression of grief (Walter, 2008a). Of course, feelings of grief and even heartfelt addressing of the deceased, were expressed in old media, such as grave inscriptions and local newspaper *In Memoriam* columns. However, talking to the dead at physical cemeteries tends to be in silence if there are others around, and in highly stylized form in *In Memoriam* columns. Online, however, the bereft's conversations with their dead are there for all to witness.

If the intimately bereaved can be more public online, what about their audience? Though mourning for someone you never met (for example, your boss's mother) is normative in Japan and Ireland, it is not in many other modern societies, expressed for example in the criticism that Princess Diana's mourners should not have been grieving someone they never met.[3] But online, mourning those you never met has become common practice, and such messages of condolence and support are often (but not always, see below) appreciated by the intimately bereaved. Thus, online memorials provide sites where both the bereft and their well-wishers can express their feelings, with 21st century sites much more likely than 20th century sites to allow for well-wishers (or indeed, see below, detractors) to post their feelings. The bereft may connect with others, previously unknown, who have suffered a similar loss (Roberts, 2004). Grief has become more public.

Depending on their privacy settings, however, many SNS pages are open not to any surfing member of the public, but to a definable online community. So a related question is whether grief online is becoming more communal? Few humans in history have been able, or wanted, to publicize their grief to the whole world, but many have found themselves grieving within their community; though radically undermined by modernity, this social practice may be resurfacing online. We now consider this possibility.

Grief: From Private to Communal?

Before the 20th century (and still today in very poor countries) the most common death was of a child, leaving behind a house in mourning: the main mourners were co-resident, so grief—however personal and emotional—was also

[3] The exception is when mourning concerns war and the nation: it *is* okay for Americans to mourn 9/11 victims not personally known to them, or for Britons to mourn their war dead.

a shared group experience. (That does not necessarily mean it was a good experience.) Through the twentieth century in industrialized societies, the most common death has become that of an old person, often leaving behind a widow or widower living on their own and adult children who have long since left home and moved town or even country, so the main mourners are not co-resident. Moreover, because of the division of home and work, and indeed of leisure activities, mourners daily interact with people who never knew the deceased. People's social networks are fragmented, in death as in life: those in my network A may know few if any of those in my other networks B, C, or D. In these conditions, grief has come to be defined as a private experience, which others can "support" but rarely share (Walter, 1996).

Pre-modern societies tended to produce a bereaved community, modern societies tend to produce bereaved individuals, and post-modern mutual help groups (online or offline) produce a community of the bereaved, that is, connections with previously unknown others who have suffered the same category of loss—the death of a spouse, of a child, of a relative by suicide, etc. (Furedi, 2004; Walter, 1999). SNSs such as Facebook, however, can produce what pre-modernity did: a bereaved community. This is because SNSs provide an arena in which all a person's friends, colleagues, and family members can interact, or at least know of each other's existence. This continues even if a person dies, or is bereaved. A person's diverse mourners may not be co-resident, but on Facebook many of them may be co-present. The person's social networks are thus de-fragmented, and mourning re-emerges as a group experience (Brubaker & Hayes, 2011; Kasket, 2009). That said, integration of a person's networks at death may be more or less partial: online networks may be segregated by age, while some people have different Facebook accounts, each intended for a different social network.

This is part of a much bigger issue in cybersociology, namely whether the internet produces social isolation or enhances community. Twenty years ago it was argued that the internet provided a "third place" outside of home and work where people could meet, compensating for the decline in community (Oldenburg, 1991; Rheingold, 2000). This was challenged by an experimental study of the first year or two online of 73 American households in the late 1990s, which found that internet use decreased interaction with both family and others (Kraut, Lundmark, Patterson, Kiesler, Mukopadhyay, & Scherlis, 1998), though a 3-year follow-up came to a more optimistic conclusion (Kraut, Kiesler, Boneva, Cummings, Helgeson, & Crawford, 2002).

