**Situating Ethics in Online Mourning Research: A Scoping Review of Empirical Studies**

**Abstract**: In the past decade, social media have put mourning practices at the forefront of daily life in ways that challenge assumptions made about the public disclosure of information often construed as being highly intimate. This paper examines how researchers conceive online mourning in empirical studies and how such conceptions inform (or not) methodological and ethical decisions. Through a scoping review, we identified 40 empirical papers addressing online mourning. Our analysis shows that, while online mourning practices have overwhelmingly been problematized in terms of privacy and publicness within the current literature, ethical issues relating to their analysis have been scarcely addressed in empirical research. In line with Foucault’s (1977) work on the *dispositif*, we then examine the performative role of privacy and data sensitivity in the context of online mourning research (notably in relation to consent procurement) and discuss our findings in light of emerging trends in context-based ethics.

**The Study of Online Mourning**

In March 2007, a friend of one of this paper’s authors passed away. A few days later, family members and friends gathered within a Facebook group that had been created specifically for them to pay their final tribute. This event has largely contributed to our personal and academic interests in death and mourning in the digital age. It has also played a big part in the development of a study that took place from 2010 to 2012 which examined how Facebook users negotiate the social and technical norms associated with online mourning (Myles & Millerand, 2016). To do so, we conducted non-participant observation in a commemorative Facebook group created in 2008 following the sudden death of a young French-Canadian woman whom we renamed Sophie, a study to which we will refer sporadically in this paper. If mourning practices taking place on social media were scarce in 2008, ten years later, they appear to have widely spread. Consequently, the interest in this topic among academics has also rapidly increased over the past decade, resulting in a growing body of studies and anthologies (Christensen & Sandvik, 2014; Graham, Gibbs & Aceti, 2013), as well as in the creation of conferences and research networks dedicated o death, mourning, and their computer-mediated expression (see, among others, the Death Online Research network and symposiums, as well as the DIGMEX research network and the Digital Experience conferences).

Online mourning constitutes a fascinating research object, as it has the propensity to exacerbate opinions and beliefs regarding the public disclosure of information that is often construed as being highly intimate in nature. In the public sphere, online mourning has been met with mixed reactions. In the North American press, while some articles have focused on how social media can help users during times of grief (Katims, 2010), others have stressed that grief expression on social media is “awkward” (Paiement-Paradis, 2010) or even downright “desperate” (Green, 2010). In reaction to the increase of public mourning practices on social media, Green (2010) asks: “How has personal tragedy suddenly become such public property?” Some would argue that it has not. Instead, it is our contemporary conception of mourning that has become more psychological and individualistic, whereas its social and communicational dimensions have been underappreciated (Bosticco & Thompson, 2005; Christensen, Hård af Segerstad, Kasperowski, & Sandvik, 2017; Walter, 1999). As Durkheim ([1912] 2008, p. 567) has pointed out long before social media came to be, “mourning is not the spontaneous expression of individual emotions”. This does not mean, however, that the emotions that we express in times of grief are inauthentic, but that mourning is highly ritualized and “provokes individual and mass behaviours (attitudes, conducts, rites) that are more or less rigorously codified depending on cases, locations and times” (Thomas, 1988, p. 44).

Indeed, studying how humans mourn their dead means to take into consideration various tensions and paradoxes. On the one hand, as argued by anthropologist Philippe Ariès (1974), our shared mentalities over death have evolved throughout history. Ariès segments this evolution into four main categories, the last one being the *Forbidden* (sometimes *Hidden*) *Death* which refers to the general observation that death and dying have become taboo and are experienced in increasingly remote or intimate settings within Western societies. Although this thesis has been the subject of well-funded criticisms that, among others, underline Ariès’ conservative – and even romantic – conception of past mourning rituals (Bauman, 1992; Walter, 1999), as well as the author’s underestimation of local differences in Western cultures (Jacobsen, 2016), researchers tend to agree that, due to numerous advancements in the field of medicine and to a relative stable geopolitical climate, Westerners now experience death and dying less directly or, at least, in later stages of life. On the other hand, if death has become somewhat of an exceptional occurrence in daily life over the last century, mediated forms of death appear in video games, movies, and television shows, as well as in news bulletins and on social media. This has led Jacobsen (2016, p. 1) to hypothesize the emergence of new mentalities toward death in contemporary societies, what he refers to as the *Spectacular Death* which contends the existence of “several paradoxical tendencies making death linger uneasily between liberation and denial as well as between autonomy and control”.

