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CULTURE, MEDIA & FILM | REVIEW ARTICLE

Intercorporeality and visual representations of carework in nursing home environments

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Abstract: Caring for the body is a central activity of care staff working in nursing home settings. While there is a growing body of literature on social dynamics of carework, less attention has been paid to embodied dimensions of this work. This paper draws upon fieldwork data, including video data, derived from ethnographic case studies of end-of-life advanced dementia care to elucidate intercorporeal aspects of carework. Focusing on practices of caring for the physical body (e.g. dressing the resident), this paper discusses how visual methods can enable researchers to carefully attend to embodied, inter-relational and ethical dimensions of carework that contributes to an aesthetic approach to caring for people with advanced dementia. In addition, this paper explores how visual representations of carework must be considered within the complex interplay between nursing home regulatory mechanisms and the socio-cultural location of both the care providers and residents.

Subjects: Death and Dying; Chronic Diseases; Nursing Older People

Keywords: carework; end-of-life dementia care; nursing homes; visual ethnography; visual methods

1. Introduction

In posing the question "how ought we to care for people with advanced dementia", ethicist Julian Hughes (2014) proposes an "aesthetic approach" to dementia care. Unlike aesthetics as a philosophical inquiry and artistic investigation, Hughes' attention to aesthetics does not centre on

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PUBLIC INTEREST STATEMENT

To a large extent, caring for people with advanced dementia who are nearing the end of life consists of providing them assistance in physical care activities such as: getting in and out of bed, dressing, bathing and eating. In nursing home settings, this assistance, labour usually provided by resident care aides, has been criticized as being task-centred and for objectifying people with advanced dementia. In this article, drawing on my own fieldwork with two individuals who were nearing their end of life, I discuss the use of video to focus on the performance of care in a nursing home. I also discuss ethical issues related to representing care or visually documenting people with advanced dementia and their caregivers. My exploration of video use relates thinking about how a sensory and embodied approach to dementia care can help researchers, practitioners and family members to develop a more nuanced understanding of dementia end-of-life care.

questions about beauty or judgements about what makes something a work of art. Rather, drawing upon the Greek root of the word aesthetics as outlined in *Shorter Oxford English Dictionary* (SOED), he foregrounds the idea of things "pertaining to perception by the senses" (p. 1407) and the moral question of how we stand in relation to each other. Aligning with the concept of tacit knowledge in care practice (Benner, 1994; Kontos & Naglie, 2009), as a relational concept, an aesthetic approach to dementia care therefore requires care staff's perception, intuition and imagination that draws upon close observance of gesture, action and interaction. It also requires a "language" that is closer to the embodied and multisensoriality of the care interaction itself; a language that captures the visual, temporal, tactile, aural and verbal domains.[1]

Caring for people with advanced dementia nearing the end of life, to a large extent, involves directly caring for their bodies through personal care assistance (e.g. help with dressing, bathing, toileting and eating). This "carework" (Twigg, 2002) is constituted through the interactions between the bodies of care staff (primarily care aides) and the older adult, and comprises less tangible dimensions of care. Therefore, carework can be conceptually understood as simultaneously being task-oriented physical labour and relational, therapeutic labour (England & Dyck, 2011; Twigg, 2002). In nursing home settings, carework has been subject to much scrutiny as it is primarily understood through an objectified lens that foregrounds the task-centredness of carework with a persistent focus on bodily hygiene and physical bodily maintenance (Twigg, 2002; Twigg, Wolkowitz, Cohen, & Nettleton, 2011). Hughes (2014) vision of an aesthetic approach to care through the focus on its embodied, relational and sensorial dimensions brings our attention to *how* care staff understand and respond to people with advanced dementia; and in so doing, can help bring a more nunanced understanding of how to provide quality person-centred end-of-life care. However, accessing the private world of carework is difficult to negotiate, which results in the tendency for researchers to privilege interview methods with care staff (Twigg et al., 2011). Such methods tend to downplay intercorporeal interactions, the nonverbal and multisensory (i.e. the aesthetic) aspects of carework. Consequently, conventional interview methods tend to translate care into words and text, "with the inevitable bias towards abstraction and bleaching out the corporeal" (Twigg et al., 2011, p. 175).

The lack of attention to more relational and embodied dimensions of carework, coupled with the challenges of accessing the private world of carework (Twigg et al., 2011) and the inclusion of people with advanced dementia in research (Black, Rabins, Sugarman, & Karlawish, 2010; Dewing, 2007), calls for a methodology (and methods) that enables careful attention to the embodied and (inter) corporeal aspects of carework. Ethnography, augmented by video observations, is one way through which we can develop a different understanding of aesthetics (and experience) of dementia care. As observation alone can miss intercorporeal and embodied expressions, as a way of seeing and listening, video methods can enable a researcher to get close to these expressions otherwise not afforded in typical observations. Therefore, the purpose of this paper is to contribute knowledge on the use of video methods in the relatively uncharted territory of dementia care in nursing home environments. Highlighting my own emergent use of video, these reflections examine how video methods (considering both audio and visual) might add to understandings of dementia care. To address this purpose, the article is structured as follows: I first will orient the reader to the research this paper is based upon. Next, with a focus on *researching* an aesthetic approach to dementia care, I discuss the use of video in data collection to augment and extend ethnographic observation and in-depth interviews. I also examine how video footage enables a "return to the carework encounter" during the analysis process, for myself as a researcher and participants (care staff and family). I then explore three dimensions related to the aesthetics of care as identified during the analysis process. Finally, I explore how carework can be communicated back to audiences (e.g. other care staff, other researchers) to prompt meaning-making and a deeper understanding of the nuances of dementia end-of-life care. I pay particular attention to the confluence between methodology and ethical research practice highlighting the commitment to maintain participant's privacy balanced with the simultaneous need for respectful portrayals of people with advanced dementia and those who give care.

