On the complexities of studying sensitive communities online as a researcher–participant

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Abstract

Purpose – This study aims to explore the complexities of methodological, ethical and emotional challenges of studying sensitive and vulnerable communities online from the perspective of simultaneously being a researcher and a research subject. The point of departure for these explorations consists of the author's past and ongoing studies of the role and use of a closed grief support group on Facebook for bereaved parents – a community of which the author is a member. The aim is not to provide ready solutions for "how to do ethics," but rather to contribute to the collective and ongoing work initiated by the Association of Internet Researchers (AoIR), among others, and to recognize the necessity of ethical pluralism, cross-cultural awareness and an interdisciplinary approach.

Design/methodology/approach – This is an explorative study, drawing on an (auto)ethnographic case study. The case serves as a point of departure for discussing the complexities of methodological, ethical and emotional challenges of studying sensitive and vulnerable communities online from the perspective of simultaneously being a researcher and a research subject.

Findings – Being a researcher and a research subject rolled into one, as it were, presents both opportunities and challenges. To conduct responsible research from both these perspectives pose high demands on the researchers' ethical as well as emotional capacities and responsibilities. Hopes and expectancies of the community under study might put the researcher into a dilemma, ethical aspects of anonymity and informed consent might have to be reconsidered as well as emotional challenges of engaging in and with sensitive research, all of which makes for a complex balancing act. Ethics and methods are inextricably intertwined, so are the emotional challenges of conducting sensitive research intermingled. Studying vulnerable individuals and closed communities online highlights the necessity for case and context sensitive research and for flexibility, adaptivity and mindfulness of the researcher. It also highlights the importance of discussing and questioning theoretical, methodological and ethical developments for studying everyday life practices online.

Originality/value – The challenges encountered in this case study contribute to the experientially grounded approach to research ethics emphasized in AoIR's ethics guidelines. This case offers an opportunity to explore and discuss complex issues arising from the researcher's insider position in a closed group devoted to the sensitive topic of supporting bereaved parents. Further, it highlights the necessity for research to be case and context sensitive as well as for the researcher and the research design to be flexible and adaptive. Research on vulnerable communities also heightens the demands of ethical responsibility of the researcher and the research process.

Keywords Social media, Informed consent, Anonymity, Internet ethics, Researcher positioning, Sensitive research

Paper type Case study

In this paper, I explore the complexities of methodological, ethical and emotional challenges of studying sensitive and vulnerable communities online from the perspective of simultaneously being a researcher and a research subject. The point of departure for these explorations consists of my past and ongoing studies of the role and use of a closed grief support group on Facebook for bereaved parents – a community of which I am myself a member.

Studying vulnerable communities and sensitive topics can be a challenging task for several reasons, and studying grieving parents' use of social media as resources for coping with the trauma of losing a child can indeed be daunting methodologically, ethically and not least emotionally. Top that with being a bereaved parent yourself and a trusted member of the community you are studying, and the complexity of the challenges you face in striving to conduct your studies as an ethically, empathically and even morally responsible researcher increases. In this paper, I will explore and discuss some of the aspects that make up this complex balancing act. In doing so, I add to the discussions of doing insider research. I argue that autoethnography contributes by bringing the personal and autoethnographic voice as valuable tools for nuanced and situated understanding of complex and sensitive cases. As Ess notes, "digital media often present us with strikingly new sorts of interactions" and that it is "not always clear whether - and, if so, then how - ethical guidelines and approaches already in place [...] for traditional media would apply" (Ess, 2020). The case I present and discuss here contributes to the collective and ongoing work initiated by, for example, the Association of Internet Researchers (AoIR) (franzke *et al.*, 2020; Ess and committee, 2002) and the Norwegian National Committee for Research Ethics in the Social Sciences and the Norwegian National Research Ethics Committees (2016). The aim is not to provide ready solutions for "how to do ethics" (Ess, 2020) but rather to highlight the need to further discuss the notion of ethics as inextricably intertwined with methods (Markham, 2006) by including emotional aspects of doing sensitive research. These guidelines recognize the necessity of ethical pluralism, cross-cultural awareness and an interdisciplinary approach. The challenges encountered in the particular complex situation of my case offer an opportunity to explore and discuss issues that many other cases studying sensitive communities online might similarly have to grapple with. The case contributes to the experientially grounded view that "ethics starts by asking and answering critical questions rather than taking a more deductive, rule-oriented approach," emphasized in AoIR's Internet Research Ethics guidelines.

