

Creative and Opportunistic Use of Everyday Music Technologies in a Dementia Care Unit

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ABSTRACT

This paper describes everyday technologies in use in a long-term dementia care ward, and ways in which these technologies facilitated creative expression for residents within. Drawing on ethnographic research focusing on participation in creative activities for people with dementia living in care, the paper details how residents engaged with technologies (such as television) in a passive way (spending hours sitting in front of the TV without engaging with others around them), and in an active way (singing and dancing to music played via stereo and record player). Findings from this research emphasise the importance for interaction design for dementia in appreciating the role of active creative participation in sustaining personhood in dementia. Given a lack of both time and resources in publicly-funded care homes, we also highlight the value of opportunistic design in the field.

Author Keywords

Ethnography; music technologies; everyday technologies; elderly; dementia; care; quick and dirty design.

ACM Classification Keywords

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

INTRODUCTION: CREATIVITY IN THE CARE HOME

Often suffering from a lack of funding, staffing, and general resources, publicly-funded dementia care wards can be experienced by people with dementia as unstimulating spaces [5, 8]. The transition from life at home to life in care can be difficult both for family who must make this decision as well as the person with dementia themselves: awakening each morning in an unfamiliar space; surrounded by strangers and by carers who (are obliged to) intervene in matters of hygiene and health, and often experiencing extended periods without meaningful activities in a (perceived to be) strange environment, this shift in lifestyle occurs at a time when the person is already experiencing significant changes in their own sense of

personhood, and it is a shift that can be very distressing for the person with dementia.

Extant research [2, 9] has indicated that rich and varied environments contribute towards neuroplasticity and are of potential help in supporting memory and through this, a coherent sense of self- and personhood. Many care homes provide art or music activities or therapy, and although these services are potentially beneficial for residents, in publicly-funded homes they can be difficult to procure. Moreover, many residents of care homes are unable to tell carers about themselves explicitly: without this communication, the activities these residents engage with may be unsuitable or inappropriate despite the best efforts of staff. The aim of the project that this paper begins to report is to understand how interaction design can contribute to identifying and supporting appropriate creative activities in residential dementia care.

Killick & Craig [4] offer some ideas on what it means to be creative in a dementia context. Creativity for people with dementia must give pleasure; this does not mean that we can ignore the very real struggles that come along with creating art in this context – issues with movement, with perception and organisation – but that these feelings must not be the overriding ones. The activity that involves creativity must be pursued and enjoyed for its own sake. Running concurrently with this is that creativity involves a making process. It may be an appropriation of raw materials – paper and paint into a portrait, flour and eggs into a cake – but the process must be pursued for its own end and also result in a ‘something’. In making something, the authors write that another vital characteristic of creativity is that it is expressive:

“Many people with dementia need constant reassurance that their selfhood is intact, and the exploration of feeling-states is helpful to that process.” (Killick & Craig, 2012, p. 14)

Killick & Craig differentiate between what they call ‘big C creativity’, where someone has spent much of their life devoting themselves to their craft and so identifies as an artist, and ‘small C creativity’, relatively everyday instances of creativity which every individual shows and which can be enhanced and brought out further by activities such as painting, singing and storytelling. This paper discusses

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instances of what Killick & Craig call ‘small C creativity’ which were observed during a year-long ethnographic study into a publicly-funded care home in the south of Ireland. These instances of creativity were notable due to the fact that they occurred not during creative activity sessions, but during the course of the day in the unit – despite the relatively impoverished space in the care unit itself. The space created by and during these ‘creativities’ was mediated by residents’ engagement with everyday technologies on the ward: notably the television, the radio, and a stereo player. The ultimate aim of this project is the generation of ideas for design to support creativity in dementia care, and this paper demonstrates how everyday interactions with these technologies might help us do just that.

METHODOLOGY

Design and analysis

This study used ethnographic methods in order to capture an ‘insider’s view’ of life with dementia in care. These ethnographic methods involved the lead author in a period of observation and constant involvement in the life of the research setting - entering the care setting 1-2 times a week for 4-6 hours across a period of 12 months. In these settings, observations were made of daily life, carers were informally interviewed, and creative workshops were held within the unit.

Field notes were taken briefly on-site and then written out in detail later that evening, and casual interviews and ‘chat’ were also transcribed later. Emergent data was analysed in the dementia care unit study using a method of Grounded Theory as laid out by Charmaz [1], where initial coding influenced iterative stages of the ethnography as the research itself narrowed down over a period of months and data saturation was reached.

Setting

The dementia care setting was a dementia-specific ward in a public community hospital (“St Eithne’s”). The ward consisted of two large ‘day rooms’, 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. Residents of St Eithne’s had to have received a diagnosis of dementia, and had to be ambulatory, in order to be placed in the ward.

Ethics

This study was reviewed and granted approval by the School of Applied Psychology’s Ethics Committee. Consent was assessed and gained using guidelines laid out by the Mental Capacity Act of 2005, and the Code of Professional Ethics of the Psychological Society of Ireland.