A number of studies have found increased disclosure online, instances where the psychological sense of community is greater than in face-to-face groups, and examples of various types of support (including tangible support) offered by online group members to each other (Roberts, 2004). A recent national representative Pew survey (Hampton, Sessions, Ja Her, & Rainie, 2009) argued that "Americans now have fewer people with whom they discuss important matters, and the diversity of people with whom they discuss these issues has declined"

(p. 55), but those who used the internet and mobile phones were bucking this trend. Digital technology, they argue, is part of the solution, not the problem. The limited evidence so far of mourning within SNSs supports this.

A study of paid obituary pages in major U.S. newspapers found that the online guestbook "reveals interesting connections between strangers or people who knew the deceased only in passing. . . . These neighbors, in-laws, distant cousins, childhood pals, co-workers, and mail carriers provide colorful stories and describe noteworthy and admirable attributes of the deceased that grieving families might not include" (Hume & Bressers, 2009-2010, p. 267). The guestbook brings together disparate individuals who comprise many modern people's fragmented social networks. Online these more distant mourners widen the circle of mourning, demonstrating the potential both of weak ties and of the internet to generate a richer and more diverse community of mourning.

In funerals where mourners do not know each other, or do not know each other well, there can be a tangible sense of temporary community, but as with liminoid communitas in other settings, such as an adventure holiday (Turner, 1974), this is unlikely to last. Interactive online memorialization, however, has the potential to enable the funeral community to continue once mourners have dispersed. For example, Pamela Roberts created a web memorial after her best friend died. This enabled friends who would otherwise only have met at the funeral to carry on talking; Roberts felt no need to make the site public by linking to other sites. Its role in turning the temporary funeral community into a more enduring one was sufficient (Roberts, 2004, pp. 73-74).

New offline mourning practices, such as writing in public condolence books and leaving flowers and messages in public places (Brennan, 2008), turned mourning into a more public practice, but those who subsequently read your condolence message or looked at your flowers do not know you; they are members of the public. The innovation of interactive social media is that grief is re-emerging as a *communal* activity, within existing social networks.

Control and Conflict

As in more traditional settings, the existence of community does not mean the absence of conflict. If the internet allows a free space for the expression of otherwise disenfranchised feelings and views, it is by no means guaranteed that these deviant narratives will always find a welcome. Not everyone approves of certain life threatening behaviors and certain griefs being paraded online.

First, there is the question of who creates and controls a memorial site? MyDeathSpace.com is a site to which deceased people's MySpace profile may be uploaded. The consent of family and friends, however, is not required, and there are instances of them being shocked to find there a family member's profile, under the site's skull logo (Ryan, 2008; Sofka, 2009). The content of some memorial postings may disturb some other people; for example, expressions of

religiosity for one who did not believe, or the expression of materialistic values (Ryan, 2008). It is precisely the internet's fostering of diverse weak ties that can cause individuals in memorial sites to encounter values or language that disturb them. Specifically, different people grieve in different ways, which before the internet often caused problems within families and among close friends (Nadeau, 1998), but now diverse grief reactions can be displayed online to a much wider social network of friends and acquaintances, so one would predict an increase in felt disturbance at how others deal with grief. And if offline there have always been etiquettes for expressing condolences, what kinds of condolence netiquettes are emerging, and with what degree of consensus?

Second, just as there is the possibility of defacing physical graves, so with online memorials. An internet troll who stalks memorial sites and RIP sites on Facebook defacing them with pictures and crude comments explained: "Public grief and grief tourism are extremely obnoxious, selfish habits that so many people on Facebook exhibit. In many cases, these memorial pages are set up by people who hardly even knew the deceased" (Jackson, 2010). This objection is similar to that against spontaneous shrines on public streets (Petersson, 2010; Walter, 2008a): grief may authentically be displayed only for those you know, and mourning should not be allowed to leak into the everyday life of passers by. In other words, death should be sequestrated, for the protection of both the dead and the living.

