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“In the driver’s seat”: Navigating vulnerability and autonomy in digital storytelling with older adults

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ABSTRACT

Digital Storytelling has emerged as a powerful tool for social change, providing a platform for uncovering and amplifying marginalized voices. While its application in gerontology has grown, previous workshops often exclude individuals in long-term care settings. This paper shifts the focus to care home residents, exploring how Digital Storytelling can facilitate participant agency in the face of their perceived vulnerabilities.

Drawing on 11 virtual Digital Storytelling workshops in care homes on Vancouver Island, B.C., Canada, this study uncovers the nuanced relationship between vulnerability and autonomy in storytelling. It challenges the notion of autonomy as strictly individualistic, showcasing vulnerability as a pathway to agency within caring relationships. The analysis contributes new understanding to an Ethics of Care framework, demonstrating the enabling role of vulnerability in terms of promoting relational autonomy. The paper calls for a caregiving approach in research practices to support the inclusion of underrepresented individuals and contributes a specific angle to Digital Storytelling research by providing in-depth insight into the interrelations of vulnerability and autonomy within facilitator-participant relationships.

Introduction

Stereotypes about long-term care residents as inherently frail and vulnerable are enduring and permeate social policy. The landscape of long-term care does little to challenge these narratives, and instead often serves to reinforce them (Higgs & Gilleard, 2021). With care home residents viewed as unable to contribute meaningfully to society, this has influenced conditions at long-term care sites, and the literature is replete with accounts of neglect and isolation (Armstrong et al., 2020; Estabrooks et al., 2020). With public concerns mounting over the social and civic exclusion of older adults (Boamah et al., 2021; Cotterell et al., 2018; Wister, 2014) – who often experience increasing limitations to autonomy with age – this research examines the transformative potential of Digital Storytelling for individuals whose lives fall within the social imaginary of the non-agentic ‘fourth age’ (Gilleard & Higgs, 2010).

Through unearthing alternative narratives and marginal voices, Digital Storytelling has long been considered an agent of social change (Hartley & McWilliam, 2009). With origins often based in Lambert’s Story Center approach (Lambert, 2013), Digital Stories are typically 2- to 5-min-long amateur video productions that involve still images timed to the storyteller’s narrative. Story themes vary significantly; the overall aim is often to provide a space for individuals to gain public voice and an enhanced sense of agency by sharing their life experiences with wider audiences (see www.storycenter.org).

This paper positions the founding sensibilities of Digital Storytelling within the context of long-term care to explore ways older care home residents can exercise their sense of agency by narrating life events. Drawing on 11 virtual workshops with care home residents on Vancouver Island, B.C., Canada, we build on experiences with Digital Storytelling to illustrate expressions of both autonomy and vulnerability, including the interplay between the two concepts, that were uncovered by the story-making process. Our analysis highlights the nuanced relationship between autonomy and vulnerability and demonstrates the role of vulnerability in contributing to meaningful caring relations. By revealing enabling aspects of vulnerability, including its capacity to facilitate autonomy to some extent, we challenge normative representations of autonomy as an individualistic ideal and vulnerability as a weakness that is antithetical to autonomy. To reconcile this false dichotomy, we utilize the Ethics of Care theory and its related concept of

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relational autonomy to highlight the ways in which agency is inherently shaped by one's social relationships and contexts. The paper contributes new understanding to Digital Storytelling research by drawing attention to the complex power relations at play in virtually mediated researcher-participant relationships and calls for a caregiving approach in research practices, one that is grounded in attentiveness, responsiveness, and mutual respect, wherein researchers adapt to participants' needs, foster reciprocal relationships, and prioritize ethical sensitivity throughout the research process.

Digital storytelling and later life

The last decade has seen an increase in research on Digital Storytelling with older adults. Workshops have aimed to support older adults to develop digital skills (Kaufman et al., 2019; Simsek & Erdener, 2012) and enhance their levels of social and community engagement (Alexandrakis et al., 2020; Hausknecht et al., 2019; Sehrawat et al., 2017). In educational settings, Digital Storytelling projects have been used for student training in social science and health care fields to support intergenerational understanding (Loe, 2013; Sehrawat et al., 2017) and have demonstrated the value of experience-based learning for students (Jenkins, 2017). While there is very limited evidence to support the effectiveness of Digital Storytelling as a tool for improving clinical outcomes for older adults (Rios Rincon et al., 2022), studies describe positive outcomes for intergenerational understanding (Hewson et al., 2015) and for older adults' confidence, perceived social positioning, and reflective well-being (Wagner & Ogawa, 2023). Studies have also noted outcomes among audiences, where older adults' Digital Stories have brought awareness to ageism and changed the way viewers think about later life, fostering empathy for older individuals and confronting stereotypes about older adulthood (Sljivic et al., 2022).

Most projects have involved community-dwelling older adults, with workshops being held in public spaces and community centers or in participants' homes (Rios Rincon et al., 2022). The limited body of research on Digital Storytelling in residential care settings has tended to focus on issues of memory and reminiscence for individuals with cognitive impairment (Rios Rincon et al., 2022). More broadly, a review of digital Life Stories projects involving people with dementia (Dellkvist et al., 2024) found that storytelling can enhance participants' social interactions and sense of self and can support carers to better understand and connect with participants. However, within residential care settings, challenges can arise relating to staff's technical know-how and time constraints on staff time, which create barriers for longer-term projects or ongoing engagement with storytelling activities. Prior work on Digital Storytelling in residential care has also shown the need for further understanding of the power dynamics between facilitators and participants and the role of contextual factors in enabling/disenabling participant engagement (Wagner & Ogawa, 2023).

