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'Just Passing Through': Research in Care Homes

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The ever-increasing need for care beyond what can be provided by one's family is causing an explosion in the number of residential care homes for older people with formal care needs. We use the term *care home* generically to include care facilities that provide a range of services, from cooking meals to full nursing care. Regardless of what services they offer, these facilities serve the dual purpose of home for residents and workplace for care professionals. This situation creates complex dynamics and contextual challenges for HCI researchers.

During the two years of our research, we have worked in 10 care homes in Scotland and England. Our research goal has been to improve understanding of those aspects of the built environment that affect residents' physical activity and social interaction [1]. Our research involves ongoing, long-term case studies with care home managers, nurses, senior care workers, and care assistants. Our methods include observing activity, co-design activities, supported conversations, interviews, and movement tracking using sensors. Many homes were involved in more than one of these studies, which involved different sets of researchers. We present here some of the researchers' stories and reflect on their experience with a particular focus on issues that influenced our ability to recruit and work with residents of the care homes.

Management Influences on Daily Patterns in Care Homes

The atmosphere and ambience of each care home is strongly influenced by the manager's vision, energy, and enthusiasm. Care home schedules can be difficult to navigate, as they vary markedly depending on the home's pattern of daily activity. At one extreme, the needs of the workplace appear to take precedence when setting schedules, while in other homes, residents seem to retain the kind of flexibility they had when living independently. The pattern in one home was that visitors only come after lunch, as mornings are taken up with getting people up, washed, fed, and dressed. In other homes, managers recognize that some residents have more energy in the mornings and that their visitors are early risers. They encourage activities and social interactions throughout the day so normal life is emulated and visitors can take breakfast with their residents. Although the timing of activities in the homes is just one example, the key here is to note the differences. Research teams needed to be sensitive to these differences and orient toward the manager's perspectives on them. As management changed, so too would the norms to which the researchers had become accustomed, a challenge for a team doing long-term work in a high-turnover field.

Reliance on Care Staff in Recruitment of Residents

To address some of the issues inherent to a home environment somewhat dominated by a workplace culture, we sought to understand the views of residents specifically. However, care home management understandably requires that recruitment happens under their auspices. In some cases, these were private-sector care home providers owning an increasing number of care homes throughout the region; in other cases they were managers of individual independent homes. In all cases we needed to continually work with managers of individual homes to ensure their cooperation and understanding. We were reliant on the care home manager's knowledge to identify residents

who could give consent to participate and were most appropriate for the requirements of the research [2].

Communication proved our biggest challenge. We found that neither staff nor residents engaged with the detail of the research studies, despite efforts to make them short and succinct. For example, when recruiting participants for a study involving sensors, explaining concepts involved in wearing the small sensors, the types of data we would collect, and issues of confidentiality was daunting.

Lack of understanding had the potential to create misconceptions and unmet expectations. In some cases, it led to mistakes such as recruiting residents who were actually ineligible for the study in some way or another. Similarly, during the consent process, participants' patience and interest were challenged both by terminology and the length of our initial consenting process. To address this, we reduced the information to an A5 postcard, using images, a larger font, and short sentences for a friendly and accessible means of conveying information (Figure 1). For informed consent, we used straightforward bullet points to highlight the conditions of participation.

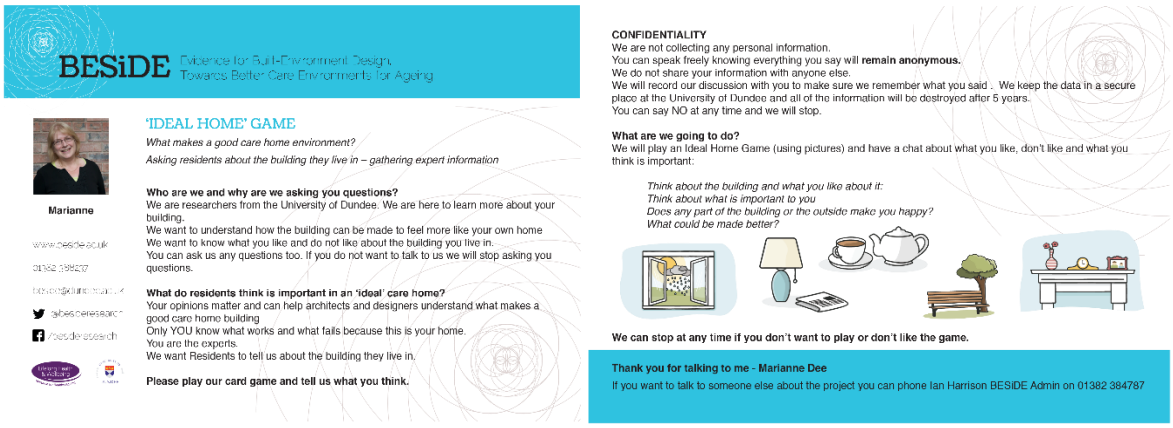

Figure 1. An accessible information card for resident participation.

Relationship building with the care home management as workers was crucial for our ongoing research. We used two key people as main contacts to sustain relationships with the managers. This facilitated communication based on trust and shared understandings.

Having solid, productive relationships with managers greatly reduced the barriers to entry. Anyone who has done fieldwork in research or attempted to sell a major system in industry recognizes the importance of these kinds of relationships. A managers' influence has major implications for anyone doing such work. Low enthusiasm for our research meant less engagement by other care staff. The understanding and cooperation of all care staff was important to enable our progress: from identifying potential participants to finding a space for conversations that didn't impede their work. Too much enthusiasm could, on the other hand, be deemed coercive. What is interesting here is the

role of managers and staff, and how the *workplace*, might influence our ability to gather data and conduct research on a *home* experience, albeit an institutional type of home.