In the following section, I provide the context for the ideas explored in this paper. Here, I outline the particular ethical, methodological and emotional considerations of being a participant in the sensitive community I studied and encountered in preparing this work. In the section following, I describe and argue for the autoethnographic approach underpinning my work. In the section on the sensitivity of sensitive research, I begin to explore aspects of what makes this particular case challenging to study. Methodological, ethical issues such as researcher positioning and the notions of anonymity and informed consent and emotional challenges are then considered.

Context of research

Providing an exhaustive account of the empirical material or results in the studies I have engaged in is not the primary focus in the present paper. Such accounts can be found elsewhere (Hård af Segerstad and Kasperowski, 2015; Refslund Christensen *et al.*, 2017). However, to give the context in which the discussion is placed, an overview is nevertheless in order.

The grief support group for bereaved parents that I have studied is a closed discussion group on Facebook. It is maintained and moderated by a physical organization supporting both bereaved parents and siblings in Sweden and serves as their primary discussion forum online. The research has been carried out in collaboration with the organization and the

administrators of the group. The work I draw upon here is a small-scale study begun in late 2012 and is still, in some measure, ongoing. Having lost my youngest daughter in 2010, I applied for membership in the grief support organization and begun engaging in the closed Facebook community. Being a trained Researcher in the interdisciplinary field of applied information technology, somewhere along the journey of my own grief work, it became more and more apparent that what was going on in the perceived safety among peers in the closed discussion group online was not possible anywhere outside of the community, given the implicit norms that regulate the expression and duration of grief in the Nordic countries. This led me to start looking into how bereaved parents use the closed community, and what role social media play in learning to cope with the loss of a child. Having presented the ideas to the board of the grief support organization, I was invited to collaborate with them in studying the community, and we agreed on a process through which we would carry this out. The board of the grief support community officially endorsed my research (minutes of the annual meeting of VSFB, 1 March 2015) and has since continuously been available for discussion, facilitated recruitment by posting invitations to participate in the studies in the discussion group. I learned that the community had previously been approached by other researchers on several occasions but that these had simply been refused by the administrators to protect their community members and the functionality of the group as a safe haven.

A colleague of mine was also accepted by the community to engage in the research, by force of having lost his older brother in childhood. However, although this qualified him as a bereaved sibling, he was not allowed access to the discussion group of the bereaved parents. Together, we formed a small research team that helped to minimize possible bias in relation to understandings assumed between research participants and the insider researcher and so contributed to ensuring analytic credibility (Blythe *et al.*, 2013).

The main focus for our studies has been on the discussion group for bereaved parents. The group was initiated in April 2011 to provide a Facebook presence and a discussion forum on social media for the grief support organization. At the time of writing, the group has some 2,500 members and is growing by 10–15 new members every week. There is interaction in the group at all hours of day or night and between 10 and 40 posts and 100 and 300 comments are produced per day. Access to the group is gained by applying for membership. Before granting access to prospective new members, the moderators/administrators in the group use a number of techniques to verify their authenticity. Based on previous bad experience from having impostors infiltrating the community, the group administrators have developed a procedure to ensure that the group consists only of individuals who have lost a child (or children, as the case might be).

Data generated for the studies consist of anonymous online surveys and semi-structured interviews with members and administrators in the closed grief support community on Facebook, as well as my own autoethnographic notes and reflections. The material has been generated during several periods: September–October 2012 and May–June 2013, May–June 2015 and December 2018–January 2019. This material has been complemented with notes from ongoing participant observations of everyday interaction in the closed Facebook group and with field notes from a training weekend for new moderators (May 2015) – both made by myself as a member in the community.

Our studies have shown that members in the community mostly use the group when they are in despair. They are often in a very vulnerable state, pouring their hearts out in the closed group, which they perceive of as a safe haven, often commenting that what they write in the group and the images they share are impossible to share outside of the group (Hård af Segerstad and Kasperowski, 2015; Refslund Christensen *et al.*, 2017). Results also emphasize that the very existence of the community itself and the social support provided by peers are

by many members conceived of as vital resources for coping with the loss of a child. Furthermore, results show that the closed nature of the group is necessary – in fact, a prerequisite – for the group to function as a safe haven for the bereaved parents, in which they feel secure that they will not be "judged by those unbereaved." The bereaved parents often mention that, elsewhere, they experience a lack of understanding from "those unbereaved" and feel pressured to "pull themselves together" and "get back to normal" as soon as possible. In the safety of the peers-only community, they find space to express the "unexpressable," experience support and understanding from others who share similar experience and are allowed to learn how to cope with their loss without limitations in time.