Although the debate as to whether we have entered a new realm regarding how we conceive death and perform mourning goes well beyond the scope of this paper, the development and the propagation of social media have contributed to reintroducing mourning practices into the realm of everydayness, but in newly configured ways. Facebook constitutes without a doubt the most eloquent example of such reconfigurations since it has adopted the Timeline (and, by extension, the life and death) architectural metaphor in 2012. In addition, Facebook has been offering the possibility to memorialize its deceased users’ profiles since 2009 and performing ongoing work on post-mortem data management (Brubaker, Dombrowski, Gilbert, Kusumakaulika, & Hayes, 2014). What we wish to underline, here, is how social media have put mourning practices at the forefront of daily life, although with differentiated levels of visibility that effectively exacerbate norms and rules surrounding the public expression of grief. Moreover, not only do social media offer new ways to mourn, but they also offer multimodal traces that can be accessed by researchers with some relative ease, what we will refer to as *found data* (Jensen, 2012) throughout this article. In turn, this leads to crucial ethical issues surrounding the use for research purposes of digital traces that relate to practices that have historically and culturally been construed as being intimate in nature. As Carmack and DeGroot (2014) argue, for some, the use of such traces inherently relies on the exploitation of a vulnerable population, while others consider their use as unproblematic when extracted from publicly accessible settings.

This issue relates directly to the study that we have conducted within Sophie’s commemorative group. Our institutional review board approved the study design in 2010. Since Sophie’s group was deemed publicly accessible, the committee decided that we did not need to procure free and informed consent, given that we would also anonymize all nominative data. Our decision to enforce the committee’s decision was not well received among our colleagues and friends who believed that this data was highly sensitive and that researchers had no right to use it without receiving proper consent. This situation allowed us to observe how people in our professional and personal networks conceive death, mourning, and their computer-mediated expression. Indeed, data generated by online mourning practices are interesting as their sensitive status does not derive from legal obligations, like health-related information protected by law. Furthermore, despite the presence of a certain social stigma, the public disclosure of online mourning practices – and the potential augmentation of their visibility through the act of scientific publication – is not explicitly linked to causing harm or prejudice, like it can be the case with data that relate, for example, to sexual orientation (in certain cultural contexts). Hence, the belief that online mourning practices are inherently intimate appears first and foremost moral in nature.

Yet, considering online mourning practices through the lens of intimacy (rather than as *being* intimate in nature) can also mean to look at their propensity to reproduce and/or challenge dominant assumptions made about privacy and publicness (Berlant, 1998). This means not only to look at how such practices are defined by actors themselves (what they are, how and where they should take place, etc.), but also at how they are studied by researchers (as a set of collective actions, as a personal process, etc.). In that sense, rather than to posit as to whether online mourning practices are private or public in nature, this paper examines how researchers conceive those practices and how such conceptions inform (or not) methodological and ethical decisions in empirical studies. First, we detail our scoping review method – which was conducted by using Jensen’s (2012) distinction between *found data* (observation and analysis of digital traces found online) and *made data* (collection techniques such as surveys and interviews) – and describe our corpus. In the context of online mourning research, the use of each type of data is known to generate different ethical issues in relation to collection, analysis, and dissemination (Hård af Segerstad, Kullenberg, Kasperkowski, & Howes, 2017). Then, we underline how online mourning practices are apprehended in the literature (*Are these practices considered private or public?*) and investigate how such conceptions lead (or not) to different methodological and ethical decisions (*Is this data considered to be sensitive?*). Finally, we reflect on the ethical issues raised by this scoping review and, more specifically, by the use of *found data* in the context of online mourning research. In line with Foucault’s (1977) work on the *dispositif*, we then examine the performative role of privacy and data sensitivity in the context of online mourning research (notably in relation to consent procurement) and discuss our findings in light of emerging trends in context-based ethics.

***Found Data*, *Made Data*: A Scoping Review of Online Mourning Research**

Inspired by Arksey & O’Malley (2005), this article relies on a scoping review which consisted of a search in peer-reviewed journals and books in the social sciences and humanities using key terms such as online, mourning, death, grief,and other related terms. We also conducted a snowball search in the papers’ bibliographies and in Google Scholar. Our main criterion for inclusion was the use of empirical methods to study online mourning. Our initial research question was: *How are issues related to research ethics addressed in the empirical literature about online mourning practices?* Given the emergence of contextual approaches to Internet research ethics (Markham, 2015), we wanted to see how different empirical contexts informed methodological design. Our objective was to map the key issues addressed in the literature, which could then be explored in more depth. As our review progressed, it became clear that there appeared to be a growing body of studies that used data found on publicly accessible sites, which presented significant methodological challenges and ambiguities. This led us to further focus our search on studies based on *found data* and pay less attention to papers addressing psychosocial well-being and social support from a health perspective. Through this exploratory process, we identified 39 papers that were written in English and one in French (n=40). Although our method does not rely on a systematic selection process, it did allow us to identify research trends and underline recurring, as well as contrasting methodological and ethical issues. Following Jensen (2012), we classified papers into three categories to facilitate comparison all the while underlining methodological specificities: the ones using *found data* (n=25)*, made data* (n=8), or both (n=7). Twenty-three additional papers were initially considered but were discarded because they did not include empirical results.

