

**Ethical issues in the use of video observations with people with advanced dementia
and their caregivers in nursing home environments**

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Research Article

ABSTRACT

The use of video allows researchers to gather rich, evocative and contextualized data, yet it also opens a space fraught with ethical challenges. In this paper, the authors describe their use of video methods in ethnographic case study research examining the experiences of persons with advanced dementia who reside in nursing homes and are nearing the end-of-life. In this research, video is used to help garner a deeper understanding of the person with advanced dementia's being-in-the-world as well as the embodied workplace practices of care staff. Drawing upon notions of emplacement and embodiment, we unpack ethical issues that arise from conducting research with a vulnerable population within a complex environment. In addition to discussing general ethical principles such as consent, assent and privacy, we argue that to conduct ethically sound research, the researcher needs a solid understanding of the complex and dynamic nature of the nursing home environment. This is, at once, a communal living setting and a home for the residents, a place of work for a diverse group of care staff, and an organizational structure emplaced in a larger socio-political environment. We shed light on, and discuss potential solutions to, the challenges and complexities of bringing a video camera into the nursing home space where ethical questions arise in ambiguous situations, where relationships shift and the ethical ground reconfigures over time.

Keywords: research ethics; video observations; end-of-life care; advanced dementia care; nursing homes

Introduction

Over the past several decades, considerable groundwork has been established for the inclusion of people with dementia in research with compelling discussion and debate on salient ethical issues such as autonomy, consent, confidentiality and privacy (see for example, Collopy, 1988; Dewing, 2002; Dewing, 2007; Goodman et al., 2011; Hall, 2009; Hubbard, Downs, & Tester, 2003; Sherratt, Soteriou, & Evans, 2007). Similarly, ethical issues related to qualitative research conducted in nursing home environments have also been explored (Baumbusch, 2011; Brown Wilson, 2011; Cassel, 1998; Tinney, 2008). However, in spite of this rich landscape of inclusionary research practices, video methodologies have made only a small contribution to the study of the practices and experiences of dementia care in nursing home environments.

A small body of research has shown video data to be instrumental for reaching a deeper understanding of the relational and individual experiences of life in the nursing home. However, the ethical terrain remains largely unexplored. While most studies that use video document the initial consent procedures, only a few researchers have described how they navigate other ethical challenges. The most common issues addressed are the notion of ongoing consent (Beck et al., 2011; Hammar, Emami, Engström, & Gotell, 2011; Husebo et al., 2007; Skovdahl, Kihlgen, & Kihlgen, 2003), and the potential for staff to feel uncomfortable or to change their behaviour while being filmed (Engström & Hammar, 2012; Hammar et al., 2011). Given the complexity of the boundaries between public and private space in nursing home environments (Hauge & Heggen, 2008), it is somewhat surprising that only one study has explicitly addressed the issue of privacy with respect to filming resident participants during personal care routines (Skovdahl et al., 2003). Finally, while outside the nursing home context, Cook's (2002) research exploring nonverbal communicative experiences of adult day program participants with dementia is notable for its exploration of the ethical issues of representation and othering that arose while reviewing video footage together with the study participants.

In wrestling with the messiness of using a video camera within complex healthcare environments (Collier, 2013), researchers are called to be critical and reflexive of their practices as "research ethics are contested, contextual and dynamic, and... best understood in real, concrete, everyday situations" (Prosser, Clark & Wiles, 2008, p. 3). Therefore, the purpose of this paper is to critically examine ethical issues that arose in the course of a research study that included video observations of people with advanced dementia and their caregivers within a nursing home setting.

Research in advanced dementia end-of-life care is dominated by a biomedical understanding of progressive cognitive and bodily deterioration, inevitably leading to the prioritization of physical care over care that emphasizes the uniqueness of person, the respecting of values, preferences and needs, and the development of consistent and caring relationships (Small, Froggatt, & Downs, 2009). To contribute a more holistic understanding of resident experiences of advanced dementia and end-of-life dementia care, we conducted an ethnographic case-based study, to elucidate how care staff

and family construct and respond to the psychosocial, spiritual and physical needs of residents approaching the end of life; how care practices shift over this time; and how the organizational and physical environment shape residents' experiences. Two cases, each involving a resident with advanced dementia identified as nearing the end of life, and the care staff and family involved in her care, were recruited from the same care facility. To understand variability in care practices, one resident lived on the special care unit, a space tailored to meet the needs of individuals living with dementia, and the other resident lived on a unit designed to meet the needs of frail elders unable to live in the community due to complex health needs. Both residents' primary diagnosis was Alzheimer's disease or related dementia, but they had no other comorbid life-limiting illness. The care facility was purposively selected as it had a reputation for excellence in holistic end-of-life care; other than contributing to the development of new knowledge, this facility had no other overt stakes in this research.