As we have seen, the case presents layers of complexity for carrying out the research. We have a sensitive topic, a large and active community online in which vulnerable individuals share stories of personal loss. Moreover, the community members regard this closed environment as private and safe. To add to the complexity, we have a research team in which one of the researchers (myself) is an "insider." These are some of the ingredients that together bring layers of challenges which have bearings on how to conduct ethically responsible research. In the following sections, I will continue by exploring some aspects what makes this case so challenging to study. These challenges particularly concern studying sensitive topics (death, bereavement and grief) and vulnerable individuals (bereaved parents). Additional and complicating challenges concern balancing the sensitive research topic and vulnerable people with care for those who participated in my research, as well as being a human being with my own grief. Some of these were to be expected, whereas others posed unexpected challenges and potential harms (Markham, 2018).

Approach

The approach that underpins the work I am conducting is rooted in the stance proposed in the ethical guidelines collaboratively worked out over the past two decades by the AoIR. These guidelines emphasize that research ethics is not a list of checkboxes on a form to tick before undertaking a study but a process which requires a deliberative process throughout a study, including design, data collection, analysis and dissemination (Ess and committee, 2002; franzke *et al.*, 2020). Markham argues that methods and ethics cannot be separated, that ethics is inextricably intertwined with methods (Markham, 2018; Markham, 2006; Markham *et al.*, 2018) and that "both methods and ethics are strengthened conceptually and practically when researchers impose the characteristics and functions of each concept onto the other" (Markham *et al.*, 2018, p. 2). I argue that studying vulnerable individuals and closed communities online further highlights the necessity for research to be case and context sensitive as well as for the researcher and the research design to be flexible and adaptive (Markham, 2006). Research on vulnerable communities also heightens the demands of ethical responsibility of the researcher and the research process. To conduct responsible research in such contexts, and – as in my own case – with the perspective of both the researcher and the research participant, poses high demands on the researchers' ethical as well as emotional capacities and responsibilities (Ellingson, 2017). Markham further argues that most regulatory guidelines and procedures are based on error avoidance and concept-driven models, which were developed for natural science but repeatedly fail in contemporary social science research (Markham, 2018; Markham *et al.*, 2018). Responsible research must go beyond the limited scope of regulatory guidelines and consider an impact- or future-driven models "which is particularly necessary for research involving networked media and the use of digital social data, as these situations present still-novel and unexpected challenges and potential harms" (Markham, 2018, p. 2). In studying vulnerable populations online, Svedmark and Granholm (2018) further highlight the stance taken by AoIR and Markham and argue for the need for

flexibility and continuity of ethical considerations throughout the whole research processes.

I take an ethnographic stance and draw on autoethnographic techniques in line with the works of Ellingson (2017), Markham (1998) and (Tracy, 2010), among others. Centralizing the researcher's experience and body in the study can provide detail and nuance not available through other methods of engagement with participants. In similarity with Raun (2017) in his studies of mourning through photo-sharing on Facebook, my own experience of loss initiated the research focus of bereaved parents' use of social media. The term "autoethnography" has sometimes been associated with self-absorbed, exaggerated subjective focus on the self in some disciplines. However, I believe that an autoethnographic approach has unique potential by contributing with nuanced understanding and building ethically sensitive and situated knowledge. The idea that researchers should be objective interpreters and presenters of fact seems to be the ideal norm in natural sciences. However, applying this approach as a guiding concept for the type of ethical social research I have immersed myself in has been long critiqued for being ill-suited for models of inquiry that follow non-biomedical procedures (Markham and Buchanan, 2012). The personal and autoethnographic voice of the researcher as a human being, rather than as objective vessel, acknowledges the researcher as an analytic tool. Through my own experiences as a bereaved parent and human being, I can bring sincerity, credibility, resonance and meaningful coherence into the analysis (Tracy, 2010). My personal experiences of losing a child bring authenticity and genuineness to the study. By being a participant–researcher rolled into one, drawing on my own experience and allowing myself to be self-reflexive and vulnerable, I am in a better position to resonate and meaningfully reverberate my audience (cf. Tracy, 2010). In line with the concept of feminist communitarianism (Christians, 2005), an ethic of care involves being empathic and caring for those you involve in your research. You have to genuinely care for the relationship, intimacy, emotionality and connectedness that you have with your research participants (Christians, 2005) throughout the research process.