Ethics of are theory

Since the 18th century, the Western political sphere has followed a "rationalist" approach that is organized around Immanuel Kant's notions of individualism, universalism, and impartiality (Tronto, 1993). Early Ethics of Care theorists, including Carol Gilligan (1982) and Nel Noddings (1988), argued that these values failed to capture the emotions required of caregiving relationships that have been historically mediated by women in the domestic sphere. In response to these gaps, they developed the Ethics of Care framework as a moral and political theory that foregrounds values of compassion, empathy, sensitivity, and responsiveness—values that have been traditionally associated with women and excluded from public consideration (Held, 2006; Slote, 2007; Tronto, 1993). The importance of these qualities extends beyond formal caregiving, and the Ethics of Care perspective can be helpful to bring clarity to the caring relationships that develop between researchers and participants in longer-term qualitative studies (Toombs et al., 2017).

The Ethics of Care theory starts from the premise that all human beings provide and receive care in interdependent relationships that sustain life (Tronto, 1993). From this perspective, vulnerability is seen not as a personal shortcoming but as a human condition that enables social connection. This conceptualization differs from prevailing political theories that assume or idealize the existence of autonomous actors, notwithstanding the relationships involved in developing, supporting, or limiting individual agency (Held, 2006; Tronto, 1993). Since its inception in the 1980s, the Ethics of Care theory has expanded from its roots in social psychology to encompass applications in public policy and healthcare research, including gerontological research (Juujärvi et al., 2019; Yu & Rosenberg, 2023).

Despite critiquing traditional notions of self-sufficiency, Ethics of Care theorists still ascribe value to autonomy, albeit in less individualistic terms. Recent Ethics of Care literature has incorporated feminist conceptualizations of relational autonomy, which acknowledge that individuals are embedded within social networks that influence personal decision-making processes (MacDonald, 2010; Osuji, 2018). In this sense, autonomy does not rest upon the individual alone; it is inherently shaped by social relationships. Relational autonomy has been increasingly utilized in gerontological research: in contexts of older adults and end-of-life care, healthcare decisions often require a nuanced understanding of the complexities of interactions with family, healthcare providers, and cultural factors (Gómez-Vírseda et al., 2020; Perkins et al., 2012; Sherwin & Winsby, 2011).

Methodology

The workshop method was based on a collaborative procedure designed by Ogawa and colleagues (Ogawa & Ito, 2010; Ogawa & Tsuchiya, 2017) to give voice to individuals who may have difficulties communicating their viewpoints. This method carries forth the sentiment of the Story Center approach but recognizes that not all individuals have a story they already want to tell (Ogawa & Tsuchiya, 2014). Rather than simply providing an opportunity for voice, facilitators worked with participants to co-construct narratives from "story seeds," including memories, frustrations, and experiences.

The workshops formed part of a larger project that aimed to support long-term care residents' sense of communicative agency by mobilizing understanding of the mechanisms of communication and digital inequalities in long-term care, applying creative and critical methods. The research targeted individuals with no or mild cognitive impairment, who form a minority within the long-term care system, following a literature review and pilot study showing that this group is often overlooked in long-term care research (Wagner, 2022). The paper presents findings from the Digital Storytelling component of the project and develops an analysis of the intersections of communication media and experiences of autonomy. The study received ethics approval from the University of Victoria and the Vancouver Island Health Authority (H21–02289).

Eleven care home residents on Vancouver Island participated in one-on-one Digital Storytelling workshops held in winter 2022/23; participants included six women and five men, ranging from 62 to 97 years of age. Care home staff provided residents with written information about the project, including a one-page invitation and a Participant Information Sheet. Residents who expressed interest in Digital Storytelling met by video or phone calls with the researchers to learn more about the project before deciding whether they wanted to participate, and provided oral, recorded consent before the workshops began. All participants' names have been changed to protect their identities and respect their privacy.

Four students from the University of Victoria, including the first and second author, worked one-on-one with participants through a series of four to eight online 'story finding' discussions, typically lasting 20 to 30 min but sometimes extending over an hour. Workshops were conducted remotely as an infection prevention measure; they took place primarily via video call, with some phone and email correspondence as needed to meet participants' preferences. The resulting stories were owned by participants, who were provided with an opportunity to share their story at a preview event held at the care home with staff, residents, and family.

All facilitators had a background in aging studies and familiarity with key concepts in critical gerontology. The workshops began by exploring participants' experiences, and the story format was co-constructed with each participant. This resulted in stories that ranged from two to 15 min in length, including audio-only stories and stories with the facilitator's voiceover. This flexible design was built on the third author's previous work on Digital Storytelling with care home residents, which showed the need for further attention to engaging participants in the workshop design and structure. Co-creating the story format in this project facilitated stories that were often personal, and four participants were not interested in sharing their stories other than directly with family members.

Analysis

The analysis developed in this paper draws on 61 pages of participant observation notes and 5 pages of transcribed audio from the preview events held with staff, family, and participants.

Our analysis was guided by a Grounded Theory approach, wherein concepts and categories were iteratively constructed from our data throughout the analytical process (Noble & Mitchell, 2016). Data analysis commenced with two team members independently developing initial codes to label emergent dimensions of data. Team members then compared and discussed initial codes with one another to identify patterns and relationships between codes, which enabled the collaborative development of wider categories that encompassed these codes. Finally, these categories were organized under overarching themes – vulnerability and autonomy – around which we structured our findings below.

We identified the Ethics of Care theory as a framework for unifying notions of vulnerability and autonomy that emerged from our data. The identification and application of theoretical frameworks at this final stage is aligned with Grounded Theory's central premise that "the theory should fit the data" instead of "the data [fitting] the theory" (Glaser & Strauss, 2006, p. 261). The Ethics of Care framework responds to vulnerability – a condition held by all individuals at different points of their lives – by centering interpersonal relationships, such as those developed between participants, researchers, and staff members in this study (Tronto, 2013). In this paper, we draw on concepts from the Ethics of Care theory to analyze and reconcile notions of vulnerability and autonomy that we see as mutually reinforcing rather than dichotomous.