In this research, the first author¹ conducted over 500 hours of participant observation and took video recordings of times when the resident participants were alone, in social activities and in personal care (approximately 30 hours of footage). Care staff participants (n=26) were involved in observations and interviews, 17 of whom consented to video observations. Care staff participants included care aides, licensed practical nurses, registered nurses, recreation and pastoral care staff, and nursing home management. Two family members also participated in interviews and observations, though neither felt comfortable with video observations. The family members were also the residents' proxy decision makers (proxies). The proxy was legally sanctioned to make health care decisions on behalf of the resident, provide consent for resident participation in a variety of facility activities (e.g., special recreation activities), and provide consent for research participation.

Over the course of the study, I became intimately familiar with the resident participants' patterns of embodied communication and how care staff interacted with them and ascribed meaning to residents' nonverbal cues. The video camera became invaluable as it enabled close attention to the embodied responses to the social, sensory, and material environment in which they are emplaced. Moreover, it documented a visual narrative of the lives of resident and care staff participants. In addition, as part of a reflexive process, video data was taken back to the study participants and the residents' proxies for their reflections and commentary on the footage. As McDougall (2011) contends,

Although films cannot get inside another person's mind or emotions, they can, by cinematic means, communicate aspects of their subjective experience. They do this partly by paying close attention to the expressions, movements, and responses of individuals and partly by following narratives in their lives...Viewers come to understand others' feelings not by experiencing them directly, but by vicariously sharing their social interactions and physical surroundings (p.111).

¹ For the duration of the paper, we write in first person singular where study procedures are explicitly referenced signifying the primary author's actions and decision-making processes in the conduct of the research. Otherwise, we write in first person plural to signify the collaboration of the co-authors.

In the discussion that follows, the visual is first contextualized by describing “advanced dementia” and the setting in which study participants are emplaced (Casey, 1993; Ingold, 2001, 2008). In the section entitled, “consent and ongoing consent” we consider consent for both resident and staff participants. Next, in the section entitled “emergent ethics and in-situ practices,” we discuss the issue of privacy in the nursing home environment, the notion of performance and relationship, and the notions of reflexivity, representation and video as a lasting legacy. Finally, we offer practical strategies to minimize the obtrusiveness of bringing a camera into the nursing home setting.

Contextualizing the Visual

Advanced Dementia Nearing the End of Life

Advanced dementia is a term used to identify the last stage of a dementia-related illness. Briefly, this stage is characterized by severe cognitive and physical impairment. People with advanced dementia have significant communication deficits to the point where they have no verbal capacities or are mute, they need full assistance with all personal care and activities of daily living such as bathing, toileting, eating, and moving around, and they have lost the ability to walk and are thus wheelchair bound (Reisberg et al., 1984). The advanced stage is characterised by a progressive dwindling of capacity and abilities and someone may live in this condition for a short period of time or for years (Mitchell et al., 2009). While determining the prognosis in advanced dementia is difficult, experts in the field advocate for a comfort-based approach to care, minimizing invasive procedures (e.g., feeding tubes) and maximizing comfort and quality of life to the end of life (Thompson & Parker-Oliver, 2007; van der Steen et al., 2014).

Nursing Home Environments

A nursing home is a communal living environment that is purpose-built for people who are no longer able to live safely at home and need 24-hour nursing care. In the jurisdiction where this study took place, the average length of stay for someone moving into a nursing home ranges from 18 months to 2.5 years. Further, up to 80% of nursing home residents have dementia or cognitive impairment (Graham et al., 1997). In this study, video observations took place in resident participants’ private rooms and in social settings.

The physical, social and organizational dynamics of the nursing home play a central role in the individual and collective wellbeing of those who move in and out of the space. A foundational assumption to this research is that to understand the experiences of people with dementia and the staff who care for them, it is also essential to understand that these experiences are poignantly shaped by the context within which people are emplaced. Casey (1993) argues that to be ‘in place’ is intimately part of who we are as human beings.

The power a place such as a mere room possesses determines not only where I am... but how I am together with others...and even who we shall become together. The “how” and the “who” are intimately tied to the “where,”

which gives to them a specific content and coloration not available from any other source. Place bestows upon them a “local habitation and a name” by establishing a concrete situatedness in the common world. This emplacement is as social as it is personal (p.23, original italics).