It also means that you have to care for yourself as a researcher–participant. In addition to the basic ethical requirements for set out in the earlier versions of AoIR's Ethics guidelines, including respect for persons, beneficence, justice and ethical norms, the IRE 3.0 (franzke et al., 2020) introduces the aspect of protecting the researcher as well as protecting the research participants. The need to protect and care for researchers stems from experience of research on violent online and offline political communities, which may introduce new risks and levels of risk to researchers whose work both when they are conducting and publishing research may trigger strong ideological reactions. Consequences of these can include threats or physical harm. So far, I have not been physically threatened as a consequence of my research but have rather been emotionally challenged as well as ethically and methodologically. I had recently experienced grief myself, and conducting emotionally intense conversations with the bereaved parents who participated in my study is not easy. These challenges involve several aspects and dimensions. Among these is my vulnerability as a grieving parent engaging in research with other grieving parents and balancing their expectations of my studies with all stages and aspects of the research process. Similar to Abidin's experiences from studying grief etiquette (Abidin, 2018), I believe that this work necessitates laborious mutual care and self-care. Being emotionally and emphatically engaged is absolutely necessary. However, it often hurts (Svedmark and Granholm, 2018).

On sensitivity of sensitive research

What makes this case such a sensitive case? In most contemporary Western societies, attitudes to death tend to be similar to the Victorian attitude to sex – "the ultimate

unmentionable" (Mander, 2007) and thus a topic often avoided (Brotherson and Soderquist, 2002). As Ess notes, how we relate to death is "highly culturally variable, as our beliefs, attitudes, practices, etc. concerning death vary widely from culture to culture" (Ess, 2020, p. 151). Attitudes also change over time (Hviid Jacobsen, 2016). As the standard of living and health care has increased over the past century, death and dying have become institutionalized, and most of us have never had to encounter it personally – we have lost "an ancient intimacy with death," as historian Peter Englund (2000) puts it. It has often been argued that death is sequestrated in modern societies (Walter, 2009). Some aspects of death certainly are sequestrated, but death is always present in abundance in news media and popular culture.

Even if we encounter public or fictionalized death on a more or less everyday basis, in the Nordic countries, private death is goverened by implicit but strong norms. Bereaved parents report that these norms regulate forms for and intensity of the expression of grief, as well as the time frame allowed to grieve (Christensen et al., 2017). This sets limitations on the possibilities for the bereaved individuals to cope with their grief and adapt to their loss (Brotherson and Soderquist, 2002). All of this is clearly echoed in the empirical material of my studies.

Many aspects of contemporary everyday life have been transformed with increasing digitalization, and social media and mobile technologies can be seen to offer new possibilities for grieving parents to find social support online. As both researchers and health-care practitioners have noted, closed communities online offer alternative forms of support, and it seems that those living with life-threatening diseases or afflicted by life-long or stigmatized conditions increasingly turn to these (Perales et al., 2016). Lingel argues more generally that a:

> critical affordance of online grief is the ability to craft individual responses to death in an open venue less constrained by still inchoate social and cultural obligations than a funeral home or cemetery (2013, p. 191).

As outlined above, my studies have shown that many of the bereaved parents have an express need for a "safe haven" in which they find a secure context among peers in learning to cope with their grief. These online communities may offer their members "digital safe havens" in which members can share their everyday life experience, receive social support, help and advice in coping with their conditions (Baym, 1995; Yeshua-Katz, 2016). However, studying sensitive communities online entails a range of ethical and methodological challenges on many levels.

The complexity of ethical, methodological and emotional challenges of studying sensitive topics and vulnerable communities online

There have been ethical concerns for researchers to even approach bereaved parents, as participating in a study might "set off" their grief and do harm. On the contrary, the parents in Kreicsberg's studies who had lost a child to cancer leapt at the opportunity to talk about their child and their loss (Kreicbergs, 2005). This is exactly the same experience I have in my own studies. Bereaved parents' eagerness to engage in research and contribute sometimes actually "set off" other kinds of ethical conundrums and is something I will return to below.

Paechter (2012) argued that the ethical issues involved in her study of an online divorce wiki and support community were considerable. Both the research area itself and the data (i.e. content published by members in the community) should be regarded as sensitive. Similar to in Paechter's case, the data that was relayed to me in the form of interviews with bereaved parents and the activities and postings I could observe in the closed community was sensitive because it was generated by people at particularly traumatic points of their lives. Moreover,

the perceived safety in the closed, peers-only discussion group on Facebook, most likely in combination with the disinhibiting effects of anonymous online communication observed by Barak, Bonniel-Nissim and Suler (2008), among others, allowed community members to share emotionally very raw content.

Made data, found data and notions of anonymity and informed consent

Bruhn Jensen's distinction between *found data* and *made data* is useful for working with and considering types of data (Bruhn Jensen, 2012). In my case, the found data consists of online material that was to be observed in the closed discussion group, such as images, texts and other digital traces left by interacting users, and the made data consists of data generated by the online questionnaires, interviews, participant observations and autoethnographic notes (Hård af Segerstad *et al.*, 2017; Ess and Hård af Segerstad, 2019). These different types of data emphasize different ethical considerations and have different implications. In this case study, the made data posed fewer ethical challenges than the found data, but that does not exclude context- and case-sensitive handling, as well as careful considerations of how to securely store and process the material.