2. Description of project

The project referenced in this article was an ethnographic case study research that explored the experiences of two women with advanced dementia who were identified nearing the end of life. Both women were nonverbal, immobile and completely dependent on care staff for assistance with all activities of daily living (ADLs; e.g. dressing, toileting, eating). Grounded in dialogical theory (Bakhtin, 1981/1992; Frank, 2012; Marková, 2003), the purpose of this research was to explore how care staff and family members understood and responded to the resident's social, emotional, spiritual and physical needs at the end of life. In addition to in-depth interviews with the resident's family member (*n* = 2) and care staff (*n* = 25), I conducted over 600 h of participant observation, including 30 h of video observation and reflexive video feedback interviews with care staff and just under six hours of self-reflexive video to document my reflections on the research process. The intention to use a video camera in this research was practically motivated as I wanted to carefully attend to the nuances of care interactions, particularly that which was nonverbal and subtle in nature. As such, the use of the video camera was informed by Pink's (2013) writing on visual ethnography and not explicitly informed by documentary film-making. Following Pink (2013), I therefore considered video as a data collection tool as well as considered the use of video footage to represent ethnographic knowledge alongside written text. This study received ethics approval from the University of British Columbia's Behavioural Research Ethics Board.

2.1. Filming in nursing home environments

In consideration of the long history of surveillance in institutional settings (Hayward, 2016; Niemeijer et al., 2010), the use of video technology has important implications for researchers, as a camera is not only a creative research tool, but also can be a tool of power. Moreover, given that carework in nursing home environments is heavily influenced by individuals' social location (e.g. age, gender, race, ability), their web of relationships and the socio-political context in which they are situated (Davis, 2008; Hulko, 2009),[2] research conducted in these settings must therefore carefully consider how particular research methods might impact individuals, including how they might perpetuate inequality and unethical relationships.

In this research, a small hand-held camera with an internal microphone was used to document the residents' everyday activities, including personal care. Grounded in the notion of relational ethics to foreground trust and mutual respect (Bergum & Dossetor, 2005) I did not commence filming right away, nor did I film every situation. Rather, what to film was negotiated between myself, the care staff, the resident and the proxy decision-maker; and, the act of filming was introduced gradually to allow for care staff and resident participants to grow accustomed to me being in their space and to allow for trust and rapport to build. I also took the utmost care to be discrete and film as unobtrusively as possible; for example, carefully considering prior to filming: the layout of the space, how a particular situation might be filmed and the position of the camera (see also Puurveen, Phinney, Cox, & Purves, 2015). I ensured that nonparticipants were not filmed, which meant that the majority of footage taken in social spaces was filmed at close range through the use of the zoom function. To mitigate the risk of breaching privacy of both the care staff and the resident, I also kept filming to a minimum while other family, visitors or non-consenting care staff where in the space. Considering the hierarchical relationship between care staff and management, I did not film care staff in the presence of management. Overall, care staff and residents appeared unfazed by the act of filming. In part, this was due to thinking carefully about how my presence (with/without the camera) would influence the dynamics between staff; and it was also due to foregrounding the fluid nature of a participant's willingness to participate at any given time. This brings me to the notion of consent and the process of negotiation involved in filming specific situations.

2.2. Considering consent

The process of securing consent for both resident and care staff participation has been articulated elsewhere (see Puurveen, 2016; Puurveen, Phinney, Cox, & Purves, 2016; Puurveen et al., 2015). Briefly, in terms of resident consent, written and ongoing proxy consent was secured for resident participation. In addition to discussing the parameters of the resident's participation, including what

could/could not be filmed, the discussion centred on how the resident responded to being photographed and/or filmed in the past and whether she would consent to participation if she were able to express herself. In addition, resident assent (Black et al., 2010; Dewing, 2007) was followed throughout the research process. At each observation, I explained my presence, showed the camera (if being used) and asked permission to observe and/or film. Because both residents did not have the verbal capacity to express their assent, I paid close attention to their vocal and embodied expressions throughout the observation to determine whether they conveyed any discomfort with my presence or being filmed. I also consulted their chart (e.g. nursing notes) and talked with care staff to get their perspective on how the residents typically responded to care interactions, how they might have responded to new staff or someone unfamiliar and any other information that would help me understand how they assented/dissented to care or other interactions. Taken together, ongoing proxy consent and resident assent meant that observations and filming was a negotiated act; and in following this process of consent-assent, three layers of filtering thus occurred: (1) proxy consent and ongoing assent; (2) care staff's perspective on resident participation; and (3) my own ethical reflection that was informed by relational ethics and the relationship that developed between myself and the resident over time. On two occasions, I felt that one resident dissented to my presence during a care interaction. The care staff interpreted the two situations as the resident dissenting to the care routine, and not necessarily my presence. However, as the situation appeared to be stressful for the resident and the care staff, I left the room. While not limited to video observation, this tension of being in residents' and care staffs' intimate space is a challenge faced by ethnographers in nursing home settings with respects to negotiating roles and boundaries whilst remaining an ethically responsible observer (see also Tinney, 2008).

Access to the nursing home itself was secured from the executive director of the facility and at the start of the project an information meeting explaining the study was held with care staff. I then held individual conversations with care staff to talk about potential participation. These conversations were held in private to minimize the potential for management and other staff to discern who consented to participate. Overall, the consent process with staff was considered much in the same way as the process followed for securing consent from the resident's proxy. While written consent was secured, I emphasized that observations, including video observations, would be negotiated with individual care staff each observation occurrence. As filming was a negotiated act, not all care interactions were filmed, and care staff gave a variety of personal reasons for not wanting to be filmed in a particular moment (though no care staff dissented to observation). Most of these reasons centred on body image or simply "not feeling like it". I also observed care staff's body language to discern whether they conveyed nonverbally discomfort in my presence and/or in the presence of the camera. In short, I took the lead from care staff to determine my approach to both video and participant observation.

