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Authors	Morrissey, Kellie;McCarthy, John;Pantidi, Nadia
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The Value of Experience-Centred Design Approaches in Dementia Research Contexts

Kellie Morrissey¹, John McCarthy², Nadia Pantidi²

¹ Open Lab, Newcastle University, Newcastle upon Tyne, UK, kellie.morrissey@newcastle.ac.uk

² School of Applied Psychology, University College Cork, Ireland, {[john.mccarthy](mailto:john.mccarthy@ucc.ie), [konstantia.pantidi](mailto:konstantia.pantidi@ucc.ie)}@ucc.ie

ABSTRACT

Experience-Centred Design (ECD) has been applied in numerous HCI projects to call attention to the particular and dialogical nature of people's experiences with technology. In this paper, we report on ECD within the context of publicly-funded, long-stay residential dementia care, where the approach helped to highlight aspects of participants' felt experience, and informed sensitive and meaningful design responses. This study contributes an extended understanding of the quality of experience and the means of making sense in dementia, as well as unpicking the potential of ECD to support enriched experience and contextual meaning-making for people with dementia. Finally, we delineate what it is about Experience-Centred Design that differentiates the approach from other often-used approaches in designing in dementia contexts: 1) explorative thinking, 2) working within 'cuttings-out of time and space', 3) careful yet expressive methodology and documentation, and 4) working together to imagine futures. We end with considerations of how the contributions of this research may extend to other experience-centred projects in challenging settings.

Author Keywords

Dementia; Experience-Centred Design; design methods; design approaches; embodiment; experience.

ACM Classification Keywords

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

INTRODUCTION

A growing public interest in dementia and in ways of preventing or reversing its effects in recent years has subsequently been mirrored by a growth in the design literature surrounding the condition. This literature tends to find a focus not on prevention, but on helping people with dementia or their carers to live with the condition in ways that are more independent or more meaningful to

them. Within the HCI and design community, designing for and with people with dementia (PWD) has also presented opportunities for designing new technologies that can tell us more about the experience of dementia itself.

Most design research in the past has focused on addressing these issues by way of designing assistive technologies – e.g., memory aids, GPS tracking devices [4]. For people with dementia (and older people in general), assistive technologies may offer relief and support – particularly in the early stages of dementia, where symptoms are often limited to mild cognitive impairment and where independent living is still possible [3]. However, as the condition progresses, memory problems can be compounded by changes in communication styles, and feelings of frustration, anger and uselessness as independence is curtailed or precipitated by a move into living in care [35]. At this point, designing for technological intervention and the idea of assistive technology becomes a more complex issue.

Experience-Centred Design [ECD - 25, 26, 48] has been applied in studies involving people with dementia as participants [41, 44], as well as when working with people facing difficult circumstances, such as migrant women with experience of domestic violence [8] and women with mental health issues living in institutions [39]. Given the complexity of living with dementia in particular, Experience-Centred Design has been indicated as a way forward in designing for and with people with dementia in order to keep the experience of participants alive and at the forefront of design projects. In a 2016 article in *interactions*, describing the value of ECD in dementia research projects, [18] writes that “*at the heart of Experience-Centred Design is an appreciation for the richness of human experience, a concern for meaning and how people make sense of their experiences, and the mindset that innovation should strive to enhance life, particularly for those who are disenfranchised*” (p. 61).

This paper applies ECD in a context in which lived experience is considered to be far from rich and in which the capacity of the person with dementia to make sense of this experience is considered lost, or greatly diminished [45]. In the process, its major contribution is to extend our understanding of the quality of experience and the means of making sense in dementia, as well as the potential of ECD to support enriching experience and meaning-making in this

context. Given the growing prominence of dementia in the design literature, this paper has two key objectives. First, we identify the key elements of an ECD approach in designing for dementia with particular reference to our own design research with people with dementia, and secondly, we delineate key differences in using ECD, when applied to a dementia context. The next section will describe these approaches in more detail.

DESIGN AND DEMENTIA

This section provides a short review of selected extant design literature pertaining to dementia. We have divided these studies into broad themes, and in a final subsection, we describe past ECD design projects that focused on design and dementia, and which offer a contrast to compensation and connection approaches. However, it should be noted that these approaches overlap significantly and cannot be considered as entirely discrete categories.

Compensation and cognition

This subsection describes design research which attempts to enhance or replace cognitive skills that have been seen to have been lost in the progress of a person's dementia. These deficits have often represented seemingly 'fixable' challenges for many designers, even when applied to real-life situations. This sort of design conceptualizes each deficit as a gap that can be bridged with the right design. For instance, the COGKNOW DayNavigator [31] is one such example of a technology that aims to displace some of the issues caused by memory loss in dementia. This is a touchscreen device with computer-mediated controls as well as a mobile device to bring along when going out for the day. Its aim is to remind its users of particular tasks in their day-to-day lives – for instance, when to attend particular appointments and when to eat.

Similarly, some design studies have attempted to solve or ameliorate problems such as wandering in people living with dementia [4, 21]. Wandering is a common symptom of dementia and manifests in different ways – people with dementia who wander may do so either seemingly aimlessly (in nursing homes, for instance, residents may do 'rounds' of the care setting with no clear destination expressed), or with a purpose in mind that is expressed to others (e.g., "I need to find the way out of here"), but eventually forgotten [22]. Wandering in dementia is commonly addressed with the use of a GPS device that is often attached somewhere to the body of the person [4, 21]. Although this may provide peace of mind for the carers, it is easy to imagine why someone with dementia may resist this. Dementia is still stigmatised, and one study of perceptions of stigma by people with dementia describes a tension between seeking medical or community care and, in receiving that help, being marked out as a 'sufferer' [23]. Another study by Hopper, Piasek & Irving [16] indicated that users of assistive technologies for dementia had concerns surrounding their implementation and visibility in home environments.

