The Ethics of Care Home Research

Marianne Dee[1]

[1]University of Dundee,
SSE, Queen Mother Building
Dundee DD14HN UK
m.b.dee@dundee.co.uk

Vicki L. Hanson[1,2]

[2]Rochester Institute of Technology, GCCIS, IST
20 Lomb Memorial Drive
Rochester, NY, US 14623
vlh@acm.org

Abstract

Despite extensive previous experience with community dwelling older adults, our research in current work with care home residents has created a number of unanticipated emotional issues. In this workshop, we share some of our experiences as they affected members of the research team, discussing, in particular, topics related to the psychological wellbeing of researchers and understanding our roles within the boundaries between residents and care staff.

Author Keywords

Care home residents; care home visitors; interviews.

ACM Classification Keywords

K.4.1. Computers and Society: Ethics.

Introduction

For the past few years we have been engaging in research "in the wild" in care homes in the UK. This work is part of a project funded by the Research Councils UK to better understand the built environment in such facilities.   Specifically, the work aims to understand aspects of the built environment that affect residents' physical activity and social interaction [1]. In understanding the living situations of the residents, members of our research team have been dealing with important considerations related to these facilities, which function simultaneously as the home of residents and the workplace of care professionals. Working in this situation has caused members of our team to reflect on many ethical issues.

We were aware going into this research that we would be confronted with ethical issues of consent to participate. Surprising to us, however, was the extent to which researchers experienced emotional and ethically challenging issues in the performance of their data collection for the work.

BESiDE research has been conducted in care homes beginning in 2013. We acknowledge that the local context for this research in the UK may differ in some respects from care home / nursing home environments in other countries. We believe that our researcher experiences, however, are similar to that which would occur in many care settings worldwide.

At the outset, we should state that the work to be discussed here involves interviews and observations. The full BESiDE project had several parts: qualitative work involving interviews and observations with architects, care home visitors, care home staff (both management and the day-to-day care providers), and care home residents; quantitative work using sensors to monitor physical activity and aspects of the care home physical environment and social interactions. The present report is related to the qualitative interviews and observations with visitors and residents.

Background on working with older adults
In previous work we actively promoted working with representative older adults through a User Pool of potential participants, mainly consisting of people aged 60 and over [2]. This pool was built up in advance of research studies through establishing links and contacts across different communities and neighbourhoods. Our experience in working with a wide range of researchers and older adults was that researchers can feel ill prepared for working with older participants. This can be problematic for both the participant (already at a disadvantage in the face of university expertise in a highly technical subject) and problematic for the effectiveness of the research study.

For many of our older participants in the research pool, the university setting, the methodologies, and the level of communication and interpersonal skills of the researcher had the potential to impact on the study results. Sensitivity to participant needs, therefore, was considered key to successful research.

The population of community dwelling older adults in that work typically were not vulnerable. We should

note, however, that there were occasions when an individual would arrive to participate in a study and it was clear that they were confused or otherwise not cognitively able to participate in the study. The user pool manager, who typically greeted participants, would talk with these individuals, thank them for participation through the gift certification given for taking part, and ensure that no data collected from these participants was used.

In this workshop, however, we consider a population for whom more than communication and interpersonal skills are required. As indicated, we have been surprised at the extent to which researchers have been drawn into the lives and the personal circumstances of the residents and those who interact with them. We here present some stories from our experiences and reflect on what this means to us as researchers.

We focus here on issues previously raised by Moncur [3], Waycott et al. [4] and Vines et al. [5]. Fleshing out these issues with specific stories and how such issues were addressed by the researchers. The emotional impact of working with vulnerable individuals is rarely offered in HCI training. Researchers can be unprepared for difficulties encountered by their participants. They can also be unprepared for degenerative changes in research such as ours that occurs when testing over extended periods of time. We relate here a couple of stories that give focus to the types of issues faced by our researchers.