From both the residents' proxy and care staff, consent was also solicited to show video footage to wider audiences. During these conversations, minimally edited footage[3] was shown to the proxy and the care staff represented in the footage. I held one video-feedback session with each care staff who was part of the video observation, and five with the residents' proxy decision-maker. The resident's proxy was shown all the footage, and the care staff only the footage of which they were a part. I will describe this process further in the section "Analysis: A Return to the Carework Encounter".

3. Using video methods to research carework

3.1. A closeness to the carework encounter
In filming care interactions, the camera was used as "another set of eyes", whereby I positioned myself and the camera as passive observers and not formally part of the unfolding action (MacDougall, 2011). Partially determined by the idiosyncrasies of the physical environment, I was directed by care staff where I could position myself in the space without being in their way. I therefore took a physically distanced position from the care routine so as not to disrupt its flow, yet simultaneously I was close to the encounter through the use of the zoom function. This did not mean that

the act of filming did not influence the enactment of care, even though care staff appeared to largely ignore being filmed and I did not observe any difference between traditional and video observations in the moment. Upon review of the video footage, while some care staff noted that they were self-conscious and performed differently than if the camera had not been present, the intention, like in traditional observations, was not to reshape every day practice (see also Puurveen et al., 2015). Getting close to the care encounter, however, required careful attention to how the bodies of the resident and care staff were being framed; being particularly mindful of filming in ways that limited exposing the resident's naked body. For example, in instances where the resident was undressed, I turned my gaze and that of the camera to the floor. This act of framing revealed to me, that while proxies gave consent to film personal care and previous research in nursing homes used video to film personal care (e.g. Husebo et al., 2007), I was not comfortable filming (or observing) personal care particularly when residents were undressed. This underscores how I was embedded in the video footage, exposing my own ethnographic and subjective gaze (Carroll, 2009; MacDougall, 2005). As MacDougall (2005) reminds us, "Corporeal images are not just the images of other bodies; they are also images of the body behind the camera and its relations with the world" (p. 3).

3.2. Analysis and a return to the carework encounter

Having the capacity to review film footage enables one to (re)encounter interactions multiple times, which allows for focusing on different aspects of carework. Therefore, analysis of video footage shifted between a focus on the whole picture to a focus on the particular and specific. To describe how care is enacted in its everyday expression, analysis involved reconstructing the sequential organization of a care interaction, which demanded attention to the fine-grained details of interaction as well as how these details cohered. This included examining care staffs' and residents' facial expression, gestures and other movement, as well as talk (including prosodic elements such as tone, rhythm and dynamics) and other sounds, and the intercorporeal interplay of these details of interaction (e.g. a care aide smiles in response to resident's eye contact). Video analysis also included the examination of the more static dimensions of the interactional environment that may influence the interaction (e.g. clothing and technical care equipment) and those elements that were seemingly less likely to overtly shape the interaction (e.g. furniture and the physical design of the bedroom). Finally, analysis included attention to the ethnographic context in which carework was situated. That is, I examined the "*institutionalized,* extra-situational features" (Knoblauch & Schnettler, 2012, p. 344, italics original) that directed how carework will, to a certain extent, be enacted. For example, policy guidelines explicate that residents who are completely dependent on care staff assistance in care routines (e.g. getting out of bed) require the support of two care staff and the use of a mechanical lifting device to ensure both resident and care staff safety.

My understanding of the aesthetic approach to care was also augmented through the practice of video feedback interviews. The collaborative researcher-participant engagement embedded in this process is a mechanism of achieving researcher honesty and reflexivity as it unveils the researcher's agency in filming and the influence of the video camera during fieldwork (Carroll, 2009). Thus, video reflexivity moves away from the notion of an objective observer and acknowledges that data (knowledge) is interactionally constructed (Carroll, 2009; Pink, 2013), as the reviewing of video footage can not only highlight shifting power relations, but also stimulate the creative potential for co-constructing knowledge. As Carroll (2009) argues, "the influences of the video camera and the agency of the researcher enter into the video footage, which provides an account of the researcher's involvement in the research process and his/her relationships with participants. One means of achieving researcher reflexivity and honesty between the researcher and participants is the sharing of video footage" (p. 249). Video footage was played back to the care staff for reflection, review and discussion and therefore I returned to the carework interaction alongside the care staff present in the footage. During these feedback sessions images acted as a catalyst through which care staff might re-imagine themselves involved in carework and provided a platform for conversation about the complexities involved in their practice. This was especially useful as I sought to understand these activities as they unfolded, but could not interrupt the enactment of carework in real time. While care staff reviewing the footage tended to judge their practice in terms of whether they were "doing the job right", they

also provided commentary on how they specifically enacted care in relation to the resident and their care partner (if another care staff was in the frame). This augmented my own observations and enabled a more focused understanding of the ways in which care staff understood their interactions and the situated/contextual environment in which their interactions unfolded. This latter function was especially valuable as it generated an idiosyncratic understanding of knowledge-in-practice as well as policies that directly related to carework as opposed to more generalized understanding of policy and practice. For example, in an in-depth interview, a care staff talked in general and technical terms about a 2-person assist, whereas in the video reflexive interview, she talked about *how* a 2-person assist was realised in practice; highlighting the intercorporeal and multisensorial dimensions of carework and how it was impacted by the environment in which it took place. Taken together, these elements contributed to my understanding of an aesthetic of dementia care that would have otherwise been left unsaid. Thus, while multisensorial and embodied dimensions of carework were already central to data collection and analysis, care staff heightened my attention to these dimensions of carework as they narrated and explained the video footage in a way that was significantly more detailed than in in-depth interviews and informal conversations, illuminating what I assumed to be happening whilst I observed the interaction. In short, playing back and sharing video materials created a route for care staff to communicate aspects of their work that were difficult to describe when they were removed from the "doing" of that work and difficult for me to observe. In the next section, I outline the dimensions of carework that were discussed as being core to giving quality end-of-life advanced dementia care; qualities that are central to aesthetics of care.

