Coping with Death and Grief Through Technology

Panel Proposal
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Organizers

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Introduction

Grieving is a complex, and often private, process in many social settings it is associated with a great deal of depth, seriousness and somberness. Conversely our present-day mobile, digital communication technologies and platforms are most commonly seen as playful, creative and rather shallow. However, the pervasiveness of these technologies in everyday life and communication makes them useful tools in coping with grief. The goal of the papers in this panel is to explore the ways in which technologies are used to cope with death and to explore the ways in which using technologies in this way affects the process of grief.

Background

Social changes in western societies have over a long period been experiencing the privatization of death (Kearl, 1989). Processes such as social, geographic mobility and urban density have enhanced the process of privatization and loss of community. In relation to death, Ariès (1981) argues, that the community feels less involved in the death of one of its members. Conversely, media development has increased the level of familiarity with death and dying with a wide range of programs, from news reports to entertainment, bringing death into the living room (Walter et al 2005). However, many of these insights into the changes in social structures are based in deep studies of pre-web society and the purpose of this panel is to explore the ways in which the more interactive internet-based technologies are transforming the ways, in which we understand death, grieving and coping with loss.

As the grief is a personal and long-term process many bereaved find it difficult to burden family members or social networks prepared to help them with their process. This creates an atmosphere in which there is little opportunity to develop healthy attitudes about death or to learn and share coping skills for managing grief. Brotherson & Soderquist (2002) argue that this also limits the exploration of experiences and possibilities for coping with grief that might be shared in a culture, and that many individuals and professionals are left to develop, find, or stumble across coping mechanisms that may or may not alleviate the difficulty of the mourning process.

Internet based technologies have come to play an important, and demonstrably supportive, role in many areas of human interaction. Its ability to fill a therapeutic role in, for example, chronic illness has been well documented (c.f. Kumervold et al, 2002; Josefsson, 2007). However, as Internet use is shifting to a heavier dependence on online social networks the design, forms and usage is also shifting. Large-scale social networks, such as Facebook, demonstrate several of the symptoms that Ariès (1981) related to the loss of community in modern life and can be seen as the ultimate large-scale population of mobile actors with weak ties. While these weak ties (Granovetter, 1983) have been seen as being useful connections (Ellison et al., 2007) they are often experienced and described as superficial (Tom Tong et al., 2008; Carr, 2011; Turkle, 2011).

Goals of the Panel

The goals of this panel is to study ways in which internet-based technologies are being used in the grieving process, and by this use the technology is playing a normative role in the ways in which death and grieving is understood, experienced and conducted.

Organization of the Panel

This panel consists of six papers from USA, Sweden, Australia and Italy that all deal with the ways in which technology plays a vital part in coping with mortality. The contributions from Lange and Leaver study the ways in which memories can be maintained online, Jones and Farkas both look at the future of post mortem interaction with the living and Micalizzi, Hård af Segerstad & Klang research the role online communities play in the grieving process. These six papers will be presented, by the authors, in the first part of the panel session. Part two is a roundtable discussion, chaired by Charles Ess. Ess will provide a discussion on these important but difficult topics. The roundtable will also include a general discussion with the audience.

Papers presented in the panel

Farkas, Ashley (2013). *Who has the last word? Posthumous social networking and its implications for online grieving.* Drexel University, USA.

Hård af Segerstad, Ylva & Klang, Mathias (2013). *The Depths of Shallow Networks.* University of Gothenburg, Sweden.

Jones, Steve. (2013). *The shadow of the uncanny valley of death: Memory, memorialization and the technologizing of communication*, University of Illinois at Chicago, USA.

Lange. Patricia (2013). *Emotional Expressions of the Studium and Punctum on YouTube Infant Memorials.* California College of Arts, USA.

Leaver, Tama (2013). *A Death on Facebook? Social Media and Posthumous Profiles.* Curtin University, Australia.

Micalizzi, Alessandra. (2013). *Cyber-narratives about perinatal death: the Italian case study of "special mummies" on-line communities.* IULM University, Italy.

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Who has the last word? Posthumous social networking and its implications for online grieving

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Abstract

This paper considers a group of internet-based companies that promise users the opportunity for posthumous social networking. Beyond a final tweet, status update or message to loved ones, these services offer avenues for sustained social media presence after death – the extent and frequency of the activity left up to the individual user. The intentionality and pre-meditation required for participation in social networks after death indicates an interest in ongoing impression management or identity work, bringing in to conversation the literature that claims this as the territory of the bereaved. The study offers insights into the role of the internet in death and grief, particularly how contact from deceased friends and loved ones might affect well-documented grieving processes that take place on sites like Facebook and Twitter. The research suggests broader implications for social media use, digital identity and digital legacy.

Keywords

social networking; grief; digital identity; digital legacy; cyber-immortality

Who has the last word?

Death often prompts loved ones, acquaintances and even strangers to flock to social networking sites (SNSs) – elevating a once innocuous, inconsequential status, tweet or post to some semblance of a person's 'last words'. But several new services are offering a way for our last words to be much more carefully curated. This paper focuses on a group of internet-based companies, recently developed and publicized, that promise users can continue their social networking posthumously. Beyond a final tweet, status update or message to loved ones, these companies offer avenues for sustained social media presence after death – the extent and frequency of the activity left up to the user.