Informed consent might be difficult to obtain when working with found data, especially if found in a large community which has been active for more than a decade. Whether or not it is necessary, or even possible, to attain informed consent from such material has been discussed in the literature (Vitak *et al.*, 2016; Vanderhoven *et al.*, 2014). In line with Markham's reasoning on unexpected consequences (2018), to always "go by the book" and follow regulations for ethical research conduct and get informed consent may actually be what causes harm. Svedmark's studies have shown examples where obtaining informed consent caused an increase in her research subject's self-harm behavior (Svedmark, 2016). Besides, the risk that explicitly announcing researcher presence might disturb the community studied and affect data reliability, as individuals might alter their behavior because they are aware of being studied (Hård af Segerstad *et al.*, 2017; Ess and Hård af Segerstad, 2019); my particular case might have the even more harmful consequence of barring individuals in despair from a resource that is of vital importance and essential for their coping mechanisms. This is the reason why I, together with my colleague, settled for obtaining administrators' consent to do (my) observations of the interaction in the closed group and requesting individual consent from the authors of quotes that we wished to use. Found data was never designed to be researched in the first place, and the contextual integrity of its authors has to be considered even though the data might technically be "public" or accessible (Zimmer, 2010). When users post content on social media, they do not generally consider that what they shared might be systematically observed, studied and disseminated for research purposes. This is the reason we decided not to scrape the data generated in the closed group.

Conundrum of researcher positioning

Being a bereaved parent myself and a member of the community I have studied, I have spent a lot of time over a long period immersed in the culture under study, so to speak. In doing so, I am drawing on ethnographic techniques. Paechter (2012) argues that traditionally, "the ethnographic researcher is an outsider who journeys to another culture and attempts to capture its essential features through participation" (74). However, in the past decades, there has been a move toward studying groups of which the researcher is, or has been, a member. This move led to extensive discussions in qualitative research about the role of the researcher in such contexts, at length debating advantages and disadvantages associated with being an insider or an outsider (Blythe *et al.*, 2013; Yakushko *et al.*, 2011; Buckle *et al.*,

2010). However, discussions have also focused on the dynamic and fluid nature of people and context, and that the role of the researcher might rather be conceptualized on a continuum, and not viewed as either/or (Breen, 2007) or both/and (Probst and Vicars, 2016) dichotomies.

Insider researchers may have easier access to and acceptance in the study population, especially marginalized groups (Blythe *et al.*, 2013; Yakushko *et al.*, 2011; Buckle *et al.*, 2010). Further, Paechter (2012) notes that such ready access is not just to the research site itself but also to "the 'real' perspectives of participants" bringing greater intimacy and openness to research and allows for richer, thicker descriptions that are "more likely to reflect the 'actual' community culture" (Paechter, 2012; Dwyer and Buckle, 2009). However, my own experience of being an insider to gain access is not just of advantages. Engaging with a closed community may be more problematic for some insider researchers than one may initially think (Greene, 2014). I will return to this issue below.

In similarity with Kirkman (1999) and Dwyer and Buckle (2009), I gained access to the closed community by being a member of the group. My position as an insider and a recognized member with an active posting history in the online community established my "bona fides as someone committed to the site" (Paechter, 2012, p. 77). I thus earned acceptance by the fact that I am a "native" to the culture I have studied, to use Kanuha's (2000) term. Kanuha (2000) argued that:

> the native researcher is grounded implicitly and situated at all moments in the dual and mutual status of subject– object; she is both the subject of her study and the participant object being studied (p. 441).

Furthermore, I was also explicitly presented as "one our own" in the invitations to recruit participants to the studies which were posted in the group by the group administrators. The trust that was bestowed on me by both the support organization and the community members provided levels of openness in my participants that would likely not have been present otherwise (Dwyer and Buckle, 2009). Just as one of the bereaved fathers in Jennifer Buckle's studies phrased it "[I]t's different if you're a member of the club [. . .] you talk differently to people who have lost somebody" (Dwyer and Buckle, 2009, p. 57), the bereaved parents I studied were willing to talk to me because I am "one of them." At the same time, this trust also bestowed obligations on a number of levels on me as a researcher (Blythe *et al.*, 2013) – a delicate balance which I will return to below.