Respecting the Residents' Home

While the care facility is the residents' home, it usually lacks the personal, private considerations typically afforded someone in their own home. People come and go continually, and unlike a private home, not everyone introduces themselves or even acknowledges they are in effect in someone's living room. Residents are often dependent on the care staff to move them to a quieter place, and in some cases their institutionalization may affect their capacity to make a decision at all. Residents indicated that they are acutely aware that they have little choice or control. Depending on their care home facility, they sometimes cannot even act as host by offering a cup of tea [2]. As researchers, this tension around dependency is an important issue in the consideration of our empirical data, as well as in the design and implementation of interventions. Certainly, the researchers are able in many ways to do things that residents cannot. We visit and we leave, while residents remain dependent on the help of others. On the other hand, our work success lay in the hands of both the care staff and the residents. In this environment, if we are appropriately self-reflective, we can actually encourage and empower residents. However, we must monitor closely the deference that residents pay to clinical staff and to the research team to the degree that we become perceived as part of such staff.

Over time, this tension became increasingly uncomfortable. We came to realize that our sudden appearance must have felt like a cold call that the residents could not avoid. To counteract this cold-call effect, we prepared for studies by leaving publicity in the home. This included photographs of the researchers, along with brief descriptions of the upcoming studies. We visited in advance to socialize. Thus, our faces were familiar to our residents when we began our studies. From our perspective, advance knowledge about a person's habits and preferences helped us better balance their personal needs with our study needs. We understood that for this target group everything takes much longer; for example, the time it takes before a meal for residents to fit in a bathroom visit and travel time to get a favorite seat in the dining room. Sensitivity to daily habits and preferences created a more comfortable exchange but made our research schedules a balancing act. Trying to schedule activities in short bursts could be stressful for the researcher but was better for the resident.

Given these challenges, one might wonder why residents participated at all. When asked, their responses varied from "something to do" to being "interested in new things" and that they enjoyed meeting and talking to new people. Overall, we found that the care home residents enjoyed social interactions, being given an opportunity to talk, reminisce, and have someone listen to them.

Figure 2. Researcher interactions with a care home resident.

Addressing the Researcher's Workplace

We have thus far described the ways in which care homes are workplaces for caregiving staff and homes for elder residents. Notably, however, during the two years of this project, the homes also became the workplace of our research team. The team had conducted prior work with similar populations [3] and prepared through literature reviews, and in-depth discussions to do work in care homes. However, little can prepare a person not typically accustomed to working in these environments for the experiences we encountered. Balancing the norms of a home with those of a workplace, the needs of the research with the needs of elders, and the general strain experienced by witnessing first-hand the challenges of eldercare (e.g., physical restraints, cognitive and emotional decline), can be extraordinarily tough.

Increasingly, HCI researchers and designers are moving into spaces that are emotionally fraught, physically dangerous, or both. Health and wellness are key issues that affect us all, and the area of interactive systems for health is fundamentally important going forward. As is best practice in fieldwork, we kept study diaries discussing care home visits so that regular debriefings and reflection became a central part of our personal and team processes. Some of the research team sought counseling support from the university to deal with concerns [4]. Over time these debriefings greatly added to our understanding of working in homes and ways we could improve some interactions. The kinds of things that ethnographers and social workers have been doing for decades and must become more central to our research practices. To further address the imbalances we began to

perceive over time, the research team also invested many hours visiting and chatting to become familiar and trusted faces in the home.

Summary and Conclusion

We found our work with care homes to be challenging on levels we hadn't anticipated despite our previous experience with older adults. Each care home is a self-contained world, and this individuality can create logistical challenges for researchers learning to tune into the social mores of different homes. They share, however, these dual roles of *home* and *workplace*. By explicitly engaging in these spaces as *workplaces* for caregivers and researchers and *homes* for residents, we could more easily balance the ethical requirements due to each stakeholder. In particular, we worked to treat residents and their space with the respect of a home while maintaining institutional boundaries required of the homes as workplaces with its organisational and task driven culture. Time spent in the homes led to warm familiarity among residents and researchers, with some of these relationships lasting long after the studies concluded.

This is not to say that we have addressed all the challenges. Indeed, many have come before us and found some of the same solutions we describe here [5] and left open some of the same challenges we experienced. In particular, we find that the flow of the research cycle can be daunting to people who are not accustomed to doing this kind of work. The regular appearance, disappearance, and reappearance of the research team over a long-term project that includes iterative design and installations can look haphazard at best and at worst like abandonment to residents. During these gaps, when researchers do not *have* to be on site, we therefore recommend *choosing* to be on site instead. This kind of engagement can be in a volunteer capacity or simply as social visits. The key here is that relationships cannot stop and start only when the technology is deployed or data is being collected. It is important to maintain momentum in the home throughout the research study. Both residents and staff should feel included and informed in ways that respect their homes and workplaces alike, and not just when the researchers need their spaces to be their workplaces.

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Insights

- Care homes are unique environments where *workplace* and *home* operate in tandem under one roof. This dual environment creates research challenges when navigating the norms and mores of the workplace whilst maintaining the etiquette of visiting a person in their living room.
- Reflective Practice proved inordinately helpful in ameliorating the emotional challenges of such research
- Long term engagement with residents in a volunteer capacity or through social visits can facilitate research encounters.