Limitations and delimitations

The virtual nature of the workshops introduced some limitations that had implications for the depth and breadth of our findings. That some participants were not familiar with video calling technologies and/or experienced difficulties hearing or seeing created a challenging context for engaging in the storytelling process; the case studies below illustrate some examples of these obstacles. A further issue related to the reliance on care aides to set up, manage, and troubleshoot video call connections, which, in some cases, created delays in the development of the story due to the limited availability of staff. This revealed the relational aspect of access to digital technologies within long-term care, which may have generated barriers to participation: residents who are less comfortable asking staff for help and experience heightened levels of exclusion may have been less likely to participate in the project. Face-to-face workshops may have supported wider participation, resulting in a more diverse data set. The research, however, does not intend to present a generalizable account of Digital Storytelling in long-term care; rather we draw on our experiences facilitating the workshops to develop insights into the interrelations of vulnerability and autonomy within virtual research, which can also inform considerations for virtual Digital Storytelling research design, as discussed further below.

A related issue that deserves attention is that facilitators' observations form our primary data source. Family members, staff, and residents provided reflections in the preview events where the stories were shared and discussed. These events provided an opportunity for reflective discussion and for participants to describe their experience developing the story, but as these were online, group events, the depth of discussion was limited. Whereas the broader research project involved in-depth individual interviews with residents to develop a more general understanding of their lived experiences using technologies, the reflections on Digital Storytelling captured in this paper are largely based on the facilitators' reflections. The detailed participant observation notes for each session included a designated section for reflection on the power relations between the facilitator and participant. These notes provide insights into how facilitators form and navigate researcher-participant relationships with older care home residents in and through the Digital Storytelling process. By focusing on these detailed reflections, this paper contributes a specific angle to Digital Storytelling research by providing in-depth insight into the procedural aspects of virtual workshops from facilitators' perspectives.

Findings

Our findings are organized around two central, interrelated themes that emerged from our analysis: vulnerability and autonomy. These themes reflect the complex dynamics observed in the storytelling workshops and are explored through participants' and facilitators' experiences.

Vulnerability

Our use of vulnerability as a concept and theme can be at times uncomfortable. While all people are vulnerable to social and physical harms (Mackenzie et al., 2014), vulnerability is often seen as the defining characteristic of old age. This outlook on aging invisibilizes the diversity of older adults' experiences of aging (Langmann, 2022) and the mechanisms and social systems by which older adults are made vulnerable (Hebblethwaite et al., 2022). Conceiving of vulnerability as situational (Mackenzie et al., 2014) allows us to recognize the interplay of social, physical, and institutional factors that influence experiences of vulnerability, including a lack of support. For example, Langmann (2022) maintains that the age-related changes individuals experience can be physical and tangible in nature (such as hearing loss) but are "perceived as limitations oftentimes only due to a lack of support… such age-related physiological changes are not to be regarded as diseases per se but depend on their context" (p. 137). In this way, socially constructed negative perceptions of aging and how they materialize in a person's experiences of vulnerability interact with physiological changes of aging to "create new vulnerabilities or exaggerate existing ones" (Mackenzie and Rogers, 2014, as cited in Langmann, 2022, p. 135).

We seek to maintain complexity in the various experiences of vulnerability, in the face of overlapping vulnerabilities that are dynamic, layered, and context-dependent (Langmann, 2022). We feel this definition is both a more just characterization of the concept, as well as an understanding that yields far more nuance and insight into ageism at large. We illustrate vulnerability through struggles in communication and difficulties being understood, as well as through power imbalances between participants and various actors in the project, including facilitators, care aides, and others. Conversely, vulnerability is also manifested in positive expressions in the context of sharing; this includes the emotions and memories participants felt during their revisitation and retelling of stories from their past. In the discussion section, we engage with Ethics of Care theory and related conceptual frameworks to challenge disempowering representations of vulnerability. From these perspectives, vulnerability can be a quality that enables meaningful social connections and, as a result, autonomy as mediated through these social connections.

Communication challenges leading to withdrawal

All facilitators made note of experiences in which communication was a significant barrier to working effectively with participants, the most common being communication difficulties due to hearing loss. The virtual nature of the workshops meant that challenges regarding hearing were often difficult to mitigate without the help of a care aid, support that was commonly unavailable. Difficulties hearing often led to participants' expressions of frustration and shame, at times culminating in participants visibly withdrawing from engaging in the workshop:

The participant seemed fairly comfortable speaking with me, but would often seem to be frustrated, putting their head into their hand and apologizing when they had trouble understanding me. (Lily, second workshop).

Unfortunately, I think that the participant was at a point where they felt very frustrated with their struggles to hear the video, and as such, they withdrew again… I really think that the participant's difficulties with hearing made them feel very vulnerable and uncomfortable at times, which really impacted the process. (Elizabeth, fifth workshop).

A secondary communication barrier was one of verbal disabilities. One resident experienced dysarthria due to Parkinson's disease; his verbal communication difficulties were significantly impactful on his engagement in the workshops:

I felt that my inability to understand [the participant's] speech impeded his ability to take control over the story-making process. There were many times when I misunderstood his story. However, I tried to repeat what I had heard back to him as much as possible so that he could clarify. (Paul, second workshop).

… [the participant's] identity is tied to his proficiency in various languages, and his ability to teach these languages. The loss of his communication abilities, due to motor issues related to Parkinson's disease, has been a source of frustration and sadness for [the participant]. He jokes – and laments – that "nobody can understand me in any language now". (Paul, eighth workshop).