Of course, such trolls do not protect contributors to memorial sites from abuse or incongruity. MySpace and other open access memorials are easily subject to spam robots promoting pornography or diet pills, which pop up in between the heartfelt messages of friends (Ryan, 2008). Temporary excursions to a link outside the memorial site may generate more spam. Sequestration works both ways (Petersson, 2010), protecting not only everyday life from the fear of death and the pain of grief, but also mourners from the profanities and mundanities of everyday life. Internet memorial users are not necessarily protected from these. Internet memorials may be compared to television disaster reporting, an incongruous "rubbish sandwich in which solemn announcements about the disaster and garment-rending calls for grief alternate with trivial quiz shows, banal soap operas (or) advertising jingles in a commercial break" (Davies, 1999, p. 256). Not everyone approves of death and everyday banality being mixed together, whether on television or in cyberspace.

Our discussion of sequestration has examined online relations between the living and the living. The next section continues this, but soon moves to examining online relationships between the living and the dead.

Social Death

Social death refers to the withering and eventual extinction of social identity and social interaction. It may begin long before death, with old age (Cumming &

Henry, 1961), chronic illness (Bury, 1982), institutionalization (Goffman, 1961), dementia (Sweeting & Gilhooly, 1997); it may start with widowhood (Mulkay & Ernst, 1991) or it may not occur till long after death (Klass, Silverman, & Nickman, 1996). How might digitization hasten or slow the dying of interaction and identity? What events can trigger an elderly person either going offline (transfer to a nursing home or hospital, a stroke?), or for the first time being persuaded to go online (becoming housebound, bereavement?) (Age Concern & Help the Aged, 2009). How do hospital and nursing home policies about computers and mobile phones promote or undermine patients' or residents' social interactions? Will a bedtop computer help keep me socially alive, so that social death comes when I can no longer e-mail or blog? Or does social death only eventually occur when nobody accesses my website any more, or my Facebook is closed down—i.e., when my digital connections have withered (Pitsillides, 2010)?

Continuing Bonds

Online, the dead continue as social actors. A consistent finding in research on online memorials is that they express continuing bonds with the dead (Moss, 2004). To what extent this finding reflects online more than offline memorializing, or simply reflects continuing bonds as a current fashion in bereavement research (Klass et al., 1996), is difficult to say; certainly you do not need a computer to maintain a continuing bond with the dead. Online messages are frequently addressed to the dead (Hastings, Hoover, & Musambira, 2005; Roberts & Lourdes, 1999-2000), but this also is common offline.

But something does occur that is perhaps not so easily found offline: a sense that online the dead are listening (Kasket, 2009). "The inclusion of updates in some of the letters . . . assumes an active listener who keeps up with the day-to-day comings and goings of the living" (de Vries & Rutherford, 2004, p. 21). A Scandinavian mother wrote: "I think of you all the time and wish that I could telephone you and hear your voice. Now I'll send this email up to heaven instead and hope that it reaches you. If you want anything, my dearest boy, I'll be sitting here at my computer for a while every day" (Gustavsson, 2010).

Why do messages in cyberspace seem to reach the dead when the telephone cannot? When addressing the living, there is co-presence (Short, Williams, & Christie, 1976) online rather than face-to-face or on the telephone. But one of the curious features of SNSs, unlike most e-mails and all letters, phone calls, and face-to-face conversations, is that a reply is not necessarily expected; communicating to a deceased person online is thus no different from communicating to a living addressee (Ryan, 2008). In sites such as MySpace or Facebook, set up pre-mortem by the deceased, there may be an uncanny sense of their presence. To put it another way, "The Net is a metaphysical space that mimics our metaphysical experience of the dead as being neither here nor there but somehow everywhere yet nowhere in particular" (Gibson, 2007).