THE TEXTURE OF CREATIVITY IN CARE

The following sections will highlight how creative expression in the unit unfolded, mediated through the presence of, and engagement with, everyday technologies

in the unit itself. We will also detail an instance of low-level design in the unit. Finally, we will present a list of considerations and possible design spaces that are indicated by these instances of engagement.

Passive engagement: television as a ‘nanny’

Following a communal breakfast each morning, residents were led by carers into the day room. The day began with a Catholic mass, which residents watched on television. This mass was ‘piped-in’ from a chapel on the site of the community hospital situated less than 20 metres from the main door of St Eithne’s. Residents rarely engaged with the mass, and indeed most spent this time dozing in their seats, though still some others spoke the correct responses and blessed themselves at the right time. Most mornings, following this mass, were passed watching television – carers would rotate through a collection of about 5-7 DVDs, mostly old films, documentaries on old Ireland, or concerts. The effect of this was that each day was passed watching the same small selection of media. Carers also switched the television to terrestrial channels, and during this time residents could watch the news or soap operas. Although activities were scheduled for residents each day, these did not occur as per the schedule and so the main source of stimulation for residents was typically the television itself. Residents did not tend to engage with everyday TV – they would sit and seem to be watching, would not be able to comment on what they were watching when asked - but were often roused by the musical media.

In being roused by the musical media, residents engaged in creative ways within this creative space. In selectively responding to certain media above others, they expressed their own preferences, made their own choices and seemed to experience a sense of joy, participation, and pleasure that allowed them to (in creative ways) connect both to other people in the unit as well as to a past sense of self.

Connection through music: dance and touch

As a researcher in the context seeking ‘ways in’ to the experience of others, observing residents’ interactions with music allowed the lead author to identify the music which each resident particularly enjoyed. She was then able to turn this music around and use it as a way to connect to residents who were otherwise somewhat unresponsive or reserved. Moreover, residents themselves could connect to one another and perform during these moments as well. These moments were just that – opportunistic and immediately creative – and were made possible by residents’ willingness to engage with technologies such as the radio and the television in the unit. The following subsections detail these moments in greater detail.

Claire and Ben: dancing to a script

One day in July, residents were seated in the day room watching a DVD the lead author had brought in of ‘Singin’ in the Rain.’ Beside her, resident Claire was tapping her feet and whooping along to the music when she suddenly

stopped, grinned, and pointed at another resident, Ben, a few chairs away.

‘That man,’ she exclaimed, ‘should get up and dance!’

Ben looked over, nonplussed. The lead author joked with the two that they should get up and dance together. Ben acquiesced, held out his hand to Claire, and the two performed a nimble two-step around the room before collapsing on the couch, laughing at each other.

This opportunistic engagement occurred suddenly for the two residents who, hitherto, had not even spoken to each other. Not only did the musical space (created by a familiar film and familiar music on the television) allow for the two to express themselves via dance, it allowed them to connect via an implicit ‘script’; here, the two were not residents, patients, sufferers – they were dance partners. Unlike the very demonstrative art sessions residents sometimes attended, this, like Killick & Craig, above, detail, was an opportunistic activity that was engaged in for its own sake – though in the end it allowed for a connection none of the participants and onlookers might have thought possible.

Valerie: touch and ritual

Modes of communication would shift during engagement with music and while verbal communication would wane, other modes of intersubjective communication would become prominent – for instance, movement, sway, tapping and touch rose to the forefront during these sessions. This shift in communication was one which was often more creative and expressive than the pleasant ‘chit-chat’ residents with which residents were often engaged.

Sitting and listening one day to an old record of Irish ballads, resident Valerie took the lead author’s hand and the two swayed from side-to-side half-singing the songs. After a while this swaying turned into a dance as Valerie guided her hand in a sort of a twirling, twisting pattern in the air in rhythm to the music. The two paused after each song to applaud the singers, but Valerie reached for the lead author’s hand immediately afterwards. At one point Valerie simply held her hand very tightly as they watched the television or chatted, or observed the people around them. Valerie squeezed her hand very tightly and ran her fingers over her knuckles. The lead author let her guide her hand again and she brought it very close to her face, rubbing it gently over her cheek and chin.

Valerie’s initial reaction in reaching out for the lead author’s hand seemed to be to guide it in a sort of dance to music, but eventually finishes with her interacting with her hand (and the author herself) as something soothing, something calming and yet communicative. Valerie was someone who carried around several keepsakes – rosary beads, a small book of poems – and would often take out these items and run her fingers through the pages or the beads. Here, she interacted with the hand in that same way: first as a communicative and responsive object in a dance, and then as a connective ‘talisman’ of sorts. Again, the

familiar music from the record player facilitated this seemingly emotional and yet wordless connection by which Valerie (and the author) were soothed.