Power imbalances between participants and facilitators

All facilitators indicated they spent significant time deeply considering the ethical implications of working with older adults during this project; facilitators were extremely cognizant of the inherent power imbalance between themselves and the participants. In addition to the privilege of academia, facilitators were more fluent in the use of technologies utilized during the storytelling process. Facilitators were extremely sensitive to the potentiality of misrepresenting the stories that older adults had chosen to tell – either by suggesting narratives that didn't quite fit (i.e., "putting words in their mouths") or by unconsciously changing so much of the story in the process of video creation that the final product may not have done justice to the participant's story, or portrayed it in ways that were truly authentic to them. This was especially true of instances where communication was difficult:

What I was able to capture represents only a fraction, and a reduction, of the wealth of stories that [the participant] tried to share with me, but that I was largely unable to understand. I can only imagine the frustration that [the participant] feels when there is such a discrepancy between one's internal thoughts and the external perceptions of others. (Paul, eighth workshop).

Facilitators felt a strong sense of responsibility in how they engaged with participants, and were dedicated to avoiding negative speech patterns, namely "elderspeak" and patronization:

Since I repeatedly asked him to repeat himself when I couldn't understand, I was wary of coming across as patronizing. I noticed that he would prefer that I asked him to repeat himself when I didn't understand as opposed to moving on to the next question. I appreciate his dedication to communicating his story as best as possible and will try my best to honor his efforts to do so. (Paul, first workshop).

Enabling manifestations of vulnerability

We found that vulnerability can also open opportunities for self-expression, care, and autonomy in terms of building trusting relationships with facilitators, accessing assistance from care workers, and "opening up" during interviews. As mentioned previously, care aids played a crucial role in facilitating access to technological tools, such as Zoom and sharing pictures online. Although such reliance on care aides placed participants in a position of vulnerability, it also facilitated digital inclusivity and empowered participants to express specific needs to which story-making processes could be tailored. Even outside of workshops, participants exerted control over the story-making process by coordinating with staff members to arrange meetings and share story materials. Notably, many participants also exercised agency by choosing to continue engaging in the story-making process despite feeling uncertain about what the project entailed, whether they would be able to communicate with facilitators, and how to access technological tools – barriers that care staff helped mitigate.

During workshops, vulnerability was often a precondition for sharing experiences and expressing emotions. When participants and facilitators were vulnerable with one another, participants felt comfortable sharing deeply personal stories and expressing emotions, enriching the stories and the story-making process. Reminiscences about loved ones, places, and accomplishments frequently conjured a mix of emotions that were positive, negative, and often bittersweet:

The participant expressed feelings of melancholy, especially when he showed me photos of his wife in Japan, as well as a sense of whimsy, which came through in a photo of him dressed as Santa Claus. I believe that the process of showing me these pictures helped to elicit emotions that I can incorporate into the story. (Paul, fifth workshop).

The participant mentioned to me that they were looking forward to hearing the story I created, and that they have found the experience to be quite uplifting. (Garth, third workshop).

The most rewarding part of the meeting was seeing the participant begin to laugh during their retelling of some stories from their life – I felt that really indicated that they had opened up a lot and were enjoying themselves. (Elizabeth, first workshop).

These excerpts also demonstrate the necessity of vulnerability on the part of facilitators in terms of understanding and vicariously experiencing these emotions, as evidenced by connections forged over laughter and empathy. Negative emotions, including frustration and discomfort, were also central to honouring and adapting to participants' voices, needs, and preferences in the story-making process. Facilitators responded to feelings of self-consciousness and uncertainty, at times through altering story-making procedures:

When I asked the participant if they would like to share their story with a small group of others, they said that they didn't believe anyone would want to listen to their story and asked me if I thought it was boring. I reassured the participant that I felt that their story was very interesting to me, and I didn't judge their experiences negatively, but acknowledged that it can feel uncomfortable to be vulnerable and share stories with others. (Elizabeth, fourth workshop).

I asked if she'd be comfortable reading the script for the video, but she preferred that I do the voiceover instead of her due to her shyness. (Shirley, fourth workshop).

Openness about participants' needs and preferences necessitated vulnerability from both facilitators and participants with respect to requesting and providing feedback:

While the participant was a bit hesitant at first to give me feedback, I don't think it was a result of them not feeling comfortable speaking with me; rather, as they later mentioned, they didn't want to hurt my feelings.

(Garth, third workshop).

Autonomy

Within Western capitalist culture, we are socialized to see autonomy as an embodied state of being; one does not exercise autonomy so much as embody it. This conceptualization posits autonomy as dichotomous: one either is or is not autonomous (Pritchard-Jones, 2017). Stereotypes of aging as being defined by a loss of autonomy are pervasive (Higgs & Gilleard, 2021). However, we have found that relational dependence is not necessarily linear. As Pritchard-Jones (2017) states, "an individualistic conceptualisation of autonomy does not adequately reflect the everyday lived experiences (both positive and negative) of older people" (p. 75). In the discussion section, we utilize the concept of relational autonomy to capture participants' expressions of agency as mediated through social relationships. Here, we provide examples of how participants exercised autonomy through reliance on care aids, collaborating with researchers to develop their story's scripts, and making meaning.

Autonomy & reliance on care aids

Nearly all workshops were heavily impacted by the necessity of relying on care workers for numerous factors, such as call setup and quality, troubleshooting technical and other issues, communication, and sending additional story materials. Given well-documented issues of chronic overworking and understaffing in the caring sector, care aids were not always readily available to step in and assist.

… there was a facilitator present to help the participant set up Zoom. … At one point in the call, our Wi-Fi got disconnected, and the participant was muted from their side. Unfortunately, they weren't able to unmute themselves on Zoom without help, and we had to end the call. … Because of technical difficulties, the meeting was cut very short. (Lily, second workshop).