Looking at participants engaging within an environment, [33] and [46] employ ambient assisted living technologies in a way that helps people with dementia to retain and use skills in an embodied way. The Ambient Kitchen utilizes several sensors in kitchen tools, paneling and flooring as well as cameras and speakers to deliver audio commands to users that guide them through simple cooking tasks such as cooking an omelette or making a cup of tea. This sort of work represents a different approach to designing in dementia – one which makes use of the skills still present in the person themselves and is mindful of the environment in which it is placed.

Although many technological interventions focus on the deterioration of cognitive skills in dementia, people with dementia do not see a total dissolution of these abilities, and many dementia scholars emphasise the interconnectedness of cognition and other aspects of experience:

... many aspects of the cognitive life of people with dementia survive into the moderate to severe stages of the disease. These cognitive abilities include (amongst others) the ability to behave on the basis of the meaning of situations, to experience a range of emotions, to experience and seek to avoid embarrassment, to feel pride and seek to maintain self-respect, to feel concern for others, to communicate effectively with facilitation by others [...], and to display at least implicit short-term and long-term memory. [19:295]

Compensatory approaches are sometimes complicated by their deployment in situations that are politically complex or in "moments when participation is organised by structures of privilege that deny difference and diversity" [27] – for instance, while living in care or under the care of family members. A different reading of ability, difference, and experience in dementia may similarly allow us to approach the 'deficits' that come with dementia in a more holistic way. When we seek to compensate in designing for people with dementia, perhaps we might also look at the environment in which the person lives, and the relationships that sustain them therein.

Connection and keeping in touch

This section describes a series of design studies which are primarily interested in keeping people with dementia in touch with their carers and families, or otherwise focusing on the social life of the person with dementia. Social and relational aspects of dementia can impact upon the person as much as the cognitive issues which come with it [34]. In the above-cited paper by [33], participants who had recently received a diagnosis state that people tend to 'stand back from dementia, because it's too heavy' (p. 33). However, it seems that an active social life in later life can delay or protect against the development of dementia, and may also slow its progression: [46] suggest that the effect may be seen via psychosocial pathways, wherein participation in meaningful activities with others can lend the person with dementia a heightened sense of self-esteem and usefulness.

HCI studies have approached this problem from several different standpoints. [2] focuses on the design of a touchscreen system for the express use of people with dementia, which may help users with dementia and their carers to participate in conversations on a more equal basis. Their prototype, developed with the advice of people with dementia as well as carers, is a touchscreen system that takes for its basis the idea of reminiscence for people with dementia as being potentially useful in stimulating discussion. The evaluation notes that the system allows its users to interact on a *‘more or less equal basis’* to others without dementia [2]. The idea that a disconnect between these sets of people rests on differences of *communication* rather than a deficit in *cognition* is one which does not propagate a notion of the person with dementia as ‘lesser’, and is a promising goal for future work in dementia care.

Other studies in HCI have used the idea of reminiscence and reminiscence therapy as a way to encourage conversation in people with dementia – for example, [20, 37], who both create web-based applications and interactive systems to deliver these services. [37] details the development of a system that delivers ‘personalised’ reminiscence therapy via a web-based platform. The personalization of this system is carried out via a short questionnaire delivered to users with dementia prior to the system starting up – from then on, the content is personalized to their interests. That the design allows for individualization is likely to be useful for people with dementia and acknowledges the multiplicity of experiences which people with dementia and their families may face in the course of the condition.

One of the most prominent issues in designing within dementia care is the complexity of the effects that are desired – ameliorating conversation, achieving therapeutic effects, or even cognitive rehabilitation. Some studies simply attempt to keep participants with dementia ‘in touch’ with larger social networks of friends, family and caregivers. [24] describes a social network design which attempts to ‘friendsource’ unmet needs of people with dementia, both by automatically capturing data from the PWD’s smartphone to track their whereabouts, and by providing a private social network group used to ‘validate’ events in the PWD’s life. The paper lists three potential uses of the system as ‘reminiscence therapy tool’, ‘in-situ communication aid’, and ‘daily routines and reminders’. The system was piloted with staff from a local dementia aid charity, and themes extracted from an interview with the staff member include a need for more balanced tools, the struggle of presenting content, engaging a larger support network, and guarding the right of privacy of people with dementia.

Although most of these papers proceed from a progressive, psychosocial perspective on dementia, many also lack *actual* connection and presence between two or more people – instead, several of these systems intend to

automate processes such as choosing material for reminiscence sessions or even conversations (such as Sakai et al’s [36] listener agent [chatbot] for people with dementia). This is despite the acknowledgement within these papers that socialization itself is important for people with dementia. If being with others is so important (as evidenced in the clinical literature and the firsthand accounts of families living with the condition [1, 6]), the technologies we design should work to enrich this co-presence rather than provide a facsimile of it.

Working with experience

The following section will unpack ECD not necessarily as an alternative to assistive designs described above, but as a different way of exploring these often deeply personal issues. Dementia is a complex condition that cannot be reduced even to a given set of cognitive, social and emotional issues – in many cases, it is not enough to identify the ways in which participants’ lives are lacking and then design to ‘cover’ those gaps – instead, we should try to understand their lived and felt experience, and position our design as an empathic response to this experience.