While any place is shaped by its historical, cultural and socio-political environment, the nursing home is a place that is an intricate mosaic consisting of layers of socio-cultural and political dimensions of the people who weave in and out of its physical structure. It is a dynamic structure that evolves and changes as residents and care staff enter the place with their own stories. In addition, it is a place where health care happens, which is shaped and reshaped by the larger socio-political environment of which it is a part. Finally, the nursing home as a site of research is also a place where research happens; thus, the researcher as an active contributor to the dynamics of place is also important to consider.

What is evident is the need to think of the nursing home as a place that is continually constituted rather than a static site for the delivery of healthcare. As video captures movement through place (Pink, 2013), it follows the dynamic rhythms of everyday life and in so doing, emphasizes a meshwork of relationships (Ingold, 2008), emplaced images (Pink, 2013), and corporeal images (MacDougall, 2005). Contextualizing the visual with reference to the social, temporal, and material environment from which it came is essential to understanding the visible and invisible depths that the visual represents. Context is also essential in casting light upon the ethical conduct of visual methods within these environments.

Given the complexities of this environment, guidance for ethical research conduct was sought from the CIHR et al. (2014) Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, which governs the ethics of all research involving humans in Canada. This policy underscores the core principles of respect for the inherent value of human beings, of concern for the wellbeing of study participants, and of the obligation to treat people with equal respect and concern. Further guidance was sought from experts in dementia care research, particularly from Dewing’s (2007) Process Consent Method, which outlines a pathway for researchers to engage with persons who have dementia. This study received ethics approval from the University of British Columbia’s Behavioural Research Ethics Board.

Consent and Ongoing Consent

Considering the emplaced nature of study participants, consent is not only considered in its written form, but also as embodied and oral, and as an ongoing and negotiated process. This section describes how I secured consent for video observations from multiple players and how I handled potentially competing interests.

Consent for Resident Participation and Monitoring Assent

In this study, I sought to recruit resident participants who were in advanced stages of dementia and were identified as nearing the end of life. In legal terms, the

resident participants were deemed to not have the capacity to consent as reasoning, comprehension, remembering, and communication were severely compromised (Hall, 2009; Hubbard et al., 2003). As such, written consent for the resident's participation was sought from the resident's proxy. This process required careful consideration of what the proxy was being asked to consent to. Consent was sought for general permission to involve the resident in the study, to take moving images, to display these images to different audiences and in different contexts, and to archive video data to be repurposed at a later date. In the process of securing consent, I sought to identify situations that best represented the ebb and flow of the resident's day and the proxy was given examples of situations that potentially could be filmed: when the resident was alone, in social interaction, at meals, and in personal care activities. The act of filming these situations was emphasized as a negotiated activity dependent on ongoing assent from the resident participant and consent from care staff (described below) as well as ongoing consent from the proxy. That is, if the proxy felt that the act of filming was not in the resident's best interest, consent for filming could be withdrawn at any time over the research process. To develop a better understanding of what would be appropriate to film with respect to the specific resident, biographical information was also considered such as, for example, how the person might have responded to a camera (video or otherwise) in the past and how the person responded to nursing home care over time. Building such understanding of the person was integral to this research to ensure that the person's values and preferences were considered.

Understanding the person also allowed for the development of an awareness of signs of well- or ill-being, which was foundational to the practice of monitoring resident assent. Securing consent from proxies is not enough. Persons who lack legal capacity to make decisions regarding informed consent may still be able to express their wishes regarding participation in meaningful ways (Dewing, 2007), and viewing this as an ongoing process is especially germane to ethical research practices with people with dementia to ensure that the person's choice to participate in research is respected. However, there is no consensus as to how to do this in practice (Black, Rabins, Sugarman, & Karlawish 2010). In this research, residents were given the opportunity to voice their assent/dissent. I explained my presence, showed them the camera, and asked permission to observe or video. This process was re-enacted with each new observation. Because the residents in this study did not have the ability to verbally express their assent, close attention was paid to their vocal or embodied expressions. However, as embodied expressions can be ambiguous, I consulted the residents' chart for information that might elucidate the residents' general response to being cared for, how they responded to new staff, and other cues of assent or dissent to care. Care staff were also consulted about how the person typically dissented to care. Finally, to determine what would be appropriate to film, I asked myself whether it would be right and good for those involved to be filmed in a specific situation. For example, care staff suggested that it would be valuable to film a resident participant being bathed. I set up the camera such that only the resident's upper torso would be framed. However, I became cognizant of my own discomfort and wondered whether this situation was indeed right to film, particularly considering that the resident's family characterized her as a private person in the past. I did not film the care interaction. On further reflection, through both reflexive memos and peer

mentoring, I concluded that to honour this resident was to not film her in a state of undress and this decision remained for the duration of the study.