So far, the literature on online mourning has focused on a variety of online platforms. Publicly accessible platforms include virtual memorials (Arthur, 2009; Barnhill & Owen, 2007; Finlay & Krueger, 2011; Lévy & Toupin, 2004), online guest books hosted by funeral homes (Giaxoglou, 2014) and organizations like the New York City Police Department (Foot,Warnick, & Schneider, 2006) and the Apple multinational (Bell & Taylor, 2016). Unlike social networking sites (SNS), these platforms allow limited interactions between users. As for their part, SNS have received growing attention among scholars in the past decade, Facebook being the site most often studied. Researchers have analyzed commemorative Facebook pages (Courbet & Fourquet-Courbet, 2014; Kern et al., 2013; Irwin, 2015), profiles of deceased users (Church, 2013; DeGroot, 2014; Getty et al., 2011; Marwick & Ellison, 2012; Pennington, 2013), or both (McEwen & Scheaffer, 2013), as well as publicly accessible (Forman, Kern, & Gil-Egui, 2012; Giaxoglou, 2014; Myles & Millerand, 2016) and closed commemorative groups (Hård af Segerstad et al., 2017). Other platforms include MySpace (Brubaker & Vertesi, 2010; Carroll & Landry, 2010), discussion forums (Bell & Taylor, 2016), YouTube (Gibson, 2016; Harju, 2015), and Instagram (Gibbs, Meese, Arnold, Nansen, & Carter, 2015). While most studies have focused on personal loss (of a friend or a family member), some have documented mourning practices following the death of public figures (Courbet & Fourquet-Courbet, 2014; Lévy & Toupin, 2004; Sanderson & Hope Cheong, 2010) and events such as terrorist attacks (Foot et al., 2006), wars (Arthur, 2009), and shootings (Vicary & Fraley, 2010). Before proceeding with our analysis, we cannot stress enough that the aim of this scoping review was not to criticize the work of the selected group of researchers (of which we are a part), but to underline the current methodological trends in online mourning research and their ethical implications.

**Problematizing Online Mourning: Between Privacy and Publicness**

Overall, researchers have highlighted that the Internet offers new opportunities for individual and collective expressions of grief. Online mourning practices have profound impacts on Western societies (Bell & Taylor, 2016; Giaxoglou, 2014; Harju, 2015; Marwick & Ellison, 2015; McEwen & Scheaffer, 2013) and could, for some, represent “a shift from a death denying culture to one that once again views death as a natural fact of life” (Barnhill & Owen, 2007, p. 5). Furthermore, our analysis shows that, so far, online mourning has overwhelmingly been problematized in the literature in relation to emerging tensions between privacy and publicness. Social media is believed to foster conversations around the taboo topic of death that had been “confined to quiet rooms in hospitals” (Church, 2013, p. 184) and kept “private and unseen” (Gibbs et al., 2015, p. 265) in the past century. These platforms give individuals an opportunity to express and share grief collectively (Carroll & Landry, 2010), to receive and offer support (Chapple & Ziebland, 2011; Forman et al., 2012; Getty et al., 2011; Pennington, 2013; Vicary & Fraley, 2010), and to develop a sense of solidarity (Barnhill & Owen, 2007; Courbet & Fourquet-Courbet, 2014; Sherlock, 2013).

Some, like Brubaker et al. (2013, p. 152), argue that there have always been private and communal dimensions to grieving, and that online practices can thus be conceptualized as “new sites in which public mourning takes place”, alongside traditional platforms such as newspaper obituaries, television programs (McEwen & Scheaffer, 2013), and in-person bereavement support groups (Barnhill & Owen, 2007). Others have pointed out that online mourning practices contribute to the blurring of traditional boundaries between public and private mourning in several ways (Arthur, 2009; Foot et al., 2006), as they have changed how we mourn, whom we mourn, and with whom we mourn (Gibson, 2016). For example, SNS offer new opportunities for “intimate mourning between strangers” (Gibson, 2016, p. 633), for public sharing of “traditionally private comments” (Brubaker & Hayes, 2011), and for collective memorialization (Kern et al., 2013), as well as increase the visibility of various “public” and “private” expressions of grief. As Foot et al. (2006, p. 92) conclude, “the distinction between public and vernacular memorializing that has been useful in scholarship of offline memorials, has been harder to sustain, and perhaps less useful, in studies of Web-based memorializing.” Several studies have highlighted that online mourning practices also give individuals new opportunities to cope with their private emotions (Marwick & Ellison, 2012) by making it possible to maintain a bond with the deceased (Getty et al., 2011; Irwin, 2015) and by allowing new forms of identity construction (Brubaker & Vertesi, 2010; Finlay & Krueger, 2011).