4. Dimensions of carework

4.1. The choreography of carework

Ingold (1993) writes, "People in the performance of their tasks, also attend to one another … By watching, listening, perhaps even touching, we continually feel each other's presence in the social environment, at every moment adjusting our movements in response to this ongoing perceptual monitoring" (p. 160). At the heart of carework is a tacit choreography performed by care staff *and* the resident, which is characterized by watching, listening, touching, feeling and moving in relation to one another. As care staff rightly pointed out, these ongoing kinaesthetic movements are fleeting and difficult to apprehend in typical observations and to describe in words, but video footage can heighten our awareness of these. Both individual and collective corporeal movement are intrinsic to the care interaction that contributes to the overall pacing and performance of carework. Care staff likened this performance to a well-choreographed dance that included gross motor movements and micro-movements involved in the act of touching and moving the resident and looking for and listening to how the resident's body responded to their actions.

Video footage can draw one's attention therefore to this choreography: the movement of weight adjustment when the resident relaxes her body as she is being dressed; the movement of a slight catch of the resident's breath as her body is repositioned; the care staff's quick glance towards the resident's face as she fixes a splint around the resident's hand; and the tightening and the loosening of the care staffs' grip as they manipulate clothing around the resident's stiff and unyielding body. These movements are a result of a careful listening, feeling and observing of how the resident responds to the care staff's ministrations in the moment as well as her attunement to the movement of her care partner. Thus, images also allow for the close examination of the intercorporeal adjustments between the care staff and the resident as they move together in the care task. The rhythm and the timing of these movements are essential to carework with care staff skillfully coordinating their bodies to be in synchrony with each other's and the resident's. Yet, it is clear when the rhythmic signature of carework is asynchronous—movement is not coordinated, the pacing appears rushed and carework seems disordered. The choreography of care from one encounter to another will therefore change in subtle ways depending on each individual's idiosyncratic way of responding to each other's presence in the moment of the encounter. As Daza and Gershon (2015) write, "Bodies are always already engaged in multisensory analyses as part of our/their becoming with/in the world" (p. 640).

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Figure 1. Video still of 2-person assist with ceiling lift.

4.2. The objects, materials, and space of carework

In addition to the choreography of carework, visual images draw attention to the notion of "emplaced aesthetics" and invites viewers to closely examine the object/material culture and the physical environment, how they are used and how they might influence the performance and experience of carework. I explicate this using the scene depicted in Figure 1.

As represented in the image, the care staff secure a harness around the residents' body, fastening the straps of the harness to a mechanism attached to the ceiling. This mechanism, called a ceiling lift, enables the care staff to safely move the resident from her bed to a wheelchair (or from one surface to another). Carework involves the use of equipment such as this. Their work is modulated by specialized chairs, tubs and showers that enables safe bathing; tilt-in-space wheelchairs that enables them to move the resident from one space to another, in addition to promoting comfort and safe seating for the resident; and hospital beds that can be raised to waist-height to enable them to safely give personal care. Additionally, as illustrated in the video still, carework involves care staff wearing latex gloves during personal care interactions. Therefore, touch, as described earlier, is mediated by synthetic materials such as gloves, the use of terry cloth towels to wash and dry the body and the use of straps and harnesses to safely move the resident. The image also shows the physical environment of the bedroom—a sparsely decorated space, with a printed "announcement" at the head of the resident's bed (which specifies a particular skin care protocol) and fluorescent lighting that casts blinding light to the ceiling. Finally, looking beyond the immediate care interaction as illustrated, the image also infers the wider space in which care takes place such as the layout and size of the room that impacts how care staff manoeuvre the equipment, and move themselves and the resident within that space.

As illustrations of "structure of social space that is constituted by architecture, bodies, technologies and other objects" (Knoblauch & Schnettler, 2012, p. 345), video footage therefore invites a fuller appreciation of the aesthetic approach to dementia care by directing the viewer's attention not only to the immediate interaction, but to the ways in which objects and space directly impacts carework, including how the resident might experience care. For example, care staff identified that the abrasive texture of the fabric of the harness and straps used with the mechanical lifts could "dig into [the resident's] skin", or "hurt" and "be uncomfortable" for the resident; they described being raised from the bed by the ceiling lift as "scary", and being lowered into a bathtub as "unsettling". Care staff also identified how objects and space shaped their interactions with the resident and with

each other. For example, in watching footage of a morning care routine, a care staff mapped out the sequence and timing of how different objects of care came into the care interaction, noting that when certain objects or materials were not in the correct position at the right time, the choreography of care was asynchronous.

Finally, undergirding these practices are organizational rules and regulations that controls, to a large extent, how work is enacted. The routine illustrated in Figure 1 is discursively known as a "2-person assist with mechanical lift", which signals to the care staff how to safely move a resident. As such, visual images also show how the "script" of such policies are achieved and how the skills of care staff make generalized policies work in specific situations. That is, the routine is not simply applied to the situation at hand, but "worked into practice depending on the local contingencies at hand" (Hindmarsh & Heath, 2007).

4.3. The sounds of carework

Alongside the objects used in carework, in reviewing the video footage, the discussion between myself and the care staff also identified the, at times overwhelming, presence of the different sounds heard within the care encounter. This included the non-musical, non-linguistic and non-symbolic expressions that are produced by technological artifacts, natural elements and that emitted by humans (Vannini, Waskul, Gottschalk, & Rambo, 2010, p. 331). In the image above, the sounds that accompanies the care interaction are the immediate sounds within the space made by technology; including, the buzz of the motor of the ceiling lift, the brrring-brrring of the care staffs' call bell, the hum of the fluorescent light and grating creaks of the bed as it is raised and lowered. It includes the sounds emitted by the care staff themselves; for example, the swish of fabric moving against fabric and the shuffle of soft-soled shoes against linoleum. It also includes the sounds from elements beyond the camera's frame that resonate through the space, such as the hum of the air coolant system, the ringing of other bells and alarms, doors opening and closing and the persistent hum of the traffic outside the nursing home itself.