Consent for Staff Participation and Ongoing Consent

The consent process for care staff participation was considered in much the same way as the process followed for securing consent from the resident's proxy. While written consent was solicited, I emphasized that the act of filming would be negotiated with individual care staff participants each time the camera's gaze could be fixed on them. Moreover, similar to observing embodied expressions of resident participants, I also observed care staff's body language to discern if they were indeed consenting to being filmed – sometimes words of consent are at odds with a body that is voicing dissent. While initially it was assumed that participants would have some degree of “camera-consciousness” (Pink 2013, p. 107), in most cases, I did not observe this over the long term. However, if care staff showed signs of discomfort and it interfered with the enactment of care, the camera was turned off.

Competing Interests

Negotiating consent with care staff requires sensitivity to the relationship between them, the organization, and the local customs of place (Pink, 2013). In this study, what became particularly crucial was to become aware of how information was exchanged between care staff and management, and in particular how messages about the research procedures were conveyed to the staff. During an introductory staff meeting, management introduced the research saying that video observations will occur. What underlies an authoritative and commanding statement such as ‘will occur’ are the potentially competing priorities of the organization, the staff, and the researcher. The organization's managers might feel they have the authority to direct staff in terms of their participation in facility-based activities (such as research); however, in so doing, care staff's right to exercise autonomy in this situation is taken away. Moreover, management might have consented to participate with the hopes of finding evidence that highlights gaps in care practices. As the staff were well-aware that the study was officially endorsed by management (a prerequisite for entry into the field), due diligence had to be taken to ensure that the care staff, particularly the care aides who are often a disempowered group (Tellis-Nayak & Tellis-Nayak, 1989), would not feel compelled to join the study because management voiced that they would. Considering the fiduciary relationship with individual staff participants, the researcher has an ethical commitment to ensure confidential research practices in garnering consent itself and moreover, in the practice of taking video. As such, great care was taken to build trusting relationships before taking the camera into care situations.

Emergent Ethics and In-Situ Research Practice

The process of securing consent from multiple players, the need to keep the conversation about consent alive through the research process, and the practice of getting to know the person with dementia and monitoring their assent are essential to the respectful inclusion of multiple players in the research process. Moreover, consent, ongoing consent, and monitoring assent are primary drivers of what can be filmed and what can be shared

with a wider audience. In everyday research practice, the nature of the nursing home environment as a collective living environment and a place of work, underscores the sensitivities needed to film within these spaces. In this section we first discuss the notion of privacy – not only in terms of the practice of filming and maintaining video footage as private and confidential, but also in broader terms of ethical tensions and potential intrusiveness of filming in a “private” home (i.e., nursing home-as-home). Second, we explore how the camera has the potential to impact the performance of care work. Third, we question to what extent bringing a video camera into the workspace impacts caregiving, work and research relationships. Finally, we explore the notions of reflexivity and representation.

In/Outside the Frame: Considering Privacy in the Nursing Home Environment

Derry et al. (2010) state that video data are “inherently non-anonymous” (p. 36). While video data can offer evocative portraits of study participants and detailed information of the place in which they are situated, as custodians of these data, researchers are called to carefully consider not only the ways in which they keep data private and confidential but, also, how they accord respect toward participants, nurture the research relationship, and protect private information over the course of the research process (Cox et al., 2014). A signed consent form does not give researchers the liberty to do with the data as they see fit (Pink, 2013). In this research, while assurances were given in terms of maintaining confidentiality and protecting personal information in the legal sense, protecting privacy of study participants in the broader sense over the research process was a little more difficult to navigate. In some regard, this challenge arose due to the nature of case study research, i.e., not everyone in the nursing home was involved in the study. However, the camera introduced another level of complexity to the issue of privacy as the camera’s gaze was fixed on certain individuals, and nonparticipants (particularly care staff and management) were well aware of who was participating or not. If relationships between staff and management are contested, staff participation could be viewed as not being compliant with the facility directive and a researcher must tread carefully around the staff-management dynamic. Care staff in this study did not seem to mind that their participation was revealed; however, they were concerned about who would actually see the footage and what footage would be shown. As such, the care staff participants and the proxies were continually assured that all their data would remain confidential unless they explicitly agreed that specific aspects of it be shared. Further conversation was held to discuss ways to maintain privacy such as the manipulation of images through blurring of faces, the use of video stills in place of moving images, and the degree to which video footage would be edited. It is often assumed by researchers that privacy is of utmost importance to participants when in fact other values may be equally or more significant (Bombard, Cox, & Semaka, 2011). After reviewing the video footage, care staff were less concerned about their privacy and were quite happy for a variety of footage to be shared; likewise, the proxies gave permission to share footage after reviewing the video of their family member.