Participants did exhibit some frustration at issues they were unable to troubleshoot themselves, and this could have contributed to a diminished sense of autonomy in regard to the technology. Some care aids were extremely willing to assist in adapting the communication strategies to help participants:

…the facilitator was on screen and [in] part of the conversation during the beginning, and also part-way through when checking in. The facilitator also brought in headphones for the participant today, which helped with communication between me and the participant. (Lily, third workshop).

Facilitators noted varied experiences working with care staff – while the majority of communication was supportive, it was clear that the care home staff were very busy and often did not have the availability necessary to fully support the residents with their video calls. One facilitator noted:

… I struggled to communicate with administrators and care workers at the residential facility where the participant lived. Given that the participant was not privy to this communication, it is difficult to know how much this impacted their experience of the workshops, but it did mean that there was a large gap in the timing of our meetings, and we had to finish the project under more of a time crunch than I had anticipated.

Co-developing the script

This project has shown that dependence on others does not necessarily preclude autonomy; rather, the collaborative process between facilitators, participants, and care aides has largely empowered participants to exert agency over their own stories. Vulnerability was often a precondition for participants to express their wishes. Facilitators reported that iterative discussions about story details and formats enabled participants to exert control over the conversation and narrative:

…I think asking for clarification and follow-up questions helped give control to the participant as well as helped engage them in the story-making process as they led to the participant steering the conversation. In asking… the participant would correct any details I was unsure of which would in many cases also lead them to expanding on the subject more. (Garth, second workshop).

Continually "checking in" with participants about the accuracy and authenticity of their stories was crucial for preserving their distinctive voices. This step was especially important given the risk of facilitators unintentionally "overwriting" participant voices while prompting, drafting, interpreting, and structuring stories. The quotes below demonstrate the reflexive processes through which facilitators and participants co-developed scripts over which participants felt a sense of ownership.

At times, I felt that I worded questions in ways that "put words in her mouth." For example, I asked if painting was a way for her to cope with the loss of her mobility, when this wasn't the case for her, and it seemed that she didn't want adversity to define her story. However, she would let me know when I interpreted her experiences incorrectly, which also made me more mindful of asking questions in ways that make space for her own narrative. (Shirley, second workshop).

The participant listened to what I had to say, but was really in control of the narrative for what they wanted to talk about and include in the story. When I asked if they wanted to expand on certain sections, they were clear to assert whether they were willing or just not wanting to. (Ella, third workshop).

Participants also exercised agency and self-expression in the process of selecting and arranging photos for the story. The photos opened opportunities for creativity and conversation and provided memories and emotions that could be incorporated into stories.

The participant then suggested several poses [for a photo to take to include with their story] and in doing so came up with a much more meaningful idea that I had originally thought; in adding their own insights, they took control of the story-making process, something they continued to do when recording the voice-over. (Garth, third workshop).

I believe that giving [the participant] the opportunity to share his photos… afforded a sense of control over his narrative. … the process of showing me these pictures helped to elicit emotions that I can incorporate into the story. (Paul, sixth workshop).

The recording of voice-overs created further opportunities for participants to refine the script and narration of their stories.

With their experience working in the acting world and their keen eye for detail, it seemed very natural for them to take the lead in narrating the story and making the calls for how it should be done. The participant definitely knew what sounded and worked for them best and was confident/comfortable in their ability vocalizing that. (Brian, fourth workshop).

Although some participants did not record their own voice-overs due to speech challenges or feelings of shyness, they demonstrated agency by requesting that facilitators narrate their stories – an active decision regarding how their story should be portrayed. In the absence of narration from participants, participants and facilitators collaboratively integrated aspects of participant voices, including phrasing and intonation, into the narrative. The following quote captures both the facilitator's and participant's strategies for doing so:

The participant was able to control her narrative by correcting misrepresentations of her story in the drafted script and voiceover, as well as relaying the meaning and significance of specific events. I believe I helped her feel comfortable doing so by encouraging her to stop me at any point. I also tried to preserve some of her phrases verbatim to use in the story. (Shirley, third workshop).

Meaning-making

The storytelling process also conferred agency to participants by enabling them to make new meaning from a lifetime's worth of memories. Participants were often very intentional about the content, structure, format, and intended audiences of their stories, as evidenced by the following observations:

She [the participant] explained to me that it was really important for her to be able to get her ideas across and that she wasn't concerned about what others would think. We talked a bit about her poetry and story, and this was what seemed to be the most exciting for her about the project – having the opportunity to share these in a new format. (Lily, fifth workshop).

The participant clearly thought about stories they wanted to share in advance, appearing to refer to some notes they had off-camera a few times, which led to a very rich discussion. (Brian, fourth workshop).

They were interested in this process as a way of maintaining a record of their life for their family, as a way of preserving their legacy. (Ronald, fourth workshop).

Many participants naturally assumed the role of "experts" in their own lives, taking the initiative to steer conversations in different, sometimes unexpected, directions. The following quotes highlight the ways in which participants claimed ownership over their stories by inhabiting an "expert" role, one to which facilitators oriented themselves with humility.

…the participant has been very comfortable in the role of "expert" during this project, and I have positioned myself as the "learner" in response – this has really helped the resident maintain control over their narrative and direction of our conversations. (Barbara, fifth workshop).

I feel that the participant was quite comfortable being "in the driver's seat" for our conversation… I think they enjoyed feeling like an expert in how they shared their perspective. (Ronald, second workshop).

Case studies

In this section, we highlight tensions and synergies between vulnerability and autonomy through two complementary case studies: one of a participant who experienced speech challenges, and another of a participant who had difficulties with hearing.

Second author's reflections: storytelling with participant Paul

Paul's speech challenges resulting from Parkinson's disease posed barriers to communication during workshops. Although I suggested supplementing interviews with written communication via email, his condition also precluded him from being able to type. As a facilitator for these workshops, I struggled to understand Paul and felt disruptive when I repeatedly asked for clarification. For Paul, my inability to understand him, despite his immense efforts and eagerness to share his life experiences, seemed to be a source of frustration.