The intentionality and pre-meditation that goes into posthumous social networking offers those who research the role of the internet in death and grief insights into digital identity and perhaps more general motivations of social networking users. It also allows considerations of how contact from deceased friends and loved ones could affect the well-documented grieving processes that take place on sites like Facebook and Twitter.

Literature Review

The use of digital technologies in grief and mourning has been well considered (Brubaker & Hayes, 2011; Carroll & Landry, 2010; Forman et al., 2012; Getty et al., 2011; Micalizzi, 2010; Walter et al., 2011). Dobler (2009) and Brubaker and Hayes (2011) find that the teenagers in their samples communicate directly to the deceased in their SNS posts, often sharing memories, offering praise, and expressing sorrow. Building on this previous work, Marwick & Ellison (2012) show the ways in which the affordances of social networking sites (replicability, scalability, persistence and searchability) shape the public vs. private navigation of grief.

Brubaker and Hayes (2011) observe that post-mortem comments "blend cybermemorial-like practices with communication practices common on SNSs pre-death." This connection with SNS communication practices pre-death offers a framework to understand ways in which users grieving on

profiles of the deceased might respond to a posthumous status update from a dead friend. A planned farewell or regular posthumous status updates indicate both a mimicking of communication practices pre-death, and perhaps also a concern for those grieving the loss.

Impression management or identity work that would ordinarily be done by the owner of the SNS profile is often taken up by the bereaved after death (Marwick & Ellison, 2012; Carroll & Landry, 2010). Previous literature has not considered the deceased as party to the grieving process; it is assumed that departure from the physical world results in a shift in identity work to the mourners left behind. Introducing the deceased back in to this equation means that digital identity is again co-constructed in ways that it was before death.

Finally, a small, but quite relevant, body of literature explores notions of lifecycle and cyber-immortality, which bears on a discussion of both the construction and maintenance of digital identity as well as posthumous social networking practices (see Hayles, 1999; Massimi et al., 2011; Muri, 2003; Steinhart, 2007). Admittedly, the notion of cyberimmortality – somehow escaping bodily death by downloading yourself into cyberspace to live forever – is at present only possible in the worlds of science fiction writers. However, without veering quite that far, considering posthumous social networking as a reality does speak to notions of digital legacy and perhaps cyber-immortality in limited forms.

Methodology

The nature of the sites under examination mean that several registered users would have to pass away and have their services activated to empirically examine how this social networking activity impacts online grieving communities. However, there are still fruitful avenues in which to investigate this topic.

This study employs what Gee and Green (1998) call a "logic-of-inquiry" approach, combining ethnographic orientations with the tools of discourse analysis. Examining popular press coverage, media interviews and comment threads will allow important themes to emerge within the context of existing literature. Participation in the services presently available (two of the four) will give further insight into user experience. Central to the findings will be a discourse analysis of promotional material (websites, Facebook and Twitter feeds, press releases, videos, etc.) for each of the four companies, interrogating how the discourses surrounding these services enact social activity and social identity (Gee, 2010). Ideally, to round out these findings, in-depth interviews will be conducted with company representatives and users signed up for the services.

The four companies that form the data set for this research are briefly described below:

1. *DeadSocial* allows users to populate status updates and tweets, pictures, etc. across their various social networking accounts to be released after death at a time they specify. The free service is in beta, but will launch in March 2013 at SXSW.

2. *If I Die* is a free Facebook application that allows users to record videos or craft status updates to be published posthumously. To promote the app, the company is running a contest: the first user to die is promised international exposure on several blogs and news outlets.

3. *LivesOn* promises a Twitter tool that posts in the voice of a specific person after he or she has died. The service monitors Twitter habits in an effort to mimic syntax and content.

4. *LastWrite* is designed to be notified by the US Social Security database (it is the only site to not require a social media executor to confirm death) of a user's death and then release letters, pictures, videos or a final Facebook post.

Discussion

Significant themes emerge from an analysis of the services that allow for posthumous participation in social networks. First, there is an emphasis placed on maintaining control of your digital identity and representations. Co-founder of *If I Die*, David Rubinstein commented, "It's an era where most of your life and most of your presence is digital, and you want to have some control over it. You want to be in charge of how you are perceived afterward" (Kelly, 2013). Other discussion focused on the ways in which posthumous messages would affect the bereaved, either soothing mourners, or disrupting the grieving process and not allowing the acceptance of a loss.

There is also the matter of whom these services appeal to and what user activity or commentary can reveal about conceptions of digital identity and grieving processes. When asked in a February 27, 2013 post on the *DeadSocial* Facebook page what had attracted users to sign up, responses varied from "to let them feel I'm still here," (indicating a consideration of the mourners), "to live forever," (a nod to cyber-immortality), and "jus tellin people I'm gonna haunt them." These last comments speak to potential negative aspects of posthumous SNS activity – trolling or haunting – already quite common on Facebook memorial sites (Phillips, 2011).