The issue of privacy also relates to what can be filmed. In this research, proxies gave consent to film social situations, times when the resident was alone, and personal care encounters such as, for example, when a resident was assisted with dressing

during morning care routines. While proxies left filming decisions to my discretion, it was understood that I would be guided by my own moral compass and would not film situations that would compromise the dignity of resident and staff participants. This was an ethically uncomfortable space to be in – having the responsibility for filming decisions left me in a vulnerable position and I was concerned that my moral principles might be inadequate or would not be aligned with those of the proxies. In part, having the freedom to film a wide range of situations was what guided the practice of getting to know the resident, monitoring assent, and holding ongoing conversations with the proxies and staff about what could or could not be filmed. However, my decisions of what to film were also guided by several questions: to what extent would video data contribute to answering the research questions that could not be answered as fully by traditional observational methods alone? In what way would participation in video observations benefit the resident – whether directly in that moment, or indirectly through the generation of new knowledge? To what extent would filming disrupt the social ecology of place as a place where healthcare happens?

Privacy and negotiating what could be filmed was also influenced by who was present beyond the camera’s frame. Much care was taken when filming in communal areas of the nursing home to ensure that nonparticipants were not inadvertently filmed. However, in reviewing footage taken in social spaces, it became apparent that while there may have been visual anonymity, often-times there was not auditory anonymity. That is, the audio captured not only names, but also vocal utterances of nonparticipants that could uniquely identify those individuals. Moreover, footage revealed identifying information about the nursing home itself. While one could argue that maintaining visual anonymity is sufficient for ethical practice, revealing other unique identifying features of place and people raises the question of whether privacy has indeed been compromised.

This broader understanding of privacy points to the larger issue of filming in the nursing home and the extent to which filming intrudes on the privacy of those who dwell and work in this environment. While the lived reality of a nursing home includes the ebb and flow of staff, family, visitors and potential strangers in the space, to what extent does bringing in a camera disrupt the natural rhythms of the space? Moreover, nonparticipants may not understand why a researcher is in their space with a camera, they might be suspicious of the camera, or they may want to be in the camera’s frame. In this research, several instances of social gatherings were not filmed because it was felt that it would be too disruptive of the spatial ambience created by care staff, even though permission to film was given. In this respect, the notion of privacy was considered in terms of the negotiation of ongoing relationships with both research participants and nonparticipants, protecting the privacy of place and according respect to all those in the space.

Performance, Relationship, and Reflexivity

Fieldnote (abridged): I hold a video feedback session with two care aide participants- showing them two minutes of minimally edited footage of them transferring a resident participant from her bed into a wheelchair using a mechanical lift. Both participants remark that it is obvious to them that they were well aware of- and uncomfortable with

- the camera focused on them and are subsequently doing their job differently: rushing care and not providing enough verbal cues to orient the resident to the tasks at hand. Though they point out care practices they are happy with, they primarily focus on “what we did wrong.” They also make disparaging remarks about their own physical appearance (e.g., “I look ugly; I am fat”) and complimentary remarks about the appearance of their care partner (e.g., “You’re beautiful!”). One participant says that she has never seen herself in a video before, and from her body language, she appears to be uncomfortable watching herself on screen. Both participants ask who else will view the video and it is apparent that they are concerned with being judged, not only by management but also by a broader audience.

This field note raises important issues about the emergent and situational ethics of bringing a camera into a workplace environment. First, it highlights that the presence of a video camera impacted the care staff participants’ performance of care work and may have impacted the experience of care for the resident participant. Second, it illustrates dynamics of relationships: the care staff participants’ relationships to themselves, each other, their work environment, and the researcher. Third, it underscores the value of engaging in reflexive dialogue with participants particularly around the notion of representation. While these points are related, we will take each point in turn.

Performance

The notion of performance reveals itself in two distinct ways. First, the video feedback discussion revealed that participants held preconceived ideas of how they performed care without being observed by a camera or the researcher, i.e., they believed they performed differently. Interestingly, after this caregiving situation was actually filmed, the care aides commented that they did not notice the camera or the researcher at all; they just went about their usual practice without any distraction. This is a similar finding to other research, which observed that care staff did not change their behaviour in the presence of a video camera (Engström & Hammar, 2012; Hammar et al., 2011). Methodologically, the notion of performance calls into question the representativeness of data and the possibility of observing a Hawthorne effect. However, if we accept as Pink (2013) contends that “in video ethnography it is the encounter between life as it is lived and performed” (p. 106), the methodological tensions are somewhat tempered; by its very nature care work is indeed enacted and performed, which shifts over time as the needs of the resident change and the care staff’s own being-in-the-world evolves. Perhaps the more pressing question is to what extent do shifting performances of care impact the wellbeing of the resident participant receiving the care? The two care aides reflecting on their practice felt that the lack of performing certain elements of practice (e.g., failing to use more verbal cues) represented substandard care, though from my vantage, care delivery did not appear to be different than what was observed without a camera or how others performed their work. However, the care aides did highlight care practices that they were quite pleased about – practices that were illustrative of embodied nonverbal communication (e.g., a caress of the cheek, a rub of the arm before it is lifted). Because a person with advanced dementia typically has limited comprehension of verbal cues, nonverbal and embodied cues are likely to be more readily understood and, in this sense, the video footage revealed the performance of an array of embodied communication. In this light, footage illuminated