Communication challenges were perhaps especially distressing to Paul, given that linguistic prowess represents a core component of his identity. His story featured a lifelong dedication to mastering and teaching different languages: he obtained Master's degrees in two languages, has lived in three countries, where he taught English for 25 years, and continues to develop educational videos for teaching language. During workshops, Paul frequently joked – and lamented – that "nobody can understand [him] in any language now." I, in turn, felt saddened by my inability to fully understand Paul's rich cross-cultural experiences.

This situation inevitably placed Paul in a position of vulnerability, and me in a position of power, as he relied on me to script and narrate his story. What I was able to capture represents only a fraction, and a reduction, of the wealth of stories that he tried to share with me, but that I was largely unable to understand. I felt that my inability to understand and thus include many aspects of Paul's story impeded his ability to take control over the story-making process. During workshops, I was caught between competing ethical considerations: on one hand, I was wary about coming across as patronizing by continually asking Paul to repeat himself; on the other, I wanted to honor Paul's efforts to communicate experiences that were meaningful to him by trying my best to understand them.

Addressing these types of tensions required vulnerability from both Paul and me. When I asked Paul about whether he was comfortable with my requests for clarification, he signaled his preference for repeating and clarifying things as opposed to moving on in conversations. I believe that my acknowledgement of Paul's efforts to communicate with me, as well as of my limits to comprehension despite these efforts, helped him feel more comfortable voicing his needs in, and thus expressing autonomy over, the storytelling process. On days when he had the most difficulty speaking, he communicated wishes to re-schedule or end workshops, as well as to engage in less structured conversations where he was also interested in learning about my life. Sharing experiences from my life, as he requested, not only relieved the onus of speaking from him but also facilitated equity, rapport, and comfort between us. After I disclosed my Chinese heritage, for instance, we connected over shared experiences of living in East Asia. I felt that sharing details about myself helped to make the conversation more reciprocal and less "extractive" in terms of me obtaining information from him. Thereafter, we would often exchange Chinese phrases in greeting and farewell – a ritual that paid homage to the linguistic talents and life experiences that speech challenges obscured but could not take away.

Paul also exercised both vulnerability and agency in the process of developing the visual component of the video. Because he was unable to narrate his story, preserving the authenticity of Paul's perspective was especially important for him to maintain a sense of ownership over the story. Selecting, curating, and presenting photos allowed Paul to convey scenes from his life that may be otherwise hard for him to describe verbally.

First author's reflections: storytelling with Elizabeth

Elizabeth experiences both vision and hearing loss. Elizabeth's difficulty hearing served as the most significant communication barrier; the tone of my voice was particularly difficult for her to hear. While communicating, I found it extremely difficult to raise my voice loudly enough to be heard while being mindful not to engage in "elderspeak." I noticed I would often slow my speech, and at times simplify my sentence structure in an attempt to mitigate the frustration that Elizabeth demonstrated when she couldn't understand me; this worried me, as I considered that this may become patronizing.

I was aware of the power imbalance between Elizabeth and me, given that communication was difficult. I noticed that Elizabeth would often defer to my judgement, suggesting that I make decisions around her story. I would do my best to reiterate that the workshop and Digital Storytelling process were truly there for her to choose the story she wanted to share. Elizabeth was not explicit in deciding a story to tell on her own, so I attempted to preserve her voice and autonomy as much as possible by suggesting some different options for her to choose from. We settled on telling a story about some childhood memories she recounted to me, as these were narratives she returned to many times.

Elizabeth told me that she wouldn't find the inclusion of photos in her story to be meaningful due to her vision loss. As the original Digital Storytelling format centered around photos, I wanted to find a way to tailor the structure to something that would suit her better. Through our conversations, I learned that Elizabeth enjoyed listening to the radio. I decided to suggest personalizing her story to connect it to a media source that she enjoyed, making it a "radio interview." I recorded her descriptions of memories from her childhood and edited them together into a cohesive audio piece, interspersed with my narration to provide context and details.

When I played Elizabeth the final story, she struggled to hear the parts in which I narrated, despite the efforts I had made to ensure the volume matched that of her speaking parts. She expressed that the difficulty was my voice, particularly the pitch and tone. The inability to hear the story fully was frustrating to her, and she appeared to withdraw from the meeting, voicing that she felt there was "something wrong" with her. I understood that this could be a context in which she felt particularly vulnerable due to her hearing loss, as she was unable to partake in this step of the storytelling process. She also seemed to have doubts about the story's content as well, voicing that she thought it would be uninteresting to others. Despite editing attempts to increase the volume and slow the pace of my speech, Elizabeth was still unable to hear. I suggested that we restructure the story and take my narration out of it completely, but she was too frustrated to continue. Ultimately, she decided she would like to stop working on her story; she made the choice to delete her story without sharing it with other residents, stating that she didn't think anyone would want to listen to it. She did decide that she would like it shared with her granddaughter, which I organized. While I believe that Elizabeth's choice was influenced by her feeling vulnerable about the story and process, I respect that the decision to stop the workshops and delete her story is grounded in autonomy. She could have followed the proposed structure of the workshops as they were suggested, but decided against it.

Discussion

Interdependent relationships

Relationships between residents, staff, and researchers were interdependent including the care, agency, and any power imbalances therein. Residents relied on researchers to record their stories, and on staff members to navigate digital tools. Likewise, researchers relied on the expertise of residents and the support of staff members to co-create the Digital Stories. These relationships are born of vulnerability, predicated on the expression of, and responses to, individual needs and limitations. Such vulnerability has not only enabled meaningful relationships but has also facilitated a sense of agency in participants by allowing them to shape the story-making process according to their needs, preferences, and goals. This finding challenges dominant narratives that posit vulnerability in opposition to agency, and that hold agency as an individualistic value (see Stumpf et al., 2022).