Twenty-five papers identified in our review drew exclusively from *found data*. By *found data,* we mean digital traces that were produced by Internet users within various online platforms (memorials, cemeteries, SNS, and so on) and recovered by researchers for qualitative, quantitative, or mixed analysis. The collection of user-generated materials for analytical purposes is a growing trend in the social sciences and humanities, particularly in interpretive research undertaken within the field of Internet Studies (Bowker, 2007; Howison, Wiggins, & Crowston, 2011; Latzko-Toth et al., 2017). In our review, using *found data* was considered as being ideal for the study of online mourning practices in a “naturalistic setting” (Brubaker, Kivran-Swaine, Taber, & Hayes, 2012, p. 44). *Found data* was also deemed more accessible and multimodal, as it consists of texts, videos, images, and so on (Barnhill & Owen, 2007). Initially, we hypothesized that certain factors related to the use of *found data* would inform more or less directly methodological and/or ethical decisions. The factors that we originally identified were the nature of the case study (*Who is mourning? Who has died and how?*), the nature of the online setting (*Are these practices undertaken on a memorial? On a Facebook page? On a Facebook profile?*), the researchers’ conceptions of online mourning (*Are these practices thought as intimate? Public or private? Collective or individual?*), and the researchers’ conceptions regarding the mourners themselves (*Do they constitute a vulnerable population?*). For example, we believed that researchers who identified grief expression as an intimate practice would be more inclined to procure consent before collecting and analyzing digital traces.

Our review shows that these factors did not appear to have influenced research designs or, at least, that this relation was not addressed explicitly by researchers. Indeed, out of the 25 papers that used *found data*, none have stated that the procurement of consent had been reached. While a majority of papers (n=23) did not formally address the issue of consent, two papers (Bell & Taylor, 2016; Sanderson & Hope Cheong, 2010) explained the decision not to seek free and informed consent before collecting digital traces. Somewhat paradoxically, these two papers were related to the death of a public figure (Michael Jackson and Steve Jobs respectively) and not to proximal loss (n=20). For Sanderson & Hope Cheong (2010, p. 331), the waiver for procuring free and informed consent was explained by using the American Code of Federal Regulations (in Walther, 2002) which states that “collecting data from publicly available sources qualifies for a human subjects exemption”, to the extent that Internet users should be aware that the information that they publish online can be accessed and exploited by any individuals or collectives. For Bell & Taylor (2016, p. 118), although the topic of death was believed to be sensitive, the contents that were retrieved online were “analyzed without the need for informed consent from the producer of each document or those represented in them” since the latter were apprehended as “published documents”. Thus, consent waiver is here linked to at least two factors: terrain accessibility (*Is the online setting open or freely accessible to researchers and other users?*) and texuality (*Are online texts apprehended as published documents? As extensions of the persons?*). This relates to ongoing ethical reflections on online space and ownership that have been discussed elsewhere (Bassett & O’Riordan, 2002).

Two additional papers addressed consent in an indirect way, as these authors explained that they had selected “unobtrusive” (Irwin, 2015, p. 126) or “non-invasive” (Getty et al., 2011, p. 997) observation and data collection methods. In the first article, the decision to use an unobtrusive method was supported by offering a definition of “computer-driven data content analysis” which looks at content that is “placed freely by people who know that it can be looked at and used by anyone who wishes to” (Hesse-Biber & Leavy, 2006, p. 308, as cited in Irwin, 2015, p. 216). In comparison, the second article argued that non-invasive methods constitute strategies that are “sensitive and respectful to mourners and to the deceased’s memory” (Getty et al., 2011, p. 997), although without further explaining the relation between non-participant observation, respect, and sensitivity. In some cases, sensitivity toward mourners was addressed not so much as a guiding principle for social researchers, but rather as a principle that should guide website designers, sometimes referred to as “thanatosensitivity” or “design that recognizes and actively engages with the facts of mortality, dying, and death” (Massimi & Charise, 2009, p. 2464), and that should inform how devices are created (Brubaker & Vertesi, 2010; Brubaker et al., 2012).