Of course, in many ways, these sites offer a continuation of offline practices, using social media to connect with those grieving your death, instead of leaving written letters. In other ways, these practices offer new insights and further research opportunities into online grieving practices, navigating public/private space online, and our emotional negotiations of death. Even broader implications may suggest that social media is democratizing immortality. These services mean fame or wealth are no longer needed for a well-established legacy – perhaps just some social media foresight.

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License

The shadow of the uncanny valley of death: Memory, memorialization and the technologizing of communication

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Abstract

This paper will use concepts of memory and memorialization to interrogate the notion of communication in the digital age. It will do so by examining technologies of memorialization and virtuality. What happens when memorials are no longer only memory but are present and interactive, essentially able not only to evoke old memories but make new ones? The development of interactive, lifelike avatars with access to a vast memory bank of personal and public information raises fundamental questions for communication and philosophy. This paper will undertake a critical and philosophical exploration of this development, and do so by examining the experience of the externalization of the self not simply as text, or recording, but as entity and incarnation, agent and interlocutor.

Keywords

Memory; memorialization; lifelike avatars; human-machine communication

Subtitle 1 (Arial 10, Bold, Aligned Left, Single Line, 20pt before 10pt after)

This paper will use concepts of memory and memorialization to interrogate the notion of communication in the digital age.

In a television science program reporting on research into aging and immortality, (Popular Science, 2009), the program's producers chose to end a segment examining the development of lifelike avatars by showing a video sequence featuring a woman looking at what seemed to be a prayer card such as those distributed at a traditional western funeral or memorial service. As she looks at the card and unfolds it, what seems to be a holographic image of the decedent is projected into space. She proceeds to have a conversation with the projected image, while the narrator's voiceover states, "Today, when a loved one dies, they leave us with only memories. But in the future, their avatars will be so lifelike, they'll interact with us long after their bodies are gone."

The video sequence is at once strange, creepy and somehow reassuring. It is strange because it augurs that we are a step closer to what Kurzweil has termed the "Singularity" (2005), a time when not only memory but consciousness itself will be uploaded and technologized. It is reassuring because it gives those who grieve another means of keeping alive the memory of a person who has died. It is creepy because it presupposes the ultimate extension of memory, a memory without forgetting that blends with mimesis, and, I believe, takes us into the uncanny valley (Mori, 1970) in particularly difficult, troubling and emotional ways.

While technology has long been used to preserve memory, such efforts at memorialization are intertwined with a long-standing human fear that technology, by externalizing our memory, will cause us to become forgetful (Hamilton & Cairns, 1963; Ong, 1991). In the case of death the lure of recording technologies, whether written, audio or visual, is particularly strong. Research has shown that "writing or talking about (death) tends to help in the long term" (Planalp & Trost, 2008, p. 224), and talking to photographs or objects can help with grieving. Furthermore, it is not uncommon for those grieving to fear losing the memory of the loved one. It is most common in the wake of a disaster such as flood

or fire, for instance, for survivors to comb through rubble and debris in search of family photos. In the case of the death of a loved one, or of a public figure, there are ritualized memorials to commemorate death and preserve memory. In both cases, that of individuals and public figures, there is a form of impression management that takes place (Bonsu, 2007; Jones & Jensen, 2005). Traditionally such memorialization and impression management has taken place through printed media (obituaries, placards, biographies). As networked digital media have proliferated memorialization has moved online, with various consequences that are only beginning to be studied (Marwick & Ellison, 2012; Garde-Hansen, 2010; McCurdy, 2010; Sanderson & Cheong, 2010; Lombard & Selverian, 2008; Veale, 2004).

The fundamental question of this paper is: What happens when memorials are no longer only memory but are present and interactive, essentially able not only to evoke old memories but make new ones? Jones (2004) noted that unlike electronic media in the late 19th and early 20th centuries, the new media of the late 20th century did not spur the kind of renaissance of spiritualism or spirituality noted by Sconce (2000) in his masterful history Haunted Media. Online memorialization, and, soon, virtual memorialization, via lifelike avatars, sets forth the possibility that ghosts will be with us and among us, interacting with us. The use of quasi-holograms of rap star Tupac Shakur and rock star Freddie Mercury in 2012 are early evidence of this possibility on a mass scale.

The development of interactive, lifelike avatars with access to a vast memory bank of personal and public information raises fundamental questions for communication and philosophy, ones that scholars should already be asking but have so far skirted and that will also be central to this paper, namely: What is the nature of communication and communication theory in light of human-machine communication? The study of communication is built on the premise of human-to-human communication (the latter, if not receiving the greatest attention in our media age, at least still being privileged). However, it is quite clear from simple observation that an enormous amount of contemporary communication occurs between humans and devices, whether it be computers, mobile devices, kiosks, automated telephone systems, avatars, and so on. Machines can be a medium of communication, but they may also be communicative. Apple's Siri, for instance, is essentially a vocal expression of a search engine result, and search engines themselves provide a form of communication, not simply a medium for it. And while it could be argued that machines such as mobile devices and search engines, since they are programmed by humans, are therefore in essence engaging users in human communication, or at the very least engaging users in interaction with a text or script written by humans, such is decreasingly the case. While humans did indeed (and for now) create the algorithms from which communication with the user is derived, machine learning means that the algorithms are refined, if not entirely rewritten, by machine.