Within a context of dementia care, Experience-Centred Design is promising in that it provides a critical approach to design, which *“gives people the chance to have a richer life, to include people who might otherwise feel excluded, to ensure that everybody has a chance to have their say especially those who often feel voiceless”* [47:10]. The approach is a humanistic one to understanding the relationships between people and technology *in felt terms*. It is not an alternative to user-centred design, but *“a different sensibility towards it, a different way of relating to familiar precepts such as know the user, iterative design, and user involvement”* [47:20]. ECD does not disavow the need for user needs and requirements; *“rather the focus is an understanding of individuals, their concerns, desires, aspirations, values, and experience”* [47:20]. Its use in design studies such as Thieme et al’s [39] exploration of mental health in women’s institutions and Clarke et al’s [8] ethnography of a migrant women’s centre in the UK is a testament to its suitability to situations where participants are facing significant challenges. In the next subsection, we will discuss its use in dementia research by Wallace et al [43, 44] in particular.

Initial explorations of ECD and dementia

McCarthy & Wright articulate a dialogical ethics which is predicated on aesthetic experience or ‘richly seeing’ [14], which is integral to keeping the experiences of participants alive. This approach is explored in research for and with people with dementia by Jayne Wallace [43, 44]. For Wallace, this approach helped her to understand the experiences of her participants in a way that made it possible for her to keep their experience alive in the resulting designs. A first project [43], situated in an adult mental health unit which housed people with dementia,

featured an interactive art piece entitled *Tales of I*, installed for the use of all residents. The art installation included a wall cabinet which housed a series of globes fitted with RFID tags, and a television unit which facilitated the ‘playing’ of videos housed within these globes when they were placed upon a certain point on the unit. These globes and videos were ‘themed’ – e.g., holiday, nature, football – and particular attention is paid to the material and tactile nature of the design engagement:

“... our use of color, variety of materials and detailed colorful scenes that were captured in resin globes were all intended to catch the eye and provoke curiosity and fascination [...] It was important to us that the piece was well made, interesting and beautiful as we wanted to convey to clients that they were valued and deserved beautiful things.” (p. 2632)

In a paper the following year [44], Wallace et al expanded their work on ECD and dementia care in a paper which described a relationship with Gillian, a woman who had recently received a diagnosis of dementia, and John, her husband, focusing on similar themes of valuing different forms of communication as Gillian’s dementia progressed. Our work extends Wallace et al’s research in a series of more experientially-impooverished care settings – primarily a publicly-funded, low-resource, and understaffed care centre. Although staff within the home were dedicated, caring and resourceful, the home itself had little funding, and, situated within the grounds of an old hospital, it was clinical-feeling and small – for instance, residents slept in communal dormitories and had relatively little privacy and personal space. Within this project, we focused on themes of participation and community, given an overriding sense of disconnect between residents within the centre. The major contribution of this account is to extend our understanding of the quality of experience in a very different context to those which have gone before, as well as to advance considerations of the means of making sense in dementia.

METHODOLOGY

Our design research for and with people with dementia took place over the course of three years (2013-2016) and was situated in three different care institutions for people with dementia (though this paper reports from engagements from one in particular – St Eithne’s). We adopted an ethnographic approach, which saw the first author entering care homes twice a week at the beginning, at first observing daily life in the institutions, before moving to carrying out creative group and one-on-one activities, and, later, design workshops with working prototypes. This research aimed to understand ways in which people with dementia could meaningfully participate in creative activities, with a secondary aim of understanding ways in which this participation might be ‘enfolded’ into design processes. We were aware that differences in communication may make the expression of residents’ experience difficult. As a result,

in our observational research, we paid particular attention to bodily forms of communication. We were influenced by Kontos [19], who describes how her participants, people with dementia living in care, would engage in competent and meaningful engagements with their environments and others around them, particularly during embodied activities such as dancing or exercising:

“Despite their severe cognitive impairment, the residents were not launching their bodies into blind attempts to perform an action. The movements of their bodies were perfectly suited to the circumstances, disclosing a practical competence in their engagement with the world.” [19: 261]

We took detailed field notes which we expanded later into field texts. These field texts placed a primacy on phenomenological aspects of being within the care centre – on the concrete, visceral and palpable character of experience [25]. Within this, we focused not only on our own experience but on the felt aspect of relations with others.

Reflexivity and dialogicality

The emotional tensions inherent to doing ethnography in dementia care are worth describing. Ethnographers face a number of issues when carrying out what Wacquant [42] dubs ‘carnal sociology’; the forms of ethnography which involve deep involvement and participation on behalf of the researcher. These forms of ethnography see the researcher “submit to the fire of action in situ” [42] and can prompt an emotional reaction from the ethnographer which is then detailed in the text produced from the research itself as a part of the action which occurred.