At one of the sharing events, digital inequalities and residents' reliance on digital support arose as a key discussion point. Participants recognised constraints on staff time and expressed appreciation for staff support throughout the project. One participant explained, "We're really short-staffed and their time is limited, and it's not to help us with our technology." Further issues that were discussed related to low bandwidth and limited Wi-Fi reach in the care home, with staff expressing their own frustrations. The storytelling events presented an opportunity for staff and residents to build mutual understanding about digital constraints, where participants could voice their concerns and learn more about staff challenges.

Participants not only exercised relational autonomy (Larkin, 2024) by voicing their needs to researchers and staff members but also by crafting stories that detailed the ways in which their lives were shaped by family and community members. For participants, the ability to share their Digital Stories with families in the sharing event was a source of pride that seemed to further their sense of autonomy. In this way, the relational act of meaning-making through storytelling became a form of resistance to the social construction of vulnerability as a disabling and shameful quality. Participants' experiences of vulnerability resulted not only from physiological limitations coupled with a lack of support in navigating those limitations, but also from disempowering social discourses. While the storytelling workshops did not change physiological realities nor the availability of structural supports in the nursing homes, they did point to the potential for challenging social constructions of aging and vulnerability, which can influence one's willingness to both give and seek support.

Just as vulnerability is socially constructed, so, too, is autonomy. In this project, the act of storytelling facilitated the construction of narratives that challenge disempowering notions of vulnerability. In the context of dependence on staff members within care homes, storytelling may offer residents a means of navigating the blurred boundary between vulnerability and autonomy, even when the storytelling process entails some degree of dependence on staff members. As Stumpf (2022) asserts, participants revealed in their storytelling how autonomous agency and meaningful lives not only persist in the 'fourth age' but also are interdependent with relational support. Similarly, Loe's (2013) research on older adults living at home, for instance, challenges traditional ideals of independence in old age, instead advocating for strengthening social networks that promote autonomy mediated by interdependent relationships. Our findings align with other studies showing the ways in which older adults exercise relational autonomy by navigating social networks and interdependent relationships to meet wellbeing needs (Hou, 2024; Roth, 2020; van Loon et al., 2023).

Navigating inequities through Ethics of Care

In recent years, Ethics of Care theorists have examined imbalances of power within caring relationships. Hankivsky (2014), for instance, noted that care providers are in positions of power and privilege over people who require care to manage the effects of physical or social vulnerability. For some participants, communication and technology challenges impeded autonomy in the story-making process over which researchers inevitably held power. Addressing these challenges and power dynamics required that researchers navigate the boundary between empowerment and patronization in the provision of care.

Navigating power dynamics has been a focus of a growing body of literature pertaining to participatory research practices informed by the Ethics of Care, particularly with respect to Tronto's (1993, 2013) five pillars of care: Attentiveness, Responsibility, Competence, Responsiveness, and Solidarity. Researchers have underscored the importance of attentiveness and responsiveness with respect to developing a more inclusive understanding of marginalized community members whose voices often go unheard in society (Brannelly, 2018). People who experience marginalization often face the epistemological violence of not being listened to (Teo, 2010). Attentive listening in research, then, is a crucial step towards building trust, inclusivity, and solidarity with participants. Attentiveness also requires that researchers be open and vulnerable, reinforcing the universal nature of vulnerability and breaking down boundaries between insiders and outsiders in a community (Bozalek, 2011; Brannelly, 2018). Moreover, the process of building relationships with, and an understanding of, research participants can disrupt stigmatizing discourses that frame marginalized individuals as socially deviant or "other." Researchers who inhabit an outsider role, such as those in this research, in turn have ethical responsibilities to participants. These responsibilities include listening to participant voices, however they are presented, amplifying these voices, and creating social change (Barnes & Brannelly, 2015; Brannelly, 2018). We interpret competence in research contexts to be the ability to practice attentiveness, responsibility, responsiveness, and solidarity in research practices.

In this study, trust between researchers and participants was largely developed through attentiveness and responsiveness to participants' wishes and health or personal circumstances, which are often in flux over the course of the project. Understanding and adapting to participants' needs and goals was a crucial part of respecting the dignity and autonomy of participants. In one instance, this meant respecting a participant's desire to discontinue the story-making process – an example that highlights the applicability of an Ethics of Care framework to supporting ongoing and informed consent in research. This example further demonstrates the entwined and mutually constitutive nature of vulnerability and autonomy. While the choice to withdraw from the project can be considered an expression of agency, this choice was also undertaken in recognition of one's personal limitations. The case studies of Paul and Elizabeth highlight the necessity of recognizing not only limitations faced by participants (Attentiveness) but also the researcher's own abilities and inabilities to support participants in navigating these limitations (Competence).

Throughout the project, researchers noted that being open and vulnerable to participants, who reciprocated the openness and vulnerability, helped to mitigate researchers' discomfort about their outsider status, as well as participants' self-consciousness about their stories, health limitations, or lack of proficiency with technology. Researchers also reflected on their responsibility to honor participants' stories and grappled with the power they held over them, including the power to misrepresent these stories, however unintentionally. When completed stories were showcased at a final meeting attended by researchers, participants, their families, and care home workers, audience members expressed solidarity with one another by acknowledging participants' autonomy in overcoming health and technological constraints to create their stories, and by recognizing the stories, experiences, and emotions by which participants wanted their lives to be defined.

Reflexivity

The communication and ethical challenges encountered in this project, born of participants' health challenges and experiences of digital exclusion, highlighted the significance of iteratively identifying and responding to inequities in research, especially those between researchers and participants.