In previous publications and presentations based on this research, we have been hesitant to be explicit about the fact that one of the researchers in the small team is a bereaved parent and thus a peer and member of the community under study. The decision to do not be explicit about who of us is the community member was partly based on an ideal notion originating from the natural sciences of researchers as objective agents. It was also based on an attempt to protect myself both in the role of a researcher and a member of the community under study. From the start, however, we have argued for the necessity of having a researcher who is an "insider" or "native." By drawing on autoethnographic techniques (Parker-Jenkins, 2018), we were able to use my lived experience as both a researcher and a research subject to give access, detail and nuance to the research (Ellingson, 2017). Reflecting on, acknowledging and making use of the subjectivity of my own role as an analytic tool is valuable in the research process. Bringing in a personal and autoethnographic voice of myself as researcher–participant adds to the sincerity, credibility, resonance and meaningful coherence of the work (Tracy, 2010). Along the lines of feminist ethics as described by Kirkman (1999), this approach also led me away from "the traditional treatment of research 'subjects'" to a consideration of the ethical implications for individual people who were

recruited to participate in my studies. Greene (2014) argues that by "engaging in the reflective and reflexive process of doing insider research," we may find ways

> in which insider researchers may navigate the twisting, winding paths of data collection and analysis in order to reach a deeper level of introspection that may assist them in the narration of their participant's stories (p. 1).

Challenges of trust and compartmentalization

Many researchers have noted that the researcher's position may not be the rigid either–or dichotomy of insider or outsider (Parker-Jenkins, 2018) and that the boundary may be more porous (Song and Parker, 1995) or on a continuum as either/or (Breen, 2007) or both/and (Probst and Vicars, 2016), as the researcher and the research subject may share commonalities such as, for example, language, background or personal experiences. In the best of worlds, the native researchers can occupy dual roles and move from one position to the other. Sometimes this takes considerable emotional capacity. As a longstanding member in the community at a divorce wiki she studied, Paechter (2012) chose to use a pseudonym when engaging in the community as a researcher, and used her own name when simply using the site as a member. In similarity with her, my position is hybrid: I observed activities in the bereaved parents' group, but at the same time, I have considerable insider knowledge. In contrast to Paechter, I have only participated in the community under my own real name but occupy different roles at different times. At times, I engage in the Facebook group as a bereaved parent, filling my own needs to talk about my loss and find social support. At other times, I am able to focus on observing activities and patterns of interaction in the community as a researcher. Most of the time it is fairly easy to compartmentalize and to know "which hat" I am wearing and to move fluidly from one position to another. However, in reality, it is probably more complicated than that. In a Heidegger (2002) sense, I am *always already* simultaneously the bereaved parent and the researcher. Most of the time, my focus is on one or the other position. Paradoxically, this duality and necessity for compartmentalization sometimes in effect bar me from the social support available in the closed community for bereaved parents.

Getting barred from social support

As outlined above, results from my previous studies have shown that access to peer support in the online community, which is available 24/7 and for as long as the members have a need for it, is vital to the bereaved parents coping abilities (Hård af Segerstad and Kasperowski, 2015). There are unexpected challenges and consequences (Markham, 2018) of being a researcher–participant rolled into one. Studying and observing an online environment that simultaneously offers the social support you might be in need of yourself as a bereaved parent can have paradoxical effects. I have found that being immersed in research on the community that simultaneously supports myself as a bereaved parent can in effect bar me from using it as a resource for coping with my own grief. Having observed the activities in the support group with a researcher's eye for such a long time has made me too aware of what and at what point in time I myself (wish to) post and share something or even how I phrase things to such a degree that I find that I can no longer truly participate for my own needs. In effect, in the process of studying it, I am making the community unavailable for my own needs and in this way barring myself from the support available there. Paechter (2012) reported somewhat similar experiences, when striving to put her participants and her responsibility to them at the center of her research, by not mixing her two personae (researcher and participant). This denied her the opportunity to meet community members

face to face in the role of a fellow community member. Following Markham's (2005, p. 277) call to put "the human subject squarely in the center of the research" to shift "the ethical considerations and allow for socially responsible research" becomes complicated when the researcher and the human subject happen to be one and the same person.