Scholars in other fields, such as psychology and human-computer interaction (HCI) have explored some of the issues in the realm of machine-human communication (Dean, 2004; Fogg & Eckles, 2007; Suchman, 2009), but with the exception of Nass (Nass & Lee, 2000; Nass & Yen, 2010), Katz (2009) and Gunkel (2012), scholars in communication have yet to explore its ramifications. This paper will undertake a critical and philosophical exploration of these issues, and do so by examining the experience of the externalization of the self not simply as text, or recording, but as entity and incarnation, agent and interlocutor.

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License

Emotional Expressions of the *Studium* and *Punctum* on YouTube Infant Memorials

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Abstract

How do people emotionally experience memorial videos made by people who have suffered the loss of their infant child? Semiotic analyses identify two states that describe people's emotions when interacting with images of people who have passed away. The first is the *studium*, or detached form of sympathy, and the second is the *punctum*, or immediate emotional wound. While most prior studies deal with expressions of sympathy as a single category, the present study uses a discourse analysis approach combined with a semiotic lens to understand nuanced levels of emotions that are indexed in text comments posted to memorial videos. An analysis of several hundred comments posted to two videos on YouTube suggests that some people experience a form of the *punctum*, which is not limited to feelings about a person one knows directly, but is often activated through sympathetic feelings toward YouTube participants experiencing similar forms of bereavement.

Keywords

YouTube; online memorials; semiotics; emotion; video

Introduction

Memorial videos commemorate people who have died. They have appeared on MySpace (Brubaker et al., 2011), Facebook (Kern et al., 2013), YouTube (Wahlberg, 2009), World of Warcraft (Gibbs et al., 2012), and on memorial websites (Finlay & Krueger, 2011). Memorials have aesthetic conventions, such as music, poetry, and photographs that depict the person in childhood and in idealized, recent moments before their death (Wahlberg, 2009). Sharing grief helps people increase social ties and establish feelings of community (Forman et al., 2012). Video memorials' popularity indicates an increased willingness in American culture to speak openly about death (Wahlberg, 2009; Doss 2002).

Brubaker et al. (2011) investigated emotional work on memorials. They coded for levels of emotional distress in comments on MySpace memorials. But additional work needs to be done to understand nuanced forms of bereavement. How do people translate emotional experiences into comments on memorial videos? How do these experiences compare with prior descriptions of mediated mourning?

In the field of semiotics, Barthes (1981) argued that photographs could be emotionally experienced through the *studium* or the *punctum*. The *studium* included contemplating aesthetic formalisms and experiencing sympathy for the photographic subject. In contrast, the *punctum* was more immediate, and included feelings of intense connection between the viewer and the photographic subject. The *punctum* was felt as a shock which pierced through the more analytical reception of the *studium*. Whereas the *studium* indexed detached sympathy, the *punctum* produced an emotional wound.

Combining a semiotic and discourse-analytic approach, this paper examines how viewers respond to memorial videos for deceased infants. The goal is to explore nuanced emotional experiences and to extend understanding of video memorials' role in the American mediated landscape.

Methods

The following case studies appeared during a two-year ethnography of YouTube. The project explored how some 150 participants formed communities by sharing and commenting on videos, as well as interacting in person. Although memorial videos only appeared twice in the qualitative corpus of 200

videos, they indexed an especially poignant way in which grieving parents received solace and social support.

William and Jane (both pseudonyms) described losing an infant in videos and ethnographic interviews. William's video was posted in 2007 and received 425 comments. Jane's video was posted in 2008 and received 38 comments. A total of 463 comments were analyzed using discourse analysis, as described by Johnstone (2002). Discourse analysis considers how meaning is produced within the context and genre of particular texts. The present study also employs a semiotic lens to analyze how people expressed different emotional reactions to videos. Close attention is paid to commenters' specific word choices and how texts exhibited sympathy and empathy with video creators.

Video Wounds

YouTube participants often bonded by sharing difficult experiences. They explained how their participation helped them deal with their pain. William lost his baby to sudden infant death syndrome (SIDS). Jane's son died of a rare medical condition soon after his birth.

William's video orients around a narrative about how he got started on YouTube. Posting memorials often enables self-reflection on a mourner's present as well as his past (Micalizzi, 2010). William used painful, past home footage to explain how his world profoundly changed after his son's death. By making videos, he formed deep-seated relationships with viewers who helped him cope.

Jane's video includes profoundly sad images. Set to music, it depicts her holding her baby in the hospital. Her video includes poetry, ultrasound pictures, photographs of her son connected to tubes and medical equipment, and quotes from medical professionals offering sympathy. In a comment Jane stated:

> *Somehow I feel like if other people see his face and know a little bit of who he was, it makes his death a little bit less pointless.*

William and Jane used video to work through their loss, and commenters enabled them to be heard. Connecting to people who will listen to their stories is considered crucial for working through grief (Finlay & Krueger, 2011). Viewers' comments reveal varied dimensions of emotional support emerging from imagined communities (Anderson, 1985) of YouTube supporters.