Consent to participate
In going into this research, we were aware of the fact that there would be considerations in our university's review of ethical applications due to working with

participants whose ability to give consent can be unclear. There were potential Informed Consent considerations related to possible perceived coercion (as residents are 'at the mercy' of their caretakers) as well as cognitive ability to give consent. In these issues, we were informed by those who have come before us and have worked with vulnerable populations. Our university has a long history of working with vulnerable participants, and their feedback greatly guided us in obtaining approval for the research.

In our case, when appropriate, Informed Consent was required from the responsible family member. We also obtained consent from participants. We note that much of our work required multiple encounters with participants on multiple days. Given the nature of the residents' physical and mental abilities, their ability to give consent could vary from day to day. Thus, a researcher could be prepared and arrive at a care home ready to conduct research on a particular day, only to become aware in talking with the participant that this day they could not consent. On such days, the research did not proceed.

Engaging residents in the research
As we visited the care homes and spoke to residents it became clear that if we were to engage the residents in discussions about our research questions we would have to think more creatively about ways in which to capture their opinions and their experiences of living in the home. Many of the more cognitively able residents had developed a level of withdrawal in their approach to 'survival' in the care home; their body language and facial expressions often blank and distant. Through engagement we discovered this seemed to be a form of self-preservation, a safeguard against disappointment if

the person approaching was not for them. Poor vision played a part but we experienced a transformation in demeanour when we attended to them. For the less sociable researcher a resident's remoteness could be difficult to overcome. We needed to discover how to create a space where they would want to talk to us in the first instance and after that, find out how to create a context that helped them focus on the research topic. Their priorities were specifics, like visitors, getting to the toilet and having *'something to do'*, not the factors that enabled these specifics. We were also very conscious that for them, we as academic researchers were to all intents and purposes, ephemeral and 'just another person passing through'. Why should they be interested? Thus in even being able to have reasonable conversations about our research topics, researchers invested many hours simply visiting the care homes in advance to chat with residents and become familiar and trusted faces in the home.

Psychological Wellbeing of Researchers
Going into this research, no one on the team considered the possibility that the research team would be psychologically affected by the stories of the residents and those who surround them. While most of us had either had some family or other personal involvement with care homes, our thinking was that our experiences were deeply related to our own personal family and friends. We did not anticipate the extent to which we would be affected by the personal circumstances of people we did not know in advance. The residents, their family, and their friends all deeply affected us.

Stories from the Care Homes

It was the former 'relationship building' which exposed us to our greatest emotional challenges. It led us to hearing their stories, revealing many personal anxieties which were difficult for us to manage as we could sympathise but had no way of resolving: One of the residents was a very articulate former professor in medicine who had led a very active life and especially enjoyed a daily hike but felt trapped in the home and spent the entire day walking around the small garden. One woman reported that all she wanted was *"a long lie"* but the *"care home rules"* meant she had to be up and have her breakfast at a certain time every day. Another resident described how she loved reading but couldn't read downstairs (due to lack of light, noise levels and appropriate seating) so she went to bed early to read. Another reported that she wasn't allowed to have *"a good hot cup of tea"* the way she liked it in case she spilled it and burnt herself. She hadn't had a cup of tea to her taste in over 12 months. One woman reported missing her dog thinking that cats might be a good idea in a care home. When we asked her why, she replied: *"It's someone to love you isn't it?"* Another resident was angry about the rules regarding toilet access. She had to wait all the time and felt she was constantly arguing with staff about being able to go when she needed to. She saw it as the rules of the home*: "you can only go when staff say you can go".* She was immobile and thus dependent on two members of staff taking her to the toilet. Staffing numbers meant she nearly always had to wait despite staff reporting that the reason she had to go often, was because she is prescribed a daily diuretic.

Such stories appear to reveal small issues but for the residents they were important. As the stories built up over time the researchers began to identify with these small daily deprivations. We became very aware of the awful lack of control people had over the most simple of things.