While this project illuminated such inequities, it also helped to bridge them by facilitating the digital and creative empowerment of participants. This process required reflexivity to mitigate potential harms and maintain safety, comfort, and rapport with participants. For example, difficulties in communication clearly left some residents feeling frustrated, and at times, led to participants' withdrawal. Facilitators noted that rapport was often developed out of acknowledging the feelings of residents in these hard moments. The second author's experiences working with Paul illustrate how sharing aspects of her own life, as they resonated with Paul's experiences, was very effective in supporting reciprocity and connection. It was extremely rewarding to amplify the voices and narratives of older adults through utilizing technology they may have felt was previously inaccessible to them. Despite our outsider status, we bonded with participants over shared identities and experiences, including gender, education, and languages – points of connection that helped participants "open up" about their lives. What enabled these points of connection was mutual vulnerability between researchers and participants, which was supported by researchers disclosing their own positionality and social identities to participants.

Conducting the workshops remotely provided an opportunity to develop some reflections on how to address the challenging context of virtual research in long-term care. Enhancing participant support in using and/or learning how to use video calling technologies would have supported participant autonomy in defining meeting times and next steps in the project. One strategy to increase participant support would be to further involve family carers and staff in the workshops. In future work, funding could be sought to cover staff time for their involvement in the workshops, and not only to provide organizational support. This was observed by a participant who reflected on the imbalance of power between themselves and staff members, many of whom were racialized. When asked about what participants would like to see in future projects, she replied:

I would really like to see this extended, but to also include the staff. Because we have a very international staff, and I think we need to know some of the stories of our staff. Some of them have had tremendous experiences that we don't appreciate enough here in non-third-world countries. (Anna, second workshop).

This quote also speaks to the invisibility of care work and care workers, whose stories often go unheard due to their own lack of power and privilege in society. Previous workshops have guided stories around a central theme, such as "stories on home" (Hewson et al., 2015). Focusing the storytelling on a topic such as everyday life within the care home could present meaningful opportunities for care staff to contribute and for care staff and residents to develop mutual understanding on navigating everyday routines.

Conclusion

Through exploring the opportunities and challenges that arose from Digital Storytelling methods with individuals living in long-term care, this study illuminates the interplay between expressions of vulnerability and autonomy that researchers, participants, and staff members collaboratively navigated within a network of caring relations. We demonstrated, on one hand, the realities of communication and logistical challenges that left participants vulnerable to inequitable power dynamics with researchers, as well as feelings of discomfort, frustration, and self-consciousness. On the other hand, we illustrated creative and adaptive ways in which participants, researchers, and care facility staff members navigated these challenges to facilitate participants' autonomy in telling and making meaning out of their own stories.

Our findings suggest that expressions of vulnerability and autonomy are not necessarily competing, but complementary. Critical gerontologists have long drawn attention to how discourses on 'autonomy' in neoliberal societies are inexorably linked with values attached to independence and individualism, where aging is feared and devalued, being framed around notions of declining or degrading independence (Gullette, 2013). This paper contributes to understanding how 'declining' autonomy is not necessarily linear or unidirectional. Rather, expressions of autonomy evolve over time and are oftentimes enabled by relational supports. Participants were able to narrate their experiences in and through the mutual entanglement of vulnerabilities with facilitators. We thus argue that vulnerability can be a means to agency but also can represent an empowering act of self-assertion.

From a theoretical perspective, this study supports a growing body of literature that demonstrates the contribution of the Ethics of Care framework to social and digital research in residential care contexts (e.g., Molterer et al., 2020; Waycott et al., 2022). Our analysis described how caring practices that facilitate relational autonomy can challenge and subvert normative and stigmatizing conceptualizations of vulnerability as oppositional to autonomy. In the process of creating and presenting Digital Stories, participants resisted disempowering notions of vulnerability in old age through agential acts of meaning-making and exercising relational autonomy to mitigate health and technological constraints. These findings support other studies that underscore the need for normalizing an Ethics of Care to promote quality of care and enriching experiences in long-term care environments, especially in contexts where long-term care systems operate under market- or profit-driven models (Berridge, 2012; Kadri et al., 2018; Lloyd, 2004; Molterer et al., 2020; Woods et al., 2017). Our findings also confirm Waycott et al.'s (2022) study, which demonstrated the role of an Ethics of Care in facilitating virtual reality experiences in care homes. Our work joins other qualitative and ethnographic studies that engage with Ethics of Care to explore long-term care residents' experiences, operating under an ethos of valuing residents' knowledge and perspectives, as Molterer et al. (2020) and van den Hooff and Goossensen (2014) do.

From a methodological perspective, the research contributes to a body of work that explores Digital Storytelling as a tool to support older adults' wellbeing by providing a creative strategy for self-expression and social connection (Stargatt et al., 2022). The storytelling process required vulnerability from researchers to establish mutual connection, rapport, and understanding with participants. Further work could build on this by highlighting the enabling nature of vulnerability in research through practices such as attentive listening and involving participants in discussions on researcher reflexivity. Our findings also exposed the interdependent nature of residents' access to digital technologies, which relied on caring relationships with staff. Further research on Digital Storytelling in long-term care contexts would be supported by engaging staff and residents in mutual storytelling exchanges, which could further support the building of caring relationships.

This study has highlighted the pivotal role of caring relationships in older care home residents' engagements with Digital Storytelling, which can be built upon by further explorations of how storytelling involving residents, family, and staff can support caring engagements with digital media.

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CRediT authorship contribution statement

Emily Graff: Writing – review & editing, Writing – original draft, Visualization, Investigation, Formal analysis, Data curation. **Audrey Tung:** Writing – original draft, Investigation, Formal analysis, Data curation. **Sarah Wagner:** Writing – original draft, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

None.

Data availability

The data that has been used is confidential.

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