The Copernican revolution may have eroded the plausibility of heaven being up there in the sky, but the digital revolution enables a plausible geography of the dead residing in cyberspace. Posting a Facebook message to the dead and posting a Facebook message to cyberspace feel just the same. If once the dead were once in heaven "up there," now they reside in cyberspace. Significantly, online references to the dead as angels or in the company of angels are frequent (Gustavsson, 2010; Keane, 2009; Walter, 2011); 21st century mourners sit at their computers addressing angels. This is not absurd. Angels are messengers, traveling from heaven to earth and back, and cyberspace is an unseen medium for the transfer of messages through unseen realms, so there may well be a resonance between how some people imagine online messaging and how they imagine angels.

Of course, people talk to the dead offline, and receive advice from them (Marwit & Klass, 1995), not least in cemeteries (Francis, Kellaher, & Neophytou, 2005). What is new about Web 2.0 conversations with the dead is that they are not private, there is no embarrassment about speaking to the dead in the presence of an audience, nor about speaking in a way that presumes the dead are listening. It may be that writing online feels private, almost like a confessional, yet there is in fact a wider audience. This is not to say that everyone welcomes the dead's online presence, which can "elicit confusion and discomfort in those who would prefer to bury their dead" (Ryan, 2008).

Objects of the Dead

The past 2 decades have witnessed growing interest—both in the academy and in the museum—in material culture, and this has been reflected in the past decade in a number of academic studies of how mourners interact with material objects representing the deceased (Gibson, 2008; Hallam & Hockey, 2000; Hallam, Hockey, & Howarth, 1999; Hockey, Komaromy, & Woodthorpe, 2010). The question now arises of how mourners give meaning to, and interact with, digital objects representing the deceased. How do mourners relate to digital remains, and how does this relate to how they relate to material connections with the dead (Massimi & Baecker, 2010; Odom et al., 2010)?

Online memorialization is possible because of the ease with which non-experts can now upload not only text, but also photographs and music. Photographs are taken precisely in order to remember people and events, so there is perhaps always a degree of intentional memorialization in photographic web material. Almost all memorial sites contain a picture of the deceased, sometimes hundreds, and possibly of their funeral. For some visitors, these pictures can represent the deceased better than words. As one mourner wrote "Damn B! Itz takin me so long to even click onto ur page kuz of all the tears that wanna come out from just puttin the curser on ur pic" (Ryan, 2008). Pregnancy loss memorial sites typically have two prominent kinds of image—idealized images of toddler-age

angels, and ultrasound scans and photos of dead stillbirths—and through these images, mothers construct the dead foetus as real and therefore worth mourning (Keane, 2009). If these images make real what society ignores, in other sites photos are used to celebrate what society deems sick or mutilated—for example, in pro-anorexia sites the photographed body validates, for site members, the beauty and legitimacy of the anorexic body (Miah & Rich, 2008).

The Presence of the Dead in Society

Over many centuries, developments in communications technologies and media have radically expanded the presence of the dead within society (Walter, 2008b). In many tribal societies the ancestors play an important role, but these are a relatively small—and often only male—number of forebears within the extended family, whose deeds and character are disseminated orally down the generations, with an ongoing culling from family storytelling and memory of those in between the recent dead who are personally known and group ancestors who are communally known (Humphrey, 1979). The development of printing and literacy radically changed this. It effectively created history, in which any literate person can become acquainted with past people who have influenced contemporary life and culture—cultural "ancestors" way beyond a person's own extended family. World religions, especially religions of the book, rely on literacy for their founders' and prophets' continuing influence. In the 20th century the photograph added another communication technology, enabling the dead to continue to exist in material form indefinitely and reminding everyone of the passing of time and of their mortal nature (Barthes, 1982; Beloff, 2007).

This argument modifies the sequestration of death thesis: though the dying and the emotions of grief may be secluded in modernity from everyday view, the dead themselves are not. There is a long history of new communication technologies giving the dead more, not less, social presence. Twenty-first century SNSs are expanding that presence yet further. We think of a girl whose mother died when she was not yet 2; when she was 12 or 13 she placed at the top of her MySpace site photographs of herself and her dad, with witty captions, and a photo of her mother with the caption "Though I can't remember you Mum, I'll always love you." Her online networks, which in her case coincide closely with her offline networks of school and other friends, thus have at their center her dead mother—a presence that is not overstated, but just there, something impossible before the MySpace era.

