Ethical Encounters with Housebound People: Location, Timing, and Personal Storytelling

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Abstract

In this paper we describe ethical challenges encountered in fieldwork conducted in people's homes. We are undertaking this fieldwork in a project that is exploring the opportunities that digital technologies provide for people who are housebound due to limited mobility and other constraints, who may have few opportunities to participate in face-to-face interactions or to share their stories with others. We are creating digital stories that can be shared within the local community on an interactive display. In this paper, we consider challenges arising from the location of the research (the private domestic space), the timing of our interactions with participants (which sometimes coincided with crises in our participants' lives), and the personal nature of the stories participants have shared with us. These challenges intersect with the challenges other researchers have encountered when working closely with vulnerable or marginalized participants. Our experiences highlight the need for great sensitivity when creating personal digital stories and conducting research in people's homes.

Author Keywords

Digital storytelling; community; housebound people

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In the past two decades digital storytelling has been widely used to empower marginalized people to share their stories (e.g., [4], [5]). Digital stories, which usually comprise a short montage of digital photographs and video footage, with a voiceover from the storyteller, are typically co-created in small group workshops [4]. The storytellers (who are often research participants) usually work in collaboration with more experienced guides or facilitators (often researchers) to create personal narratives that aim to be both engaging and true to the storyteller's experience. Many digital storytelling projects take place in the context of

community health research [5], but similar work has been undertaken in HCI – for example, Clarke and colleagues have used participatory arts action research to support women who are rebuilding their lives after domestic violence [2]. Projects such as this often aim to empower people to express themselves through digital communication and provide a forum for people to describe difficult experiences. For this self-expression to be meaningful, however, there may be a need for an empathetic and engaged audience. The aim of many digital storytelling projects, then, is to share the stories, whether that be with a familiar audience of family members and friends or a broader public audience [11].

We are exploring how digital storytelling can be used to enable people who are housebound to share their stories with others in order to foster social engagement within the local community. For many people who are housebound, opportunities to participate in the local community are limited. The project is investigating the use of a community display to share digital stories within local communities. In this paper, we focus on the process of *creating* (rather than sharing) the stories, although we recognize that awareness of audience shaped the creation of the stories and informed the ethical challenges we encountered. Because our participants are largely housebound due to various mobility constraints (not all participants had physical disabilities), the workshop style format that is typical of digital storytelling projects was inappropriate for our project. We visited participants in their homes to discuss the story content, collect digital photographs of meaningful artefacts within the home, to review the edited stories, and to relay audience feedback to participants. Conducting research in participants'

private domestic space creates ethical challenges. It means researchers become privy to the complexities of participants' lives that may not be immediately apparent in other settings and can make it difficult to maintain boundaries around both the research (e.g., excluding nonparticipants such as family members who are present) and the researcher's role [3][6].

The timing of research interactions becomes significant when they take place in the home. We can never be certain that our visits will occur at the most convenient time, or what crises we will encounter when we visit participants. This can be complicated when working with people whose lives involve the day-to-day challenges associated with being housebound. Two of our participants lived in poverty and isolation and were experiencing specific difficulties relating to these aspects of their lives during each of our visits. A third participant had a traumatic health diagnosis during the project. The timing of our visits to each participant impacted on our interactions and the stories they shared with us and created challenges for managing the emotional context of the research.

A further challenge we have encountered is the personal nature of the digital stories we are creating with participants. Researchers have clear ethical responsibilities to protect participants from harm during both the creation and dissemination of personal digital stories [5]. We have to be mindful of content that might be difficult for participants to talk about or to review, and to be cautious when deciding (in collaboration with participants) if or how the stories should be disseminated. Other researchers have clearly articulated the need for researcher sensitivity when disseminating stories that may expose participants to

potential harm and negative responses if shared among a broader audience (e.g.,[4][5]) and we had to be mindful of these considerations during our research.

Ethical Encounters in our Fieldwork

In this section we reflect on the ethical encounters in our fieldwork, with reference to specific examples from our interactions with participants. We draw on our experiences working closely with three housebound participants who live in Melbourne, Australia. Participants were recruited through a local organization that provides health services to disadvantaged people living in the area. The project received approval from the University of Melbourne's ethics committee before fieldwork commenced. Each participant is referred to by a pseudonym. One researcher (the lead author) attended all visits to participants; on two occasions a second researcher attended. However, we use the plural first person when describing our encounters.

Location of research
Qualitative researchers working in sensitive settings have noted the importance of location when working with vulnerable participants ([3], [12]). When we meet participants in their own environment there are opportunities to build rapport and empathy that may not be as easy in other locations [12]. However, this creates challenges of role conflict and managing the relationship between researchers and participants, which can become complicated if participants come to rely on researchers for support [9].

Housebound people with limited family support may be socially isolated; visitors to their homes could be limited to professional support staff and the presence of a researcher can become very significant; the

researchers may become confidants with whom participants share very personal details of their life [9]. Indeed, in our project the aim was to give participants an opportunity to share their stories. Doing this in the home environment was both rewarding and challenging. One participant, Brian, said on arrival that he was unsure if we were coming (although we had left messages) as his phone had not been working for over a week. We spent the first part of our meeting reconnecting Brian's phone. This helped to build trust and rapport and set the tone for subsequent visits when we would help with other matters. This reciprocity is important for creating a productive research partnership [1] but sometimes it can be difficult to determine how much researchers should intervene [6]. In addition, participants may expect ongoing support from researchers. We experienced this with Brian who commented during our third visit that he thought he would never see us again. There was a sense that he was hoping we would return. Such interactions present difficult responsibilities for researchers who, due to limited project resources and the short-term nature of the work, are unable to commit to visiting participants on a long-term basis [3]. It is important in these circumstances to collaborate with health and community care services, to ensure that vulnerable participants have access to ongoing support as needed (as discussed further in [14]).