Overall, researchers who used *found data* to document online mourning practices conducted their analyses in publicly accessible terrains, such as in open SNS pages and groups, open Web memorials, and other commemorative spaces. While some authors specified that their terrains were open or publicly accessible (Bell & Taylor, 2016; Brubaker & Hayes, 2011; Brubaker et al., 2012; Carroll & Landry, 2010; Gibbs et al., 2015; Irwin, 2015; Marwick & Ellison, 2012; Mitchell, Stephenson, Cadell & Macdonald, 2012), terrain accessibility was addressed implicitly in most papers. Moreover, no papers included a sustained explication about the relation between terrain accessibility and consent procurement. While ethical reflections were generally scarce, some papers did briefly address issues regarding data anonymization, as some authors used verbatim quotations (Church, 2013; Giaxoglou, 2014; Marwick & Ellison, 2012; Mitchell et al., 2012; Sanderson & Hope Cheong, 2010), whereas others decided not to do so to account for the “private nature” of the mourners’ practices (Kasket, 2012, p. 64). Additional issues were raised not so much in relation to research practices *per se*, but to the potential ethical implications of mourning practices themselves, especially in the context of pervasive online visibility (Barnhill & Owen, 2007). Risks associated with increased visibility were addressed in terms of “voyeurism” and “rubbernecking” (DeGroot, 2014), of “grief tourism” and “context collapse” (Marwick & Ellison, 2012), and of dangers linked to personal disclosure (Finlay & Krueger, 2011).

Other studies (n=8) have explored individual experiences and attitudes regarding online mourning drawing from *made data*. This data was produced through the use of surveys and interviews among individuals who had experienced the death of someone they knew (Chapple & Ziebland, 2011; Rossetto, Lannuti, & Strauman, 2015; Vanderwerker & Prigerson, 2004; van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010), as well as with individuals from the general population (Brubaker, Hayes, & Dourish, 2013). These studies have focused on the ways in which the Internet may be changing individual experiences (Chapple & Ziebland, 2011) and on the impacts of online grief-related activities on emotional well-being and quality of life (Rossetto et al., 2015; Vanderwerker & Prigerson, 2004; Vicary & Fraley, 2010). Two papers discussed the issue of consent explicitly (Chapple & Ziebland, 2011; Vicary & Fraley, 2010) and specified that participants had to sign a consent form prior to an interview or a survey. Chapple & Ziebland (2011, p. 177) offered the participants the opportunity to review interview transcripts and “remove or clarify sections if necessary”. Overall, studies relying on *made data* did not allude to ethical issues specifically related to studying online mourning practices, arguably because methods that generate data are regulated through seemingly widespread ethical guidelines in Western institutions that might not need further explaining (such as consent procurement before proceeding with an interview).

Our scoping review also encompassed studies (n=7) that used both *made* and *found data* which presented contrasting ethical decisions. Some papers (Kasket, 2012; McEwen & Scheaffer, 2013) assured that consent was obtained for interviews, but did not specify if the latter had been obtained prior to online observation and analysis. While Courbet & Fourquet-Courbet (2014) did not specify whether consent was procured before undertaking both phases of their study following the death of Michael Jackson (online observation of fan pages and qualitative interviews with fans themselves), Pennington (2013), who paired content analysis and interviews with Facebook users who had experienced the death of a Facebook friend, explained that informed consent was obtained prior to meeting with participants. During the interviews, which “took place in the researcher’s office, as a private location was deemed best due to the sensitive nature of information being discussed” (Pennington, 2013, p. 623), participants were asked to log into their Facebook account and, with their consent, the researcher saved the most recent posts from the profile of their deceased Facebook friend. For their part, Christensen et al. (2017, p. 61) did inform readers that “all data collection [on the closed support group] has been subject to informed consent” in a paper that drew from various data collection techniques (interviews and surveys with members and administrators of a closed Facebook grief support group, analysis of postings on the same closed group, and online observations on open-access memorial pages), suggesting again that terrain accessibility constitutes a determining factor in consent procurement.

To summarize, our scoping review has shown that papers on online mourning do address issues related to methods, but rarely underline their ethical implications, although consent procurement and data anonymization did emerge as important – if often implicit – issues. Evidently, this does not mean that researchers do not think about these implications at various stages of their research (they surely did, as did we), but it does indicate that these reflections have not been formalized and made available to readers. Furthermore, unlike terrain accessibility, the consideration that mourning or grief expression constitutes an intimate object of study did not appear to be a significant factor in terms of consent procurement among papers drawing from *found data*. Indeed, if researchers have overwhelmingly addressed the ways in which the Internet has blurred the boundaries between what is considered public and private when it comes to mourning, these reflections remained theoretical and did not seem to be formally operationalized into methodological decision-making processes. Thus, there appears to be somewhat of a consensus which considers that *found data* can be used without the procurement of consent in publicly accessible terrains, while practices related to anonymization and to the use of verbatim quotes are less unanimous. In the next section, we will further reflect on the methodological practices underlined by our scoping review and situate the ethical issues that they raise in the broader context of online research.