‘Entering’ media: dementia and ‘delusions’

Dementia can bring along with it instances of hallucinations and delusions which can be distressing both for the person with dementia and the caregiver/family alike. However, one resident in St Eithne’s, Maggie, experienced these delusions in a way which allowed her to interact deeply with the media with which she engaged – for example, presenting Maggie with a magazine about children would often see her interact with the pictures of the babies within, carrying out conversations with them and, if approached, would tell stories about the times she and the child had had together.

This immersion was even more marked when Maggie watched television. Early on in the ethnography, Maggie fell and broke her leg. Carers needed to ensure Maggie would not move around too much on her broken leg, and so placed her on a moveable armchair fitted with a pressure alarm. Noting that Maggie ‘came alive to music’, they placed this seat close to the television and switched on her favourite concert DVD – Daniel O’Donnell. Observing Maggie during this time, she began to act as though enchanted and in a reverie – she sat, smiling widely at the screen with rapt attention as well as adoration. As the song finished, she would applaud loudly and wave to the smiling singer onscreen, blowing kisses. As I sat beside her, she began to tell me that she and the singer were friends.

‘He came to visit me last summer,’ she said. ‘His wife is a lovely woman.’

The delusions and hallucinations which come with dementia are often listed as a negative characteristic of the disease; here, however, they acted as a way for Maggie to both make sense of her experience retroactively, as well as a conduit into media that clearly gave her a sense of pleasure.

LOW-LEVEL DESIGN IN THE UNIT: A SONGBOOK

The previous observations have constructed a picture of St Eithne’s as a place in which residents received good medical care, but where residents’ creativities were self-constructed in and through a space mediated by music-playing, everyday technologies. Given the lack of resources in the unit and in many other units in the UK and Ireland, personalised creative care and design may be unlikely. Opportunistic or ‘quick and dirty’ design in settings such as St Eithne’s have the potential to be valuable as long as they are guided by a commitment to key values – here, ‘small c’ creative values such as experiencing pleasure and creating a ‘something’ where there was previously nothing – but also an acknowledgement of, and respect for, the personhood of the other.

Therefore, we offer the following observation as a jumping-off point for situational, low-level design in dementia care to support creativity and connection to self. In principle,

this is not limited to music – in the earlier observations, we saw residents engaging meaningfully with television as well – however, in this paper we will concentrate on the role of music due to the rich potential it offered residents.

Bill and the songbook

Bill's difficult transition to living in care resulted in the formerly talkative man withdrawing almost entirely into himself, becoming disinclined to participate in talk and in group activities. Nurses and carers did not know what to do with Bill – they knew a little about his life outside the unit, but he was not as easily prompted into storytelling as he had been. This resulted in a sort of depersonalisation of Bill; day after day, the lead author would come into the unit to see him sitting, often sleeping, on a sofa in the parlor as others around him chatted or watched television.

Remembering that Bill used to love to sing, and prompted by a chat with him one day in which he spoke deprecatingly about himself, the lead author created a basic songbook for Bill and filled it with his favourite songs. This meant that activities with Bill in the future were enriched due to the presence of this personalised songbook. However, even in authors' absence, the presence of this book meant that carers who interacted with Bill still had a portal or a 'way in' to his experience. 'He carries that book around the whole time,' carer Libby remarked. The ward occasionally rotated carers from other wards, which meant that residents did not always have a fixed set of carers to interact with, and thus this songbook could say something about Bill which he, in his present state, could not. Music that has been selected by residents, in this way, can act as a signal or a beacon to others who cannot find a way in, and through even low-level design, it can give a voice to an experience that is presently voiceless.

OPENING THE DESIGN SPACE & OTHER CONSIDERATIONS

The authors intend for this paper to begin to open several possible design spaces in dementia care wards. In particular, we have highlighted the following:

1. Media selection is important for participants with dementia, and a well-stocked media library can be enriching;
2. Particular music can transform and create spaces through activities performed within (e.g., Claire and Ben's dance);
3. Design surrounding music in dementia should incorporate movements and gestures, both explicit and performative (e.g., dance, tapping) and personal or soothing (e.g., Valerie's seeking to hold hands).
4. Although 'designing for deficit' is potentially inappropriate, design should be cognisant of cognitive and perceptual abnormalities (e.g., Maggie's 'delusions')
5. Basic design, if informed by a well-developed and respectful knowledge of our participants, can be enriching, connective, and communicative.

Although we do not intend these considerations to constitute formal guidelines for design research in the area, they represent areas of possible research and innovation in the area of dementia, design, and creativity.

CONCLUSION

This paper presents observations from an ethnographic study that found that many creative interactions on dementia care residents' behalf were mediated through engagement with music technologies. The importance of music for people with dementia has often been noted [6, 5], and engagement with music can be something which is intensely personal, evocative of one's own past and yet by another turn, playful and social. These observations of everyday creativities point to the potential inherent even in existing technologies (such as television) to become an active, immersive and creative technology in the setting of a dementia ward, as well as describing the kinds of enriching interactions that can arise from their use.

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