Stereotypical Expressions of Sympathy: Indexing the Studium

A few comments directly addressed aesthetic choices. Many included generic video assessments such as "nice," "beautiful," and "touching." Such stereotypical expressions of sympathy or aesthetics index the *studium*. An index is a sign exhibiting an existential relationship to that which it represents (Peirce, 1955). Such common forms of support index a person's experience of sympathy for someone else's pain. Expressions of sympathy in American culture include words like being "sorry" for a person's "loss" and providing religious images of comfort. Examples from the videos include:

> *I hope you find or have found happiness. You're baby boy will be waiting for you in heaven*

> *Probably the best cover of this song I've heard so far. Very moving and I am so sorry about the loss of your son*

> *Very touching, thank you for sharing.*

> *im sorry to hear about your loss. bless you and your strength*

Such words evidently comforted William and Jane, who often individually thanked commenters, and offered their support to fellow mourners.

Translating Raw Emotions: Evidence of the Punctum

Several commenters were intensely moved in an immediate and almost non-verbal way. These sentiments index the *punctum*, or emotional wound or shock aroused through media. As Barthes' (1981, p. 51) stated, "The incapacity of name is a good symptom of disturbance." Several comments began with the word, "Wow," as an index of a stunned reaction that was difficult to verbalize. Examples include:

> *I don't know what to say...That was really touching. I'm sitting here now and I'm crying- but thank you very much...*
>
> *This was so touching. I'm speechless and moved.*
>
> *the words really struck me there.*
>
> *wow. speachless. i am a mother and in tears.*
>
> *Wow! I'm in tears. What a beautiful sweet little child. I'm speechless.*

The *punctum* produces an emotional shock that pierces through ordinary words and stereotypical expressions of sympathy. One commenter expresses being "struck" by the video, indexing an unanticipated reaction. Visceral bodily involvement is indexed through terms such as being "speechless," "moved," and "crying." Barthes argued that the *punctum* was metonymic, meaning that a small moment of viewership might invoke a far larger field of emotions and memories. Commenters similarly indexed an emotional wellspring of memories through detailed descriptions and comments about direct loss or fears of loss as parents of small children.

Conclusion

Expressions of sympathy are often generically analyzed. Yet, they include nuances, ranging from detached support to intense emotional wounds. The former category is consistent with the *studium*, or sympathetic reactions one has not only to photographic subjects, but to video **creators** who have experienced loss. Although Barthes was dubious about experiencing the *punctum* from a moving image, several participants posted video comments that indexed an emotional wound stimulated by actual or fears of loss.

Future studies might explore the nuances of the *studium* and *punctum* as expressed through comment systems to understand the work they accomplish for viewers and video creators. Discourse analysis is only capable of dealing with the translation work that appears in text comments that index emotional reactions. Future studies might use interviews to delve more deeply into how people experience emotions when watching videos created by mourners.

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License

A Death on Facebook? Social Media and Posthumous Profiles.

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Abstract

Due to their size, online platforms and social networking services increasingly have to deal with the question of deceased users. Facebook offers to either memorialise or delete Facebook accounts after the user has died, while other companies such as Google may allow access, but only after extremely laborious processes, which include mailing legal identification and death certificates. Google has the additional challenge of linked services, meaning deleting the overall user account also deletes content they created such as YouTube videos. In general, official digital death policies are very blunt. Emerging digital legacy and asset management companies are allowing users to bequeath their online profiles and tools to others, allowing more complex posthumous management and curation. Digital death will increasingly need to be addressed, and more nuanced options made available, as the number of deceased users grows, while more and more of their legacy is only available online.

Keywords

digital death; identity; social media; Facebook; Google.

As social media has normalized as one of the main communication channels for users across the globe, a variety of social practices are transforming as they are translated onto, and transformed by, digital affordances. While certain areas of etiquette and norms have cohered as social media practices and platforms expand, death remains a profoundly unclear area for the largest social media companies and online platforms. While negative publicity has forced some companies, such as Facebook, to adopt official stances toward posthumous users, the policies addressing deceased users tend to be fairly blunt. Moreover, as online tools and services transform over time, and identity work online includes big companies becoming identity authenticators (for example Facebook, Twitter or Google accounts being used to log into other services), the way in which these companies respond to the death of a user become increasingly important. This paper will examine the official policies of representative online corporations – namely Facebook and Google – both in terms of reporting a death, and the options presented once it has been confirmed. The paper will then explore the question of how such corporations address posthumous profiles given that the profile's creator/owner is clearly no longer using that service, and thus not going to be generating profit for these companies by viewing advertising (or any other direct means). Finally, the paper speculates on the future importance and utility of posthumous profiles both in terms of the friends and loved ones left behind and the broader historical and archival record. These conclusions will include the suggestion of future directions and policy priorities which might make practices around death on social media more meaningful and useful for those left behind.