care practices that otherwise are left unrecognized and unacknowledged.

Second, the two care aides’ narrative of their performance could be seen as an element of their negotiations with me in terms of representation and knowledge production. Thus, it prompts the question of how video representations contribute to an understanding of care work and the organizational policies that undergird this work. However, in reading and interpreting the work context and the care practices depicted in the footage it is important to emphasize that because care work is framed in a particular way, only a partial understanding can be realized (Pauwels, 2010). As such, in showing the footage to participants and discussing what transpires on the screen and what other contextual elements are missing from the camera frame, we can gain a deeper understanding not only of care work, but also of how participants evaluate their own performance.

Relationship

If we accept that the act of being filmed will in some ways impact the performance of care work, it follows to ask the question of how, if at all, the camera shapes relationships between the care staff, residents, and the researcher. This has ethical implications in terms of how we are with one another in the moment and whether it is right and good to introduce an intermediary object between oneself and study participants (MacDougall, 2011). The fieldnote vignette reveals several questions to ponder where the gaze of a camera impacts the moral responsibility we have to each other as being part of human relationships. First, if the camera’s gaze changes the way care staff perform care work, how does this impact a resident’s experience of the caregiving relationship? While I did not observe any negative implications on care work and perhaps care staff were even more attentive, particularly in an embodied way, what are the long-term implications for the staff-resident relationship? It is possible that care staff could reduce their attention to other residents, negatively impacting their experiences of life in the nursing home. Second, if performance changes, how does this impact the working relationships amongst care staff? Again, while I did not observe a negative impact on staff-staff relationships, it is conceivable that if one staff person is more camera-conscious than another, workload will be affected. Thus the camera has potential to disrupt the care staff’s responsibility to each other and the trust in each other to do their job.

In consideration of the participants’ comments about body image, another question to ponder is the emotional impact of viewing oneself or one’s relative on screen. By asking participants to view themselves on the screen, participants are asked to take a critical gaze and subject themselves to scrutiny (Pink, 2013). This was particularly relevant for care staff participants. While staff participants readily engaged with the reflexive process, some found it difficult to watch themselves on screen – judging themselves harshly on an array of attributes: body image, clothing, work practice, relationships with colleagues. This not only gives one pause to consider the ways the camera influences the participant’s relationship with him or herself, it also calls into question whether it causes more distress than acceptable when care staff are so afraid of being judged by others. In this study, while care staff were reassured that no footage would be shown without their consent, some saw the camera as an immediate threat and the video footage as an enduring threat to their professional integrity, and being judged by management (whether praised

or otherwise) would put them in an uncomfortable position.

Similarly, video footage was shared with proxies, and the emotional impact of observing their relatives was quite evident. While on some level an emotional response was anticipated, I found it challenging to hold and contain their surge of emotion. Video footage showed images of their relatives in situations that they otherwise would not observe (e.g., care routines) and observing their relatives' frailty and vulnerability was often confronting. At the same time however, they expressed feeling grateful for being shown the footage as they could see for themselves their relatives' everyday reality. The ethical dilemmas inherent in this context also relate to whether viewing footage of care interactions between staff and their relative reshapes the relationships between proxies and facility staff. In this study, proxies considered their relationships with care staff to be respectful and supportive working relationships. However, this is not always the case in family-staff relationships, which often can be considered contested (Bauer, 2006).

The final question relates to the relationship between the researcher and participants and in what ways these relationships shift over time. For example, by enabling care staff and family to reflect upon video, my role as a researcher shifted from a facilitator/analyst to a collaborator. In addition, my emotional connections to participants also shifted. This relates both to the act of filming and the practice of reviewing and analyzing the video data. In this study, as video data also served as a visual narrative of resident participants' lives, bearing witness to the person who was moving nearer to the end of life was emotionally and spiritually very difficult, and made somewhat surreal by reviewing the data over and over again and returning to the nursing home for continued observations. Thus, the ethics of care for oneself (Dickson-Swift, James, Kippen, & Liamputtong, 2008) is of paramount importance in order to be sustained throughout the research process.

