

Community in dementia care and the role of familiar technology

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Abstract. People with dementia living in publicly-funded long-stay units constitute an in-between community: one whose members do not (typically) wish to reside alongside one another, but whose circumstances dictate that they must. This paper discusses, with reference to a longitudinal ethnography exploring life in dementia care, the tensions which are created by this sort of in-between living, the novel ways of being which community members negotiate with one another, and ultimately, the potential for moments of connection and belonging in community, which are, in the care unit, very often mediated by everyday technologies such as television and music players.

1 Living with transition

Common conceptualisations of community entail a group of people who are united by common interests or circumstances; moreover, the word can carry a connotation that the community itself is something that is valued by its members or something which is entered into voluntarily. In terms of HCI projects interested in community life, McCarthy & Wright (2015) warn against reified notions of community – community, they suggest, is constituted by the lived experiences of its members, in the ways of being which these members perform, always in dialogue with each other. Using Probyn’s notion of ‘outside belongings’, they describe how the experience of belonging in community is often one which is more complex than a notion of being on the ‘inside’ or the ‘outside’ – an experience of life in community may see people living ‘in between’, instead.

Unable to live independently or with families or friends, people with dementia are often placed into care as the condition progresses. In Ireland, a large percentage of those living with dementia who do not live at home live in publicly-funded care units (Cahill, O’Shea & Pierce, 2012), which are typically not built for the purpose of housing those with dementia, and which, in recent years, have suffered from a lack of resources. Although such care homes tend to provide a safe, warm environment, concerned with the health of its residents, and offering appropriate medical care, life in such situations can be dissatisfying for people with dementia.

One of the primary issues with life in care for people with dementia is the experience of living communally with strangers, usually for the first time in their lives. Compounding this experience is the nature of the condition itself: not only are residents waking up every day in an unfamiliar environment, surrounded by others, but the cognitive deficits inherent to the condition mean that residents also do not tend to have the ability to remember where they are, who these strangers are, and thus life in care can occasionally be alienating, distressing and unsatisfying. In this setting, although these residents are indeed a group of people united by several similarities – age, disease, and most notably, geography – and who spend much of their lives alongside one another, it is difficult to consider them as a coherent and conventional community.

2 Life in care: insights from the literature

Previous ethnographic research into the lived experience of residents of dementia care indicates that residents of care homes can often, at first, be unhappy with their placement in the care home, resulting in a period of restlessness which can last several months and see the resident engaging in ‘challenging behaviour’ – in particular, an often incessant search to escape the unit (Amieva et al, 2010). This period is also characterized by a lack of engagement with other residents, or indeed a sense of exclusion from other residents; however, after some time in the home, residents tend to acclimate somewhat to life in care. A paper by McColgan (2005) describes how residents in dementia care use creative ‘resistance strategies’ to navigate a life in care that’s lived communally and not necessarily under their terms. This includes pretending to be asleep in order to not have to talk to certain people, refusing to characterise themselves as belonging to the care home, and claiming certain space in the home for themselves.

Much research on social interactions in dementia indicates that having a healthy, active social life (including meaningful participation in community life) is protective against dementia (Padilla et al, 2013); however, relationships tend to dissolve after a diagnosis of dementia, which has led many researchers to conclude that people with dementia suffer from deficits in social cognition which render the formation of new relationships extremely difficult if not outright

impossible (Snowden et al, 2003). Research such as this suggests that life in care may be bleak indeed; however, work by Sabat & Lee (2011) challenges the notion of a deficit in social cognition and instead posits that relationships in dementia are simply experienced and formed in different ways than before the condition. They illustrate this with evidence from an ethnographic study of life in a care home, where two female residents form a sustained companionship which is enacted in unconventional ways – for example, these ladies do not know each other’s names, but save seats for each other at teatime as a matter of course. Meanwhile, other residents enact community, but in performative, ineffable and less explicit ways – one resident apologises for blocking the view of others at a film screening by miming sawing off her head, for example. However, social life in dementia care can lead to the formation of in- and outgroups: research by Sandhu et al (2013) has indicated that relationships in dementia care form along lines of ‘functional similarity’ – that is, residents who are at similar stages of dementia will tend to form relationships, while those whose dementia is more progressed will be excluded.