The notion of the soundscape of carework resonates with Hughes (2014) conception of the aesthetic approach in several ways. First, as carework is mediated by equipment, the sound of this technology can detract from the care interaction. For example, in a video observation of a care staff preparing the bathing room for a resident's bath, the resident (who is off screen) is being asked if she would like the spa (jets) function of the bath; yet the sound of the water filling the tub overpowers her question. In viewing this footage, the care staff remarked, "I didn't realise how loud that bath sounds … it's impossible for the resident to hear me". Second, deliberately considering sound draws our attention to how care staff make use of and attend to sound themselves within the care interaction. This relates to the prosodic elements of their speech (tonality, dynamics, etc.) and how they (un)purposefully use these elements in interactions. It also relates to the sounds they emit whilst going about their tasks; for example, mimicking the sounds of the mechanical lift. Third, paying attention to the sounds of carework relates to the care staffs' assessment of how the nursing home as a sounded space might directly impact the resident. For example, in the comment about the sound of the bath, the care aide identifies how it overpowers the space rendering other sounds unintelligible. Finally, on a conceptual level, research generally, including video-based research, has focused heavily on representing the visual and sound (other than its relation to what is being said) has often been overlooked. Daza and Gershon (2015), educators who examine sound as inquiry, argues that sounds/noise are often left out of accounts of everyday life, arresting the potential for viewers, listeners and readers to engage with the totality of experience, to the extent possible. In nursing home research, this is a significant oversight as the sound environment contributes much to the experiences of those who live and work in that space. Yet, it is difficult to represent sound outside of embedding soundtracks into text-based documents made available in online formats. This issue points to the challenges in representing an aesthetic approach to dementia care.

5. Representing the aesthetics of care

With the growing availability of online journals and Open Access publications, the "orthodoxy that articles are things to be read can be challenged" (Dean, 2015, p. 167). Indeed, research reports can be read, seen and heard through embedding visual images (including sound and moving images) in the text. Alongside the burgeoning interest in artistic modes of dissemination, this availability offers possibilities for new knowledge to be engaged with in different ways. This is particularly appealing for representing carework, as outlined above, much of carework is to do with the sensory and inter-corporeal realm. As such, moving images offers a "sense of *virtual intimacy*" (Biella, 2009, para 5) and may provide routes through which researchers can communicate new knowledge and propel readers/viewers to awareness and understanding of untapped dimensions of giving and receiving care. However, visual artefacts generated through research can take on a life on its own, particularly in the context of publishing in electronic journals and public websites and the subsequent archiving of audiovisual data. Therefore, the potential for misrepresentation of research participants and doing harm is very real. Before discussing the notion of representation as it relates to carework, it is important to outline what is at stake, for those represented in the images.

First, carework is typically provided by women increasingly drawn from marginalized sectors of society (Banerjee, Armstrong, Daly, Armstrong, & Braedley, 2015). Reductionist assumptions associated with how carework is enacted and the hierarchies of knowledge (i.e. the privileging of medical knowledge) contributes to the systemic exclusions of care staff, care aides in particular, in the organization of work (Banerjee et al., 2015). Care aides are therefore situated on the lowest tier in the healthcare hierarchy and are, at times, afforded very little power, respect or recognition (Banerjee et al., 2015; Tellis-Nayak & Tellis-Nayak, 1989). Representing carework through images must therefore carefully consider how images reveal cultural background, age and gender, and how they infer socio-economic status and job category. These identifying factors cannot be concealed without manipulating the image to a point that renders the image un-useable in terms of representing carework. In addition, images of carework not only represent the individual care staff and her practice but they engender practice that reflects policy and procedures of the nursing home itself and that which has been mandated by governing and regulatory bodies. An image therefore not only prompts potential judgement of the care staff's individual practice, but also an evaluation of the broader policies that shape her practice and the degree of alignment between the two. That is, images reflect how care staff enact certain policies and procedures sanctioned by the nursing home organization. This issue was a deterring factor for one care staff to participate in video observations; she was concerned that management would judge her practice unfairly if images showed that she did not follow established protocol. The issue was also identified by two other care staff during feedback interviews in which they identified that, even though they were pleased with how they embodied an aesthetic approach to care, their practice did not fully reflect *generalized* procedures that govern carework across different populations. Images reflecting individual care practices thus hold care staff up for scrutiny against both the viewers' personal judgements as well as their assessment of whether the parameters of policy/procedure regulations are being followed. At issue here is not whether the care provided is "good" or "bad", but whether it reflects regulations, which might not capture the *individualized* nature of care provision as such. The question that thus needs to be asked is the degree to which publishing images of carework may be harmful to the reputation of care staff and whether images contribute to the ongoing "epistemological violence" against care staff (Banerjee et al., 2015).

Second, in addition to the care staff, images of carework reflect individuals with advanced dementia. Visual images, as Richards, Warren and Gott (2012) argue "play a complex and subtle role in shaping and communicating the experience of old age in everyday life" (p. 66). It is rare for images of "deep old age" in all its wrinkles, skin folds and fleshy signs of encroaching death to be shown in popular culture (advertising in particular) other than to serve as an illustration of carework (Richards et al., 2012; Twigg, 2002). Moreover, as carework is enacted in an asymmetrical context, the caregiving relationship illustrated may perpetuate power relations and further objectify individuals with advanced dementia. Indeed, the narrative of dependency, bodily deficits and decline dominate text and visual representations of the experiences of advanced dementia, subverting subjective accounts

of wellbeing and relationship (Kontos, 2004; Phinney & Chesla, 2003; Puurveen, 2016). What this means is that conscious efforts must be taken to counter biomedical and asymmetrical representations, yet simultaneously not denying the reality of death and physical decline as well as the carework involved in supporting individuals in this last phase of life. If this reality is denied, individuals with advanced dementia and those who care for them become "obscured, hidden from view, [and] rendered unutterable" (Twigg, 2002, p. 188).