Several researchers have attempted to produce accounts of this empathic approach to navigating and configuring relationships ‘in the field’. Wang [47] details her reactions to the formation of relationships during her ethnographic work in an international school in mainland China. Being of closer age to the younger students, she quickly develops relationships with them, which she intermittently refers to as friendships. However, she notes that the intimacy of their relations may have brought her perilously close to ‘boundary violations’, which have the potential to hurt those who are being researched as a part of the study. For instance, encountering a student-participant one day who was distressed by the behaviour of certain teachers, Wang found that she had to ‘check herself’ so as not to appear biased towards a certain subset of participants over others:

“Honestly, I did feel devious at that moment. I could not help questioning myself: were they hurt by my restrained attitude? Were they disappointed in my friendship?” [47:773]

Navigating relationships within ethnography, Wang concedes, is like navigating between ‘falsehood and reality’. In this way, researchers may don a mask of sorts to appear more amenable to talking about participants’ lives than really is the case. We straddled a different line

between falsehood and reality – suffering from dementia as they did, our participants often believed that we were someone who we were not; a carer, a daughter, a co-worker – and thus our relationship proceeded by way of this ‘falsehood’, arguably more ethically than it might have, had we chosen reality over falsehood. We will discuss our experiences in navigating this schism responsively and responsibly later in this chapter.

It also bears acknowledging at this point that it is, of course, never possible for us to really *know* the experience of our participants, and this process is one which is even more complicated when there is a great mismatch in the cognitive and linguistic abilities between ourselves and our participants. However, over time (we spent over a year in St Eithne’s), and through a dialogical though not necessarily verbally rich process of attentive listening [11], we came to be able to write about participants’ experiences with some confidence, and triangulated these experiences with care staff and family members (when available).

Ethics

The research was granted approval by the University College Cork’s School of Applied Psychology’s research ethics committee, which consists of six senior research psychologists. Proxy consent was sought from families and appointed caregivers; however, the capability of some participants (whose dementia was at early stages) to consent to inclusion in the research was also assessed by medical staff who knew the clients and residents well. In order to ensure ongoing opportunities for participants to question their involvement in the project, we provided them with information sheets for themselves and for family members regarding what it meant to participate in the project. We also introduced the project at the beginning of each visit, and spent time individually with participants to ensure their continued consent. As a matter of course, participants and settings are anonymised throughout this paper.

Grounded Theory in ethnography

Using Grounded Theory (GT) as a method of organising these field notes, we followed Charmaz & Mitchell’s [7] guidelines for carrying out qualitative data collection and analysis in ethnographic settings (“*what is the setting of action? What is the distribution of its actors over space and time? What do actors pay attention to?*”). GT is a systematic method of analysing and collecting data which begins with inductive inquiry. The process involves comparing data and analysis against itself in several iterative rounds, and emphasises the interactivity of the method, with the researcher as a kinaesthetically active participant within the analysis. Although GT is often characterised as a fairly rigid data analytic method, Charmaz’ own work on chronic illness, which saw her iterative and interpretive collection and analysis of accumulating data, was a model for us as we worked to organise our field texts.

Grounded Theory is often characterised as a method for studying processes [7], making it a sensible choice for our purposes, and beyond this, was chosen early on as a data analytic method for our research due to its openness to all possible theoretical understandings, as well as its inbuilt systematic checks and refinements of major theoretical categories. Our analytic process began with a deep immersion into the data itself (typically a narrative field text), and proceeded with line-by-line coding. As per Charmaz, we coded for processes, actions, and meanings, which helped us to define connections between data. This process of open coding was followed by secondary coding, at which point memos taken from reflective accounts and rough field notes were taken into consideration to begin to build a tentative set of themes (set to change over iterative analyses).

In the below sections, we refer many times to field notes and personal encounters which were almost solely on the behalf of the primary researcher and first author, Kellie – when excerpts refer to ‘I’, they are extracted from her field notes. This next section expands on four seminal moments in our research process which were either guided by, or embody, certain Experience-Centred Design practices.

DOING ECD IN PUBLICLY-FUNDED, LONG-TERM CARE FOR PEOPLE WITH DEMENTIA

Self and song: Charlie and the songbook

Charlie was a resident who had recently moved from day care to full-time care, and had suffered a decline in his condition at the same time, itself possibly a consequence of the move. Charlie was one of the first residents with whom we connected in our time in St Eithne’s – a vibrant, kindly man, he walked with two canes when really he needed only one. Initial field notes in the unit describe him as being “*well-turned out... wearing tweed and carrying a newspaper,*” and we spent a lot of time with him, sitting and talking about his childhood in the locality – fishing in rivers with his father, selling apples from crates in the local market. Charlie spoke to us about these experiences in-depth, chuckling as he recalled grasping the fish, slippery and cool from the river, wistful as he recounted walking the two miles home across fields, even as he was unable to tell us about the food he ate for lunch or the names of his children.

Charlie’s home life was becoming increasingly difficult – his wife was very ill (though he couldn’t tell us with what, exactly), and nurses told us that his grown family was busy and dispersed through the country. He became a full-time resident, and went from being chatty and fond of telling stories to instead becoming withdrawn, quiet, and relatively isolated as one of the only men in the care unit. Speaking to him now became difficult – he would repeatedly ask if he could leave with Kellie, ask for his car, or instead return to cyclical conversations surrounding a sense of a loss of power he felt. At the same time the unit was understaffed, and new and substitute staff found it difficult to connect

with Charlie, of whose life outside the unit they knew quite little.

It was difficult for us to think how we could respond in a designerly way to this situation. The unit in which Charlie was living was one which was low on resources and time, and staff were reluctant for us to initiate contact with family members of people living in the unit (an initial idea was to create digital life story books for people who might be interested). Experience-Centred Design is explicitly interested in how people make sense of themselves in the context of their personal histories and anticipated futures – which is complicated in dementia, where an explicit recollection of past selves can be difficult, and even more difficult when family members are not available to discuss this in more depth with researchers. Most extant design work with people with dementia has involved carers or family members in ‘informing’ about the person with dementia. Despite these limitations, given Charlie’s increasingly difficult experiences as a full-time resident, we knew that a rich response, which expressed something about our own positive relationship with Charlie, who we had come to know as an intelligent, lively and generous man, was warranted.