Some design research has attempted to engage with the problems that are often concurrent with living life in a nursing home – projects such as the Photostroller (Gaver et al, 2011) and the interactive art exhibition Tales of I (Wallace et al, 2012) have created technologies which aim to facilitate and create spaces for sharing and ‘chat’ for people living in nursing homes. The project that this paper begins to describe builds on the knowledge these contribute, but in contrast to these papers, this project is interested in naturally occurring moments of community for people with dementia in the nursing home, informed by extensive ethnographic research. Such an understanding will serve to enrich any future design research in the home with a fuller understanding of configurations of community for these residents as it existed prior to any design intervention.

Being with others at this time, as mentioned above, is particularly difficult: not only is it a time of illness, and for many, a time of separation from family and friends, but, with the transition into care, it is also now a time of change and upheaval – leaving a family home to live communally with strangers. Literature indicates that this does not necessarily mean that the experience for every resident is a lonely one; however, work has tended to focus on single experiences or on ‘pockets’ of relationships in care. The remainder of this paper will discuss a doctoral research project exploring the experience of belonging in dementia care with regard to residents’ participation in community, how this sense of belonging and unbelonging in community unfolded and ultimately how it was facilitated through the use of everyday technologies in the care unit.

3 Method

3.1 Setting

The dementia care unit ('St Eithne's') involved in this study was a publicly-funded long-stay unit in a community hospital. The ward consisted of a large parlour and a day room, two outdoor gardens and two communal dormitories where residents slept. Throughout the course of the ethnography, 8-10 full-time residents lived in the unit, with 3-5 day residents visiting for 6-8 hours a day, 2-3 days a week.

3.2 Design

This study used ethnographic methods in order to capture a deep insight into life in dementia care. I entered the care unit for 4-6 hours, 2-3 times a week across a period of about a year (2013-2014). In these settings, observations were made of daily life, carers were informally interviewed, and creative workshops were held within the unit.

4 Enacting community in dementia care

The following sections will detail some of the thematic evidence which emerged from the research concerning the experience and enactment of community life in the dementia care unit.

4.1 Community as given: tacit responses to communal living

Although some residents (particularly new and anxious residents) were occasionally dissatisfied with life in the care unit, as a whole, residents tended to 'get on' well with each other. Although there were occasionally certain underlying tensions regarding some aspects of communal living (i.e., sharing a dormitory) or carer intervention (i.e., being helped to bathe by a carer), the mood of the unit was seldom adversarial or unpleasant.

Instead, the 'feel' of life within was one of quiet amiability – residents tended to co-exist with one another happily enough, but did not often engage with one another beyond everyday chat. Most days were spent passively, watching television for much of the day, or occasionally carrying out group activities organised by carers (i.e., painting or baking). Residents would also display social niceties to one another – for example, one resident would pull a chair out for another to sit in, would say 'please' and 'thank you', and at mealtimes, residents

would ask to be excused from the table. Although such interactions may not seem particularly communicative, they are indicative of the sort of community which residents saw themselves engaged in: one which is respectful to others, but not necessarily close.

4.2 Friendships formed in dementia care

Despite this lack of closeness in everyday interactions between residents, certain friendships did form in the unit. Perhaps the most developed friendship I witnessed during my time in the unit was one between Val and Moira, two female residents who had been in St Eithne's for several years by the time I entered the setting. Moira was a particularly nervous resident – she withdrew from almost all social interactions with other residents, and having become settled in the unit, disliked change in her environment. Val, on the other hand, was a vivacious resident who easily engaged in chat and prized her independence. Nevertheless, Val would 'take care' of Moira in many ways – she would gently coax Moira into participating in larger group activities, but if Moira were unwilling to engage, she would remain sitting with Moira to provide companionship. The two sat together almost every day, and Val would frequently read aloud the paper to Moira, who was had problems with her sight.