**Situating Ethics in Online Mourning Research**

Our scoping review has shown that empirical studies on online mourning that use *found data* most often do not seek informed consent or, at least, do not indicate doing so. Is this practice problematic? A first element of response might come from asking the question: “Problematic for whom?” Doing research on online mourning can be challenging, as researchers need to take into account the sensitivities of various individuals and groups toward death and dying. This proved true in our personal research experiences, as we tried to respect the privacy of the members that engaged in Sophie’s group, while keeping in mind the social stigma that surrounds online mourning practices (sometimes considered “awkward” or “desperate”, as we have mentioned in the introduction of this article). The difficulty of considering these often contradictory objectives has been best illustrated by Carmack & DeGroot (2014, p. 319):

Recently, we submitted several pieces related to online public grieving for publication in peer-reviewed journals (both communication and thanatology journals). One reviewer condemned the use of pseudonyms in the write-up because the postings are “public behavior” and do not require the researchers to shield the posters’ identities. Other reviewers took stances to the contrary, arguing that we should not include the blogs in the reference list or in-text citations […]. In a review of a study analyzing a grief-related blog […], one reviewer criticized the authors’ use of the blog’s name, even though, as the reviewer noted, he or she could easily Google the blog and find the public blog entries. The reviewer continued to assert that the authors have an ethical responsibility to contact the blog author to let her know that the blog was being analyzed. An additional peer review of a similar manuscript called to reject the piece solely based on the authors’ “exploitation through voyeurism of a vulnerable ‘population’”.

 This quote illustrates how the use of *found data* in the context of online mourning research gives way to conflicting interpretations of what constitutes ethical research practices, notably in terms of anonymity, ownership, and, most notably, consent. Over the last 15 years, consent has been the subject of numerous books and articles on online research ethics (Beaulieu & Estalella, 2012; Eysenbach & Till, 2001; Hudson & Bruckman, 2004; Markham & Buchanan, 2012; Vitak, Shilton, & Ashktorab, 2016). Briefly put, consent can be defined as an operational process through which privacy is ensured (or at least aimed). In turn, Buchanan (2009, p. 89) defines privacy as “control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others”. Indeed, the respect of privacy is one of the main principles on which ethical research guidelines rely and is the subject of sustained academic debates. The assumption behind the respect of privacy is that researchers should pay close attention to the integrity of research participants and their right to self-determination. As Sveningsson (2009, p. 69) argues: “each and all individuals should have the right to decide for themselves what and how much others get to know about them. It is only the information that they choose to reveal that should be known to others.” Other underlying principles are identified within the literature on Internet research ethics, such as the researcher’s responsibility to work with beneficence and the importance to cause no or limited harm to participants by using a risk/benefit analysis which considers participants, researchers, and society alike (Vitak et al., 2016). According to the literature, the necessity to seek consent when using online data that is publicly accessible depends on various factors, such as the nature of the location where activities take place (*Does the researcher need to use login information to gain access to the site?*), the nature of activities themselves (*Are they considered to be intimate or private in a specific context?*) and the participants’ own perceptions of privacy (Eysenbach & Till, 2001; Markham & Buchanan, 2012; Sveningsson, 2009). Traditionally, privacy and data sensitivity have been conceptualized jointly (Buchanan & Hvizdak, 2009; Sveningsson, 2004). For example, sensitive and private information might take the form of “data from medical listservs or sexually explicit data”, whereas “entertainment or hobby-based data on a public newsgroup” have been considered public and non-sensitive (Buchanan & Hvizdak, 2009, p. 46). But how do such data categories come into existence? And what does labeling the data generated by online mourning practices as “sensitive” perform?