Hopes and expectations from the community

Both the positive and negative aspects of being an insider, or native, can be challenging to handle. Raun (2017, PAGE REF in proof) highlights the importance of actively use ones' "own experience of loss as a prerequisite for building trust and enriching the dialogue" with those you study. But your position as an insider can also bring drawbacks. As a researcher–participant you must also pay extra attention to if and how your own individual experience and assumptions might have an impact both on how you frame your research, design questionnaires, conduct interviews, perform analyses and interpret and frame results. As Paechter (2012, p. 75) notes, communities can have particular expectations when they are researched by one of their members and "particularly around how the community is represented." My status as a native put heavy obligations on myself as an ethically responsible researcher on how to frame the research for my research subjects to be willing to participate in the studies, but also on how to select, collect, store, manage and present results – even within my small research group. As noted above, I did not invite my colleague (who is not a bereaved parent and thus not a member in the community) to actually observe the closed Facebook group. However, I showed examples and discussed the interaction and patterns I observed with him, which contributed to minimizing the possible bias I might have in relation to the data and also contributed to ensuring analytic credibility (Blythe et al., 2013). The community members who participated in the studies have gifted me with their narratives of their most traumatic experiences in life (Abidin, 2018), and I had to find ways to honor this trust throughout the research project and beyond. Data had to be stored, processed and disseminated with empathy and care in mind, making sure that the narratives are not distorted or misused (Kirkman, 1999) and that the human is always in the center (Markham, 2005).

As an insider, I found that the support organization, administrators as well as community members often expressed their high expectancies and hope that the research I was conducting and that they contributed to would change attitudes toward bereaved parents on a societal level as well as in their everyday social encounters. In similarity with the experiences of Blythe et al. (2013), research participants recognized me as an insider "with means and influence beyond their own" and "expected me to be able to bring about change in a way that they themselves could not" (p. 13). In some small measure, perhaps I can, but this type of qualitative, small-scale studies cannot be used for changing the social security system or claiming that such and such a dose of participation in online support groups will decrease sick leave or need for medication with this or that percent. Further, as Taylor (2011) notes, there is sometimes an expectation that an insider will be sympathetic to the group when analyzing and presenting data. I have had the opportunity to present the studies on many occasions to the bereaved parents' community, and the impression I have had so far is that the findings I present and the interpretations I make have resonated well with the community. But some aspects of what I present might perhaps not fit what the organization and members wish to be emphasized. One example that I found came to sit a little uncomfortably with the community was when I "exposed" the fact that the privacy the community perceived in the safety of a closed discussion group in fact is not really all that private. When users create a Facebook account, they agree to the conditions stated in Facebook's user agreement, i.e. that all content produced by users is owned by the platform provider and may also be sold to third parties. However, what this means in practice, and

the extent to which Facebook monitors and harvests user interactions, is not always evident
to the user (Zimmer and Proferes, 2014). The high expectations of privacy that the bereaved
parents have are, in practice, contradicted by Facebook's terms and conditions (Zimmer and
Proferes, 2014). Having your trusted champion researcher pointing out that you can rest
assured that Facebook keeps an eye on and uses our activities might be a little
disappointing. Such information might even make people hesitant to use the safe haven.
Hopes and expectations that I have encountered during my studies have thus led me to
revisit the notions of anonymity and informed consent.

Complicating the notions of anonymity and informed consent

I firmly believe that ethics and methods are interdependent. In undertaking the study of
sensitive topics and vulnerable communities, I have come across situations that particularly
highlight certain aspects that complicates the ways that ethics and methods are intertwined. I
have encountered bereaved parents participating in my studies who – at least at one point in
their grief – wished me to NOT anonymize quotes when disseminating results. Rather, they
explicitly asked me to use their names, the name of their deceased child and their experiences of
loss and grief to contribute to raising awareness of bereaved parents. Walter (2017) argues that,
in some cases, anonymity may prove disrespectful to both the bereaved and the deceased.
Similarly, the case for non-anonymity has also been argued from a more legal standpoint,
suggesting that quotes should be treated as literary works with attendant copyright issues
(Kozinets, 2010). Instances such as these force us to return to the notions of anonymity and
informed consent and question if vulnerable research participants (or indeed, any research
participant!) fully grasp what informed consent entails in the short and long run, in terms of
academic work and dissemination. One example from my studies particularly illustrates this:
one of the bereaved mothers in the community I studied enthusiastically gave her consent for
me to quote one of her postings in the Facebook group in an academic publication. When the
article was published, I sent it to her and contacted her to hear her views. Fervently,
she thanked me for conducting and persisting with the research, expressing how happy she
was to have contributed. She was still happy about her decision to let me quote her the post in
the community, and that her case and her experiences would contribute to furthering the
knowledge about the situation of bereaved parents. However, she ended by saying that she
hardly remembers anything from that period of her life when she grieved the loss of her child
so intensely. This incident forced me, again, to revisit and complicate the notion of informed
consent and what that means in relation to a traumatized person and to grief work over time.
As a case, it reminds us of the necessity that an ethical researcher is one who "works from the
center," which entails "being knowledgeable and prepared; present and aware; adaptive and
context sensitive; and honest or mindful" (Markham, 2006; Markham *et al.*, 2018).