Coping with these emotional issues

In working with a care home population, it is apparent that the death and degenerative conditions of residents can take a toll on researchers [6]. What we relay here is that even in small ways the continuous interactions with residents can also take its toll. There is the shock of some of the situations and the build up of a large number of these 'smaller' incidents. And, in the end, there is the guilt. The guilt that at the at end of the day we are able to go home. And there is the lasting guilt that at the end of the project we leave. Having built up trusted relationships with residents, ultimately, the researchers leave.

To deal with the emotional impact on researchers, our university offered six counselling sessions for each of the researchers involved. Not all researchers used all six of the sessions, but researchers did avail themselves of these services. The counselling was helpful and may be something that other researchers in these environments should consider.

Boundaries in the Unique Home / Work Environment

A care home represents an interesting situation in which the dwelling is the home of residents, while being the workplace of the staff who care for the residents. This paper does not consider issues that affect care staff. However, we do note that this dichotomy between home and work has the potential to influence dynamics. While the facility may be the home of the

residents, it does not enjoy the personal, private considerations that are typically afforded of someone in their home.

Story 1
There is an instant realisation of independence versus dependency when talking to care home residents. It is the first thing they refer to and you become aware of, and self-conscious about. The stark contrast of an adulthood with choice and control, which the researcher enjoys, as opposed to the residents' complete dependency (where food, drink and even toileting can be determined by the care home timetable) becomes very conspicuous. We were present when two cognitively able, but physically immobile, residents constantly and plaintively called (for more than 20 minutes) to be taken to the toilet. During that time the researchers also felt obliged to make staff aware that residents wanted the bathroom and were told they would be taken in time. The residents could not focus on any interactions with us and we were helpless. We felt we could not walk away yet, legally, we could not help.

Although our research is not about the quality of care or the organisational culture, the management of a home and the work of the care staff does impact on how we are able to conduct our work. How at ease both we and the residents feel, had an impact on their feedback and our findings.

Story 2
Relationship building and becoming 'familiar faces' in the home was an important aspect of the work. An issue in one home was how to engage in conversations in a setting where all the residents sat in one living room arranged around the walls, with no social seating for visitors. To create a social situation required help from care staff to move the resident elsewhere for a chat. In moving the resident we were conscious that this was both an upheaval for the resident and extra work for the care staff. The use of hoists to move immobile residents is not a pleasant experience for the resident and a primitive scene to observe. In one case the worker brought the wrong wheelchair so that the resident was literally hanging for what felt like ages, but probably minutes, in the most distressing fashion while the correct chair was found and we waited and tried not to watch. The resident's response was just a heavy sigh and much head shaking followed by a deep breath. When we were settled she said it wasn't unusual and if she thought about it too much it would upset her, so she doesn't. Anyway *'they are doing their best'* and she *'has to make the best of it'*. We followed her lead and moved the conversation on. However that scene has replayed in our minds many times since. The hoist experience in any circumstances is at best undignified and at worst uncomfortable but when she was left hanging it was both of these things and humiliating for the resident. Yet we were equally aware that the finite staff resources working long shifts and spread thinly across a population of very dependent residents plays an equal part in such events.

Researcher dependence on care staff
These stories show examples in which researchers experienced concern about resident and staff interactions. While researchers might have wanted to comment to the staff, we were cognizant of the fact that we were very dependent on care staff for access to residents. In short, it was important to keep the staff

on our side. Positive and respectful interactions with care staff are crucial to keeping the door open for a return visit and we always needed to return.

As researchers, we walk a delicate line. The natural desire is to step in to try to help residents in need. Sometimes for legal reasons (such as if our helping someone walk might result in a fall) and sometimes for 'political' reasons (we are dependent on the staff for providing us access to residents), as researchers we often are placed in awkward positions.

Summary
We discovered that despite extensive reading of both social sciences and previous HCI work with older participants nothing prepared the researchers for their experience in the care homes. Every care home encounter we experienced, both good and not so good, left us physically and emotionally exhausted even after becoming familiar and regular accepted visitors over a full year.

Acknowledgements

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