Facebook only instituted an official policy in relation to deceased users after current users began complaining that Facebook's suggested friends lists were recommending people connect with others who had died (Kelly, 2009). Facebook, at that point, had no consistent ways of addressing issues arising from the death of a user. The policy Facebook formulated makes in mandatory to either memorialize the Facebook account and timeline of a deceased user (the default option) or the account can be deleted altogether at the request of immediate family members (Facebook, 2013). Memorialisation locks an account, meaning no one can log in, nor can new connections can be made, but existing connections persist. In effect, this makes the Facebook profile of a deceased user a memorial space, open to posts from existing 'friends' who can direct message at the deceased user, or share a variety of comments or content intended to celebrate the recently departed. Of course, memorializing an account relies on Facebook being aware that someone has died, and many users don't chose to reveal this fact. In some cases, loved ones are left the password and take over a deceased user's Facebook account, making final decisions about what content remains or gets deleted,

along with policing more actively any future communication with or by that account. Users may also create public memorial pages (that are not profiles) which are often popular sites for various grieving practices, especially around high-profile deaths, such as those involving young people (Buck, 2011; Kaleem, 2012; Kern, Forman, & Gil-Egui, 2012; Marwick & Ellison, 2012).

While Google's policies do not directly state that a deceased user's account must be altered or locked in a particular way, they do make it very difficult for loved ones to gain access to the Google account of a recently deceased user. Indeed, the process of requesting access involves the physical mailing of various proof of identity, a death certificate and an archived email from the deceased before Google will even investigate providing access. At any point, for reasons they will not disclose, Google may decide not to release a Google account to any beneficiary or executor (Google, 2013b). For those who do gain access, there are dangers in managing someone else's Google account which are not always obvious. One important example comes as a result of Google's recent merging of various tools under a unified Google account. As Google's support documents explain, deleting a Google account attached to a Gmail address will also delete all other Google services attached to that identity. So, for example, a loved one who gains access to a recently deceased person's Gmail account might extract the necessary emails and then decide to – quite sensibly – delete the account since it's no longer needed. However, in the process of doing so, any photographs shared by that user on Google Plus, or any videos uploaded to YouTube would also be deleted (Google, 2013a). This fact may not be obvious to a digital executor until they seek out an important family video on YouTube only to find it has been inadvertently erased due to the blunt tools a digital executor has at their disposal in terms of Google account management.

In the case of both Facebook and Google, the official responses are fairly blunt – Google my grant access, but only after a laborious process, and Facebook will not grant access to posthumous profiles at all, but will automatically memorialize them, enshrining the final state of that timeline, whatever it may have displayed. As the number of posthumous profiles grow, it seems likely that users will push to more nuanced controls; digital executors of Facebook profiles may be able, for example, to do a final curation and remove any superfluous or embarrassing material, creating a more fitting memorial in the eyes of remaining loved ones. Of course, niche companies and services are emerging to address these issues well ahead of the online giants. Legacy Locker, for example, allows users to set up a digital will, name executors and beneficiaries, and keep an up-to-date list of social media passwords to be passed on after death (Pitsillides, Jeffries, & Conreen, 2012). While not strictly speaking in line with many Terms of Use, this nevertheless gives loved ones and relatives the chance to make changes to a recently deceased user's various social media presences and decide whether they remain or are closed. In the longer term issues may also arise about archives and history; eventually Facebook will have millions of memorialized profiles that no one has access to. Perhaps these will have historical value, but currently policies forbid Facebook from making them public ever again. No doubt this issue will arise in the coming years for any social media company or online service that lasts the test of time.

While issues around digital death and online services are relatively new, a survey of existing policies and practices leads to the following tentative conclusions and broad recommendations for change:

- at present the official policies of social media companies and online corporations are minimal and relatively blunt;
- where a single account or authentication service is a gateway to different tools, services and content, there should be some ability to separate and curate these posthumously, allowing final curatorial decisions by digital executors;
- due to the lack of available options and the lack of awareness of official options, many users resort to ad hoc responses, such as transferring control of online profiles to immediate family members after a user's death;
- as digital executors and online wills increasingly address social media, policies and practices will need to emerge which provide more fine-grained control over the digital legacies; and

- private corporations will increasingly need to decide and officialise their position on the maintenance of posthumous profiles, including a commitment to either maintain or export the user data of deceased users.

Digital death is a new and emerging area of concern, but as social media and online sharing platforms increasingly house the rich history of individuals, the way those legacies are managed can only become more important across the coming years.

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License

Cyber-narratives about perinatal death: the Italian case study of "special mummies" on-line communities

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In the recent year, the idea of a monolithic identity, stable and predestined, has been replaced by a perspective that sees identity as a "process", a complex and constant ongoing work that regards the individual, his relations and the contexts he moves in. As Di Fraia argues, "rather than an original and unchangeable piece of data, or an immutable property an individual has, identity is conceived of as something that one does, like a task one continues to perform throughout one's life." (Di Fraia, 2007, p. 37).

Identity is a complex issue that can be examined from different standpoints, one of which is the narrative approach, according to which identity is constructed through cognitive and communicative processes based on stories (Mc Adams, 1993; MacIntire, 1988).

Moreover, each individual's identity is not only the result of an interior (narrative) process, but is instead the result of an ongoing interaction between the most significant relationships in which he or she is involved, relationships that contribute to the creation of an interwoven fabric of ontological stories. This relations take place, above all, by the exchange of significant narratives.

Ontological narratives, as Sommers (1994) defines them, are about the self and allow the individual to express the personal identity to others. Writing (or talking) about oneself is a narrative process that involves others, in a dialogue that takes shape in the narration itself. The role of the other is fundamental because he/she is a witness to our being in and of the world: "basically, we need others to understand who we are and, for this reason, we are speaking to ourselves when we constantly tell our story to others" (Di Fraia 2007, p. 46).