Emotional challenges

The case I have presented here has illustrated that studying vulnerable individuals' use of
closed groups online can be challenging for several reasons. Ethical and methodological
dimensions are always entwined, and equally entangled are the emotional aspects in my
case. Studying people in despair suffering from what some researchers (Schwab, 1990;
Riches and Dawson, 1996) have deemed one of the most devastating experiences an
individual may experience in life is definitely challenging. As ethics and methods are
inextricably intertwined, so are the emotional challenges of conducting this type of research
intermingled. With a feminist approach, this is also necessary. However, sometimes it is
almost impossible to handle. As a researcher and as a bereaved parent, sharing this
experience with those you study can sometimes be a resource and sometimes utterly

overwhelming. The stories and situations, photos and thoughts shared by members in the group and the sheer amount of intense and desperate interaction in the closed Facebook group is often hard to regard in any sort of objective way, and at times impossible to face. Countless times, I have just broken down and wept in my office from seeing it all. The researcher's hat does not always sit so firmly on my head. I am *always already* simultaneously the bereaved parent and the researcher. I am *always already* a human being in a social world, and as a human, I sometimes break down with the experience. Being overwhelmed by what you encounter in the discussion group seems not to be a challenge exclusive to me as a researcher–participant but is indeed a recurring pattern in what I have observed in the interaction in the group: from time to time, members explicitly announce that they have to take a break "from all the misery" shared in the community, that it is "too much to handle in their present stage of grief." Both as a bereaved parent in the process of adapting to my own loss and as a researcher, I have to take a break now and then from observing what is happening in the closed group. Similar to the experiences Eva Svedmark (2016) reported from studying the online activities of vulnerable individuals, these affect me and stay with me. The interview situation has similar characteristics: *because* you are a researcher–participant; a precious connection between the interviewees and yourself as a researcher is often established, which can have both emotional and methodological impact, even if acknowledged (Blythe *et al.*, 2013). I believe that an autoethnographic approach makes this type of research even more valuable, as opposed to a more distant recount of results in any sort of objective way.

Closing remarks

Based on my past and ongoing studies of the role and use of a closed grief support group on Facebook for bereaved parents – a community of which I am myself a member – I have explored the complexities of methodological, ethical and emotional challenges of studying sensitive and vulnerable communities online from the perspective of simultaneously being a researcher and a research subject. Being a researcher and a research subject rolled into one, as it were, presents both opportunities and challenges. To conduct responsible research from both these perspectives pose high demands on the researchers' ethical as well as emotional capacities and responsibilities. Hopes and expectancies of the community under study might put the researcher into a dilemma; ethical aspects of anonymity and informed consent might have to be reconsidered as well as emotional challenges of engaging in and with sensitive research – all of which makes for a complex balancing act. Ethics and methods are inextricably intertwined, so are the emotional challenges of conducting sensitive research intermingled. Studying vulnerable individuals and closed communities online highlights the necessity for case- and context-sensitive research and, for flexibility, adaptivity and mindfulness of the researcher. It also highlights the importance of discussing and questioning theoretical, methodological and ethical developments for studying everyday life practices online. By contributing to our collective knowledge base on the practice of conducting sensitive research, I hope deliberation with a wider research community from a variety of academic backgrounds will widen both research scope and understanding, and that by exchanging insights and experiences, we will jointly continue to further the development of responsible research in the field.

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Ylva Hård af Segerstad is an Associate Professor in Applied Information Technology at the University of Gothenburg in Sweden. She earned her PhD in general linguistics from the University of Gothenburg (2002). With a background research interest largely focusing on aspects of text-based interaction in digital communication technologies, her current research concerns qualitative inquiry of information and communication technologies in social contexts. She is especially interested in examining the role and use of mobile communication technologies and social media in our increasingly digitalized society. This work is relevant for understanding how digital technologies intervene in and transform important aspects of everyday life, such as communicative patterns and relationships. Knowledge is renewed and changed and experiences are developed and negotiated in our technology-intensive society. These are issues that are just as important for schools and education, for business and the public sector as it is for the individual. A perspective in which technology issues are based on research in humanities and social sciences is necessary for our understanding of digitally mediated communication and the use of digital tools for private and professional activities. Throughout her career, Ylva Hård af Segerstad has actively contributed to the international research community with her keen interest in developing methods and ethical issues related to ethically responsible research conduct, which is particularly necessary for research involving networked media and the use of digital social data. Ylva Hård af Segerstad can be contacted at: ylva.hard-af-segerstad@ait.gu.se