 The notion of *dispositif* (Foucault, 1977) enables us to answer such questions by apprehending research ethics as a set of heterogeneous yet interrelated entities that work together to perform a specific objective. For Agamben (2009, p. 14), the *dispositif* is “literally anything that has in some way the capacity to capture, orient, determine, intercept, model, control, or secure the gestures, behaviors, opinions, or discourses of living beings”. As Peeters & Charlier (1999) argue, a *dispositif* is both symbolic and technical. Thus, understanding research ethics as a *dispositif* means to pay attention to both the symbolic (discourses, shared conceptions, universal values, ideologies, and so on) and technical/material (institutions, committees, researchers, guides, and so on) entities that come together to generate a certain effect (here linked to the protection of research participants among others). It also means to focus on how certain values such as fairness, beneficence, and respect are socially and historically construed during key moments (the promulgation of the Belmont Report, the Declaration of Helsinki, and the Nuremberg Code, among others) and are effectively enacted through specific research practices (such as consent procurement and data anonymization). From this Foucauldian perspective, consent procurement is not only understood as a strategy to ensure the participant’s right to privacy and self-determination, but also as a social and historical construct that is part of a larger apparatus whose objective is to offer a dominant vision of social reality and to promote acceptable ways to act upon it. In the last decade, however, research ethics (and particularly online research ethics), have moved away from a restrictive or constraint-based *dispositif* to a more “human-centered” model. As Peeters & Charlier (1999) contend, a human-centered *dispositif* is not exclusively coercive, as it no longer orients the individuals, but rather allows individuals to orient themselves within it. This is best illustrated by the evolution of the *Recommendations from the Association of Internet Researchers (AoIR) ethics working committee* which contained declarative statements in its 2002 version, before abandoning such statements in favor of questions that encompass the diversity of Internet research (Markham & Buchanan, 2012). In terms of consent procurement, this means that it is increasingly up to the researchers themselves to think critically within this ethical *dispositif* about, for example, when and why reaching out to Internet users before analyzingthe content generated by themis a good idea. Yet, if the adoption of a more human-centred model means less cookie-cutter constraints and solutions, it also means that researchers have the responsibility to reflect on their own praxis and its ethical implications. And so, researchers are increasingly invited to think contextuallyabout ethics and make “ethical judgment in practice” (Markham, 2015, p. 10).

 This means that the decision of procuring consent (or not) before using *found data* can only be informed within and by the context in which the research takes place. In our own regulatory context, the *Canadian Tri-Council Policy Statement* (TCPS, 2014, p. 16) claims that:

Research that is non-intrusive, and does not involve direct interaction between the researcher and individuals through the Internet […] does not require REB review. Cyber-material such as documents, records, performances, online archival materials or published third party interviews to which the public is given uncontrolled access on the Internet for which there is no expectation of privacy is considered to be publicly available information.

 Again, two main factors come into play here, one technical (the nature of access, which relies on an assumption of implied consent among Internet users) and one normative (the Internet users’ expectations of privacy). Hence, it could be argued that online mourning practices can be used for research purposes without consent if they take place in publicly accessible terrains like certain SNS. However, this position can be problematic, as the decision relies on a technical argument (the fact that SNS have built-in affordances that favor visibility and self-disclosure) and not on an actual ethical reflection. That is not to say that visibility and access are not to be taken into consideration, but to resort to technological affordances as central arguments can potentially render researchers less accountable and, in a way, less empowered toward the technologies that they study. One could also argue that online mourning practices are private since users might share reasonable expectations of privacy even in publicly accessible settings. From this standpoint, the ideal solution would be to contact mourners to ask them about their privacy expectations and adopt ethical guidelines based on the latter. This is sometimes difficult to put into practice, especially since expectations surrounding privacy in relation to mourning are culturally situated and rarely consensual. This perspective relates to concepts such as “dialogical ethics” (Beaulieu & Estalella, 2012), “perception of privacy” (Eysenbach & Till, 2001; Jacobson, 1999; Stern, 2009) or “perceived privacy” (King, 1996). Again, this dialogical ideal is often hard to enforce, especially when studying large communities in which obtaining consent from all members is impossible and seeking consent from community moderators generates additional issues regarding participants’ right to self-determination. In cases of proximal loss, engaging with mourners might also disrupt undergoing grieving processes and cause distress among individuals.

More importantly, procuring consent is a performative act itself which relies on assumptions regarding what we consider to be intimate, who we see as vulnerable, and so on. In the case of online mourning, procuring consent based on the consideration that grief expression constitutes a sensitive topic can potentially enforce social stigma. Researchers first need to identify where their own conceptions on mourning come from (such as “mourners are vulnerable”, “grieving is a private endeavor”) and reflect on how these conceptions inform their work. As Bassett and O’Riordan (2002, n.p.) argue, an “assumption that sensitive material should be accorded special privacy rights should not be made unconditionally, as the initial definition of 'sensitive' is ideological and is itself a process that is subject to ethical questions”. To this effect, could it be that considering mourning as a highly intimate and private topic *sometimes* conceals a certain awkwardness toward death and grief expression rather than a concern for the well-being of the bereaved? And, more importantly, to what extent can consent procurement contribute to stigmatizing online mourning practices by implicitly considering that, since they are intimate and private in nature, maybe people shouldn’t *publicly* engage in them on the Internet in the first place? Similar issues can be raised regarding anonymization strategies that can alternatively be seen as respectful of mourners’ privacy or as rendering mourning and mourners invisible.