Reflexivity, representation, and lasting legacy

In many respects, while the fieldnote presented earlier about the feedback session held with care staff reveals emergent ethical issues to negotiate when filming in the nursing home environment, it also reveals that by holding reflexive feedback sessions with study participants, these issues can be explored in dialogue with study participants themselves. This feedback mechanism is much more than just being aware of how a camera might impact performance and affect relationship; rather as Pink (2013) writes, "video invites us to move forward with it, and as such to make new knowledge as we engage with it" (p. 107). Reviewing minimally edited video footage with participants provided them with the opportunity to discuss, share, analyse, and even problem-solve daily practice. In terms of care staff participants, I asked them to reflect on their practice in order to facilitate a greater understanding of how they interpret and respond to the residents' nonverbal cues. What care staff said about themselves and their practice was very revealing – not only of how they perceived themselves in practice and their relationships, but also of how practice is embedded in the larger context, including facility policies and the physical environment, that impacts the care encounter. Likewise, sharing video with proxies was a powerful feedback method revealing their understanding of their family members' experiences, thereby giving new meaning and interpretations that would otherwise remain untapped. However, with both care staff and proxies, the sharing experience

requires a great deal of sensitivity on the part of the researcher. Decisions about what footage to share and when to share it need to be carefully contemplated in advance. Moreover, it is necessary to weigh the risks to the participants of sharing footage that may evoke a strong emotional reaction. While participants can make their own decisions of whether they want to view something or not, giving a preamble to some of the video content may be wise.

The value of holding video feedback sessions cannot be emphasized enough. Not only do such sessions generate new knowledge, they also inevitably lead to discussions about representation and sharing video with broader audiences. While care staff participants were concerned about being judged, they were given control of whether footage could be viewed with others if the proxy was also in agreement. In discussions about representation and dissemination, I asked participants and proxies to think about the notions of privacy and lasting legacy and what that might mean for them as care workers and as family members.

Ensuring privacy of those who are inside and outside the camera frame requires a weighing of burden and benefit. Anonymizing the data and obscuring identifying information is a standard ethical qualitative health research process. However, to what extent is this effective without rendering video data meaningless (Derry et al., 2010)? In this study, embodied nonverbal communication was of central import to the research questions and blurring images did not make sense. Does this mean that images cannot be disseminated? Cook (2002), who also focused on nonverbal communication, argued that she could not disseminate footage, as it compromised the privacy of participants and had potential to perpetuate negative stereotypes of people with dementia.

Thus, the author used artistic methods to recreate the research findings as a way of dissemination. However, it is my position that video images can contribute to positive perceptions of dementia, aging, dying, and the care work involved. Sherratt et al. (2007) contend, "an element of proportionality may need to be applied, based on developing an understanding of the level of infringement that would counter any expected benefit" (p.475). In weighing burdens and benefits, an important question to ask is to what extent the images impact the reputations of the people and places represented in the images. Understandably, the researcher cannot control what an audience might interpret; however, she does have the responsibility to uphold the principles of respect for persons and doing no harm. Of course, this ethical muddiness is not limited to visual methods.

However, the visual image that depicts the nursing home environment reflects more than the image portrayed; it may invoke a strong visceral reaction from the viewer, and can be interpreted in multiple ways. Thus, how the researcher stories the image, or whether the researcher chooses to leave meaning making to the audience can result in unintended consequences for who/what is represented in the image. In addition, it is also important to question the purpose of sharing the video images, asking to what extent they forward new knowledge and to what extent the images can be meaningfully understood.

Study participants and proxies were also asked to carefully think about their lasting legacy

and the impact of having images of themselves or their family member made available to a wider audience. These were difficult questions to answer – who knows what a future-self might want (Marcus & Nuris, 1986)? To help care staff think about this issue, I asked them to consider how they would want to be perceived as a caregiver and to think about the implications for them as working professionals to have images that depict their work accessible to others over time. Some care staff were quite pleased to have footage of themselves disseminated to a variety of audiences over time and were not concerned about their professional image. However, others held more concern and were agreeable to heavily edited moving images or still images that only displayed certain profiles. In terms of the proxies, as video footage would likely be the last tangible images of their relative at the end of her life, I asked them to think about how they wanted their relative to be remembered after she died. Proxies gave permission to share a variety of footage and one requested copies of select footage to share with other family.