4.3 Unbelonging in the care unit

Much like the findings of Sandhu et al (2013), and although the mood of the unit was typically amiable and peaceful, certain residents in the unit faced exclusion from the larger group due to their dementia being at different stages, or due to behaviour that they exhibited that was strange or irritating to the larger resident group. This exclusion affected two resident subsets who, because of this, constituted de facto 'outgroups': those who were new to the unit and those whose dementia was particularly severe.

Residents entering the unit for the first time were often unsettled and frequently tried to escape the unit. During my time in the unit, one resident, Yvonne, was particularly affected by her move to St Eithne's, and would spend much of her day attempting to escape the unit, or believing that the unit was her family home and thus interacting with the unit as though it were her own house. This behaviour disturbed and irritated the other residents as she weaved behind their chairs to try windows and began to close doors so as to prevent her cat from getting out: the larger resident group would shout at Yvonne and tell her to 'get away', which upset and alienated her from the group further.

Residents whose dementia had progressed to a severe stage were also often excluded from the larger resident group due to difficulties in verbal communication; often, these residents had illnesses as well as dementia, which often saw their behaviour being similarly 'disruptive' to the status quo of the unit.

Early in the ethnography, one resident, Lizzie, was often in pain and would call repeatedly for the nurse; not understanding this pain, other residents would scold her for raising her voice and even threaten to hit her if she would not be quiet. Other residents who were blind or had trouble communicating verbally were not as forcefully excluded from the larger, more settled resident group, but nevertheless, did not participate in group activities as much, and spent a significant amount of their time alone, except for carers.

4.4 Community ‘moments’: music and togetherness

The previous sections have described the community of residents in the unit as a somewhat fractured one; although willing to engage in low-level community interactions, individual differences in dementia meant that meaningful participation was often experienced only in one-on-one interactions between smaller groups of residents. Although I had initially run some art workshops with residents, I found that residents did not tend to engage with these activities. During the course of the ethnography, however, it became clear that residents engaged much more with music than art: they both seemed to enjoy music much more and it prompted an engagement with each other that had been hitherto lacking. What is more, this engagement was facilitated and mediated by everyday technologies within the unit itself – a TV and DVD player combination as well as a music player as well as a small media library of about five DVDs and ten CDs. The final sections will briefly describe some of these interpersonal and community interactions that occurred within this space.

4.5 Group participation

Carers knew that music was important for residents, and thus would put on particular DVDs for residents almost daily. Music could enliven a previously passive room by virtue of the participation of some becoming the participation of all – one resident in particular, Claire, enjoyed singing along to music, but in particular, enjoyed encouraging others to do the same. She would cheer and applaud as residents listened to music, shout out ‘yoohoo!’, and attempt to get other residents involved as well. Though initially her behaviour seemed to be amusing to these residents, it would often spur them on to sing, cheer, and applaud in the same session.

Group participation in music sessions, however, could be something even more subtly contagious than the participation spurred on by Claire: once one resident began to sing, it was likely that other voices would join. This carried over into more subtle, bodily participation such as touch and tapping.

4.6 Tapping, touch and dancing

As verbal communication wanes in dementia, other forms of communication tend to rise to the fore. In the music sessions I observed in the unit, engagement with familiar music saw residents participate and ‘tap along’ using their fingers and their feet. During these music sessions, residents would tend to seek each other out by reaching for each other’s hands and swaying along to music.

Music also acted as a ‘script’ for activities and interaction which otherwise would not have happened in the unit – one day in June, Claire and another male resident, Larry, got up from their seats during a viewing of ‘Singin’ in the Rain’ to dance together for several minutes before collapsing into their seat and chatting for the remainder of the film. These two residents had not met each other before, and though Claire was enthusiastic about music, they were both typically introspective. However, music allowed for a performance space for the two which not only allowed them to engage in an activity together, but which also allowed them to connect afterwards.