These ontological narratives are also exchanged by personal media, and above all on the Net. For this reason and from this perspective, it is interesting to explain the relationship between narration and the Internet. According to Walker's definition (2001), the Internet is basically a narrative technology, a specific relational context where fragmented stories are shared.

The Internet can be also considered an identity technology, one of the available "digitalized extroversions of psychological processes, through which every human being constantly produces and reproduces his identity" (Di Fraia, 2007, p. 36).

This papers aims at preseting the main results of an empirical research about the role of the Web in the processing of bereavement after a perinatal death.

Perinatal death mourning refers to the loss of a child during pregnancy or before completing the second month of life (Ravaldi, 2006). Very often this kind of experience isn't recognized like a "real" loss and the family – above all the mother –is invited to react in few weeks.

 From a strictly narrative point of view, it is a very painful turning point that, besides completely reorganizing one's life story, also puts some aspects of individual and social identity into question.

I wondered if the Internet, as a narrative technology, could make the process of reorganizing one's identity easier by providing areas in which to share painful experiences.

The case of perinatal death mourning is an example of a situation in which there is a discrepancy between the social self – defined by how others see you – and the individual's perception of the self (Pecchinenda, 2009).

My study was focused on three on-line communities about perinatal death. The objective of the research was to determine whether the Internet could develop a new area for socialization and discussion of a loss, with reference to a case of mourning that is not yet fully recognized socially.

I opted for dividing the fieldwork in two phases. During the first phase, I used the ethnographic method and participated as a researcher in three communities dedicated to this topic for six months. After becoming acclimated, I was able to create bonds with some of the women and I started the second phase of the research, in which 25 e-mail interviews were administered on the theme of loss and on the meaning of participating in a virtual community.

The study lead to underline some cultural elements that affect the process of mourning and consequently the use (and the role) of the on-line communities.

In the first place, in Italy, perinatal death mourning receives no support from the national health care system and, similarly, there are only a small number of virtual spaces dedicated to sharing this experience. Nevertheless, in the past few years, there have been numerous initiatives designed to raise awareness and form groups, which were principally spontaneous and local associations. For example, it was within one of the groups in the study that chatting was first used to meet and discuss in groups. They tried to create a setting for mutual self-help groups.

In the second place, perinatal death mourning is often thought to be a purely female experience, since the mother is seen as the only person involved. Some of the main results can be synthesized by the following points:

- the communal boundaries have precise limits, defined by some procedural and technological markers. In fact, it doesn't deal with filters to the platform set by the log in, but the meaning of the identity that is behind the choice of a particular account. Users access the community with a nickname that expresses the identity denied them – as mothers.

- writing about oneself on the Net is of fundamental importance to those elaborating a loss and trying to make sense of a traumatic experience. In fact, the use of written language, even if concise, instantaneous and immediate, forces net users to utilize a more linear and rational process of communication than spoken discourse.

- In terms of interactive technology, the web also gives members of this community the possibility of reflecting on their own entries and those of others.

- Therefore, the Internet is also a place for social recognition, a place where it is possible "to be a mother again" and to satisfy this role through the preservation of the memories of the lost child.

It is possible to end up affirming that the interactive contexts I analyzed offer a valid support for the mourner in the double passage of identity: from expectant mother to mourner; from mourner to special mommy.

The principal theories regarding the mourning process (Kaplan, 1996) show how the *work of elaboration* (Freud, 1917) is done at the moment one is able to interiorly shift the associations with the memory of the deceased. The process ends when it is possible to disassociate the pain of the tremendous loss from the images of who was lost, putting it in an interior space created specifically for the memory of the moments shared with a loved one.

The web, and above all the on-line communities, contribute to making this passage possible, defining a space in the memory and letting the mourner recover her lost identity.

Keywords

Grief, mourning, on-line communities, digital narratives, digital emotions

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The Depths of Shallow Networks

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Abstract

Parental grief has been recognized as the most intense and overwhelming of all griefs and research has shown that bereaved parents' need to talk about their late child continues over an extended period of time. New understandings of parental grief focus on continuing bonds and holding on, which often counteracts with cultural norms and expectations by society. Results from a pilot-study, with the aim of gaining insight into the use of Facebook as a tool for learning to cope with death, grief and mourning, support previous research which argue for a new understanding of grief. The technological affordances of online social networks support and give access to the exchange of experience with other grieving parents in ways that begin to fill an evident need for the bereaved, allowing for profound use of what is often perceived as shallow networks.

Keywords

parental grief, coping, networks, mourning, death

Introduction

Large-scale social networks, such as Facebook, demonstrate several of the symptoms that Ariès (1981) related to the loss of community in modern life and can be seen as the ultimate large-scale population of mobile actors with weak ties. While these weak ties (Granovetter, 1983) have been seen as being useful connections (Ellison et al., 2007) they are often experienced and described as superficial (Tom Tong et al., 2008; Carr, 2011; Turkle, 2011). The popular social media discourse has a tendency to focus on the harmful or frivolous nature of the technology use. Despite this perceived superficial social network, profound interaction does indeed take place. Among them, and the focus of this work, is the use of Facebook as a tool for learning to cope with death, grief and mourning, thus highlighting the possible depths of perceived shallow networks.