Our response was to create a simple songbook for Charlie that consisted of songs which we had heard him singing as a day resident (in fact, his performance of one song – The Moonshiner, a humorous Irish song about the illegal alcoholic drink poitín – had recently won him a prize at a local concert). We saw this songbook in use became a balm for the anxiety he felt in the care unit, and singing its songs together provided him a break from his cycle of dehumanising, difficult thinking. Our field notes report that, earlier in the week, prior to this gift-giving, *“he sat far back in his chair, shoulders slack and eyes alternately downcast and seemingly glazed over”*, but now, *“he leaned forward in his chair, the two of us holding the book open together. The space around us seemed changed.”*

Leaving the unit, the day that we had given him this songbook, he turned to us and said *‘My worries are gone. You reminded me I could sing, and I had forgotten that.’* Charlie’s sense of his own cognitive decline, coupled with a move into vastly different living circumstances, had been mitigated at least partially by a reminder of aspects of his own self, history and proficiencies which were still very present. As the research process wore on, we saw this small token become an object which Charlie carried with him, and which nurses and staff members used to catch a glimpse of his inner life – for them, it became a ‘way in’ to

Charlie’s rich inner experience. Not only was this object a reminder of past experiences, but now something which facilitated a different type of interaction – not the medicalised relationship of professional care, but instead a re-affirmation (which Charlie voiced himself) of his proficiencies. For Charlie, singing meaningful songs was an aesthetic act; mirroring this, McCarthy and Wright write that *“the aesthetic act in daily life involves a reassumption and reconfirmation of one’s own place after the other is encountered”* – here, it allowed us to create something which facilitated a positive social positioning of Charlie in the care unit.

Moving together: touch and embodied interaction

We were particularly surprised by the ways in which touch was important to residents of the care units – perhaps given a general change in inhibition in dementia, or to generational differences, many residents would reach out to us, hold our hands, embrace us or kiss us gently on the cheek. Although initially taken aback by this, we came to accept these gestures as being communicative of emotions and experiences which perhaps were not readily expressed in verbal means. This touch seemed to be tied to strong emotion – one resident, Marie, who believed that Kellie was her daughter, would hold her hand tightly and tell her that she loved her very much. It is a strange position for a researcher to be placed into, but Kellie reaffirmed these feelings through her response – not confirming Marie’s idea of her as a daughter, but not disrupting it either.

One particular interaction with Marie illustrates the deeply emotional potential of touch in dementia. One day, as Kellie rose to switch the television to a new channel, a resident named Ros *“slapped the hand that [Kellie] reached out”*:

“Immediately, Marie is out of her seat and stalking towards the two of us. She grabs Ros’s arm tight at the wrist. ‘Don’t you dare,’ she says, hotly, ‘touch my daughter. Who do you think you are? Who do you think you are?’ The two stand, grappling together for a moment. I attempt to disentangle their hands, urging them to stop.”

Finally, Ros wrenched free and left the room, wailing. Marie paused for a moment before turning and walking to another section of the room. After some time, Kellie followed her. She stood, looking out at the window. Field notes from Kellie go on to say: *“... she turns to me when she hears me enter, tears in her eyes. ‘I’m sorry,’ she says. ‘I just can’t bear anyone doing anything to my family. She’s awful. She’s awful.’ I place my hands on her shoulder, and shortly afterwards we re-enter the parlour.”*

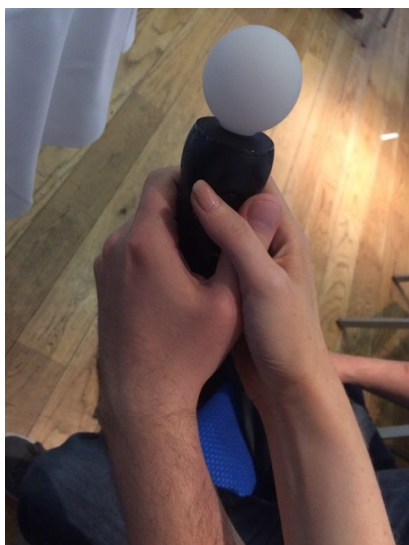


Image 1: SwaytheBand held by two hands at once

Here, different forms of touch (slapping, grabbing, disentangling, wrenching, a hand on the shoulder) provoke deeply felt emotions which are communicative of the relationships between actors within the situation, even when sense-making processes have broken down or changed due to dementia. Responsivity was important for us within these negotiated relationships, as it is in ECD, which describes how we can create the conditions for selfhood through the particulars of our affective and valuational responses to others. Therefore, Kim describes returning the soothing touch that Marie first extended to her in an attempt to make her feel better.

However, touch remains a complicated concept in dementia care. Twigg [40] writes that touch in care is ‘structured according to gradations of intimacy and power’ [40:41]; in our interactions, we did not want to remind residents (who were already enduring significant carer intervention into activities such as washing and dressing) of these power imbalances in their current lives. We let them lead by example. One example is that of Valerie, with whom Kim spent an afternoon sitting and swaying gently to music – we detail in earlier publications [29, 30] how, within this interaction Valerie reached for Kim’s hand, guiding it, twisting it in time to the music before bringing it gently to her face, rubbing it against her cheek and chin before finally kissing it and laying it down.