The ethical issues that we raise here are not new, nor are they specific to online mourning research. A significant body of studies has already underlined the role of participants in interpretive research (Palmer, 1987; Lincoln, 1995), that is by questioning who has the right to produce knowledge and in what acceptable and valid ways. Interpretive research underlines the hermeneutics of what we know of and what we learn from social phenomena (Gohier, 2004). As Palmer (1987, p. 22) argues, “every mode of knowing contains its own moral trajectory, its own ethical direction and outcomes”. From an inclusive perspective, interpretive research should mobilize mourners in the co-construction or at least validation of researchers’ interpretations (Gohier, 2004). In contrast, authors like Latzko-Toth and Pastinelli (2014, p. 161) argue that, in the context of Internet studies, actors’ interpretations should not automatically be considered as true and that the role of social analysts often consists of providing analyses that are “just, relevant, and enlightening” even if the latter are received poorly by other actors. Again, this shows how practices of participant inclusion vary and how they relate to contrasting – but, most importantly, to *situated* and *explicit* – epistemological postures in interpretive online research.

 Ultimately, our scoping review underlined how ethical issues regarding online mourning research are scarcely addressed in empirical studies. Although some theoretical papers do address such issues, this finding is problematic if we wish to implement a context- and method-based online research ethics. The idea, here, is not to promote a practice regarding consent procurement over another, but rather to invite researchers to document their ethical reflections and make them accessible to readers. In turn, if research ethics are indeed heading toward a more contextual and human-centred approach (versus a restrictive one), then the academic field and its representatives (editors, conference organizers, publishers, and so on) need to offer greater latitude and space to researchers who wish to share their ethical reflections. Hence, our objective is not to determine whether using *found data* in the context of online mourning research without procuring consent is an acceptable practice, but rather to advocate for more visible and situated discussions about research ethics. These discussions could also constitute an opportunity for researchers to explain their own conceptions of death and mourning, as well as how their methods and research designs are informed by these conceptions. To conclude, our scoping review has shown that online mourning practices have often been problematized in relation to privacy and, consequently, to ethical issues such as consent procurement and data anonymization. As argued by Hoffmann & Jonas (2017), future Internet research would also benefit from problematizing ethical issues in terms of justice and fairness. In keeping with this perspective, Christensen et al. (2017) have recently conceptualized mourners as counter-publics (Fraser, 1990) and thus (re)affirmed the political dimension of public grief expression. This axiological stance is not insignificant, as it goes beyond privacy issues and consent procurement, and focuses on the stigma associated with online mourning. That is not to say that issues related to privacy are not relevant today – they still are –, but it does bring us to (re)consider the ways in which online mourning has been conceptualized and generate new conceptual and methodological potentialities. The focus, then, is not so much on mourning practices themselves, but rather on the lived experiences of stigma among mourners and on the affects that this stigma generates (shame, culpability, resilience, empowerment, and so on). Consequently, researchers themselves could move from being online lurkers to partners who give the bereaved a voice. What remains is to identify the best ways to do so, both in terms of research methods and ethics.

**Conclusive Remarks**

This article offers a scoping review of the current empirical research on online mourning. Although it might lead to practical implications, our reflection is mainly theoretical (for more practical guidelines, see Carmack & DeGroot, 2014; Hård af Segerstad et al., 2017). Results show that in empirical studies based on data found within publicly accessible sites, ethical issues have been scarcely addressed. While the analysis we performed is not exhaustive, it did allow to identify emerging trends within online mourning research, notably in terms of consent procurement and data anonymization. Today, the topic mourning appears particularly relevant to understand the role of social media in shifting the boundaries between the private and public spheres, as well as between casualness and intimacy. As demonstrated by public discourses and by personal experiences, online mourning practices – and the ways we study them – draw from and generate various and often contrasting stances. While the data that is generated by mourning practices should not be given a *de facto* sensitive status to avoid paternalizing and further stigma, understanding contextually how mourners themselves make sense of their own practices remains important to inform the methods that we should (dis)use. Indeed, for online mourning research, the use of data found on publicly accessible sites without procuring consent should be given more thought. Not because this practice is itself unethical – such judgment could only be made in context – but rather because it gives a preponderance to technological affordances, while muting the voices of researchers and limiting the reach of their ethical reflections that become somewhat inaudible. Given that the beliefs surrounding mourning are diverse – and often contradictory – and that online research ethics guidelines are increasingly context-based, researchers need to expand on their decision-making processes so that these decisions become an integral part of scientific publication and writing practices and serve as points of reference for researchers who will be designing, implementing, and evaluating future studies on online mourning.

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