In consideration of the vulnerability of both care staff and residents, the troubling notion of privacy and the potential for misrepresentation and misinterpretation has significant impact on communicating an aesthetic approach to dementia care to broader audiences. Yet, with the tendency to downplay the (inter)corporeality of carework, to minimize carework as a space where relationships are forged and knowledge gained and to shirk away from images of ageing and dying, it is important to explore ways in which these tensions can be reconciled. One way this issue can be partly resolved is through the process of ongoing consent and participatory approaches, which privilege the perspectives of the participants about the use of visual data (Pink, 2013; Puurveen et al., 2015, 2016). As described earlier, video feedback sessions were used as a space to talk about disseminating images, manipulating images to protect privacy and what this might mean for individual participants, including the residents. During these conversations, care staff were primarily concerned that the residents were shown in "dignified" and "respectful" ways, and less worried about how they themselves were depicted (outside of their concern about their practice being judged). Raw footage was also shown to residents' proxy decision-makers, who expressed that they were pleased with how their relative was represented. For both care staff and proxies, while video footage illustrated residents in a state of dependency it simultaneously illustrated an intimate and very personal glimpse into the lives of two older women with dementia and the relationships with those who cared deeply for them. As one proxy expressed, "You can see that she [the resident] is well cared for ... they love her". The collaborative feedback potential of video footage therefore prompted discussion about ethical representations of residents and care staff and the complexities embedded in carework practices. That said, a care aide wisely asked, "will others know what they are looking at?" This comment points to another way in which the tension between privacy and representation might be reconciled.

As images reflect the ethnographic context in which they were produced (Pink, 2013), it is essential to consider the contextual information needed to facilitate sense-making. This is particularly important in conveying the notion of the aesthetic of dementia care as viewers, having not participated directly in the nursing home environment depicted visually, may be unfamiliar with carework and may not be appraised and sensitized to these ephemeral and multisensorial aspects of carework. Therefore, to facilitate sense-making, researchers could consider providing viewers with guidance in terms of what it is they are observing. For example, in Figure 1, I could point out the height of the bed, the texture of the ceiling lift harness and the use of latex gloves; with the care staffs' attention focused on securing the harness properly, I could point out the task-centredness captured in that moment; I could also point out that this image freezes a moment in time, which conceals the action and interaction as it unfolds over time, veiling much of the sensorial and intercorporeal and the "caring for" aspects of the aesthetics of care. In addition, I might interweave images with contextual narratives about the experience of advanced dementia at end of life, of carework, and the setting in which work is enacted and embodied. Providing such guidance is not to take away from the agency of individual readers/viewers. Indeed, as Eisner (2002) points, "there is, in the arts, more than one interpretation...more than one way to describe ... more than one meaning" (p. 197). Rather, such guidance is to offer a visual and textual vocabulary for aesthetic dimensions of carework, and to facilitate and encourage audiences to look beyond the task-centredness of carework to those nuanced aspects of dementia end-of-life care that is about relationship, emotion, embodiment and the senses; aspects of carework that are not typically discussed.

However, while my intentions are to show respectful portrayals of someone with advanced dementia, the care staff who are in relationship with her, and the carework that is wrapped around her

in the last stage of life, I cannot stop others from turning their evaluative eye on carework, nor control whether they judge the image to be a respectful portrayal that does not demean or reduce individuals represented in the images. As Warr, Waycott, Guillemin, and Cox (2016) caution, "representations (images, words and numbers) that are generated through research may operate to confirm, rather than challenge the assumptions and possible prejudices of different audiences" (p. 12). Further, an image's meaning is flexible (Carroll, 2009) and sense-making of video footage is located in the perspective of the viewer; "all representations are constructed through perceptual systems that are unique, personal, and complex" (Goldman, 2007, p. 19). Moreover, although research participants may consent to share their images, neither they, nor the researcher, can fully anticipate in the short- and long-term how different audiences will respond or interpret the image (Pink, 2013; Wiles, Coffey, Robinson, & Heath, 2012). While this holds true for textual data as well, video representations illustrate and display giving and receiving care in a more immediate way than text, adding another layer of complexity to representing visual data (Goldman, 2007; Pink, 2013; Wiles et al., 2012). Considering the potential for judgement and misinterpretation, some researchers have therefore suggested that images be anonymized (Mannay, 2016) or the footage be artfully portrayed in another way (e.g. research-based play; Cook, 2002). In this research, I have proceeded cautiously; although I have received consent to share an array of images, I have yet to fully realise what has been entrusted to me.

6. Conclusion

In this paper, I examined video methods in relation to Hughes' notion of "an aesthetic approach" to dementia end-of-life care and the desire to bring forth/represent the sensual, intercorporeal and emplaced dimensions of carework to the forefront of discussion. I first highlighted how Hughes' conception of an "aesthetic approach" to dementia care could help counter the overly objectified understanding of giving and receiving care. I then discussed how video methods can accentuate the aesthetic aspects/elements of carework (choreographed interactions, seeing the ageing body or sounds etc.) through enabling the researcher to "get close" to carework interactions and return to these interactions through repeated viewings of video footage. Underscoring the co-production of knowledge through the practice of reviewing video with care staff, I highlighted three dimensions of carework that resonate with an aesthetic approach; namely, the choreography of care, the equipment used in care and the built environment and the sounds of care. Finally, I outlined some of the challenges in representing carework, offering some potential ways in which researchers could overcome some of the ethical issues involved in representation to provide respectful portrayals of individuals with advanced dementia and those who care for them.