These and many other experiences with our participants led directly to several design configurations of our final digital prototype – SwaytheBand, a system of batons which flash to the beat of music to encourage residents to sway and spend time with one another to music (see image 1 for an early prototype using PS Move batons).

We designed the batons to be held by two hands at once, replicating the stretching of arms and touch and grasp of hands which were so prominent during our fieldwork. In

this way, we paid particular attention to the sensual nature of explosion; in articulating the sensual thread of experience, McCarthy and Wright hold that this thread is “concerned with our sensory engagement with a situation which orients us to the concrete, visceral and palpable character of experience... when senses are fully realised, the interaction between person and environment becomes participation and communication” [25:80]. In working with dementia, the embodied and sensual nature of experience needs to be brought to the fore, not just out of aesthetic concerns, but because a heightened appreciation of this can help people with dementia to communicate in felt and embodied ways.

Making and feeling: absorptions and aesthetics

We carried out numerous small design-centred engagements with people with dementia – these were less like workshops and more like chats which had objects at their centre. For example, one engagement saw Kellie crouched in front of three ladies – Aideen, Teresa and Linda – going through swatches of cloth in an attempt to explore how they felt about the various materials. The end goal would be to use one of the materials in our SwaytheBand prototype, but for now we were simply interested in their ways of interacting with the cloth. To our surprise, the ladies did not give the sort of straightforward feedback we might have expected, but instead talked about the material in terms of the sort of purpose they might have made of it:

“Aideen refused to touch the furry cap I had brought in, muttering under her breath as I reached out to touch her hand with the fabric, jerking her hand back. Teresa was more receptive. She took the cap, stroking the smooth fur first with the back of her hand, then grasping the fur itself, fingers disappearing into the pelt. She moved to the tail of the cap, which make her laugh. She wagged the tail at the other ladies, and they laughed together. ‘I like that,’ she said. ‘It’s lovely.’ The ladies began to guess at ideas for what the materials could become. ‘For a window,’ said Teresa, as we held out a piece of white lace. ‘A pyjamas,’ said Linda, for a piece of linen.” [from field text]

Taking the time to engage with materials in this way provided a window into the lives of our participants and allowed them to display and experience past skills. We occasionally brought along a ball of knitting, and, sitting with Máire, Kellie told her about failed attempts to knit a scarf for a sister. Asking Máire for her advice, she was surprised as Máire willingly took the knitting, and then watched Máire’s fingers deftly push out row after row of neat stitches atop her own “large, messy, loops”. Experience, for Dewey as well as McCarthy and Wright, is constituted by the relationship between self and object: feeling people acting and the materials and tools they use. But not only can objects and materials tell us about the people who interact with them: so too can they facilitate aesthetic experiences.

Absorption characterizes aesthetic experience possibly above all else – it is “*a breaking down of barriers between self and object, an outpouring of self into object*”. It bears similarity to the notion of “flow”, and Killick & Craig [19] use ‘flow’ to describe an encounter where a participants’ engagement with his creative task, and the apparent mastery he displayed, had them wondering if he really had dementia at all. For us, aesthetic experience is defined by absorption, but is also deeply sensual and emotional. In our design workshops which progressively began to incorporate more and more interactions with music, leading to the design of our SwaytheBand prototype, we noticed how people could become absorbed in music when previous art-based engagements would prompt unease and impatience. One resident, Ben, tipped his chair back, closed his eyes, and sang along; another resident would choose to sing the same song over and over, explaining that it was the song her husband used to sing to her early in their marriage. This interpretation of ‘material’ is one which is loose – here, our materials were songs, sung from memory – but they told us as much about our participants as did engaging with textiles, and much than attempting to sit down with them with paints and pens:

“Claire had seemed to really dislike the art session, calling herself ‘useless’ – with a bit of coaxing I got her to shade in part of a beach scene I had drawn, and with a little more coaxing she added some features to the painting, but then slammed her pencil down abruptly.” [from field text]

Although music may seem like an unconventional way to progress a series of design engagements, for our participants, it made sense. Claire, who slammed her pencil down when we carried out art sessions, ‘*came alive*’ to music. As music played in the background, she would “... *cackle, slide over in her seat towards me and grab my arm, shaking it a little and smiling. Her song would be punctuated by ‘woohos’ and ‘yoohos’ which garnered many curious looks from other residents; this yelling of hers was, I thought, designed to whip up participation from others.*” [from field text]

Claire would look to others as she shouted, saying ‘come on’ and gesture to them to begin cheering as well. She would be met with bemusement, but residents would often begin singing once they’d finished laughing. Claire’s spectating, we thought, was designed to reach others; designed to spur others on to participation, to make light of the singing and the situation she found herself in and designed to respond not only to the music, but to those around her. Through music, Claire create opportunities to connect and communicate. Her rich engagement with others through music again provided a strong basis for our deployment of SwaytheBand within group settings (see image 2, below).

Anticipating futures: sense-making and improvisation

The final interaction we will describe here concerns the act of sense-making in dementia. McCarthy and Wright

articulate this process as consisting of *anticipating* (the notion that our experience is shaped by what has come before), *connecting* (the immediate, prelinguistic sense of a situation), *interpreting* (finding narrative in the encounter), *reflecting* (making judgements on the encounter as it unfolds and placing value on it), *recounting* (considering the encounter in context of other people’s experiences), and *appropriating* (relating the experience to past and future experiences – making it our own). We can never be “*outside an experience*”, but thinking about processes of sense-making in this way helps to understand processes of meaning-making in dementia in particular.