When visiting another participant, Fiona, for the first time, we encountered her in the middle of an angry telephone conversation with a public housing representative. We sought to wait outside, but she insisted we enter so we tried to give her an element of privacy but this was difficult in the small space available. We then suggested we postpone the visit, but

Fiona was adamant she wanted to continue at that time. We offered to make her a cup of tea to help her regain her composure, but realized this may have been construed as an overly familiar gesture; not everyone is comfortable with visitors making themselves at home in your kitchen. This anecdote highlights one of the challenges of conducting research in the home. When researchers enter participants' homes, roles can become blurred. We entered Fiona's home as guests and strangers, but were privy to a difficult and upsetting conversation and felt we needed to offer support. In doing so, we had to become familiar with the domestic space and play host, rather than guest.

It can be challenging in the home environment to maintain boundaries around the research. When researchers have access to private domestic spaces, participants might inadvertently reveal more information about themselves than they would in other settings. The presence of family members, too, makes it difficult for researchers to ensure participants' confidentiality. On one occasion we visited a participant to review her digital story while her husband and daughter were present. Wendy wanted her family members to view the video with her but we felt it should be viewed privately first. The presence of Wendy's husband was problematic, as elements of their life together were touched on in the digital story.

We were acutely aware that our presence in people's homes was significant. Each participant wanted to present their home in a positive light and had arranged artefacts that they wanted to bring to our attention. How their home was captured and presented in the digital story, then, was an important element of trust in the relationship between researcher and participant.

Timing of the visits
Qualitative researchers "go into other people's lives, sometimes at a time of crisis and stress, and we ask them to talk in detail about their experiences" [3]. We did not set out to enter our participant's lives at times of crisis, but found that the timing of our visits – although planned in advance – inadvertently raised challenges for managing the emotional impact of the research. Our visit to Fiona clearly occurred at a difficult time. For Brian, the visits coincided with times when he was in need of practical support and feeling vulnerable. Our third visit to Brian occurred ten days before Christmas. The visit was punctuated by his attention to the television, which was showing a news item about a terrorist siege occurring at the time. Brian was concerned for the hostages, and wanted to talk about this. We felt this event may have left Brian feeling more vulnerable. Occasions such as Christmas can be a particularly difficult time for socially isolated people [13]. We knew Brian would be spending Christmas alone, as he had commented on this in his digital story ('family and friends are very important – but I've got neither' and 'Christmas's are very cheap!'). We felt uneasy leaving Brian that day. HCI researchers working in sensitive settings may not always feel fully equipped to offer the support participants need [7], which can present significant emotional challenges for researchers [8].

For Wendy our visits coincided with significant stages in her health trajectory. During the second visit, Wendy explained she had been diagnosed with terminal cancer. This was obviously an extremely difficult encounter for all involved. Reviewing her completed digital story was an emotional experience; Wendy found it difficult to view herself when well ('it looks like

a different person'), and her illness meant the digital story took on a new significance for her, becoming a legacy to leave for her family.

Each visit had been arranged with participants in advance and at their convenience, in line with the research process. However unforeseen circumstances influenced the ensuing interviews and digital stories, and impacted on the interactions between researchers and participants. While some of these events could not have been anticipated (e.g. national televised events, diagnosis of terminal illness) we were keenly aware of the significance of Christmas for our participants. Recognizing that timing presents ethical challenges, other researchers are investigating alternate methods for negotiating the timing of interviews with vulnerable people [10].

Personal nature of digital storytelling
The personal nature of digital storytelling often presents challenges for researchers [5]. In this project we aimed to enable participants to create the stories themselves using iPads, with some support from the researchers. This plan had to be revised once fieldwork commenced and it became apparent that participants preferred to tell their stories to the researchers, using artefacts and objects from within the home as a focus, in a video-recorded format. These recordings were shaped and edited by the research team and reviewed by participants to ensure they included the topics and photographs that were most important to them. Although participants were engaged in this process, in future work we would like to explore ways of enabling people with limited mobility to create, edit, and share digital content themselves. Creating the digital stories involved more of our input than we had anticipated,

giving rise to complex ethical issues regarding the relationship between researchers and participants, and the potential for power imbalances to come to light.

The aim of this project was to explore opportunities to build connections within the community for people who are housebound. Therefore the stories were being created to be shared on an interactive display that was to be shown in an empathetic local community setting (at the Open Day of the community health organization with whom we were collaborating). Because the stories were to be shared in public, choosing the content posed significant ethical challenges. We excluded footage that discussed family members as these people had not given permission to use their names and stories. This highlights issues of informed consent with non-participants. Visual anthropologists and sociologists have discussed these issues in relation to visual research, which may be particularly prone to the risk of identifying and referring to nonparticipants [15].

When making editing decisions, we drew upon our collective sense of responsibility to present participants' experiences in a way that would be true to their stories while not exposing them to potential harm or negative responses when shown in public. Brian's video posed the most challenges as he had a very colorful life and wanted his story to be 'warts and all,' saying that 'if I can survive my life anyone can survive theirs'. We excluded topics we considered too personal for a public audience and realized in this process the enormous responsibility that resided in our role as researchers. These challenges are common in digital storytelling projects, particularly when creating highly personal stories about sensitive topics ([4], [5]).

Conclusion

Our experiences show that the timing and location of interactions with housebound participants, and the personal nature of participants' stories, present ethical challenges that highlight the need for great sensitivity when conducting research with vulnerable groups, as well as the need for researcher care and ongoing support for participants. When the research involves creating content that is to be shared in public this adds significant ethical complexity and requires constant reflection about the aims and approach of the research.

Acknowledgements

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