In pondering the question of "how ought we care for those with advanced dementia?" Hughes concluded that,

> [A]n open-mindedness, a receptivity and a degree of humility are required as we struggle to understand the world, the burden of the mystery, the life of the person with dementia. We shall not only learn about them by their brain functioning, we shall also learn about them by observing closely their gestures, their actions and their interactions. Our intuitions may be uncertain. But our approach must be aesthetic, so that we hear what they say and see what they do … (p. 1412).

As care aides, in particular, embody such an approach, it is prudent to turn to them to help researchers to develop a deeper understanding of this aesthetic of dementia care. And, with careful consideration, video methods can help facilitate this understanding.

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Notes

1. The notions of perception, intuition, imagination and multisenoriality as key dimensions to nursing practice have been widely examined in nursing literature. The author draws the readers' attention to Caper's (1978) theory on nursing epistemology and her articulation of nurses' "aesthetic knowledge"; Benner's (1994) edited work on intuition, embodiment, ethics and caring; Kontos and Naglie's (2009) work on tacit knowledge of caring and embodied selfhood.

2. For further reading on the strong tradition of critical inquiry in nursing home research, I direct the reader to Baumbusch's (2008), Kelson's (2013) and Lopez's (2006) critical ethnographies.

3. Care staff and residents' proxy decision makers were given a choice between viewing unedited or minimally edited footage. Minimally edited footage comprised footage that was edited for length, footage that inadvertently captured non-participants either visually or aurally (e.g. care staff talking about another resident) and footage that might compromise resident's dignity. For more detail, see Puurveen (2016).

References

Bakhtin, M. (1981/1992). *The dialogic imagination: Four essays*. (C. Emerson & M. Holquist, Trans). Austin, TX: University of Texas Press.

Banerjee, A., Armstrong, P., Daly, T., Armstrong, H., & Braedley, S. (2015). "Careworkers don't have a voice:" Epistemological violence in residential care for older people. *Journal of Aging Studies, 33*, 28–36. doi:10.1016/j.jaging.2015.02.005

Baumbusch, J. (2008). *Decommissioning citizenship: The organization of long-term residential care* (Unpublished doctoral dissertation). University of British Columbia, Canada. Retrieved from http://www.circle.ubc.ca

Benner, P. (1994). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. Thousand Oaks, CA: Sage.

Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. Hagerstown, MD: University Publishing Group.

Biella, P. (2009). *Visual anthropology in a time of war: Intimacy and interactivity in ethnographic media*. Retrieved March 2, 2017, from http://userwww.sfsu.edu/biella/biella2009b.pdf

Black, B. S., Rabins, P., Sugarman, J., & Karlawish, J. H. (2010). Seeing assent and respecting dissent in dementia research. *American Journal of Geriatric Psychiatry, 18*, 77–85. https://doi.org/10.1097/JGP.0b013e3181bd1de2

Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science, 1*(1), 13–24. https://doi.org/10.1097/00012272-197810000-00004

Carroll, K. (2009). Outsider, insider, alongsider: Examining reflexivity in hospital-based video research. *International Journal of Multiple Research Approaches, 3*(3), 246–263. doi:10.5172/mra.3.3.246

Cook, A. (2002). Using video observation to include the experiences of people with dementia in research. In H. Wilkinson (Ed.), *The perspective of people with dementia: Research methods and motivations* (pp. 209–222). London: Jessica Kingsley Publishers.

Davis, K. (2008). Intersectionality as buzzword: A sociology of science perspective on what makes a feminist theory successful. *Feminist Theory, 9*(1), 67–85. https://doi.org/10.1177/1464700108086364

Daza, S., & Gershon, W. S. (2015). Beyond ocular inquiry: Sound, silence, and sonification. *Qualitative Inquiry, 21*(7), 639–644. doi:10.1177/1077800414566692

Dean, J. (2015). "Submitting Love?" A sensory sociology of Southbourne. *Qualitative Inquiry, 23*(3), 162–168. doi:10.1177/1077800415605050

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*, 11–25. https://doi.org/10.1177/1471301207075625

Eisner, E. W. (2002). *The arts and the creation of mind*. Harrisonburg, VA: Yale University Press.

England, K., & Dyck, I. (2011). Managing the body work of home care. *Sociology of Health & Illness, 33*(2), 206–219. doi:10.1111/j.1467-9566.2010.01331

Goldman, R. (2007). Video representations and the perspectivity framework: Epistemology, ethnography, evaluation, and ethics. In R. Goldman, R. Pea, B. Barron, & S. J. Derry (Eds.), *Video research in the learning sciences* (pp. 3–37). New York, NY: Routledge.

Hayward, B. A. (2016). The arguments against camera and closed-circuit television surveillance in the homes of people with disabilities to protect from abuse and neglect. *Research and Practice in Intellectual and Development Disabilities*. doi:10.1080/23297018.2016.1252942

Hindmarsh, J., & Heath, C. (2007). Video-based studies of work practice. *Sociology Compass, 1*(1), 156–173. https://doi.org/10.1111/soco.2007.1.issue-1

Frank, A. W. (2012). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds.), *Varieties in narrative analysis* (pp. 33–52). Thousand Oaks, CA: Sage. https://doi.org/10.4135/9781506335117

Hughes, J. (2014). The aesthetic approach to people with dementia. *International Psychogeriatrics, 26*(4), 1407–1413. doi:10.1017/S1041610214001100

Hulko, W. (2009). The time- and context-contingent nature of intersectionality and interlocking oppressions. *Affilia: Journal of Women and Social Work, 24*(1), 44–55. https://doi.org/10.1177/0886109908326814