Conspiracy of Silence

The experience of death is a universal human experience. However, the death of a child is said to be the most stressful of all the possible losses individuals may experience in life (Schwab, 1990). Parental grief has been recognized as the most intense and overwhelming of all griefs (Rando 1986; Rees 1997 in Davies, 2004), a particularly severe type of loss that tends to ignite extreme distress or grief over an extended period of time (Parkes, 1988).

The death of a child as a topic of conversation is often avoided in western culture. Fitzgerald (1994) points out that there is a "conspiracy of silence" about the subject in our cultural conversation which, together with the limitations of our understanding of parental grief, contributes to the challenges in helping parents cope with a child's death. Riches and Dawson's study (2000) shows that bereaved parents cannot always find someone in their own families or in their social surrounding prepared to listen to them talking about their deceased children. Dyregrov (2002) also argues that many bereaved experience family and friends withdrawing after a while, that they can no longer bear the constant need for talking about the dead child and the crying. As Davies (2004) points out, Riches and Dawson's study showed many experience social isolation and intense loneliness and find it difficult to talk about their late child to partners, surviving children and the wider social world, which is also supported by Brotherson & Soderquist (2002). Grinyer (2012) remarks that as the loss of a child goes against the 'natural order', bereaved parents may not know others who have endured a similar loss;

thus their grief may be neither shared nor understood. Riches and Dawson's study also showed that some parents find it difficult to discuss their dead children with those who have not suffered the same loss. All this creates an atmosphere in which there is little opportunity to learn and share coping skills for managing grief.

Re-interpreting Grief

Theoretical perspectives on parental grief have undergone a paradigm shift over the last century (Davies, 2004). Theoretical understanding have gone from traditional perspectives emphasizing concepts of breaking bonds, or of letting go of one's relationship with the dead, while new perspectives focus on continuing bonds and holding on. This counters the often unrealistic expectations by society and even some practitioners that parents should get over the death of their child and as soon as possible get back to functioning as a productive member of society. As we have seen above, it has been shown that grieving parents' need to talk about their late child continues over an extended period of time. Studies have shown that grieving parents find solace and comfort by holding on to their lost children by sharing memories as well as retaining mementos such as photographs and toys (Rosenblatt (2000) and Talbot (2002) in Davies (2005). Laakso & Paunonen-Ilmonen (2001) report that bereaved mothers used reading and writing about their grief and loss as coping strategies.

Brotherson & Soderquist (2002) argue that the cultural avoidance of talking about death also limits the exploration of experiences and possibilities for coping with grief that might be shared in a culture, and that many individuals and professionals are left to develop, find, or stumble across coping mechanisms that may or may not alleviate the difficulty of the mourning process. Consequently, there are not many places or situations where grieving parents may talk about their dead children or their experiences and feelings in trying to cope with their loss.

Social Networks as Subversive Technology

Internet based technologies have come to play an important, and demonstrably supportive, role in many areas of human interaction. Its ability to fill a therapeutic role in, for example, chronic illness has been well documented (cf. Kumervold et al, 2002; Josefsson, 2007; Hagen, 2012). However, as Internet use is shifting to a heavier dependence on online social networks the design, forms and usage is also shifting. Online grief communities represent relatively new forms of peer support (Swartwood, et al., 2011). The technology of social networks supports and facilitates what previous research has found to be important factors in the process of learning to cope with the death of a child. Web-based and mobile technologies offer formats and fora, which allow grieving parents to do this in new ways.

Results from a pilot-study (Hård af Segerstad & Klang, 2012), with the aim of gaining insight into the use of Facebook as a tool for learning to cope with death, grief and mourning, support previous research which argue for a new understanding of grief. The study comprised a survey and interviews with members in a closed group for bereaved parents on Facebook. As we have seen, the demands outside the closed group - in other "open" fora in social media as well as in the physical world by friends, family, health care system and society - require the bereaved parent to let go of their deceased child. Within the community in the closed group, holding on is the norm, which means that Facebook is being used as a subversive technology, in an attempt to transform the established social order and its structures of power, authority and hierarchy. In the closed group, the bereaved parents may get in touch with other parents who share their experience of losing a child, read others stories of loss and iteratively write about their own. Knowledge and experience of losing a child, and of coping with grief and loss is distributed among the members of the closed group and made available, as it were, to everyone in the group. Means for continuing the bonds are also facilitated by the technology itself: members post status updates ventilating their grief, ask advice, comment and support one another, post photos, videos, links related to their children and mourning.

Existing structures within healthcare systems in western societies are unable to efficiently provide for a long-term therapeutic support in cases of bereavement. This may be seen as a failure of a healthcare system to adequately enable citizens to return to a well-rounded life. As the need for this support is not provided other structures emerge, it is in situations such as these that lay experts may provide an important social service. The technological affordances of online social networks support and give access to the exchange of experience with other grieving parents in ways that begin to fill an evident need for the bereaved, allowing for profound use of what is often perceived as shallow networks.

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