5 Discussion and conclusions

There has been some design research that has centered around attempts to facilitate social connection in institutions meant for elderly people or for people with dementia; however, this research has focused on the creation of new technologies which, while offering several outstanding benefits in terms of the range of interactions possible, is still typically unfamiliar to residents. Beyond this, although these technologies often facilitate reminiscence, they do not tend to engage residents in participative activities and their use remains relatively individualised.

This paper positions people with dementia living in care as a certain kind of community – one, perhaps, which is occasionally fractured and whose members do not necessarily wish to live with one another. The following observations, we feel, may serve to flesh out the design space in these settings:

- (1) ‘Conventional’ community in care is tacit and performed by residents, but not necessarily felt or highly intentional;
- (2) Friendships can form – and persist – in care, but these friendships are unconventional;
- (3) ‘Unbelonging’ in community is frequently experienced by certain members of the resident group – however, this is something which shifts and changes;
- (4) Gathering around familiar technologies – i.e., music, television – is frequently active and participative for residents of care.

The importance of music for residents within St Eithne's became apparent very quickly. For this generation, it is likely that music, dance, and singing were activities which were much more common interests in their youth than photography and art, which are often the centre of participative HCI projects with vulnerable persons. Moreover, the fact that interaction in this 'musicked' space was mediated by engagement with everyday technologies (available in many such units) such as televisions and CD players has certain practical implications for further design.

With a lack of staff time and resources, it is possible that the mindful use of everyday technologies in publicly-funded care units could improve activation and participation in activities for residents who otherwise spend much of their time passive, alone, or engaged only in individual activities. Sensitive and experience-centered design of new technologies which retain the familiarity of televisions and music players yet which place an emphasis on forms of participation such as performance, group interaction, touch, and inclusion of often-excluded others might indeed be a fruitful avenue for designing to enrich the experiences of residents of dementia care.

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7 References

- Amieva, H., Stoykova, R., Matharan, F., Helmer, C., Antonucci, T. C., & Dartigues, J. F. (2010). What aspects of social network are protective for dementia? *Psychosomatic Medicine*, 72(9), 905-911.
- Cahill, S., O'Shea, E., & Pierce, M. (2012). Creating excellence in dementia care: A research review for Ireland's national dementia strategy. Retrieved from https://www.tcd.ie/Communications/content/pdf/Creating_Excelsence_in_Dementia_Care2012.pdf
- Gaver, W., Boucher, A., Bowers, J., Blythe, M., Jarvis, N., Cameron, D. & Wright, P. (2011, May). The photostroller: supporting diverse care home residents in engaging with the world. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1757-1766).
- Wright, P., & McCarthy, J. (2015). *Taking [A]part*. Chicago: MIT Press.
- McColgan, G. (2005). A Place to Sit Resistance Strategies Used to Create Privacy and Home by People with Dementia. *Journal of Contemporary Ethnography*, 34(4), 410-433.

- Padilla, D. V., González, M. T. D., Agis, I. F., Strizzi, J., & Rodríguez, R. A. (2013). The effectiveness of control strategies for dementia-driven wandering, preventing escape attempts: a case report. *International Psychogeriatrics*, 25(03), 500-504.
- Sabat, S. R., & Lee, J. M. (2011). Relatedness among people diagnosed with dementia: Social cognition and the possibility of friendship. *Dementia*, 11(3) 315–327.
- Sandhu, N. K., Kemp, C. L., Ball, M. M., Burgess, E. O., & Perkins, M. M. (2013). Coming together and pulling apart: Exploring the influence of functional status on co-resident relationships in assisted living. *Journal of Aging Studies*, 27(4), 317-329.
- Snowden, J. S., Gibbons, Z. C., Blackshaw, A., Doubleday, E., Thompson, J., Craufurd, D., & Neary, D. (2003). Social cognition in frontotemporal dementia and Huntington's disease. *Neuropsychologia*, 41(6), 688-701.
- Wallace, J., Thieme, A., Wood, G., Schofield, G., & Olivier, P. (2012, May). Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 2629-2638).