Husebo, B. S., Strand, L. C., Moe-Nilssen, R., Husebo, S. B., Snow, A. L., & Ljunggren, A. E. (2007). Mobilization-observation-behavior-intensity-dementia pain scale (MOBID): Development and validation of a nurse-administered pain assessment tool for use in dementia. *Journal of Pain and Symptom Management, 34*(1), 67–80. doi:10.1016/jpainsymman.2006.10.016

Ingold, T. (1993). The temporality of the landscape. *World Archaeology, 25*, 152–174. doi:10.1080/00438243.1993.9980235

Kelson, E. E. (2013). *Challenges of person-centred dementia care: A critical ethnography of culture change in long-term care* (Unpublished doctoral dissertation). University of British Columbia, Canada. Retrieved from http://www.circle.ubc.ca

Knoblauch, H., & Schnettler, B. (2012). Videography: Anlaysing video data as a 'focused' ethnographic and hemeneutical exercise. *Qualitative Research, 12*, 334–356. doi:10.1177/1468794111436147

Kontos, P. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer disease. *Ageing & Society, 24*, 829–849. doi:10.1017/S0144686X04002375

Kontos, P., & Naglie, G. (2009). Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness, 31*(5), 688–704. doi:10.1111/j.1467-9566.2009.01158.x

Lopez, S. H. (2006). Culture change management in long-term care. A shop-floor view. *Politics & Society, 34*(1), 55–70. https://doi.org/10.1177/0032329205284756

MacDougall, D. (2005). *The corporeal image*. Princeton, NJ: Princeton University Press. https://doi.org/10.1515/9781400831562

Mannay, D. (2016). The politics of visibility, voice and anonymity: Ethically disseminating visual research findings without the pictures. In D. Warr, M. Guillemin, S. Cox, & J. Waycott (Eds.), *Ethics and visual research methods: Theory, methodology and practice* (pp. 225–235). New York, NY: Palgrave. https://doi.org/10.1057/978-1-137-54305-9

MacDougall, D. (2011). Anthropological filmmaking: An empirical art. In E. Margolis & L. Pauwels (Eds.), *The SAGE handbook of visual research methods* (pp. 99–114). London: Sage. https://doi.org/10.4135/9781446268278

Marková, I. (2003). Dialogicality as an ontology of humanity. In C. B. Grant (Ed.), *Rethinking communicative interaction* (pp. 29–51). Philadelphia, PA: John Benjamins Publishing Company. https://doi.org/10.1075/pbns

Niemeijer, A. R., Fredriks, B. J. M., Riphagen, I. I., Legemaate, J., Eefsting, J. A., & Hertogh, C. M. P. M. (2010). Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: An overview of the literature. *International Psychogeriatrics, 22*(7), 1129–1143. doi: 10.1017/S1041610210000037

Phinney, A., & Chesla, C. A. (2003). The lived body in dementia. *Journal of Aging Studies, 17*(3), 283–299. doi:10.1016/S0890-4065(03)00029

Pink, S. (2013). *Doing visual ethnography: Images, media and representation in research* (3rd ed.). London, UK: Sage.

Puurveen, G. (2016). *Constructing the experiences of people with advanced dementia who are nearing the end of life* (Unpublished doctoral dissertation). University of British Columbia.

Puurveen, G., Phinney, A., Cox, S. M., & Purves, B. (2015). Ethical issues in the use of video observations with people with advanced dementia and their caregivers in nursing home environments. *Visual Methodologies, 3*(2), 16–26.

Puurveen, G., Phinney, A., Cox, S. M., & Purves, B. (2016). Ethical considerations in the use of video observations in dementia end-of-life care research. In D. Warr, M. Guillemin, S. Cox, & J. Waycott (Eds.), *Ethics and visual research methods: Theory, methodology and practice* (pp. 105–115). New York, NY: Palgrave Macmillan. https://doi.org/10.1057/978-1-137-54305-9

Richards, N., Warren, L., & Gott, M. (2012). The challenge of creating 'alternative' images of ageing: Lessons from a project with older women. *Journal of Aging Studies, 26*, 65–78. doi:10.1016/j.jaging.2011.08.001

Tellis-Nayak, V., & Tellis-Nayak, M. (1989). Quality of care and the burden of two cultures: When the world of the nurse's aide enters the world of the nursing home. *The Gerontologist, 29*(3), 307–313. https://doi.org/10.1093/geront/29.3.307

Tinney, J. (2008). Negotiating boundaries and roles: Challenges faced by the nursing home ethnographer. *Journal of Contemporary Ethnography, 37*(2), 2002–2225. doi:10.1177/0891241607312487

Twigg, J. (2002). The bodywork of care. In L. Andersson (Ed.), *Cultural gerontology* (pp. 173–189). Westport, CN: Auburn House.

Twigg, J., Wolkowitz, C., Cohen, R. L., & Nettleton, S. (2011). Conceptualising body work in health and social care. *Sociology of Health & Illness, 33*(2), 171–188. https://doi.org/10.1111/shil.2011.33.issue-2

Vannini, P., Waskul, D., Gottschalk, S., & Rambo, C. (2010). Sound acts: Elocution, somatic work, and the performance of sonic alignment. *Journal of Contemporary Ethnography, 39*(3), 328–353. doi:10.1177/0891241610366259

Warr, D., Waycott, J., Guillemin, M., & Cox, S. (2016). Ethical issues in visual research and the value of stories from the field. In D. Warr, M. Guillemin, S. Cox, & J. Waycott (Eds.), *Ethics and visual research methods: Theory, methodology and practice* (pp. 1–16). New York, NY: Palgrave. https://doi.org/10.1057/978-1-137-54305-9

Wiles, R., Coffey, A., Robinson, J., & Heath, S. (2012). Anonymisation and visual images: Issues of respect, 'voice' and protection. *International Journal of Social Research Methodology, 15*(1), 41–53. doi:10.1080/13645579.2011.564423

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