The web has developed as a new *milieu de mémoire*, with the potential to democratize memory. Until modernity, memory was constructed by ordinary people, typically through ephemeral forms such as parades, performances, and temporary interventions, but these have been largely replaced by official archival memory, as found, for example, in the museum. So we find in the late 20th century both historical amnesia, and a memory boom (Nora, 1989). The

internet, however, is vernacular, interactive, and participatory, like pre-modern memory. In the 21st century, official memorials and museums are now trying to engage with unofficial memory (the prototype being the archiving of all objects left at the Vietnam Veterans Memorial), "but their capacity to share memory work with ordinary people pales in comparison with digital memorials and archives" (Haskins, 2007, p. 405).

CONCLUSION

How the internet affects how we die and grieve depends on how interactions online relate to interactions offline, and how both affect the experience of those who are dying, caring, mourning, or remembering. In the research reviewed, the relation between interaction and experience has not always been clear. Nevertheless, in this article we have shown how the internet affects key concepts in death studies—sequestration, disenfranchisement, illness narratives, private grief, social death, continuing bonds with the dead, and the presence of the dead in society. The internet changes, or at least has the capacity to change, the way we die and mourn, certainly interactionally, and possibly experientially. While recognizing the trap of hailing each new communications technology as humankind's new savior, we conclude that there are two significant changes or potential changes that the internet can make to dying and grieving.

First, 21st century media have the capacity to desequester the dying, death, and mourning of personally known individuals. SNSs bring death back into everyday life—from both the private *and* the public sphere—in a way that older media such as television and even virtual cemeteries were largely unable to. If late 20th century mass media enabled grief to become more public (to the dismay of some members of the public), 21st century Facebook enables grief to become more communal, that is, shared within the deceased's social networks—something very different.

Second, if social dying is the decay of social interaction and identity, digital technology—including the internet—provides considerable potential for keeping social interaction and identity alive. We should not be over-optimistic about the current generation of the very old going online, nor of future generations of the very old embracing as yet unknown communications innovations. But after physical death, for mourners who are digitally connected, cyberspace provides a remarkable new medium for conversing with the dead, enabling their ongoing presence to be as much social as private.

But the internet is a rapidly changing medium, affording radical new possibilities almost yearly, so thanatologists will have a hard time keeping up with developments. Research findings in this field date quickly. Nevertheless, a number of agendas for the future may be outlined. Research thanatologists need to analyze what has happened so far, as we have tried to do in this article, though most studies will be more detailed and focussed than the present overview.

Clinical thanatologists will wish to keep up-to-date with how the internet can assist both their clients and themselves as professionals (Sanders, 2011; Sofka, 1997). And computer scientists will be designing new technologies for assisting the dying, their carers, mourners, and future historians, and evaluating their use. As death radically affects social interaction, we suggest two research agendas on which both thanatologists and computer scientists could co-operate.

First, more work needs to be done on the potential of SNSs to return dying and grieving to a meaningful network of intimates, friends, and well wishers. A number of SNSs provide (a very limited number of) privacy settings that enable users to determine who may and who may not view their pages. Do these settings coincide with the ways in which people actually categorize their more intimate or more diverse networks? If not (Gibson et al., 2010), there are limits to updates on a dying person's health, or memories of the deceased, being shared within a meaningful community, rather than to a disparate audience of close intimates and possibly unknown "friends of friends." How may more sophisticated sites be developed that respect privacy, as understood by old as well as young, sharing information and feelings to appropriate, rather than inappropriate, networks (Moncur, 2010)?

Second, what is the role of the internet in social network disruption and repair before and after death? How can information technology assist the maintenance of social interaction—for the dying, for their carers and friends, and for the bereaved? The internet may not, except in unusual circumstances, affect physical death, but it can profoundly and routinely impact the process of social death—both before and after physical death.

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