It is useful to think through the challenge of representation and legacy through the lens of emplacement, which enables us to question how video footage conveys the dynamic and intimate entanglements of everyday life in a nursing home – as lived by the residents and care staff alike, and interpreted by audiences through processes of engaging with and making meaning of the images (Ingold, 2010). In the end, it is about being sensitive to the wishes and beliefs of participants (Prosser, Clark & Wiles, 2008) and actively engaging with them to understand what they think is appropriate. Much of my research is encompassed in the lens of an ethic of care – coming from working in and researching with those who live out the end of their lives in care facility environments. My decisions are based on a desire to act out of care and compassion and in ways that benefit the residents, care staff, and organization that are part of my research. Through this lens I seek to cultivate good practice with integrity, trustworthiness, and a great deal of humility, allowing research participants to guide me in terms of what is right and good for them.

Practical Strategies to Minimize the Obtrusiveness of Filming

In consideration of how the camera influences relationship and performance, it is important to be mindful of the act of filming. As such, we offer some practical suggestions to minimize the obtrusiveness of using a video camera in a nursing home environment.

When to Introduce the Camera

Showing a camera early on in the process may be preferable from “a moral and practical point of view [as it shows] one’s subjects straightforwardly what one is doing and allowing the relationship to grow around that” (MacDougall, 2011, p. 107). However, in this research, the camera was not used immediately, but it was always close at hand – being one of the tools that were carried around the space along with pen/paper. In part this was driven by the methodological decision to not film everything but rather to focus on situations that emerged throughout a given day, and also by a relational decision to shape the perception that the camera was

part of the researcher; as Pink (2013) argues, “The camera becomes part of its user’s identity and of how he or she communicates with others” (p.107). Care staff and residents were used to seeing the camera, though it was not used at all times. In this respect, active filming was introduced gradually and participants had time to grow accustomed to the situations that would likely be filmed (Pauwels, 2010).

Being Technically Proficient

Practically, knowledge of place and learning the act of filming (Derry et al., 2010) in the nursing home environment is essential to minimize any disruption on the flow of care. Learning the layout of the space, the limits of space, and negotiating where to position oneself and the camera within the space is essential to remaining unobtrusive. While to some degree bringing a camera into the space will shift the nature of the space and the relationship with participants, being unfamiliar with place calls undue attention to the act of filming (MacDougall, 2011) and will contribute to participants’ camera-consciousness.

Paying Attention to Nonverbal Cues

Sensitizing the participants to the camera is not foolproof. Some people simply don’t like to be under the gaze of a camera, and while they may have consented on paper and given oral consent, in practice, they may be conveying a different message through their embodied expressions. Ongoing consent is important, but so are observation skills – what is the person’s body saying and is this related to being filmed? It is important to consider these cues as valid and remind participants that they can opt-out of being filmed at any time.

Conclusion

Auilina and Hughes (2006) so aptly observed that “the idea of dementia is so negative and powerful it makes dementia one of the more terrifying illnesses to envisage” (p. 144). Reflected in some discourse communities, dementia has been equated with the “loss of self” (Behuniak, 2011, p.78). Yet, by using language such as “the living dead,” people with dementia are malignantly positioned, deeply damaging their personhood and leading to depersonalized care interactions (Sabat, 2006). Yet, picture this scene:

Ella listens to Schubert’s Ave Maria. With her head tilted slightly back, her silvery white hair catches the sunshine, setting her aglow. Her breathing is audible and seems to match the rhythm of the aria. As the music slows and the cadences signal the ending of the song, Ella stirs, she pulls herself up in the chair and is about to vocalize. But the music launches into the da Capo, and she resettles; her breath seems once again entrained with the rhythm of the song.

This example underscores the powerful insights that video can offer- Ella appears to be aware of, if not engaged with music. It is far from an image of “the living dead.” This video excerpt does more than document Ella’s embodied experiences. It also invites the audience to share in the profundity of the moment: it invites us to listen with her, to breathe with her, and to enter into our shared humanity. These are important moving images to describe, if not share, and by making visible meaningful moments, video offers

a different way to look at the complexity of the lived experiences of those living with, and dying from advanced dementia and the care work involved.

Video observation is a powerful research tool and mechanism to further our understanding of the experiences of advanced dementia. However, to make visible these moments in advanced dementia care, researchers are called to tread carefully and to ponder, deliberate, and document procedural and emergent ethical issues. It calls for careful consideration of the specific social, material and political contexts in which the images were created. It calls to act responsibly and respectfully when negotiating informed and ongoing consent from all involved – including the person with advanced dementia. It calls to reflect upon how the camera might impact the performance of care work and the relationships between staff, residents, and the researcher. It calls the researcher to be critical, reflexive and honest about ethically meaningful moments.

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