Living in care for the first time at an advanced age, often experiencing illness beyond dementia, and living with strangers with whom you have nothing else in common, can be very difficult. When this happens, intersecting realities can make for contested space in dementia care. For example, one resident, Gilly, in her early days in the unit, would wander the halls incessantly, searching for a way out. She would then become convinced that she *was* at home, and was confused at the strangers in her house. Gilly would weave behind their seats to open windows in order to ensure her cat, Micky (who she had in fact left at her family home), could get in if he needed to. This caused consternation in the other residents, whose shouts would upset Gilly. Her situation did not make sense to her – in many ways, her wandering, opening of windows and doors, were all attempts at sense-making. For her, the process had broken down.

Over time, Gilly settled into the care unit. However, working with residents’ whose processes of sense-making were different to our own was difficult. In one instance, a resident, Fionnuala, highlighted this by turning to Kellie and saying:

“‘I told the doctor about your problem,’ she said to me, her eyes flicking to my face.

‘You did?’ I asked, again.

‘Yes. Did he not give you a call?’” [from field text]

Fionnuala already had an idea of their relationship in her head – one that Kellie was not privy to. She believed she had told the doctor about a problem. If Kellie answered ‘incorrectly’ here, it might throw the whole conversation off-kilter. When that happened, Fionnuala had a tendency to ‘realise’ where she was and grow distressed at being unable to leave.

“‘No,’ I said. ‘He didn’t call me yet. Soon though, I hope.’ She looked at me a little oddly but then her gaze shifted away. Our relationship, or at least the script of it that she kept running in her mind, was safe for now.” [from field text]

Again, the ways in which Kellie responded to Fionnuala helped her to preserve a continuous sense of herself. We often wondered as well who *we* were to her in those

moments; how she was positioning us. In writing about relationships in dementia, Oppenheimer [34] says that: *“it is the emotional context of these relationships (or their absence) that determine how much the person flourishes or withers, how much his potential for affection, enjoyment, humour, and the vivid communication of feeling, are stifled or expressed”* [34:321]. Our ability to improvise and help to retain Fionnuala’s sense of self was brought into play later in the work, as well, where she would seem to have delusions concerning her knowing a famous singer and even believing she was sitting in a concert of his. Although this was unusual and even alarming, we worked with her sense-making processes as well as we could rather than ignore or contradict them.



Image 2: a family using SwaytheBand together

Dementia can make it difficult for people to comprehend a future, which means that many conventional design activities (*“How would you envision using this technology in your future day to day life?”*) are inappropriate. However, dementia doesn’t rob them of that future – it simply cuts away the longitudinal ways in which we might construe that future. People with dementia may have fragmented pasts that are unequally buoyed by their rich and intense present, but their futures are still open in that they can be spontaneous, creative; they can improvise, plan at least some seconds into the future.

Improvisational skills are important for designers within this area. Sawyer [38] writing about the nature of improvisation, holds that:

‘... unpredictability and contingency results in performances that, at each moment, have a combinatorial complexity: A large number of next actions is possible, and each one of those actions could result in the subsequent flow of the performance going in a radically different direction.’ [38:33]

The very unpredictability of working with people with dementia itself indicates the vast amount of potential participants might have to offer via their inclusion in design. For now, what is important to take away from our ethnographic work is the value of working within the present moment – with an eye half-open to the future – and

that, with participants with a diminished ability to reflect on past experiences, the ethnographer’s role should be to ‘keep experience alive’ via their field notes and other means of data collection.

This brings us to a final point concerning working with rather than against dementia. In an earlier section, we described how many design studies in dementia position the condition as a series of problems to be fixed by the intervention of technology. Although these designs may indeed be useful for many with the condition, it must be tiring and dehumanising to be the object of studies that want to fix you, and which pathologise your symptoms and behaviour as ‘wrong’. You may want to be fixed; you may understand that your condition has brought about significant negative change in your life. However, working to create technologies that explore the strengths of people with dementia – the remaining proficiencies, preferences, and passions – is not just ethical; it is likely to produce a design which is more in tune with their lives and likely to enrich their experiences.

DISCUSSION

The above case study contributes an account of Experience-Centred Design ‘in action’ within the setting of a publicly funded residential care unit for people with dementia. Through illustrated case examples of 1) selfhood being expressed through meaningful song, 2) touch and embodied interaction, 3) absorption in ‘making’ processes, and 4) sense-making and improvisation, we underline key practices in Experience-Centred Design which helped to ‘anchor and capture’ the experiences of our participants in a way which then allowed us to create a design response.

Our account differs from existing articulations of Experience-Centred Design in dementia contexts given the very different setting – i.e., a publicly-funded long-stay unit for people with dementia which, during the course of our research, was frequently understaffed and saw little family involvement. Although many people with dementia live in settings which have more resources and can afford richer experiences for them, the truth remains that many people do live within settings where they are dissatisfied. What is more, people can live within these places, often co-habiting with strangers for years at the end of their lives, when they are also possibly sick beyond a diagnosis of dementia. Although we are not suggesting that even the most sensitive digital design can ‘fix’ these difficult circumstances, we argue that a closely worked and carefully considered account of experience offers opportunities to enrich these experiences.

The picture we are often confronted with of life in nursing homes is grim. Gubrium [13] reflects on his 1975 ethnography of a nursing home to write that life within *“is filled with intimate social ties, the celebration of small accomplishments, agonizing losses, boredom, conspiracies, anger, pride, humiliation, trust, love, hope, despair – in short, all the complexities that occur when a group of*

people spend their daily lives together” [12:5]. Writing about life in ‘total institutions’ like nursing homes, Goffman [12] notes that “*every [institution] can be seen as a kind of dead sea which little islands of vivid, encapturing activity appear*” [12:67]. Applying ECD within a dementia care context highlights these moments of ‘vivid, encapturing activity’ to find their significance within the everyday. The next and final section will highlight how we have delivered our contributions of a) extending our understanding of the quality of experience and the means of making sense in dementia, and b) extending the potential of ECD to support enriching experience and meaning-making in this context.

What does an Experience-Centred Design approach offer?

Experience-Centred Design offers a critical perspective on the design of technologies for people with dementia, but it is worth unpicking what this perspective offers in practical terms. This section delineates four critical points which highlight, for us, some of the particularly important lessons which helped to move our work with people with dementia along creative yet sensitive lines.

1. Explorative thinking vs. solutionist thinking

A critique of solutionism within HCI has risen within recent years, where it has been characterised as actively finding problems to solve, usually with quick fixes, without taking into account the complexity of the overall situation [5]. An explorative, open-ended approach can remain open to where experience takes the research – for example, our choosing to design via musical interactions given our participants’ reaction to music, despite a discomfort on the part of the researcher. In ECD, being explorative means to find ways of engaging with and responding to experience, and not necessarily solutions. In this case, it has seen us rely less on language and more on gesture and movement which extended our appreciation of the experience of dementia as different styles of communication which can sometimes painfully pass each other by. This, for us, lead to an emphasis on modalities other than language in which both researchers and people with dementia could come together to make sense of experience.

2. Working within ‘cuttings out of time and space’

Experience-Centred Design is frequently situation-specific design, which seeks to understand a person or people in the context of their surroundings. McCarthy & Wright [26] describe this as working within ‘cuttings out of time and space’, where working within these boundaries helps to keep experience alive within the design process and design interactions.

The notion of working within ‘cuttings out’ of experience is heightened in dementia, where, as we’ve described above, you do not simply inhabit a researcher’s or designer’s reality, but often several at once: consider Marie, who believed the researcher Kim was her daughter, or Fionnuala, who ‘called the doctor’ on Kim’s behalf. We

found that, in dementia care, it was more important to re-orient ourselves to our participants’ realities than to correct them to the ‘right reality’ instead. Notions of empathy [23], ambiguity [11], and enchantment [27] are likely to enrich much design research with people with dementia.

3. Careful yet expressive methodology and documentation

Experience-Centred Design is typically centred around the use of qualitative methods such as interviews, ethnography, and diary studies – however, within these methodologies, there is a critical recognition of the researcher as a thinking, feeling tool in the design process. McCarthy and Wright describe ethnography as used in design research as a ‘turn away from neutral description’ [25:36], and as ‘writing others’ sense-making in a language that we can understand’ [25:6]. Experience in ECD is never finalized, and as such our documentation of this experience is only ever to be understood as a snapshot of a ‘cutting out of time and space’ – however, doing ECD still requires careful documentation of the researchers’ engagement within the world. For our work, it was only when we turned to what it *felt* like to be in the care setting – the scents and textures of care, which so frequently are medical and unfamiliar – that our field notes became rich enough to proceed from. This turn to phenomenological expressions of experience saw us asking how we can be said to understand another’s experience when that experience was frequently linguistically incoherent and unlike any experience we have previously had.

4. Working together to imagine futures

Experience-Centred Design is often participative as it engages with people from the ground-up to negotiate a shared understanding of their experience. Moreover, it does this in a way which strives to be on the terms of the participants themselves – for instance, by visiting their homes or other familiar environments, and positioning them as experts in the design process. Although Experience-Centred Design is a research process that involves the elicitation and analysis of the experience of others, it is less a process of translation of experience than a co-negotiated conversation (that is often worked out with design materials). ECD is a process which results in the co-creation of new knowledge, and it is not focused on the representation of past knowledge, but is instead oriented always towards possible futures that are made possible by working together; McCarthy & Wright [26] explain that, in ECD approaches, persons and things are always in a dynamic process of becoming, and are always open to the future – even if that future, in dementia, is one whose horizon may sometimes appear lower than most.

REFLECTIONS ON OUR RESEARCH

This paper has delivered an account of lived experience in dementia care where experience itself is often impoverished and not satisfying, and in which participants’ ability to make sense of experience is often vastly different to that of the researchers’. Through an elaborated case study of our own use of the approach within dementia care, this paper’s

major contribution is to extend our understanding of the quality of experience, and ways of making sense of experience, in dementia. We have also indicated the potential of ECD to support enriching experience and meaning-making in this context.

It is worth considering the scope of research such as this. Our research extended initial work into doing ECD with people with dementia by carrying the work out in experientially impoverished spaces – publicly funded, long-stay units for people with dementia, where family participation was often totally absent. Our application of ECD design principles within a dementia care setting allowed us to open up to new and different ways of communicating with residents in a way which responded to their strengths, interests and values, while being sensitive to the changes which a diagnosis of dementia can bring. ECD, within a dementia care context, allows researchers to focus on certain qualities of experience which are humanizing and sensitizing in working with participants who are non-verbal, yet sometimes extremely expressive via bodily movement, touch, gesture, and facial expression. Beyond this, combined with a flexible, inductive Grounded Theory analytic approach, the dialogical nature of our ECD approach ensured that any design response we created was anchored in the particular expressions of experience of our participants, and therefore lived within the network of relationships which sustained and enriched that same experience.

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